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HIV/AIDS Prevention *and* Care *in* Resource-Constrained Settings

A HANDBOOK FOR THE DESIGN AND MANAGEMENT OF PROGRAMS



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HIV/AIDS Prevention *and* Care *in* Resource-Constrained Settings

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PREFACE

In 20 years of responses to the AIDS pandemic the world has learned many hard lessons. We have learned that half-measures do not work: progress is made only when communities and nations wholeheartedly embrace the fight against AIDS. We have learned that there is no “one-size-fits-all” solution in designing and delivering the most effective prevention and care initiatives. We have learned that HIV feeds on social inequality, especially the inequality between men and women. This is why we must confront the need for long-term, structural change to effectively address the pandemic.

Above all, we have learned that we are not powerless to change the course of the pandemic.

Communities and whole nations have demonstrated that it is possible to reduce the spread of HIV. Many have taken action before the epidemic has taken hold, but others have managed to pull back the epidemic even in their countries after its growth to devastating scale. And while scientists continue working to find a cure or an effective vaccine, great advances have been made in care and treatment. Where these have been within financial reach they have immensely improved the quality of life of people living with HIV/AIDS (PLHA).

This Handbook is a valuable tool for extending the reach of effective responses to HIV/AIDS where they are needed most. There are 40 million PLHA in the world today, and 95 percent live in resource-constrained countries. Until and unless the impact of AIDS is reduced, these countries face little prospect of building a more secure and prosperous future.

While every community needs to devise the prevention and care solutions that are most effective in its own local context, there are some universal principles on which success has been built:

- **Leadership is required at every level of society to ensure a comprehensive and coordinated effort against HIV/AIDS.** Leadership is the key to lifting the veils of denial and discrimination as well as to mobilizing resources and creating synergy between different elements of the response.
- **We must know what drives the pandemic to respond effectively to it.** This means understanding patterns of sexual practice and drug use, as well as the distribution of HIV infection.
- **Prevention and care are not competing priorities; they are mutually reinforcing strategies.** Extending access to comprehensive care, including antiretroviral therapy, is a priority even in the most resource-constrained settings, because it brings renewed hope and greater energy to the response.
- **Social exclusion must be tackled as one of the drivers of the pandemic.** People are more vulnerable to HIV when they are deprived of respect and community support. The most successful response strategies are those that have given a leading role to PLHA and others seen to be most at risk.
- **At this stage in the global pandemic the overwhelming need is for an increase in the scale of responses.** An AIDS response must take root across every region, throughout every nation, from town to town and village to village.

Reversing the AIDS pandemic is about changing the world we live in—our behaviors and relationships, where money flows and who makes decisions. It requires every one of us to play our part.

PETER PIOT, MD

Executive Director

Joint United Nations Programme on HIV/AIDS
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I N T R O D U C T I O N

PAUL R. DE LAY
GUNILA ERNBERG
KAREN STANECKI



We are in the third decade of what has become the most important infectious disease epidemic of the last century. Since AIDS was first recognized in 1981, an estimated 60 million men, women and children have become infected with the virus worldwide. Nearly half of all persons who acquire HIV are under age 25 and most will die before they reach 35. As of the end of 2000, 22 million people had died of AIDS. Approximately 13 million children under age 15 have lost one or both parents to AIDS, and the number of AIDS orphans is expected to exceed 40 million by 2010. HIV/AIDS is now the fourth leading cause of death worldwide, and the single leading cause of death in sub-Saharan Africa.

Over the past 20 years, we have continued to be surprised, shocked and devastated by this pandemic, which the global community has consistently underestimated. We have underestimated the level of HIV prevalence that has been attained in some general adult populations (such as in Botswana and Zimbabwe); the scope of the pandemic around the world (HIV infection is now found in even the most remote and isolated countries such as Bhutan and Mongolia); and the rapid growth of specific country epidemics (such as those in Cambodia and the countries of Southern Africa). At the beginning of the 21st century, HIV/AIDS prevalence among adults has exceeded 20 percent in seven countries in the developing world—all in Africa—and is above 10 percent in nine additional countries. In another 38 countries, prevalence equals or exceeds one percent; 22 of these are in Africa, 11 in Latin America, four in Asia and

one in Eurasia. In contrast, HIV/AIDS prevalence in the United States was 0.6 percent at the end of 2000.

AIDS was first described in 1981, and it appears likely that the virus is less than 100 years old. It is theorized that the various strains and subtypes of HIV originated through multiple mutations of animal retroviruses, which facilitated a “species leap” to humans. Through back-estimating the time needed to achieve the existing varieties of viral mutations, it appears this jump from animal to humans probably occurred in the late 1930s or early 1940s. The mutations that resulted in HIV-1 most likely arose in west-central Africa, in the countries of Gabon, Equatorial Guinea and Cameroon. What occurred after humans became infected demonstrates a pattern that we have seen repeatedly throughout the world. Due to the upheavals that were occurring in the Belgian Congo during the 1950s, it is likely that the earliest infected humans seeded the Great Lakes region of the African Rift Valley. Mass movements of people, disruptions of families and culture, changing sexual behavior, an increase of other risk behaviors and fluxes in economic status have all fueled the pandemic—in Africa and around the world. Because HIV is new to humanity, we still have much to learn.

STATUS AND TRENDS OF THE HIV/AIDS EPIDEMICS

Although the AIDS pandemic is complex, tracking and analyzing its evolution and diversity enables us to intervene more effectively and to more accurately predict future trends. We assumed in the late 1980s that any country with evidence of widespread risk conditions for HIV transmission would inevitably suffer an extensive epidemic once HIV was introduced into the population. This “evidence” of risk behaviors included the presence of a commercial sex industry, high background prevalence of other sexually transmitted diseases (STDs) in the population, low condom use by men and the existence of injection drug use (IDU). But this was a far too simplistic view of the underlying dynamics of the pandemic. In Asia, for example, we have seen the epidemic explode in Cambodia, Burma, Thailand and in some states of India, yet remain very concentrated and in low prevalence in the Philippines and Indonesia.

The pandemic continues to defy simple models and formulas. We now recognize that there are a number of host, viral and social factors that determine transmission and vulnerability. These interact in a complex manner in the mosaic of global settings. Figure 1 lists the most predominant determinants.

It has become increasingly important to integrate improved biological surveillance data with detailed information about the social and economic patterns that lead to increased risk behaviors and vulnerability. These “second generation” surveillance systems will improve our ability to describe the state of local epidemics and target our interventions for the future. But it is challenging to collect this range and depth of data for each country. Among this array of determinants, there are a number of predominant factors. Sexual behaviors and the pattern of sexual networks are clearly the most important factors in the most severe sexually transmitted epidemics. We have recently learned that subtle quantitative differences in behavior can either cause the epidemic to explode or stabilize at a relatively low level of prevalence. It is not a matter of whether commercial or casual sex exists in a society, but how much, of what kinds, when it is practiced and by whom.

Besides risk behavior patterns, there are increasing data on the possible role of STDs, HIV-1 subtypes and male circumcision in the efficiency of various

Figure 1 FACTORS THAT INFLUENCE THE SPREAD OF HIV

Viral Factors

- HIV-1 strains
- Viremia

Local Genital Factors

- Presence of STDs
- Male circumcision
- Use of vaginal products

Sexual Behavior

- Rate of partner exchange
- Sexual mixing patterns
- Type of intercourse
- Size and rate of contact with core groups
- Level of condom use

Demographic Factors

- Percentage of sexually active age groups to other age groups
- Male to female ratio
- Urban: rural percentage
- Migration patterns

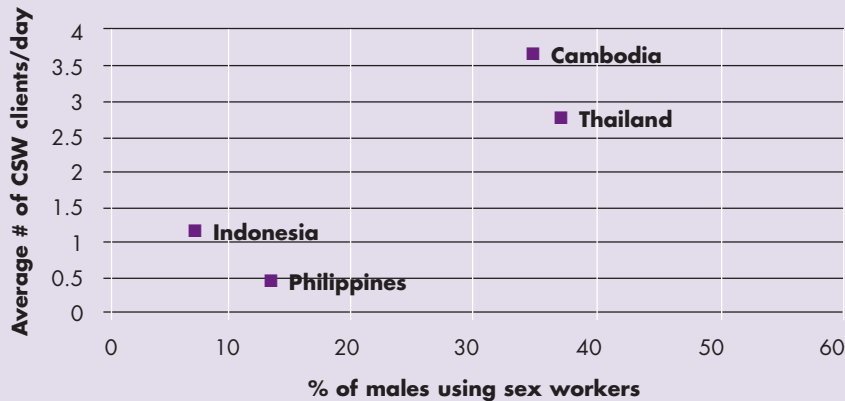
Economic and Political Factors

- Level of poverty
- War and social conflicts
- Status of transport and mobility of population
- Performance of health care system
- Response to epidemic

(from Piot-1994)

Figure 2

COMPARISON OF AVERAGE NUMBER OF CLIENTS PER COMMERCIAL SEX WORKER (CSW) VERSUS PERCENTAGE OF YOUNG MEN WHO UTILIZED SEX WORKERS



modes of transmission. These have yet to be adequately delineated and entered into the complex equation of epidemic dynamics.

THE EPIDEMICS OF SUB-SAHARAN AFRICA

The global pandemic consists of a mosaic of individual epidemics in countries around the world. The oldest set of epidemics can be found in sub-Saharan Africa. Of the 36 million people living with HIV/AIDS globally, more than 25 million (70 percent) are in sub-Saharan Africa. This region includes only 11 percent of the world's population. Nearly one in 10 adults between the ages of 15 and 49 is already living with the virus throughout the sub-continent.

In Africa women are harder hit than men, the opposite of what is found on all other continents. The difference between men and women is most pronounced in those under age 25. A population-based survey in Kisumu, Kenya, showed HIV rates in 15- and 16-year-old girls of 8 percent and 18 percent, while no infections were documented in boys of the same age. In 19-year-old girls the rates were up to 33

percent, and only 9 percent in boys. We do not fully understand the reasons for these extremely high rates in girls. Young girls' biological vulnerability and the fact that girls frequently have sex partners of much higher age—with high levels of infection—likely play a role.

There are at least three patterns of transmission in sub-Saharan Africa:

In the countries of East Africa, the oldest HIV epidemics in the world have had slow, steady progress over the past 30 years. These are seen in the Great Lakes regions of East Africa—in the countries of Uganda, Tanzania,

Malawi, Kenya, Zambia and the Democratic Republic of the Congo (formerly Zaire).

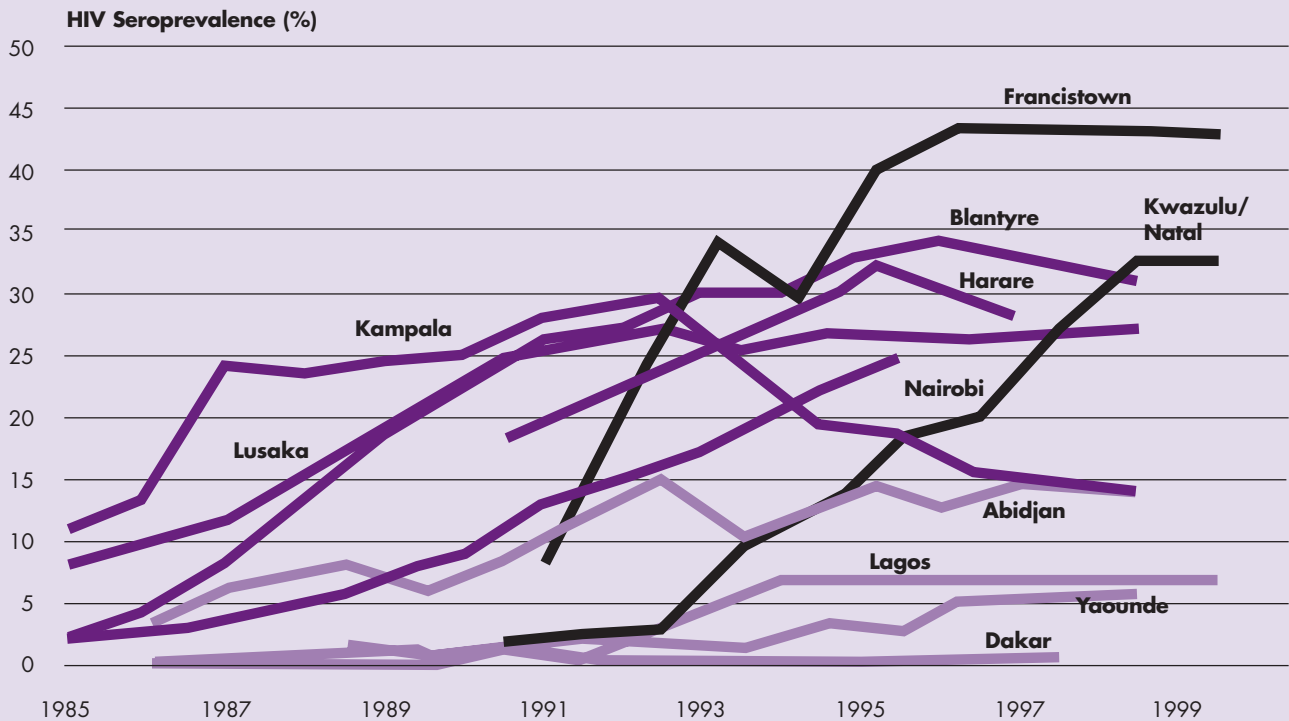
In the countries of West Africa, where the epidemic seems to have started about 10 years later, progression of the epidemic has been more indolent and is further complicated by the presence of both HIV-1 and HIV-2. The national prevalence rates are generally lower, between one percent and eight percent, except for Côte d'Ivoire.

In Southern Africa, where the epidemic started in the mid-to late 1980s, there has been a series of explosive epidemics over the past eight years, reaching the highest prevalence levels on earth, 20 percent to 40 percent. These countries include South Africa, Namibia, Zimbabwe, Botswana, Swaziland and Lesotho.

Among the features of the epidemics in this region:

- Half of new infections in Africa are among 16- to 23-year-olds, three-quarters of them young girls and women. More than 80 percent of HIV transmission is heterosexual, with more than 55 percent of infections in sub-Saharan Africa occurring in women due to increased physiological and socio-economic vulnerability.
- Several studies in sub-Saharan Africa have noted that HIV prevalence is high in young women within the first few years of sexual activity, but rises

Figure 3
**HIV SEROPREVALENCE FOR PREGNANT WOMEN
 IN SELECTED URBAN AREAS OF AFRICA: 1985–1999**



Note: Includes infection from HIV-1 and/or HIV-2.
 Source: U.S. Census Bureau, HIV/AIDS Surveillance Data Base, 2000.

more slowly in young men. Recent data from four urban populations and one rural population confirm dramatic male-female differences (see Figure 4). In this vicious cycle young girls are infected by older men; the girls as they age then infect their same-age partners and husbands; and these men as they age in turn infect young girls.

- The increasing number of HIV-infected women has led to the infection of nearly 600,000 infants each year. Although new, more realistic interventions to reduce mother-to-child transmission (MTCT) of the virus are being developed, fewer than five percent of women in sub-Saharan Africa have access to these treatment regimens.

THE EPIDEMICS OF ASIA

With a population of nearly 3.5 billion—representing nearly 60 percent of the world’s population—the Asia-Pacific region has the potential to greatly influence the course and overall impact of the global HIV/AIDS pandemic.¹ HIV began to spread in this region in the early to mid-1980s, reflecting risk behavior in two discrete areas: commercial sex work (CSW) and injection drug use (IDU). During the 1980s and early 1990s, there was extensive spread among men who have sex with men (MSM) in several Asian Pacific countries, including Australia, New Zealand, Japan, Malaysia,

Singapore and Hong Kong. There were intense focal epidemics in the late 1980s among IDU populations in Australia, Thailand, north-east India, several provinces in China, Malaysia, Myanmar, Vietnam and, most recently, Nepal. Major heterosexual epidemics, primarily driven by sex work, have reached seroprevalence levels of one percent to three percent among the 15- to 49-year-old population in Cambodia, Myanmar, Thailand and several states in India. Epidemiological studies over the past decade also have shown that HIV epidemics among MSM, IDUs and heterosexual populations may develop independently of each other, depending upon the sexual bridges between these populations.

HIV prevalence has remained relatively low (less than .01 percent) in the total 15- to 49-year-old age group in some developing countries in the region, despite comparably high levels of other STDs in segments of this population. Even among CSWs in the Philippines and Indonesia, HIV infection levels have remained minimal. As we come to better appreciate the quantitative differences in sexual behavior—as influenced by culture and religion—between these countries and those that have experienced severe sexual spread, it should be increasingly possible to make longer term predictions of the trends in the spread of the epidemic over the next several decades.

From a regional perspective, the ultimate impact of HIV/AIDS in this region will be determined by the extent of ongoing epidemics in a number of key countries: Cambodia, Myanmar, Thailand, and, because of their population size, Indonesia, India and China.

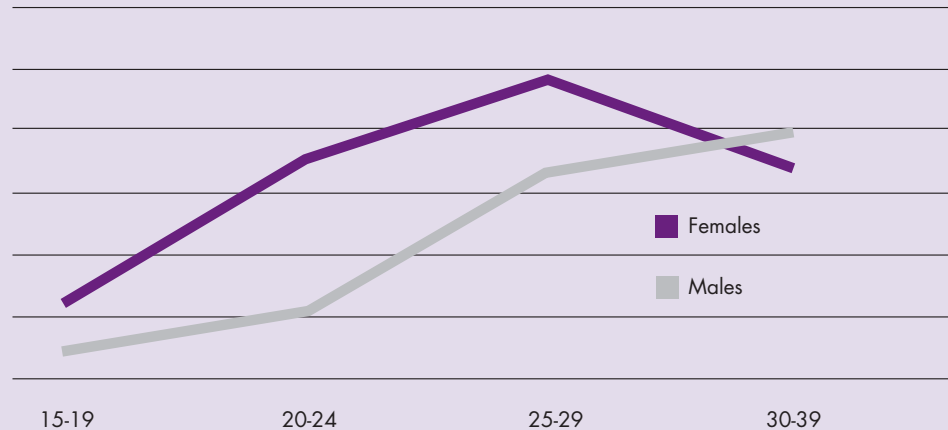
The epidemics in this region feature:

- An exceedingly complex epidemic in India that involves multiple epidemic foci, such as outbreaks among IDUs and extensive HIV spread among female CSWs and their clients in several regions.

Figure 4

HIV PREVALENCE FOR GENERAL POPULATION BY SEX, 1995–1996, ZAMBIA, URBAN

HIV Prevalence (%)



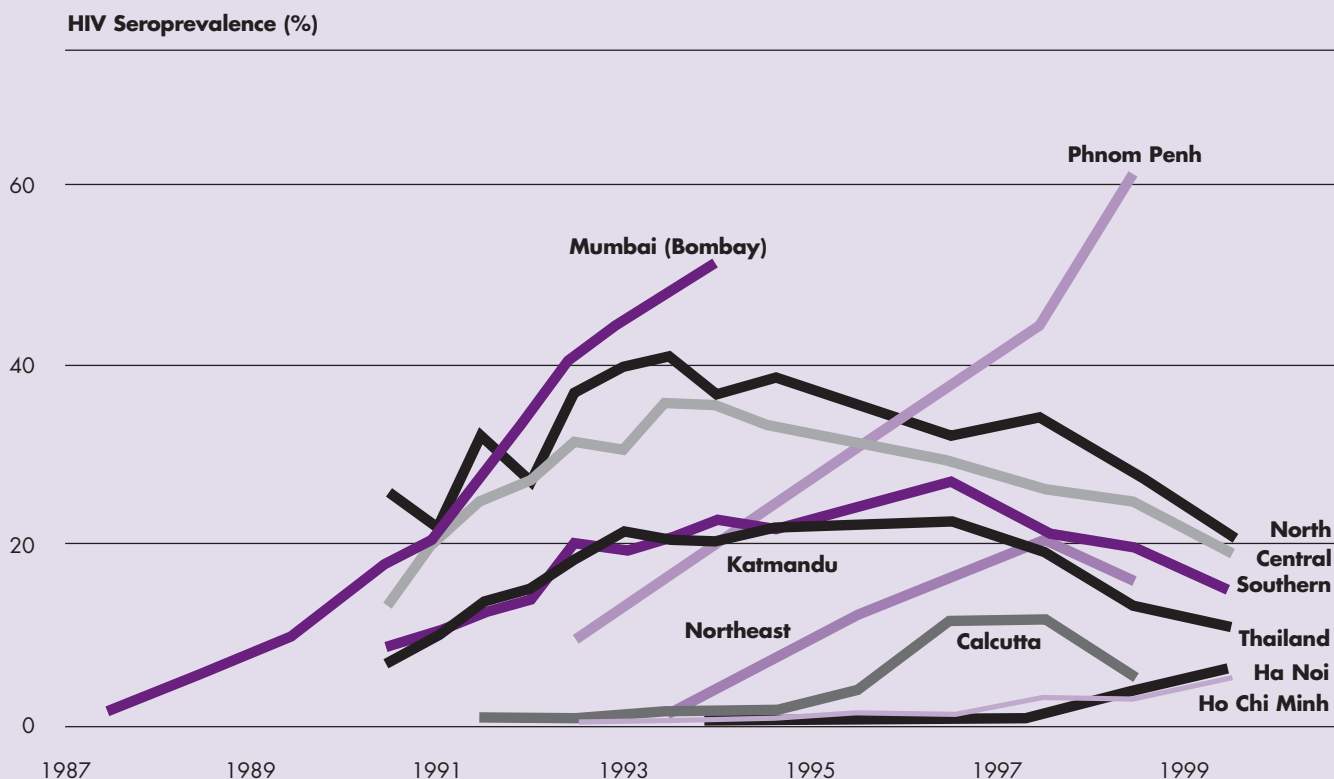
Fyllkenes

- Substantial heterosexual epidemics with comparably high levels of HIV in pregnant women in Thailand, Cambodia and parts of Myanmar, with concentrations among IDUs and CSWs in other countries, such as Vietnam.
- Ongoing low HIV prevalence (less than 0.1 percent) in the total 15- to 49-year-old population in some countries. In the Philippines, HIV surveillance has found only a few cases of HIV infection among female CSWs, male STD clinic patients and MSM. Indonesia likewise has reported only a small number of AIDS cases and low levels of HIV infection.

THE EPIDEMICS OF LATIN AMERICA AND THE CARIBBEAN

There are two distinct epidemics in Latin America and the Caribbean, one in the island and coastal countries of the Caribbean, another in mainland South America. With eight percent of the world's population, the Latin American and Caribbean region is home to

Figure 5
**HIV SEROPREVALENCE FOR COMMERCIAL SEX
 WORKERS IN SELECTED URBAN AREAS OF ASIA: 1987–1999**



Source: U.S. Bureau of the Census, HIV/AIDS Surveillance Data Base, 2000.

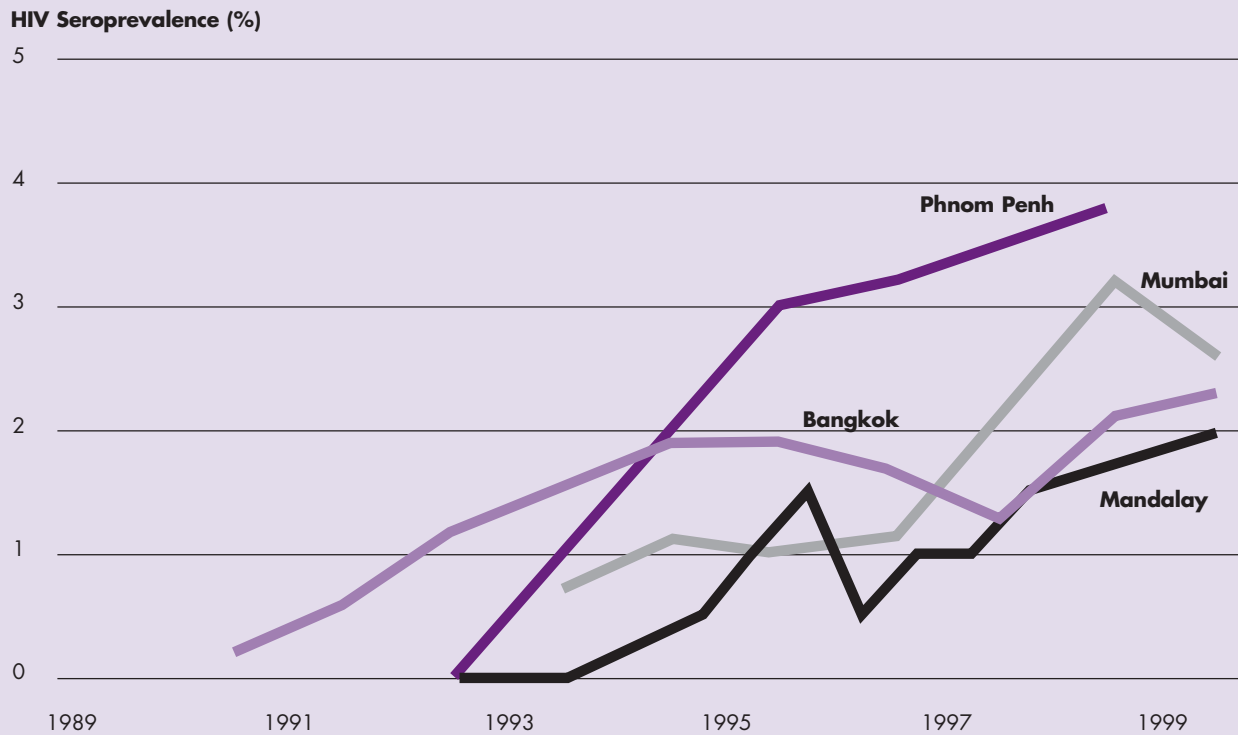
4.9 percent of all people living with HIV/AIDS (PLHA) at the beginning of the 21st century. There are close to 1.3 million PLHA in Latin America and another 360,000 in the Caribbean. Because of the wide diversity of HIV epidemics, these regional figures mask huge differences in epidemic levels and patterns of transmission.

Although the Caribbean is geographically small, it has a total population of more than six million. Some parts of Haiti and the Dominican Republic have HIV prevalence rates higher than any other country in the world outside of sub-Saharan Africa. HIV testing of pregnant women attending antenatal clinics suggests that at least one in 12 adults between ages 15 and 49

is living with HIV. Guyana has also been hit harshly by HIV. In 1996, 7.1 percent of pregnant Guyanese women tested for HIV were found to be infected.

Outside the Caribbean, the hardest hit area in this region is Central America. In Honduras, Guatemala and Belize, the epidemic appears to be heterosexually driven and increasing. In San Pedro Sula, the HIV epicenter in Honduras, HIV infection among pregnant women has fluctuated between two percent and five percent for several years. In Costa Rica, on the other hand, HIV is concentrated among MSM and seems to be contained at relatively low levels.

Figure 6
**HIV SEROPREVALENCE FOR PREGNANT
 WOMEN IN SELECTED URBAN AREAS OF ASIA: 1989–1999**

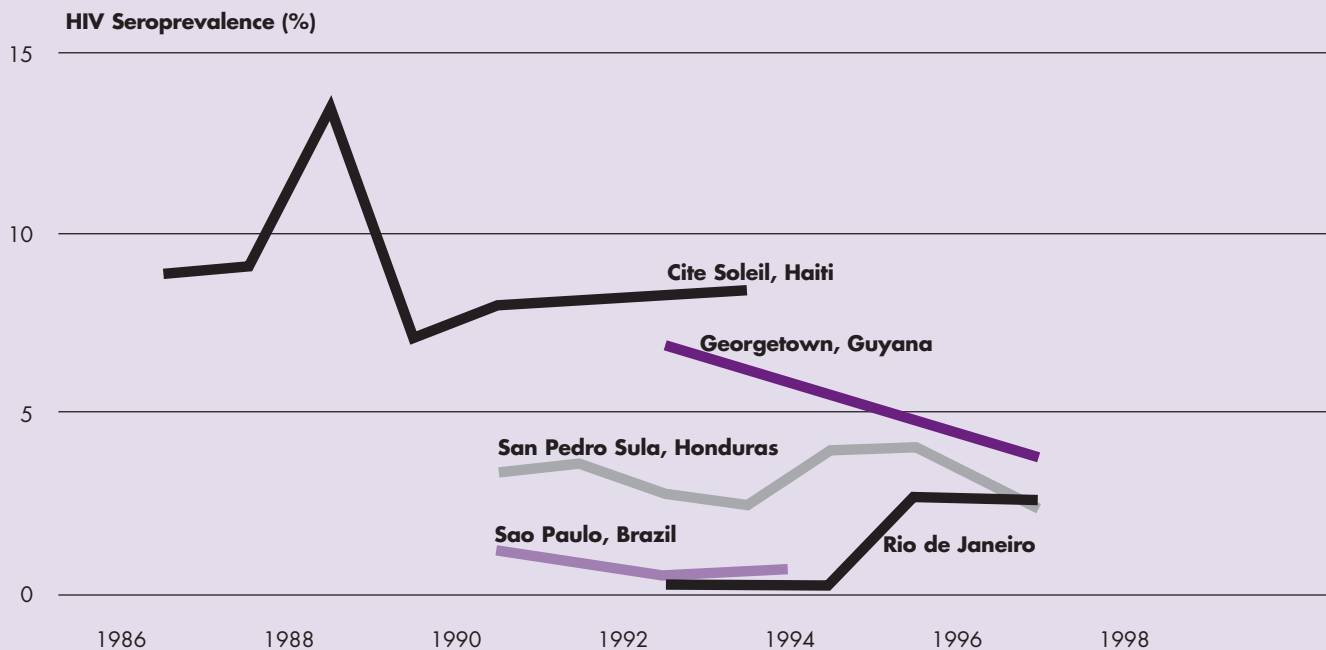


Source: U.S. Census Bureau, HIV/AIDS Surveillance Data Base, 2000.
 Cambodia Data: married women of reproductive age.

Sixty percent of those currently living with HIV in Brazil are believed to be concentrated in the major urban areas of São Paulo and Rio de Janeiro. AIDS case reporting suggests that the vast majority of early infections were among MSM. But that picture has changed in recent years, with unprotected sex between men and women now accounting for more AIDS cases than ever before. This does not mean that other risk behaviors can be neglected. Recent studies show that MSM and IDUs continue to be at high risk for HIV infection.

The Andean region and the Southern Cone so far seem to be relatively little affected by HIV. Colombia in 1998 estimated that 67,000 people were living with HIV in the country, but the pattern of infection seems to vary between regions. In Peru, an estimated 44,200 people were living with HIV in 1999. In 1998, 0.23 percent of pregnant women tested in Lima were HIV positive. Chile performs sentinel surveillance in pregnant women and STD patients, and has found little or no HIV infection in the general population in several areas of the country, including Santiago, the capital. In Argentina a high proportion of pregnant women attending antenatal clinics choose to be tested for HIV in order to receive help in preventing transmission of the virus to their baby if necessary. Of more than

Figure 7
**HIV SEROPREVALENCE FOR PREGNANT WOMEN IN
 SELECTED URBAN AREAS OF LATIN AMERICA: 1986–1997**



Source: U.S. Bureau of the Census, HIV/AIDS Surveillance Data Base, 2000.

66,000 Argentine women tested in 2000, 0.56 percent were HIV positive.

The epidemics in this region feature:

- Severely affected populations of several Caribbean countries. Some countries are more affected by the epidemic than any other country in the world outside of sub-Saharan Africa.
- An epidemic in Mexico driven largely by unprotected sex between men. Studies among MSM have shown that some 14.2 percent are infected with HIV.
- The largest number of PLHA—an estimated 540,000 by the end of 1999—are in Brazil, the most populous country in the region.

- Of all of continental Latin America, the northern countries of Central America appear to be the hardest hit by HIV, though there is considerable diversity even within the isthmus.

THE EPIDEMICS OF EASTERN EUROPE

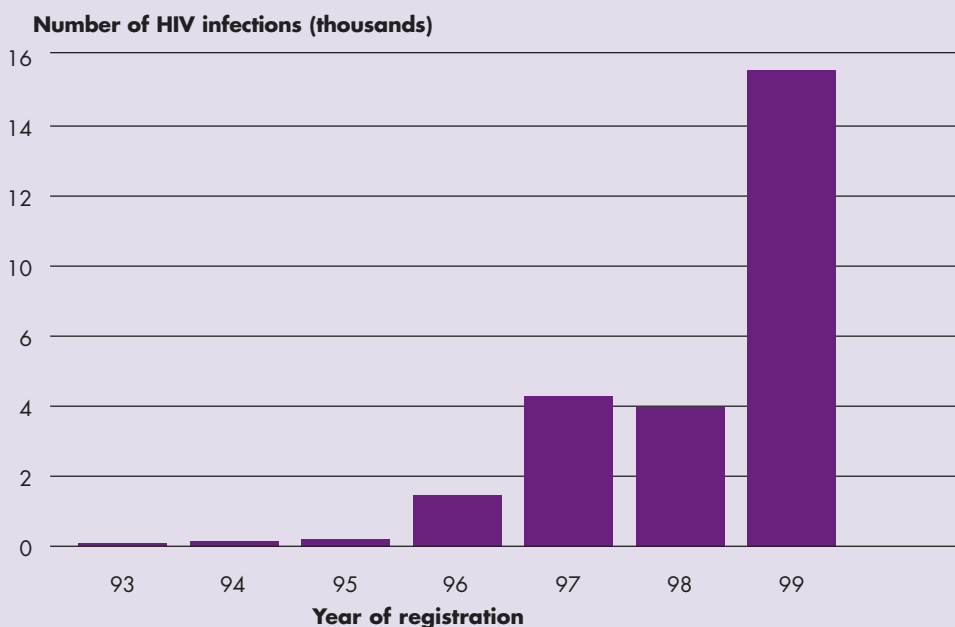
In the countries of the former Soviet Union, the HIV epidemics continue to be mainly concentrated among IDUs. Although the IDU-associated epidemic in the Newly Independent States began in 1995-6, it already affects a large number of cities and virtually all administrative regions in Ukraine, Russia, Belarus and Moldova. More than 5,000 IDUs were identified as HIV infected in Moscow alone as of 1999. Due to this outbreak in the Moscow region, more HIV infections in Russia were registered in 1999 than in all previous

years combined. HIV prevalence varies from fewer than two percent of IDUs registered officially in Russia, to about 30 percent in sentinel surveys in Ukraine and Russia, and more than 60 percent in Svetlogorsk in Belarus and in drug-injecting CSWs in Kaliningrad. HIV prevalence among other population groups seems to have remained low so far.

While about 130,000 Russians are believed already to be living with HIV, the Russian Ministry of Health estimates the number of IDUs in Russia at about three million—two percent of the total population—providing a large pool of highly vulnerable but not yet infected persons. Although not confirmed in scientific studies, similarly high estimates also have been made for Ukraine and other Newly Independent States. With the deteriorating economic situation of women, the number of women engaging in sex work and potentially at high risk of infection is believed to have increased considerably.

At the same time, large epidemics of syphilis and other STDs have been reported from these countries. In Russia alone, between 200,000 and 400,000 new cases of syphilis have been reported annually in the past few years. This may be only the tip of the iceberg, as under-reporting is believed to be high. Although major spread of HIV via heterosexual transmission in the population at large has not yet been confirmed, the massive increase in STDs in the populations of Eastern European countries proves the potential for more widespread HIV/AIDS epidemics.

Figure 8
ANNUAL NUMBER OF NEWLY REGISTERED HIV INFECTIONS, RUSSIA, 1993–1999



Source: Russian Federal AIDS Centre, Moscow.

The epidemics in this region feature:

- An estimated 420,000 adults and children living with HIV in Eastern Europe and in the countries of the former Soviet Union by the end of 1999. Only a year later that number was estimated to be more than 700,000, with the Russian Federation, Ukraine, Belarus, Kazakhstan and Moldova the most severely affected.
- Most HIV infections in this region are due to IDU, with HIV prevalence rates greater than 60 percent in some cities, including Odessa and Nikolaev in the Ukraine, Svetlogorsk in Belarus and Kaliningrad in the Russian Federation.
- Men account for three-quarters of all HIV infections registered in the region, with as many as 60 percent of infected persons between the ages of 15 and 24.

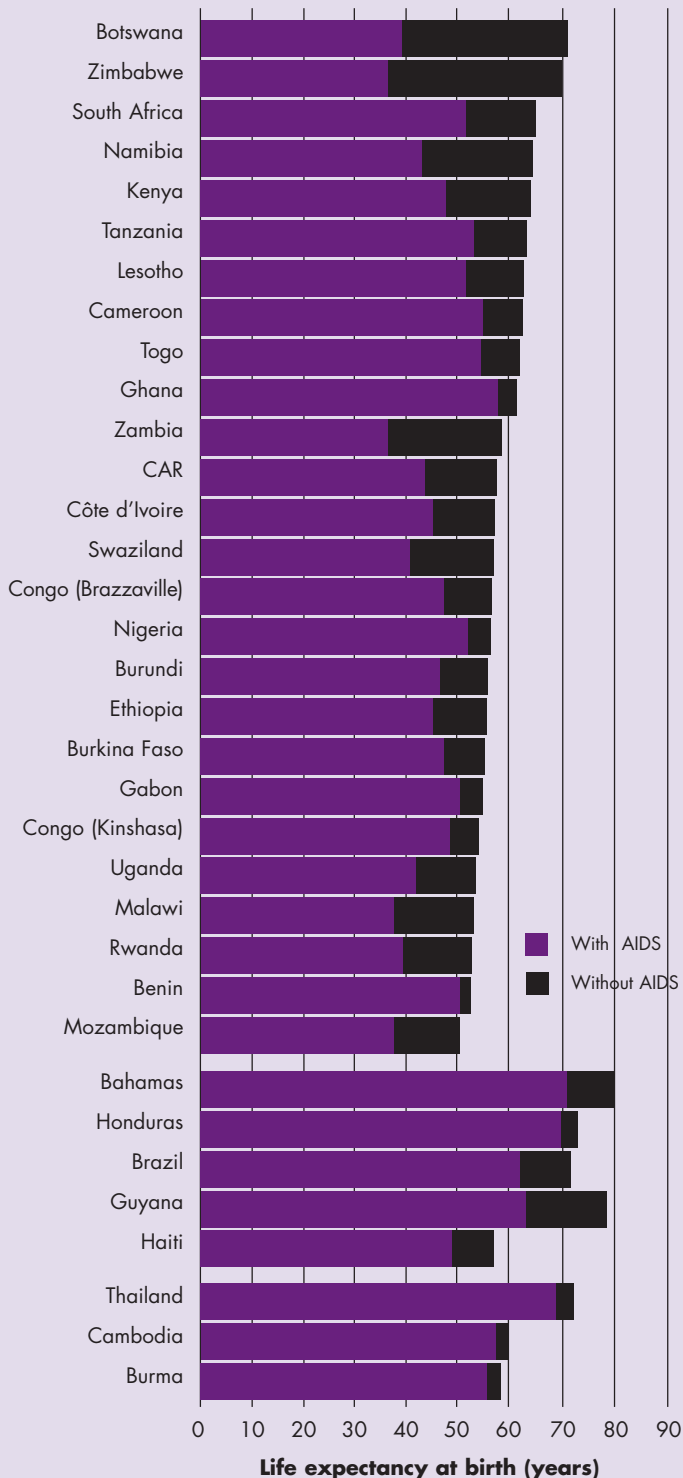
IMPACT OF THE EPIDEMICS

The pandemic has not only affected the health sector, but it cuts across societies and affects every aspect of human development. There are significant differences in the impact of AIDS throughout the world depending upon the stage of the epidemic within a country and the level of society under examination. The magnitude, severity and timeframe in which change is seen vary according to the type of analysis—whether the effects are examined at the household level, in specific labor sectors, at the level of population demographics or a country's macroeconomic status.

HEALTH

Without access to the combination antiretroviral drug (ARV) therapies now used in the United States and other industrialized countries, essentially all newly infected adults will sicken and die of HIV-related disease within three to eight years of becoming infected—many without ever truly knowing their HIV status. The impact will be especially severe for women who are not only biologically more vulnerable to infection but also bear the burden of care for the sick. HIV/AIDS will undoubtedly be a major cause of mortality in both adults and children for many more years to come. AIDS in sub-Saharan Africa already imposes a huge burden on the health infrastructure: More than 60 percent of hospital beds are occupied by persons with HIV-related disease. One disturbing effect of the growing burden of HIV disease is an increasing rate of inpatient mortality in HIV-negative patients. This is the result of losing key health care staff, a steady deterioration of health service delivery systems and overcrowding of hospitals with AIDS patients that forces HIV-negative patients to wait longer before being admitted—often in more severe, if not terminal, condition. And because tuberculosis (TB) is so common in HIV-infected persons—and is the leading cause of death in AIDS patients—the TB epidemic in areas of sub-Saharan Africa has increased by more than 400 percent.

Figure 9
LIFE EXPECTANCY WITH AND WITHOUT THE AIDS EPIDEMIC IN 2000



Source: U.S. Census Bureau, International Data Base and unpublished tables.

DEMOGRAPHIC IMPACT

In some countries, such as Botswana and Zimbabwe, life expectancy is plummeting while infant and child mortality is increasing. In countries with high HIV prevalence levels and low fertility rates, population growth rates have been reduced to near zero. Other countries with sharply reduced growth rates include Malawi, Namibia, South Africa, Swaziland and Zambia.

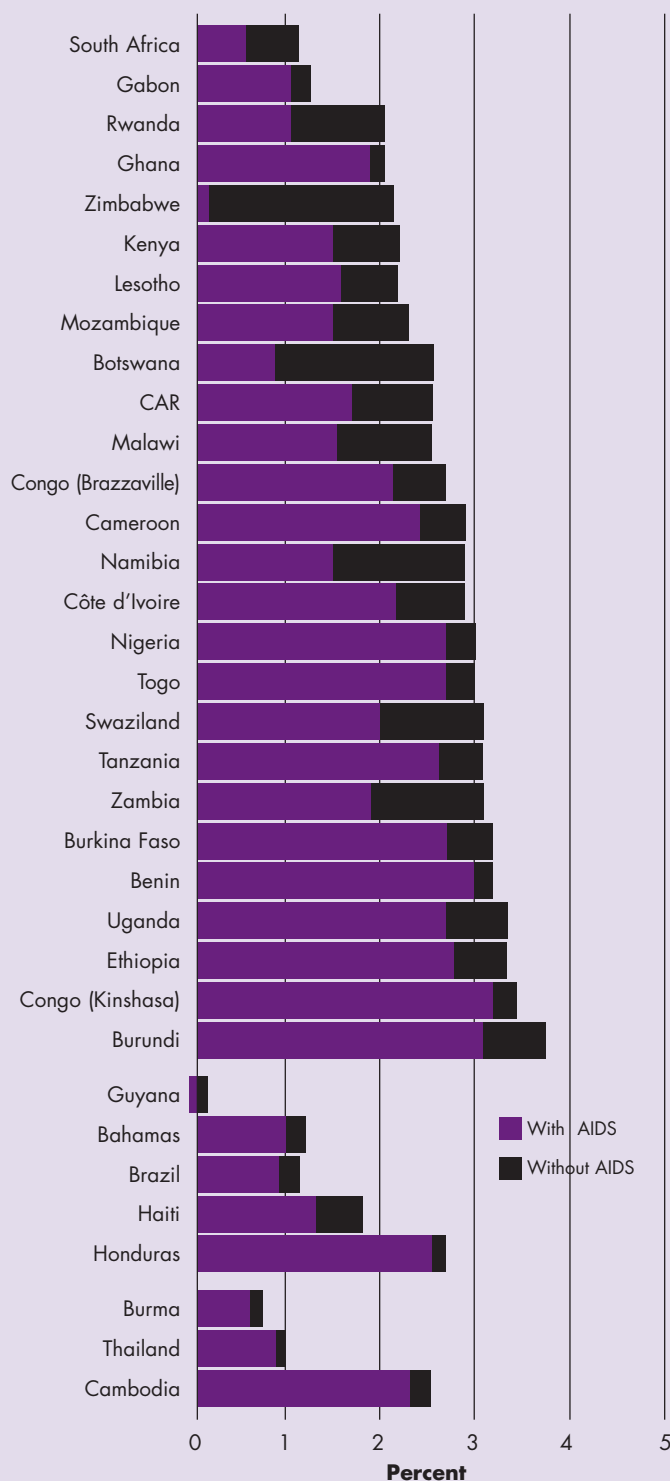
Life expectancies in many countries in sub-Saharan Africa have fallen dramatically from the levels they would have been without AIDS. In Botswana, life expectancy is now 39 years rather than 71 years; in Zimbabwe it is 38 years rather than 70 years. In fact, six countries in sub-Saharan Africa (Botswana, Malawi, Mozambique, Rwanda, Zambia and Zimbabwe) have life expectancies below 40 years. They would have been 50 years or greater without AIDS.

In some sub-Saharan African countries, AIDS mortality has reversed the declines in infant mortality in the 1980s and early 1990s, and the rates are now higher than they were in 1990. The relative impact of AIDS on infant mortality will depend on both the levels of HIV prevalence in the population and the infant mortality rate from other causes. In 1990 the infant mortality rate in Zimbabwe was 54, and in 2000 it was 62. In Kenya the 1990 rate was 67, and in 2000 it was 69. Without AIDS, these rates would have been 30 in Zimbabwe and 55 in Kenya.

Altogether 26 sub-Saharan African countries have experienced increases in child mortality rates because of AIDS. The impact on child mortality is highest in countries that had significantly reduced child mortality due to other causes and where HIV prevalence is high. Many HIV-infected children survive their first birthdays, only to die before age five. Seventy percent of all deaths among children under age five in Zimbabwe, and 45 percent of the same age cohort in South Africa, are AIDS-related.

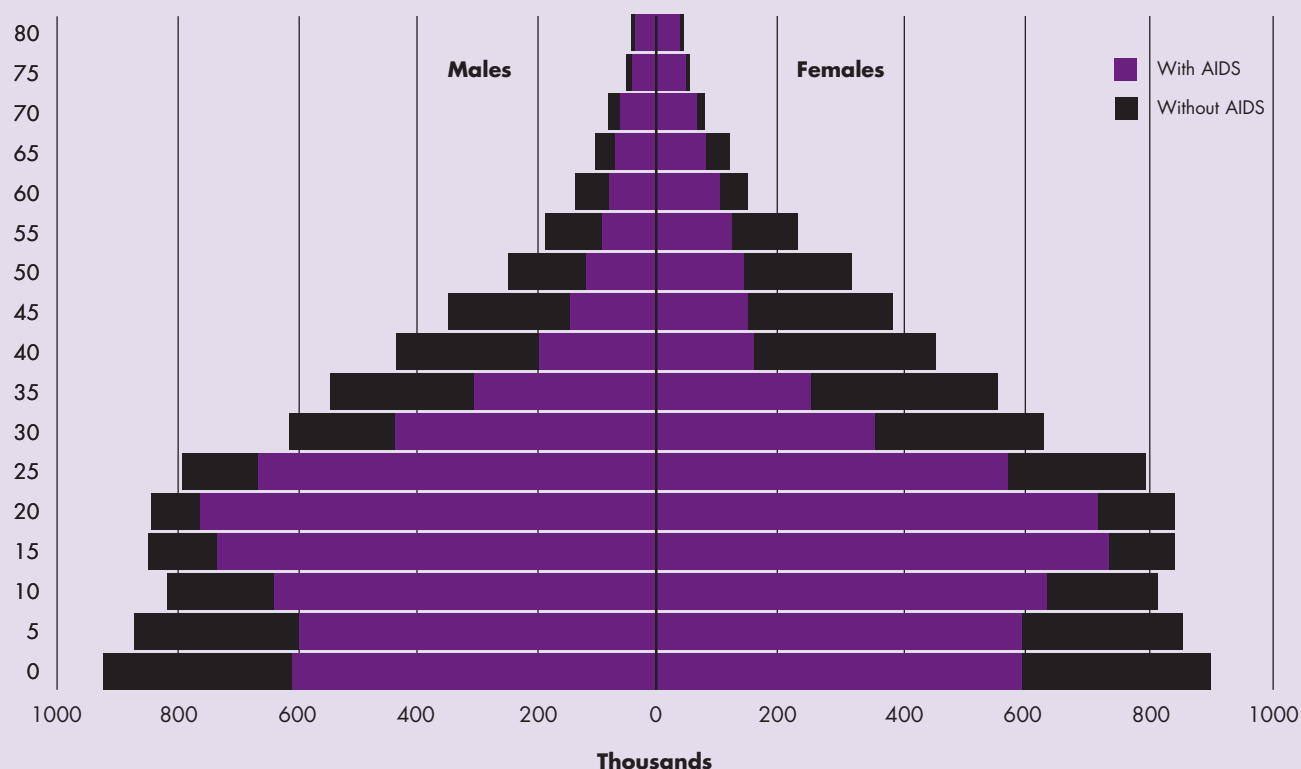
The impact of AIDS is most profound on population structures. Recent national census surveys in Kenya and Malawi show significant overall AIDS-related mortality that has not been anticipated in

Figure 10
GROWTH RATE WITH AND WITHOUT
THE AIDS EPIDEMIC IN 2000



Source: U.S. Census Bureau, International Data Base and unpublished tables.

Figure 11
**POPULATION OF ZIMBABWE,
 WITH AND WITHOUT AIDS: 2010**



Source: U.S. Census Bureau, World Population Profile 2000.

current population projection modeling. The most extreme examples are those countries—such as Botswana, Zimbabwe and South Africa—where there will be negative population growth within the next three to four years. The resulting population pyramids show a dramatic restructuring of the population, with decreasing numbers of children and middle-aged adults and more males than females.

ORPHANS

By 2010, at least 44 million children under age 15 will have lost one or both parents to all causes in the 34 countries most severely affected by HIV/AIDS. Of these orphans, 68 percent will have lost their parents due to AIDS. This represents a dramatic increase from 1990, when AIDS accounted for 16.4 percent of parental deaths. Orphans are distributed among areas of the world in the same patterns as HIV prevalence, so that countries with the highest infection levels also tend to have the highest orphan rates. The orphan crisis is most acute in sub-Saharan Africa, where as many as 35 percent of children under age 15 in at least eight countries have lost one or both parents. Eleven countries will reach this rate by 2010.

ECONOMIC IMPACT

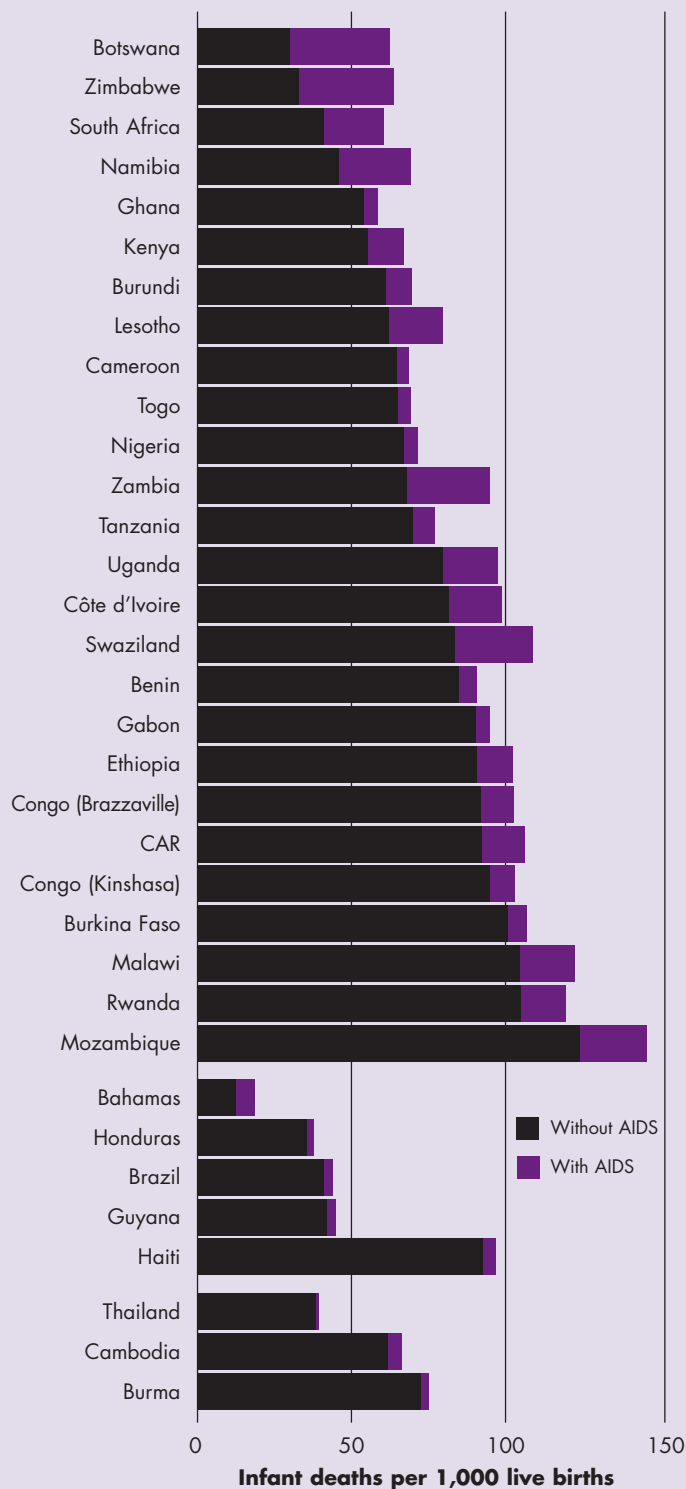
Early research on the economic impact of AIDS focused on the macroeconomic aspects. This showed that increased deaths and decreased investment could be expected to slow economic growth and reduce per capita income, albeit not dramatically.²

There have also been attempts to examine how AIDS would affect the private sector and households. Not surprisingly, it has proved difficult to collect complete and credible data. Indeed, poor management information systems were a constant source of frustration for researchers who were working with companies in affected countries.³ AIDS clearly had measurable costs in the private sector, mainly through absenteeism and the payment of benefits. These costs could be as high as eight percent of the payroll, depending on the nature of the industry and scale of the problem. But in general the impact was not great, manageable or transferred onto the households.⁴

The relatively limited number of studies of household impact have shown that HIV/AIDS leads to impoverishment of those affected. In Ethiopia and Tanzania, the average cost of basic symptomatic treatment, funeral and mourning expenses amounts to several times the average annual household income. Affected children are more likely to be malnourished and, particularly the girls, removed from school.⁵ Although the importance of these dramatic increases in the number of orphans has been recognized, their long-term economic implications have not been assessed.

Part of the problem in assessing the impact of HIV/AIDS is that it is long term and the data have not been available. But in the last few years a number of new publications have appeared that give a much more pessimistic view of the potential and actual impact of the disease at all levels. The most significant may be studies suggesting that the impact on national economies and growth is more complex and serious than previously modeled, perhaps because the speed and scale of HIV/AIDS have been much worse than expected; HIV/AIDS reduces the stock of human and physical capital because it also reduces the incentive to

Figure 12
INFANT MORTALITY WITH AND WITHOUT
THE AIDS EPIDEMIC IN 2000



Source: U.S. Census Bureau, International Data Base and unpublished tables.

invest; and feedback further amplifies the impact of HIV/AIDS on economic growth.

This can result in a vicious cycle in which AIDS reduces growth and increases poverty, thereby accelerating the spread of HIV.⁶ These concepts have been enumerated in a recent paper from the Harvard Institute of International Development which suggests that the impact of AIDS has been systematically understated because these feedback effects have been ignored.⁷ The impact on productivity due to HIV status is particularly important. The study focuses on Zambia and suggests that by “stripping countries of some of their best talent and undermining the incentive to invest, these difficulties may be condemning African countries to extended periods of stagnation and decline.” Macroeconomic analysis is clearly entering a new phase.

Recent work on the private sector shows that companies also are beginning to take AIDS more seriously. But the tendency—which is economically rational—is to avoid or shift the costs of the disease, though this may not be in the interests of the national economy or workforce. A classic example is a company in South Africa that diversified to Eastern Europe after looking at the impact of AIDS on its market.⁸

The worst impact is at the household level, and here the data are limited. Mitigation will need to focus on the household level because it is there that care must be delivered and prevention messages may have the most meaning.

RESPONSE TO THE HIV/AIDS EPIDEMICS: COMPONENTS FOR AN EXPANDED COMPREHENSIVE RESPONSE

Even as we recognize the devastation of AIDS during the nearly two decades since HIV was first identified, it is important to note that there has been remarkable progress in our understanding of various aspects of the global HIV/AIDS pandemic. There is now an abundance of information on the basic pathogenesis of the infection; the epidemiologic

advancement of the disease around the globe; the multiple factors that determine vulnerability; the scope of the pandemic’s macro- and microeconomic impacts; the development and use of highly active antiretroviral therapies (HAART) to retard the clinical progression of HIV-related disease; the financial and political environment that can facilitate an effective response; and, most critically, the constellation of interventions needed to achieve a national-level impact on HIV transmission.

REDUCING RISK BEHAVIORS

Our ability as a global community to achieve reductions in new HIV infections is predicated on a very basic principle: We can reduce unsafe sexual and other risk behavior in a sustainable way. We now have ample evidence that public health programs can affect change in the most private and basic of human behavior—sex. While it is impossible to attribute declining national HIV rates to any single program, it is increasingly evident that people are responding to widespread, consistent education messages about HIV/AIDS prevention and care, and to dramatic increases in the availability of key tools and services. In poor urban neighborhoods in the Dominican Republic, for example, rates of sexually active youth declined from 73 percent in 1993 to 30 percent in 1996, and rates of participation in “transactional sex” (exchanging food, money, school fees, etc. for sex) declined from 27 percent to 7 percent among males. In Bali, Indonesia, a peer education project with sexually active 15- to 25-year-olds led to an increase in consistent condom use from 22 percent to 72 percent.

Sustained investments in a select number of countries have resulted in two kinds of national-level success: maintaining low HIV rates in countries at risk and reducing national-level HIV prevalence during a severe generalized epidemic. Senegal has maintained one of the lowest HIV prevalence rates in sub-Saharan Africa, with rates rising only slightly—from 1.2 percent for the general adult population in 1995, to 1.8 percent at the end of 1999.

Prevention activities in the state of Tamil Nadu in India began in 1996. By the end of 1998 the vulnerable groups served by the program achieved significant, sustained change in sexual behavior and demonstrated significantly increased condom use among CSWs and their clients. Consistent condom use with non-regular sex partners increased from 56 percent to 80 percent among CSWs, and by male factory workers from 17 percent to 50 percent.

Uganda has become a model for curbing a severe HIV epidemic in developing countries. Behavioral surveillance has demonstrated significant increases in condom use, decreased casual partners and delayed sexual debut by one to two years. The proportion of Ugandan girls who have ever had sex declined by almost half between 1989 and 1995, and more than half of young sexually active Ugandans report using condoms in their last sexual contact. This rate was close to zero at the outset of the epidemic. As a result, HIV infection rates among 15- to 19-year-old girls declined from 22 percent in the early 1990s to 8 percent by 1998. National HIV adult prevalence decreased from 14 percent in the early 1990s to 8.3 percent at the end of 1999. Recent surveys in Zambia show a 42 percent reduction in prevalence rates for the 15- to 19-year-old age group in Lusaka and other urban areas, from 28 percent to 15 percent between 1994 and 1998.

But there are no magic bullets. Implementing an effective behavior change program is complicated, resource- and time-intensive and must be based on locally collected information and careful strategic planning. We have also learned that we must appropriately target our behavior change interventions to those most likely to transmit or contract HIV infection. The specific targeted groups may differ from country to country, but across all regions of the world they invariably involve men, single women and youth.

Knowledge alone is not enough. Behavior change is complex and painstaking for individuals, communities and societies as a whole. It requires far more than having basic knowledge about AIDS, or even being disturbed or concerned about it. Knowledge surveys have demonstrated that more than 95 percent of the adult population of Zimbabwe has learned about AIDS and more than 80 percent know two or more modes of prevention. Yet the epidemic in Zimbabwe is still out of control, with nearly one in every four adults now infected with HIV and the number of new infections continuing to rise.

This gap between knowledge and practice has been observed all over the world. It has forced public health and development specialists to deal with individual health behavior—including sex—in its social and cultural context. In much of the world, traditions make it unnecessary for individual men, and unthinkable for women, to refuse sexual relations. We have learned that promoting monogamy and condom use, and encouraging young people to wait, involves mobilizing women and men, individuals, communities and opinion-leaders to rethink policies and social norms and create environments where individuals who “get the message” are supported, not derided, shunned or beaten. We have learned that HIV/AIDS risk reduction involves positive social change that links health, gender and human rights in new and productive ways.

This is why we should not be surprised that in the absence of such social change—even in countries with raging, visible epidemics such as Botswana, South Africa and Zimbabwe—people have continued to deny their own danger of becoming infected. This is one of the pernicious effects of the stigma associated with AIDS: AIDS is always someone else’s problem. We have seen this phenomenon in virtually every country in the world, including the United States. To counter this lack of perceived personal risk, we are now using what we call a “second generation” of behavior change tools that include social mobilization, skills building, intensive interpersonal counseling and, increasingly, the addition of HIV testing. Having an HIV test often provokes a critical moment of personal awareness.

REDUCING MOTHER-TO-CHILD TRANSMISSION

The number of infants infected with HIV each year through mother-to-child transmission (MTCT) is growing with the increasing number of women infected with HIV. About 55 percent of all new HIV infections in Africa occur among women, most of whom are in their childbearing years. Ten percent of infections—representing some half a million infants—are believed to be attributable to MTCT.

The 1998 findings from the Thai Short Course Zidovudine (AZT) Regimen study in Thailand, and 1999 findings from the Nevirapene Field Trial in Uganda, demonstrated that even simple, relatively inexpensive ARV regimens can substantially reduce MTCT. Recognizing that comprehensive interventions can reduce MTCT rates by as much as half, we now have the tools to expand MTCT prevention programs, especially in those countries with high HIV prevalence. These programs must set standards; promote voluntary counseling and testing (VCT); provide training to health care workers; establish linkages to community-based care services; and scale-up primary prevention for all women.

CARE AND TREATMENT

Basic HIV care services are minimal in many resource-constrained countries. Few infected persons know their HIV status; most health care workers lack the training to treat HIV and its associated infections; and only a few settings have the capacity to use state-of-the-art ARVs, which remain unavailable to the majority of those infected.

Even without ARVs, much can be done to improve the well-being of HIV-infected persons and their families. Foremost must be assuring access to a basic package of care that includes treatment of TB, treatment and prevention of other opportunistic and AIDS-related illnesses and palliative care to reduce suffering and enhance the quality of life. To achieve this goal, networks will have to be established to connect hospital, clinic, faith-based and community-based services.

There must be an investment in expanding effective TB prevention and control programs in key countries. TB is a growing epidemic itself with two million deaths per year worldwide. Because it is the leading cause of death for people with AIDS, efforts to prevent and treat TB must receive special attention.

There is increasing interest in the developing world in the use of combination regimens of ARVs, which can prolong the lives of PLHA. It is inevitable that the cost of these drugs will decrease. Even now, local production of generic drug equivalents and recent price reductions by the pharmaceutical companies have lowered the annual cost for a combination of ARVs to approximately US\$1500 per patient. But it is critical to grasp the complexity of providing ARV therapy in a developing country setting. An effective ARV program requires, at a minimum, four basic components:

1. **A sustainable supply of drugs:** This is life-long treatment and improper use will result in drug resistance.
2. **The capacity to use the drugs:** Most African countries lack the necessary trained health care workers, labs, drug management systems, etc. It is important to remember that the health infrastructure in many of the hardest hit countries is on the verge of collapse. Such basic services as childhood immunization rates are often less than 50 percent (Uganda), the number of attended births is only 33 percent (Nigeria) and the number of trained physicians can amount to only one for every 13,000 persons (Zambia).
3. **An equitable system to apportion treatment in settings where there is not enough to go around.**
4. **Recognition that treatment of HIV does not prevent new infections and cannot replace sound prevention programs.** As ARVs become less costly and the regimens simpler, HIV/AIDS efforts must incorporate ARVs as critical components of their programs.

CHALLENGES IN HIV/AIDS PREVENTION AND CARE, AND MITIGATING THE IMPACT OF THE HIV/AIDS EPIDEMIC

PROVIDING ASSISTANCE TO ORPHANS AND OTHER CHILDREN MADE VULNERABLE BY HIV/AIDS

An estimated 13.2 million children worldwide have lost a mother or both parents to AIDS. Many more children have lost a father to AIDS. Still others are living with and often caring for an ill parent. Ninety-five percent of the children orphaned by AIDS live in Africa. The overwhelming majority of children orphaned and otherwise made vulnerable by HIV/AIDS are living within their extended families and communities. But unfortunately, AIDS is undermining family and community capacity to protect and care for the growing number of vulnerable children.

As part of an expanded comprehensive program, the global community must help build and support local responses through which public, private and voluntary sector donors in the industrialized world can channel resources to national and grassroots programs in the countries hardest hit by HIV/AIDS. The most promising interventions for strengthening the capacity of families and communities to protect and care for orphans and other vulnerable children are systematic community mobilization, capacity building and microfinance services. Together these approaches can be mutually supportive and produce significant, sustainable results.

Community-based programs must support interventions that improve access to education for the most vulnerable children in areas seriously affected by HIV/AIDS. This will include a wide variety of interventions, ranging from policy reforms to direct interventions that enable orphans and other vulnerable children to return to or stay in school.

Grassroots groups urgently need funds and food to support home care for PLHA and to integrate the identification and support for vulnerable children into such programs. These programs need ongoing access to food and medicines to treat the most common opportunistic infections. This can enable parents living with HIV/AIDS to live longer and more comfortably and can also greatly benefit their children. Strengthening these programs can make them an initial point of identification and support for children whose safety and well-being are being undermined by HIV/AIDS.

Our children's children will confront the legacy of this pandemic, and what we are now doing in HIV/AIDS prevention and care will significantly determine the size of the social and economic burden they will have to bear. We are not powerless against the epidemic—there are large-scale responses that have proven successful. Key elements of such responses include strong leadership, openness about the issues and broad-based multisectoral programs at all levels in the community. But the global response thus far has been limited by the following major factors:

- **Political commitment:** There is still a profound lack of political commitment at all levels of government in some of the most severely affected countries, though there has been considerable progress in political mobilization in many countries throughout the world during the past several years.
- **Available resources:** The global pandemic has outstripped available resources. About US\$500 million from all sources (donors, lending agencies and host country contributions) is now being spent on HIV/AIDS prevention programs in all of sub-Saharan Africa. The World Bank, United Nations Joint Programme on AIDS (UNAIDS), U.S. Agency for International Development (USAID) and others in the international community have analyzed the costs of successful programs and developed models to estimate resource needs for the basic components of prevention and care. The estimated costs for sub-Saharan Africa range between US\$2.5 and US\$5 billion per year. This funding would provide prevention services for a majority of the population and basic care and support services for approximately 30 percent of those infected. These funding levels include access to ARV therapies for only about three percent.
- **Stigmatization:** This epidemic is still plagued by the immense problem of stigma. Until persons can talk openly about risk behaviors and whether they are infected or not, we will continue to have weak behavior change and care and support programs.

Figure 13

HIV SEROPREVALENCE IN ADULT POPULATIONS AT THE END OF 2000

Rank	Country	% Prevalence	Rank	Country	% Prevalence
AFRICA			AFRICA — continued		
1	Botswana	36	33	Benin	2
2	Swaziland	25	34	Mali	2
3	Zimbabwe	25	35	Gambia	2
4	Lesotho	24	36	Senegal	2
5	Zambia	20	37	Guinea	2
6	South Africa	20	38	Niger	1
7	Namibia	20			
8	Malawi	16	LATIN AMERICA / CARIBBEAN		
9	Kenya	14	1	Haiti	5
10	Central African Republic	14	2	Bahamas	4
11	Mozambique	13	3	Guyana	3
12	Djibouti	12	4	Dominican Republic	3
13	Burundi	11	5	Belize	2
14	Rwanda	11	6	Honduras	2
15	Cote d'Ivoire	11	7	Panama	2
16	Ethiopia	11	8	Guatemala	1
17	Uganda	8	9	Suriname	1
18	United Rep. of Tanzania	8	10	Barbados	1
19	Cameroon	8	11	Trinidad and Tobago	1
20	Burkina Faso	6			
21	Congo	6	ASIA AND THE NEAR EAST		
22	Togo	6	1	Cambodia	4
23	Dem. Republic of Congo	5	2	Thailand	2
24	Nigeria	5	3	Myanmar	2
25	Gabon	4	4	Sudan	1
26	Ghana	4			
27	Sierra Leone	3	EUROPE AND EURASIA		
28	Eritrea	3			
29	Liberia	3		Ukraine	1
30	Angola	3			
31	Chad	3			
32	Guinea-Bissau	3			

practices and legislation that can empower women. But the real impact of these programs has yet to be determined.

- **The scale of interventions:** Existing prevention programs are not large enough. It is likely that prevention services reach only 10 percent of the world's vulnerable populations. This lack of scale is further complicated by the fact that the global community urgently needs a better understanding of the numbers of persons (coverage within a targeted community) and level of behavior change (e.g., condom use in casual relations) that must be reached to achieve measurable changes in incident infections.
- **Basic care and support:** Incorporating basic care and support for HIV-infected individuals, their families and their survivors (orphans), as well as introducing new interventions—such as the short-course ARV regimens to reduce MTCT—must be done in ways that will enhance rather than diminish the primary prevention agenda.
- **The need for vaccines and microbicides:** There is still a lack of critical technologies that would radically alter our ability to reduce new infections and provide compassionate care to the infected. These include

- **Gender vulnerability:** For both biological and socioeconomic reasons, girls and women are particularly vulnerable to HIV/AIDS. To counter these inherent gender inequities, innovative programs have been implemented that involve a range of activities—such as improving girls' access to basic education, providing women with microfinance opportunities and modifying or adapting cultural

rapid, simple diagnostics for STDs; a vaginal microbicide; simpler, cost-realistic ARV regimens; and, most important of all, an effective preventive vaccine. We urgently need an HIV vaccine and an effective topical microbicide. Our existing interventions do work, if implemented properly and to scale. But these additional tools would make an enormous difference in our ability to combat HIV/AIDS.

INTRODUCTION TO THE HANDBOOK

The Handbook is intended to provide a comprehensive source of information on the design and management of HIV/AIDS prevention and care programs in resource-constrained settings. It is designed to help in the strategic planning, technical and programmatic design of interventions, management of public health programs and resource allocation, and budgeting and financial management.

The Handbook emphasizes cross-cutting issues such as gender, human rights, capacity building, sustainability and community involvement in the design and implementation of interventions.

The Handbook's intended audience includes:

- Program managers, and technical and programmatic field staff.
- Staff of donor and international partner agencies.
- Health care providers.
- Field researchers.

The Handbook chapters are grouped into seven sections:

- I: Design and Management of HIV/AIDS Programs
- II: Reducing Risk and Vulnerability to HIV Infection
- III: Strengthening STD Management and Services
- IV: Reducing Risk of HIV Infection to Infants
- V: Reducing Risk of Parenteral Transmission
- VI: Management and Support of People Infected and Affected by HIV/AIDS
- VII: Prospects for the Future

Each chapter addresses state-of-the-art knowledge on its topic, relevant strategies and approaches, key lessons learned in resource-constrained settings, selected case studies illustrating successful approaches to HIV/AIDS prevention and care in different environments, and offers suggested further reading on the subject.

The editors and authors hope the Handbook will lead to the improved allocation of funds and enhanced knowledge and skill in the management of interventions and control of the HIV/AIDS epidemic.

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glossary of **A C R O N Y M S**

ACTG	AIDS Clinical Trials Group	FCO	Final cost objective
AED	Academy for Educational Development	FHI	Family Health International
AIDS/SIDA	Acquired Immune Deficiency Syndrome	FP	Family planning
AIDSCAP	AIDS Control and Prevention Project	GDP	Gross domestic product
ANC	Antenatal clinic	GPA	Global Programme on AIDS (<i>World Health Organization</i>)
ART	Antiretroviral therapy	HAART	Highly active antiretroviral therapy
ARV	Antiretroviral	HCP	Health care provider
AZT	Zidovudine (<i>also ZDV, generic name</i>) or azidothymidine	HIV	Human immunodeficiency virus
BCC	Behavior change communication	IA	Implementing agency
BSS	Behavioral surveillance surveys	IAA	Inter-agency agreement
C & T	Counseling and testing	ID	Infectious disease
CAPS	Center for AIDS Prevention Studies (<i>University of California-San Francisco</i>)	IDU	Injection drug use(r)
CARAM	Coordination of Action Research on AIDS and Migration	IEC	Information, education and communication
CBA	Cost-benefit analysis	IMPACT	Implementing AIDS Prevention and Care Project (<i>administered by FHI, funded by USAID</i>)
CBO	Community-based organization	KABP	Knowledge, attitudes, behavior and practices
CDC	U.S. Centers for Disease Control and Prevention	KS	Kaposi's sarcoma
CEA	Cost-effectiveness analysis	LE	Life expectancy
CMV	Cytomegalovirus	LOA	Letter of agreement
CSM	Condom social marketing	LTP	Long-term plan
CSW	Commercial sex worker	M & E	Monitoring and evaluation
CUA	Cost-utility analysis	MAC	<i>Mycobacterium avium</i> complex
DAC	District AIDS Committee	MAP	Multi-country HIV/AIDS Program (<i>sponsored by UNAIDS and the World Bank</i>)
DAI	HIV/AIDS Drug Access Initiative	MCH	Maternal and child health
DFID	Department for International Development (<i>United Kingdom</i>)	MOH	Ministry of Health
DHS	Demographic health survey		
DOTS	Directly observed therapy (short-course)		
ECR	Expanded and comprehensive response		

MSM	Men who have sex with men	SOTA	State-of-the-art
MTCT	Mother-to-child transmission	STD/STI	Sexually transmitted disease/infection
MTP	Medium-term plan	STGs	Standard treatment guidelines
NACP	National AIDS Control Program	TA	Technical assistance
NAP	National AIDS Program	TB	Tuberculosis
NASCOP	National AIDS and STD Control Program	TBPT	Tuberculosis preventive therapy
NGO	Non-governmental organization	UNAIDS	Joint United Nations Programme on HIV/AIDS
OI	Opportunistic infection	UNDP	United Nations Development Programme
OVC	Orphans and other vulnerable children	UNICEF	United Nations Children's Fund
OW	Outreach worker	USAID	U.S. Agency for International Development
PCP	<i>Pneumocystis carinii</i> pneumonia	VCT	Voluntary counseling and testing
PEP	Post-exposure prophylaxis	WHO	World Health Organization
PHC	Primary health care	WTO	World Trade Organization
PI	Protease inhibitor (PI is also an acronym for prevention indicators)		
PLHA	Person (or people) living with HIV/AIDS		
PSI	Population Services International		
PVO	Private voluntary organization (<i>U.S.-based, registered with USAID</i>)		
RA	Resident advisor		
REDSO	Regional Economic and Development Support Office		
RH	Reproductive health		

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INTRODUCTION

After many years of inadequate funding for HIV/AIDS programs and speculation that “donor fatigue” was beginning to set in, there seems to be renewed interest and global commitment to redouble efforts and mobilize resources for prevention and care. In this context, it is essential to make optimal use of available resources and integrate the lessons learned to date with the level of response required for scaling-up to achieve national level impact.

The dynamics of HIV and its multifaceted determinants are such that HIV situations now prevailing in a country or even within a specific population may change, sometimes rapidly and dramatically. Planning for effective and relevant responses to HIV/AIDS therefore demands approaches that take into account these different and changing situations and the unique dynamics of HIV. Such approaches are the essence of strategic planning.

Following a brief historical overview of the evolution of national AIDS planning and programming, the first part of this chapter focuses on essential elements and key aspects of strategic planning, specifically of strategic approaches to planning as they relate to HIV/AIDS. The second part addresses specifics of program design and management, particularly in the context of HIV/AIDS programming.

STRATEGIC PLANNING

STRATEGIC APPROACHES TO PLANNING FOR HIV/AIDS

A strategic planning process examines and answers several key questions:

- What is the current situation?
- What is the desired future situation?
- How does one get there?
- How would one go about it?

This section outlines some of the key elements that should be incorporated in a strategic approach to planning.

STRATEGIC PLANNING AND HIV/AIDS

With such a wide range of specific and changing HIV/AIDS situations, planning effective responses to the epidemic requires approaches that take into account the dynamics of HIV and the complex cultural, political and socioeconomic determinants that underpin its spread and influence the consequences. Effective HIV/AIDS programs set priorities, address the complex web of underlying determinants, and recognize the links between prevention and care.

HIV/AIDS AND DEVELOPMENT

The devastating consequences of the AIDS epidemic on the socioeconomic fabric underscore the importance of tackling HIV/AIDS within a broad framework of health and human development. A strategic approach to HIV/AIDS planning must therefore be informed by a thorough understanding of the human development context that shapes and is shaped by the dynamics of the HIV/AIDS epidemic.

THE STRATEGIC PLANNING PROCESS FOR A NATIONAL RESPONSE TO HIV/AIDS

If there is to be a sustainable, effective national response, national governments must be responsible for setting the agenda and leading the entire strategic planning process. Another overarching principle relates to the widespread recognition of the multifaceted nature of HIV/AIDS, its roots in and consequences for human development—and the need for a multi-sectoral, broad-based program that extends beyond the health sector and engages all concerned communities. Key stakeholders, including the broad range of national participants and international partners, must participate genuinely and strongly throughout the planning process.

The three key steps in a strategic planning process, examined in depth in this section, are:

- Situation analysis
- Response analysis
- Strategic plan formulation

PROGRAM DESIGN

The strategic plan will have defined goals, priority objectives, key strategies to reach those objectives, broadly identified responsibility for implementation and a set of broad targets and indicators. The next step will be to translate the objectives into specific work plans—“implementation plans”—for putting the strategic plan into action. This section uses the development of an implementation plan for increasing access to VCT as an example.

EFFECTIVE PROGRAM DESIGN

An effective program design requires careful, rigorous planning to ensure that all of the required program elements are identified and addressed.

It will:

- Start with a clear goal and purpose.
- Define clear program components or “outputs.”
- Spell out major activities.
- Define measurable results.
- Assess risks and assumptions.

This section examines these aspects of effective program design.

THE PROGRAM LOGICAL FRAMEWORK

One method for rigorously formulating an effective program design is the Program Logical Framework, or LogFrame, an organizational schema for conceptualizing and presenting the goal, purpose, outputs, major activities, measurable results and critical risks and assumptions of a proposed program. This section presents the VCT example used in the program implementation section in LogFrame format.

MONITORING AND EVALUATION

The monitoring and evaluation plan is intricately tied to the planning process and needs to be put in place at the start of the program.

A comprehensive program evaluation plan will address process and outcome, and possibly even impact data needed to determine program progress and effectiveness. This section describes two key steps in the implementation process:

- Timeframe and responsibilities
- Budgeting and financial management

SUSTAINING AND SCALING-UP PROGRAMS

The issue of sustainability must address not only financial sustenance but also organizational, technical and management readiness. Planning for sustainability requires, among other things, constructing careful networks and alliances of key partners. Program scale-up is one of the most timely concerns of HIV/AIDS programs worldwide: Unless programs are able to move from “boutique” to massive coverage, even successful programs on the national-level epidemic will continue to have a marginal impact in many instances.

PROGRAM MANAGEMENT

Successful programs require a sound design. But even the most effective design will be jeopardized by a lack of skilled management of human, financial and technical resources within supportive structures and systems. This section examines some of the program management issues that can improve the likelihood—or alternatively reduce the chances—for program success. Many are particularly relevant to HIV/AIDS programming in resource-constrained countries. They include:

- Organizational Development
- Leadership
- Staffing
- Alliance Development
- Advocacy

CONCLUSION

Years of experience, valuable lessons, emerging new technical strategies, expanded partners and increased donor funding all suggest the importance and relevance of strategic planning at all levels and for strong program and project management. It is time to transform limited demonstration projects into an effective, multi-layered, national-level response guided by across-the-board strategic approaches to planning and implementation. Careful, participatory planning will help make the best use of available and future resources as well as offer greater flexibility to respond to new challenges and opportunities.

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I N T R O D U C T I O N

Although there has been considerable progress in understanding and appreciating the many facets and determinants of HIV infection, the likely course of the epidemic is still unpredictable in many countries. The response to the potential threat or the reality of HIV/AIDS is often inadequate and late in coming. Program efforts in most countries have been modest and limited to demonstration-level coverage. After many years of woefully inadequate funding for HIV/AIDS programs and speculation that “donor fatigue” was setting in, there seems to be renewed interest and global commitment to redouble efforts and mobilize resources for prevention and care. In this context, it is essential to make optimal use of available resources and integrate the lessons learned to date with the level of response required for scaling-up to achieve national-level impact.

It is now clear that the pandemic is not uniformly distributed around the globe. And as more and more countries adopt good, reliable surveillance methods, it has also become apparent that the dynamics of HIV and its multifaceted determinants are such that HIV situations now prevailing in a country or even within a specific population may change, sometimes rapidly and dramatically. Planning for effective and relevant responses to HIV/AIDS therefore demands approaches that take into account these different and changing situations as well as the unique dynamics of HIV. Such approaches are the essence of strategic planning.

Following a brief historical overview of the evolution of national AIDS planning and programming, the first part of this chapter describes and focuses on essential elements and key aspects of strategic planning, specifically of strategic approaches to planning as they relate to HIV/AIDS. The second part addresses specifics of program design and management, particularly in the context of HIV/AIDS programming.

STRATEGIC PLANNING

FROM NORMATIVE TO STRATEGIC AIDS PLANNING: A HISTORICAL PERSPECTIVE

One of the characteristics of the early response to HIV/AIDS in the mid- to late 1980s was the remarkable global nature of the effort. Coordinated by the World Health Organization's (WHO) Global Programme on AIDS (GPA), and benefiting from unprecedented financial support from donors, this effort translated within a short time of its inception into more than 145 national AIDS programs (NAP) in resource-constrained countries. Between 1987 and 1991, short-term plans (STP) and national medium-term plans (MTP) for the prevention and control of AIDS were drawn up and implemented with the assistance of WHO/GPA. At the same time, in some of the more affected countries other AIDS projects or programs took shape, funded and often driven by bilateral donors.

In these early years, national plans were naturally articulated around public health approaches and responses to an epidemic. With virtually all NAPs coordinated by and located within ministries of health, it was not altogether surprising that these first plans, largely uni-dimensional and mono-sectoral, focused on the health sector or addressed the biomedical and health-related aspects of HIV/AIDS. But as useful as they often were in providing a framework for planning and implementing a "national" response, the MTPs were largely viewed by countries as "external," or as WHO plans. These perceptions can be attributed to the process of development of the first MTPs, which drew upon local expertise and knowledge but relied on significant international inputs and framework from WHO/GPA.

One important feature of these early planning processes was the application of universal norms and the assumption of uniform contexts in defining strategies and activities. Such normative planning meant there was little attention to individual situations or national needs and capacities. But as the epidemic's growth accelerated in the late 1980s and early 1990s, so too did the realization that an effective response to

HIV/AIDS had to take into account the complex dynamics, determinants and consequences of HIV infection and be relevant to the different situations prevailing in and between countries. By that time, most countries in the throes of an AIDS epidemic had become all too aware that the disease was a multisectoral problem requiring a multisectoral response.

Since the beginning, many NAPs, as well as WHO/GPA, effectively promoted closer collaboration on HIV/AIDS programming between health and other sectors. Still, the responsibility for tackling the problem usually rested squarely and solely on ministries of health. Despite multisectoral representation on national AIDS committees and the commitment of many political leaders to the issue, implementing a coordinated multisectoral response posed a continuing challenge. As a rule, the less visible HIV/AIDS was in a country, the bigger the challenge. But it was to prove no easier even in some of the more severely affected countries.

Against this background, the first MTPs proved to be an inadequate framework for engaging different sectors of government—to say nothing of nongovernmental organizations (NGOs) and other national partners—in a truly national response. The focus of many MTPs on the health sector's responsibilities was as responsible for this failure as the planning processes themselves with their own lack of participation or involvement of key national stakeholders.

WHO/GPA by 1991 had revisited the general approach to the design and formulation of MTPs by NAPs. The process of so-called "second-generation" MTPs sought to generate a more strategic reflection on countries' diverse needs and, consequently, plans that were relevant to the different national situations. It also aimed to address the critical issue of stimulating a truly multisectoral response. This process resonated particularly well with countries where AIDS had by then become a painful reality, with noticeable impact on families, communities and society at large.¹

The second-generation MTPs represent a significant milestone. Within the context of what could be called “the natural evolution” of national AIDS programs from a narrow health focus to a broader multisectoral approach, these new MTPs were useful tools. Despite their limitations, they marked a definitive move from a mostly normative approach to what could be considered a more strategic approach to HIV/AIDS planning.²

But what is actually understood or implied by the term “strategic” and the concept of “strategic planning”? Why is it critical to adopt strategic approaches to HIV/AIDS planning and implementation? What are the key elements or steps in a strategic approach, and what is the broad scope of strategic planning and implementation for HIV/AIDS? These issues are addressed in the next section.

STRATEGIC APPROACHES TO PLANNING FOR HIV/AIDS

What is “strategic” and what does “strategic planning” imply?

It is important at the outset to have a common understanding and appreciation of the term “strategic” and, specifically, what is meant by “strategic planning.” It is easy to create a certain mystique around the subject of strategic planning and argue that it should be left to experts or specialist strategic planners. At the same time, it is often tempting to use the term “strategic” loosely to qualify anything that is even remotely the outcome of a process of reflection and analysis. It is therefore necessary to demystify the subject and spell out the minimal prerequisites of a truly strategic process.

The term “strategy” has its roots in the Greek word *strategia* and refers to the art of generalship in war, i.e., the ability to plan ahead and direct the complex maneuvers and operations of a military campaign. Regardless of the issue or program area it is addressing, a strategic planning process examines and answers the following questions:

- What is the current situation?
- What is the desired future situation?
- How does one get there?
- How would one go about it?

Box 1

KEY ELEMENTS OF A STRATEGIC PLAN

- Assessing all relevant factors that could be contributing to, or impacting on, the situation in question. Depending on the issue or area of work, these may be economic, social, cultural, political and/or geographical.
- Analyzing the current status of these factors and their likely future dynamics.
- Assessing and analyzing the current overall response and/or any specific responses to the issue or program area.
- Identifying major obstacles to such responses and working out how to overcome or circumvent these obstacles.
- Pinpointing opportunities to improve and/or strengthen the response.
- Assessing available and potential resources to enable realistic planning.
- Weighing the most important factors and setting priorities for future action.

Although each question is important in its own right, the first one is fundamental. Any approach to planning that claims to be strategic must be grounded in, and informed by, a systematic in-depth look at the prevailing situations with regard to the specific area or issue. (Box 1 outlines some of the key elements of a strategic plan.)

Such an analysis lies at the core of all strategic thinking and underpins the whole strategic planning process. It serves to map out the steps—or strategies—that enable planners and beneficiaries to adapt a program from a current situation to a desired new situation. These steps can then be translated into discrete activities or groups of activities that are costed out, have specified targets and have defined management and implementation responsibilities.

STRATEGIC PLANNING AND HIV/AIDS

It is particularly critical to plan strategically with regard to HIV/AIDS for at least two good reasons. First, the HIV/AIDS situations at any one time vary between regions and countries as well as within countries, states, provinces or districts. Second, the HIV/AIDS epidemic and its context are far from static and are subject to potentially rapid changes. With such a wide range of specific and changing HIV/AIDS situations, planning effective responses to the epidemic requires approaches that take into account the dynamics of HIV, and the dynamics of the complex cultural, political and socioeconomic determinants that underpin its spread and influence the consequences.

TWO REASONS TO PLAN STRATEGICALLY FOR HIV/AIDS:

- In space—there are diverse and specific HIV/AIDS situations and contexts.
- Over time—there are dynamic changes in the HIV/AIDS situations and contexts.

There are other good reasons to be strategic in HIV/AIDS planning. After all, the HIV/AIDS epidemic has been at least 20 years in the making and there have been many positive as well as some less-than-positive lessons in HIV/AIDS prevention, care and support. With the recent progress made in anti-retroviral (ARV) therapy, the focus has shifted once again to care and the biomedical aspects of HIV/AIDS. But primary prevention lessons from many different settings suggest the continued importance of prevention programs and, above all, that they can work when tailored to specific situations and applied consistently within an enabling environment.

By the same token, clearly effective HIV/AIDS programs are those that set priorities, address the complex web of underlying determinants and recognize the links between prevention and care. Notwithstanding the relentless advances of the epidemic in many parts of the developing world, HIV/AIDS program planners are continually learning *in vivo* what works and what does not. A strategic approach to HIV/AIDS planning requires integrating these many lessons into new responses, and applying or adapting them to specific as well as changing situations.

HIV/AIDS AND DEVELOPMENT

In the last few years, national HIV/AIDS programs have faced the growing challenge of addressing the impact of the epidemic. In many sub-Saharan African countries, and also in parts of Asia, AIDS is increasingly affecting the health care system, communities and families, and indeed the whole social and economic fabric. With the growing number of orphans, the loss of teachers and other skilled professionals and the effects on agricultural production, psychosocial care and support and planning for and managing the socioeconomic impact of the epidemic have become imperative for many countries. Besides the negative impact of AIDS on national development, strategies for development—particularly when they put people in situations that increase their vulnerability to HIV—may actually exacerbate the epidemic.

The devastating consequences of the AIDS epidemic on the socioeconomic fabric underscore the importance of tackling HIV/AIDS within a broad framework of health and human development. At the same time, the dramatic consequences also underscore the importance of prevention and heighten appreciation of the factors that contribute to the situations of risk and vulnerability that drive the spread of HIV. These factors include poverty, illiteracy, gender inequities and inequalities of power and autonomy. A strategic approach to HIV/AIDS planning must therefore be informed by a thorough understanding of the human development context that shapes and is shaped by the dynamics of the HIV/AIDS epidemic.

THE STRATEGIC PLANNING PROCESS FOR A NATIONAL RESPONSE TO HIV/AIDS³

Before looking in detail at the discrete steps in a strategic planning process, it is important to mention some overarching principles.

KEY PRINCIPLES OF A NATIONAL STRATEGIC PLANNING PROCESS

- National or government leadership
- Participation of key stakeholders throughout the process

One of the major lessons of the first decade of national responses to AIDS, and specifically of the development and implementation of national plans, was the importance of national ownership of these plans and the AIDS programs that emanated from them. If there is to be an effective and sustainable national response, it is vital that national governments be responsible for setting the agenda and leading the entire strategic planning process. Nevertheless, when governments are slow to respond it is quite appropriate for NGOs and external agencies to take the lead and show the way. Indeed, in many countries external agencies have often played a key role in provoking and stimulating commitment by governments. But the fact remains that the national authorities should—sooner rather than later—assume a lead role in directing the pace and scope of the national response to HIV/AIDS.

Another overarching principle relates to the widespread recognition of the multifaceted nature of HIV/AIDS, its roots in and consequences for human development, and the need for a multisectoral and broad-based program that extends beyond the health sector and engages all concerned communities. As with governments, there must be genuine and strong participation of key stakeholders throughout the planning process, including the broad range of national actors—public and private sector, NGOs, people living with HIV/AIDS (PLHA)—and international partners, such

as international agencies, NGOs and bilateral donors. Securing their participation from the outset is essential to mobilizing their resources.⁴

THE THREE KEY STEPS IN A STRATEGIC PLANNING PROCESS

- Situation analysis
- Response analysis
- Strategic plan formulation

SITUATION ANALYSIS

The previous section has highlighted the importance of an in-depth situation assessment and analysis as the starting point of a “strategic” approach to planning for any issue or area. The following section looks at this first step in a strategic planning process, specifically with regard to HIV/AIDS planning at the national level. It examines the approaches to carrying out a situation analysis and the elements of information needed to elicit and distill from such an analysis.

The process of situation analysis

A greater understanding of the complex factors that influence the course and evolution of HIV/AIDS in a particular situation has resulted in an appreciation of the range of expertise required for a real in-depth national situation analysis. Assessment teams should include:

Breadth and depth of skills. Moving beyond the biomedical (i.e., epidemiological and medical) focus of the early days of AIDS programming, the team will bring together the breadth and depth of knowledge and skills needed to capture and analyze the social, economic, cultural, religious or other factors that may be contributing to the dynamics of HIV.

All relevant key stakeholders. As many of the key national and international stakeholders as possible should be involved. Not only will they contribute a rich diversity of skills and expertise but, as noted, their participation is important in mobilizing resources. It is particularly important that PLHA

be involved in the planning process. Those who are infected or affected by HIV have much to contribute to this and other relevant activities through their lived experience and the unique perspective it offers on the HIV/AIDS situation.

Box 2 lists the main questions all teams will want to address in a situational analysis.

In probing for answers and deciding upon the areas or factors that are most relevant to in-depth analysis, the team will be guided as much by the available body of epidemiological, social and other research as by the different interests and specific knowledge of the members. As the assessment progresses, the different country situations will dictate the focus of enquiry and distinct areas to emphasize. Many of the factors to be scrutinized overlap or are interrelated, and each team will wish to draw up an appropriate checklist. Such a checklist could include in one form or another these broad categories:

- Population (demographic patterns, population movements).
- Health (health services, health indicators, data on sexually transmitted diseases [STDs]).
- Sociocultural (risk behaviors, education, communication, gender issues, religion).
- Economic (employment patterns, labor migration, etc.).
- Political (administrative structures, government commitment).
- Legal (relevant national policies, discrimination issues, etc.).

Box 2

HIV/AIDS SITUATION ASSESSMENT AND ANALYSIS—MAIN QUESTIONS

- Where does the country stand in terms of HIV/AIDS? What are the likely trends in the near and medium term?
- What major factors and which risk behaviors are driving the epidemic?
- What are the main social or environmental factors contributing to the vulnerability of individuals and communities, and/or placing them in risk situations?
- What impact has the epidemic had or is it likely to have? How and in what areas?
- What are the priority areas or issues that need to be addressed now and in the short and medium term?
- What obstacles are there to improvement or change in priority areas?
- What opportunities are there for positive changes?

The outcome of a situation analysis

The situation assessment provides the team with background information on and insight into the broad context within which the HIV/AIDS epidemic is evolving in the country. The analysis takes this a step further—distilling the relative importance of the various factors at play as well as the interaction between them. The outcome is therefore is not a mere description of the status of the HIV/AIDS epidemic in the country; it is a diagnosis of the major underlying determinants and an identification of groups or populations most vulnerable to HIV and the epidemic's impact. In the process, the team also pinpoints the major obstacles to, and potential opportunities for, improving the situation and strengthening the response. It thus paves the way for elaborating the most appropriate strategies.

OUTCOME OF THE SITUATION ANALYSIS

Provides insight into the specific context of HIV/AIDS in the country, namely:

- Who is most vulnerable and the reasons why.
- What are the priority areas for effecting change.
- What are the major obstacles and how to overcome them.
- What are the opportunities and how to seize them.

SITUATION ANALYSIS IN BURUNDI ⁵

Burundi conducted an HIV/AIDS situation analysis in 1997 involving national program staff, NGOs, PLHA, bilateral agencies, various ministries and the country's UNAIDS technical working group. Besides noting the marked increase in the prevalence of HIV in both urban and rural areas, the analysis underscored the impact of the epidemic on health services and society at large, including a growing number of orphans. It also stressed the contextual factors—war and sanctions—contributing to the vulnerability of large sections of the population to HIV and other harms. These factors had given rise to massive displacements and dislocations, with attendant risks of violence, including sexual abuse. The analysis highlighted the scale of sex work, driven by poverty and conflict (among other forces), and the particular vulnerability of children and young adults, not least within the confines of refugee camps.

Against this background the analysis pointed to the opportunities presented by a very dynamic community environment and the emergence of several NGOs and CBOs. At the same time, it indicated a need for greater coordination and building capacity within those sectors to mitigate the impact on PLHA and their families. Specific obstacles and challenges identified included the sociocultural and religious barriers to effective condom programs as well as the lack of access to appropriate services for care and treatment of STDs.

The situation analysis team arrived at three broad priority areas for the national program: prevention of sexual transmission of HIV; improvement of care and support for PLHA; and reduction of the HIV/AIDS impact on affected families. For each of them, the team further defined strategies for which an adequate response was required.

RESPONSE ANALYSIS

It is clear that a country's response to the epidemic is an integral part of its HIV/AIDS situation. But it is important to distinguish between the situation and response analyses, and to promote them as discrete steps in a strategic planning process. Even though the situation analysis takes into account many elements of an ongoing national response, promoting response analysis as a discrete sequential step after a situation analysis underscores the importance of analyzing the response in relation to the specificities of a situation, especially the priority areas defined by the situation analysis. Were they not separate, the response analysis would tend to focus on what is actually going on rather than what should be done. In short, the conclusions of the situation analysis guide the response analysis.

The response analysis process

Given that situation and response are so intimately connected and that the response analysis overlaps to some extent with the situation assessment and analysis, it makes sense for the same team to be responsible for both steps.

A response analysis primarily seeks to answer the following major questions:

- Is the response relevant to the current HIV/AIDS situation?
- Is it addressing the priority areas and needs identified in the situation analysis?
- What is and is not working? Why?

These in turn will generate critical questions whose answers will guide the formulation of a new strategic plan and inform the development of new strategies. Box 3 lists some of these key questions.

For a start, the team will want to appraise the major activities underway and, in particular, activities in priority areas or priority issues as identified in the situation analysis. It will note any evaluations that may already have been carried out. Besides all the information from the situation assessment itself, a body of specific information and documentation is likely to be available with regard to the priority areas. In areas with apparent information gaps, the team will want to investigate further—through specific interviews with key informants, for example, or through field research and site visits.

Relevance and adequacy

This initial phase of the process will answer key questions about both the adequacy and relevance of the response. What is actually being done to address areas and issues that the situation analysis has pinpointed as critical to HIV/AIDS prevention and impact mitigation in the country? Is it relevant in terms of specificity and adequate in terms of coverage? Are there still major gaps? And, importantly, are there ongoing initiatives that are no longer relevant to the current situation? This inquiry is especially relevant today as countries begin planning for significantly expanded responses.

Box 3

RESPONSE ANALYSIS – KEY QUESTIONS

- How is the country responding to HIV/AIDS?
- Are the responses relevant to the current situation?
- Are some of them no longer relevant?
- Are there adequate responses in priority areas?
- In which areas are they inadequate?
- Are there major gaps?
- Are the responses in priority areas effective or not?
- What is working? Why?
- What is not working? Why not?

Effectiveness and efficiency

After ascertaining the priorities from the situation analysis and determining what responses are still relevant in the current situation, the team will ask questions about the effectiveness and efficiency of the response specifically in relation to the priority areas and issues, including the potential for a scaled-up national response. Is everything working equally well and/or having an impact on the situation in these priority areas? What is and is not working?

Obstacles and opportunities

These answers in turn will prompt questions as to why some things are working and others are not, and stimulate reflection on obvious and not-so-obvious obstacles. Are human and financial resources inadequate? Or are they just inappropriate? Are the activities or strategies plainly unsound? Are the activities culturally unacceptable? Is there resistance from communities or key decision makers? Is there a conflict with pressure groups?

At the same time there should be some reflection on possible opportunities that may have been missed. Are there potential new partners who may contribute to the effectiveness and coverage of activities? Are there opportunities to integrate HIV/AIDS-related activities

into ongoing initiatives? Are there new program initiatives—such as rapid testing technologies or new strategies for reducing mother-to-child transmission (MTCT)—that should be considered for introduction?

THE FOCUS OF A RESPONSE ANALYSIS IS ON:

- ✓ Relevance
- ✓ Adequacy
- ✓ Effectiveness
- ✓ Efficiency
- ✓ Impact
- ✓ Obstacles
- ✓ Opportunities

The outcome of the response analysis

Many national programs rely on program reviews to assess whether they are meeting their objectives and to guide their programming. To the extent that some of these programs are now broad-based and concern several sectors, these reviews generate a fairly comprehensive assessment. But with the changing and dynamic characteristics of HIV situations, program objectives may also need to change.

As such, program reviews may not always provide the strategic focus and reflection on current areas of major relevance to the epidemic and its impact. In contrast, a systematic in-depth situation analysis followed by a response analysis ensures that kind of strategic focus. Together with the situation analysis, the response analysis provides critical and objective insight into the overall context of HIV/AIDS in a country.

CAMBODIA⁶

The National Program in 1997 conducted a situation and response analysis which brought together all the major stakeholders, from provincial AIDS offices to NGOs, bilateral donors, international organizations and the United Nations (UN) system. By that time the country already rated as one of the hardest-hit countries in Asia. The analysis clearly pointed to an epidemic that had spread from core vulnerable groups to the general population and pinpointed the major factors fueling its growth: poverty, migration within the country and across the borders, high levels of STDs and the availability of and demand for commercial sex.

The team of reviewers set out a number of priority strategies and approaches based on the above analysis. Among others, they recommended that the country base geographic and population priorities on the current epidemiological situation. Given the burden of HIV/AIDS they also recommended that provision of care and support be a priority cross-cutting strategy.

With regard to commercial sex work and STDs, major factors in the spread of HIV, specific priority activities were recommended to initiate and expand interventions among commercial sex workers (CSWs) and their clients, promote condom use, especially in sex work settings, and improve the accessibility and quality of STD services. Another area for development and/or improvement was the capacity for voluntary testing and counseling (VCT). At the same time the team emphasized the need for a response to match the dynamics of the epidemic, recommending that socio-behavioral and socioeconomic research be strengthened so as to better inform program design and guide policy.

Box 4 summarizes the ideal cumulative outcome of a situation and response analysis and underlines the importance of these two steps in a strategic planning process.

STRATEGIC PLAN FORMULATION

The situation and response analysis will provide planners and all key stakeholders with the information they need to plan effectively for the future.

The essence of a strategic plan is its relevance to a specific situation. The issues of relevance and specificity are fundamental given that HIV/AIDS situations and contexts are not only different at any one time between and within countries, but they are also prone to often rapid changes over time. HIV/AIDS strategic planning is therefore not just about being relevant but also about remaining relevant. It is about mapping out strategies that are relevant to current situations while remaining alert to the dynamics of these situations and being flexible enough to accommodate changes.

Strategic plan formulation process

Once the situation and response analysis has identified or pointed to specific priority areas for action, the formulation of a strategic plan entails a number of sequential planning steps.

KEY STEPS IN THE FORMULATION OF A STRATEGIC PLAN

- Setting criteria for prioritization.
- Defining and agreeing on the priority areas.
- Setting clear objectives within these priority areas.
- Developing or mapping out the strategies to attain these objectives.
- Defining the broad activity areas within these strategies.
- Identifying and assigning broad responsibilities for implementation.
- Setting broad targets and indicators for monitoring and evaluation.

Box 4

OUTCOME OF A SITUATION AND RESPONSE ANALYSIS

Data and guidance on activities and strategies:

- ✓ What should continue.
- ✓ What could be expanded.
- ✓ What should be reoriented.
- ✓ What should be discontinued.
- ✓ What should be initiated.

It is imperative that there be national leadership and genuine involvement of all key stakeholders, not least those institutions and sectors that are expected to be the major implementors and/or partners in implementation. As stated already, many of the early national plans against HIV/AIDS did not fully address the multidimensional aspects of the problem and many lacked national ownership, being seen as externally driven.

The lessons learned from the past need to be applied most diligently at this stage of formulating a strategic plan. Involvement of all would-be implementing partners will ensure ownership of the plan and have the added benefit of setting up a platform for the kind of collaborative partnerships that are now the hallmark of the more successful and sustainable HIV/AIDS programs.

The outcome of strategic plan formulation

When examining the outcome of strategic plan formulation it is also useful to look at the scope of national HIV/AIDS strategic planning.

SCOPE OF NATIONAL STRATEGIC PLANNING

National strategic planning is often seen as referring only to the process by which a national or central-level plan or framework is developed. But in fact its scope is much wider and includes strategic approaches to planning for HIV/AIDS at decentralized levels—provincial, state, even municipal—and also with respect to planning on thematic areas or project development.

Within large countries it is evident that different situations need to be understood and addressed accordingly. In China, India or Nigeria, adopting strategic approaches to planning at provincial, district or county levels is clearly as critical as the need for a national or central-level framework. But even moderate-size countries can exhibit more or less important internal differences with regard to the epidemic, its determinants and impact.

Likewise, when planning for national responses in specific “thematic” areas (e.g., injection drug use and HIV, STD prevention and care, blood safety) or even when it comes to discrete projects from NGOs or community groups, the application of strategic approaches and thinking as described for national-level planning remains as valid and important.

The content and scope will naturally differ for “national” strategic plans per se and those that are developed for decentralized levels or “thematic” areas. At a national level, the outcome is likely to be a framework that sets out key principles and policies, major objectives and the broad strategies to reach those objectives. Progressing to a more decentralized level—with provincial or district plans, for example—more detailed objectives would be expected, with correspondingly more detailed strategies and discrete activities.

Strategic planning should not be confused with implementation planning. Strategic planning will focus broadly on the strategies, resources and targets of the national (provincial or district) program, while implementation planning will provide more detailed attention to how the strategies are to be carried out. It will look in particular at how resources will be allocated as well as the annual, interim steps for achieving the broader strategic planning targets.

CHINA⁷

In 1997 the Chinese Ministry of Health carried out an HIV/AIDS situation assessment with support from the UN system and other national and international partners to map out the priorities and needs for an effective Chinese response to the problem.

The result was a national-level, medium-to long-term plan that set out broad national objectives and strategies. These have to be reflected in specific provincial and local government policies and strategies according to their respective situations. Given the size of China, these situations are as different as they are complex and there has to be a strategic approach to planning at the local level.

The UN system and others are collaborating with a core working group on strategic planning at the central level and with local authorities to address these different and specific situations. A pilot situation and response analysis is being conducted in one province, Guangxi, at the provincial as well as the more decentralized prefectural and county levels. These served to guide similar processes in other provinces in 2000.

In this way China is implementing its policy of planning its AIDS prevention and care activities in a way that matches the diverse and changing determinants between provinces, counties and municipalities.

In all cases, successful strategic approaches to HIV/AIDS planning result in plans that are relevant to specific and changing situations, have clear responsibilities for implementation, appropriate targets and indicators for monitoring and evaluation and are realistic about available resources.

RESOURCE MOBILIZATION

Resource mobilization is often seen as an activity that complements and takes place exclusively after the planning process and the elaboration of a plan. Often it also equates with the mobilization of new or additional resources, or only with financial resources.

Resource mobilization is in fact an integral part of a truly strategic planning process and should refer to mobilizing financial resources, people, communities, goods and services. It has at least as much to do with making better use of available resources as with securing additional ones.

RESOURCE MOBILIZATION IS ABOUT

- ✓ **Funds . . .** but also people, goods and services
- ✓ **Mobilizing new resources . . .** but also better utilization of available ones

There are a number of ways in which resource mobilization effectively takes place through a well-managed strategic planning process. First is the involvement of key stakeholders and potential donors throughout the process. Besides the ownership issue it resolves, such involvement goes a long way towards mobilizing the resources of the various concerned communities for future implementation. At the same time it helps to strengthen partnerships and build new ones. Identifying new partners and involving both public and private sectors in the planning process is a fundamental strategy for countering the multifaceted determinants and consequences of HIV/AIDS.

Secondly, the processes of situation and response analysis contribute to the optimal allocation and use of available and potential resources by provoking reflection on, and providing answers to, the following key questions:

- Is the current response relevant?
- Are current responses effective? Are they cost-effective?
- What are the priorities now?
- Are there opportunities for reprogramming and/or reallocating resources?

By pinpointing interventions that are less than effective, adopting and adapting “best practices” or lessons learned, setting priorities and allocating resources accordingly, strategic planners are indeed maximizing the use of available resources.

Of course additional or new technical and financial resources will be required in the resource-constrained settings within which most national HIV/AIDS programs have to operate. But by demonstrating their ability and commitment to make judicious use of existing resources, national programs will be all the more successful in raising new ones. Plans that result from genuine strategic planning processes are a concrete expression of that ability and commitment, as is demonstrable national political leadership on the issue. Together they are a powerful means of mobilizing both external and international resources.

The next section looks at the issues of program design and management which are so critical to successful implementation.

PROGRAM DESIGN

PROGRAM IMPLEMENTATION⁸

The strategic plan will have defined goals, priority objectives, key strategies to reach those objectives, broadly identified responsibility for implementation and a set of broad targets and indicators.

The next step will be to translate the objectives into specific work plans (or “implementation plans”) for putting the strategic plan into action.

There are key implementation strategies for each objective: a purpose, strategic outputs, measurable anticipated results, activities, inputs, an estimated timeframe, responsibilities for all partners, a monitoring and evaluation strategy and a budget.

As with strategic planning, operational planning and execution can be carried out at central, provincial or local levels. Strategic plans are often set within a timeframe of three to five years, but the implementation plans or work plan should be set year by year to allow for greater specificity of the work being planned and the flexibility needed to adapt to change in future years.

It is always tempting to overdo an implementation plan by making it too ambitious, perhaps to impress funders, boards or departmental heads. Program managers should resist this as much as possible so that the plan remains feasible, realistic and one that can be successfully delivered.

The plan's focus is *well-planned action*.

- Great plan and no action = no use
- No plan and lots of action = little use

MAIN ELEMENTS OF A WORK PLAN/IMPLEMENTATION PLAN

For each strategy there will be a program design that clearly articulates the

- Purpose
- Strategic outputs
- Measurable anticipated results
- Activities
- Inputs
- Estimated timeframe
- Responsibilities of all partners
- Monitoring and evaluation strategy
- Budget

This section uses the development of an implementation plan to increase access to VCT as an example. (For a comprehensive examination of the role of VCT in HIV care and prevention programs, see Chapter 23.)

VOLUNTARY HIV COUNSELING AND TESTING (VCT): THE ISSUES AND A LOCAL SOLUTION

Background

Imagine that the situation analysis has estimated that less than five percent of those believed to be infected with HIV actually know they are infected. In addition, virtually all those interviewed and involved in the situation analysis expressed the concern that despite estimated adult HIV prevalence levels of 25 percent, very few people in urban or rural areas are involved in HIV care and prevention.⁹ The response analysis revealed that only three dedicated VCT centers exist, and these are located in the capital city. It also revealed that there is little integration of VCT in either STD services or primary care services, and found that training in VCT is sporadic and not systematized.

Thus, a program's strategic *objective or purpose* might be to increase the accessibility and use of HIV counseling and testing services. If this is achieved, it will contribute significantly to the overall objective or goal of reducing the incidence of HIV.

Objective Target

Increase by five percent per year the level of those estimated to be HIV infected who receive testing and counseling.

Strategic Outputs

- Establish national policy on VCT.
- Improve accessibility of VCT services.
- Establish post-test support clubs for PLHA.
- Institute VCT service providers skills development program.
- Establish VCT program management and coordination structure.

EFFECTIVE PROGRAM DESIGN

An effective program design requires careful, rigorous planning to ensure that all the required program elements are identified and addressed. It also ensures that extraneous activities—those that take up scarce resources and time but do not specifically help to achieve program outputs—are avoided. It also takes into account the external but relevant conditions and collaborations necessary for success.

Effective program design will:

Start with a clear goal and purpose

The program goal is the highest level, a program's ultimate objective. The program alone generally can't achieve this objective—reducing the incidence of HIV in a specific country, for example—though it will help achieve it. The overall objective of the program is its main purpose. The program should be able to achieve this objective if the design is successfully implemented. The purpose needs to be carefully and specifically articulated since it is the ultimate measure of the program's effectiveness. The purpose of a VCT program might thus be “to increase the accessibility to and use of HIV VCT in country X.”

Define clear program components or “outputs”

Program outputs are the major components that need to be undertaken to achieve the purpose. These must be clearly defined from the beginning since activities will be directly linked to them. A VCT program's major outputs might be: (1) Establishing a national VCT policy; (2) Improving access to VCT services; (3) Establishing post-test VCT clubs for PLHA; (4) Establishing a VCT service providers training institute; and (5) Establishing a management/coordination structure for the program.

Spell out major activities

Major activities are those broad tasks to be completed to produce a given output. Activities that are not specifically relevant to achieving outputs should be avoided since they will, in fact, draw time and effort away from successfully achieving the program purpose. Carefully articulating the major activities and resource inputs needed to achieve the desired outputs will help the designers judge whether the planned outputs are realistic given the available resources. Major activities for establishing a national VCT policy, for example, might include establishing a working group, consulting with relevant communities, developing and presenting a consensus strategy for consideration, adapting it as a result of the consultative process and finalizing and disseminating it.

Define measurable results

Program indicators describe how the program will define success. They need to be articulated for the purpose and outputs. The program indicators specify in measurable terms what is to be ultimately achieved; benchmark indicators allow one to assess periodic progress toward reaching the target. Effective indicators are those that are specific, measurable, appropriate, realistic and time-bound (SMART). An indicator for improving accessibility of VCT services might be “three integrated services in the capital city and one rural center established by program month 12” or “A hundred VCT clients tested per week by month 18.”

Assess risks and assumptions

Every program relies on specific external factors and conditions that need to exist for it to run smoothly. An NGO’s post-test club program for HIV-positive youth, for example, may rely on government-provided condoms and quality public sector STD services. External policy factors, e.g.,

legal restrictions on the promotion of condoms to youth or the openness of the community in allowing meaningful dialogue with youth on matters of sexual health, can present challenges to key program components. It is useful for each output to carefully consider and clarify its inherent key assumptions for successfully reaching the planned outcomes. In many instances, factors that initially appeared “external” may well be within some realm of action by the program. For example, if the district health team or NGO is not confident about community reaction to condom promotion for sexually active youth, program managers can simply risk launching the program and hope for the best—or they can build in an early consultation and advocacy component to cultivate the support and seek the ideas of key stakeholders and influencers in the community for working with youth who are living with HIV. It is important that programs carefully monitor the external assumptions and risks for any negative impacts and consider alternative strategies should they become necessary.

THE PROGRAM LOGICAL FRAMEWORK

One method for rigorously formulating an effective program design is the Program Logical Framework, or LogFrame. A LogFrame is an organizational schema for conceptualizing and presenting the goal, purpose, outputs, major activities, measurable results (and how those results will be captured) and critical risks and assumptions of a proposed program. At the activity level, the LogFrame summarizes resource inputs required to undertake the program. When used as a participatory design tool with key stakeholders, the LogFrame provides a structure for clearly defining the program purpose, logically thinking through the key program elements (outputs) necessary to achieve the purpose and the major activities needed to produce each output. By actively considering the external risks and assumptions at the time of design, program planners are able to assess whether these “externalities” can be internalized or incorporated into the program design. They can also assess whether the program can identify strategic alliances and partnerships that will

Program Description	Objectively Verifiable Indicators	Means of Verification	Risks & Assumptions
<p>Goal: To reduce the incidence of HIV in Country X.</p>	<p>HIV incidence reduced from ___% to ___% by 2004 among target populations.</p>	<p>Incidence study</p>	<p>Those tested adopt risk reduction behaviors.</p>
<p>Purpose: To increase accessibility to and use of HIV VCT services in County X.</p>	<p>The level of PLHA who receive counseling and testing increases by 5% per year through 2004.</p>	<p>Clinic records</p>	
<p>Outputs:</p> <ol style="list-style-type: none"> 1. National policy on VCT established. 2. Improved accessibility of VCT services 3. Post-test support clubs for PLHA established. 4. VCT service providers skills development program instituted. 5. VCT program management and coordination structure established. 	<ol style="list-style-type: none"> 1.1 Policy adopted by month 12 and disseminated broadly by month 18. 2.1 Three integrated services in capital city and one rural center by month 12. 2.2 One hundred clients per week being tested by month 18. 2.3 Three new rural VCT sites established serving 20 clients per week by month 12. 3.1 Post-test clubs to have membership base of 150 by month 12. 3.2 One new financial supporter identified by month 12. 4.1 X staff trained per year. 5.1 Organizational structure approved by MOH by Month 2. 5.2 All management unit staff in place by Month 6. 	<ol style="list-style-type: none"> 1.1 Policy document 2.1 Clinic records 2.2 Clinic records 2.3 Clinic records 3.1 Quarterly program reports 3.2 Quarterly program reports 4.1 Quarterly program reports 	<p>Donor funding is available to ensure a steady supply of test kits.</p> <p>Strategic alliances are formed with community groups who can provide follow-on PLHA and their families.</p> <p>Stigmatization regarding HIV testing is reduced.</p>
<p>Activities:</p> <ol style="list-style-type: none"> 1.1 Establish working group. 1.2 Consult with communities. 1.3 Present consensus strategy. 2.1 Integrate VCT into existing antenatal/MCH services. 2.2 Expand capacity of central referral clinic. 2.3 Establish three new VCT clinics in rural centers. 3.1 Appoint board for post-test clubs. 3.3 Establish full range of services. 3.4 Establish new financial supporters. 4.1 Develop curricula for service providers. 4.1 Conduct training for staff. 5.1 Identify key staff. 5.2 Produce organizations structure proposal. 5.3 Finalize structure based on MOH input. 	<p>Inputs required:</p> <ol style="list-style-type: none"> 1. Staff salaries, transportation costs, facilities for meetings, printing and distribution costs. 2. Staff, training, test kits, local promotion, facilities renovation, stationery. 3. Staff, training, volunteer support, meeting costs, material support for PLHA. 4. Staff, training, teaching materials, facilities. 		

need to be established. By providing in a one-page table the descriptive program information, anticipated results and how they will be measured and the key assumptions, the LogFrame is also a very useful overview and monitoring tool. LogFrames can be used inappropriately by some as a prescriptive model to achieve the ends of planners (to have a plan) without respecting the process of consulting key stakeholders. To be effective, they must be used in a participatory, consultative manner.

The VCT example discussed above is presented above in LogFrame format.

MONITORING AND EVALUATION

Managers need to monitor the progress of program implementation and find out whether activities are being carried out as planned, with regard to the timeframe and planned resources, and whether the activities are having the anticipated impact. (For a comprehensive discussion of program evaluation and surveillance, see Chapter 5.)

Developing a monitoring and evaluation plan is a critical task and a key management tool for:

- Assisting and guiding managers in adapting the strategies and activities to increase their effectiveness in a timely fashion.
- Providing information about the program's progress and effectiveness to decision makers and funders.

A comprehensive program evaluation plan will address process and outcome and possibly even impact data needed to determine program progress and effectiveness. Process data will allow the program managers to measure implementation targets such as the number of people reached, condoms distributed, people seeking STD services, individuals referred for counseling and HIV testing, schools that have instituted HIV education programs or PLHA who have been referred to community support services. Outcome data reflect behavioral results of target audiences such as the percentage of the target audience who report condom

use with the last non-regular partner, knowledge of prevention methods or who were treated correctly with standard treatment protocols. Impact data generally refer to biologic targets, such as reductions in STD or HIV incidence.

The overall program evaluation plan will probably be articulated in the broader, multi-year strategic plan. For the work plan, it will be important to note the evaluation/monitoring activities to be conducted during the specific year, as well as the periodic targets. Paying attention to the process data that measure the progress of program implementation will help determine whether the program is reaching its service objectives. If not, it will provide an opportunity to analyze what the program needs to do to get on track.

The monitoring and evaluation plan must be put in place at the start of the program. Setting goals and productivity targets helps to motivate and assess performance, particularly when the targets are realistic and relevant to available resources. The monitoring and evaluation plan is thus intricately tied to the planning process.

Timeframe and responsibilities

This step provides a “reality test” for the design by spelling out the implementation partners and the timing of activities. Considerations at this step will include assessing the readiness of partner institutions to participate, the feasibility of implementation staging and the time proposed for program start-up and implementation. It will also provide an indication of the intensity and timing of funding requirements as the program moves through the stages of planning toward launch and full-scale implementation.

An implementation schedule provides in tabular format a summary of the major activities in a timeline. It shows who does what, by when and in what order. It also clearly displays the temporal relationship between major activities and helps to ensure internal consistencies for program launch and implementation. Thus, for example, behavioral research that will serve as the evaluation baseline for a post-test club PLHA support program will need to be conducted early on in program implementation. These data will also be useful in preparing outreach educational materials, and

SAMPLE TIMELINE FOR STRATEGIC OUTPUT 1

Timeline	Month 3	Month 6	Month 9	Month 12
Strategic Output 1: Establish National policy on VCT				
1.1. Convene working group.	X			
1.2. Consult communities, rural areas, major NGOs.	X			
1.3. Prepare draft policy for circulation and comment.		X		
1.4. Finalize draft policy based on input.				X
1.5. Present revised document for departmental approval and financial support.				X
1.6. Disseminate policy to all health centers and other appropriate entities.				

Figure 1

SUMMARY BUDGET

Title: Kenya VCT — Project ID #: 4558-89

	Fiscal Year 02	Fiscal Year 03	Life of Project
	1 October 2001 30 September 2002 12 months Kenya shillings	1 October 2002 31 March 2002 6 months Kenya shillings	1 October 2002 31 March 2002 18 months Kenya shillings
1. Salaries	326,667	163,333	490,000
2. Fringe Benefits	65,333	32,667	98,000
3. Consultants	1,658,000	410,750	2,068,750
4. Equipment/Procurement	108,500	11,500	120,000
5. Travel/Transportation	433,333	216,667	650,000
6. Office Expenses	115,403	57,701	173,104
7. Other Direct Costs	1,854,007	270,993	2,125,000
Total Project Costs	4,561,243	1,163,611	5,724,854

are thus key to the process. Educational materials must be made available before interpersonal outreach can begin. The timeline will help determine the sequencing of inputs and activities. It also will help program managers take into account realistic timeframes for the various program stages—planning, launch, pilot testing, planning for scale-up and

program expansion. The implementation schedule will also provide a quick reference for monitoring progress of activities and anticipating where subsequent, dependent program activities may either be ready to start earlier or need to be delayed. It is therefore useful to keep the implementation schedule in a visible place so it can be referred to often and easily updated as needed.

Budgeting and financial management

Among the data that program managers should monitor closely is financial information. Budgeting is a straightforward process that defines the financial resources needed to implement the proposed work plan. Budgets need to:

- Provide enough detail to allow effective monitoring, but be simple enough to allow managers to easily comprehend what is important and be periodically updated without too much trouble;
- Distinguish between recurrent costs (e.g., salaries, rents, fuel, transportation costs) and less frequent capital costs (e.g., computers, vehicles); and

- Provide sufficient estimation leeway to accommodate small, unanticipated costs or small cost overruns.

Standard line items are salaries, salary benefits, consultants, travel/transportation costs, procurement, and other direct costs. A sample budget is provided in Figure 1.

It is not uncommon for program managers to relegate development and monitoring of the program budget to “finance people.” But it is clearly important in managing a program to know whether the budget

Figure 2

FAMILY HEALTH INTERNATIONAL
Kenya VCT — Project ID #: 4558-89

Budget Line Item	FY02 Budget	Q1	Q2	Q3	Q4	Total FY01	Budget Remaining
I Salaries	326,667	74,321	95,788	95,788		265,897	60,770
II Fringe Benefits	65,333	14,864	19,158	19,158		53,179	12,154
III Consultants	1,658,000	258,845	455,858	501,852		1,216,555	441,445
IV Equipment/Procurement	108,500	45,850	54,790			100,640	7,860
V Travel/Transportation	433,333	75,855	89,523	154,852		320,230	113,103
VI Office Expenses	115,403	24,458	35,450	43,500		103,408	11,995
VII Other Direct Costs	1,854,007	156,384	569,211	456,235		1,181,830	672,177
VIII Total	4,561,243	650,577	1,319,778	1,271,385		3,241,739	1,319,504
Budget Summary							
FY02 Budget	3,816,569						
Total Expended	3,241,739						
Remaining Balance	574,830						

is adequate and spending is proceeding as planned. Financial expenditures are one important indication of program pace. By actively monitoring program expenditures it is also possible to identify over-expenditures that may jeopardize the availability of funds for other elements of the program or, alternatively, any budget savings that can be applied in a timely manner to unfunded or underfunded program areas. Program managers should work closely with financial officers to regularly study the budget and program expenditures tracked against it.

A number of simple tools can help in monitoring the budget. A simple graph plotting planned quarterly expenditures against actual expenditures provides a useful visual presentation of spending rates. A quarterly expenditures table by major line items showing annual budget and remaining balance allows managers early on to identify expenditure trends and potential financial constraints.

SUSTAINING AND SCALING-UP PROGRAMS

The concept of sustainability generally relates to the ability of the implementing organization and partner organizations involved in the program to continue to pursue the objectives when initial funding ceases or is diminished. While securing long-term financial resources is critical to a program's continuity, it is essential for program managers to look more broadly at the issue of sustainability.

First, one must ask whether the program should be sustained and, if so, at what level and via what mechanisms. Determining whether a program should be sustained is a matter of assessing the need for it and its level of success in addressing this need. If there is a need and the program is successfully addressing it, the implementing organization must consider the appropriate level and mechanisms for continuing it. Is the program meeting all of the identified need? If not, how can it be expanded or scaled-up? Can the current implementation structure be extended to accommodate the need for growth, or should the implementing agency/agencies take on additional partners? Should the primary implementing agency evolve from an

implementing body to a facilitating agency, catalyzing the participation and adoption of the program by other organizations? Is there sufficient capacity to continue or expand the program?

In this context, the issue of sustainability must address not only financial sustenance but also organizational, technical and management readiness. Planning for sustainability requires, among other things, constructing careful networks and alliances of key partners who share a common vision and commitment to the point of contributing their own unique resources to seeing it fully take hold. If, for example, a pilot life skills program is being carried out in the education sector, a comprehensive alliance of educators from the senior education policy arena—from decision makers to the teachers who will ultimately be responsible for teaching the curriculum—must be involved from the beginning so they have a sense of ownership in continuing and expanding the program after initial funding runs out.

Program scale-up is one of the most timely concerns of HIV/AIDS programs worldwide. Clearly, unless programs are able to move from “boutique” to massive coverage, the impact of even successful programs on the national level epidemic will continue to be marginal in many instances.

Table 1
KENYA VCT FY 02 BUDGET—
EXPENDITURE ANALYSIS (PROJECT ID#: 4558-89)



PROGRAM MANAGEMENT

As noted earlier, successful programs require a sound design. But even the most effective design will be jeopardized in the absence of skilled management of human, financial and technical resources within supportive structures and systems. It is not uncommon for competent technical experts, specialists and community activists to find themselves in management positions though they have little training or experience making decisions, which can leave them at times feeling uncertain or even uncomfortable. Finding the time to access formal management training, even finding time to read management books, is often difficult for busy managers who relegate skills upgrade to the bottom of their priority list. Finding a mentor, someone with good management skills who can regularly consult and provide support and feedback, is often a more viable strategy with timely benefits.

The remainder of this chapter examines some of the program management issues that can improve the likelihood—or alternatively reduce the chances—for program success. While many of the points apply broadly to management, many are particularly relevant to HIV/AIDS programming in resource-constrained settings.

Successful program implementation rests on effective management of human, financial and technological resources.

ORGANIZATIONAL DEVELOPMENT

The way that individuals in an organization relate to each other through formal structures and shared values will have a major influence on their effectiveness.

Organizational structure

Structure should always follow the objectives and functions of the program, not the other way around. It is important to articulate the organization's objectives and functions before determining the kinds of skills and structures an institution needs to achieve its mandate. Structures, systems and processes that facilitate rather than hinder the achievement of an organization or program's objectives will be:

- As simple as possible.
- Clearly articulated and understood by all.
- Transparent in their rationale.
- Responsive to the evolving size of the organization and program mandate.

This last point is important as it suggests that structures, systems and processes need to be reviewed periodically so they continue to be relevant and support the organization and its programs. This is especially important for HIV/AIDS programs, which often start small but may grow rapidly, particularly with the emphasis on program scale-up. In these instances system development often lags.

Organizational culture and values

Organizations often rely too much on structure alone for their smooth functioning. When major problems arise, their automatic reflex is often to restructure the organization rather than deal with its underlying values and culture.

In one STD clinic there were major problems with staff morale and conflict, leadership and job performance. The staff blamed these problems on the physical surroundings of the clinic and its internal structure. These were both changed, but the problems remained simply because the central issues of leadership, performance management and staff morale were not addressed.

The values to which a program aspires and adheres should be developed with the broad participation of all parts of the organization, and be clearly articulated, disseminated and strongly supported by all staff, particularly the leadership team. Such values might include honesty, openness of information, integrity and teamwork. The process of articulating organizational values should be more than an exercise in brainstorming lofty rhetoric. Giving lip service to values that are not put into action will contribute to declining staff morale and lower productivity.

The culture and values that are adopted should be consistent with the values needed for effective HIV prevention and care, such as the participation of those infected and affected by HIV, commitment to dissemination of open and honest information and non-discrimination.

Posting your culture and values on the wall will encourage you and other staff to stick to them.

LEADERSHIP

HIV/AIDS programs around the world have notably been led by strong, charismatic individuals, whose distinctive styles and characteristics are clearly imprinted on the work of their organization. While their drive and passion have frequently been primary motivators for program success, effective leaders know that more than “star quality” is required to consistently deliver productive and sustainable programming.

Characteristics of leaders

There are many different analyses of the characteristics of effective leaders and managers. While different characteristics and skills are needed in different cultures, the following are typical leadership qualities¹⁰:

- **Self-awareness:** the ability to recognize one’s moods, emotions and drives, as well as their effect on others.
- **Self-regulation:** the ability to control or redirect disruptive impulses and moods, to act rather than just react.
- **Motivation:** a passion for work that goes beyond status and money.
- **Empathy:** the ability to understand others.
- **Social skills:** skills in managing relationships and building networks, and the ability to find common ground and build rapport.

Effective leaders also:

- **Understand the difference between leadership versus management.** Leadership involves providing the vision, inspiration and encouragement to all program participants, and management involves direct supervision of staff who report to a manager. Effective leaders will manage only the staff members who report to them and leave management of other staff to the managers concerned.
- **Delegate.** In many public health programs where managers often have little formal management training, managers often try to “over-control” program implementation and their staff. Organizations and individuals invariably work most productively when staff have clear delegation of responsibility together with the necessary authority.

- **Manage information efficiently.** Most AIDS programs manage a huge amount of information, including correspondence, requests for briefings, reports and new information about the many aspects of the epidemic. Effective leaders will develop a mechanism for dealing with issues rapidly, such as using the principle of “touching paper only once.” It is important to make a decision about the appropriate action generated by a briefing—such as write a letter, request more information or send an e-mail—at the time of first encounter, rather than deferring action and possibly forgetting about it. Such delays in responding can be very demoralizing for staff or stakeholders who may have gone to great lengths to prepare the document or briefing and whose follow-up is stymied until a response is received. This also relates to the next issue.
- **Set priorities.** Most AIDS programs place too many demands on too few managers who may find themselves reacting only to the urgent issues or the easy ones that do not require much “thinking time.” But it is the important issues—particularly those addressed in the implementation plan—that need to be dealt with as priorities, not the urgent or easy ones. Effective leaders try to spend some time every couple of weeks to refocus on the major issues in the implementation plan.

Effective leaders or would-be leaders often have a personal plan for building their leadership skills, including identifying a mentor for ongoing advice and guidance.

STAFFING

Most HIV/AIDS programs struggle with staffing issues. All too often in the public sector, HIV/AIDS responsibilities are added on to already full portfolios. In the private NGO sector, staffing is limited by insufficient funding. In both sectors, inadequate remuneration, poor skills and burnout affect performance. This is why recruiting, supporting and guiding high quality and suitable staff are key to effective HIV/AIDS programming.

Post descriptions

Position descriptions need to be well-formulated and clear and fit into the overall structure of the organization (see below). As a guide they should cover the following areas:

- Objectives (what the job is trying to do).
- Organizational context (how the job fits into the overall structure and function of the organization).
- Responsibilities (specific tasks and areas covered).
- Accountability and reporting (clear account of reporting requirements, which should also include responsibilities of the supervisor).
- Special features (of the job, the organization or the external environment).
- Knowledge and skills requirements (these are key selection criteria for the post).

Recruiting

The process for selection should be clear to all concerned and should be as open as possible to find the best candidates and be consistent with organizational values of transparency and integrity. After a clear position description is prepared, it should remain at the core of assessing and recruiting the candidate. Candidates whose skills and background are simply not well matched to the post—regardless of how impressive or passionate about the work they may be—should not be selected with the intent of “fitting them in” or recasting the job. It is important to match the requirements of the post with the skills and experience of the candidates.

As HIV/AIDS programs evolve beyond their originally limited scopes, there is a tendency to promote people beyond their level of competence. Premature promotion can be damaging both to the individual as well as the organization. To the extent possible, program managers should actively support professional development to prepare staff for additional responsibilities before they are considered for promotion.

Professional development

As noted, it is in the best interests of the organization and staff to institute a system for professional development. Most people come to a job with only 60 percent to 80 percent of the skills and experience needed to best carry out the post. So it is important that they have the opportunity to develop some level of skills “on the job,” for which time and a small budget need to be allocated. This professional development also becomes part of performance management.

One often overlooked area of professional development is communication and presentation skills. Most programs require interaction with a large number of internal and external colleagues and partners. Several staff across the program should be able to convincingly and clearly articulate the program’s goals, activities and successes.

Performance management

This is perhaps one of the most difficult, but essential, areas of human resource development. Performance management requires regular formal and informal communication between managers and staff. It is key to ensuring reflection and analysis of effectiveness and efficiency, and to identifying in a timely fashion adjustments that may be needed to schedules and objectives. Managers should remember to praise strong performance, identify performance problems and address how the manager can facilitate greater performance.

Individual work planning

Individual work plans articulate the expected output from each staff member. They also spell out the distinct contributions of various team members across the program toward the achievement of the program objectives. Individual work plans should be derived from the implementation work plan of the program as a whole, and then from the work plan of the units or teams. Often a great deal of time is spent in developing detailed work plans that are not followed. This is why it is important to develop flexible, relatively easy and quick individual work plans that can be referred to regularly.

Moving staff on

Sometimes people are in positions where they are not performing and, despite their own and their supervisor's best efforts, their performance may not improve. This can refer to staff who do not have the skills they need to perform well in a specific job, may be "burned out" or insist on controlling or blocking the activities of colleagues or the staff they supervise. In this case it is in both the individual and organization's interest to help the individual find alternative employment.

Volunteer staff

Many community-based HIV/AIDS programs rely heavily on the support of volunteer staff. Volunteers significantly expand the capacity of NGOs and CBOs. But they present special human resource management issues. Performance management takes on special nuances for these programs. Individuals who volunteer often hope their volunteer status will evolve to paid employment at some point. They can become quickly disillusioned when this does not materialize. Sustaining motivation and expecting quality performance can be challenging. Many projects find they need to search constantly for volunteers to replace those who have faded out of the program.

Despite their heavy reliance on volunteers, many programs have only a rudimentary knowledge of how to manage these special staff. It is essential for programs that rely on volunteers to understand what motivates people to volunteer and what will retain their interest in doing so. Program managers need to ensure that there is consistency between volunteer motives and what the program can reasonably offer in return. Aside from the possibility of paid employment, many people volunteer out of a strong desire to help or be seen as a leader in their community. HIV/AIDS programs can satisfy these motivations, though doing so requires specific action on the part of program management. This can include:

- Involving volunteers in program design, implementation, monitoring and evaluation decisions.
- Reporting back to them on the successes of their combined efforts (e.g., comparing current and previous behavior change survey results or counting the number of people in the community

reached by the program, those who have come forward for counseling and HIV testing, or the number of condoms that have been distributed).

- Providing volunteers with a "career path" of increasing responsibility (e.g., from peer educator, to peer educators group leader, to peer educator volunteers coordinator).
- Taking time to recognize their efforts (e.g., writing letters of thanks or congratulations for personal achievements; celebrating their birthdays; selecting "Volunteers of the Year"; honoring them at an annual general meeting and sending a press release to the local media; and encouraging them to help promote the program in press conferences and in meetings with donors).

It is important to recognize and plan for the possibility that volunteers will eventually want to leave the program. The program should clearly show its appreciation for their participation through whatever means may be possible, and volunteers should be encouraged to be informal "ambassadors" for the program within their community.

This kind of support for volunteers takes time but offers real benefits in terms of retained, motivated volunteers. To ensure this support, programs should identify a staff person with specific responsibility for coordinating and supporting volunteers.

ALLIANCE DEVELOPMENT

It is evident that neither governments nor NGOs alone can effectively combat HIV/AIDS. This is why program management and implementation depend upon the willingness of different partners in the local, provincial or national response to build alliances, particularly with sectors outside health. In successful, sustainable alliances all parties achieve benefits they could not achieve on their own. To build such alliances program managers should fully involve potential planners early on, look for common ground, identify the comparative advantages of each partner, ascertain where everyone's interests intersect and articulate how responsibilities and workloads can be coordinated and shared for mutual benefit.

TANZANIA'S NGO CLUSTERS

Tanzania is a country rich in community-based organizations (CBOs) serving the diverse needs of numerous specific constituencies. When USAID in the early 1990s wanted to develop a program to support the NGO response to HIV/AIDS, the agency struggled for a mechanism to reach out to a large number of these organizations. In collaboration with Family Health International and local NGOs, USAID created the concept of “NGO clusters.” Under this mechanism, NGOs and CBOs in the same geographic area met together, conducted joint strategic planning exercises, and developed joint regional plans for HIV/AIDS prevention and care. The cluster concept allowed each NGO or CBO to contribute its unique strengths to the combined effort, and to achieve broad coverage while minimizing redundancies and internal competition. NGO clusters have expanded across the country and now include local government offices as cluster partners.

Governance boards, management committees

Most programs have some form of internal advisory committee or council. If used inappropriately, these bodies can present obstacles to getting things done. If used well and supported by the program with good information, they can provide strong political protection, support and advice to the program. Given that in virtually every country effective HIV programs require political and bureaucratic courage in challenging the cultural and political status quo, an influential council or board can indeed be useful. These boards and committees are most useful for their strategic guidance and support, and also for their influence and networks. They should not be involved in running day-to-day programming.

Key points to remember in selecting a board or management advisory committee include:

- **Do not simply select friends or colleagues to sit on the board.** The program will be served best by individuals who maintain some distance and objectivity, not those who will merely “rubber stamp” the ideas of program managers.
- **Aim for membership from a broad spectrum of society beyond only health professionals.** People from banking, local government, successful private sector businesses, social welfare agencies, religious institutions, and PLHA can all help to open doors for the program when necessary.
- **Ensure that there is a well-defined mandate of responsibilities and length of service for the board.**

Constituent feedback and collaboration

Besides management advisory councils, programs will want to have direct and regular contact with their target audience and the communities they are serving to make sure program activities are both responsive to and supported by their constituency. This contact can be achieved through such strategies as regular focus groups, informal but purposeful interaction by peer educators and outreach workers, more formal periodic meetings with program management staff and by convening constituent advisory councils.

Program monitoring isn't these efforts' only goal. Other goals include appropriate, two-way discussion of program goals and objectives; implementation strategies; and results to motivate continued community action—such as sustained behavior change by the target audience or continued political, economic and social support for the program by key stakeholders. Promoting program activities and successes through meetings, the media, newsletters, etc., will help to ensure political support for the project. It can also strongly motivate individuals in the community to adopt and sustain behavior change strategies, directly helping to achieve the program's goals.

ADVOCACY

Arguing for resources and appropriate policies and legislation requires careful planning and strong advocacy skills. Inside government, managers need to “manage upwards.” This requires persistence and attention in presenting well-argued proposals to senior staff and government ministers. National AIDS programs likewise require other government offices and sectors in society to commit time, personnel and finances to HIV control. From the NGO perspective, it is often difficult for community groups to get governments to take their roles and responsibilities appropriately, see them as true partners and allocate sufficient resources to them. Whether it is securing funding or policy change, advocacy is a key strategy.

Important characteristics of effective advocates include:

- **Credibility.** To influence others, one must first be seen as knowledgeable and trustworthy. Policy makers and funders need to be convinced that advocates know the issues and can substantiate their position.
- **Strong communication skills.** It is essential to be able to clearly and persuasively share information.
- **Familiarity with the system.** Successful advocates know “how things get done,” who are the key influencers, the processes available for achieving changes, the pressure points and the most critical timing. Finding a “champion on the inside”—someone who will benefit from taking up the cause—can improve the likelihood of success.
- **Ability to find win-win situations.** Successful advocates structure policy advocacy so that both sides find some benefit from a policy or agreement. One-sided wins may be successful in the short-term but will make subsequent negotiations and alliance building more difficult.
- **Taking the long-term view.** Success often does not happen overnight. Being patient and persistent is often critical to eventual success. Successful advocacy also requires compromise.
- **Being strategic.** Often there may be a number of ways to achieve the same result. Successful advocates will find the most plausible, least politically costly strategy.

CONCLUSION

The HIV/AIDS epidemic has evolved over the past 20 years to the point that HIV/AIDS experts refer not only to epidemics and sub-epidemics at global and regional levels, but within individual countries as well. The scope and nature of the responses to HIV/AIDS have also evolved over this time, in some countries more effectively than in others. Early, externally driven planning processes and plans have been replaced by participatory, community-driven strategies responsive to resource levels and citizen sensitivities. The notion of a national HIV/AIDS program is often over-simplistic and naïve. More often than not the national program is really a loosely connected array of discrete public and private sector activities that may or may not be guided by common goals, objectives and targets. Years of experience, valuable lessons, emerging technical strategies, expanded partners and increased donor funding all suggest the importance and relevance of strategic planning at all levels, as well as strong program and project management.

It is time to transform limited demonstration projects into an effective, multi-layered, national-level response guided by across-the-board strategic approaches to planning and implementation. Careful, participatory planning will facilitate optimal use of available and future resources now as well as greater flexibility to respond to the new challenges and opportunities that lie ahead.

Program scale-up presents new challenges. The way forward is unclear and there is much debate about next steps: Can community-based efforts effectively be grown into district and multi-district programs? Should community-based programs be overlooked in favor of programs that can start and sustain themselves at the national level? Will strategies that work at a community level be equally successful when they are franchised, multiplied and repackaged? Will NGOs be able to transform themselves to work on larger scales, or will they lose those qualities that make them most successful?

What is known for certain is that coverage must increase. But while funding scenarios now appear more positive than they did in the recent past, additional resources will still not be enough to address global requirements. This is why program managers must vigilantly promote effective strategic planning and solid program design, and maximize the effectiveness of management and implementation.

RELEVANT CHAPTERS

- Chapter 5 *Evaluation and Surveillance Approaches for HIV/AIDS Programs*
- Chapter 23 *Counseling, Testing and Psychosocial Support*

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C H A P T E R

2

*Approaches to
Economic
Evaluation
of HIV/AIDS
Interventions*

STEVEN FORSYTHE



Approaches to Economic Evaluation of HIV/AIDS Interventions

INTRODUCTION

HIV/AIDS program planners and policy makers are often confronted with a wide range of worthy and effective interventions but severely limited resources for carrying them out. In the past it may have been acceptable simply to allocate resources to specific interventions based on the best judgment of those making the decisions—such as evenly dividing the prevention resources for condom distribution; information, education, and communication (IEC); and sexually transmitted disease (STD) interventions. But today there is a growing need to prove that resource allocation decisions are made strategically, based on sound principles, and represent good value.

The increased emphasis on accountability often necessitates accessing data that have never been collected before, and health economists are often asked to contribute to the decision making process.

This chapter is for HIV/AIDS program planners and decision makers who are thinking of using an economic evaluation to determine how to focus their financial resources and demonstrate that their interventions are producing good value. The chapter is designed to define and differentiate the various forms of economic analysis that can be used to evaluate HIV/AIDS interventions, as well as to identify the problems associated with each approach.

STRATEGIES OF ECONOMIC EVALUATION

The four types of economic evaluation are: cost analysis, cost-effectiveness analysis (CEA), cost-utility analysis (CUA) and cost-benefit analysis (CBA). All have a number of advantages and disadvantages when applied to HIV/AIDS issues. Each of the four types of economic evaluation is preferable under certain circumstances, depending on the type of information required and the resources available for performing the study, and each one has been used to address issues of HIV/AIDS.

COST ANALYSIS

A cost analysis is the simplest form of economic evaluation, as it involves evaluating the costs of HIV/AIDS interventions but does not require estimating the value of the output produced. It usually includes at least the following components:

- Methodology and assumptions
- Full cost
- Incremental cost
- Future cost
- Cost recovery

COST-EFFECTIVENESS ANALYSIS (CEA)

A CEA allows program planners and other decision makers to move beyond a simple evaluation of costs and attempt to assess the value (in non-monetary terms) of the outputs produced. In the field of HIV/AIDS, CEA has been the most frequently used approach for economic evaluations.

COST-UTILITY ANALYSIS (CUA)

CUA usually states the denominator of an economic evaluation in terms of Quality Adjusted Life Years (QALYs), Disability Adjusted Life Years (DALYs), or Healthy Years Equivalent (HYEs), rather than illness averted or treated. CUA is useful for politicians and policy makers because it allows them to compare or rank different interventions in league tables.

COST-BENEFIT ANALYSIS (CBA)

A CBA puts a monetary value on both the cost of the program and its output. The greatest problem with this approach is that it is very difficult and controversial to assign a monetary value to changes in a person's health. There are two economic methods of measuring benefits within a CBA for HIV/AIDS interventions in developing countries:

- Cost of illness (COI) approach
- Willingness to pay (WTP) approach

LESSONS LEARNED

The application of economic techniques to evaluate HIV/AIDS interventions in developing countries has revealed a number of challenging obstacles. This section offers recommendations for pursuing the four approaches in a number of hypothetical scenarios that illustrate the immediate need of policy makers in evaluating their HIV/AIDS programs.

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I N T R O D U C T I O N

Program planners and policy makers in the field of HIV/AIDS often confront a wide range of worthy and effective interventions, but have severely limited resources for carrying them out. In the past it may have been acceptable simply to allocate resources to specific interventions based on the best judgment of those making the decisions—such as evenly dividing prevention resources for condom distribution; information, education, and communication (IEC); and sexually transmitted disease (STD) interventions. But today there is a growing need to prove that resource allocation decisions are made strategically, based on sound principles, and represent good value. For example, when new research shows there are effective prevention and care interventions—such as voluntary counseling and testing (VCT), nevirapine for limiting mother-to-child transmission (MTCT) and tuberculosis (TB) prophylaxis—decision makers must determine whether strained HIV/AIDS budgets should be stretched even further to pay for these new interventions.

The increased need for accountability also often necessitates accessing data that have never been collected before. In some cases it may be enough to make informal estimates for donors or the government about the money spent on each intervention and the amount of output produced. But it is increasingly necessary to make difficult decisions based on knowledge concerning each intervention's "value for money."

Health economists are often asked to contribute to this decision-making process. Health economists have a range of evaluation tools available to them, each with its own distinct advantages and disadvantages. When program planners and policy makers are confronted with this range of different approaches to economic evaluation, they often have a hard time understanding which one is appropriate for the given needs and audience.

When is a cost analysis of different HIV/AIDS interventions sufficient?
How theoretically sound are cost-effectiveness and cost-utility analyses?
What resources are required to conduct each type of analysis?

As a result of this confusion about the proper use of economic evaluation tools, some policy makers consent to research studies that are more complex than is actually necessary for answering their questions. In other cases, policy makers recommend certain types of economic evaluations that lack the rigor they need to be truly useful.

The most common economic analyses used with HIV/AIDS interventions are cost analysis, cost-effectiveness analysis (CEA), cost-utility analysis (CUA) and cost-benefit analysis (CBA). These can be seen as a continuum, with cost analysis being the simplest but least informative. On the other end of the scale, CBA is often the most difficult type of evaluation to conduct, though it often provides the most comprehensive picture of the intervention.

This chapter is intended for HIV/AIDS program planners and decision makers who are thinking of using an economic evaluation to determine how to focus their financial resources and demonstrate that their interventions are producing good value for money. The chapter is designed to define and differentiate the various forms of economic analysis that can be used to evaluate HIV/AIDS interventions and identify the problems associated with each approach. It is not intended to be a technical “how-to” manual but an introduction to the basics of economic evaluation, as applied to the field of HIV/AIDS.

Each of the four forms of economic analysis serves a different purpose. None of them is right for every situation or audience. But it is important for program planners and decision makers to know when to use each approach and to understand their pitfalls.

STRATEGIES OF ECONOMIC EVALUATION

Each of the four different types of economic evaluation is preferable under certain circumstances, depending on the type of information required and the resources available for performing the study, and each one has been used to address issues of HIV/AIDS. The four types of economic evaluation are described in greater detail below.

COST ANALYSIS

A cost analysis is the simplest form of economic evaluation, as it involves evaluating the costs of HIV/AIDS interventions but does not require estimating the value of the output produced. Cost analyses are particularly useful for evaluating budgetary requirements or determining if an intervention is affordable or sustainable. A cost analysis can also provide a breakdown of costs to describe current and future cost requirements, as well as to measure cost changes that are likely to occur as a result of changes in an intervention's scale.

If the program planners determine that a cost analysis is appropriate and sufficient, the analyst must fully understand how the particular intervention operates. This will require observing the intervention and interviewing staff involved in providing the service. It is also necessary to interview those who manage the finances of the intervention. The analyst must be able to disaggregate the intervention into the various services provided. To estimate the cost of voluntary counseling and testing (VCT) within a health center, for example, the analyst would need to allocate all costs according to the various services provided—such as family planning, antenatal care, VCT and maternal and child health. This will enable the analyst to identify both the total cost of providing VCT (including all direct and indirect costs) and the incremental cost of adding VCT services to an existing health center.

Cost analyses are most successful when they begin by calculating the value of all resources used in any way to carry out the intervention. This includes identifying recurrent and capital costs, direct and indirect costs, and fixed and variable costs.

Cost analyses are increasingly being used to address the issue of scale. As small pilot projects become national programs, it is necessary to fully understand

how costs are likely to change. For example, many countries are currently attempting to develop nationwide VCT, home-based care and MTCT programs. It is probably not going to be enough to project the costs of such national programs based solely on the costs of pilot projects. Program planners and policy makers need to consider whether economies of scale will result in substantial savings. For example, the scale-up of a home-based care program in Zimbabwe found that costs declined substantially as the size of the program increased.¹ Economists also need to consider whether the pilot projects were actually conducted under ideal circumstances. Pilot projects are often conducted in districts that are accessible and already have well-motivated staff. If this is the case, a national program might actually be much more expensive on a per-client basis than the costing of a pilot project might suggest.

There are guidelines available for program planners who wish to learn the technical aspects of evaluating the costs of HIV/AIDS interventions. Some of these guidelines are listed in the Recommended Reading section at the end of this chapter.

A cost analysis usually includes at least the following components:

- **Methodology and Assumptions.** This component describes the intervention and the approach used for evaluating costs, including the approach for assessing shadow prices. It also includes basic assumptions used in the cost analysis, including information regarding inflation, discount rates, land prices and taxes.
- **Full Cost.** This component identifies the full value of all resources used by an intervention, including donated items and resources shared with other interventions.
- **Incremental Cost.** This component assesses the additional resources required to conduct an intervention when different from a full cost analysis.
- **Future Cost.** This component assesses the future resources needed to carry out an HIV/AIDS intervention.

- **Cost Recovery.** A cost recovery component evaluates opportunities to sustain an intervention by assessing how much the consumer of the service can pay for it relative to the total cost of the intervention.

These five components form the basis of a cost analysis that may provide policy makers with sufficient information to address the necessary issues.

Follow-up issues may include addressing the ways in which costs can be minimized. Cost-minimization studies, for example, have attempted to determine such things as the least expensive way to distribute condoms, treat STDs and offer VCT services. But such cost-minimization studies are often criticized because they fail to take into consideration the quality and effectiveness of the intervention, the result of focusing only on the intervention's cost and to some extent output, but not on the actual outcomes. This is why it is often necessary to move beyond simply analyzing costs and include an outcomes evaluation. In this case, it is necessary to move to CEA, CUA or CBA.

COST-EFFECTIVENESS ANALYSIS (CEA)

A CEA allows program planners and other decision makers to progress beyond a simple evaluation of costs and try to assess the value (in non-monetary terms) of the outputs produced. An explanation of CEA should begin with a definition of the numerator and denominator used. The numerator is typically defined as the cost, and should include any cost savings expected as a result of the intervention. An analysis of the cost of cotrimoxazole, for example, should include not only the cost of the medication, but also the cost savings expected from a reduced number of future hospital visits. The denominator, or the measure of effectiveness, can be any measure that accurately reflects the main output. In the field of HIV/AIDS prevention, the most frequently used measure of effectiveness has been the number of HIV infections averted.

At this point it is important to note that cost-effectiveness is a relative term that reflects a comparison of interventions with similar goals. An intervention cannot be deemed inherently "cost-effective," but can only be cost-effective relative to other interventions.

In other words, an intervention with an incremental cost per HIV infection averted of US\$2,000 cannot be assumed to be cost-effective unless data are available indicating that other interventions have a higher incremental cost per HIV infection averted.

One advantage of the CEA approach is that it can be relatively easy for policy makers to comprehend. For example, for every US\$1,000 invested in HIV/AIDS prevention, an average of 20 infections can be averted. Another advantage to this approach is that the denominator (effectiveness) does not have to be converted into monetary terms (in other words, the 20 infections averted do not need to be assigned a specific dollar value). An economist can therefore avoid the political pitfalls of making any direct judgment regarding the controversial issue of valuing the life that has been saved.

CEA also is particularly useful when there is a limited budget to achieve a particular goal. For example, if a project has US\$1 million to spend on HIV/AIDS prevention, CEA can be useful in identifying the cost per infection averted for a number of approaches. While it is not perfect, CEA can provide policy makers with an idea of which priorities to pursue. In this case, we might assume that the intervention with the lowest cost per averted HIV infection should be the first to be pursued.

CEA is also useful when comparing two interventions with similar objectives. For example, a study in Kenya and Tanzania determined that VCT is less cost-effective than the use of NVP to limit MTCT.²

If a program planner determines that a CEA is necessary, the analyst must be able to develop cost estimates as well as a model that can provide estimates of the number of infections that can be averted as a result of the intervention. Some macro models have been used (e.g., *iwgAIDS**) to estimate how an intervention can influence behavior within a population, which in turn can be used to estimate infections

Table 1
COST-EFFECTIVENESS OF HIV/AIDS INTERVENTIONS IN AFRICA

Country	Intervention	CEA	Source
Kenya	VCT	\$241 per HIV infection averted	ref. 3
Kenya	STD treatment and condom distribution	\$8-\$12 per HIV infection averted	ref. 26
South Africa	Reduced MTCT	\$1,484 per HIV infection averted	ref. 27
South Africa	Directly observed therapy for TB	\$879 per case of TB treated	ref. 28
Sub-Saharan Africa	Female condoms	\$38 per HIV infection averted	ref. 29
Sub-Saharan Africa	Use of nevirapine to reduce MTCT	\$138 per HIV infection averted	ref. 30
Sub-Saharan Africa	Use of AZT to reduce MTCT	\$3,748 per HIV infection averted	ref. 31
Tanzania	VCT	\$243 per HIV infection averted	ref. 32
Tanzania	Improved treatment of STDs	\$218 per HIV infection averted	ref. 33
Zambia	Blood screening	\$31.62 per HIV infection averted	ref. 34
Zimbabwe	Blood donor deferral	\$127-\$773 per HIV infection averted	ref. 35

averted. Such macro-models require an extensive amount of data and significant amounts of time to conduct modeling. Others have used micro models (e.g., AVERT[†]) that focus on the direct infections averted that can be attributed to the intervention within certain subpopulations (e.g., commercial sex workers [CSWs] and their clients). Such micro models tend to be simpler to use, but generally produce more conservative estimates of impact, since they fail to capture any “downstream” infections averted.

In the field of HIV/AIDS, CEA has been the most frequently used approach for economic evaluations. Table 1 illustrates some of the CEA studies that have been performed on HIV/AIDS interventions in Africa. The wide variation in estimates is due in part to the interventions’ differing levels of effectiveness, but they also vary with the HIV prevalence in the selected country and the method pursued for measuring costs and effectiveness. The methodological differences in analyzing costs and effectiveness make a comparison of these interventions very difficult.

Although the CEA approach is popular, it is also problematic for several reasons.³ First, to compare interventions requires that all services have the same

measure of effectiveness. But all HIV/AIDS services do not necessarily produce one common output. The effectiveness of a condom distribution program may be measured in terms of infections averted. The measure of effectiveness for antiretroviral therapy may be the number of patients successfully treated. The effectiveness of VCT is likely to be composed of some combination of treatment and prevention gains. This is why these three interventions, designed to address the same illness, cannot be compared using CEA.

Next, prevention programs are often extremely difficult to associate with a specific number of illnesses averted.⁴ In the case of HIV/AIDS, this is due in part to a lack of knowledge about such basic inputs as the probability of transmission for any particular sex act. This problem is confounded by the lack of data regarding the impact of interventions on “downstream infections.” An intervention may prevent an HIV infection within the target audience, but it also is

* *iwgAIDS is a comprehensive prediction and analysis tool used to understand the spread of HIV/AIDS around the world by public health officials and academics. It uses nonlinear partial differential equations to model the demographic, behavioral and epidemiological components of the HIV/AIDS epidemic. It includes partial factorial sensitivity routines to assess the impact of “soft” data in the model and an intervention facility to allow the user to perform “thought experiments.”*

† *AVERT is a computer model developed by FHI, which uses information that is readily available to many programs to derive estimates of the reductions in HIV infections achieved through interventions. This model enables users with little experience in modeling to develop estimates of program impact.*

likely to prevent many more subsequent HIV infections among the people that a targeted person might have infected. As a result, most static models designed to measure the effectiveness of preventing infectious diseases have been unable to reliably estimate the number of infections averted as a result of any particular intervention.

Another problem arises when trying to develop one measure of effectiveness for any particular service. Unless the measure of effectiveness truly reflects all the benefits of a particular service, it will inevitably underestimate its value. A good example of this would be VCT, which has been evaluated using CEA.² The problem is that the benefits of VCT are much broader than simply the number of averted infections. VCT has value not only because it prevents new infections, but also because it: 1) informs clients; 2) opens up access to treatment for those who are infected; and 3) increases discussion and “normalization” of the epidemic. Thus narrowly defining the gains of VCT in terms of only HIV infections averted underestimates the true value of the service, and CEA will not reflect the real value for money invested in the provision of this service.

CEA is also problematic in that it assumes that an intervention has succeeded in preventing or treating an illness for an indefinite period of time. But “model estimates on HIV infections averted should be interpreted cautiously, especially in populations with high-risk behaviors where the observed behavior changes suggest that the interventions may only postpone the timing of infections rather than prevent infections indefinitely.”⁵ Thus a CEA may exaggerate the benefits of an intervention if it really only postpones, rather than prevents, new infections.

A CEA can also provide results that contradict the recommendations of epidemiologic evaluations. For example, an epidemiologist might recommend that

interventions be pursued in countries that are at an early stage of the epidemic, so as to limit the possibility of future spread. But a health economist using CEA over a short time span might recommend investing in HIV/AIDS prevention in countries where the epidemic is already well established (and where the cost per HIV infection averted would presumably be lower).

Finally, a CEA does not necessarily reflect the utility of the service from the community’s perspective. In CEAs, each HIV infection averted is of equal value. But in reality society may not view all lives in equal terms. For example, the health economist performing a CEA on an intervention that prevents a healthy adult from becoming infected might deem it to be of equal value as NVP in preventing the transmission of HIV from an infected mother to her child. The society, however, may put a very different value on preventing the infection of a child who will be orphaned relative to the prevention of an adult infection. Thus the health economist is making a value judgment that the society itself may not hold. This is contrary to one of the basic tenets of welfare economics, which states that people themselves are the best judges of their own utility.

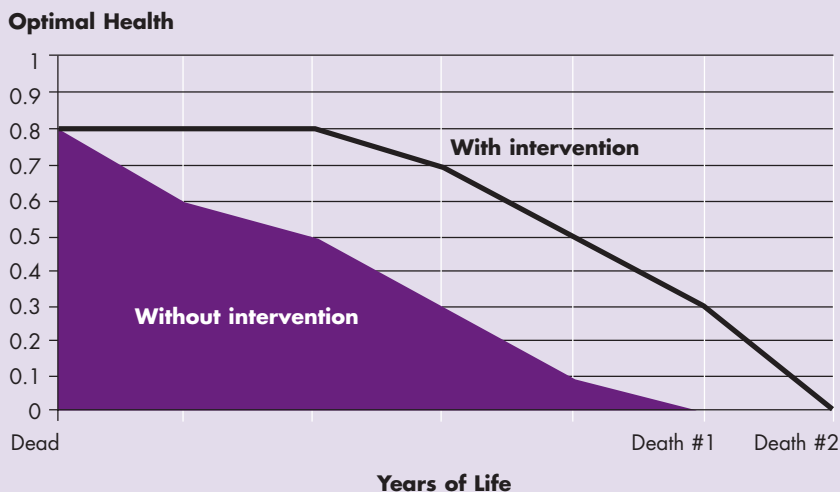
COST-UTILITY ANALYSIS (CUA)

CUA* usually states the denominator of an economic evaluation in terms of Quality Adjusted Life Years (QALYs) Disability Adjusted Life Years (DALYs) or Healthy Years Equivalent (HYE), rather than illness averted or treated. The CUA approach has been shown to reflect the effectiveness of the intervention in more comprehensive terms than CEA since it combines both changes in quality of life and mortality in one measure.

CUA is useful for politicians and policy makers because it allows them to compare or rank different interventions in league tables, such as showing the impact of investing in directly observed therapy (DOTS) for TB versus more traditional forms of TB care. Policy makers who have a fixed AIDS budget to achieve a particular output are able to use CUA by

** Some economists categorize CUA as a subset of CEA, while others identify CUA as a separate form of evaluation.*

Figure 1
IMPACT OF INTERVENTION



funding the intervention with the lowest CUA first, then funding the next lowest CUA intervention, etc., until all available funds have been allocated to achieve the greatest utility.

CUA also has the advantage of being a technique with which economists, donors and policy makers are increasingly familiar. Many donors, including the World Bank, ask that projects demonstrate a sufficiently low cost/DALY to receive funding. The advantages and disadvantages of the CUA technique are also increasingly understood, which makes the tool more useful for policy makers.

CUA also is preferable to CEA because it places interventions in a context of healthy years of life saved, rather than simply counting the number of lives saved. As noted, a CEA cannot distinguish between a permanently prevented infection and one that is sim-

ply postponed. For example, a project may convince a CSW to use a condom today and she thereby avoids infection. But next week she may not use a condom and become infected. A CEA would only indicate that the intervention prevented the CSW from becoming infected, while a CUA would provide a more realistic assessment by revealing that there was only one week's delay in the woman's infection and illness.

As illustrated in Figure 1, an individual's health can be measured on a scale from 1 (perfectly healthy) to 0 (dead). Tools for measuring quality of life include Euroqol, SF36, and SF12. **

These tools have been developed

by various European and U.S. groups to develop quantitative estimates of health. They involve asking respondents to evaluate their own health in a limited number of questions about the person's physical and emotional well-being. In Figure 1, the average person without an intervention—such as antiretroviral therapy (ART) or cotrimoxazole—will decline and die quickly (death 1). This person's QALYs are equal to the area under the curve without any intervention. With the introduction of an intervention, though, the person's quality of life may improve and their death be postponed for a number of years (death 2). The difference between the areas under the two curves (with and without the intervention) is the number of QALYs saved as a result of the intervention. Programs that save the greatest number of QALYs for the smallest amount of money are considered to be cost-effective.

In its 1993 World Development Report, the World Bank developed a list of diseases and estimated the average number of DALYs incurred by each disease. The diseases with the largest health impact were: 1) respiratory disease, 2) diarrhea, 3) perinatal causes, 4) neuropsychiatric diseases, and 5) cancer.

** Table 2 provides a list of questions that are asked in the SF-12 to measure a person's quality of life.

Table 2

SF-12 Health Survey Scoring

1. In general, would you say your health is:

- Excellent
 Very Good
 Good
 Fair
 Poor

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.

- Yes, limited a lot
 Yes, limited a little
 No, not limited at all

3. Climbing several flights of stairs.

- Yes, limited a lot
 Yes, limited a little
 No, not limited at all

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

4. Accomplished less than you would like.

- Yes
 No

5. Were limited in the kind of work or other activities.

- Yes
 No

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

6. Accomplished less than you would like.

- Yes
 No

7. Didn't do work or other activities as carefully as usual.

- Yes
 No

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- Not at all
 A little bit
 Moderately
 Quite a bit
 Extremely

These questions are about how you feel and how things have been with you during the past four weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past four weeks...

9. Have you felt calm and peaceful?

- All of the time
 Most of the time
 A good bit of the time
 Some of the time
 A little of the time
 None of the time

10. Did you have a lot of energy?

- All of the time
 Most of the time
 A good bit of the time
 Some of the time
 A little of the time
 None of the time

11. Have you felt downhearted and blue?

- All of the time
 Most of the time
 A good bit of the time
 Some of the time
 A little of the time
 None of the time

12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

- All of the time
 Most of the time
 Some of the time
 A little of the time
 None of the time

Table 3
COST-UTILITY OF HIV/AIDS INTERVENTIONS IN AFRICA

Country	Intervention	CUA	Source
South Africa	Reduced MTCT	\$47 per DALY gained	ref. 27
South Africa	HAART for people living with HIV/AIDS	\$10,000 per DALY gained	ref. 36
Sub-Saharan Africa	Female condoms	\$29 per DALY gained	ref. 29
Sub-Saharan Africa	Use of nevirapine to reduce MTCT of HIV	\$5.25 per DALY saved	ref. 30
Tanzania	Improved STD treatment services	\$10.33 per DALY saved	ref. 33
Zambia	Blood screening	\$1.32 per year of life saved	ref. 34

Table 3 lists some of the CUA studies that have been carried out for HIV/AIDS interventions in Africa. Most recent studies have used DALYs as a measure of utility, which has made these studies more comparable. Given that most interventions are viewed as cost-effective if they cost less than US\$50/DALY, these HIV/AIDS interventions generally appear to produce good “value for money,” with the exception of highly active antiretroviral therapy (HAART) in South Africa, which had a cost/DALY of US\$10,000.

When a program planner determines that a CUA is warranted, the analyst must determine an appropriate way to measure changes in the quality of a person’s life. The easiest way to do this is to use published figures that attempt to associate infections averted with some measure of utility gained. A more complex approach is to conduct a study that attempts to measure changes in utility.

CUA is most often performed using either the standard gamble (SG) or the time-trade-off (TTO) approach. Both of these tools are designed to evaluate the utility of an intervention from the perspective of the individual. In the case of SG, the probability of death is varied and compared to the value of the intervention by using such questions as, “Would you choose to receive HAART if there were a five percent

chance of immediate death?” In the case of TTO, the change in life expectancy is varied and compared to the intervention in a question such as, “Would you choose to take HAART if it would make you fully healthy, but would reduce your life expectancy by two years?” Asking such questions of people living with HIV/AIDS, particularly in a developing country, is obviously very challenging and sensitive.

Like CEA, CUA requires a comparison among interventions.^{***} An intervention should ideally be compared to a “league table” of health interventions measured in terms of their cost/QALY (or DALY or HYE) saved. One problem with this approach is that few countries have such league tables, which means policy makers have a hard time determining whether an intervention is truly a good investment of limited resources. Policy makers are left wondering whether a CUA represents a comparatively good or poor investment, since they lack the data necessary to compare interventions.

Another problem with this approach is that CUAs do not have much meaning to most policy makers or their constituents. A policy maker who is presented with the “good news” that their wise investment in health has produced 10,000 QALYS is usually either unimpressed or unable to translate this accomplishment for their constituents. As a result, CUAs are often unsuccessful in convincing policy makers on the best way to invest their limited health resources or the wisdom of already taken public investments.

^{***} Unlike CEAs, CUAs can be used to compare interventions that deal with different diseases.

CUA is also problematic because people place value on health outcomes and because of the information conveyed. As shown in various studies,⁶⁻⁸ information has value even if it does not change the treatment eventually proposed. This may be particularly true of VCT when knowledge of one's HIV status is likely to have significant value even in the absence of treatment. Thus CUA, like CEA, may seriously underestimate the value of VCT.

Finally, CUAs, like CEAs, do not necessarily reflect the utility of the services to the community. Using the example of MTCT, a CUA might conclude that saving the life of a newborn would have greater value than saving the life of the mother, since the uninfected newborn may have a greater number of future healthy years than the mother. But as already indicated, the community may place a much greater value on the life of the mother**** CUAs therefore do not necessarily reflect the judgment of society regarding the value of different lives saved and therefore may not produce a welfare-maximizing recommendation.

COST-BENEFIT ANALYSIS (CBA)

A cost-effectiveness analysis gives the narrowest options for comparison. It may only facilitate comparisons between different ways to treat a specific disease. Cost-utility analysis has been developed to facilitate comparisons between different medical specialties. Cost-benefit analysis offers a direct comparison between costs and outcomes, since both are expressed in monetary terms.⁹

A CBA puts a monetary value on both the cost of the program and its output. This produces information that is often more appealing to policy makers, especially those concerned about assuring value for money. CBA gains from the fact that any intervention

can be evaluated on its own merit, rather than requiring a comparison of interventions. CBA also allows programs that have very different objectives to be compared (e.g., should the government focus its limited resources on new roads or new malaria control projects?).

One weakness of cost-effectiveness analysis is that its foundation in welfare economic theory is unclear. The classical tool of economic evaluation based on welfare economic theory is cost-benefit analysis, where both costs and health effects are measured in the same units.⁹

While CBA is a theoretically and politically appealing tool, it also faces tremendous obstacles in implementation. The greatest problem with this approach is that it is very difficult and controversial to assign a monetary value to changes in a person's health. This is further confused when making comparisons across countries. For example, should the value of someone's life in a developing country be worth less than the life of someone in a developed country, simply because people in developed countries are, on average, wealthier?*****

There are two economic methods for measuring benefits within a CBA for HIV/AIDS interventions in developing countries: 1) the cost of illness (COI) approach, and 2) the willingness to pay (WTP) approach. Both of these methods are described below.

Cost of illness (COI)

The COI approach uses two components in measuring benefits. The first values the benefit of treating or preventing HIV/AIDS by the change in the net cost of health care associated with treatment. The second is the aversion of indirect costs, which are equated to the value of lost earnings attributable to that illness.¹⁰ Thus, the total benefit from, for example, pre-

**** Although it is possible to adjust the discount rate to reflect the value of life to the community, most CUAs instead use a standard discount rate that does not necessarily reflect a community's value.

***** In fact, CEA, CUA and CBA all make certain assumptions about the value of life. But CBA studies usually require that these assumptions be made explicit.

venting an HIV/AIDS infection is equal to the amount the infected person (or the government) would have had to pay for treatment plus the amount of income that would have been foregone because of the HIV/AIDS-related illness and death.

When it is determined that a CBA using a COI technique is warranted, the analyst must choose a way to calculate the direct and indirect value of a person's life. The direct cost analysis may include assessing the cost of the labor, materials, medication and overhead required to treat hospitalized patients living with HIV/AIDS. More extensive analyses may also include an assessment of such other costs as outpatient and home-based care, and investments in traditional medicine.

Indirect cost estimates are often performed simply by multiplying the discounted per capita income by the years of life expected to be lost as a result of HIV/AIDS. More extensive analyses actually attempt to evaluate whether the income of people living with HIV/AIDS differs from those in the general community. It is still debatable whether the value of an individual's consumption should be deducted from the income lost to illness.

Assume, for example, that a case of AIDS costs US\$1,000 to treat and that the patient loses US\$5,000 in lifetime discounted earnings due to the illness and premature death. The benefit of averting that illness would be equated to US\$6,000. A public program to prevent HIV/AIDS would be recommended if it cost less than US\$6,000 per case averted, but would be considered too expensive if it cost more than US\$6,000.

One of the first studies on the economic impact of HIV/AIDS on developing countries was published using this COI methodology in Tanzania and Zaire.¹¹ COI was subsequently used in a variety of other developing countries, including Kenya,^{12,13} Malawi,¹⁴ Mexico,¹⁵ Honduras¹⁶ and Thailand.¹³ The COI approach has the advantage of being relatively simple for economists to calculate and for policy makers to understand. *****

***** Most of these studies were actually designed to illustrate impact, and therefore did not go so far as to use the COI approach to determine which interventions were cost-beneficial.

But for a number of reasons, the COI approach has been viewed as a theoretically inadequate methodology for evaluating the benefits of preventing or treating diseases and has been widely rejected by most economists.¹⁷ The COI approach has problems, among them:

- Direct cost analyses generally ignore the fact that the cost of care does not reflect the full benefits of care to the patient. For example, patients may put a high value on a life-saving drug, but its price would not necessarily reflect that value. In this case, the cost of the treatment does not reflect its benefit to the patient.
- Because COIs are so strongly influenced by direct costs, they may inaccurately recommend that life-prolonging treatment should never be pursued, since allowing a patient to die is frequently the least expensive treatment alternative. Thus, even when society places a high value on treatment strategies, COI will frequently suggest that such treatment is not cost beneficial.
- Indirect costs are a poor measure of a human being's value, especially in terms of work that is not compensated such as education, homemaking and child rearing. This means the value of saving or extending a woman's life, particularly when she is not formally employed, is often underestimated or completely ignored.
- A methodology for determining indirect costs has never been clearly defined, so it remains unclear if the indirect costs should reflect the fact that individuals consume as well as earn. If so, should an elderly person who consumes but has no potential earnings then be considered of negative value?
- By assigning a monetary value to an individual's life, the COI makes some implicit assumptions about the different values associated with different people's lives. It has typically been assumed in CBA that a wealthier individual's life has greater value than a poor person's, because the loss of a

wealthy person would result in greater monetary losses in terms of productivity. Human life is likewise assumed to have more value in developed countries than in developing countries when performing COI studies.

- COI does not permit an adequate comparison between diseases. The fact that one disease creates a greater impact than another does not necessarily mean that public funds should be invested in the disease with the greater impact. Instead, society may favor equity in health care over reducing the overall impact of disease.
- COI lacks any basis in welfare economic theory. The COI technique does not necessarily reflect the value associated with a change in health since any measure of benefits should be capable of satisfying the Pareto criterion. An allocation of resources is only “Pareto efficient” if it is impossible to make one person better off without making someone else worse off. Future earnings are not necessarily related to such an improvement.¹⁸

[V]aluing benefits in terms of rates of pay neglects the health benefits that accrue to people who are not employed—for example, non-working wives and retired people. It also ignores the non-financial costs of pain, suffering and grief that are often associated with illness. But from an economist’s perspective, the main criticism of the approach is that it is not based on an individual person’s valuations of benefits. Indeed, a third party view is taken about people’s “worth” to society in terms of their productive potential. This viewpoint is inconsistent with the prevailing view among economists that the individual person is the best judge of his or her own welfare.¹⁹

Because of these and other significant problems with the COI approach, economists have begun to use alternative methodologies to evaluate benefits as part of a CBA.

Willingness to pay (WTP)

WTP is the approach most often preferred by economists for measuring benefits because it has a sound theoretical basis in welfare economics. WTP is the most commonly used approach for evaluating benefits in the environmental field, and is rapidly becoming more popular in the field of health economics.

The advantage of WTP over QALYs stems from the fact that the latter permits the valuation of health gains only. It could be argued that, although health gain is the main attribute of health care, there are other important attributes which QALYs and other health indices do not take into account. Such attributes include the “process of care,” which often means more to the patient than do clinical outcomes.²⁰

There are two ways to determine willingness to pay:

- **The indirect approach** determines someone’s WTP by observing his or her market behavior and identifying how much he or she is apparently willing to pay to avoid a disease. For example, it may be possible to determine someone’s benefit from averting an HIV/AIDS infection by observing how much he or she spends on condoms, STD treatment or blood screening, if such a private market exists. But because there are so many confounding factors associated with people’s behavior, the indirect approach has never been used in evaluating the benefits of HIV/AIDS prevention, to the author’s knowledge.
- **The direct approach**, known as contingent valuation (CV), is generally conducted by interviewing people and determining their WTP through one of a variety of techniques. CV allows the user of the service—and in some cases the community as a whole—to indicate how they value a particular health service by asking about their willingness to pay to obtain that service or, less commonly, their willingness to accept its unavailability. The approach resolves some, though not all, of the problems associated with the COI.

CV was originally developed as a tool for measuring the benefits that people obtain from the environment. The technique was subsequently refined to address other public goods, including health care. (For a review of the CV technique as applied to health, see the Recommended Reading section.) The CV approach involves creating a hypothetical market for goods or services that could not otherwise be readily exchanged.

The use of CV to evaluate HIV/AIDS interventions in developing countries is a very new concept. But it is being used to assess VCT, chronic care services, antiretroviral (ARV) therapy and a hypothetical AIDS vaccine in Kenya.²¹ Studies also have been designed to determine the possible value of an AIDS vaccine in developing countries.²²⁻²⁴

If a program planner believes it is appropriate to determine CBA using the CV approach, it will be necessary to interview all of the intervention's potential beneficiaries. In the case of care that has no aspect of a public good, interviews would need to be conducted only with those who are infected. But most HIV/AIDS interventions do contain some public good components, so it is also necessary to interview people in the general community. By asking people how much they would give up to have access to an HIV/AIDS service—or to assure access for other people in the community—it should be possible to develop a more comprehensive assessment of the intervention's benefits.

Some criticize the CV approach on philosophical grounds, arguing that the desires of individuals should not be the major determining factor in choosing to publicly subsidize a good or service. In other words, policy makers may prefer to finance public goods based on grounds of paternalism rather than economic demand.²⁵

Another criticism of the CV technique concerns its hypothetical nature. It is easy to say you would be willing to pay a substantial sum to obtain a service until you are actually asked to pay for it. CV is also criticized on logistical grounds, since carrying out surveys of sufficient size is also expensive and extremely complicated.

LESSONS LEARNED

Using economic techniques to evaluate HIV/AIDS interventions in developing countries has revealed a number of challenging obstacles. Although cost analyses can provide a simple assessment of the resources needed to introduce or sustain an intervention, they are not particularly useful for actually comparing interventions.

Health economists have attempted to use measures such as “HIV infections averted” in CEAs. These studies have particular appeal because of their clear message to policy makers and usefulness for advocacy purposes. But they can also be criticized because of their lack of rigor and inability to consider the wider benefits that can be obtained using interventions such as VCT.

The World Bank has continued to promote CUA as a more rigorous way to evaluate HIV/AIDS interventions. But CUA appears to have less appeal in developing countries, where results are more difficult to use for advocacy purposes and comparable figures are often not available.

CV as a tool for performing CBA has an appeal to economists and those who are looking to use economic evaluations for advocacy purposes. But this technique is still somewhat experimental and further research is required before using it on a wide scale.

Given the advantages and disadvantages of each of the four approaches, it is now useful to provide a few illustrative scenarios, along with recommendations, about which approach to pursue. Table 4 provides a number of hypothetical scenarios that illustrate the immediate need of policy makers in terms of evaluating their HIV/AIDS program.

Table 4 illustrates that in some circumstances it may be adequate to focus on a simple cost analysis. This is particularly useful when the program planner

Table 4

DETERMINING THE APPROPRIATE FORM OF ECONOMIC EVALUATION

Scenario	Recommended form of economic evaluation
"I only need to know how much my program costs."	Cost Analysis
"I want to know my future resource needs to reach scale for my interventions."	Cost Analysis
"I am not concerned with theory, only clearly illustrating the significant impact that will be incurred if we don't intervene."	Cost-of-Illness Approach
"I want a form of economic evaluation that simply and clearly illustrates the advantages of my intervention."	Cost-Effectiveness Analysis Contingent Valuation
"I want the approach that is the most theoretically sound."	Cost-Utility Analysis Contingent Valuation
"I want to compare different HIV/AIDS interventions and/or prevention vs. care"	Cost-Effectiveness Analysis Cost-Utility Analysis
"I want to know how much cost-recovery is feasible, so that I can financially sustain my intervention."	Cost Analysis Contingent Valuation
"The benefits of my intervention are much wider than simply infections averted or health improved."	Contingent Valuation
"I want an economic evaluation that is simple and requires the fewest resources possible."	Cost Analysis
"My primary audience is my constituency."	Cost-Effectiveness Analysis
"My primary audience is the National AIDS Control Program."	Cost Analysis Cost-Effectiveness Analysis
"My primary audience is the Minister of Health."	Cost-Utility Analysis
"My primary audience is the Minister of Finance."	Contingent Valuation

needs to collect budgetary information, but does not actually need to compare various interventions. It is also useful when attempting to assess the resources required for scaling-up interventions.

CEA can be a simple but powerful policy tool for program planners presenting an evaluation of their intervention to policy makers. Making policy makers aware of the number of HIV infections the intervention can avert is often enough to demonstrate value for money. CEA is particularly useful as an advocacy tool, as it can be used to present simple messages about infections averted per dollar invested in the intervention.

CUA is most frequently used when it is necessary to compare interventions. Donors are increasingly requiring that program managers and national policy makers demonstrate that their interventions produce good value for money by estimating cost/DALY.

Finally, CBA using the COI approach can be useful when demonstrating impact for advocacy purposes. CBA using the CV approach can be useful when a more theoretically sound approach is needed and resources are available for carrying out surveys.

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C H A P T E R

3

*Responding
to the
Socioeconomic
Impact of
HIV/AIDS*

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Responding to the Socioeconomic Impact of HIV/AIDS

INTRODUCTION

AIDS mainly strikes adults in their most productive years, which has major implications for economic activity and social structures. The greatest impact is at the household level, where the implications of even one adult developing AIDS can be disastrous for an entire family as breadwinners lose the capacity to generate income due to illness or the need to care for other household members. HIV/AIDS also imposes extra expenditures on affected households for health care and funerals.

Although the macroeconomic impacts of HIV/AIDS are difficult to predict, attempts to model impacts suggest that severely affected African countries will experience average reductions in gross domestic product (GDP) growth rates of around one percent per annum over the first 25 years of the epidemic. Impacts on human and social development are expected to be much more profound. Increased illness and reduced life expectancy will clearly compromise development objectives. Affected people, particularly orphans, will also have greatly reduced chances of fulfilling their human potential.

This chapter focuses on key areas where action is needed to reduce socioeconomic impacts but has often been lacking. Each section reviews the impact of HIV/AIDS on particular sectors and suggests responses that can help mitigate it. A final section examines specific issues around mobilizing intersectoral responses to HIV/AIDS.

PUBLIC SECTOR RESPONSES

Government has a central role to play in mounting effective responses to the socioeconomic impact of the epidemic, and can potentially influence it in several ways. Individual ministries and workplaces will need to develop customized responses to their own circumstances.

MANAGING IMPACTS ON PUBLIC SECTOR EMPLOYEES

Because the government is usually a nation's largest employer, it has the ability to influence the scale and severity of the HIV/AIDS impact on huge numbers of employees, their dependents and communities. In general, managing the impact of HIV/AIDS on organizational efficiency, capacity and costs is often more difficult for government than for the private sector.

RESPONSES TO EMPLOYEE IMPACTS

A comprehensive impact assessment generally makes it easier to respond to the impact of HIV/AIDS on employees in a strategic manner. Assessments will help to identify the scale of the expected impact; pinpoint factors that increase the susceptibility of employees and vulnerability of core functions; and allow the development of a well-informed, coherent, prioritized approach to the problem.

THE HEALTH SECTOR

The health sector is affected early and most obviously by HIV/AIDS, and has several important roles to play in mitigating the socioeconomic impact of the epidemic. The goal of an appropriate health care policy is to reduce the burden on the formal health care system without shifting an unsustainable burden onto individuals, families and communities.

IMPACT ON NEED FOR SERVICES

The main effect of HIV/AIDS on health needs is that adults—who are usually among the healthiest members of society—and large numbers of children will now suffer from a serious, chronic disease. This means there is a dramatic increase in the need for health care to levels well above those previously assumed in planning.

IMPACT ON CAPACITY TO DELIVER SERVICES

HIV/AIDS compromises capacity for health care in the same way it affects any organization through its direct and indirect impact on employees. Illness and death among health care workers can worsen existing inefficiencies and capacity constraints.

HEALTH SECTOR RESPONSES

HIV/AIDS will be the biggest single need facing the health sector in many developing countries. All components of health services will be affected through competition for resources, the need for referrals, and the impact on employees. It is also critical to approach HIV/AIDS responses in a sound, strategic manner based on the kind of planning principles that should be applied to any major health issue.

THE EDUCATION SECTOR

The education sector has a key role in reducing the short- and longer-term socioeconomic impact of the HIV/AIDS epidemic. The sector is uniquely able to influence the future course of HIV/AIDS epidemics by changing the risk behavior and infection rates of large numbers of young people who are at an age when HIV incidence tends to be highest.

IMPACT ON NEEDS TO BE MET BY THE EDUCATION SECTOR

The traditional role of the education system in cultivating numeracy and literacy will have to be supplemented by a role in supporting and nurturing large numbers of children in crisis, and giving them life and survival skills from a relatively early age.

IMPACT ON CAPACITY TO PROVIDE EDUCATION

Teachers at all levels of the education system are at significant risk of HIV infection. There are indications that they may be at even greater than average risk as their high status and incomes create opportunities for high-risk behavior.

EDUCATION SECTOR RESPONSES

A clear understanding of the potential impact on needs and capacity is crucial to mobilizing HIV/AIDS responses and enabling effective planning, action, and the efficient use of available resources. This should clearly identify the key areas of susceptibility and vulnerability of learners, educators and overall system function. Projecting the scale of various impacts is likely to be critical for informed planning in many severely affected countries.

OTHER GOVERNMENT SECTORS

The AIDS epidemic affects and requires the collaborative response of multiple sectors, including social support sectors that specifically address community services, women, youth, agriculture and national defense. This section examines how government sectors can support integrated prevention programs that address HIV vulnerability and risk reduction strategies.

THE PRIVATE SECTOR

There is limited information on the impact of HIV/AIDS on business, which makes it harder for the business community to respond. But there is going to be a steady and large increase in illness and death in the working-age population, which will inevitably impose some degree of cost and uncertainty on business.

IMPACT ON COMPANY COSTS

The major HIV/AIDS-related concerns for businesses are reduced productivity and increased costs. Productivity will fall and costs rise due to the same kinds of HIV/AIDS impacts discussed above for government employees.

IMPACT ON MARKETS

HIV/AIDS could reduce the absolute number of potential customers, making vulnerable the markets that are relatively saturated and that depend critically on population size. In countries where the need for goods is far from saturated, many consumers who die or see their disposable income reduced by HIV/AIDS will be replaced by new earners and consumers, if overall GDP and consumption expenditure remain largely unaffected by the pandemic.

THE BUSINESS ENVIRONMENT

AIDS may substantially affect the business environment even though it is not expected to be a dominant influence on macro-economic growth. There may be greater, though less predictable, effects through the impact of AIDS on other aspects of the political, social, and business environment.

THE BUSINESS RESPONSE

What can and should companies do about AIDS? Essentially, there can be four response areas:

- Employees
- Costs
- Markets
- Society

INTERSECTORAL RESPONSES TO HIV/AIDS

Intersectoral responses and cooperation are desirable for several reasons, including:

- HIV/AIDS cannot be considered just a health issue.
- Overreliance on the capacity of a particular sector, usually health, to drive responses has several potential drawbacks.
- Input or support from other sectors in any one sector will probably be needed for effective planning and implementation of responses.
- Inadequate responses by any individual sector have the potential to create negative effects in other sectors.
- Difficult decisions on the allocation of resources between and within sectors will have to be made in many countries.
- The private and NGO/CBO sectors have considerable financial and other resources to apply to the socioeconomic challenges of HIV/AIDS.

CONCLUSIONS

This chapter emphasizes that the epidemic in many developing countries is so huge that responses must be guided by a clear, comprehensive strategy across and within sectors. The authors identify major issues relevant to mitigating the impact of HIV/AIDS.

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I N T R O D U C T I O N

Societies in which the level of HIV has risen above five percent, will inevitably have to deal with markedly increased illness and death and all their consequences. Although the impact will not be uniform between, or even within, countries, the AIDS epidemic is distinct in that it mainly strikes adults between the ages of 25 and 45. This means people are ill and die in the years in which they are most economically productive and have the greatest role as providers, caregivers and nurturers in families and communities. This has major implications for economic activity and social structures.

The greatest impacts of HIV/AIDS occur at the household level. Although AIDS often strikes more than one family member, the implications can be disastrous for an entire family if even one adult develops AIDS and loses the capacity to generate income due to illness or the need to care for other household members. HIV/AIDS also imposes extra expenditures on affected households for health care and funerals. Once adults die, many households dissolve or become headed by elderly or child members. This results in large numbers of orphans who tend to have special needs and disadvantages, even in societies with relatively strong extended family structures. Social stigma often exacerbates psychological trauma of all household members. Women and female children, at higher risk of infection than men, tend to be disproportionately affected by HIV/AIDS and often assume the greatest burden in caring for ill people. In many societies they are also disadvantaged by social, legal and economic factors.

Macroeconomic impacts of HIV/AIDS are difficult to predict. Forecasting impacts is complicated by methodological problems in projecting economic growth per se, uncertainties around demographic impacts, lack of good data on HIV/AIDS-related costs and the long time period over which the epidemic unfolds. Previous attempts to model impacts suggest

that severely affected African countries will experience average reductions in gross domestic product (GDP) growth rates of around one percent per annum over the first 25 years of the epidemic. In some countries this could lead to an increase in per capita GDP, since the reduction in growth of the population could be greater than the reduction in growth of the economy. There is no clear empirical evidence of the impact of HIV/AIDS on economic growth, although the World Bank has recently suggested that HIV/AIDS is a major reason why growth is slowing in 10 sub-Saharan African countries. Once again, it is difficult to prove that HIV/AIDS is responsible for a particular macroeconomic phenomenon.

The impact on human and social development is expected to be much more profound than reflected in such limited indicators as GDP or per capita GDP. Increased illness and reduced life expectancy will clearly compromise development objectives. Affected people, particularly orphans, will also have greatly reduced chances of fulfilling their human potential. Apart from the disadvantages of reduced nurturing, many affected children will have fewer educational and other opportunities. HIV/AIDS is also likely to increase socioeconomic disparities when the poor are disproportionately affected by the epidemic. Poor households are most vulnerable to the impact of death and illness and will fall deeper into poverty. Many other households will be pushed back into poverty. Labor market trends in response to HIV/AIDS, such as increasing capital intensity or informalizing labor, may also contribute to increasing inequality.

The scale of the epidemic in many developing countries and communities requires a well-informed, strategic approach to managing socioeconomic impacts. This chapter focuses on key areas where action is needed to reduce the socioeconomic impact of HIV/AIDS, but has often been lacking. Each section reviews the impact of HIV/AIDS on particular sectors and suggests responses that can help mitigate it. A final section examines specific issues in mobilizing intersectoral responses to HIV/AIDS.

PUBLIC SECTOR RESPONSES

Government has a central role in mounting effective responses to the socioeconomic impact of the epidemic. It can potentially influence responses in several ways:

- **By providing leadership for a society's response.** This includes advocacy, mobilizing resources, coordinating a coherent overall strategy (in much the same way as in other large-scale public health threats or war) and providing strategic information and resources to strengthen the responses of other role players.
- **Meeting increasing and changing needs as a service provider.** The most obvious needs tend to include health care and welfare services. But they also include needs for broader development to address conditions that put people at ongoing risk of HIV infection and make them more vulnerable to the impacts of HIV/AIDS.
- **As an employer.** Government is typically one of the major employers in developing country economies.
- **As a legislator and regulator.** Governments have the ability to enhance the effectiveness of various role players' responses by creating incentives or removing constraints.

The following discussions of particular sectoral impacts and responses illustrate key issues to be confronted in ensuring effective government responses to socioeconomic impacts.

MANAGING THE IMPACT ON PUBLIC SECTOR EMPLOYEES

Government responses to HIV/AIDS have tended to concentrate on prevention and impact management in communities served, rather than on employees. But because government is usually the single largest employer, it has the ability to influence the scale and severity of impacts on huge numbers of employees, their dependents and communities. Effective responses to HIV/AIDS among employees are also important to ensure minimal compromise to a government's ability to respond to other HIV/AIDS-related socioeconomic impacts and broader development agendas.

As with private sector employers, HIV/AIDS among government employees results in increasing costs and/or inefficiency for several reasons:

- There is increased absenteeism due to ill health of individual employees, but also because workers take time off to care for their families and attend funerals. In many countries entire government departments have come to a standstill because so many attend the funerals of senior colleagues.
- Sick workers are less productive at work, particularly in physically demanding jobs.
- Costs of employee benefits may escalate.
- Recruitment and training needs increase. Replacements for employees who die or retire due to ill health may be less skilled and experienced, and workers' average age may fall.
- Market wages may increase as skilled workers become scarcer.
- The psychological impact of HIV/AIDS on infected and affected employees can reduce productivity.

In general, managing the impact on organizational efficiency, capacity and costs is often more difficult for government than for the private sector. Government systems tend to be less flexible and responsive to needs created by absenteeism and increasing competition for scarce skills. (See Chapter 9 for more discussion on HIV/AIDS prevention programs in the workplace.)

RESPONSES TO EMPLOYEE IMPACT

Responding to the impact of HIV/AIDS on employees involves addressing two key questions:

- How can employee infections be prevented?
- How can government reduce the impact of existing and future employee infections?

A comprehensive impact assessment generally makes it easier to respond to these questions in a strategic manner. Assessments will help to identify the scale of expected impacts; pinpoint factors that increase the susceptibility of employees and vulnerability of core functions; and allow the development of a well-informed, coherent, prioritized approach to the problem. Impact assessments will use projections or other data to estimate current and future levels of infection, HIV-related sickness and AIDS deaths and identify categories of employees who may have greater exposure to particularly high-risk situations.

If there is substantial susceptibility, the next step is to identify vulnerabilities, work processes, departments or workplaces that are key to developing responses. Issues to be covered include assessing:

- The adequacy and effectiveness of prevention programs for employees
- Work processes or occupations that are particularly vulnerable to temporary or permanent loss of staff or skills shortages
- Performance management systems to identify and address any productivity problems related to HIV/AIDS

- Recruitment and training systems' costs, capacity and ability to cope efficiently with increased staff turnover
- Employee benefits that can be affected, such as medical insurance, sick and other leave, loans, retirement, death and disability coverage and funeral benefits
- Whether management and employees' attitudes and support mechanisms make it easier for employees to disclose their HIV status to mobilize support and allow forward planning
- Employees with special vulnerability and needs, such as women
- Adequacy of systems to monitor key HIV/AIDS impacts such as absenteeism and impacts on costs, as well as evaluate effectiveness of responses
- Capacity and systems to respond to HIV/AIDS among employees, which are likely to include:
 - Adequately resourced committees, teams or individuals responsible for HIV/AIDS
 - AIDS-literate line and other managers, and support from leadership
 - An HIV/AIDS or chronic disease policy, which is widely known and based on sound knowledge of impacts on individuals and the organization
 - Support mechanisms for infected and affected employees

After identifying susceptibility and vulnerabilities, a prioritized response can be developed based on feasibility, affordability and the likely cost-effectiveness of various actions.

Individual ministries and workplaces will need to customize their responses to suit their own circumstances. But many aspects of prevention and impact management will require coordination and action by central departments dealing with employment frameworks and systems, such as a Department of Public Service Management. In many other areas, networking and resource sharing between different components of government will greatly enhance the overall response.

THE HEALTH SECTOR

The health sector is affected early and most obviously by HIV/AIDS, and has several important roles to play in mitigating the socioeconomic impact of the epidemic. Effective health care can relieve the suffering of infected individuals and extend their productive lives. It can also have several less direct benefits, such as reducing individuals' stress and psychological trauma, relieving the economic and other burdens of care on households and combating broader public health problems such as tuberculosis (TB).

The challenge to developing an appropriate health care policy is to reduce the burden on the formal health care system without shifting it onto individuals, families and communities. Interventions such as home-based care, for example, are often highly effective at minimizing the impact of HIV/AIDS on the public health care system. But unless families are given adequate support, home-based care can overwhelm family members by their role as caregivers. (See Chapter 24 for in-depth discussion of home-based care for people with HIV/AIDS.)

Providing health care can help promote HIV testing and knowing one's HIV status. This facilitates prevention and effective planning by infected individuals and households. The health sector also tends to play a critical role in HIV prevention and broader impact management by informing intersectoral and community programs, and in interventions that take place through conventional health services.

IMPACT ON NEED FOR SERVICES

People living with HIV/AIDS (PLHA) generally have a range of health care needs. Most HIV-related conditions can be managed effectively at the primary care level, and basic treatments and care can considerably improve the quality and length of life of an individual infected with HIV. As the disease progresses, HIV-infected people have an increasing need for hospitalization, both for acute, treatable illnesses and for terminal conditions. In settings where antiretroviral drugs (ARVs) may be affordable, new systems will often be required to manage complex therapies and ensure adherence to treatments. (Chapter 25 provides guidelines for effective use of ARVs in resource-constrained settings.)

The main effect of HIV/AIDS on health needs is that adults—who are usually among the healthiest members of society—and large numbers of children will now suffer from a serious, chronic disease. Thus, there are dramatic increases in needs for health care, to levels well above those previously assumed in planning. In one relatively well-resourced South African province, projections indicate that HIV/AIDS alone will more than double the required number of hospital medical beds between 1997 and 2006, unless more efficient ways are implemented to care for people infected with HIV. In other countries, the costs of care per PLHA have been estimated to be around 2.7 times per capita GDP.

This scale of extra need is particularly problematic, as many developing country health sectors have had difficulty in meeting basic health care needs even without the burden of HIV/AIDS. Simply meeting only a portion of these needs will consume a substantial share of these countries' health care spending. In 1995, HIV/AIDS care was estimated to account for 27 percent of public health care spending in Zimbabwe and 66 percent in Rwanda. But it is almost certain that in most severely affected countries the intensity and costs of care per patient will decrease as needs increase. Resources to care for people with other health care problems will also potentially be reduced. Many HIV-infected and other people will therefore have unmet needs, even if health services do not actually collapse under the extra burden of disease.

IMPACT ON CAPACITY TO DELIVER SERVICES

HIV/AIDS compromises capacity for health care in the same ways it impacts on any organization, through its direct and indirect impact on employees. Several aspects of the impact on health workers are particularly significant:

- **Health workers are at high risk for HIV/AIDS and its complications.** In most developing countries, the greatest risk of infection to health workers is by far through sexual exposure, although risk of occupational exposure to HIV also has to be considered. In Lusaka in 1991-92, HIV prevalence was 39 percent among midwives and 44 percent among nurses. Kinshasa, Zaire hospital workers were shown to have levels of HIV infection comparable to the general community.^{1,2} In two Southern Zambian hospitals, mortality rates among nurses rose from 0.5 percent per annum in 1980 to 2.7 percent in 1991, due to HIV/AIDS.³ The death rate of health care workers in Malawi was three percent in 1997, a sixfold increase in pre-epidemic levels.⁴
- **HIV-infected and other workers are also at risk of occupational exposure to opportunistic infections, particularly TB.** The annualized incidence of TB cases among health staff has increased five-fold over five years in health services in certain high HIV prevalence areas, with up to 86 percent of tested cases also infected with HIV.⁵
- **Huge extra service needs make the health sector more vulnerable to inefficiencies.** Many health services struggled to provide effective services, even before the HIV/AIDS epidemic. Illness and death among health care workers can worsen existing inefficiencies and capacity constraints. The impact of HIV/AIDS on morale is particularly drastic in the health sector as workloads increase dramatically, and stress and burnout are exacerbated by factors such as high mortality among children, young adults and colleagues.

HEALTH SECTOR RESPONSES

HIV/AIDS will be the biggest single issue facing the health sector in many developing countries. The epidemic has to be considered a core business of all components of the health service, not just something to be dealt with by an HIV/AIDS unit. For example, HIV/AIDS directly affects the need for laboratory, physical therapy, nutrition and primary health care (PHC) services. All components of health services will be affected through the competition for resources, need for referrals and effects on employees. It is also critical that HIV/AIDS responses are approached in a sound, strategic manner based on planning principles that should be applied to any major health issue. Incremental, ad hoc approaches, which may have sufficed in an era when health needs increased gradually and in line with previous experience, will almost certainly be inefficient and overwhelmed by HIV/AIDS.

As with any health planning, this should begin with a thorough situation analysis or impact assessment. This analysis needs to assess current needs and resources as well as projections of future needs and resources as these may differ hugely from those now being experienced. A comprehensive assessment will give an indication of the types and scale of impacts and allow clear option appraisal, prioritization and strategic choices. Formal, detailed health sector impact assessments have been conducted in relatively few countries, but have helped with planning, refinement of existing programs, advocacy and mobilization around HIV/AIDS.^{6,7}

A well-informed, effective response to HIV/AIDS in the health sector should consider such issues as:

■ **The role of the health sector in prevention programs.** This includes:

- Directly involving sector capacity and services in education and empowerment, providing condoms and STD treatment
- Participating in overall program design, capacity building and technical support for other sectors
- Evaluating programs
- Developing strategy around prophylaxis, secondary and tertiary prevention of complications of HIV infection
- Ensuring a safe blood supply

■ **Projected needs for HIV/AIDS care.** These may include PHC visits, hospital days, terminal care days, counseling visits and TB cases.

■ **Identification of affordable, cost-effective and feasible ways to address each type of need.**

Interventions that are not cost-effective can lead to large-scale inefficiency in the use of available resources, while other interventions may simply be unaffordable or impractical on the scale required. Home-based care, for example, is not cost-effective in all settings and may not be feasible for all people needing chronic or terminal care. On the other hand, certain models of hospice care may simply be unaffordable on a large scale. Service organizations, capacities and priorities will differ in different settings, but certain issues and approaches tend to apply in many circumstances. These include:

- **Establishing priority medical and other needs of PLHA and their households.** These frequently indicate that health care is only one of the priority needs of PLHA, and may be less pressing than their need for financial or other support.⁸ These insights can guide the planning

and prioritization of resource use. PLHA should be actively involved in this process, as well as in service design and monitoring.

- **Addressing general health system inefficiencies that waste existing capacity.** HIV/AIDS care can compound existing inefficiencies in, for example, unnecessarily extended hospital stays, poor referral systems or inefficient staffing norms or task allocations.
- **Considering options for care of people with late-stage disease or recovering from severe illness at earlier stages of infection.** Care in late-stage disease, particularly hospital care, tends to be very expensive and has limited benefits for quality and length of life. Terminal care must at least be adequate to minimize unnecessary suffering or the loss of infected people's dignity. Home-based care (HBC) may be feasible and cost-effective for some areas, conditions and individuals, but not for a significant number of others. Other options, such as respite care, hospice and lower intensity inpatient care for the terminally ill, need to be considered.
- **Including effective PHC services in HIV/AIDS responses.** PHC has an important role because it is often more accessible than hospital care, and can prevent and treat illnesses before they become severe and require hospitalization. PHC-oriented care strategies often have been shown to be more cost-effective than hospital-oriented approaches. Effective PHC is also a key link in the continuum of care, allowing more efficient use of hospital resources and ensuring that community-based terminal or other care is adequately supported.
- **Including effective TB programs and services in the responses of the most heavily affected countries.** They will directly benefit HIV-infected people, with a substantial impact on their survival, and reduce broader public health impacts.
- **Addressing specific psychosocial care and support strategies, including counseling and testing services.**

- **Paying special attention to referral chains and systems from higher to lower levels of care, and vice versa.** The overall system of care is likely to be inefficient and inequitable unless referral systems are effective.
- **Considering broader development impacts of HIV/AIDS beyond direct health service costs in the choice of strategy.** For example, HBC may sometimes reduce health service costs but impose large costs on households if taking care of a sick household member prevents other adults from working or children are withdrawn from school. These effects can seriously undermine other development and impact management goals.
- **Developing guidelines and systems for clinical care, admission, discharge and referral.** These need to be in line with overall care strategies, resource constraints and plans for a continuum of care if they are to help clinicians make inevitable, difficult decisions about limitation of care.
- **Implementing rapid piloting, evaluation and roll-out of new models of care.** This is particularly important as new low-cost treatment strategies become available.
- **Training staff and others involved at all levels of HBC.** This will make them confident and effective in HIV/AIDS care and guideline use.
- **Assuring reliable supplies of priority basic consumables and drugs at each level of care should be assured for effective and acceptable care.**
- **Human resource management and planning.** Staff susceptibility and service vulnerability due to suboptimal management and utilization of staff need to be addressed, as in any other workplace. In particular:
 - Planning should accommodate increased needs for care and loss of staff. It should target training and staff categories that are most cost-effective and feasible to train on the scale required by HIV/AIDS-related need.
 - Burnout and stress on all types of staff need to be actively considered in work organization and planning.
 - Policies, programs and procedures for HIV prevention, including workplace exposure to HIV and opportunistic infections, are needed to avoid unnecessary infections, stigma and demoralization.
- **Reducing the stigma of PLHA among staff and patients.** Even in heavily affected societies, stigma is surprisingly prevalent and undermines prevention, care, and support.
- **Mobilizing leadership within the health sector.** Political and senior management commitment to HIV/AIDS is essential to ensure that adequate resources and leadership drive the development and implementation of a response. The interlinked roles of all health system components in confronting HIV/AIDS requires the active and ongoing involvement of planners and managers of hospitals, PHC and other health system components at all levels.
- **Mobilizing and facilitating the role of other sectors in prevention, care and support.** Health sector capacity to run sustained programs across sectors is usually limited, which reduces effectiveness. Overreliance on health sector inputs reinforces the perception that HIV/AIDS is only a health problem. Available health sector resources can also become preoccupied with other sector initiatives, neglecting the development of specific strategies for the health sector. Health services cannot respond efficiently to needs without support from such sectors as welfare because, for example, household capacity for HBC may be too limited by economic factors to allow for earlier discharge of hospitalized people.
- **Developing and supporting the roles of non-governmental (NGO) and community-based organizations (CBOs).** HIV/AIDS prevention, care and support provided by NGOs or CBOs may often be more appropriate, effective and cost-effective than if it were provided directly by the

government. In addition, the scale of the epidemic often overwhelms the health sector's capacity, requiring that other resources be drawn into responses.

- **Engaging the commercial private health care sector.** Experience in many countries shows that effective private sector responses to key public health problems such as HIV prevention, STDs and TB cannot be assumed. In addition, private sector HIV/AIDS responses may not be cost-effective and may make private care increasingly unaffordable, with negative implications for the efficient use of overall health system resources and equity.
- **Involving traditional healers.** In many instances, traditional healers have been valuable contributors to prevention and care programs, particularly for TB and palliation. Their exclusion can also seriously undermine health system initiatives.
- **Improving available information.** Information on many aspects of HIV/AIDS needs and system responses tends to be inadequate for planning and management. Decisions based on poor information can have large-scale implications, so it is critical to make better information a priority. This typically includes information on epidemiology, utilization patterns, costs and cost-effectiveness. Impact and program monitoring and performance evaluations are also critical. Although many areas requiring more detailed research are likely to be identified, it is critical not to hold up action while seeking “perfect” information. Available information also should be efficiently analyzed and disseminated.
- **Review of policies, legislation and regulations.** Some of these may lead to suboptimal prevention and care. Staffing norms and job descriptions, for example, may not facilitate rapid, cost-effective adaptation to absenteeism or staff loss, or may make training and appointment systems unable to meet urgent, large-scale demand.

THE EDUCATION SECTOR

The education sector plays a key role in reducing short- and longer-term socioeconomic impacts of the HIV/AIDS epidemic. The sector is uniquely positioned to influence the future course of HIV/AIDS epidemics by changing risk behavior and infection rates of large numbers of young people at the age when HIV incidence tends to be highest. The sector can also have a major influence on managing the immediate effects of HIV/AIDS on educators, children and older learners. In the medium to longer term, effective responses can also limit “lost investment” in learners who become infected, reduce the severity of skills shortages in an economy and communities and ensure that children and learners are equipped to lead more fulfilling, productive lives.

IMPACTS ON NEEDS TO BE MET BY THE EDUCATION SECTOR

The education sector is confronted by changes in the scale and types of needs to be met. Demographic impacts of the epidemic will tend to result in smaller numbers of potential enrollees in education, as fewer children will be born and many HIV-infected infants will not survive to school age. A recent impact study in Swaziland suggests that by 2016 there will be a 30 percent reduction in the size of the primary school population for each grade, with somewhat lower, but still substantial, reductions in the need for secondary and tertiary education.⁹ Enrollment may be further affected by household economic difficulties and children's responsibilities for care, which makes them more likely to drop out of school or repeat grades.

At all levels of education there will be many learners with new special needs:

- Vast numbers of children will be orphaned. In Swaziland, orphan rates are projected to be three to four times higher than before the epidemic, with orphans constituting an estimated 36 percent of children under age 15 by 2005, and the likelihood that the orphan population will be disproportionately high for at least the next 30 years.¹⁰ Several studies have indicated that orphans are at high risk of being educationally disadvantaged.¹¹

- Huge numbers of children—up to a third of the children in Swaziland,¹² for example—will be exposed to infectious diseases and emotional trauma due to living with, and caring for, family members with HIV/AIDS. Discrimination and isolation often exacerbate the psychological trauma caused by peers and teachers in children who are infected or who are members of infected families.
- Children in households where a parent is ill or has died, and possibly children in families that take in orphans, will face increased economic difficulties and responsibilities for care and household maintenance. Economic pressures may make it impossible for them to pay fees, buy books and uniforms, maintain adequate nutrition or avoid having to work to sustain themselves and their households.
- Significant numbers of learners will themselves be HIV-infected. Although the majority of children infected around the time of birth will die before the age of two, some will survive to reach school age, and many more will become infected as teenagers.¹³

Thus the traditional role of the education system in cultivating numeracy and literacy will have to be supplemented by roles in supporting and nurturing large numbers of children in crisis, giving them life and survival skills from a relatively early age.

IMPACT ON CAPACITY TO PROVIDE EDUCATION

Teachers at all levels of the education system are at significant risk for HIV/AIDS infection. There are indications that they may be at even greater than average risk as their high status and incomes create opportunities for high-risk behavior. Zambia's Ministry of Education reports that 2.2 percent of teachers died from AIDS in 1996. This is already more than the number produced by all its teacher training colleges. The death rate is expected to triple by 2005.¹⁴

Implications for education will include the general areas of cost and inefficiency that will affect employers in general. But several specific impacts on education warrant further mention:

- Death or absence of even a single teacher is particularly serious because this tends to affect the education of 20 to 50 children.
- Loss of key individuals at the leadership level—including planners, school inspectors, and principals—may further compromise quality and efficiency of the education system. The average age and experience of teachers is expected to fall.

EDUCATION SECTOR RESPONSES

In many countries, HIV/AIDS challenges the very core of the education system's mission. There will be huge levels of "wasted investment" in individuals if learners die after they have been trained and educated. The epidemic also undermines the ability to develop the potential of many other learners who are disadvantaged by HIV/AIDS in their households. Strategic, large-scale mobilization is required to respond.

Understanding the potential impact on needs and capacity is key to mobilizing HIV/AIDS responses and enabling effective planning, action and efficient use of available resources. This should clearly identify key areas of susceptibility and vulnerability of learners, educators and overall system function. Informed planning in many severely affected countries requires projections of the scale of various impacts. In Swaziland, for example, a 1999 impact assessment has helped to identify the scale and type of impacts on the capacity to provide formal education, as well as the sector's preparedness to reduce the scale of the epidemic and mitigate impacts on society. This has led to increased mobilization around HIV/AIDS in the sector and beyond, as well as to the initiation of various planning and other processes to mitigate impacts. Mobilization and planning have been assisted by participatory approaches to impact assessment and strategy development, including focus group discussions at school and community levels and workshops involving key decision makers to identify priorities and strategies.⁹

Effective responses will typically need to:

- **Mobilize political will and leadership within the education sector and beyond.** In Swaziland, for example, other key role players identified were the minister of economic planning and development, the king, cabinet, parliament and traditional leaders.
 - **Create dedicated processes, capacity and structures to drive HIV/AIDS responses.** This is required to drive the overall program, as well as in specific areas such as prevention programs and obtaining information to inform planning and management.
 - **Develop strategies to slow the rate of new infections among learners that will:**
 - Provide adequate core knowledge about HIV/AIDS to learners and other key stakeholders—parents, teachers, traditional and religious leaders—remains critically important, even in quite advanced epidemics. The 1999 Swaziland impact study found that despite antenatal HIV prevalence of more than 30 percent, almost all stakeholders felt strongly that they were still confused about HIV/AIDS.¹¹ In addition, the emphasis on changing attitudes among educators, students, parents or guardians and community leaders was considered to be critical. Key issues to be addressed included attitudes towards women’s role in sexual decision making, casual sexual partners, PLHA and various aspects of denial. Stigma around HIV/AIDS is recognized as a key obstacle to prevention and impact management in many settings.
 - Recognizing that most countries need life skills programs. These focus on skills and empowerment to change behavior and avoid high-risk situations, rather than simply providing information on HIV and sexuality issues. To date, life skills programs have had mixed success. They require careful design and implementation, with ongoing monitoring and evaluation. Common challenges to anticipate include attitudinal, moral or skills barriers among educators; ensuring the active participation of learners in program design and implementation and in life skills classes; ensuring the active support of parents, religious leaders and other stakeholders (the Swaziland study found that, contrary to popular belief, most parents were supportive of sex education in schools⁹); knowing whether and how to integrate life skills and HIV education into other curricula; and knowing how to sustain programs and roll out pilot projects.¹⁵
- Providing access to protection such as condoms.
 - Addressing rape and sexual abuse in schools and communities.
- **Provide in- and pre-service HIV/AIDS training for teachers.** This should build skills for prevention to avoid infection of trainees and teachers, as well as skills for managing impacts among learners and fellow staff.
- **Adapt estimated numbers of learners and educators to be trained in plans for sectoral development.** It is essential to plan for any changes in numbers.
- **Consider adapting the structure and curricula of schooling and higher education courses.** For example, course structures that allow for modular, part-time and accelerated learning may increase flexibility to respond to rapid increases in needs for trained people. This may also increase system efficiency by giving HIV-infected learners more of an opportunity to “pay back” investment in their education through active teaching for a longer time.
- **Remove barriers to ongoing schooling among affected children.** In Swaziland, for example, suggested responses included establishing an educational fund to pay for orphans’ education; offering exemptions to homesteads or institutions with orphans to enable the children to attend school; waiving school uniform requirements when affordability is a problem; expanding school-based feeding programs for school children; and introducing flexible schooling hours, where possible, to keep in school those children who might otherwise have to drop out due to labor requirements elsewhere.⁹

- **Identifying and responding to particularly susceptible or vulnerable groups of learners.**
 - Orphans may need specific care and support programs. Looking into a support program for orphans and caregivers was identified as a key priority in Swaziland.
 - Girls and young women may face strong social or economic pressures that force them to withdraw from school and potentially engage in sexual networking.
 - Programs to increase access of out-of-school youths to HIV/AIDS and general education may be required.
 - The needs of infected children are likely to require special attention.
- **Mobilizing intersectoral initiatives at all levels to strengthen prevention, ensure adequate support for infected and affected learners and allow appropriate responses to broader development and impact management needs.** Key sectors will often include finance or development planning, both of which influence the availability of resources for education. Health and welfare sectors tend to provide important technical support and assist in prevention and the development of mitigation strategies. To guide education planning, all sectors will need to provide guidance on anticipated areas of skills shortages.
- **Legislating, regulating and creating incentives to improve prevention and impact management.** For example, tax incentives to increase employers' roles in orphan support were suggested as a possible option in Swaziland.⁹ In some societies, incentives for direct private-sector involvement in training and education may be warranted.
- **Generating key information, including monitoring and evaluation of trends in impacts, such as dropout rates and absenteeism, and success of program implementation.** In Swaziland, studies to understand the needs of orphans were considered a major priority.⁹
- **Identifying costs and considering affordability in strategy development, based on impact projections and the needs identified.** In Swaziland, for example, the cost of the epidemic to the educa-

tional system has been estimated at upwards of E2 billion between now and 2016, funds which are unlikely to be available to the system. This has led to recommendations that the Ministry of Education prepare revised guidelines and develop detailed strategies on educational provision that increase flexibility to use available resources more effectively. Suggestions included re-hiring retired educators, involving senior students in teaching and adopting learner-centered approaches to education to allow class sizes to grow without compromising educational quality.⁹

OTHER GOVERNMENT SECTORS

Although this chapter focuses primarily on the impact of HIV/AIDS and the roles of the health and education sectors, clearly this epidemic has implications for and requires the collaborative response of multiple sectors.

Social support sectors that specifically address community services, women and youth are obvious partners for an effective public sector response to HIV/AIDS. These ministries often have direct and credible contact with the populations most vulnerable to HIV. They are also frequently on the frontline in providing support services and strategies addressing many of the determinants of HIV vulnerability, including economic and social inequality and instability. Finally, they may be both direct providers of support as well as have established linkages with NGOs for support to PLHA.

In many developing countries, agriculture provides a living for up to 80 percent of the population.¹⁶ HIV/AIDS affects the agricultural sector by reducing human resources and capital, which can result in lower productivity, less land area under cultivation, and changes in the patterns and yields of crops. Given the high proportion of women traditionally engaged in agriculture, the diversion of these women to taking care of infected family members can result in severe

Figure 1
**PROGRESSION OF CASES AND COSTS OF
 WORKFORCE HIV/AIDS**

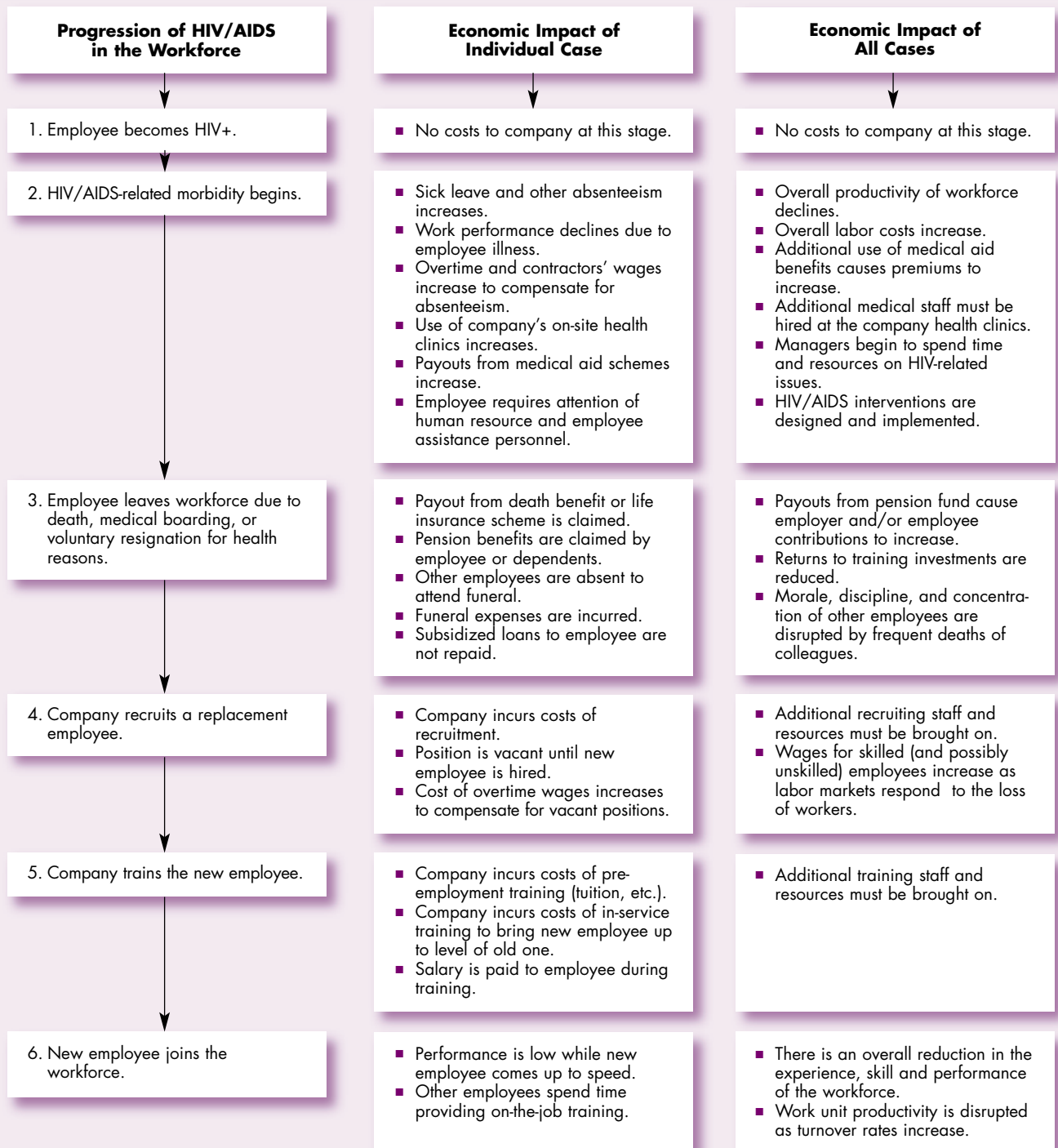
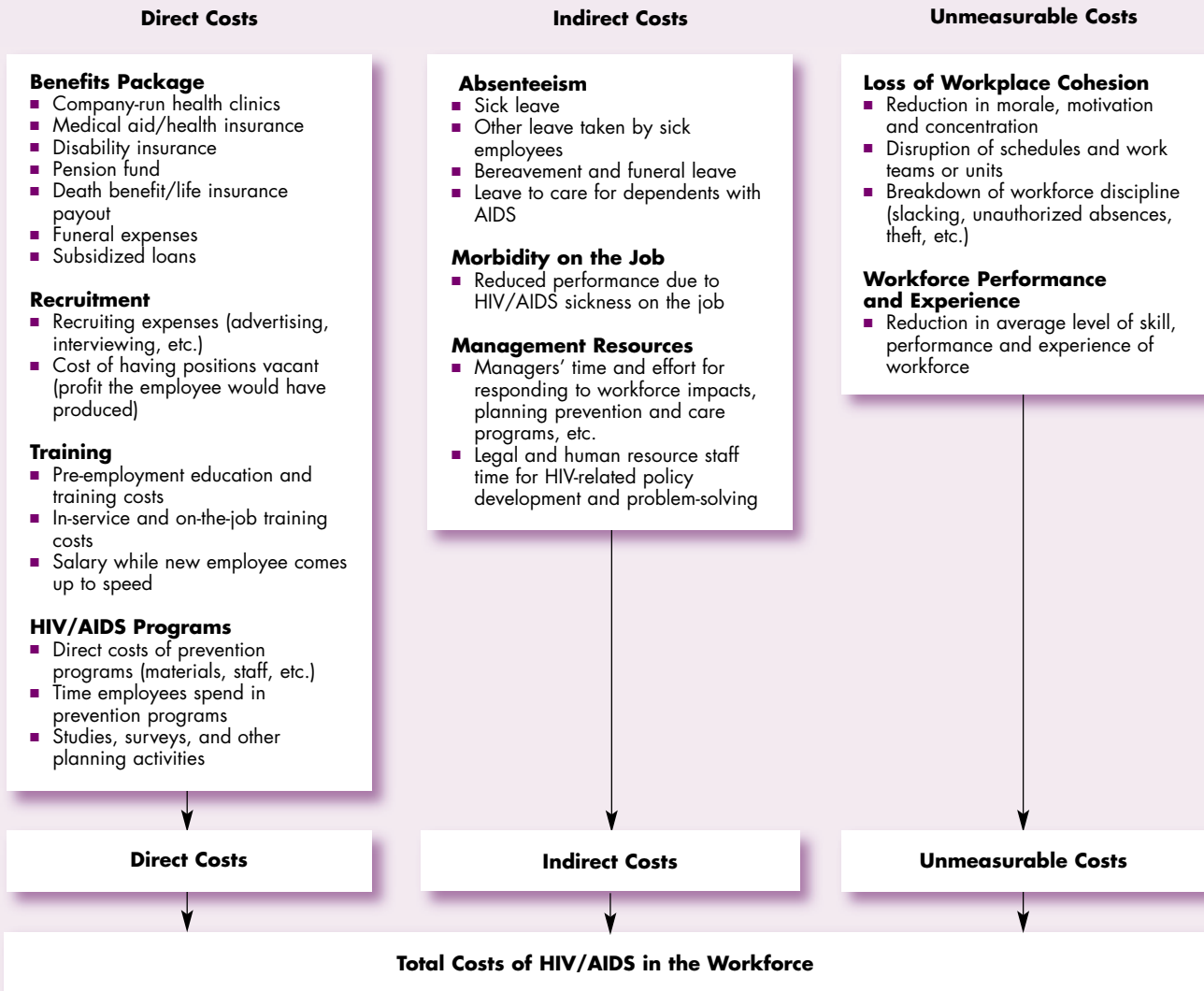


Figure 2
ECONOMIC IMPACT OF WORKFORCE HIV/AIDS



temporary or even chronic reductions in food security for families. As noted earlier, HIV/AIDS also diverts children from pursuing educational opportunities to work family agricultural plots. Ministries of agriculture can support integrated prevention programs that address HIV vulnerability and risk reduction strategies, especially as they relate to human capital constraints, mobility of migrant farm laborers, and strengthening sustainable rural development.

National defense is also compromised by HIV/AIDS and has an important role to play in reducing HIV/AIDS within the military and beyond. Military leaders in many high prevalence countries worry about their ability to attain and deploy full contingents as well as their ability to retain the skills of highly trained experts and leadership. As military forces increasingly participate in peacekeeping and other long-term deployments away from home, the likelihood of risky behavior increases. The mobility of military forces and their greater interaction within their temporary communities also puts the civilian population at risk. Ministries of defense are crucial partners in HIV/AIDS prevention through the direct implementation of prevention education and services for armed forces.

They can also examine approaches for reducing underlying vulnerability, including (1) changing posting practices to shorten the time recruits are away from families and finding opportunities for keeping families together whenever possible; (2) adapting the “risk-taking ethos”¹⁷ of the military to be more discerning about necessary versus unnecessary risks; and (3) encouraging more responsible interactions with civilian populations based on human rights and strict codes of conduct. It is also essential to integrate military health services with community-based health services, particularly HIV/AIDS prevention, to avoid service gaps and disconnects.

THE PRIVATE SECTOR

How will AIDS affect the business sector? How is the sector responding to the epidemic? How should it respond? There is no clear answer to any of these questions, and very limited information on the impacts of HIV/AIDS on business. This lack of information makes it harder for the business community to respond. But there is going to be a steady, large increase in illness and death in the working-age population, which will inevitably impose some degree of costs and uncertainty on business.

IMPACTS ON COMPANY COSTS

The major HIV/AIDS concerns for businesses are reduced productivity and increased costs. Productivity will fall and costs rise due to the same kinds of HIV/AIDS impacts discussed above for government employees. There is a range of methods to assess the impact of HIV/AIDS on businesses and a recent publication presents two cost models.¹⁸ Figure 1 shows a chronological model designed to demonstrate to business managers how HIV/AIDS among employees is likely to affect a company’s expenses and labor productivity. For purposes of data collection and analysis, the costs identified in Figure 1 can be reconfigured into a second model (Figure 2).

There is little information in the public domain about the scale and significance of these costs. A 1994 USAID-sponsored AIDS Control and Prevention (AIDSCAP) Project assessment of companies in Kenya and Botswana found that costs to business would vary from less than 1 percent of profits to a high of nearly 9 percent, with most costs resulting from employee absenteeism.¹⁹ In contrast, a five-company study in Botswana found that HIV costs were still relatively low there as late as 1997: an average of 0.7 percent of the total wage bill.²⁰ Another study examined three companies in Zambia and found that although there was a marked increase in absenteeism and mortality, costs were still low.²¹ In Malawi a detailed study of a large tea estate in 1996 came to similar conclusions.²² The firm was able to cap costs by adjusting its employee contracts and benefits policies. A more recent analysis of a sugar mill in South Africa estimated an annual cost of approximately US\$1,600 per

Table 1
COSTS TO COMPANIES

Company name	Total annual cost of AIDS	Annual cost of AIDS/employee
Botswana Diamond Valuing	US\$ 125 941	US\$ 237
Botswana Meat Commission	US\$ 370 200	US\$ 268
Côte d'Ivoire food processing firm	US\$ 33 207	US\$ 120
Côte d'Ivoire packaging firm	US\$ 10 398	US\$ 125
Muhoroni Sugar, Kenya	US\$ 58 303	US\$ 49
Uganda Railway Corporation	US\$ 77 000	US\$ 300

Source: Stover & Bollinger, 1999.

infected employee during the last two years of the employee's life, including two extra months of absenteeism over this period.²³

In these studies, the share of costs attributable to absenteeism, medical care, pensions, training, etc., varied widely, as did the impact on the companies' bottom lines. The inconsistent methodology and scarcity of reliable data used in these studies make their conclusions difficult to interpret.¹⁸ Much of the data also refer to years in which the AIDS epidemic was not yet very advanced. But overall, the evidence suggests that HIV/AIDS costs are unlikely to be disastrous for most firms, although cumulative costs over time will be substantial.

The highest HIV/AIDS cost to companies is likely to be loss of labor, due to deaths and absenteeism. The second highest area of costs to companies relates to employee benefits. These will depend on the conditions of employment, the level of staff and the benefits provided. It is likely that the more advanced African economies will be more adversely affected. For example, in South Africa benefits include group life insurance,

pensions and medical aid. If payroll costs do not rise, benefits will be reduced. One example from the insurance industry showed that in Zimbabwe, life insurance premiums quadrupled in two years because of HIV/AIDS. A study of businesses' main concerns about the impact of HIV/AIDS in Zimbabwe found they were most worried about the loss of skilled labor (33 percent), loss of labor generally (24 percent), reduced future productivity (24 percent), increased insurance and pension costs (13 percent) and other associated economic costs (12 percent).

IMPACT ON MARKETS

HIV/AIDS could reduce the absolute number of potential customers, making the markets that are relatively saturated and depend critically on population size the most vulnerable. The epidemic's impact on specific markets will depend on the demographic profile of consumers (age, sex and geographic location), with consumers age 25 to 49 likely to be most affected. In countries where needs for goods are far from saturated, many consumers who die or have their disposable income reduced by HIV/AIDS will be replaced by new earners and consumers, if overall GDP and consumption expenditure remain largely unaffected by the pandemic. But consumption patterns may be significantly affected when spending is diverted to meet such HIV/AIDS needs as health care and funerals.

In countries such as South Africa, labor market adjustments to HIV/AIDS—such as increasing capital intensity, or using less-skilled labor that is cheaper to replace—may exacerbate economic and political polarization. This means that markets for goods and services targeted at upwardly mobile households may be more severely affected. A major concern for the retail sector in southern Africa is the provision of credit. Many clothing chains offer credit that is written off if the customer dies. Store cardholders may also be offered funeral benefits in the event of their or their dependents' death. An insurance company in Durban, South Africa, that underwrites the death and funeral benefits of a major retail chain, reported a 50 percent increase in the number of claims during 1998, result-

ing in a need to increase premiums in line with the expected increase in deaths.²⁴ Retailers of household appliances and furniture will also be affected as many of these items are sold on a lease-purchase basis.

THE BUSINESS ENVIRONMENT

AIDS may substantially affect the business environment even though it is not expected to be a dominant influence on macroeconomic growth. AIDS may have greater though less predictable effects on other aspects of the political, social and business environment, including:

- The increase in orphans and street children may increase crime rates.²⁵
- The security apparatus, labor movements, and political leadership will experience increased mortality that may compromise stability.
- The overall pressure on health systems may lead to deterioration in the level and quality of service, and poorer health even among the uninfected.
- Any government diversion of resources to HIV/AIDS care and prevention may have significant opportunity costs in other sectors and investments in infrastructure.
- Government efficiency in key areas may fall significantly due to impacts on employees, leading to delays in granting licences, approving applications and so on.
- In some countries there are likely to be problems arising from policies to develop and favor local skills to replace expatriates and affirm previously disadvantaged groups that may be at high risk for HIV/AIDS. The epidemic may delay and reverse the implementation of these policies. If government policies do not recognize the new realities created by AIDS when it is necessary to do so, there may be substantial negative effects on businesses and economies.

THE BUSINESS RESPONSE

What can and should companies do about AIDS? Essentially, there are four areas in which they can respond: employees, costs, markets and society (see Chapter 10).

The impact on employees

Private sector attempts to reduce impacts on employees may benefit not only employees and the employer, but may also have major spin-off benefits for the broader community and society as a whole. The private sector will often be better able than governments or communities to access and effectively apply resources to mitigate HIV/AIDS impacts. Private sector employees also tend to have substantial numbers of immediate or indirect dependents. Two main response areas to consider are:

- Preventing HIV infection in current and new workers through HIV/AIDS education, providing condoms and STD services and addressing root causes of HIV transmission. There are many examples of education, condom programs and enhanced STD services. These have been shown to reduce STD levels, suggesting that they also reduce HIV infections. But companies need to recognize that their employees are members of the community where transmission occurs. This is why interventions must extend into employees' communities. Programs also need to address root causes of high risk, such as migrant labor or work that requires employees to spend large amounts of time away from home. Solutions require imagination and lateral thinking. Some transport companies, for example, have begun to make drivers exchange their vehicles midway between cities to avoid spending nights away from home.
- Providing care and support services. In or outside the workplace, effective affordable health care to manage ill health among employees becomes increasingly important. Access to adequate workplace or off-site primary medical care has been shown to reduce absenteeism. Assisting workers with TB treatment has helped to ensure that they are diagnosed and cured, thereby prolonging their productive lives and protecting fellow employees

from infection. Home-based care systems have been used to help employees recover more quickly from bouts of illness and to support the terminally ill.

Other types of support, such as funeral, disability and death benefits, can strongly influence the socioeconomic impacts of HIV/AIDS on employees' households. Many employers provide on- or off-site counseling and assistance programs for employees who are HIV-infected or affected.

The impact on costs

Managing the impacts of HIV/AIDS on costs—through mechanisms similar to those discussed for public service employees—can have important, broader socioeconomic benefits by ensuring that firms remain viable, competitive and able to provide employment. Responses such as improved training, teaching multiple skills and providing medical and other support to keep employees productive as long as possible have clear socioeconomic benefits. But cost-reduction strategies adopted by companies also can have negative socioeconomic implications. If a company controls costs by reducing medical or death benefits, for example, HIV/AIDS costs will have to be borne by individuals, households, communities or the state.

The negative impact of HIV/AIDS responses may be limited to some extent once firms recognize that crude attempts to minimize costs may actually be cost-ineffective. For example, poor health benefits or other benefits may reduce productivity by accelerating death and illness and lowering workforce morale. Discriminatory hiring practices also may make it impossible for firms to find skilled workers in skills-scarce economies. It is nevertheless unclear whether and when business responses in these areas will be appropriate to serve the overall objectives of reducing the socioeconomic impacts of HIV/AIDS.

The impact on markets

The impact of HIV/AIDS on markets will be a significant issue for certain companies, and each will have to assess the vulnerability of their particular markets. For those likely to be affected, responses such as limiting credit or investing in other countries may have either negative or positive impacts on development whose significance is unknown.

Business and society

AIDS is such a serious and far-reaching problem that it will define how societies develop in Africa over the first half of this century. The epidemic and how society responds will determine the structure and shape of society and the business environment. Business has an important role to play.

PRIVATE SECTOR RESPONSES IN PRACTICE

There are limited data to indicate whether, even in companies that are concerned about HIV/AIDS, the overall response has addressed socioeconomic impacts in a definitely positive or negative manner. Part of the problem is that the interventions that do succeed are unlikely to produce benefits in terms of AIDS cases averted for seven to ten years. Many companies have not even monitored impacts effectively, or appear to have merely accepted them, while others have actively tried to address at least some impacts. Several other companies concerned about HIV/AIDS have showed a similar pattern in their responses:

- **Stage 1.** The company became aware of the epidemic. Being a responsible employer, it implemented an AIDS education package, usually aimed at workers rather than management (who did not regard it as their problem).
- **Stage 2.** HIV prevalence in the national population climbed and deaths began to occur in the workforce.
- **Stage 3.** The company now wanted to know the scale of the problem it faced. Projections and/or workforce surveys using non-invasive saliva tests were used. It became clear that despite AIDS edu-

education programs the levels of infection in the company workforce were probably very similar to those in surrounding populations.

- **Stage 4.** Outside academics or consultants were brought in to collect data or guide the company in its own data collection and analysis.
- **Stage 5.** It is impossible to say what has happened beyond increased prevention activities. This is the stage when companies are least likely to share information, either because they believe it is commercially sensitive or their actions, which are rational for the company, may not be best for the nation.

In countries such as Botswana, Thailand and South Africa, business coalitions on AIDS have been formed to strengthen private sector responses. Firms in the same sector (e.g., transport) or local areas have also showed some cooperation. Such partnerships have coordinated initiatives for training, skills development, care and prevention; shared knowledge and experience; identified and accessed HIV/AIDS management resources for member firms; researched issues of interest to business; and developed common approaches to certain key issues. But the scope and effectiveness of such initiatives has varied substantially.

Certain general themes emerge:

- **Academic methodologies and ways of thinking about and responding to the epidemic are too esoteric for most business managers.** Effective responses to HIV/AIDS often require expertise, understanding and resources which may be

difficult for individual companies, particularly smaller firms, to develop. Thus partial responses—rather than optimal management of internal or broader socioeconomic impacts—are probably more realistic initial goals of programs to mobilize private sector responses.

- **Some businesses tend to respond to HIV/AIDS when they see clear, usually financial, business benefits in doing so.** The immediate significance of other business issues, and effective ways to address them, are often easier to identify, so they tend to be given greater priority than HIV/AIDS. The benefits of developing HIV/AIDS responses early on may seem too distant to effectively motivate firms. There is no guarantee that HIV/AIDS initiatives will appeal to companies' corporate social investment programs, although many invest in areas such as education, which can address important HIV/AIDS impacts.
- **Financial reasons are not always the main motivating factor for developing a prevention strategy.** Many businesses do not necessarily need to have proof that the benefits of intervening exceed the cost of doing nothing. Some business leaders respond because they want to see themselves as good community leaders. Others respond because they see fellow business leaders responding and they want to imitate the leaders in their profession. In India, for example, trucking companies were interested in developing HIV/AIDS programs only after they saw that industry leaders were intervening. Ultimately, a combined message of self-interest, community leadership and altruism is likely to be most effective in attracting business leaders.
- **“Market failures” have to be recognized and addressed.** Individual companies may not have an incentive to develop certain initiatives alone if they see other firms reaping the benefits of improved in-house training and HIV prevention.

INTERSECTORAL RESPONSES TO HIV/AIDS

Intersectoral responses and cooperation are desirable for several reasons:

- **HIV/AIDS cannot be considered just a health issue.** All sectors will be affected and need to respond directly to various impacts.
- **There are several drawbacks to overly relying on the capacity of a particular sector, usually health, to drive responses.** The health sector often has relatively low status among other departments, hampering its ability to lead. Individual sectors such as health also often have limited capacity. Stronger core responses within key sectors, such as health, tend to be neglected if they are consumed by dealing with issues that can be addressed by other sectors.
- **In any given sector, input or support from other sectors will probably be needed to effectively plan and implement responses.** The education sector, for example, may require input from the finance sector on financial resources and priorities, and from the health sector in certain technical areas. On the other hand, each sector also needs to plan with a view to reinforcing the responses of other sectors. The education sector, for example, has to pinpoint requirements for appropriate numbers and types of workers and graduates to manage the impact on needs and human resources in other sectors such as health or the general labor force.
- **Inadequate responses by any individual sector have the potential to create negative effects in other sectors.** Poor support from the welfare sector, for example, makes it much more difficult for the health sector to implement home-based care (HBC) as an alternative to hospitals for terminal care or discharge. Cost shifting by the private sector may also substantially increase burdens on a state and communities that are already struggling to cope.
- **Difficult decisions on the allocation of resources between and within sectors will have to be made in many countries.** There is a risk that decisions can be arbitrary and inefficient. Avoiding this requires an inter-sectoral process to develop a shared understanding of impacts across sectors. This offers a clearly defined way to allocate resources to meet HIV/AIDS-specific and broader developmental needs.
- **The private and NGO/CBO sector have considerable financial and other resources to apply to the socioeconomic challenges of HIV/AIDS.** Government resources are likely to be overwhelmed by the huge new needs, and the public sector tends to have less flexibility to efficiently and cost-effectively address them. Even if we can only ensure an effective response by business to the direct impacts on firms and employees, it will have substantial ripple effects throughout society.

CONCLUSIONS

This chapter has covered a number of issues to be considered in developing effective responses to mitigate the impact of HIV/AIDS on families, communities, businesses, the health sector and government. It emphasizes that the epidemic in many developing countries is so huge that responses must be guided by a clear, comprehensive strategy across and within sectors. Piecemeal responses cannot be expected to have a major effect on the epidemic's socioeconomic consequences. Actions that are not situated within a strategic framework will often prove to be unaffordable, cost ineffective or simply ineffective and unfeasible on the scale required.

In many respects the impact of HIV/AIDS is equal to that of a war, and fighting it requires a similar level of commitment and sophistication in planning. Several major issues are relevant to mitigating the impact:

Rapid initiation of responses. While aspects of a strategy may need to be refined as better information becomes available and there is more detailed planning, it is critical that responses begin rapidly. Many types of action or activities will clearly be required in any strategy, and should not be delayed. In sectors such as education, for example, which can influence large numbers of teenagers at risk of new infection, each month and year of delay can result in hundreds or thousands of new infections. Not only are opportunities for prevention lost in all other sectors, but the capacity to develop responses can also be significantly depleted and unsustainable precedents may already be entrenched. Any delay in mobilizing action therefore worsens the epidemic, raises death rates and makes future actions less effective.

Active commitment by leadership. This is essential to planning and implementing an effective response to HIV/AIDS, and ensuring sustained commitment of leadership—the minister, permanent secretary and/or directors—should be high on the agenda in any response.

Consideration of “radical” options. The scale of the epidemic would challenge current service delivery, management and other systems even if they were highly efficient. But it cannot be assumed that existing ways of doing things—from human resource management to organizing service delivery—are appropriate. A broad, innovative range of options should be considered. This may include finding new ways to reach people with prevention messages, new cost-effective programs to treat PLHA and more effective ways to support people affected by HIV/AIDS—and similarly vulnerable groups—in society.

Prioritization of actions and responses, and making difficult choices. At all levels the needs created by HIV/AIDS will far exceed resources available to satisfy them. Priorities will have to be established as action in all areas at once will often not be feasible. Difficult decisions will have to be made on appropriate allocations of resources to HIV/AIDS-specific needs in light of the interests of infected and affected individuals and broader social and development goals. The priority of health care for PLHA and support of surviving dependents, for example, will have to be established within available resources for meeting AIDS-specific needs. Each choice will have to consider the most cost-effective use of resources and be most affordable and practical on the scale required.

Improving information. Current information is inadequate to guide strategy development, operational planning and management decisions in almost every area of HIV/AIDS. Data collection should be prioritized to provide the information that is most important and feasible to collect within immediate constraints.

Flexibility and decentralized solutions. Strategies to reduce socioeconomic impacts can create common frameworks and foundations for responses. But any effective strategy and response is likely to include an element of flexibility. One reason is that information on impacts is often inadequate to remove key uncertainties. It is usually unclear, for example, which communities are likely to be affected more or less severely than average, or which aspect of the HIV/AIDS impact will be most important to address in specific communities. This is why responses must accommodate variation and uncertainty if resources are to be used effectively.

Secondly, many HIV/AIDS impacts demand more flexibility than current systems allow. The Swaziland education sector impact study, for example, identified a need for greater flexibility in areas including the academic schedule, education of out-of-school youth and teacher supply. All sectors will require greater flexibility in human resource use to make up for temporary or permanent shortages in certain staff. To respond to various uncertainties at the systemic or local level, it is likely that effective decentralization of decision making on many issues for local communities and officials will be highly desirable.

The HIV/AIDS epidemic is a long-term problem that will be a feature of most developing countries for many decades. Strategic approaches that are developed now could pay major returns over the many years the epidemic unfolds.

RELEVANT CHAPTERS

- Chapter 9 *HIV/AIDS Programs in Private Sector Businesses*
- Chapter 24 *Home Care for People with AIDS*
- Chapter 25 *Management of HIV Disease and its Complications in Resource-Constrained Settings*

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C H A P T E R

4

*Improving
Access to
Drugs for
People Living
with HIV/AIDS
(PLHA)*

FRANÇOISE RENAUD-THÉRY
JONATHAN D. QUICK



Improving Access to Drugs for People Living with HIV/AIDS (PLHA)

INTRODUCTION

Improving access to HIV/AIDS-related drugs presents political, social, ethical, economic and medical difficulties. Most countries face these to some degree, but they are particularly challenging in resource-constrained countries, where 95 percent of the estimated 36 million people infected with HIV live and there is a serious lack of access to even the most basic drugs.

This chapter proposes a four-part strategy to help guide and coordinate the steps needed to improve access to drugs for PLHA: 1) Ensure rational selection and use of HIV/AIDS-related drugs; 2) Make drugs affordable to public health systems and individuals; 3) Allocate adequate resources and develop sustainable financial mechanisms; and 4) Strengthen reliable health care services. At the country level, each component should be considered within the broader context to be effective and sustainable, and must be integrated within the national drug policy and the locally implemented essential drug program.

STATE OF THE ART APPROACHES, STRATEGIES AND EXPERIENCE

Ensure rational selection and use of HIV/AIDS-related drugs

Many of the symptoms and medical conditions related to HIV infection can be treated with drugs. These include anti-infective agents, palliative drugs, and antiretroviral drugs (ARVs). To ensure the rational selection and use of such drugs, the following steps should be taken:

- Assess the morbidity pattern.
- Select the appropriate drugs for PLHA.
- Quantify drug needs.
- Promote rational drug prescribing and use.

MAKE DRUGS AFFORDABLE TO THE PUBLIC HEALTH SYSTEMS AND INDIVIDUALS

In countries where the average health expenditure per capita ranges from less than US\$10 (in the poorest) to around US\$200 (in the richest), treatments for opportunistic infections and ARV therapy are still beyond the financial means of many public health care systems and most individual patients. To make any positive impact on drug affordability and increase availability, governments must consider the following suggested combinations for improving drug affordability:

- Consult market information on drug sources and prices.
- Create generic and therapeutic competition.
- Verify patent status of drugs.
- Organize bulk procurement of drugs.
- Apply the safeguards of the new patent rule that affects new drugs.
- Negotiate with pharmaceutical companies for price reduction.
- Advocate for equity pricing.
- Remove import and value-added taxes and reduce distribution costs.

ALLOCATE ADEQUATE AND SUSTAINABLE FINANCIAL RESOURCES FOR HIV/AIDS-RELATED DRUGS

Between 50 percent and 80 percent of the cost of drugs is paid out of pocket by patients in resource-constrained countries—the most inequitable method of health care financing.

To obtain additional public funds, the health ministry should submit well-prepared, justified and realistic budgets to the finance ministry. Financing strategies should be based on careful considerations of the major drug-financing alternatives, which include public financing; health insurance; donor financing and development loans; special mechanisms (such as solidarity funds); debt relief funds; better use of out-of-pocket spending; and cost-sharing with patients

DEVELOP RELIABLE HEALTH CARE SERVICES

In resource-constrained countries, most patients have no access to HIV/AIDS care and drugs, and only five percent of those infected know their HIV status. Early voluntary counseling and testing (VCT) should therefore be advocated and supported. In addition, steps should be taken to:

- Understand local needs and capacities to respond adequately to HIV/AIDS care needs and drug supplies
- Ensure a reliable supply of HIV/AIDS drugs by increasing access through the private sector and NGOs
- Expand and monitor access to treatment, shifting the focus of health care systems to the periphery, where most patients are found

LESSONS LEARNED AND RECOMMENDATIONS

Ensuring better access to drugs for PLHA demands new relationships and alliances at international, national and local levels. Responses that have proved useful are outlined.

CASE STUDY

Implementation of an HIV/AIDS-related drug access initiative in Uganda. The program demonstrated that AIDS patients can be managed successfully with ARV therapy in a resource-constrained setting. It also has served to increase awareness of AIDS care and the fact that patient management, record keeping, laboratory monitoring and capacity building for the early diagnosis and management of opportunistic infections are all critical to the appropriate care and support of AIDS patients.

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I N T R O D U C T I O N

Many of the symptoms and conditions related to HIV infection, and the progression of HIV itself, are manageable with drugs. But in many parts of the developing world—home to 95 percent of the estimated 36 million people infected with HIV—there is a serious lack of access to even the most basic drugs. While therapeutic progress is being made and HIV/AIDS-related drugs are becoming available in the industrialized world, AIDS patients continue to die at an alarming rate in resource-constrained countries.¹

Improving access to HIV/AIDS-related drugs presents especially difficult political, social, ethical, economic and medical challenges, which face most countries to some degree. These include:

- The complexity of drugs needed to care for HIV/AIDS patients, with both prophylactic and therapeutic regimens for opportunistic infections, palliative drugs for symptoms and pain relief and antiretroviral drugs (ARVs) to fight against HIV infection;
- Problems with prioritizing the drugs needed, as occurrences of diseases associated with HIV vary greatly from one country to another;
- The cost of the most recent drugs, which makes them inaccessible to public health systems and the majority of people who need them;
- Limited financial resources in all affected countries where resources are already stretched;
- Complex treatment regimens and common side effects;
- Health systems that don't yet have the capacity to diagnose and monitor HIV infection and HIV/AIDS-related conditions; and

- Lapses in treatment due to patient factors, inadequate funds, supply system failures and other problems, which lead to drug resistance.

The response requires the coordinated efforts of all the international and national-level stakeholders: governments, international organizations, pharmaceutical companies, nongovernmental organizations (NGOs) and people living with HIV/AIDS (PLHA) groups. This chapter proposes a four-part strategy to help guide and coordinate action to improve access to drugs for PLHA: 1) Ensure rational selection and use of HIV/AIDS-related drugs; 2) Make drugs affordable to public health systems and individuals; 3) Allocate adequate resources and develop sustainable financial mechanisms; and 4) Strengthen reliable health care services.

This strategy follows the United Nations (UN) Strategy on Access to HIV-Related Drugs.¹ It depends widely on the international legal and commercial environment, which needs to be continuously attuned to public health interests. At the country level, each component should be considered within the broader context to be effective and sustainable, and must be integrated within the national drug policy and the locally implemented essential drug program.

¹ *The Interagency Task Team on Access to HIV-Related Drugs consists of representatives from nine agencies: UNAIDS, UNDCP, UNDP, UNESCO, UNFPA, UNICEF, WHO, WIPO and the World Bank. It is one of several Task Teams established in late 1999 by the UNAIDS Secretariat to coordinate work among UNAIDS co-sponsors and partners.*

STATE OF THE ART APPROACHES, STRATEGIES AND EXPERIENCE

ENSURE RATIONAL SELECTION AND USE OF DRUGS FOR PLHA

Living with advancing HIV infection is complicated by a variety of symptoms and medical conditions, many of which can be treated with drugs. The types of drugs most important to PLHA are:

- Anti-infective agents to treat or prevent opportunistic infections such as cryptococcosis and candidiasis
- Anti-cancer drugs to treat malignancies such as Kaposi's sarcoma and lymphoma
- Palliative drugs to relieve pain and discomfort, both physical and mental
- ARVs to limit the damage done by HIV to the immune system, to prevent mother-to-child transmission (MTCT), for post-exposure prophylaxis and for care of HIV/AIDS patients²

The Appendix provides an overview of the drugs that offer significant benefits to PLHA.

Assess the morbidity pattern

The combination of HIV/AIDS treatment drugs may differ from one country to another, as the diseases related to HIV occur in diverse combinations and at varying rates among PLHA in different parts of the world. Assessing morbidity patterns should be the first step in the process of prioritizing drug needs. In practice, very few countries have this kind of data available to adapt their national and district-level drug needs to the HIV epidemic. As a precursor, Brazil has established an HIV sentinel surveillance system that includes the surveillance of HIV/AIDS-related morbidity and mortality.³ Table 1 lists the diseases, both opportunistic infections and malignancies, reported among PLHA in Brazil.

A recent World Health Organization (WHO) study of morbidity data available from resource-constrained countries revealed important differences between them (see Figure 1). These differences may be attributable to the presence of pathogenic organisms in the environment, the susceptibility of populations to diseases and the difficulties faced by the health sector, such as limited health coverage and diagnostic capacity, and inadequate record keeping. In general, data collection

Table 1
FREQUENCY RATES OF HIV-RELATED
OPPORTUNISTIC INFECTIONS
AND MALIGNANCIES REPORTED IN BRAZIL

Infection or malignancy	Average frequency
Candidiasis	43%
<i>Pneumocystis carinii</i> pneumonia (PCP)	29%
Tuberculosis	17%
Toxoplasmosis	13%
Herpes simplex	7%
Kaposi sarcoma	6%
Cryptococcosis	5%
Cryptosporidiosis	3%
<i>Mycobacterium avium</i> complex infection	2%
<i>Salmonella</i> septicaemia	—
Histoplasmosis	2%

Source: Table adapted from Ministry of Health of Brazil. "National AIDS Surveillance data, Opportunistic infections at time of AIDS diagnosis." AIDS Epidemiological Bulletin 1994.

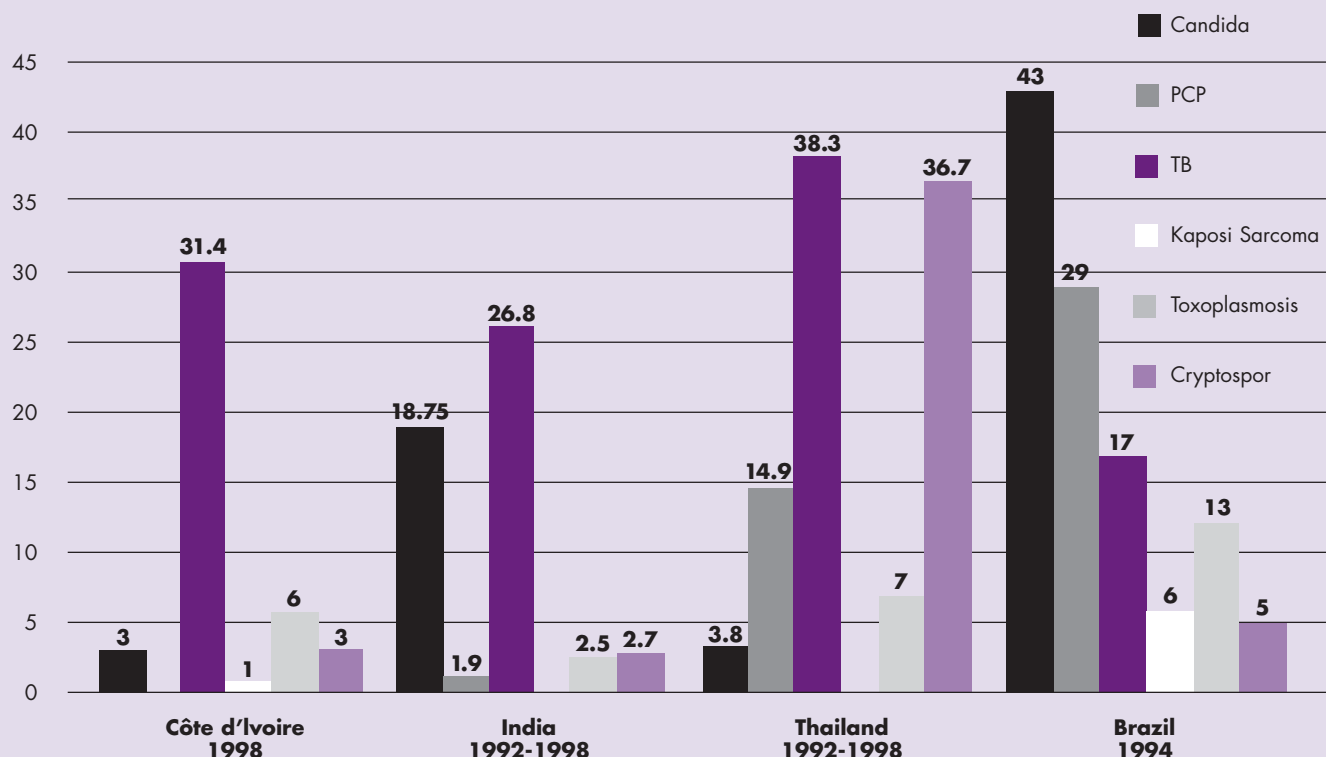
focuses on reportable conditions and hospitalized patients, and tends to underreport less severe conditions and those that occur among outpatients.⁴

Conducting local morbidity studies will help health ministries to prioritize drug needs and formulate treatment policy based on identified local needs. Well-designed short studies on morbidity can be rapidly performed at the country level. In the long run, countries should set up and integrate HIV morbidity surveillance in their HIV sentinel surveillance system.

Select the appropriate drugs for PLHA

Careful selection of priority drugs is essential to progress in HIV case management.⁵ A rational drug selection and subsequent quantification correlates with the improvement of supply and quality assurance of drugs. It focuses therapeutic decisions, professional training and public information leading to rational prescribing and lower cost. Selection and use of HIV-related drugs should be based on locally developed treatment guidelines, drawing on the best available

Figure 1
HIV-RELATED MORBIDITY VARIES CONSIDERABLY ACCORDING TO PATIENT GROUP, DIAGNOSTIC CAPACITY AND OTHER FACTORS



Source: WHO/EDM, UNAIDS, non pub, Review 1999.

evidence concerning efficacy, safety, quality and cost-effectiveness in a given country.

In most resource-constrained countries, national standard treatment guidelines (STGs) and national essential drug lists can respond adequately to HIV/AIDS prevention and care for PLHA. To follow up on and update STGs and the essential drugs list, a sub-committee within the National Drugs and Therapeutics Committee should be established, with members selected from various health care levels and facilities, from primary to tertiary care. There is no need for a separate structure.⁶ STGs, which should be

adapted from international guidelines, should include only drugs on the national list of essential drugs and cover the lower levels of care such as health care centers and dispensaries.⁷

In Africa, as in industrialized countries, a large proportion of PLHA have turned to traditional practitioners who use herbal treatments and other forms of complementary medicine for palliative and supportive care. Traditional practitioners are well known in the communities in which they work for their expertise in health care and prevention of many sexually transmitted diseases (STDs).⁸ Consequently, such therapies should also be considered.⁹

* Researchers in some countries have noted that although some other illnesses and conditions are not classified as sexually transmitted in biomedical nosology, they may be regarded as such by traditional healers and their clients.

Quantify drug needs

Quantification of drug needs should be based on HIV/AIDS-related morbidity patterns, STGs for each level of care, the referral system and health coverage. A software package has recently been developed that can assist in estimating drug quantities and forecasting drug needs and costs.¹⁰

Promote rational drug prescribing and use

Seventy to 80 percent of health care takes place in the home, rather than in hospitals or clinics, with people making their own decisions about which drugs to use. In many settings, however, continuous education and training of care providers is limited and reliable information is not available.

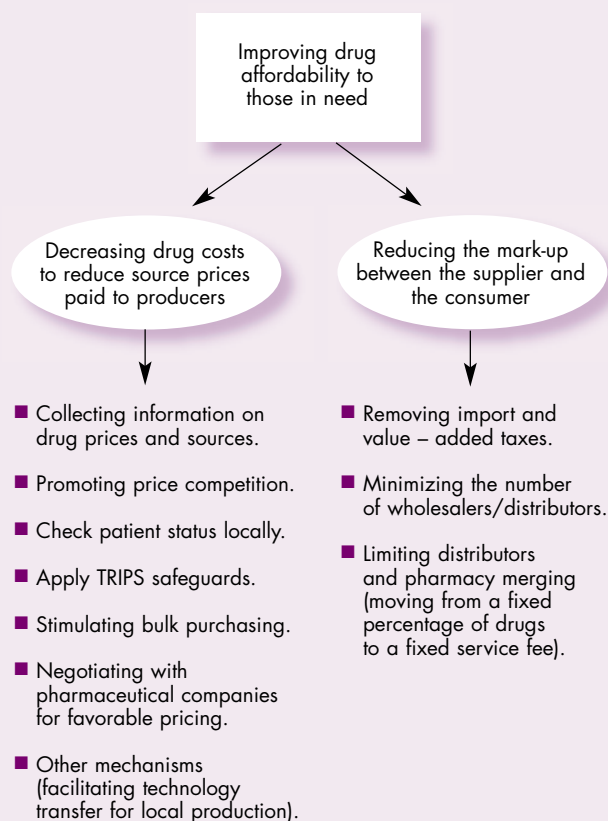
Doctors, nurses, pharmacists and other care providers require additional training and information on the appropriate use of drugs for HIV treatment.² The list of essential drugs and STGs can provide this information and be used to train health care workers in rational prescribing and use. Effective treatment also depends on PLHA becoming actively involved in and well informed about their treatment, and on a functioning continuum of care and support.

MAKE DRUGS AFFORDABLE TO THE PUBLIC HEALTH SYSTEMS AND INDIVIDUALS

Cost is not the only reason people cannot obtain the drugs they need, but it is probably the single most important one. In countries where the average per capita health expenditure ranges from under US\$10 (in the poorest) to around US\$200 (in the richest), treatments for opportunistic infections such as cryptococcosis and candidiasis and ARV therapy are still beyond the financial means of many public health care systems and most individual patients. To improve drug affordability and increase availability, governments must consider the suggested combinations for improving drug affordability, presented in Figure 2.

Figure 2

A MIX OF COMBINATIONS TO IMPROVE DRUG AFFORDABILITY



Consult market information on drug sources and prices

Most HIV/AIDS drugs are internationally available from multiple sources. Because prices vary widely on the international market, access to up-to-date, accurate information on drug prices and sources is essential for procurement agencies and purchasing groups to identify new suppliers, negotiate better prices, and assess the efficiency of the local market. Price information on generic drugs offered by non-profit international suppliers and procurement agencies is published annually.¹¹ In addition, a market information database established by the United Nations Children's Fund (UNICEF) Supply Division, in collaboration with the

Joint United Nations Programme on HIV/AIDS (UNAIDS), WHO and Médecins sans Frontières (MSF) provides information on identified suppliers, supply-related information, and prices for 44 HIV/AIDS drugs.¹² These sources are available on the Internet (see References and Recommended Reading).

(Tables 2 to 5 in the Appendix provide indicative prices from generic suppliers. These are only indicative as price information is rapidly outdated.)

Create generic and therapeutic competition

Generic and therapeutic competition can be powerful tools for price-reduction. Generic competition can achieve price reductions in the range of 75 percent to 95 percent in comparison with the original brand name prices. In large producing countries such as Brazil, generic competition between more than two manufacturers has been an essential factor in reducing ARV drug prices.¹³ (See Appendix, Table 5.)

When several single-source drugs have the same therapeutic effect, therapeutic competition allows consumers to select the lowest-cost equivalent drug, such as less expensive ARVs or antifungals. Clinical studies supporting alternative therapeutic regimens can also contribute substantially to more affordable care. For example, clinical studies conducted in the field of MTCT prevention identified the possibility of short regimen zidovudine for pregnant women and, in 1999, the one-dose regimen of nevirapine for mother and child.¹⁴

Verify patent status of drugs

Drug prices depend on many factors. One of the most important of these is whether the drug is a patented product or exists as an off-patented product or generic. Patent protection provides exclusive rights (monopoly) to an invention—a new formulation or a new indication—and therefore prevents generic equivalents. These drug treatments are less affordable than those for which there are generic alternatives. This is why the question of whether a drug is under patent protection in a given country is important for defining treatment and drug procurement policies.

PRICE DIFFERENCE FOR ZIDOVUDINE AND FLUCONAZOLE

The wholesale price for a 100 mg capsule of zidovudine is US\$0.37 from a pharmaceutical company in Thailand, while a 100 mg capsule costs US\$2.06 wholesale from the multinational originator company in the Netherlands, where the product is under patent. Interestingly, the originator reduced its per unit wholesale product price in Thailand to the market price of US\$0.44 for the same capsule, making it more competitive with the locally produced product.

A 200 mg capsule of fluconazole used to cost US\$7 in Thailand when it was exclusively marketed by Pfizer. But when generics were introduced in Thailand at the cost of US\$0.06, Pfizer cut its price to US\$ 3.60 (July 1998). South Africa has granted fluconazole a patent and therefore cannot import the product from Thailand. Pfizer, the patent holder, makes the drug available at US\$9.34 per unit wholesale. Médecins sans Frontières calculates that the cost of maintenance treatment per 10,000 patients using the Thai product is US\$2.16 million, while it is US\$34.8 million using the South African product, which is beyond the budget of the South African Ministry of Health.

Source: Médecins Sans Frontières, Campaign for Access to Essential Drugs, 1999.

A 1999 review by WHO and UNAIDS of the patent situation of HIV/AIDS-related drugs in 80 countries revealed that most ARVs and drugs for opportunistic infections are not patent protected in many resource-constrained countries.¹⁵ This implies that these drugs can be imported freely from multiple sources. For example, zidovudine is patented in European and North American countries, some Asian countries such as Japan and Korea, and also in South Africa. It is not patented in most African countries such as Côte d'Ivoire, or in Latin American countries such as Chile and Brazil.

The patent status of each drug in a given country can be verified locally with the national authorities responsible for intellectual property rights, often under the Ministry of Trade and Industry.

Organize bulk procurement of drugs

Bulk purchasing of medicines helps countries achieve the lowest possible prices by increasing buying leverage and negotiating power. It also helps countries improve their national buying performance by commonly sharing and adopting “best practices.” Examples of these best practices are: adopting international bidding procedures; simplifying drug registration procedures for introducing a drug already registered in another participating country; defining a basic or limited list of medicines with agreed specifications; and coordinating drug policies to ensure better use of drugs and improved care of patients.

EXISTING EXPERIENCES WITH JOINT BULK PURCHASING SCHEMES¹⁷⁻¹⁹

- Since the late-1970s there have been a number of initiatives and experiences with joint bulk purchasing of generic drugs. The Mahgreb countries (North Africa and the Middle East) as well as the Gulf countries have initiated such schemes that would enable them to obtain price reductions ranging from 15 percent to 20 percent.
- In West Africa, the African Association of Central Medical Stores for Generic Essential Drugs (ACAME) was created in 1996 with the support of the WHO Regional Office for Africa. For a selected number of drugs, ACAME obtained prices 7 percent to 27 percent lower than the lowest prices each of the participating countries had obtained for more than three years.
- The Eastern Caribbean Drug Service (ECDS), established in the mid-1980s, is one of the most successful regional pooled procurement organizations. Through a combination of rational drug selection, pooled tendering and reliable payment, the service saved more than 60 percent of pre-ECDS prices in its first year.
- Revolving fund mechanisms for joint purchases of vaccines have been around for some time. One of the best known is that of the Pan American Health Organization's (PAHO) Extended Program of Immunization. It has operated since 1979, realizing a turnover of almost US\$50 million in 1998, buying vaccines and syringes at rock-bottom prices for 37 countries. The success of this revolving fund and bulk purchasing strategy has stimulated its extension to other priority health supplies. It will soon include anti-malaria and anti-tuberculosis (TB) drugs. The feasibility of including ARVs is being investigated, and will depend on the capacities of the Latin American countries to allocate needed funds.

Starting with pilot tenders for a small number (five or six) of commonly shared formulations would help candidate countries optimize the procurement process. Joint bulk purchasing should be initiated among a group of countries, preferably limited according to geography or common language. (For more information on minimum requirements and critical success factors for joint bulk purchasing, see selected key materials in References.) Building on existing experiences, the practical set-up of a joint bulk procurement structure for HIV/AIDS-related drugs could be initiated through such international procurement agencies as UNICEF and international low-cost essential drug suppliers.

Apply the safeguards of the new patent rule that affects new drugs

For the nearly 140 countries that are now members of the World Trade Organization (WTO), the patent situation has changed for all “inventions”—such as new drugs, new processes or formulations and perhaps new indications—developed after January 1, 1995. All WTO members must make patents available through their national legislation for pharmaceutical products and processes, for at least 20 years after the filing date.¹⁹ These new requirements are contained in the WTO Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS). This means that WTO members have to modify their patent laws accordingly. Specific transition arrangements apply, but industrialized and resource-constrained countries must comply with the TRIPS agreements by 2006 at the latest.

The new WTO TRIPS rules may stimulate additional research and development, but they also have the potential to increase problems related to access to drugs in resource-constrained countries, since they will

delay the period before which generic competitor products become available. But the TRIPS agreement contains certain safeguards that may facilitate access to drugs. These include specific provisions and requirements for compulsory licensing (authorization by the government to a third party to produce or commercialize a patented drug without the permission of the patent holder), exceptions that can facilitate prompt availability of generic equivalents upon patent expiration and extension of the transition period. Another measure that may improve competition is parallel importation, the legislative provision that allows drugs to be registered and imported if they have been legally sold by the patent holder in any other country. This is attractive when prices in the other country are substantially lower. Parallel importation is neither prohibited nor protected by the TRIPS agreement.²⁰

Government, health institutions, consumer groups and PLHA associations need to ensure that national legislation and regulation consider including TRIPS safeguards in responding to their HIV/AIDS epidemic—which can be a public health emergency—and related drug needs.

Negotiate with pharmaceutical companies for price reduction

There have been ARV drug price negotiations between pharmaceutical companies and the governments of Thailand and Uruguay, and the UNAIDS Drug Access Initiative (DAI) has been implemented in Chile, Côte d'Ivoire, Uganda and Vietnam. The negotiations facilitated by UNAIDS through DAI led to bi- and triple therapy price of 20 percent to 60 percent of their cost in industrialized countries.²¹ Negotiations with pharmaceutical companies should also include drugs for opportunistic infections, laboratory tests, and reagents.

Negotiations with pharmaceutical companies can also be organized among a group of countries within the same geographical region. In 2000, five multinational pharmaceutical companies announced that they will offer price reductions of ARVs to resource-constrained countries through a process of negotiations.

Advocate for equity pricing

ARV drug prices remain high relative to the purchasing power of low-income countries with high HIV prevalence. The option of equity pricing needs to be further discussed at the global level with industry, NGOs and international organizations. This means that the poorest countries would benefit from substantial price cuts and not be charged for the research and development costs of the newly developed drugs.

Remove import and value-added taxes and reduce distribution costs

Import duties on essential drugs or raw materials can increase the price of drugs considerably and thus decrease access to essential care. They should be reduced and later abolished. In several countries, such as Chad and Malawi, drugs are exempted from import taxes and duties.²³

ALLOCATE ADEQUATE AND SUSTAINABLE FINANCIAL RESOURCES FOR HIV/AIDS-RELATED DRUGS

In most countries, public funding for health and social services has declined over the past year while private (out-of-pocket) spending has increased. Between 50 percent and 80 percent of the cost of drugs is paid out-of-pocket by patients in resource-constrained countries.²³ This is the most inequitable method of health care financing. To obtain additional public funds, the health ministry should submit well-prepared, justified and realistic budgets to the finance ministry. To ensure that care and drugs for PLHA are part of the political agenda, they must be addressed clearly in the national AIDS strategic plan and supported by the national drug policy. It is important to explore all drug financing mechanisms to respond to the extra burden on the health and drug budgets by consulting all key stakeholders—including the government health and finance ministries, NGOs, bilateral and multilateral organizations, the local and international pharmaceutical industry and PLHA.

Financing strategies should be based on careful consideration of the major drug-financing alternatives, including:²⁵

- **Public financing.** Strong advocacy is needed, not to reallocate funds from other public health priorities such as vaccination programs but to receive additional funding for the public health sector. Information is needed on essential and cost-effective health care interventions to justify allocation of public health funding.
- **Health insurance.** While virtually 100 percent of the population has health insurance of some form in most industrialized countries, median coverage is 35 percent in Latin America, 10 percent in Asia and less than 8 percent in Africa. Coverage for drug reimbursement in general and HIV/AIDS-related drugs in particular varies greatly between countries. Supporting health as a human right requires mandating coverage of all HIV/AIDS-related drugs through well-developed national health insurance schemes.
- **Donor financing and development loans.** Bilateral donor assistance and development loans or grants from the World Bank and other development banks are short-term solutions for providing sources of health sector financing, which can include funding for HIV/AIDS-related drugs. In the meantime, sustainable health and drug financing mechanisms have to be developed.
- **Special mechanisms.** These can include solidarity funds and other private voluntary mechanisms and financing schemes installed by NGOs, PLHA and community organizations.
- **Debt relief funds.** These funds should give priority to health and social development, with an emphasis on strengthening national health care systems, capacity building and scaling up cost-effective health interventions.

- **Better use of out-of-pocket spending.** In resource-constrained countries, 50 percent to 90 percent of drugs are bought by households directly in the formal and informal private markets. Although this situation is far from ideal, better regulation of the private sector, public education campaigns, information programs by PLHA and other groups, training of drug sellers and other measures can help households get the best health care value for their spending.
- **Cost sharing with patients.** Many governments increasingly rely on user fee schemes to fund their public health services. Originally created to receive additional funds to improve the quality of health services, these funds in some countries are gradually becoming the main source of funding for public health care. These schemes risk collapse when households face the difficulties of paying a large share of the total cost of HIV-related care.

Latin American countries have explored new financial strategies to make ARVs available given their actual cost. They have tried to obtain additional funding by establishing national foundations and negotiating with manufacturers and distributors on price reduction. They also have established a regional rotating fund supported by PAHO (Regional Office of the Americas of the World Health Organization) to increase purchase power and thus achieve price reductions.

DEVELOP RELIABLE HEALTH CARE SERVICES

Availability and access to HIV/AIDS care and drugs vary greatly within and between countries. In resource-constrained countries, most patients have no access to HIV/AIDS care and drugs, and only five percent of those infected know their HIV status. Early voluntary counseling and testing (VCT) should therefore be advocated and supported. (See Chapter 23 for more information on VCT.) Many patients seek health care only in the late stages of the disease. Seriously ill

patients are subject to home care, which is not often developed by the public health system but provided by relatives and friends, many of them women. Home-based care imposes an extra burden on households as it takes time away from income-earning activities. (See Chapters 3 and 24 for more information on home-based care and its economic consequences.)

Understanding local needs and capacities

To respond adequately to HIV/AIDS care needs and drug supplies, HIV medical staff require updated information about treatment, national treatment guidelines, HIV drugs and their possible side effects, up-to-date drug management (ordering, storing, and distribution) and expansion of the existing and potential capacity of the local health system. To collect such information, UNAIDS and WHO have developed and tested a rapid assessment tool using standard qualitative research techniques in communities.^{25,26} The assessment should be followed by a closely monitored implementation phase. (See Recommended Reading.)

Ensure a reliable supply of drugs

Supply strategies should be closely linked to financial mechanisms and must recognize the unique features of HIV treatment. Many resource-constrained countries do not have adequate distribution systems in place and lack personnel sufficiently trained to deliver HIV/AIDS-related drugs to the people who need them. Most countries rely on a mix of public, private and often NGO drug supply systems. Improvements are badly needed in the areas of transport systems, drug handling, warehousing, stock control and record keeping.⁸

Where there is demand, the private sector is usually efficient in making drugs available in urban areas, while often failing to adequately reach people in rural and remote areas. Among the problems frequently encountered with private sector distribution are misleading and unethical drug promotion, irrational prescribing and self-medication, high prices (leading to consumers purchasing small quantities of drugs) and sometimes poor drug quality. Actions to increase access to HIV/AIDS drugs through the private sector and NGOs may include:²

- Organizing joint purchasing arrangements by PLHA groups and procuring priority HIV/AIDS-related drugs through existing low-cost essential drug supply agencies
- Involving local pharmacy associations and associations of licensed drug sellers in promoting safe dispensing and appropriate advice, especially for HIV/AIDS-related drugs
- Strengthening regulatory control, drug registration and quality assurance systems
- Initiating local partnerships with the pharmaceutical industry to ensure the quality in the distribution chain and availability of priority drugs

Expand and monitor access to treatment

The health budgets in many resource-constrained countries address less than 20 percent of drug needs, and are biased toward central and referral facilities. In many countries, a large number of NGOs are actively involved in advocacy and networking, prevention and counseling services, logistics, capacity building and providing clinical care. It is the role of the government to provide financial and human resources to sustain these activities. In health care systems the focus should be shifted from the center to the periphery, where most of the patients are found. Staff in rural and district facilities should be trained in HIV/AIDS-related diseases, such as TB, and basic HIV/AIDS care. Traditional practitioners can play a prominent role when they become involved in HIV/AIDS care, as in Uganda. They can be trained in voluntary counseling and spiritual support, and can even provide treatment for simple opportunistic infections.

In the DAI programs in Uganda and Côte d'Ivoire, treatment for opportunistic infections and ARVs is provided through a limited number of accredited facilities, mainly in the capital cities. These projects have led to the development of national treatment policies, monitoring systems, research programs, staff training and general experience in delivering a continuum of care. (See Chapters 24 and 25 for more information on continuum of care.) While only a small percentage of the population has access to ARVs, the initiative has helped improve the management (prevention and treatment) of opportunistic infection.²⁷

LESSONS LEARNED AND RECOMMENDATIONS

Ensuring better access to drugs for PLHA demands new relationships and alliances at local, national and international levels. Responses that have proved useful in various parts of the world include:

Ensuring rational selection and use of drugs for PLHA by:

- Achieving important progress in HIV clinical management and ensuring appropriate drug supplies through a rational selection and quantification of drugs
- Conducting local morbidity studies to assist health ministries in prioritizing drug needs and formulating treatment policies based on local needs
- Developing core health care interventions, treatment guidelines and essential drug lists specified for each level of health care, drawing on national and international information
- Establishing an HIV/AIDS subcommittee within the national drugs and therapeutics committee which involves all stakeholders
- Providing training and information for doctors, nurses, pharmacists and other care providers on proper prescribing and use

Making HIV/AIDS-related drugs available at affordable prices to public health care systems and families by:

- Improving affordability of HIV/AIDS drugs through a combination of actions to reduce drug prices, including competitive procurement through generic and therapeutic competition, bulk purchasing, negotiations with pharmaceutical companies for better prices and reduction of import duties and taxes

- Introducing the use of generic drugs of assured quality as an essential factor in reducing the price of ARVs and drugs for opportunistic infections
- Maintaining knowledge about the patent status of important HIV/AIDS drugs to define whether direct importation, parallel importation or compulsory licensing may be applied to improve access
- Including options for compulsory licensing, prompt marketing of generic equivalents, and parallel import in national legislation to implement and comply with the Agreements on Trade Related Intellectual Property Rights (TRIPS)
- Reducing or eliminating import duties and taxes on essential drugs or their raw materials

Allocating adequate financial resources and developing sustainable financial aid mechanisms to provide HIV/AIDS-related drugs to the majority of the population by:

- Advocating for additional public funding for the care of PLHA, while safeguarding that funds are not reallocated from other health sectors
- Pooling public and donor funds to pay for the most cost-effective health interventions
- Using debt relief funds for health and social development, with an emphasis on strengthening public health care systems and cost-effective health interventions
- Exploring alternative sources of income such as national solidarity funds, community schemes and NGO financing mechanisms
- Helping to ensure that household spending is directed at treatment options that represent the best value for money

Strengthening reliable health care services by:

- Including access to HIV/AIDS-related drugs in the national AIDS strategic planning process and coordinating with the national drug policy and health care financing strategy
- Integrating access to HIV/AIDS-related drugs into the national essential drug program and supplying all HIV/AIDS-related drugs according to national treatment guidelines and priorities
- Establishing early diagnosis and treatment service through voluntary VCT services
- Strengthening NGOs and communities in their role in service delivery such as home-based care and clinical management
- Allocating financial and human resources to rural facilities for expansion of the HIV/AIDS care system to the periphery, where most HIV patients live
- Improving drug supply systems, drug handling, stock control, warehousing and record keeping⁹
- Strengthening the important role of PLHA in care partnerships, especially in the field of advocacy for building political commitment, providing information to assist in the process of priority setting and advising on rational use of drugs

CASE STUDY

IMPLEMENTING AN HIV/AIDS-RELATED DRUG ACCESS INITIATIVE IN UGANDA

With a population of 21 million, Uganda has an estimated 1.5 million persons living with HIV/AIDS (PLHA). The UNAIDS/Ministry of Health HIV/AIDS Drug Access Initiative (DAI) was launched as a two-year pilot project in Uganda in November 1997, and became operational in June 1998. The initiative's goal was to improve the quality of life of PLHA by increasing access to HIV/AIDS-related drugs. After the pilot period, the UNAIDS DAI is being transitioned to the Uganda Ministry of Health as the Uganda Drug Access Program.

The initiative was intended to create the proper environment and induce relevant changes in the health care delivery system to improve HIV/AIDS care by:

- Developing a distribution system to ensure an adequate supply of drugs
- Implementing mechanisms for improved access to HIV/AIDS-related drugs without disruption of existing essential drug programs
- Providing appropriate information and training to health workers and communities, including establishing and improving the medical information system
- Making HIV/AIDS-related drugs more available in Uganda

Prior to the establishment of the DAI, one treatment center was providing ARV therapy as part of clinical care for approximately two years. But training and support were necessary to improve clinical practices and patient management in other participating centers. In the initiative, patients paid for all medical care, medications and laboratory testing. Participation was therefore limited to those who could meet these costs or whose employers or medical insurance would cover them. Choice of drugs, frequency of follow-up visits and laboratory monitoring were directed by the primary care physician, taking into consideration the

availability of drugs and the patient's clinical status and ability to pay for medications and laboratory monitoring. In 1998, one clinical laboratory had the capacity to perform viral load testing. In general, the relatively high cost of viral load and CD4 cell count testing limited their use. Starting in June 1999, the Uganda Virus Research Institute (UVRI)/United States Centers for Disease Control and Prevention (CDC) Collaborative Program provided free HIV-1 RNA and CD4 count testing for the pilot phase of the initiative.

STRATEGIES AND APPROACHES USED IN THE INTERVENTION

Institutional framework

The government of Uganda and UNAIDS signed a mutual agreement to implement the DAI. In accordance with the terms of the agreement, an advisory board, a project coordinator and a communications consultant were appointed under the Ministry of Health.

The National Advisory Board

A multidisciplinary advisory board reports to the Ministry of Health. Among its various activities, the board has served to:

- Recommend to the government HIV/AIDS drug policy on clinical management of HIV/AIDS.
- Develop estimates of the country's needs for HIV/AIDS-related drugs.
- Recommend to the government a policy on prescription, distribution and use of HIV/AIDS-related drugs.
- Recommend minimum requirements for health care centers to be qualified as locations where the prescription and use of HIV/AIDS-related drugs can be assured.
- Recommend objective criteria of patients who may participate in the initiative.
- Recommend an action plan to improve the health care infrastructure over time to make HIV/AIDS-related drugs more widely accessible.
- Recommend regulations concerning privately funded purchases and the proper use of HIV/AIDS-related drugs in Uganda.

Drug supply, procurement and distribution

The government appointed a pharmacist and facilitated the establishment of a nonprofit company, Medical Access Uganda, Ltd., to promote mechanisms through which drugs could be purchased at discounted prices and distributed to participating treatment centers in the country. The company is responsible for procuring drugs from the participating companies at reduced costs and selling them to the accredited centers. The company receives orders, pays the drug companies on a long-term credit basis and monitors the initiative's accountability and internal control mechanism. Prices were negotiated with pharmaceutical companies at the international level by UNAIDS and at a regional level by Medical Access Uganda, Ltd.

Participating centers

Standardized criteria for selecting of treatment centers were developed, including:

- Clinical expertise in the management of HIV/AIDS, including appropriate management of opportunistic infections.
- Adequate laboratory facilities for basic and sophisticated AIDS tests.
- Adequate psychosocial support and counseling.
- Good facilities for drug storage, stock management, and accountability.

TRANSITION TO UGANDA MINISTRY OF HEALTH

Following the pilot program, the DAI is being transitioned into the Uganda Ministry of Health. This program will be incorporated into the country's strategic framework for combating HIV/AIDS.

INDICATORS OF SUCCESS

From August 1, 1998, through July 31, 2000, 912 patients accessed ARV drugs (ARVs) at five centers through the DAI. These patients were at advanced stages of illness, as evidenced by a median CD4 cell count of 84 cells/mm³ and viral load of 190,256 copies/ml. More than two-thirds were in WHO stage three or four. Approximately half the patients were started on regimens that included two nucleoside reverse transcriptase inhibitors (RTI), and the other half on highly active ARV therapy (two nucleoside RTIs (2NRTI) plus a nonnucleoside RTI or a protease inhibitor) based primarily on what the patient could afford. The probability of a patient surviving and remaining on ARV therapy at six months was 77 percent and 67 percent at one year. The drug costs to the patient are lower on 2NRTI, and patients on 2NRTI clearly fared better than would have been expected without therapy. But there were greater virologic responses among those on HAART than among those on 2NRTI. Median CD4 counts among patients receiving 2NRTI returned to baseline by one year of treatment.

USEFULNESS FOR OTHER SETTINGS

The early successes of the DAI have been achieved through important human and financial investment and national commitment. Training and capacity building have proved to be important components of a program aimed at expanding access to ARV therapy in Uganda.

By December 2000, price reductions for ARVs had declined dramatically, with some as much as 91 percent below the cost of the drugs in the United States. Some HAART regimens can be constructed for less than what 2NRTI cost just a few months earlier. Persons who could afford 2NRTI will now be able to afford HAART, and additional patients will be able to afford 2NRTI. Since currency depreciation can affect the patients' ability to afford drugs, proactive measures should be implemented to offset anticipated short-term fluctuations in currency value.

Even if patients meet the costs of their medical care, there must be substantial investment to meet the costs of training, development, implementation of

treatment guidelines and expanded access to laboratory diagnostics. Although reduced drug costs have been implemented, scaling up of ARV treatment programs will be limited by the rudimentary laboratory infrastructure in the periphery and the median US\$300 annual per capita income. In this context, HIV prevention must remain the cornerstone of programs to prevent AIDS-related morbidity and mortality in Uganda.

That being said, the benefits are already evident for patients who have accessed this initiative. Changes in viral load and CD4 counts suggest that patients are taking their medications and responding to treatment. In this regard, the program has demonstrated that AIDS patients can be managed successfully with ARV therapy in a resource-constrained setting. Promoting access to therapy earlier in the course of the disease would be expected to further improve patient outcome in this initiative.

The initiative also has served to increase awareness of AIDS care and the fact that patient management, record keeping, laboratory monitoring and capacity building for the early diagnosis and management of opportunistic infections are all critical to the appropriate care and support of AIDS patients. More work is needed to determine whether alternative, less expensive monitoring strategies can be developed and implemented in resource-constrained countries. Promoting AIDS care rather than merely AIDS drugs has been an important reason for the success and evolution of this pilot program.

Programs are now underway to expand access to prophylaxis, diagnosis and treatment of opportunistic illnesses in Uganda. These will benefit both patients who are on ARV therapy and those who are unable to afford or otherwise access ARVs. In addition to clinical training activities, these initiatives will need to address issues of drug procurement and distribution, stock management and quality control of drugs used for the prophylaxis and treatment of opportunistic illnesses. This way, improved AIDS care can be expanded to reach more of those in need.

This case study was written by Paul Weidle (CDC), Dorothy Ochola (UNAIDS, Uganda), and Badara Samb (UNAIDS, Geneva).

APPENDIX

DRUGS THAT OFFER SIGNIFICANT BENEFITS TO PLHA

The following tables cover:

- **Anti-infective agents:** Table 2 lists some of the drugs most in demand to treat or prevent opportunistic diseases. Costs are as high as several thousand dollars per year for treatment or prophylaxis, and many are not widely available in resource-constrained countries. In addition, some are difficult to administer—because they require highly trained medical staff or expensive equipment—and to monitor.
- **Anti-cancer drugs:** Table 3 lists drugs used to treat Kaposi's sarcoma and lymphoma, two of the most common AIDS-related malignancies. Although generics exist, availability is low.
- **Palliative drugs:** Table 4 lists drugs needed to relieve pain and discomfort, both physical and mental, and other symptoms in PLHA. Even though most of the symptoms listed can be treated or alleviated with essential drugs, access to palliative care is hampered by limited availability of major analgesics such as codeine, morphine and pethidine. In addition, some cheap and effective palliative drugs are classified as illegal narcotics and thus are not listed, even if the palliative benefits at a late stage of disease outweigh the risk of addiction.
- **ARVs:** Table 5 lists drugs that combat HIV, a retrovirus, and thereby limit the virus's damage to the immune system. All are very expensive and must be used in combination to be effective.^{28, 29}

These tables are available from the UNAIDS technical update "Access to Drugs" (October 1998). Although price information has been updated, the tables are not meant to be used as definitive pricing information because prices are constantly changing.

Table 2
ANTI-INFECTIVE AGENTS

Drug	Galenic	Dosage	Indication	Wholesale price US\$ per unit* FOB	Obstacle
Acyclovir	Tablet	200 mg	Herpes zoster	0.04 – 2.81	\$, O
Acyclovir	Vial	250 mg	Extensive herpes simplex	2.58 – 13.58	
Albendazole	Tablet	200 mg	Microsporidiosis	0.01 – 0.04 (MSH)	
Amphotericin B	Injection	50 mg in vial	Systemic mycosis cryptococcosis	2.28 – 5.20 (Spain, UK)	\$, A, M, O
Anti-TB drugs			Tuberculosis treatment	15-45 / treatment course, MSH 1996	
Azithromycin	Capsule	250 mg	Mycobacterium complex (MAC)	0.37 – 2.17 (MSF)	\$, O
Clarithromycin	Tablet	250 mg	MAC	0.55 BNF	\$, O
Clindamycin	Capsule	150 mg	Toxoplasmosis	0.08 – 0.94	\$
Fluconazole	Capsule	200 mg	Systemic mycosis cryptococcosis	0.20 – 7.25	\$, O
Fluconazole	Injection	2 mg/ml unit 100 ml	Systemic mycosis cryptococcosis	1.80	\$, O
Foscarnet	Intravenous infusion	24 mg/ml	Cytomegalovirus (CMV) disease (alternative to ganciclovir) Herpes simplex virus (alternative to aciclovir for prophylaxis)	21.60 (bottle 250 ml) 35.99 (bottle 500 ml) BNF	\$, A, M, O
Ganciclovir	Capsule	250 mg	Cytomegalovirus (CMV) disease (prophylaxis)	2.08 BNF	\$, A, M, O
Ganciclovir	Powder for reconstitution (as sodium salt)	500 mg vial	Cytomegalovirus (CMV) disease (prophylaxis and treatment)	23.41 BNF	
Isoniazid	Tablet	300 mg	Tuberculosis prophylaxis	0.01 (MSH)	
Itraconazole	Capsule	100 mg	Systemic mycosis	0.50 – 0.80	\$, O
Ketoconazole	Tablet	200 mg	Thrush	0.08 – 0.35	\$
Miconazole	Gel	Nitrate 2%	Thrush	0.01/mg	
Nystatin	Oral suspension	10,000 IU/ml	Thrush	0.03/ml	O
Nystatin	Tablet	50,000 IU	Thrush	0.04	
Pentamidine	Powder for injection	300 mg (isetionate in vial)	<i>Pneumocystis carinii</i> pneumonia (PCP)	10.74 – 46.05	O
Pyriméthamine	Tablet	25 mg	Toxoplasmosis	0.003	O
Rifabutin	Capsule	150 mg	MAC	1.81 BNF	\$, O
Sulfadiazine	Tablet	500 mg	Toxoplasmosis	0.02 – 0.33	O
Sulfametoxazole – trimethoprim (SMZ – TMP)	Injection	80 mg +16 mg/ml 5 ml	PCP	1.08 BNF	\$, A, M, O
Sulfametoxazole – trimethoprim (SMZ – TMP)	Tablet	400 mg + 80 mg	PCP prophylaxis Diarrhea due to <i>Isospora belli</i>	0.0005 – 0.0229 MSH	

FOB: Free on board price

Source: Essential Drugs Used in the Care of People Living with HIV: Sources and Prices. Joint UNAIDS – UNICEF SD – WHO/EDM project, Oct. 2000. <www.who.int/medicines/docs/pagespublications/hiv_relatedpub.htm>.

MSH: International Drug Price Indicator Guide, 1999, Management Sciences for Health.

BNF: British National Formulary, March 2000 (for drugs not listed in other sources). Prices converted at £1 = US\$1.45

MSF: Médecins Sans Frontières

Symbols: \$ = high price, A = administration to patients is difficult, M = monitoring of patients is difficult, O = not offered on market, I = International regulations limit distribution

Table 3
ANTI-CANCER DRUGS

Drug	Galenic	Dosage	Indication	Wholesale price US\$ per unit*	Obstacle
Bleomycine	Injection	15 mg in vial	Kaposi sarcoma	8.00 – 22.91 (Spain, UK)	O, A, M
Doxorubicine	Powder for injection	10 mg in vial	Kaposi sarcoma	4.33 – 26.33 (Spain, UK)	O, A, M
Methotrexate	Tablet	2.5 mg	Lymphoma	0.04 – 0.14	O
Vinblastine	Powder for injection	10 mg	Lymphoma	19.90 (UK)	O, A, M
Vincristine	Powder for injection	1 mg (sulfate) in vial	Lymphoma	3.35	O, A, M

* See footnote to Table 2

Table 4
DRUGS FOR PALLIATIVE CARE*

Drug	Galenic	Dosage	Indication	Wholesale price US\$ per unit*	Obstacle
Amitriptyline	Tablet	25 mg	Depression (Treatment with anti-depressants)	0.0052 (MSH)	
Amitriptyline	Tablet	10 mg	Depression (Treatment with anti-depressants)	0.0064 (MSH)	
Anticholinergic, e.g. atropine	Injection	0.5 mg/ml	Hypersecretion	0.0880/ml (MSH)	
Calamine lotion	Topical		Itching skin, rash	0.0027/ml (MSH)	
Carbamazepine	Tablet	200 mg	Epilepsy, convulsion	0.0277 (MSH)	
Chlorpheniramine	Tablet	4 mg	Allergy/anxiety/itching	0.0025 (MSH)	
Chlorpheniramine	Injection	10 mg/ml	Allergy/anxiety/itching	0.0989/ml (MSH)	
Chlorpromazine	Tablet	100 mg	Severe anxiety, psychosis, intractable hiccups (treatment with neuroleptics)	0.0176 (MSH)	
Codeine	Tablet	30 mg	Pain, cough, diarrhea	0.03 – 0.05	I,O
Diazepam	Tablet	5 mg	Anxiety/convulsions	0.0039 (MSH)	
Diazepam	Injection	5 mg/ml ampoule	Anxiety/convulsions	0.0439/ml (MSH)	
Haloperidol	Tablet	1.5 – 2.0 mg	Severe anxiety, psychosis, intractable hiccups (treatment with neuroleptics)	0.0075 (MSH)	
Loperamide	Tablet	2 mg	Diarrhoea	0.0061 (MSH)	
Methadone	Tablet	5 mg	Drug addiction	0.04	I,O
Morphine	Tablet	10 mg	Severe pain	0.09	I,O
Morphine	Oral solution sulfate	10 mg/5 ml	Severe pain	11.73 (UK)	I,O
Pethidine	Tablet	50 mg	Severe pain	0.14 (UK)	
Pethidine	Injection	HCl 50 mg/ml	Severe pain	0.24	I,O
Promethazine	Injection	25 mg/ml ampoule	Allergy, anxiety, itching	0.0964/ml (MSH)	
Promethazine	Suspension (po)	1 mg/ml	Allergy, anxiety, itching	0.0059/ml (MSH)	
Sodium valproate	Tablet	200 mg	Convulsions	0.0660 (MSH)	

* See footnote to Table 2

Table 5

PRICE (US\$) OF A DEFINED DAILY DOSE OF SELECTED ANTIRETROVIRALS IN FIVE COUNTRIES

Drug	Defined	USA ¹	Côte d'Ivoire ²	Uganda ³	Brazil	Thailand ⁶
Didanosine 100 mg	400 mg	7.25	3.48	5.26	2.04 ⁴	2.73 ⁷
Efavirenz 200 mg	600 mg	13.13	6.41	NA	6.96 ⁵	NA
Indinavir 400 mg	2400 mg	14.93	9.07	12.79	10.32 ⁵	NA
Saquinavir 200 mg	1200 mg	6.50	4.82	7.37	6.24 ⁵	NA
Stavudine 40 mg	80 mg	9.07	4.10	6.19	0.56 ⁴	0.84
Zidovudine 100 mg	600 mg	10.12	2.43	4.34	1.08 ⁴	1.74

¹ Prices, 2 April 2000, from <www.globalrx.com>, a US mail-order pharmacy that offers proprietary antiretrovirals with a minimum mark-up (shipping not included).

² End-user prices, UNAIDS Drug Access Initiative, Côte d'Ivoire, March 2000.

³ End-user prices, UNAIDS Drug Access Initiative, Uganda, March 2000.

⁴ Generic drugs produced in Brazil (US\$1 = R\$ 1.8).

⁵ January 2000 cost to the Brazilian Government of imported drugs (US\$ 1 = R\$ 1.8).

⁶ Generic drugs produced by Government Pharmaceutical Organization, Thailand (US\$ 1 = 38 baht).

⁷ 115 mg powder formulation, equivalent to 100 mg tablet.

Source: Report on the Global Epidemic, Geneva, June 2000: UNAIDS.

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RELEVANT CHAPTERS

- Chapter 3 *Responding to the Socioeconomic Impact of HIV/AIDS*
- Chapter 23 *Counseling, Testing and Psychosocial Support*
- Chapter 24 *Home Care for People with AIDS*
- Chapter 25 *Management of HIV Disease and its Complications in Resource-Constrained Settings*

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C H A P T E R

5

*Evaluation and
Surveillance
Approaches
for HIV/AIDS
Programs*

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Evaluation and Surveillance Approaches for HIV/AIDS Programs

INTRODUCTION

The evaluation of HIV/AIDS prevention and care programs is a never-ending challenge. Recognizing the importance of evaluation in improving current interventions may help to enhance the success of future initiatives. This chapter is intended to provide designers and managers of HIV/AIDS prevention and care programs with evaluation and surveillance concepts and approaches recommended for different levels of effort and stages of the epidemic.

Program evaluation and epidemiological surveillance activities are different but both play essential, complementary roles in determining the intermediate and long-term effects of prevention and care programs. By tracking risk behaviors and monitoring STD and HIV prevalence trends, behavioral and biological surveillance systems provide essential data for assessing program outcomes and program impact.

PROGRAM EVALUATION

A number of theorists and evaluation practitioners have proposed various paradigms of evaluation. These paradigms differ in their conceptions of evaluation, the relationship with the primary client and other stakeholders, who should be making the relevant value judgments regarding the program and the criteria for judging the evaluation process itself.

EVALUATION FRAMEWORK

To improve program performance or affect policy change, multiple complementary evaluation approaches and methodologies (qualitative and quantitative) have to be applied to address the different evaluation needs. Evaluation approaches include:

- Formative evaluation
- Process evaluation
- Effectiveness evaluation (assessment of outcome and impact)

DIFFERENTIATING EVALUATION EFFORTS

Using a multidimensional approach to prioritize the degree of rigor needed to evaluate programs and projects may alleviate some of the tension that arises when using universal, standardized evaluation practices

conflicts with the objectives of individual projects. A useful approach for differentiating evaluation efforts is to define them in three different dimensions:

- Individual project dimension
- Country program dimension
- International dimension

ESTIMATING PROGRAM IMPACT THROUGH MODELING

Evaluating the effect of HIV/STD prevention interventions in reducing HIV infections remains an elusive goal for most AIDS control programs because of the prohibitive costs and methodological difficulties associated with field-based program impact evaluation. The alternative is to apply modeling approaches to estimate program impact.

CHOICE OF INDICATORS

One of the critical steps in designing and implementing the evaluation of an HIV/AIDS program is selecting the appropriate indicators. Choosing the indicators for evaluating many programs, even with well-defined objectives, requires careful thought and consideration of both theoretical and practical elements.

A NEW FOCUS: EVALUATING HIV/AIDS CARE

Monitoring and evaluation of care and support activities are still new activities, and effective monitoring tools and methodologies are still in the early stages of development. Guidelines are urgently needed that allow program implementers to track activities that are rapidly being implemented in response to the demand for care and support services for people affected by HIV.

BETTER SURVEILLANCE DATA FOR DECISION MAKING

IMPROVING HIV SURVEILLANCE DATA

There is an emerging consensus among decision makers that prevention programs need to investigate both trends in HIV infection and behavior that may lead to infection. To this end, HIV data have to be collected in conjunction with behavioral, socioeconomic and sociodemographic data.

ADJUSTING ANC SENTINEL DATA

In the absence of true HIV incidence data, a system of sentinel surveillance for monitoring HIV infection among selected populations has been recommended. Antenatal clinic (ANC) attenders have been selected as a particularly suitable “sentinel” group thought to represent most closely the HIV prevalence of the general sexually active population. The following must be considered:

- Selection biases
- Focusing ANC sentinel surveillance on the younger age groups
- Linking behavioral data collection and HIV serosurveillance

RECOMMENDED MIX OF BEHAVIORAL DATA COLLECTION METHODS

Different behavioral data collection methods deliver different products, and with varying degrees of cost and complexity. To use its resources most efficiently, a national program must make choices about the mix of methods it adopts, their frequency and on what scale. Doing so will require preliminary assessment.

STAGES OF THE HIV EPIDEMIC

The HIV epidemic has developed differently in different parts of the world. Countries will have different information needs in each epidemic state, and these needs may shift if the epidemic develops and moves from one type to another. UNAIDS and its partners have developed a classification that groups HIV epidemics into three types:

- Low-level epidemic
- Concentrated epidemic
- Generalized epidemic

DISSEMINATING AND UTILIZING THE DATA

Behavioral data are of little value unless they are used for the benefit of the people from whom they were collected. Once collected and analyzed, the data can be used to:

- Encourage policy makers to support and promote HIV prevention.
- Make the public aware of the threat posed by HIV.
- Improve prevention programs.

ISSUES AND CHALLENGES: WHAT DO THE DATA MEAN?

The detection of significant behavior changes is becoming increasingly difficult over time, especially after there already have been substantial changes (ceiling effect). In these cases, interventions have reinforcing rather than new effects. These effects may look small when they actually indicate the maintenance of reported behavioral change or the prevention of relapses in unsafe behavior.

Several measurement and data interpretation issues deserve mention, such as measuring risk behaviors in relative terms, and attributing behavior change to interventions in the face of a growing AIDS epidemic. It is also important to realize that behavior change interventions have to be implemented for sufficient amounts of time and on a large enough scale to have an impact on personal behavior, social norms in communities and on the epidemic.

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Evaluating HIV/AIDS prevention and care programs is a never-ending challenge. Recognizing the importance of evaluation in improving current interventions may help to enhance the success of future initiatives. This chapter is intended to provide designers and managers of HIV/AIDS prevention and care programs with evaluation and surveillance concepts and approaches recommended for different

I N T R O D U C T I O N

levels of effort and stages of the epidemic.

Planning evaluation and data collection activities in a participatory fashion is important for achieving the delicate balance between practical needs and methodological desirability. Key stakeholders should be included in the planning process, and every effort should be made to effectively use limited resources. The active support and participation of key stakeholders who have an interest in the results obtained by various data collection systems are particularly important for programs funded by external donors that use host-country institutions for data collection activities. Data produced by these efforts will have a better chance of being timely and of acceptable quality. Whenever possible, participants—including implementing institutions, host-country collaborators and local representatives of donor agencies—should attempt to reach consensus on their data needs.

Program evaluation and epidemiological surveillance activities play essential, complementary roles in determining the intermediate and long-term effects of prevention and care programs. By tracking risk behaviors and monitoring STD and HIV prevalence trends, behavioral and biological surveillance systems provide essential data for assessing program outcomes and impact.

PROGRAM EVALUATION

Selecting an appropriate evaluation concept for an AIDS prevention program is crucial because it determines the guiding philosophy behind the actual evaluation process. Various evaluation paradigms have been proposed by a number of theorists and evaluation practitioners. These paradigms differ in their conceptions of evaluation, the relationship with the primary client and other stakeholders, who should be making the relevant value judgments regarding the program and the criteria for judging the evaluation process itself.

The paradigm debate was, and is for the most part, a debate about how best to measure and interpret behavioral or epidemiological change. It has highlighted a series of methodological dimensions among which there are variations in emphasis. These dimensions focus attention on some of the options available for making decisions about methods. Today there is consensus that both quantitative and qualitative data are valued and recognized as legitimate for program evaluation. In fact, these methods are by no means incompatible and should be used in combination.¹

Deciding what, and how much, data to gather in program evaluation involves difficult methodological decisions and trade-offs between the quality and utility of information. An evaluation approach, which uses both quantitative and qualitative data collection methods, is more likely to address diverse evaluation needs. At the same time, evaluation priorities must be sensitive to competing needs for resources in an environment where evaluation is sometimes considered a luxury in the face of a rapidly growing HIV/AIDS epidemic. It is a major task of the evaluator to match data collection methods to the reality of particular evaluation questions and available resources.

EVALUATION FRAMEWORK

AIDS prevention programs need to be evaluated at different phases of the program cycle. A framework for comprehensive program evaluation is outlined in Table 1. All stages of evaluation have to be considered together to provide an overall picture of the program. No single data collection approach can supply all the information necessary to improve program performance or affect policy change. Multiple, complementary qualitative and quantitative evaluation approaches and methodologies have to be applied to address the different evaluation needs.

Formative evaluation

Assessing the needs and opportunities is a key task of formative evaluation that should be conducted during the planning (or replanning) stage of a prevention program to identify and resolve intervention and evaluation issues before the program is widely implemented. This is the time when flexibility is greatest and program sponsors are freer to make decisions about how to proceed.

Formative evaluation is used to:

- Explore the need for interventions.
- Provide the information necessary to define realistic goals and objectives for the program interventions.
- Help to make tentative decisions about effective, feasible intervention strategies and how to implement them.

Formative evaluation can also be used as an exploratory tool during project implementation to provide feedback to project managers that will help them adjust program objectives to changing situations. Formative evaluation research can identify unacceptable or ineffective intervention approaches, designs and concepts.

Field-testing of proposed (untested) intervention strategies is an important but often neglected element of formative evaluation. Because of the urgency of the problem, many AIDS prevention programs have rushed into a full implementation stage without the necessary preparation through thoughtful formative evaluation. Community-based interventions designed

Table 1
EVALUATION FRAMEWORK

Types of Evaluation:			
Formative Evaluation Research (Concept & Design)	Project Monitoring (Input & Output)	Outcome & Impact Assessment (Including Modeling)	Cost-Effectiveness Analysis (Including Sustainability Issues)
Basic Questions Related to the Different Types of Evaluation:			
Is an intervention needed?	To what extent are planned activities actually realized?	What outcomes are observed?	Do program priorities have to be changed or expanded?
Who needs the intervention?		What do the outcomes mean?	To what extent would resources have to be reallocated?
How should the intervention be implemented?		Does the program make a difference?	

Fortunately, formative evaluation is being applied more frequently in the design of prevention programs. But even with adequate formative evaluation at the program planning stage, there is no guarantee that a prevention program will be effective when it is finally implemented; it may not be implemented adequately enough to be effective.

Process evaluation

Once activities are being implemented, the specific activities need to be examined to determine whether they are being implemented correctly, in time and within budget. Process evaluation addresses basic questions such as:

- To what extent are planned intervention activities actually realized?
- What services are provided, to whom, when, how often, for how long and in what context?

Qualitative evidence of how and why a prevention program works or fails to work is equally important. Process evaluation requires getting close to data, becoming intimately acquainted with the details of the program and observing not only anticipated effects but also unanticipated consequences. Understanding the processes through which intervention activities achieve effects can help to explain the outcome of the intervention. Process evaluation, however, does not demonstrate whether interventions are effective.

Process evaluation can also play an important role in improving or modifying interventions by providing the information necessary to adjust delivery strategies

to reduce sexual transmission of HIV have felt the effects of having no evaluation. In many cases the intervention concepts were based on ideas that had nothing to do with the lives of the people for whom the interventions were intended. The literature on behavioral change interventions is full of ideas that made perfect sense in the abstract but failed completely in the real world—mainly because they were unacceptable to the target audience or not stated in ways that were relevant to the lives of real people. A fuller understanding of these issues might well lead to a redesign of the intervention to make it more appealing to the selected audience.

Formative evaluations use a combination of qualitative and quantitative research methods that can rapidly provide relevant information to program designers. These methods include:

- Reviews of existing information
- Focus group discussions
- In-depth individual interviews
- Participant observations
- Short quantitative surveys with structured questionnaires

or program objectives in a changing epidemic. Process-oriented evaluation is carried out throughout the course of the program implementation. It should use different methodological approaches to assess service delivery, including reviews of service records and regular reporting systems, key informant interviews, exit interviews of service users, direct observations by “mystery clients” (e.g., in STD and VCT services) and quantitative population-based surveys to assess program coverage and barriers to service use. Different but complementary qualitative and quantitative study designs provide the most comprehensive information. (See Chapter 23 for an in-depth discussion of VCT services.)

Effectiveness evaluation: assessment of outcome and impact

Evaluating the effectiveness of AIDS prevention programs will almost always require quantitative measurements. These measures will assess the extent to which the objectives of the program were achieved. Outcome and impact evaluations are used to answer these questions:

- What outcomes were observed?
- What do the outcomes mean?
- Does the program make a difference?

Taking into account the various implementation stages of HIV/AIDS prevention programs and the fact that, over time, new age cohorts become sexually active, it is advisable to stratify effectiveness evaluation by short-term and/or intermediate program effects (program outcome) and long-term program effects (program impact). Table 2 illustrates examples of program outcome and impact measures for these different stages. Changes in HIV/AIDS-related attitudes, the reduction of risk behaviors and adoption of protective

Table 2

POTENTIAL PROGRAM OUTCOME/IMPACT MEASURES

Program Outcome (Short-Term and Intermediate Effects)	Program Impact (Long-Term Effects)
<ul style="list-style-type: none"> ■ Changes in HIV/AIDS-related attitudes. ■ HIV/STD-related risk behaviors. ■ Trends in STD rates (e.g., gonorrhea). ■ Increase in social support/community response. 	<ul style="list-style-type: none"> ■ Sustained changes in HIV/STD-related risk behaviors. ■ Trends in HIV/AIDS rates. ■ AIDS-related mortality rates. ■ Reduced individual and societal vulnerability to HIV/AIDS. ■ Sustained changes in societal norms.

behaviors, and changes in STD rates are considered to be the most appropriate proximate (short-term or intermediate) outcome measures for interventions designed to reduce sexual transmission of HIV. Long-term effects include impact on HIV/AIDS trends, sustainability issues and improved societal response.

Outcome and impact evaluation are intimately connected to process evaluation. Process information can help the evaluator to understand how and why interventions have achieved their effects and, perhaps, what is actually making the difference. Examining the outcome or impact indicators without an assessment of the process of program implementation can potentially lead to erroneous conclusions about the effectiveness of the intervention.

Program goals and objectives have to be carefully defined to allow the selection of appropriate outcome and impact measures to assess the effectiveness of an AIDS prevention program. Effectiveness evaluation is generally based on indicators that provide quantitative value by which to measure the outcome and impact of interventions.

Disentangling the attributable effects of a prevention program from the gross outcome and impact observed is a vexing task in assessing program effectiveness. Such estimates can be made only with varying degrees of plausibility, rather than with certainty. A general principle applies here: The more rigorous the research design, the more convincing the resulting estimate.^{2,3} Interpreting program evaluation data should

always be approached with caution. In most situations, the program and evaluation process as a whole is not a rigorously controlled experimental trial. The ability of an evaluation to precisely determine the true extent of a program's effectiveness is often limited by time, resources and the lack of a rigorous design.

Many factors can confuse or confound the results measured, and biases can be introduced by a range of factors inherent to the problem of HIV/AIDS, the available measurement options, and those conducting the evaluation. One of the most difficult questions to answer in any evaluation is whether the program being evaluated has had a measurable effect. Defining the web of interacting and overlapping influences is extremely difficult, and is one of the reasons so many programs have difficulty attributing results to their actions. At some point, we need to stop worrying about attribution in such settings and focus on monitoring changes as they occur.

Cost-effectiveness analysis also measures program effectiveness, but expands the analysis by adding a measure of program cost per unit of effect—in their case, averted HIV infection. By comparing the costs and consequences of various interventions, cost analyses and cost effectiveness estimates can assist in priority setting, resource allocation decisions and program design. Although cost-effectiveness studies are often carried out at a later stage of the evaluation process, they should be planned quite early to collect the necessary information.

PLANNING AN INTEGRATED EVALUATION PROCESS FOR A COUNTRY PROGRAM

Incorporating evaluation at the program design stage is essential to ensure that research activities will produce useful results. Planning an intervention and designing an evaluation strategy are inseparable activities. To ensure the relevance and sustainability of evaluation activities, project designers and local stake-

holders—such as the national AIDS program and the health ministry—must work together to outline the evaluation process. An evaluation plan should contain the following key elements:

- **Scope of the evaluation**
 - Goals and objectives
 - Conceptual framework correlating inputs, processes, outputs and outcomes
 - Ethical issues
- **Methodological approach**
 - Study design
 - Indicators
 - Means of verification
 - Interval between data collection
- **Implementation plan**
 - Selection of geographical areas
 - Roles and responsibilities
 - Timetable for identified activities
 - Establishment of budget
- **Dissemination plan for evaluation results**

Evaluation planning generally involves several common but critical steps (see Box 1). These steps are presented here in a generic enough way to allow for differences among program types, target populations, stakeholders' needs for information and the different dimensions of evaluation efforts described in the following section. Involving members of the target community also helps inform the evaluation planning process. This stakeholder involvement in the early phases helps to ensure that the evaluation results will be used in the end.

LogFrame

To assist in carrying out the steps outlined above, a tool such as the logical framework (LogFrame) can help link the program goals, objectives and activities to specific indicators and data collection systems. This instrument can be used to:

- Detail program objectives and activities.
- Develop objectively verifiable indicators of success linked to objectives and activities.
- Determine what means of verification will be used to measure indicators and who will be responsible for providing the data.

Box 1

CRITICAL STEPS IN DEVELOPING A COMPREHENSIVE EVALUATION PLAN

Step 1: Identify program goals and objectives.

The first step involves identifying the program goals and objectives and establishing a program logic model. This is basically a clearly written statement defining the program's goals and objectives (and sometimes sub-objectives) and how the program plans to achieve them. When this is done, the evaluation logic can easily be diagrammed and used to establish the evaluation plan.

Step 2: Examine existing data and past evaluation studies. The second step begins with an investigation of existing data sources and past evaluation studies and activities. This investigation should identify existing data sources and other evaluative activities that may have been done in the past, are ongoing or may have been sponsored by other donors. It is also helpful at this step to assess whether any other groups are planning similar evaluations and invite them to collaborate in this comprehensive evaluation plan.

Step 3: Identify internal and external evaluation resources and capacity. This step involves identifying internal and external evaluation resources and capacity. This means not only identifying the funds for the evaluation, but also identifying personnel experienced in evaluation to help plan and conduct the evaluation activities. It also means determining capacity to manage and link various databases and computer systems.

Step 4: Determine evaluation questions, their feasibility and appropriate designs and indicators.

The fourth step involves the evaluation experts and program managers in clarifying the priority evaluation questions, appropriate evaluation designs, outcome measures or indicators, data needs and the methods by which this information will be collected and analyzed. Practical ways for obtaining data and maintaining a data system that is sustainable and easily accessed should be discussed. An operational plan for the comprehensive evaluation should also be developed at this step. This step should conclude with a written plan briefly outlining the evaluation questions and design, data collection methods and analysis plan and overall timeline for the comprehensive plan.

Step 5: Plan for dissemination and use of evaluation findings.

The fifth step is not always performed but is extremely useful in ensuring that the evaluation findings are used to inform program improvement and decision making. This step involves planning how the evaluation results will be used; how they will be translated into program policy language and then disseminated to all relevant stakeholders and decision makers.

(Source: Rugg DL and Mills S. In: Rehle T, et al. 2000.)

USAID's results framework

The Results Framework serves as a tool for planning, communication, managing and reporting, as well as consensus building and ownership. It is a tool used by USAID and affiliated organizations to illustrate the development hypothesis. There should be a results framework for each outlined objective, which should provide enough information so that it adequately illustrates the development hypothesis—or cause and effect linkages—represented in the strategy. It will also assist in communicating the basic premises of the strategy. The results framework will also include any key results that are to be produced by other development partners such as NGOs, the host country governments, other donors and customers.

Specifically, the Results Framework:

- Identifies organizational responsibility and time-frame for each result.
- Shows integration of results from other strategic objectives (SOs) where appropriate.
- Serves as a reporting and learning tool.
- Defines performance indicators and targets.
- Shows SOs and key intermediate results (IRs) and the linkages between them.
- Identifies all IRs necessary to achieve the SO regardless of who is taking responsibility.
- Highlights the mission's development hypothesis, since it is part of the strategic plan.
- Identifies critical assumptions or conditions outside of USAID control.

To maximize the effectiveness of monitoring and evaluation systems, these questions should be taken into consideration at the design stage:

- What human and financial resources are available to support data collection activities?
- What gender and age-specific groups will be targeted by program activities and how will data collection efforts cover these groups?
- In what stage of the HIV epidemic are the various target groups and what are their corresponding data collection needs?
- With what frequency should data be collected and what is the scheduled timeframe in which data are required?

- Which data are needed at the country or regional level and which are needed at the individual project level?
- What will be the scope and reach of the program activities, in terms of geographic coverage and urban/rural mix, and does this correspond to planned data collection activities?
- Is coordination of data collection activities assured to enable linking biological and behavioral data?
- Are ethical aspects taken into consideration?

DIFFERENTIATING EVALUATION EFFORTS

Because of various constraints—such as on time, available funds and trained staff—the evaluation approach has to balance what is ideal or preferred with what is feasible, useful, relevant and essential.

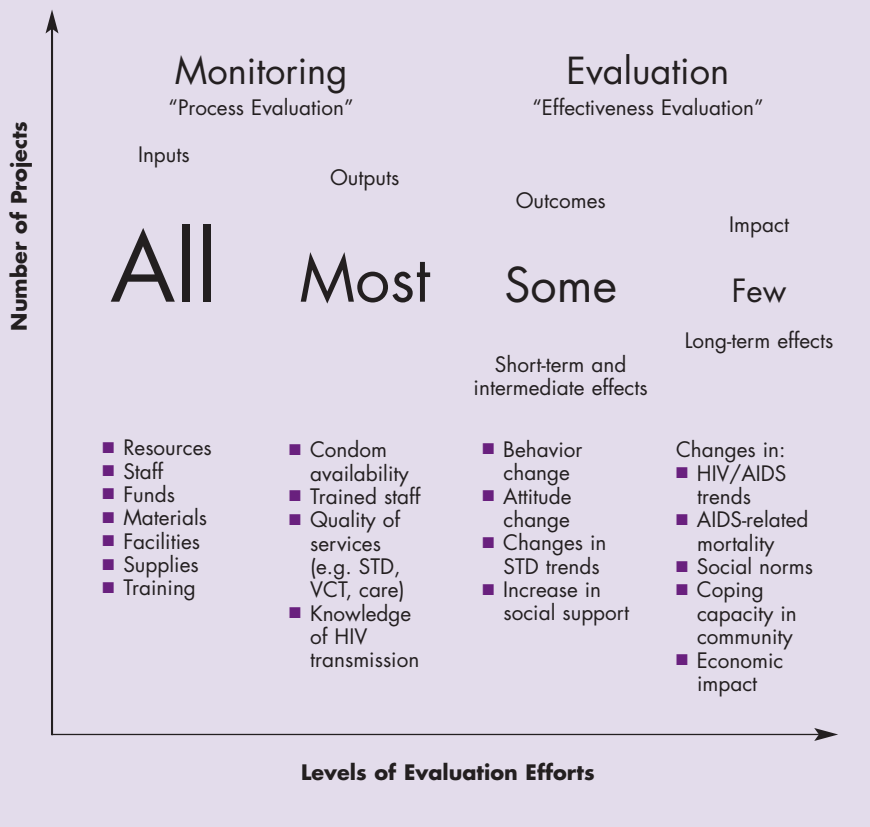
USING A MULTIDIMENSIONAL APPROACH

It is useful to differentiate evaluation efforts by defining them in terms of three different dimensions: (1) the individual project dimension; (2) the country program dimension, and (3) the international dimension. By helping to prioritize the degree of rigor needed to evaluate programs and projects, this multidimensional approach may alleviate some of the tension that arises when universal, standardized evaluation practices conflict with the objectives of individual projects.

Individual project dimension

The individual project dimension can be thought of as the area of service delivery which in most cases does not require a rigorous research design to judge its proficiency, unless it is a demonstration project piloting a new intervention or responding to an unanswered research question. Individual projects implementing proven intervention strategies should focus their evaluation activities on formative evaluation

Figure 1
MONITORING & EVALUATION PIPELINE



(when needed for project planning), process monitoring and capacity-building assessment. Only in the case of a demonstration project would there be justification for a more rigorous research design. Figure 1 shows the number of projects in relation to the different levels of evaluation efforts and reflects the current situation in program evaluation. The monitoring and evaluation “pipeline” illustrates that there is usually a smaller number of projects that actually warrant evaluation of the effectiveness of their implemented prevention activities.

Country program dimension

Within the dimension of a country program, several categories of evaluation should be addressed with emphasis on intervention outcomes, socioeconomic impact and changes in societal norms. The guiding principle here is that in a situation where multiple implementing agencies are conducting a number of interventions with overlapping target groups, certain types of evaluation are not appropriate for the scope of an individual project, but rather should be coordinated and conducted by country or regional programs. Using such an evaluation approach, especially in the area of behavioral surveys, not only saves money but also makes sense in environments where the effects of individual projects from different implementing agencies cannot be sorted out anyway.

Country program evaluation includes analyzing behavioral trends in different population

groups in conjunction with an analysis of HIV/STD surveillance data and evaluation topics. These include social marketing activities related to condoms and drugs, STD case management, HIV/AIDS case management and support, scoring of the overall effort of the national program (see the AIDS Program Effort Index in the following section), socioeconomic impact assessments and epidemiological modeling of the country’s HIV epidemic. Each country will have a different profile of evaluation activities. It reflects the different information needs determined by the stage of its epidemic, its political and social environment, existing capacity for research and available financial resources.

International dimension

Evaluation efforts of the international dimension may address uncertainties about which set of prevention interventions works best, in which setting, for whom and under what circumstances. There is an emphasis on cost-effectiveness analysis. This type of evaluation, however, requires large-scale community-based controlled trials, which are certainly beyond the scope of most individual projects or even national programs.

Given the difficulties and high costs associated with directly measuring the impact of HIV prevention programs through large-scale HIV incidence studies, there is now more emphasis on developing other methods for assessing impacts.

ESTIMATING PROGRAM IMPACT THROUGH MODELING

Prohibitive costs and methodological difficulties associated with field-based program impact evaluation make it difficult for most AIDS control programs to evaluate the impact of HIV/STD prevention interventions on the reduction of HIV infections. The alternative is to use modeling approaches to estimate program impact. One example is FHI's AVERT computer model, used to estimate the impact of prevention programs on HIV transmission with input parameters that are more readily available to programs.⁵ AVERT is a less complex, user-friendly modeling tool that can provide plausible and defensible estimates of program impact and is accessible to users with little experience in modeling.

The model's estimates were validated in an African country setting, and the evaluation indicated good agreement with observed seroincidence.⁵ The AVERT model has now been widely disseminated to country programs, researchers and academic institutions. This type of model provides an additional analytical tool for epidemiologists, decision makers and planners in setting appropriate program priorities and analyzing the cost-effectiveness of different intervention combinations.

CHOICE OF INDICATORS

One of the critical steps in designing and implementing the evaluation of an HIV/AIDS program, or any program for that matter, is the selection of appropriate indicators. This can be a fairly straightforward process if the objectives of the program have been clearly stated and presented in terms that define the quality, quantity and timeframe of a particular aspect of the program. But the indicators used in evaluating many programs, even with well-defined objectives, require careful thought and consideration of both theoretical and practical elements. Questions to ask include:

- Does the objective involve a behavior or concept that can be measured accurately and reliably?
- Are there alternative measures that need to be considered?
- What human and financial resources does the require?
- Are there areas for congruency, either in the content of the indicator or the means of gathering the data?
- Are there any additional measures that would help interpret the results on the primary objective?

Selecting indicators and setting targets is usually done during the process of program planning and re-planning, preferably in a participatory fashion with the implementing agency and key stakeholders. Setting targets and benchmarks should consider information from similar types of interventions so they will be realistic from the perspective of the target population, resource allocation and intervention type.

While the level of attainment to be measured by the indicator is not actually part of the indicator itself, it is a critical factor. The magnitude of the level to be measured affects the size of the sample population needed to accurately estimate that level. It may also assist in selecting additional or supplemental indicators that can be helpful later in interpreting results.

An indicator ideally should:

- Measure the condition or event it is intended to measure (valid).
- Produce the same results when used more than once to measure the same condition or event (reliable).

Table 3

EXAMPLES OF INDICATORS BY LEVEL OF PROGRAM EVALUATION.

Levels of Evaluation	Indicator
	Resources allocated (e.g., percentage of national budget); Condom availability at central level (PI 2); Knowledge of HIV transmission (PI 1); Condom availability in periphery (PI 3); Proportion of 12-17 years receiving AIDS/sexual health education; % of services with improved quality, e.g., STD case management (PI 6 and PI 7); % of blood transfusion facilities with uninterrupted supply of appropriate HIV screening tests.
Outcome	
Proximate determinants addressing the risk per sexual contact	Condom use during last act with non-regular partner (PI 5); Prevalence of urethritis among men 15-49 in last year (PI 9); Prevalence of positive RPR/VDRL serology among antenatal women 15-24 (PI 8);
Proximate determinants addressing the frequency of sexual risk contacts	Proportion of men with non-regular partner in last year (PI 4); Prevalence of concurrent partnerships in last month; Median age at first sex of boys and girls; proportion of young women having had sex with men over 30 last year;
HIV incidence/prevalence	HIV prevalence among women under 25 in antenatal clinics (to approximate incidence) (PI 10); HIV prevalence among high-risk groups, e.g. STD patients/CSW/IDU; HIV prevalence among adult men 15-49;
AIDS mitigation	HIV-associated mortality rates among adults 15-59 years; Number of communities with increased coping capacity;
Overall program effort	AIDS Program Effort Index (API) (under development)

PI = WHO/GPA Prevention Indicator; Ref. [6]

- Measure only the condition or event it is intended to measure (specific).
- Reflect changes in the state of the condition or event under observation (sensitive).
- Be measured or quantified with developed and tested definitions and reference standards (operational).
- Be measured with reasonable cost.
- Have feasible indicator data collection.

Table 3 lists possible indicators related to different levels of program evaluation. Relating indicators to specific evaluation levels is advantageous in that it also helps to identify opportunities for triangulating data. Survey data on condom use, for example, can be compared with information on condom distribution and availability in a defined intervention area. Likewise data on incident STDs such as gonorrhea in the surveyed population, if available, can be correlated with the condom data.

UNAIDS/WHO in collaboration with national and international partners has developed a standard set of indicators for country programs that will refine and expand the prevention indicators (PI) developed by WHO's former Global Programme on AIDS (GPA).⁷ Since HIV/AIDS/STD prevention and care programs are affected by many factors—including political commitment, available resources and the socio-cultural and economic context—a new approach has been developed to capture the overall effort of national HIV/AIDS programs, the AIDS Program Effort Index (API).

The API is a composite score comprised of the main components of an effective national response. The instrument's advantage is that it may yield useful information on the above issues, even in the absence

of more rigorous monitoring and evaluation systems. Using the key informant assessment approach, it also allows an assessment of areas that are difficult to capture with more objectively measurable indicators, such as political support and commitment. But there are major concerns about the subjectivity and reliability of the API approach. The score depends entirely on the choice of informants, and the informants are likely to change from year to year. There have also been questions about the utility of a single composite score in which improvements in some areas may be obscured by deterioration in other areas.⁷

A NEW FOCUS: EVALUATING HIV/AIDS CARE

Responses to the care needs of people living with HIV/AIDS (PLHA) in resource-constrained settings that are highly affected by HIV/AIDS have been slow, diverse and uncoordinated. Institutional responses have been dominated by research, while community responses have focused on social and primary care needs. Only a few programs have tried to respond to the broader care needs—clinical, psychosocial and preventive—in an integrated fashion.

The support required to meet AIDS care needs, either from national governments or international donors, has been difficult to obtain and limited in financial terms. Indeed, care has never been high on the priority list of national HIV/AIDS programs in the developing world. As a result of the weakness and scarcity of comprehensive HIV/AIDS care programs, monitoring and evaluating such programs has been limited. This has prevented project implementers and donors from receiving the necessary information on program successes or failures.

But monitoring and evaluating care and support activities are still new activities, and effective monitoring tools and methodologies are still in the early stages of development. Guidelines are urgently needed that allow program implementers to track activities rapidly being implemented in response to the demand for care and support services for people affected by HIV. Only by monitoring and evaluating the care and support activities that are provided at all levels of the health care system will we begin to understand the

strengths and shortfalls that determine our ability to meet those demands successfully.

Monitoring and evaluation results will range from information about the multitude of outputs generated by efforts to provide quality care to the effects these have on a wide array of outcomes, such as reduced disability associated with HIV/AIDS, changes in treatment-seeking behaviors and reduced stigma towards PLHA and their families. It is also important to understand the ultimate impacts on restored productivity and quality of life to assess cost-effective options that link the effectiveness of care systems to the availability of resources.⁸

The opportunity to use monitoring and evaluation results to refine, adapt and strengthen the implementation of care and support activities for PLHA is increasingly appreciated. Ongoing health care reforms—which emphasize that decision making, executive responsibilities and accountability should be vested at implementing levels—will further expose the need for monitoring and evaluation skills at all levels. In fact a decentralized health system requires that monitoring and evaluation generate information for policy and decision makers, as well as provide feedback that is relevant at the local level and fulfill requirements for accountability to the beneficiary population.⁹

HIV care indicators have recently been proposed to measure progress in HIV care delivery at the country level.⁷ More detailed indicators—focusing on the scope, quality, and coverage of care and support services—are needed at the project implementation level to provide the necessary feedback for site-specific performance enhancement. The examples in Box 2 list some potential indicators for the various elements of comprehensive care. Measuring these indicators will involve health care facility-based surveys and household surveys, complemented by a mix of qualitative assessment methods previously described for process evaluation.

BETTER SURVEILLANCE DATA FOR DECISION MAKING

IMPROVING HIV SURVEILLANCE DATA

Program evaluation is complicated by the evolution of epidemics and our poor understanding of how different behaviors and epidemiological factors influence epidemic patterns as they move from an epidemic phase to an endemic state. Changes in HIV prevalence may be indicative of the long-term effect of multiple HIV/AIDS prevention interventions, but it is difficult to prove that observed decreases in prevalence trends are the result of HIV prevention programs. Other factors such as mortality, migration and saturation of the population at risk may also account for such changes.¹⁰

Consensus is emerging among decision makers that prevention programs need to investigate both trends in HIV infection and behavior that may lead to infection.¹¹ To this end, HIV data have to be collected in conjunction with behavioral, socioeconomic and socio-demographic data. The combined analysis of these data sets serves a dual purpose: (1) It provides the necessary context and range of information to interpret and explain the epidemiological data collected by sentinel serosurveillance surveys; and (2) It allows a more valid assessment of the effects of prevention programs on the course of the epidemic in a given country.

ADJUSTING ANC SENTINEL DATA

In the absence of true HIV incidence data, a system of sentinel surveillance for monitoring HIV infection among selected populations has been recommended.¹² For HIV sentinel surveillance of antenatal clinic (ANC) patients, use unlinked and anonymous residual blood specimens left over from samples collected for clinical purposes. Using this approach, it is possible to minimize the possibility of participation bias associated with voluntary testing.

ANC clients have been selected as a particularly suitable “sentinel” group because they are believed to represent most closely the HIV prevalence of the general sexually active population. ANCs are the primary source of data for monitoring HIV prevalence trends in most developing countries, especially in sub-Saharan Africa.

Box 2

EXAMPLES OF INDICATORS FOR CARE AND SUPPORT

Clinical Management

- Percentage of health care units that have trained staff to manage HIV-related illnesses, manage referrals for HIV-infected patients and supervise palliative care in accordance with national standards or protocols.
- Percentage of health units that are currently stocked with drugs to treat and prevent common opportunistic infections and for palliative care, and report no stock-outs in the past 12 months.

Voluntary Counseling and Testing (VCT) in the Context of HIV/AIDS Care

- Percentage of health care-providing sites that have an accessible VCT service staffed by trained counselors providing HIV counseling and testing services free or at affordable rates.
- Percentage of people tested HIV positive who have been referred to appropriate clinical care and social support services.

Stigma/Discrimination

- Percentage of health care providers showing acceptable attitudes towards people with HIV during their clinical work.

Support

- Percentage of households with a chronically ill adult (age 15 to 49) in the last 12 months that have received external help in caring for the patient or replacing lost income.
- Percentage of households caring for orphans that have received free help with care from outside the family.

Sources: UNAIDS 2000.

Van Praag E and Tarantola D. In: Reble T, et al. 2000.

Comparisons between ANC sentinel surveillance and general population serosurveys, however, have shown that data from pregnant women may differ significantly from the general population data, and the relationship can go in different directions at different stages of the epidemic and for different age groups.^{13,14} The considerable variation in the findings suggests that extrapolations from ANC data should be made with caution. Because of the large denominator used (the general population of women), even a small percentage difference in HIV prevalence between pregnant women and women in the general population would result in a substantial over- or underestimation of the total number of women infected.

Selection biases

ANC sentinel data are subject to selection biases related to convenience sampling (sites are not randomly chosen), usage and coverage of ANC services, differences in risk behaviors, contraceptive use, fertility between HIV-positive and HIV-negative women and such other socio-demographic factors as age distribution of those using ANCs, level of education, socioeconomic status and migration patterns. There are insufficient data on the relative importance of these factors in different settings, and even less is known about how these factors may vary over time.

Lower fertility rates were found among women with HIV-1 infection.¹⁵ And it has been shown that differentials in fertility between HIV-infected and uninfected women can have substantial effects on ANC prevalence estimates and the total number of prevalent infections estimated from them. The effect due to differential fertility is expected to be most apparent in older ANC age groups, especially in mature epidemics.

If the factors that lead to selection biases remain the same over time, serial data from ANC sentinel sites will provide a solid basis for analyzing HIV trends in that population. But the selection biases may change over time. In that case, HIV trends recorded over time in ANC sentinel populations may differ from those in the general population.

Population-based studies carried out periodically in the catchment areas of ANC sentinel sites can help to evaluate these sources of bias in different country settings. Periodic surveys of this type are needed to compare data on HIV prevalence trends in the general population with those obtained from routine ANC sentinel surveillance systems. This approach would allow the necessary calibrations of results obtained from pregnant women.

Focusing ANC sentinel surveillance on the younger age groups

In mature epidemics, the majority of new HIV infections are occurring in young people.¹⁶ By concentrating resources on younger age groups in ANC surveillance efforts, it will be possible to obtain more information on relatively recent infections. Bias due to differential mortality and fertility will be of less concern in young ANC clients. For this reason it has been recommended that over-sampling should be attempted among 15- to 24-year-olds, while continuing to collect data in all age groups.¹⁷ Because sample sizes must be large enough to allow a more detailed age-stratification, key sentinel sites with a high volume have to be identified. This could mean that countries may have to downsize the number of sentinel sites in the interest of concentrating resources where they will be most useful.

Linking behavioral data collection and HIV serosurveillance

To minimize biases, not jeopardize the validity of the serological data and gather less biased behavioral data on the population as a whole, it is recommended that blood samples and risk behavior interviews be obtained from different individuals. But to establish a clear association between behavior and HIV prevalence

in the community, the data on HIV serostatus among ANC attenders and behavior in the general population have to be drawn from the same source population.

This means carefully defining the population from which a key sentinel surveillance site—such as a large urban antenatal clinic—draws its clients and collects behavioral data from a random selection of households in the same catchment area. If this is done as part of national or regional behavioral surveys, it may mean deliberately oversampling in the catchment populations of key sites (that is, the population served by the particular site in question).

To link the behavioral data with the HIV prevalence data, it is recommended that a minimum set of socio-demographic questions be asked of all ANC clients at sentinel sites. This data would include age, parity, last birth interval, level of schooling, occupation and length of time living in the area (as an indicator of migration). These parameters can then be compared with those collected in the population-based behavioral surveys, allowing any systematic differences between the two groups to be identified and adjusted in the analysis.

RECOMMENDED MIX OF BEHAVIORAL DATA COLLECTION METHODS

Different data collection methods deliver different products with varying degrees of cost and complexity. To use its resources most efficiently, a national program must choose which mix of methods to adopt, with what frequency and on what scale. These choices will reflect the stage of the country's epidemic as well as its political and social environment, existing capacity for research, and available resources.

Family Health International/IMPACT and UNAIDS have made recommendations for a minimum package of behavioral data collection for each major stage of the epidemic.¹¹ These recommendations conform to the UNAIDS/WHO guidelines for second-generation HIV surveillance systems,¹⁷ and are

based on the assumption that HIV sero-surveillance is in place or being developed in line with those guidelines. Our recommendations draw upon the experience of several organizations and countries in collecting behavioral data, and are intended to guide national programs in setting up efficient behavioral assessment and monitoring programs to assist them in program design, direction and evaluation. Tables 4, 5 and 6, which summarize the minimum package for each stage of the epidemic, can serve as a checklist for countries planning to strengthen their behavioral data collection efforts.¹¹

The main objective of the recommended behavioral surveillance systems is to track trends in key indicators over time, through multiple rounds of data collection with a consistent sampling strategy.¹⁸ This is in contrast to traditional pre- and post-test knowledge, attitude, practice and belief (KAPB) surveys which focus mainly on the measurement of changes in indicators between two points in time. Although repeated surveys are also subject to measurement error, the feature of repeated surveys adds an element of robustness to the obtained data. What distinguishes repeated surveys from a pre/post survey design is that we are able to recover from one round of inaccurate survey data, since multiple rounds let us identify a particular round as an “outlier.”

Preliminary assessment

The development of any system of behavioral data collection should begin with a careful preliminary assessment of the behavioral situation, if this has not already been done. Such an assessment will have several components. These include a review of existing behavioral studies and data sources in the country; a rapid assessment of risk behaviors; mapping of where the risk is and who is at risk; and formative qualitative research to identify opportunities, barriers and appropriate approaches for promoting behavior change.¹¹

Rapid assessments, mapping methodologies and qualitative research approaches have been developed in a number of fields, but are equally applicable to the study of risk behavior—especially for hard-to-reach populations about which national programs know little. These methods assist and complement the

formative evaluation efforts described earlier in this chapter in prioritizing prevention activities and deciding where efforts should be focused.

The three approaches deliver two major benefits:

- They allow the risk situation in a given vulnerable population or community to be quantified in terms of number of settings or size of the population.
- They provide a greater in-depth understanding of risk behaviors and the factors that influence and motivate them.

Without this type of information, it is difficult if not impossible to develop relevant prevention programs. Qualitative approaches are particularly valuable for prevention program designers because they allow respondents to express their own concerns, rather than only responding to researchers. If such information is applied intelligently, it is likely to lead to more appropriate prevention programs for particular communities.

STAGES OF THE HIV EPIDEMIC

UNAIDS and its partners have developed a classification that groups HIV epidemics into three types: low level, concentrated and generalized. Countries will have different information needs in each epidemic state, and they may shift if the epidemic develops and moves from one type to another.

Low-level epidemics are epidemics with an HIV prevalence assumed to be less than five percent in all known sub-populations presumed to practice higher risk behaviors. Countries in the low-level stage of the epidemic may initially focus their surveillance efforts on populations with higher levels of behaviors transmitting HIV, such as commercial sex workers (CSW), truckers, migrant workers, the military, men who have sex with men (MSM) and injection drug users (IDUs). The aim will be to monitor the trends and levels of infection within these groups and to map the dynamics of infection and sexual mixing patterns that are construed as high or low risk. (See Chapters 8, 11, 15 and 22 for more information on HIV prevention strategies for special groups.)

Concentrated epidemics are epidemics with an HIV prevalence that has surpassed five percent in one or more sub-population presumed to practice higher risk behaviors, but prevalence among pregnant women is still less than one percent.

Generalized epidemics are epidemics in which HIV has spread far beyond the sub-populations with higher risk behaviors, which are now heavily infected, and the prevalence among pregnant women is above one percent. In such epidemics the rural population may be fast mirroring the infection levels in urban areas. Most sub-Saharan African countries have established epidemics that go beyond populations practicing high-risk behaviors. The generalized nature of the epidemic in this region calls for surveillance systems that give a cross-sectional profile of the infection in the general population.

Behavioral data collection in a low-level epidemic

In low-level epidemics, the risk of HIV infection is likely to be concentrated among those with higher levels of risk behavior in the country. Depending on the country, these might include sex workers and their clients, IDUs, MSM or other populations. In this type of epidemic, it is recommended that HIV prevalence studies also focus on those with higher risk behaviors. But risk behavior may also exist in the general population, so the links between higher- and lower-risk populations need to be investigated.

Many countries with low-level epidemics have not felt the need to invest resources in collecting behavioral data, assuming that if the virus is largely absent, risk behavior must be limited. But it is exactly at this point of the epidemic that behavioral data can act most effectively as a warning system. Where behavioral data and other indicators—such as STD or

Table 4

BEHAVIORAL DATA NEEDS AND METHODS IN A LOW-LEVEL EPIDEMIC

Data Needs	Method	Questions Answered	Frequency	Duration*
Preliminary assessment	Review existing data.	What is already known? What are the gaps in current knowledge?	One time	
	Rapid assessment of risk behaviors.	Which high-risk behaviors are driving the epidemic in this country?	One time	3 months
	Mapping of at-risk populations.	Where do people engage in risk behavior? How many people are associated with each site?	One time	1 month
	Qualitative research.	What particular behaviors must change? Is there resistance to change? What are links with general population? What type of intervention is the most appropriate?	One time	2 months
Behavioral monitoring	Repeated surveys in population with high-risk behavior.	How widespread is risk in defined high HIV-risk behavior groups? How widespread are safer behaviors? How common are links with general population? How has behavior changed over time?	Annually/ bi-annually	3-6 months
	Where qualitative research points to links between high- and low-risk groups: Repeated surveys in the general population.	And since before the intervention? What proportion of the general population? Every 4-5 years is a sexual partner of someone with high-risk behavior? Which behaviors put them at risk?	6-9 months	

*Duration: includes all research or survey stages from preparatory work to the production of findings.

Hepatitis B prevalence—show that people are having unprotected sex with multiple partners or are sharing injection equipment, it may simply be a matter of time before HIV follows.

Collecting information on behavior at this stage spotlights potential flash points for HIV infection.

It can raise awareness among the public and policy makers of the dangers of not doing anything to keep the virus confined at low levels. And it can help suggest what must be done and for whom.

Behavioral data collection in a concentrated epidemic

In a concentrated epidemic, HIV may remain confined to circles of people with higher risk behavior because there are few links between those populations and the general population. It may remain concentrated because there is very little risk behavior in the

general population. There may be links and generalized risk behavior, but HIV may not have infected a sufficient number of individuals to make for explosive growth. In that case, it may just be a matter of time before the epidemic becomes generalized. Determining which of these is the case and designing and measuring the success of the appropriate interventions are the main purposes of behavioral data collection in a concentrated epidemic.

At the concentrated stage of the epidemic, countries should continue sero-surveillance activities in the groups in which infection is concentrated and begin monitoring HIV in the general population, especially in young people. Behavioral data collection will work in tandem to increase the usefulness of the serological data.

Table 5

BEHAVIORAL DATA NEEDS AND METHODS IN A CONCENTRATED EPIDEMIC

Data Needs	Method	Questions Answered	Frequency	Duration*
Preliminary assessment (if not yet done; or if needed to be broadened geographically; or in other groups)	Review existing data.	What is already known? What are the gaps in current knowledge?	One time	
	Rapid assessment of risk behaviors.	Which high-risk behaviors are driving the epidemic in this country?	One time	3 months
	Mapping of at risk populations.	Where do people engage in risk behavior? How many people are associated with each site?	Repeated if survey data shows population or behavioral shift	1 month
	Qualitative research.	What particular behaviors must change? Is there resistance to change? What are links with general population?	One time	2 months
Behavioral monitoring and explaining trends in HIV prevalence	Repeated surveys in populations with high-risk behavior.	How widespread is risk in high-risk behavior groups? How common are links with the general population? How do these behaviors change over time?	Annually/ bi-annually	3-6 months
	Repeated surveys in the general population.	What proportion of the general population has sex with someone with risk behavior? Which behaviors put them at risk?	Every 4-5 years	6-9 months
	Sampling with emphasis on geographical areas with key HIV sentinel sites.	What are the risk behaviors among young people? At what age do they begin? How do they change over time?		
	Repeated surveys in young people.	Do trends in self-reported risk behavior correlate with observed changes in HIV prevalence (e.g., explaining transition to generalized epidemic)?	Every 2-3 years	3-6 months
	Sampling with emphasis on geographical areas with key HIV sentinel sites.			

*Duration: includes all research or survey stages from preparatory work to the production of findings

Behavioral data collection in a generalized epidemic

Groups with particularly high levels of risk behavior may continue to drive new infections in a generalized epidemic, but the pattern of HIV spread goes far beyond higher risk individuals and their immediate partners. By the time an epidemic becomes generalized, the major risk behaviors are usually clear. Systematic and repeated behavioral data collection in the general population is essential for explaining changes in prevalence and tracking changes in behavior over time. It must also focus on identifying the

risk behaviors that have been neglected or failed to respond to prevention efforts. New qualitative research may choose to explore the social, economic, and cultural context that determines who continues to be vulnerable to HIV infection and why.

DISSEMINATING AND UTILIZING THE DATA

Behavioral data are of little value unless they are used for the benefit of the people from whom they were collected. The various reasons for tracking behavior were discussed at the start of this chapter. This section describes the particular uses of the data once they are collected and analyzed.

Encouraging policy makers to support and promote HIV prevention

Public health officials need no convincing of the importance of dedicating time and resources to prevent the further spread of HIV. The same cannot always be said for policy makers in other sectors, who are confronted with pressing priorities of their own.

In the early phases of the epidemic, well-designed, credible behavioral data can warn of the possibility of rapid HIV spread and encourage policy makers to act to prevent that spread. But this can happen only if the data are presented in language that policy makers can understand, and in ways to which they can respond. This will vary according to the target audience. A ministry of education may be interested in knowledge and attitudes among youth, while a ministry of manpower may want to know how widespread risk behavior is in the urban adult population. The finance ministry may be startled by the implications of financing health care if 10 percent of those reporting risk behavior were to become infected with HIV.

A comprehensive approach to promoting HIV prevention requires data on both the general population and those at high risk for infecting themselves or others. Behavioral data on a mix of these groups improves understanding of who is at high risk and whether and how risk patterns are changing. In other words, general population data provide information about unknown levels of risk in the overall population, whereas data on groups with high levels of risk behavior provide more immediate information on sub-populations that have the biggest impact on the epidemic.

Demonstrating that behaviors do change following prevention activities—in groups with higher levels of risk behavior and in the general population—is one of the most effective ways to increase support for prevention activities. Behavioral data showing changes over time should be presented simply and rapidly to policy makers who have the power to influence spending and program direction.

Making the public aware of the threat posed by HIV

Many generalized epidemics have reached their current stage because people in the general population did not know or want to believe that they were at risk of HIV infection. Behavioral surveys in the general population as well as in selected population groups can illustrate the extent of continuing risk behavior. Presented to target audiences, with the help of the media or through other avenues, the findings of such surveys will increase awareness of the risk of unprotected sex with any partner.

It is also important to be aware of trends in behavior over time. Knowledge that others are adopting safer behaviors can help reinforce behavior change, especially among young people who respond to peer pressure. This is why the targeted dissemination of relevant behavioral data to the communities can enhance the effectiveness of prevention efforts over time.

Improving prevention programs

As the picture of risk behavior builds up and changes over time, it will indicate which behaviors have changed following prevention programs and which remain entrenched. This information can and should be used to improve prevention programs. Prevention packages that appear to be associated with behavior change in certain sub-populations may be continued and expanded. Behaviors that remain unchanged despite efforts to promote safer alternatives indicate the need for a new approach, perhaps one that pays closer attention to the social or economic context that affects the way people behave.

ISSUES AND CHALLENGES: WHAT DO THE DATA MEAN?

Evaluation efforts for behavior change interventions have focused on the assessment of accurate knowledge about HIV risks, reducing risk behaviors and adopting protective behavior as the most appropriate intermediate outcome indicators for interventions designed to reduce sexual transmission of HIV. Existing evaluation results suggest that prevention activities made a difference in most intervention settings. It should be noted, however, that the detection of significant behavior changes is becoming increasingly difficult over time, especially after there already have been substantial changes (ceiling effect). In these cases, interventions have reinforcing, rather than new, effects. These effects may look small when in fact they indicate the maintenance of reported behavioral change or the prevention of relapses in unsafe behavior.

MEASURING RISK BEHAVIORS IN ABSOLUTE VERSUS RELATIVE TERMS

Percentage figures of condom use measure the proportion of sexual exposures considered to be safe, which may or may not reflect the absolute number of sex acts that place individuals at risk for exposure to sexual transmission. For example, 10 percent condom use in 10 HIV-associated sexual episodes is still safer than 75 percent condom use in 100 HIV-associated sex episodes (nine versus 25 unprotected HIV-associated sexual episodes, respectively, when expressed in absolute terms). This is why it is important to determine the frequency of condom use in absolute terms in a given risk situation. Behavioral surveys have begun to address this dilemma by collecting additional data on “always or consistent” condom use in the context of sexual episodes with non-regular partners.

OBSERVED BEHAVIOR CHANGES— IS IT ENOUGH TO AVOID INFECTION?

Since HIV infection through sexual intercourse is the result of accumulated risk exposures, preventing infection at one point in time will not ensure that a person remains uninfected in the long term. The size and range of observed behavior changes, especially in

populations with high-risk behaviors, suggest that the interventions may only postpone the timing of infections rather than preventing them indefinitely.

Although the lifetime risk of infection may not have been reduced among individuals with high-risk behaviors, preventing HIV infections among those likely to transmit HIV to others will have a considerable impact on the incidence of HIV at the population level. A reduced HIV incidence rate in populations with high-risk behaviors also will mean fewer infections among their networks of sexual partners—resulting in a decrease in the rate of new HIV infections in the general population.

OBSERVED BEHAVIOR CHANGES— PRODUCT OF INTERVENTIONS?

The question of whether observed changes in behavior reflect the natural history of the epidemic or are due to intervention effects is a critical one. There is evidence that there will be trends toward risk reduction, especially when evaluating behavior change in the face of growing numbers of people with AIDS-related illnesses. Having a friend with HIV/AIDS, for example, may influence adolescents to delay the onset of sexual relations or motivate those with non-regular sex partners to use condoms. Human sexual behavior is influenced and shaped by many factors, and exposure to an HIV prevention program is only one of them.

In the absence of more rigorous evaluation designs, triangulation procedures have to be applied to substantiate a link between interventions and observed behavior changes. For example, combining process evaluation data on condom sales, the intensity of peer education, or the quality and coverage of media campaigns with an analysis of behavioral outcome data can provide an understanding of the process through which interventions achieve effects. Results from behavioral surveys also should be analyzed together with findings from qualitative evaluation research—focus group discussions, key informant interviews and

rapid ethnographic studies—carried out in sub-samples of surveyed target populations. This analysis will allow a more appropriate interpretation of observed outcome data since the data are likely the results of the aggregate effects of multiple interventions as well as environmental and personal factors.

It is also important to realize that behavior change interventions must be implemented for sufficient amounts of time and on a large enough scale to have an impact on personal behavior, social norms in communities and on the epidemic. The example of Thailand shows that a focused intervention strategy implemented at a national scale can result in substantial declines in HIV incidence and prevalence in targeted populations.

There are other examples of successful national efforts to reduce HIV infection and increase safe behavior. In Uganda, later age at first sex and rising condom use reported in repeated behavioral surveys were reflected in decreasing HIV infection rates in young women.¹⁹ In Senegal, a strong political and community commitment led to an early response to the HIV/AIDS epidemic that has been extended since 1986. As a result, Senegal has managed to contain the spread of HIV at a relatively low level.²⁰

Documenting such success stories is an important task of program evaluation and epidemiological surveillance, and is instrumental in generating public support for continued prevention and care efforts.

RELEVANT CHAPTERS

- Chapter 8 *Reducing HIV Risk in Sex Workers, Their Clients and Partners*
- Chapter 11 *Reaching Men Who Have Sex with Men*
- Chapter 15 *Issues in STD Control for Special Groups*
- Chapter 22 *Risk Reduction in IDU*
- Chapter 23 *Counseling, Testing and Psychosocial Support*

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C H A P T E R

6

*Behavior
Change
Communication
to Reduce
Risk and
Vulnerability
in Resource-
Constrained
Settings*

CAROL LARIVEE

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Behavior Change Communication to Reduce Risk and Vulnerability in Resource-Constrained Settings

INTRODUCTION

The AIDS epidemic forces societies to come to terms with the perceived ideals of traditional cultures and the harsh realities of practices that are discordant with those ideals. Behavior change communication (BCC) plays a vital role in this process and can set the tone for a compassionate and responsible response. BCC strategies can function to support all components of a comprehensive prevention and care program and create a cohesive environment for behavior change. In addition, BCC strategies can help to support all components of a comprehensive prevention and care program and create a cohesive environment for behavior change.

This chapter outlines the various roles for communication, and details the step-by-step process of developing a comprehensive BCC strategy for STD/HIV/AIDS programs in resource-constrained settings.

THE ROLE OF BCC IN STD/HIV/AIDS PREVENTION AND CARE

A comprehensive HIV/AIDS program will contain a combination of prevention, care and support services, community mobilization and political support. The BCC component can link these various elements together and contribute to changing the way in which individuals, communities and societies deal with the underlying issues.

Some of the BCC theories helpful to understanding the role of communication and programming comprehensive communication strategies are outlined in this section. They include:

- Diffusion of Innovations model
- Stages of Change model
- Behavior Change Continuum
- UNAIDS communication framework

STEPS IN DEVELOPING A COMMUNICATION STRATEGY FOR HIV/AIDS/STD PROGRAMS

Good strategic planning for BCC helps program planners make better decisions on how to utilize limited resources. This section outlines the various steps required to develop and implement such a communication strategy for STD/HIV/AIDS programs. Topical areas covered include:

- Problem identification
- Target population
- Formative assessment
- Behavior change objectives
- Stakeholders
- Communication design
- Communication objectives
- Targeted interventions
- Monitoring and evaluation
- Feedback and redesign

LESSONS LEARNED

There are many lessons learned in developing BCC in resource-constrained settings. Some of the most important points are summarized in this section.

CASE STUDIES

Linking mass communication with community programming in Kenya. Kenya is a country with high knowledge of HIV/AIDS and low levels of behavior change. To support HIV/AIDS prevention and care strategies and to initiate a dialogue in the communities on risk settings and risk behaviors, PATH/Kenya in partnership with IMPACT has evolved an innovative communication strategy using an interactive radio program linked to a magazine format.

USING MASS MEDIA TO STIMULATE COMMUNITY DISCUSSION ON STIGMA AND DISCRIMINATION

Recent well-publicized, dramatic human rights abuses involving PLHA in India, as well as comprehensive audience research, show clearly that Indian society has failed to accept and integrate the reality of HIV/AIDS. The concept was developed for a film addressing the core attitudes towards HIV/AIDS that must change before India can develop a social and policy environment where effective HIV/AIDS prevention can take place.

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I N T R O D U C T I O N

To reduce vulnerability to HIV/AIDS, individuals and communities need three things: the basic facts to understand the urgency of the epidemic, access to appropriate services and an environment supportive of changing and/or maintaining safe behaviors.

As HIV is primarily a sexually transmitted disease (STD), reducing the risk of transmission requires national and community discussions on sex

and sexuality, risk settings and risk behaviors. It also requires

dealing at the national and community levels with the secondary epidemic that follows in the wake of HIV/AIDS, one of stigma, fear and discrimination. The AIDS epidemic forces societies to come to terms with the perceived ideals of traditional cultures and the harsh realities of practices that are discordant with those ideals. Behavior change communication (BCC) plays a vital role in this process and can set the tone for a compassionate and responsible response. In addition, BCC strategies can function to support all components of a comprehensive prevention and care program and create a cohesive environment for behavior change.

Developing effective BCC in resource-constrained settings presents unique challenges. The approaches must be effective and efficient, building on existing systems and structures and utilizing a variety of channels—from targeted mass media to traditional and interpersonal communication—to create a critical mass to stimulate discussion and action on the key issues that motivate and support behaviors. Over the last decade, many lessons have been learned on how to apply basic BCC strategies in

resource-constrained settings. The greatest of these is the need for systematic assessment and planning, coupled with monitoring and evaluation, to ensure the development of BCC strategies that will have the greatest impact and use scarce resources most effectively.

BCC is a vital component of all interventions focused on reduction of risk and vulnerability. Within this context, the various roles for communication will be outlined in this chapter and the step-by-step process of developing a comprehensive behavior change communication strategy for STD/HIV/AIDS programs in resource-constrained settings will be detailed.

THE ROLE OF BEHAVIOR CHANGE COMMUNICATION IN STD/HIV/AIDS PREVENTION AND CARE

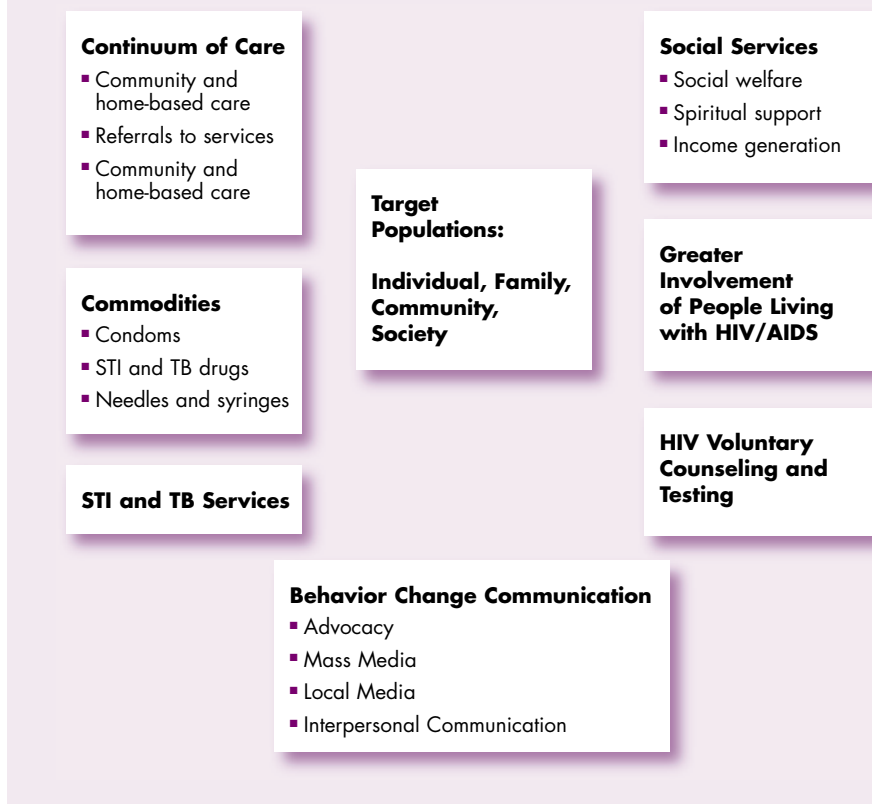
A comprehensive HIV/AIDS program will contain a combination of prevention, care and support services, community mobilization and political support. The BCC component can link these various elements together and contribute to changing the way in which individuals, communities and societies deal with the underlying issues. Specifics on how these elements are programmed for key groups can be found in subsequent chapters. But it is important to place BCC within the context of a broader program from the outset. Figure 1 highlights the various inter-linking elements of a comprehensive HIV/AIDS program.

Communication has many different but related roles to play in HIV/AIDS/STD programming. These include:

- **Community dialogue.** Stimulate community and national discussion on the underlying factors that contribute to the HIV/AIDS epidemic, i.e., risk behaviors, risk settings and the environment that creates these conditions and produces demand for information and services.
- **Advocacy.** Ensure that policy makers and key opinion leaders take the epidemic seriously. Advocacy takes places at all levels, from the national to the community level.
- **Provision of information.** Make sure that people receive the basic facts in a comprehensible language and using visual and media they can understand and relate to.
- **Stigma.** All communication on HIV/AIDS must incorporate a component dealing with the issue of stigma, and attempt to influence the social response.

Figure 1

COMPREHENSIVE HIV/AIDS PROGRAM



- **Promotion of services.** All STD/HIV/AIDS programs are developing services for prevention, care and support. Communication plays a vital role in promoting these services, which include STD, voluntary counseling and testing (VCT), support groups, people living with HIV/AIDS (PLHA) networks, orphans and vulnerable children (OVC), mother-to-child transmission (MTCT), clinical care for opportunistic infections and social and economic support.
- **Influencing the discourse on HIV/AIDS.** Communication can also play a role in influencing the discourse on HIV/AIDS by attempting to stimulate dialogue and prompt action for reduction of risk, vulnerability and stigma.

CHANGING THE DISCOURSE ON HIV/AIDS

Discourse is still an unfamiliar concept to many people. The discourse on any subject can be defined as the way people talk and think about that subject in a given society—the facts and opinions they cite, as well as the images, concepts, norms, values and assumptions behind them. A discourse always includes many points of view, but usually one is dominant.

It is increasingly clear that interventions representing the state-of-the-art in prevention, and clearly appropriate to the groups at risk, are not likely to be implemented if they run counter to the dominant discourse on AIDS in that society. For example, interventions targeting men who have sex with men (MSM) may not be implemented in a society where most people deny the existence of such a group. Similarly, compassionate injection drug user (IDU) interventions may not be implemented in a society where people view drug users as evildoers rather than victims. Sex worker interventions based on peer communication and aiming at women's empowerment may not be allowed in a society with a dominant discourse of male supremacy.

Since the discourse on any subject forms the background to communication, understanding the discourse on HIV/AIDS is an essential first step in developing a comprehensive strategy for HIV/AIDS prevention. While this is usually done intuitively, it is possible to study and address the discourse in a purposive way. As with any other behavior change project, an attempt to change the discourse begins with research and analysis. A discourse analysis looks

critically at the media and at the rhetoric of institutions (political, religious and educational) to see how HIV/AIDS is presented. Such a study should yield insights into images of HIV/AIDS and risk groups; awareness of the existence of risk behaviors; gender-based behavioral expectations; levels of fatalism and blame; popular refuges (“why I cannot get AIDS”); and myths and distortions, among other factors.

Once they are identified, these insights can lead to the formulation of behavior change objectives, concepts, messages and, ultimately, to a carefully constructed media campaign targeting those changes.

Some special communicators' tools are available to those who want to address discourse level changes in a purposive way:

“**Agenda setting**” is the name given to one of the best documented communication effects, expressed through a communicator's axiom: “You can't tell people what to think, but you can tell them what to think about.” Agenda setting is the conscious choice and effort to introduce new ideas into the public forum for debate. For example, the yearly theme for World AIDS Day is an attempt to do this by choosing a topic that is proposed as a year-long agenda for public discussion. The effect this theme will have on popular knowledge, attitudes, and behavior in the short term is unpredictable, but once the subject is on the agenda to be addressed, a number of changes are possible, ranging from shifts in media representation to changes in law and policy.

Legitimation is the process by which categories of people or information are brought into the spotlight

and validated as subjects of concern. Wherever media portrayals are dominated by a certain category of person, that type of person appears more important or even more real than other types. In the extreme case of “symbolic annihilation,” a lack of media recognition seems to deny a group its very existence. In terms of HIV, in the early years of the epidemic in the United States, attention focused overwhelmingly on young and middle-aged gay white men, while the needs of HIV-positive women, minorities, and older PLHA were largely ignored. Since then, advocacy groups have made efforts to direct attention to increasing the visibility of these groups, until the discourse more closely reflects reality.

Reframing Concepts. Another tactic for changing the discourse on gender is the conscious attempt to recast or reframe concepts in order to challenge the assumptions they conceal. An example of this is a change in the label given to people who exchange sex for money, from “prostitute” to “sex worker.” This change of name, now in process throughout the world, implies a change from criminal to worker. This subtle shift has potentially far-reaching implications for policy and HIV/AIDS prevention.

Attempts to influence the discourse may have an advocacy aspect and frequently involve partnership with the media. Although they are not yet part of the repertory of many HIV/AIDS communicators, they can play a key role in a comprehensive HIV/AIDS program.

BCC is an important component and support to STD/HIV/AIDS programs, and a BCC strategy must be developed in the context of the overall program goals and objectives. This applies to a national campaign as well as to the BCC strategy of small nongovernmental organizations (NGOs) working with one specific target group.

BEHAVIOR CHANGE THEORIES

Behavior change is a process many theorists have mapped and analyzed, and BCC has its roots in theories that have evolved over the last few decades and continue to evolve. Behavior change of individuals, communities, organizations and institutions is fundamental to reducing risk and vulnerability to HIV/AIDS. The Diffusion of Innovations model, the Stages of Change model and the Behavior Change Continuum are some of the theories helpful to understanding the role of communication and programming comprehensive communication strategies. But program planners need to base designs on ground realities and not tailor programs to fit any particular theory.

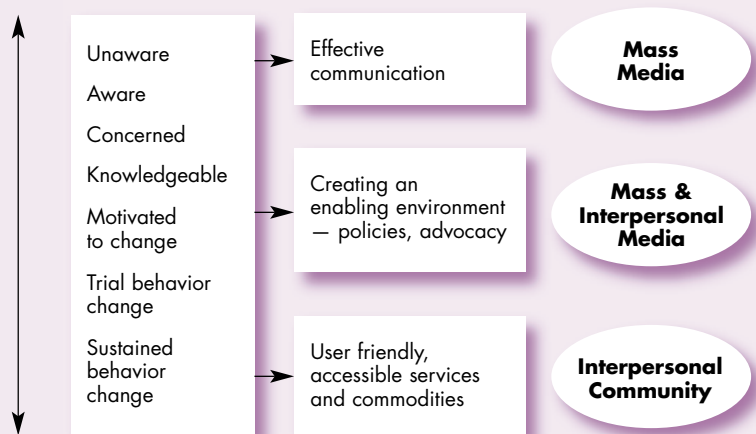
The Diffusion of Innovations model leads planners to examine the natural process of change, as innovations (new behaviors) are adopted by different categories of people in a community over time, due to the nature of communication of information among them. This model leads planners to examine social networks and viable communication options within that network—including identifying gatekeepers. Diffusion is the process by which innovation is communicated through certain channels over time among the members of a social system.¹ Studies in this tradition have been conducted since the 1940s, making this a particularly well-documented body of research. It is still widely applied in BCC for HIV/AIDS.

Initially developed for anti-smoking campaigns, the Stages of Change model assists planners in developing strategies for certain stages in the adoption of a new behavior.² Stages are outlined as:

- Pre-contemplative
- Contemplative
- Decision/Determination
- Action
- Maintenance

Figure 2

PROGRAMMING BEHAVIOR CHANGE



ables such as cultures and gender relationships.”³UNAIDS proposes a communication framework that looks at governmental policy, socioeconomic status, culture, gender relations and spirituality.³

In practice, programmers are using a combination of theories and practical steps in designing and implementing HIV/AIDS BCC strategies. Figure 2 demonstrates how the above theories and framework can be combined for effective design.

The individual, community or institution goes through a series of steps, not always in a linear fashion and often taking steps forward followed by steps backward. Even when an individual or group has adopted safe behaviors, relapse into

This model, based on individual behavior change, has been modified and applied in many different forms.

The Behavior Change Continuum expands on the Stages of Change model, delineating the steps from:

- Unaware (Pre-contemplative)
- Aware/concerned/knowledgeable (Contemplative)
- Motivated to change (Decision/Determination)
- Tries new behaviors (Action)
- Sustains new behaviors (Maintenance)

This continuum, outlined by the World Bank, provides some suggestions for possible communication strategies for each stage.¹

The Joint United Nations Programme on HIV/AIDS (UNAIDS) maintains that the above theories neglect the role of community and culture in behavior change. “The assumption that individuals can or will exercise total control of their behavior has led to a focus on the individual rather than on the social context within which the individual functions, and a disregard for the influence of contextual vari-

unsafe behavior is common. Knowing where a group is in this process is crucial in designing a BCC strategy. At each step, different types of media and influences take on importance. Effective communication through mass media or other channels can ensure that basic information reaches a target population, but policies and the overall environment become more important when an individual or community is motivated or ready to attempt new behaviors. Again, once the environment is conducive to change, the action points, or services and commodities, have to be set up and ready.

The various steps required to develop and implement such a strategy will be outlined in the following section.

STEPS IN DEVELOPING A COMMUNICATION STRATEGY FOR STD/HIV/AIDS PROGRAMS

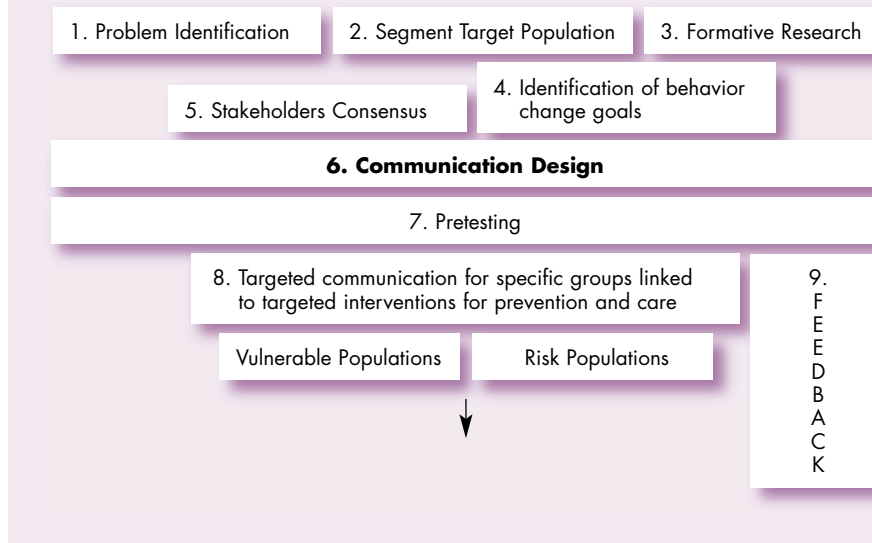
Figure 3 depicts a practical step-by-step approach to developing and implementing a BCC strategy. Good strategic planning for BCC helps program planners make better decisions on how to utilize limited resources.

These steps can be applied to a national BCC strategy or a local initiative. Ideally, a consistent, well-tested message will be disseminated through a variety of channels to reach a critical mass to ensure that the target audience is receiving consistent messages from many different channels—mass media, interpersonal media and traditional media. Reinforcing messages can legitimate them and stimulate discussion and dialogue in the community. Today it can be difficult to exercise control over the multitude of often conflicting media broadcasting messages on HIV/AIDS. For example, in many countries, religious organizations promote fidelity and are against condoms while the public health programs promote condom use. Although organizations or institutions engaged in HIV/AIDS BCC do not usually have control over the various media, with proper planning, BCC planners can build on the existing communication and take advantage of opportunities that exist.

PROBLEM IDENTIFICATION

A BCC strategy is not developed in a vacuum; it relates directly to the overall goals of the HIV/AIDS program. Comprehensive problem identification is made based on reviews of existing data, epidemiological information and in-depth program assessments. HIV/AIDS is not a problem—it is a disease. An example of a problem is that rates of HIV transmission remain high and condom use low among young adults nationwide, in spite of widespread awareness of risk and knowledge of the protective effect of condoms.

Figure 3
STEPS IN DEVELOPING A BEHAVIOR CHANGE COMMUNICATION STRATEGY



A BCC strategy must be developed to form an integral part of the solution to any given problem, and clear formulation of the problem is a key first step. In Jamaica, for example, the problem was identified as low motivation of peer educators for HIV due to high unemployment. In response, the Ashe Performing Arts Ensemble and Academy developed a program combining peer education with employment in the performing arts to address this problem. (See Chapter 7.)

SEGMENT TARGET POPULATION

The problem statement will provide an overall sense of the target populations for the BCC strategy.

The target group, or target population, is the group whose knowledge, attitudes and/or behavior need to change in order to solve the problem. A complex problem for a general population will probably involve

several target groups, some as gatekeepers or permission givers for the primary target group. In this case, these groups may require different interventions. A general population problem, such as widespread stigmatization of PLHA leading to general reluctance to admit risk and accept testing, has many target groups—ranging from all adult men and women to special subgroups of gatekeepers within that population, such as doctors and nurses, landlords and employers.

A broader target population will often need to be further segmented. This is necessary when the methods used to reach a particular subgroup would be different for reasons such as whether the population is rural or urban, the language they speak, their ethnicity, religion, etc.

In resource-constrained settings it is important to prioritize target populations based on risk behaviors, political importance and other such factors. It is not possible to give equal attention to all target populations. In a particular intervention, a commercial sex worker (CSW) may be the primary target audience and the madam, pimp or health care worker may be the secondary or gatekeeper population. To reach sex workers in Sonagachi in Calcutta, for example, it was necessary to first work with the madams who run the brothels where the sex workers live. The sex workers were further segmented by income categories, as the networks to reach them differed.⁴ (See Chapter 8 for details on sex worker interventions.)

FORMATIVE ASSESSMENT

In resource-constrained settings it is important first to review studies of the target population the project is trying to reach and find out which organizations are already working with them. These studies can include existing knowledge, attitude, belief and practice (KABP) studies and behavioral surveillance surveys (BSS), as well as small qualitative studies. A formative assessment guide can then be developed, based on the existing data, for key informant interviews, in-depth interviews, and focus group discussions. To develop a BCC strategy it is necessary to look at the community as a whole, at the geographical and social setting for

behavior, including structural, societal and environmental risk factors. An individual assessment is needed for an in-depth look at the individuals within that broader social context.

For the BCC strategy it is important to obtain information on the following:

- Perceptions of risk and risk behaviors
- Settings for risk behavior
- Key opinion leaders in issues related to sex and sexuality
- Structures and systems utilized by the target population
- Hopes and fears for the future (this information will provide a hook for getting people's attention).
- Media habits
- Entertainment habits
- Health care-seeking behavior

If appropriate, the NGOs or community-based organizations (CBOs) directly working with the target population should be involved in the qualitative formative assessment. This data-gathering is the first step in an intervention with the target population and the initial contact for the BCC strategy.

At this stage it is important to identify all key stakeholders who will be involved in decisions regarding BCC with the target population. For example, CARAM—a partnership of seven NGOs based in Bangladesh, Thailand, Malaysia, Cambodia, Vietnam, Indonesia and the Philippines—developed a participatory assessment methodology for a regional program of action research on mobility and AIDS. The participatory research uses quantitative and qualitative methods to ensure that the migrants' realities are described and understood in relation to HIV. The research resulted in a participatory program for mobile populations that uses a combination of interpersonal communication (outreach workers) linked to targeted and appropriate services. (See Chapter 10.)

IDENTIFY BEHAVIOR CHANGE OBJECTIVES

Whether the target population is the general public or a specific group, it is important first to ascertain the basic behavior change objectives of the overall STD/HIV/AIDS program. BCC is both an essential component of and a support to the overall program, in both prevention and care. Some basic behavior change goals include:

- Safer sexual practices (condom use, reduction in partners)
- Health care-seeking behavior for STDs, tuberculosis (TB)
- Promotion of VCT
- Blood safety—better practices, donor recruitment
- Drug compliance
- Harm reduction of IDU
- Elimination of stigma
- Health care worker attitudes and practices

The specific behavior change goals will be identified during the formative assessment and based on other studies and data available in the country. In Santiago, Chile, for example, the Chilean AIDS Prevention Council implemented a project at public sex sites. The BCC aim was to increase self-risk assessment at the sites where public sex takes place. (See Chapter 11.)

STAKEHOLDERS

It is important that all key stakeholders be involved in the development of a BCC strategy from the beginning. But after information on the target population has been gathered and behavior change objectives have been identified, it is important to hold a stakeholders meeting to discuss the formative assessment findings and reach a consensus on the overall communication objectives. In Eritrea, this approach is being used to ensure that the religious community, who oppose to condom social marketing ads, is comfortable with the overall communication approach.

This is also the time to forge linkages for future collaborative work. One organization may be doing mass media work, while another is doing community work with a related target audience. In Nigeria, for example, stakeholders meetings have been held in four IMPACT states to share findings from the in-depth assessment and ensure consensus on the overall program development for the key communities in the state. Participants have included state and local government authorities, NGOs and CBOs, unions and associations, health care professionals, religious organizations and women's groups. The resulting meeting has led to the development of community programs and a common communication strategy among the many different partners dealing with prevention and care.⁵

OVERARCHING COMMUNICATION DESIGN

Communication design is more than developing key messages for dissemination. It is necessary to find the right approach to reach and get the attention of the target population. The aim is to stimulate a demand for information, services and skills development, not just provide information. Depending on the target population's needs and social context, key messages and themes need to be developed that provide an overall umbrella under which more targeted interventions can take place. The communication design, or "creatives," includes communication objectives, overall concept and theme, key messages and a decision on channels for the effective dissemination of those messages.

COMMUNICATION OBJECTIVES

Based on the formative assessment, communication objectives need to be developed to specify the changes envisaged by the communication interventions as part of the overall HIV/AIDS program goals. Behavior change is a final outcome; prior to that, smaller changes need to be targeted. These may include knowledge objectives (adding needed information or correcting specific misinformation), attitude objectives (for example, increasing perceived risk or changing the image of condoms) or behavior objectives that are precursors to the ultimate change objective (for example, getting young men to remind each other to carry condoms

when they go out drinking.) Consciously formulating these objectives and developing communication for them keeps communicators aware of the small steps that mark the path to a major behavior change like consistent condom use. In Kenya, a formative assessment revealed that people see those vulnerable and infected as a threat and not people in need of care and counseling. This negativity leads to denial and inhibits self-risk assessment.⁶

Concept/Theme

A communication concept describes how one or more communication objectives can be fulfilled through a communicative approach, comprising a channel and a general idea of the message. The concept begins to give concrete form to the communication.

It should be developed according to the communication objectives and the overall program goals. Many lessons have been learned about approaches to avoid in developing HIV/AIDS programs. It is now commonly understood, for example, that fear campaigns are not effective, nor are campaigns blaming any one group. Finding a balance between effective messages on prevention and care and the traditional moral and cultural climate of a country is a continual challenge. In Kenya, for example, Family Health International's IMPACT Project, working with PATH, developed an overall campaign theme called "Nuilise" (or "Question Your Relationships") in response to the overall communication objective of decreasing the perceived distance between the individual and the epidemic.⁶

Message

A message is the carefully crafted information you want your target population to receive. It is developed based on the qualitative assessment and designed to respond to the communication objective, stimulate discussion, dialogue and action. It is important to ensure that services and training programs exist if the message promotes specific services and skill development. In the Nuilise Campaign, the key message is to stimulate discussion and dialogue on risk, risk behaviors, risk settings and local solutions. In another

example, the key messages for youth in Guyana relate to stimulating self-risk assessments and discussion on risk, promoting the use of STD and VCT services and promoting condom use for the sexually active. All messages fall under the "Ready Body" theme: "What is a "Ready Body"? A Ready Body is healthy, physically fit, eats good food and has safe sex. Take the Ready Body Test!"⁷

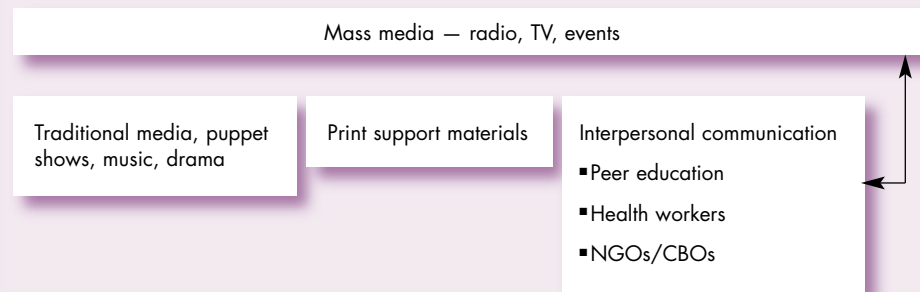
Channel

A channel is the medium used to disseminate the message. When making decisions based on resources, it is important to think about how a particular medium will be used to achieve certain goals, and to know which channels can provide the most effective reach and coverage for the specific target population. Different media have relative advantages and disadvantages, and are best used at different moments during a campaign to achieve different communication objectives. For example, diffusion research has demonstrated very well that mass and targeted media are useful for awareness and knowledge of specific facts, because the accuracy and completeness of the information can be assured and media can give those facts authority. But at later stages of adopting a new behavior, audience members are less interested in media authority than in the opinions of those close to them. At this stage, interpersonal communication becomes primary, while mass and targeted media plays a supporting role.

Looking at cost benefit for using particular channels is essential in resource-constrained settings. It may be ideal to air TV spots on prime time every night, however airing them can be costly. Printing posters, brochures and handouts can also be expensive.

Figure 4

POSSIBLE CHANNELS OF COMMUNICATION



If mass media are being used, it is important to know which radio and TV programs and stations reach the target population. It is not cost-effective to use the national radio station if the target population is youth who only listen to FM music stations.

Peer education, or peer facilitation, is a cornerstone of all interventions with vulnerable populations. One literature review of studies examining the impact of peer education found an overwhelmingly positive impact on STD or HIV incidence and/or risk behaviors.⁸ Peer educators, or peer facilitators/leaders, can play an important role in reaching specific groups by modeling safe behaviors, stimulating community discussion and providing referrals to appropriate services.

“Because HIV/AIDS prevention involves a motivational, rather than an informational challenge, interpersonal communication from peers, perhaps stimulated by certain types of mass communication, is crucial.”⁹ Using a combination of channels to stimulate a critical mass of discussion and dialogue is most effective. In resource-constrained settings it is important to look for opportunities to make the link between channels and media. Consistent messages through a variety of channels can stimulate community discussion on risk and action. The Nulise campaign utilizes interpersonal communication through peer educators, traditional media such as murals and drama and interactive radio drama or magazines. The combination of channels creates synergy to meet the objectives of open discussion on risk and solutions.

Pretesting

It is always important to pre-test communication concepts, messages and materials with a sample of the target audience to ensure that the message you want to send out is actually being received and having the desired effect on the target population. It is important to pre-test several alternative versions to compare their effect on the audience. Pre-testing should not limit itself to finding out if the audience likes and understands the materials, but should include a number of variables—including comprehension, attraction, persuasion, acceptability of the message and personal identification of the target audience member with the message.¹⁰ There should also be pre-testing with key stakeholders to ensure there is no objection. This, however, cannot substitute for pre-testing with members of the target audience. This is doubly important in resource-constrained settings. In a U.S. Agency for International Development (USAID)-funded Guyana HIV/AIDS Youth Project, youth volunteers received training in pre-testing and pre-tested with the target populations both an overarching communication theme—“Ready Body. Is It Really Ready?”—radio and TV spots, and support communication materials. Results from the pre-test led to changes in the materials and a correction of the Ready Body theme.¹¹

TARGETED INTERVENTIONS

Target interventions are a crucial element of any BCC strategy. (Chapters 8 to 12 detail effective approaches and strategies for reaching specific groups.) There will be interpersonal communication strategies using peer education, community events and local media with a targeted intervention. The BCC component of these projects is both a support and a critical element. For maximum impact, it is important to link these interpersonal communication strategies and target BCC to any national media and messages.

Interventions addressing vulnerable populations

UNAIDS defines vulnerability as resulting “from societal factors that affect adversely one’s ability to exert control over one’s own health.”¹² Interventions to address vulnerable populations may examine such areas as gender and human rights issues, quality and coverage of services, stigmatization of those affected, poverty, etc. Interventions addressing vulnerable populations may target policy makers and social norms, along with practical income-generation schemes and interventions to reach orphans and other vulnerable children. BCC and advocacy approaches will be needed. (Chapter 13 examines the links between broader development issues and HIV in the context of vulnerability.)

Interventions addressing risk populations

“In the context of HIV, risk is defined as the probability that a person may acquire HIV infection. Certain behaviors create, enhance and perpetuate such risk—for example unprotected sex with a partner whose HIV status is unknown; multiple unprotected sexual partnerships; lack of adherence to infection-control guidelines in health-care settings; repeated blood transfusion, especially of untested blood; and injection drug use with shared needles and syringes.”¹³ (Chapters 7 to 11 examine specific target populations at higher risk, from youth to MSM. BCC plays a vital role in these targeted interventions.)

In resource-constrained settings it is important to take advantage of all opportunities. If there is a national campaign, the interpersonal media used for a targeted intervention should link to any national campaigns being broadcast on radio and TV. If there are talk shows for youth on population radio stations, links should be made to make AIDS issues for youth a topic for discussion. If there is a social marketing campaign for condoms, there should be links to those messages when dealing with condom promotion among truck drivers or sex workers. In Abidjan, Côte d’Ivoire, for example, the Ministry of Health initiated *Projet de Prévention et de Prise en charge des femmes libres et leurs Partenaires (PPP)* to provide health education sessions to sex workers at their work site, along with peer education. The project linked to a *Clinique de Confiance* operated by another organization, *Projet RETRO-CI*, to provide the sex workers with STD diagnosis and treatment, HIV/VCT and condoms. The project saw approximately 30 percent increases in reported condom use and STD care-seeking behavior. (See Chapter 8.)

MONITORING AND EVALUATION

Monitoring and evaluation are essential components of a BCC program in resource-constrained settings, allowing the program planner to ascertain how effective are the strategies and approaches. This is vital information when resources are scarce.

Monitoring

Monitoring is the regular assessment of the project inputs and outputs. To effectively monitor the course of a BCC strategy, it is necessary to set up an information gathering system. The type of information needed is linked to the overall monitoring system for a program.

First, this means checking to see whether the planned work has taken place and is being disseminated as planned:

- If TV and radio spots have been produced, it is important to monitor when they are being aired.
- If print materials have been produced, it is important to monitor their distribution and use.
- If the communication promotes services, it is important to know if there is an increase in use of those services.
- If there is peer education, it is important to monitor what is actually said in the sessions.

It is also essential to monitor the perceptions of the target population through periodic focus group discussions and in-depth interviews. In Kenya, peer educators are being used to collect questions from the target populations which provide a good reflection of the trends and patterns that are evolving based on the program and the overall epidemic.¹⁴

Evaluation

Evaluation is the assessment of project implementation and its success in obtaining its pre-determined goals and objectives. BCC interventions should be evaluated relative to their stated objective as a part of the overall program and in reference to a baseline that may be either quantitative or qualitative. For large-scale interventions, baseline quantitative research may be repeated to show changes in knowledge, attitudes and reported behaviors, according to the communication objectives and project-level behavior change objectives. But change can also be assessed through qualitative research into audience or target-group response to the intervention. Qualitative evaluation—or assessment of communication effects—examines anecdotal evidence for change in audience research.

FEEDBACK AND REDESIGN

The communication circle is not complete without feedback. A well-developed communication activity includes a means for audience feedback so that the response to the communication interventions can be monitored. Target populations are changing their communication needs as any project evolves, so it is crucial to periodically reassess the needs of the target populations and communities to understand where they are in discussing the risk, risk behaviors, risk settings and their active response, and to reassess where they are in the behavior change continuum. As an epidemic develops, the types of information and communication needed by the target populations will change, evolving from demand for basic information on AIDS to discussion on issues related to stigma, care and support and overall impact. Monitoring and evaluation studies should lead directly to a change or modification of the overall program and the BCC strategies, messages and approaches.

LESSONS LEARNED

As discussed throughout this chapter, many lessons have been learned in developing BCC in resource-constrained settings. Some of the most important points are summarized below:

- Behavior change communication cannot be developed in isolation from the overall program goals and objectives. BCC is a critical element of a program and also provides support for the overall program, and must be linked to policy initiatives and service provision.
- Besides encouraging individual behavior change, BCC can help create environmental conditions that facilitate personal risk reduction.
- Fear campaigns do not work; in fact, they contribute to an environment of stigma and discrimination.
- All BCC must take the issue of stigma into consideration.
- Monitoring and evaluation should be planned and integrated at the outset of any BCC program.
- The target population should be involved in every phase of developing a BCC program.
- Using a variety of channels to stimulate a community discussion on risk and risk behavior is more effective than relying on only one. Peer education, for example, needs to be supported by mass approaches.
- Systematic audience research or formative assessments should be conducted to reveal specific needs for change in knowledge, attitudes or behaviors in the general population.
- Communication objectives should specify the changes expected in audience members after exposure to the intervention. These may include changes in behavior and in the antecedents of behavior (specific knowledge, attitudes, concepts and images).
- Society-wide change is slow but profound. Do not expect changes to happen overnight.
- Make allies of the media and policy makers, and use opportunities for linking interpersonal communication to local and mass media.
- Court the gatekeepers and key stakeholders as they can derail a program if they are not involved.

CASE STUDIES

LINKING MASS COMMUNICATION WITH COMMUNITY PROGRAMMING IN KENYA

Kenya is a country with high knowledge of HIV/AIDS and low levels of behavior change. To help close this gap, Family Health International/Kenya, under the IMPACT Project, is working in 10 priority Kenyan communities for prevention and care. Organizations participating in the project are using peer education, outreach strategies, and care and support services to reach sex worker populations, workers in workplace settings, youth and low-income communities.

To support those strategies and initiate a dialogue on risk settings and risk behaviors in the communities and in the country as a whole, PATH/Kenya in partnership with IMPACT, has evolved an innovative communication strategy using peer educators who collect questions they receive from the community. These questions and initial assessments of the key target populations have been used to develop an interactive national radio program linked to a magazine format. The program will feature a drama based on the lives of the community members, to be aired in segments. Each segment will leave the audience with a question as to how the characters should proceed in difficult situations related to risk and risk settings.

Peer facilitators will form radio groups to discuss the issues raised by the drama and elicit feedback from the community. Individual suggestions and models for change will be presented to the broader community through the radio magazine. Subsequent segments of the drama will reflect the community feedback. This model aims to stimulate community discussion on risk behaviors and risk settings, highlighting the barriers to adopting safe behaviors and devising community solutions.

The initial scripts were developed through a participatory process with members of the more vulnerable and high-risk segments of the population in the priority communities. While the mass communication effort is targeted to support the community initiatives, its broader aim is to stimulate active community discussion.

USING MASS MEDIA TO STIMULATE COMMUNITY DISCUSSION ON STIGMA AND DISCRIMINATION

Recent well-publicized, dramatic human rights abuses involving PLHA in India, as well as comprehensive audience research, show clearly that Indian society has failed to accept and integrate the reality of HIV/AIDS.¹⁵ This becomes in itself a risk factor for HIV/AIDS, because discrimination and stigma lead not only to abuses, but also to secrecy and denial about serostatus. Ignoring the reality of HIV means that many people will not protect themselves because they do not believe in the real and present risk of infection. Others may deny their risk because the social consequences are so frightening. Targeting PLHA alone will not bring about the needed changes; public opinion itself must be targeted.

The concept was developed for a film addressing the core attitudes towards HIV/AIDS that must change before India can develop a social and policy environment in which effective HIV/AIDS prevention can take place. The film targets not only those infected and most immediately at risk of HIV/AIDS, but also society at large, through India's highly active and enthusiastic general film-going population.

The following objectives were developed after research into popular attitudes toward HIV/AIDS and PLHA. These objectives are guiding the film's development and will provide a basis for assessing its effects:

After seeing this film, audience members will:

1. Feel less blame and fear of PLHA and more acceptance and understanding of them.
2. Realize that someone dear to them could be HIV positive.
3. Realize that lax norms of male sexual behavior are dangerous for men and their wives (and future wives), and believe that family members should not encourage them.
4. Believe it is better to know your HIV status so that you can proactively protect your health.
5. Believe it is important to continue normal relationships with an HIV-positive person.
6. Realize that stigma and rejection are potentially as harmful to a PLHA as the physical consequences of HIV.
7. Expect HIV-positive people to have longer productive lives with a healthy life style, love and support.
8. Respect and support HIV-positive people who are willing to declare their status, and try to create a social environment that will allow them to do so.

A systematic BCC methodology is being used to develop this film. Both the story line and completed script are being reviewed by a panel of experts and pre-tested with a sample of the target audience. Focus groups are planned in several sites, with a representative sample of moviegoers to establish a qualitative baseline. Entrance and exit interviews will measure the film's immediate effect. There are plans for follow-up qualitative research six months after the release of the film with focus groups of viewers and non-viewers to gauge recall and the film's long-term effects.

This engaging story of a likeable heroine who, with her son's support, takes a courageous stand to acknowledge her positive status, should help change the discourse on HIV/AIDS in India by challenging expected notions of stigma and discrimination against PLHA.

RELEVANT CHAPTERS

- Chapter 7 *Youth Intervention Programs*
- Chapter 8 *Reducing HIV Risk in Sex Workers, Their Clients and Partners*
- Chapter 9 *HIV/AIDS Programs in Private Sector Businesses*
- Chapter 10 *Programs for Mobile Populations and Their Partners*
- Chapter 11 *Reaching Men Who Have Sex with Men*
- Chapter 13 *AIDS and Developmental Constraints*

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C H A P T E R

7

*Youth
Intervention
Programs*

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Youth Intervention Programs

INTRODUCTION

HIV prevention efforts targeting young people have traditionally focused on delaying the onset of sexual intercourse, promoting abstinence, decreasing frequency and number of sexual partners, safer sexual practices and condom use and treatment for sexually transmitted diseases (STDs). Despite these efforts, more than half of all new HIV infections in the world occur among young people under age 25.

The key to working successfully with young people is to develop genuine adult-youth partnerships early on in the planning of interventions. This is essential for developing shared objectives, as well as to better understand the specific determinants of positive behavior change, including the enabling factors that can create a supportive environment for change.

YOUNG PEOPLE'S VULNERABILITY TO HIV

In most countries, first sexual intercourse occurs during the adolescent years. But this early sexual initiation does not necessarily correlate with personal knowledge regarding sexual functioning and associated risks. Many young people are still denied access to information, and other contextual and environmental factors play an even more significant role in placing young people at risk of HIV infection.

A key challenge to success in HIV prevention with young people is to ensure their direct involvement in the assessment, planning and implementation of programs that affect them. Since young people live in their own distinct environments and sub-cultures, this requires a flexible and collaborative approach based on genuine youth-adult partnerships.

GUIDING PRINCIPLES FOR YOUTH HIV PREVENTION PROGRAMS

The expanded AIDS pandemic requires focusing equally on care and prevention, including impact mitigation and the development of better coping strategies for young people and communities already affected. Issues of care, support and impact mitigation cannot be totally dissociated from prevention strategies.

APPROACHES TO HIV AND YOUTH

In general, evaluation of adolescent reproductive health programs indicates that the following areas need to be addressed, ideally simultaneously, to increase effectiveness:

- Youth: Increase knowledge, encourage healthy attitudes, develop skills and form or change behaviors.
- Community: Improve the social environment.
- Infrastructure: Increase access to and use of health and social services.

APPROACHES INVOLVING YOUNG PEOPLE LIVING WITH HIV/AIDS (PLHA)

Many youth programs presume that young people's needs are limited to prevention. But there also are increasing numbers of young PLHA. Some were born with HIV and are now reaching puberty. Not all young people know that they are HIV positive, so voluntary counseling and testing (VCT) may be a crucial element of behavior change interventions.

WORKING WITH YOUNG PEOPLE IN DIFFERENT SETTINGS

This section outlines effective programming targeting youth in schools, displaced youth and young injecting drug users—groups that require very different strategies. As a general rule, schooling provides the opportunity to access information and develop skills that may help prevent risk behavior. But reaching the nearly 40 percent of the world's youth who are excluded from basic school life often implies working within the constraints of multiple and immediate survival needs. In approaching drug use issues, it is essential to devise a community-based intervention that engages drug user social networks.

PEER EDUCATION AS A PROGRAM METHODOLOGY

In this section, peer education is cited as one of the most important approaches to youth programs. In AIDS prevention/care programs, peer educators are trained in the information and factual issues surrounding HIV/AIDS and, in some programs, basic family planning and sexual health issues.

Peer education is an opportunity for competent adults to transfer their knowledge and experience to young people in such a way as to give a sense of ownership to the young participants. This process increases decision making skills, self-esteem and—most important of all—motivation to continue as peer educators.

LESSONS LEARNED: PLANNING AND IMPLEMENTING PROGRAMS FOR YOUNG PEOPLE

There are many lessons learned in youth programs as a whole—and not only from peer education approaches. This section summarizes these in a step-by-step introduction to developing HIV prevention programs for young people, providing a framework for using them in a variety of settings. Setting up and implementing a youth prevention program will involve carrying out several parallel sets of activities at the same time.

CASE STUDIES

ASHE-COMBINING ARTS WITH PEER EDUCATION, JAMAICA

The Ashe Performing Arts Ensemble and Academy has become a leader in the Caribbean in behavior change communication (BCC). Since 1994, Ashe has been creating and performing theatrical pieces on issues related to STD/HIV, adolescent reproductive health, drug prevention, environmental protection and violence prevention. Every ensemble player and academy student is trained through a rigorous peer education program.

COMMUNITY COUNSELORS IN SEXUAL HEALTH: ZIMBABWE WORK CAMPS ASSOCIATION

The Zimbabwe Work Camps Association, a youth volunteer service providing manual labor to community building and agro-forestry projects, developed an integrated youth AIDS/STD prevention strategy. A training focus for their work camp leaders was developed to enable them to carry out sexual health counseling as an integral part of their existing community work—and to experience this counseling approach for themselves, as part of their training as behavior change agents.

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I N T R O D U C T I O N

HIV prevention efforts targeting young people have traditionally focused on delaying the onset of sexual intercourse, promoting abstinence or decreasing the frequency and number of sexual partners, promoting safer sexual practices and condom use and providing treatment for sexually transmitted diseases (STDs). Despite these efforts, more than half of all new HIV infections in the world occur among young people under age 25. In countries where HIV prevalence is 15 percent or more, at least 35 percent of boys now age 15 will die of AIDS.

Young people are difficult to categorize as a single group since they live within extremely variable contexts. This is why prevention programs are developed and implemented in a host of settings and for a wide range of youth groups. Contradictions abound in any society's hopes for the next generation. Despite the collective ideal of providing healthy, caring, safe and happy environments for children to grow in, reality uncovers a series of physical, sexual, psychological, social and moral abuses. Despite decades of program and community efforts targeting adolescents, health services continue to neglect the specific needs of youth, schools still debate the inclusion of sexuality education in curricula and programs still resist benefiting from the dynamism, wisdom and courage of young people. Regardless of the importance that children and youth have across cultures, millions of young people live, love, survive and die on the streets. And yet these millions of young people have immediate life and death needs that could easily be responded to.

“Kids think they know everything but have all kinds of misconceptions about HIV, STD and birth control. Actually, they don’t know what to do about sex when it’s time—they’re too confused to think about condoms.”

—Teenager in Rotterdam

The key to working successfully with young people is to develop genuine adult-youth partnerships early on in the planning of interventions. This is essential for developing shared objectives, as well as to better understand the specific determinants* of positive behavior change, including the enabling factors that can create a supportive environment for change. What do youth want? What do they really need? What are they able to achieve and with what support? Once answers to these questions have been found, projects (or programs) can then adopt more effective strategies.

This chapter focuses on how to work with young people, the importance of youth and community participation and of building youth-adult partnerships. It emphasizes the experience and lessons learned from peer education programs—one of the most popular and innovative approaches to HIV prevention among youth.

** These are factors that influence individual behavior, and are identified in different behavioral models and formative research. They are usually psychosocial, and can include: belief that a new behavior is important; intention/motivation; skills/ability, as well as physiological factors such as withdrawal symptoms when attempting decreased drug use. Environmental factors of individual behavior change are sometimes called enabling factors. They can include “any characteristic of the environment that facilitates action and any skill or resource required to attain a specific behavior.” Absence of the characteristic, skill or resource blocks behavior. In this way, absence of male or female condoms, antiretroviral therapy, palliative care, MTCT prophylaxis and so on, can block specific behavioral changes.*

YOUNG PEOPLE'S VULNERABILITY TO HIV

Adolescents (ages 10 to 19) comprise approximately one-quarter of the total population in most resource-constrained countries and one-seventh in industrialized countries.¹ First sexual intercourse commonly occurs during the adolescent years. In most sub-Saharan countries, for example, 40 percent or more of women ages 20 to 24 have had sexual intercourse prior to their first marriage and before age 20.¹ But this early sexual initiation does not necessarily correlate with personal knowledge regarding sexual functioning and associated risks. Well into the second decade of the AIDS epidemic, many young people are still denied access to information on the grounds that it may “stimulate” sexual behavior. In Russia, for example, less than 10 percent of adolescents receive sex education from schools or medical professionals.³ In Bangladesh, more than 90 percent of girls and almost 90 percent of boys ages 15 to 19 did not know how to protect themselves from HIV; the same was true for more than 70 percent of the girls and 80 percent of the boys of the same age group in Mozambique.²

Other contextual and environmental factors play an even more significant role in placing young people at risk of HIV infection. For example, gender distinctions increase risk for both young girls and boys, even if girls are more acutely affected. Violence is another key factor. In Uganda, 49 percent of sexually active primary school girls reported being forced to have sexual intercourse and 22 percent anticipated receiving gifts or money in exchange for sex.¹ Limited economic resources, the selling of sex for survival, widespread migration from rural areas to urban centers and increasing trafficking of girls for prostitution are among other important determinants of vulnerabilities.

Family-level vulnerabilities include less stable living arrangements, lack of parental presence or destructive parental influence, and little parental awareness of young people's sexuality. In Cameroon, a recent household study demonstrated that young people living in single-parent households were 1.6 times as likely as those living in two-parent households to be sexually active, 2.8 times as likely to have concurrent partners, 1.7 times as likely to have had casual sex in the previous year and 1.1 times as likely not to use condoms.⁴

“Young people never talk about HIV and don't think it involves them. They can't imagine it, and don't want to think or hear about it, either. They are afraid of their futures and what will happen to them. Many are indifferent to their lives.”

—Teenage immigrant from Africa in Portugal

“Girls are afraid to talk about HIV, STD and pregnancy prevention. If a girl brings up using a condom with boys she is considered too loose or a bad girl. So everyone just forgets about it.”

—High school student in Berlin

Health policies and legislation often interfere with the delivery of services for at-risk youth, access to commodities and the implementation of harm reduction programs in places where injection drug use (IDU) is an important mode of HIV transmission (see *Chapter 22*). Stigma and discrimination may hamper services for young people with special needs, such as injecting drug users, youth with homosexual orientations or with disabilities and young people living with HIV/AIDS (PLHA).

Young people are confronted with rapid changes in their bodies, social and gender roles, identities and emotions. Intercourse at premature age, genital mutilation and forced sex resulting in injuries to the genital tract, place young girls at a higher biological risk of HIV than boys, while young boys may have difficulty using condoms that are too large for undeveloped penises. Most prevention programs acknowledge these factors, together with the associated sense of invulnerability and risk taking that often characterizes the behaviors of young people. Nevertheless, promoting and maintaining risk reduction behaviors involves dealing with broader and more complex behavioral determinants and enabling factors.

Youth programs need to be adapted to specific cultures, sub-groups, lifestyles and ages.⁵ With so many risk factors and vulnerabilities to consider—at the individual and environmental levels—planners of programs targeting young people face the challenge of identifying multiple behavioral determinants and selecting the most important factors for their programs to address.

YOUTH PARTICIPATION AND WORKING WITH YOUNG PEOPLE

As mentioned in the introduction, a key challenge to success in HIV prevention with young people is to ensure their direct involvement in the assessment, planning and implementation of programs that affect them. Since young people live in their own distinct environments and sub-cultures, this requires a flexible and collaborative approach based on genuine youth-adult partnerships—the forging of which is a skill in itself.

To actively involve young people in programs and decision making, adults may need to reconsider their own views. Adults often consider young people to be too immature, irrational and generally unqualified to participate in the decision making process. The issue becomes highly sensitized and controversial because HIV prevention involves debate surrounding cultural values, gender roles, condoms, drug use, relationships, family and a broad spectrum of sexual behaviors and social norms.

The situation today for young people is very different than the one faced by their parents. Young people are usually more in tune with social change than their parents, and as a result their thoughts, pressures, feelings and attitudes can be difficult for adults to understand. The situation is amplified for those young people who are marginalized or disenfranchised due to poverty, stigmatization, social instability, drug use and the failure of adult mentors or institutions to help them. In many cultures, youth groups and support networks have taken on roles once played by parents and gatekeepers.

In many societies young people have been kept under direct control of adults, in passive roles that do not allow them to influence the policies and decisions that affect them. Many young people feel disenfranchised and need to be guided into a fully participatory role. But the dangers of manipulation or tokenism, where young people merely become ornaments in a political process⁶ need to be avoided. The aim of youth participation is not simply to give young people a vote, but to enable and empower them to take responsibility for their own health.⁷

When seeking to involve youth, it is worth considering:

- Whom do the intended youth participants represent? Do they represent genuine youth-serving organizations, and/or the intended beneficiaries of the program?
- Whether the program design is based on sound needs assessments among the intended youth beneficiaries, regardless of whether youth are formally represented within the program management?
- How can the views and perspectives of the youth beneficiaries be synchronized with those of the donors and other stakeholders?

GUIDING PRINCIPLES FOR YOUTH HIV PREVENTION PROGRAMS

The expanded AIDS pandemic requires focusing equally on care and prevention, including impact mitigation and the development of better coping strategies for young people and communities already affected. Issues of care, support and impact mitigation cannot be totally dissociated from prevention strategies. There are many synergistic links. HIV prevention and care approaches both require dealing with deep human concerns, such as irrational fear of and discrimination against youth living with HIV, or those marginalized due to ethnicity, social class, sexual orientation or background. The following guiding principles reflect the key lessons learned internationally in youth AIDS programs:

- **Humanize the epidemic:** HIV is about people, and when young people are placed at the center of the response it becomes clear that HIV prevention is more than information dissemination. A humanized vision of the epidemic acknowledges the fact that program responses differ according to the characteristics of the young people in need. It also recognizes HIV prevention as an opportunity to help young people understand the complexities of behavior, strengthen their decision making processes and spur their self-development. Humanizing the epidemic also promotes

the importance of support and mutual solidarity, particularly for young people living with or affected by HIV/AIDS. It includes awareness of both individual and collective rights and responsibilities.

- **Build upon what already exists:** It is not necessary to reinvent effective approaches because much has been learned over the decades of implementing programs targeting young people in a variety of settings. Systems have been created, curricula and materials have been developed, and young people, practitioners, researchers and policy makers have been trained and can serve as a resource. Access to this information and the possibilities of sharing experience are improving through electronic means and specific practitioner and research networks.
- **Prioritize the most vulnerable:** Most communications programs and curricular activities are meant to reach as many young people as possible, but not all young people are at the same risk for HIV. Often outside the mainstream, high-risk youth should be taken into consideration during strategic planning.
- **Engage communities and bring in parents and extended families:** Vulnerability to HIV increases when contextual factors—such as poverty and abuse—are exacerbated by weakened social support mechanisms. With the progressive dissolution of the nuclear family brought about by migration, turmoil, socioeconomic stresses or disease, society has charged schools and youth programs with molding healthy and responsible youth. But schools and programs are no substitute for family structures, however good they may be. Programs should take into consideration the concerns of parents, extended family members or other available adult mentors, together with community leaders and professionals, to secure their interest and support in maintaining and strengthening available “social capital” for the support of young people.

- **Establish mutual support systems between schools, services, programs and communities:** Schools and health services often isolate themselves from the community where they are located and from the places young people spend most of their time. Integrating school programs and health services into community-based activities reinforces messages and provides mutually beneficial support mechanisms. For many young people, the HIV epidemic is not felt as real enough to influence behavior change.
- **Design programs with a gender perspective:** Vulnerability to HIV as well as health-seeking behaviors and coping mechanisms are different for boys and girls. Gender-sensitive programming is essential for effective HIV prevention. Programs should take this into consideration and provide conditions to address specific gender-related needs.
- **Define roles and responsibilities for different levels:** A program will benefit from participatory planning processes that take into account the concerns of beneficiaries and the roles and responsibilities of stakeholders.
- **Ensure appropriate supervision and an ongoing learning process:** Capacity building is an ongoing process and not a one-time intervention. Technical support systems using traditional and innovative approaches should be developed to ensure the quality of the interventions. Providing technical support includes facilitating the coordination of activities and maintaining communication between sectors to ensure synergy, i.e., that the whole becomes more than the sum of the parts.

APPROACHES TO HIV AND YOUTH

In general, evaluating adolescent reproductive health programs requires addressing the following areas, ideally simultaneously, to increase effectiveness:

- Youth: increase knowledge, encourage healthy attitudes, develop skills and form or change behaviors.
- Community: improve the social environment.
- Infrastructure: increase access to and use of health and social services.⁸

YOUTH: INCREASING KNOWLEDGE, ATTITUDES, SKILLS AND BEHAVIORS

HIV/AIDS-related topics are closely associated with personal and cultural values. As noted, issues touch upon deep human concerns. This is well illustrated in the irrational fear of, and discrimination towards, people living with HIV/AIDS (PLHA). Topics related to sexual risk-taking touch upon relationships, sexualities, religious faith, taboos, gender roles and the nature of family.¹

There are wide variations in the attitudes and beliefs held in any group of young people, so it is important that program participants gain not only knowledge, but also an appreciation of differences in values, lifestyles and beliefs.² This can be done through discussions and interactive exercises in which young people learn from each other's experience or from experiences outside their immediate cultural environment.

Whether the program uses media campaigns, educational entertainment, peer education or interactive group discussion, information needs to be presented in a way that leads to personal understanding of the topics that arise. Programs should take into account the local myths, including misinformation, and gain an appreciation of the local world views that lie behind them. The participation of young people in this process of self-analysis increases motivation to change behavior. Young people need to have questions answered by informed adults whenever necessary. But the adults should present information from the perspective of young people's own age-related experience. Creative repetition may be necessary to allow for proper understanding and help dispel misinformation.

Care should be taken not to overload youth with information. Addressing the key determinants of risk reduction behaviors is more important than imparting factual knowledge.

Program experience shows that two individual determinants are important to delaying sex, decreasing the frequency of sex and lowering the number of sexual partners among youth, and these are common to many different programs:¹⁰

1. Intention or motivation (to delay sex, have sex less often or have sex with fewer sexual partners).
2. Skills or ability (to delay sex, have sex less often or have sex with fewer sexual partners).

Exactly how to develop intention or motivation depends upon the context and the behavioral change models used. Exactly which skills need to be developed again depends upon the young people at issue and the risk-taking contexts. Motivation can involve simply understanding that HIV is serious and recognizing one's own risk, or it may involve more complex issues such as motivation through spiritual or other personal growth.

Skills can include life planning and decision making, negotiating saying "no" or having safer sex, proficiency in condom use and, among injecting drug users (IDUs), safely using syringes. Young people will eventually need to practice what they have learned and develop communication skills for handling risk situations. This is usually done through interactive exercises, counseling and feedback from other young people, such as through role playing.

Self-development components in programs offer greater personal understanding of sexuality, gender, relationships, sexual orientation, drug use, risk assessment and improved social skills. Young people need to understand how they and others make decisions that can lead to risk taking and unhealthy behavior. This includes the personal decision-making process and development of an increased awareness of how peer pressure, social norms and mass media influence decisions.¹¹

Risk-related decisions are often spontaneous and based upon complex motives. Risk-taking in general can be a natural tendency among young people; they need to gain the self-confidence to translate healthy intentions into real-world practice. One useful method is to act out real-life scenarios where tough decisions have to be made, then using group discussion to reflect on the process.

COMMUNITY: IMPROVING THE SOCIAL ENVIRONMENT

Most behavioral change is affected by factors within the social environment. Young people are especially vulnerable to social and environmental conditions because they are enmeshed in a range of highly influential contexts including the adult world, institutions and their peers.¹² Key enabling factors, as well as barriers to specific behaviors, need to be identified and strengthened or overcome to create a supportive environment. Cultural norms can have both protective and adverse effects on behaviors.¹³

“We have strong traditions in our country. We don’t usually speak about sex. It’s not a topic of education in schools. To this is connected the total disregard of AIDS. Young people say it’s not a problem. Another thing is misunderstanding from the state institutions.”

—Youth peer educator from Slovakia.

Abusive or coercive gender interactions usually increase vulnerabilities and need to be addressed. Collaborative efforts are often more successful since individual program attempts alone do not have the power to generally influence norms. In fact, they may actually put individual program implementers and participants at risk for violent backlash. For this reason, it is important that programs link with newly emerging expanded and comprehensive responses (ECR) at the national level (see the section below, under planning and implementing programs).

Building young people’s social capital is crucial. For instance, family or proxy-family relationships are a

good starting point for change, since parents and significant adults greatly influence young people’s lives and aspirations. Working with those who have significant relationships with targeted youth can provide reassuring guidance and motivation for the youth themselves, enabling a young person to act on the vision and inspiration provided by a role model, rather than on impulse.

Community action is a key element in creating a supportive environment for young people. When the community endorses an HIV prevention program, people of all ages get involved in addressing the underlying factors that influence the spread of the virus. This facilitates alliances between local institutions, policy makers and grassroots associations.¹⁴

Young people, the community and its institutions have a common aim, and young people can contribute greatly to designing and implementing prevention programs. If the young people are old enough, this may result in a new youth organization or the integration of the program into existing youth association activities. Such an approach requires solid support from a community’s adults and a healthy alliance between local agencies, institutions, parents and policy makers, and requires successful coordination of the alliance to keep it together and involved.¹⁵ This is achieved through personal contacts, meetings, seminars, training programs for intermediaries and even recreational activities. These programs often begin at a single agency or health center and then expand to include other youth in the community.

INFRASTRUCTURE: INCREASING ACCESS TO HEALTH AND SOCIAL SERVICES

Health-seeking behavior is a key aspect of prevention and care strategies. Barriers to the use of services can be related to distance, cost, inconvenient hours, fears around confidentiality, poor provider knowledge and behaviors and general policies that interfere with delivering services to young people.

Youth-friendly services require several characteristics:

- Health providers who respect young people and are specially trained to work with them in a way that ensures privacy and confidentiality.
- Health facilities that accommodate the needs and characteristics of the young people they serve and provide comprehensive reproductive health and other locally appropriate services.
- Program design that involves youth, is user-friendly and has a well-established field referral system and integration of prevention and care strategies.

APPROACHES INVOLVING YOUNG PEOPLE LIVING WITH HIV/AIDS (PLHA)

Many youth programs suppose that young people's needs are limited to prevention. But there are increasing numbers of young PLHA. Some were born with HIV and are now reaching puberty. Not all young people know that they are HIV positive, so voluntary counseling and testing (VCT) may be a crucial element of behavior change interventions. (See Chapter 23 for in-depth discussion of VCT.)

But this, too, holds its challenges. Young people are not able to cope alone with the shocking impact of an HIV-positive test result, and may find their situation more hopeless and catastrophic than someone in their mid-adult years. In any event, receiving such news is not only a drama—it is a crisis. Carefully researched support structures need to be in place before VCT services are made widely available to youth. They should make full use of existing social capital networks and train appropriately placed counselors to provide adequate support before, during and after the process of deciding to test. If these supports are not in place, young people can be driven to suicide rather than confront a new reality of living with HIV.¹

Even assuming that a young person gets to the point where he or she can cope with his or her diagnosis, programs need to be in place that address their specific needs.¹⁶ Youth with HIV need to be able to

discuss their sexual desires, rehearse negotiation of safer sexual practices, plan and cope with the frightening experience of sero-status disclosure, have access to family planning services, learn coping mechanisms and receive support to continue living productive and meaningful lives. They also need special care and support services that can tend to their other needs such as nutrition, psychosocial support or legal services to ensure such basic rights as schooling.

Programming for young PLHA should:

- Ensure confidentiality.
- Assist in creating a support network that includes establishing a referral system to health and social services and self-help groups.
- Build skills for disclosure of HIV status and coping strategies to face stigma and discrimination.
- Support participation in prevention activities without the pressure of disclosing HIV status.

WORKING WITH YOUNG PEOPLE IN DIFFERENT SETTINGS

YOUTH IN SCHOOLS

There is a correlation between formal schooling and vulnerability to HIV. Studies suggest that in high-prevalence countries men and women with more education tend to have less risky behavior and that better educated girls tend to delay their sexual debut. But this is not necessarily true for young men who, in some countries, may be more likely to have more sexual partners the more educated they are. As a general rule, though, and depending upon the socioeconomic context, schooling provides the opportunity to access information and develop skills that may help prevent risk behavior.

Schools are responding to HIV in a variety of ways. Some limit themselves to lectures on biological facts. Others use life-skills education, which aims to reinforce existing positive attitudes and reduce risk behavior by further developing social, cognitive and emotional coping skills.¹⁷

HIV may be integrated into a broader sexual and/or reproductive health agenda, and there is evidence to suggest that rather than standing alone, HIV

prevention programs are more effective if they are integrated into the curriculum.¹⁸

But implementing HIV programs in schools requires more than curriculum development and para-curricular youth activities. To be effective they must:

- Build awareness among adults as well as young people, so that communication between teachers, students, parents and community members can be established.
- Provide teachers with ongoing technical support, supervision, networking and institutional support for developing sustainable and effective approaches.
- Establish systems to ensure youth participation in designing and delivering curricular and extracurricular activities.
- Ensure referral systems to STD and other health and social services in addition to information and skills building.
- Introduce, early on, the issues of stigma and discrimination.
- Respond to the needs of students living with HIV/AIDS.

DISPLACED YOUTH

Nearly 40 percent of the world's youth are excluded from basic school life.¹⁹ Approximately half of the world's refugees are under age^{18,20} Reaching youth in marginalized circumstances often implies working within the constraints of multiple and immediate survival needs, rapid transformation of the characteristics of the key population, violence, substance use and abuse and a fundamental distrust of adults.

The erosion of social capital or personal support structures, brought about by whatever means, hampers the very development of self in youth.²¹ In these circumstances, sex may be a mechanism of survival, the only source of affection or another manifestation of a lack of self-esteem, anger, pain or violence. HIV and other reproductive and sexual health problems are seldom seen to be a priority; more immediate survival concerns take precedence. Even if the more painful and obvious symptoms of STDs are recognized, treatment is made difficult by the lack of appropriate services.

Programming for street youth should consider ways to:

- Incorporate HIV while responding to broader needs, thus addressing the risk environment and not only individual risk behaviors.
- Acknowledge limitations and set realistic priorities.
- Manage time, since street life makes it difficult for young people to concentrate on activities for a long period, especially if they are under the influence of alcohol or other drugs.
- Reach out to young people and design services that are accessible and available at convenient times.
- Develop learning methodologies that reflect young people's realities.
- Pay attention to the needs of outreach workers, who are often overwhelmed with the serious needs of numerous individuals.

DRUG USE

Drug and alcohol use is an increasing health, social and economic problem throughout the world, and young people are especially vulnerable to it. Individual background, social networks and peer relations can be powerful mechanisms in adolescent drug use.²² Attitudes towards drug use, drug users and drug paraphernalia are based on cultural norms and history, religion and national legislation. In approaching drug use issues, it is essential to devise a community-based intervention using maximum resources and including a strategy that engages drug user social networks.^{23,24}

Drug prevention and treatment can involve several government agencies and legal structures, including law enforcement, justice, public health authorities, social health services, youth support systems and parents. In many countries, there are harsh legal penalties for drug use, which can drive it underground and, consequentially, limit the possibilities for offering safe practice information, support and treatment. Tackling the problem requires comprehensive packages involving young people, drug users, the community, stakeholders and decision makers. Young people need to become active participants so that programs are reality-based and meaningful to them. Drug prevention among young people needs to be integrated into social, health and educational policies and services.

PEER EDUCATION AS A PROGRAM METHODOLOGY

Education alone is not sufficient to reduce risk behavior. Highly vulnerable young people who are active IDUs require packages offering AIDS education, condom distribution, confidential counseling and HIV testing, access to clean needles and syringes, bleach materials and referrals to various treatments.²⁵

Young IDUs also need to be informed about specific practices they can use to protect themselves and others. Outreach can be used for those groups that are not reached by existing services, and peer education can be a useful approach. Programs and outreach efforts should not neglect to focus on unsafe sexual behaviors that put IDUs and their partners at risk.

IDU and HIV are closely connected, and IDU is the major mode of HIV transmission in many parts of the world. High-risk behaviors are common among drug- and alcohol-using youth, and new harmful drug use patterns and drugs continue to emerge. HIV is also spread through unsafe sexual practices among IDUs and is commonly associated with the sex industry, further complicating the matter. Runaway, street youth and disenfranchised young people can be especially vulnerable to HIV infection through drug use and high-risk sexual practices because they lack access to health, social and drug treatment services. (See Chapter 22 for more information about HIV and IDU.)

There are many young PLHA who also inject drugs. They and their families need care and support, including access to affordable clinical and home-based care, social services, psychosocial support and counseling services.

Slowing the epidemic among young people requires the strategies mentioned elsewhere in this chapter, as well as a strategy that:

- Prevents drug abuse
- Facilitates various forms of treatment and social support
- Establishes programs that involve active drug users and their communities in HIV prevention efforts

This will require increasing the knowledge, understanding, and skills of parents, youth workers, drug workers, opinion leaders and decision makers.²⁶

“Peer education” is used here in its broadest sense to illustrate the various uses of a participatory, youth-to-youth approach to health promotion. In this section, peer education is cited as one of the most important approaches to youth programs, but it is by no means the only methodology. Other programs, particularly those that identify, train and support the participation of significant adults are also extremely important. Indeed, successful programs have often taken a two-pronged approach, where both adult mentors and peer educational approaches work synergistically, such as school programs that reach pupils through both teachers and peer educators.²⁷

OVERVIEW OF PEER EDUCATION

Peer education is distinct from general youth program participation, since the former requires selecting individual youth to be trained as peer educators who are then seen as better informed relative to their peers. They are encouraged (and supervised) to act as information disseminators or behavioral change agents. In AIDS prevention/care programs, peer educators are trained in the information and factual issues surrounding HIV/AIDS and, in some programs, basic family planning and sexual health issues. Some are trained in health promotional methodologies and skills, such as life planning promotion, community facilitation and primary level counseling and referral skills.^{28,29}

For peer education programs aimed at promoting individual behavior change, the place to start is with the peer educators themselves, so these young promoters will be able to facilitate change in others.³⁰ This change may involve attitudes, skills, motivation, beliefs and actual behaviors (individual level), as well as youth norms (at the group level), depending upon the training and program design.

“The training has been like a parcel for us [which we carry] everywhere we go. It is not just for others.”

—19-year-old male sexual health community counselor, Zimbabwe.

If the peer education training fails to engage the trainees and they fail to internalize any change, the results of the program will undoubtedly suffer. Because change takes time, a two-day course will achieve very little, if anything. Training in co-counseling skills for youth, which really can effect behavioral changes in peers (as illustrated in the quote below) can take three to four weeks of experiential learning in a workshop situation, with field experience and feedback as an additional process.

“I had been involved before in a two-day family life education peer educators course. After that training I just forgot about it. But here, in this training [see Zimbabwe case study below] I now go to pubs and sex workers come to talk and drink—and I say I want to stop that now (even if they offer it with condoms). Some of my friends have also changed, and are even now talking about this change with friends of my mother’s.”

—Young male sexual health community counselor, Zimbabwe.

Peer educators are ideally representative of the target youth group or social network they seek to influence, and operate within a previously recognized, sometimes well-defined, “sphere of influence,” before then branching out into other groups or communities if and when appropriate.³¹ The peer education approach advocates the right of young people to gain access to information about sexuality, STDs (including HIV), condoms, contraception and drugs, in contrast to programs that use more traditional educational structures.

Peer education as a methodology is the result of years of practical experience in HIV prevention throughout the world, as well as experience with the health promotion movement and social science research.³² The general approach also reflects the changing role of youth in many societies. In some parts of the world, peer education has become a movement in the sense that supporters advocate change in current information hierarchies, greater political representation, increased youth participation, and recognition of young people’s rights to adequate sexual health information and services.³³

Peer education has its critics who believe that overidealization of the methodology has led to its overly enthusiastic adoption.³⁴ There is a clear need to increase the monitoring, feedback mechanisms, evaluation and operations research of peer education programs.³⁵ This in itself involves transferring monitoring, evaluation and documentation skills to program managers, peer educators and their field supervisors.

LEVELS OF PEER EDUCATION

Peer education as a behavioral change strategy draws upon such well-known behavioral models as:

- **Diffusion of Innovation Theory:** Certain individuals from a given population act as agents of change by disseminating information and influencing group norms in their community.³⁶
- **Social Learning Theory:** Some people serve as models of human behavior and these “significant others” are capable of eliciting change in their peers or other community members, based on their values and interpretation system.³⁷
- **Theory of Reasoned Action:** One of the influential elements of change is an individual’s perception of social norms, or of what people who are important to that individual think or do about a particular behavior.³⁸

Both theory and practice indicate the importance of training peer educators not only in information dissemination, but also in levels of awareness and skills needed to influence others on a behavioral level—such as through providing a role model, sharing skills in negotiating abstinence or safer sex, making referrals to STD or other services and playing a facilitation or counseling role.

Peer education can involve a range of approaches, depending upon the level of “change facilitation” expected of the educators. A program may aim for any combination of the following levels of change facilitation (all of which can apply to one or more of the behavioral models mentioned above):

1. Information dissemination
2. Individual and group behavior change
3. Community awareness and mobilization

Information dissemination

This may be carried out using a pedagogical approach or outreach methodologies. A pedagogical approach involves presenting information in a formal setting, typically a classroom or youth center. A typical project involves peer educators giving presentations in a lecture setting using didactic and interactive techniques, with or without an adult present. The activities or session can include adult facilitation, but the presence of peer educators will ensure the use of an implicit and explicit language more adapted to the young students, and resulting questions may be more direct, as long as the adult presence does not inhibit openness. Usually, however, young students know when and where to approach the peer educators after a formal session has ended. The approach is often used as a complement to other curricular activities, such as school-based sex education or life planning skills.

The outreach approach is best used to reach out-of-school youth or youth in a more informal setting, often where risk behaviors are common, such as in bars or night clubs, at transport stops or other gathering points. Using peer educators can be a steppingstone towards reaching marginalized and otherwise harder-to-reach youth, who require special efforts due to their vulnerability to HIV.³⁹⁻⁴¹ In time, youth reached through peer educators may themselves become educators among their own very specific groups.⁴²

Facilitating individual behavior change

This level relies upon informal peer-to-peer communication and social or sexual networking influences, creating the right conditions for dialogue, contemplation and action. This includes spontaneous discussions between young people as well as planned activities carried out by peer educators—such as games, plays, condom distribution, World AIDS Day events, film and music sessions, setting up information kiosks or simply being active as a group member during local community events.⁴³

This approach focuses more directly on influencing the key determinants of behavioral change, which may or may not be specially researched and identified in a program. In general, these determinants include intention or motivation to change and the skills and abilities needed to change. It involves influencing others’ opinions and beliefs and building skills to negotiate the desired changes. Perceived norms within a group may also change gradually as a result of the role-modeling of the peer educators and their contacts.⁴⁴

The role of peer educators is based on the premise that they possess “critical and unique access to their intended audiences.”⁴⁵ It is important to select peer educators on this basis, seek to better understand their sphere of influence and monitor their progress to maximize project impact.

Using natural opinion leaders with large social networks can qualitatively and quantitatively amplify the effect of peer education. If the target group is large or diverse, peer educators representing various subgroups can be useful. A sense of ownership by the target group and identifiable peer educators will contribute to the project’s strength. This approach can be particularly effective in reaching high-risk marginalized groups, such as street youth, gay, lesbian and bisexual youth, young sex workers and young IDUs.⁴⁶ (See also Chapters 8, 11 and 22.)

Peer-facilitated community mobilization

Due to social structures and the sensitivity of the subject of AIDS, a youth peer education project is only possible in some contexts if it is supported by a broad range of community leaders. Where there is support, young peer educators are typically responsible for developing and implementing activities throughout

the community. In this context, peer educators represent broader sectors of the community—such as family groups or participants in a village meeting—rather than only youth. This work is essential to creating a more supportive environment for the individual behavioral change process mentioned above.

THE CHALLENGES OF PEER EDUCATION

Peer education ultimately aims to empower members of the target group to design and implement their own programs. This involves adult support in coordinating action plans and maintaining support from policy makers, administrators, intermediaries, medical and social science professionals and parents.⁴⁷

Peer education is an opportunity for competent adults to transfer their knowledge and experience to young people in a way that imparts a sense of ownership to the young participants. This process increases decision-making skills, self-esteem and—most important of all—motivation to continue as peer educators. Some programs start up and continue to rely upon small gifts or monetary incentives to keep peer educators motivated.

Caps, T-shirts, transportation costs and refreshments all help, but in the longer term, cultivating a continued sense of personal growth, independence and self-esteem in these young educators makes them the most effective change agents. This can be achieved in a variety of ways, depending upon the social context, including: refresher training and diversification of locally appropriate skills, such as education in family planning, childhood nutrition, STDs, drugs and harm reduction; access to credit and training in small-scale enterprise skills; status-enhancing credentials such as project business cards, certificates or letters of introduction.

Many lessons have been learned in youth programs as a whole, not only from peer education approaches. The following section summarizes these in a step-by-step introduction to developing HIV prevention programs for young people. Since this chapter cannot cover all youth groups and settings, it aims to provide a framework so it can be used in a variety of settings.

LESSONS LEARNED: PLANNING AND IMPLEMENTING PROGRAMS FOR YOUNG PEOPLE

SETTING UP YOUTH HIV PREVENTION PROGRAMS

Setting up and implementing a youth prevention program will involve carrying out several parallel sets of activities at the same time; namely:

- Procuring resources
- Involving young people
- Planning
- Building a project coalition
- Implementation and monitoring
- Support and maintenance
- Designing and carrying out an evaluation

Procuring resources

Like most public enterprises, programs will require funding, which can come through grants, allotments and subsidies, or utilizing current resources. Policy-making agencies, private sponsors, or research foundations can also be potential sources of funding. Financial sources need not be limited to those sponsoring HIV and drug prevention. Since expanding AIDS peer education reflects expanding youth development approaches, there are potential sources of sponsorship in many local, national and international systems. It is not unusual for funding to be earmarked for vulnerable groups such as migrants, certain ethnic groups and displaced youth. Whatever the source of financing, the organization responsible for allocation will have to be convinced of the project's worthiness and will need to see that young people are already investing their time and motivation in the general idea. This is why planning and youth involvement should be underway before applying for grants. The energy and motivation of young people and the caring of adults are, perhaps, the most valuable start-up resource.

Involving young people

The main focus throughout the program will be the young beneficiaries, the group(s) of young people targeted. Young people often have little true awareness about HIV—what it entails and how it affects them personally—unless they come from high-prevalence countries where they are already losing their parents and older siblings. They will need to be approached, informed, have their opinions heard and eventually be given a sense of participation in the program. This relationship will need to be maintained. The hosting agency will have to take responsibility for the continuity of the program and stay attuned to the needs and concerns of the young implementers and beneficiaries. This is essential if any positive change process is to be expected.

Systematic social assessments with youth require participatory approaches that can help them identify their key concerns, needs, priorities and hopes for change.⁴⁸ HIV is seldom initially identified as a priority, especially when other pressing issues—such as unemployment, street violence and crime—are overwhelming. These assessments are vital, since programs must be seen as beginning from the young people's own starting point. When analyzing the results, however, efforts need to be made to clarify the linkages between stated concerns and vulnerability to HIV, making beneficiaries aware of the linkages and how their vulnerability could be reduced.

Planning an intervention

Once there is baseline data on the needs and concerns of the target group and their vision for change, a project plan can begin. A project should ask itself the following basic questions:

- Where are the youth now relative to their sexual health and well-being?
- What would the youth like to achieve regarding their sexual health and well-being? This is the project goal or overall objective.
- What do they have to do to get to their desired situation? These are the project's specific objectives or outcome.

- How can the project help them do this? State clearly what the project's products and services—sometimes called results or intermediary objectives—will be. The youth will use these to help them make changes to arrive at their desired situation.
- What activities must the project carry out to produce these products and services? These are usually listed in the work plan.

The following graphic illustrates the basic planning process for developing a project logic model, and the four key steps involved:**

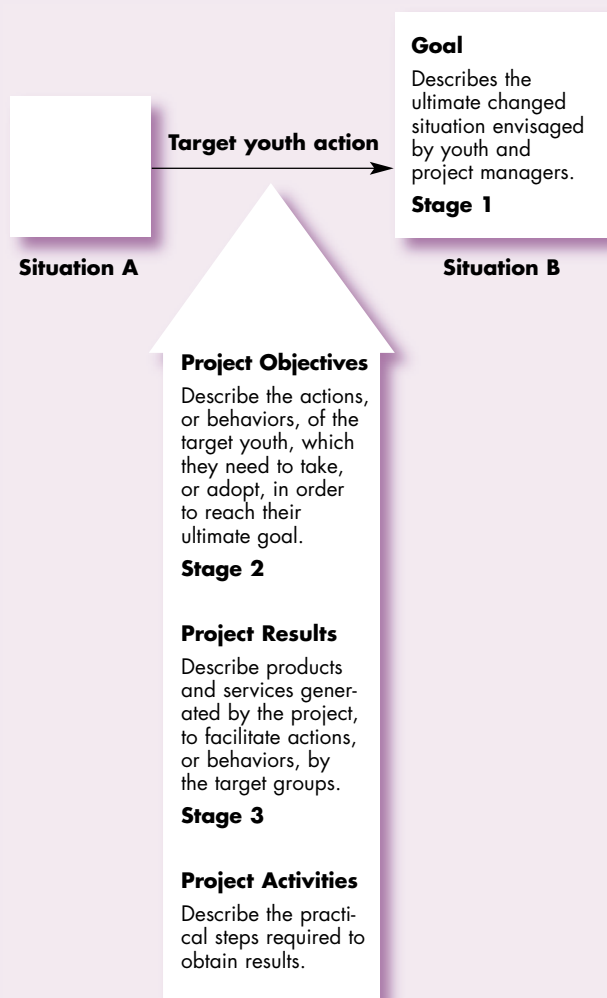
Where possible, wording should illustrate that the project goal and objectives form a specific part of shared, perhaps much broader, goals or objectives stated in the relevant planning framework(s) of expanded and comprehensive responses to HIV/AIDS at the national level (ECR). (See relevant sub-section below.) Operational links to ECR should also be discussed at the initial planning stages.

Different donors, or implementers, use different planning language, but steps one to four, outlined in Figure 1, are common to most intervention plans. These steps appear obvious and logical enough. But a significant proportion of youth projects around the world often start to plan from the activities level, making assumptions that doing X will lead to the youth doing Y at the objectives level.

In the case of AIDS prevention, most youth projects have a behavior change focus. Assumptions are made in these projects that, for example, providing IEC materials and condoms will raise the use of condoms among youth. But this misses a vital part in the planning process: the causal link between levels three and two. The project should ask itself what young people need to be able to do Y, to reduce their vulnerabilities to HIV? What are the current barriers to them doing it? Which are the most important? Can the project address those barriers? That is, what are the key determinants to adopting safer sexual practices for the targeted youth, and can the project help? Although these determinants need to be assessed locally, they

** Adapted from Objectives Oriented Project Planning - A Planning Guide for New and Ongoing Projects and Programmes, 1997, GTZ. Adapted and applied to behavior change interventions for HIV/AIDS prevention and care programming by H. Hughes, in The Behavioral Change Process in Objectives/Results Oriented Program Planning. Unpublished technical support document, Malawi, June 1999.

Figure 1



will invariably be related to increasing the intention/motivation and skills/abilities of the youth to change certain behaviors.¹⁰

A planning approach that is based on what youth really need to make the changes they desire will often lead projects away from a simplistic focus on IEC and condom use. The focus may shift—for example, to helping youth make more realistic personal risk assessments, developing their vision for a personal and col-

lective future, building skills in condom negotiation or other safer sexual behaviors for use with present or future sexual partners, or avoiding risk situations—as appropriate.

In summary, planning should not begin by thinking about specific project products and services or activities. It should start according to the changes that youth can imagine themselves making and which they feel are realistic (given specified intervention support) and with an analysis of what help they need to make this change. This ensures that youth will participate voluntarily, that the final benefits will be recognized and therefore sustained by them and that the project will be evaluated as a success.

The evaluation plan should be made at the planning stages. This means that key indicators of change need to be selected, at least for stages two to four, and a plan drawn up showing the data for each indicator that need to be collected, who is responsible, using which collection methods, and by when. (See the evaluation sub-section below.)

It is rare that a single project or program can address the range of interrelated issues that emerge from doing participatory needs assessments and planning. A project coalition is necessary, both to prioritize an area of focus for the eventual plan, and to help reach the chosen objectives through collaboration with others.

Building a program coalition

Working with young people, especially those who have not reached the age of majority, means involving gatekeepers and intermediaries such as parents, teachers, religious leaders, district and other health workers and youth workers. Constant negotiation is needed to gain support of key stakeholders and validate the perspective of the young people involved. The building of a project coalition depends upon the nature of the initiating agency, the setting, the young people and the model being used. In outreach programs, the coalition may include, for example, pub or café owners, youth and outreach workers and youth leaders.

One of the main difficulties is the process of consensus building when the coalition is composed of individuals and institutions with different perceptions,

roles and responsibilities. But it is the coalition that often energizes a project or program and helps define different roles. A solid coalition is composed of representatives of the young beneficiaries and the adults or institutions responsible for or involved with them.⁴⁹ It includes practitioners, those who provide political, technical and financial support and, most of all, community leaders. Good leadership is essential to energize people and maintain their interest, involvement and cooperation.

Links to expanded and comprehensive responses (ECR)

The AIDS pandemic has now been around long enough for many countries to be planning on a larger, more integrated scale, with more comprehensive services to targeted populations, addressing a broader range of prevention and care needs.⁵⁰ Youth are a high priority target in many of these programs, with national indicators stating significant reductions in prevalence rates among 15- to 24-year-olds in high-prevalence countries, or maintenance of low incidence among 15- to 49-year-olds in low prevalence countries. In terms of youth, these expanded programs aim to rapidly reach the most vulnerable youth, build capacity to provide care and treatment and adapt and use development interventions—such as existing youth exchange programs—as appropriate. This requires considerable liaison, collaboration and multisectoral involvement. For sustainability and political support, youth project coordinators should aim to have their project role clearly articulated within a more comprehensive country-level planning framework, as appropriate to their planning situation.

Priority areas for expanded responses for youth in resource-constrained settings include:

- Provision of IEC, or preferably defined behavior change interventions, including life skills
- STI syndromic care

- HIV VCT services
- Harm reduction services specific to IDUs
- Vocational training, microfinance

Sectors involved in expanded and comprehensive planning for youth include:

- Health
- Youth
- Sports
- Education
- Religious
- Popular culture and its media
- Economic
- Social services
- Community development
- NGOs
- Private sector
- International donors

Planning any youth intervention warrants, more than ever, establishing strategic links with national and district-level strategic responses and adopting some common approaches to monitoring and evaluation, including indicator areas and targets.^{***} These links should be made to ensure that the key determinants to change among youth are addressed collaboratively in a comprehensive fashion. Joint efforts also need to ensure the set-up of resource transfer systems, such as cost-effective and affordable supplies of essential commodities, including STD drugs.

Implementation

Once a coalition has been created and key links to relevant expanded and comprehensive programs at the national/district level have been identified, the project plan can be further developed. This process of ongoing collaboration needs to include additional facilitation of youth participation, empowerment and sense of project ownership.⁵¹

**** For example, to find country-specific estimates of baseline and target levels of coverage for youth interventions in sub-Saharan Africa up to year 2005, see Cost of Scaling HIV Program Activities to a National Level in Sub-Saharan Africa: Methods and Estimates by the AIDS Campaign Team for Africa (ACTAfrica). New York: World Bank, November 2000.*

Involving young people in this way—together with the input from potential coalition members—can lead to the creation of a realistic work plan and external relations strategy to which everyone feels committed. The need for flexibility in both planning and implementation arises from working with dynamic young people who have a wide range of interests, gatekeepers and intermediaries who may have second thoughts and policy makers who may develop new priorities.

Once consensus has been built around the basic project strategy, a work plan can be drawn up specifying who is responsible for various results or activities, by when they are expected, and what indicators would show that progress has been made.

Support and maintenance

Technical support should be provided as needed to those involved in the program. It should be emphasized that there are limitations to what young participants are independently capable of doing, and that this situation is age-dependent. Despite their enthusiasm, they should not be overloaded with adult responsibilities and roles.

Young program staff or volunteers typically need:

- Skills training in information dissemination, presentations, activities and developing and implementing a strategic external relations plan.
- Access to databases and wider information networks.
- Understanding of group dynamics and conflict management.
- Critical feedback for their work, encouragement and emotional support.

Program staff will need to apprise other stakeholders of the needs, issues and interests of the young beneficiaries and participants. Young people may offer critical opinions and resistance. Rather than seeing resistance as a source of negative conflict, it can be seen as an opportunity for improvement. The program may need to negotiate with young people and stakeholders to meet the aims of longer-term change and increased youth participation.

The program coordinator

The program coordinator will not only coordinate the program's action plan but also set its style. The coordinator's key external relations work will include negotiating with policy makers, administrators, intermediaries, medical and social science professionals, parents and the targeted young people. During the planning stage, it is important to give attention to hiring or appointing the appropriate person. This person should have excellent interpersonal skills and be well trained or experienced in key areas. The coordinator needs to enjoy working with young people, understand their spirit and have a sense of responsibility for their care and development—something not everyone feels or can demonstrate.

Designing and carrying out an evaluation

There is a huge body of theory and practice around evaluation. In the field, this can sometimes seem overly complex. At the most fundamental level, an evaluation is an extension of the project model and implementation plan, and is simply a way of assessing the model's success or failure in terms of achieving its objectives or actual implementation (i.e., a process evaluation). For each of the four planning stages mentioned in the planning graphic above, project managers can gather opinions—from the youth themselves as well as other key stakeholders—on indicators that show change and achievements. Many individual projects can only really evaluate from levels four to two, since the goal of level one has so many other influencing factors outside the control of the project, including other projects and programs. But the individual project contribution to a common goal or objective at the national or district level can be made more attributable to project data if the project has good documentation on target group coverage and measurement of its success.

As mentioned in the ECR sub-section above, countries are increasingly adopting a more comprehensive and scaled-up approach to HIV/AIDS programming. This hinges on collection and analysis of the sum total of project efforts, under common goals and objectives, to help identify gaps, trends and future strategies.

Table 1

AN EXAMPLE OF GENERIC INDICATOR LEVELS IN YOUTH HIV PREVENTION AND CARE BEHAVIOR CHANGE INTERVENTIONS

Strategy	Objectively verifiable indicators	Some helpful hints
<p>Goal Stage 1</p> <p>Reduced vulnerability to HIV among targeted youth.</p>	<p>At the national level, this may be indicated by lowering HIV and STD epidemiological trends and risk reduction trends in behavioral surveillance surveys (BSS)</p>	<p>An individual youth project goal will invariably form a more specific part of an overall goal articulated by the country/district AIDS plan. NGO projects should try to build links with national level plans, including M&E plans.</p>
<p>Objectives Stage 2</p> <p>Youth changing their high-risk behaviors to lower risk behaviors (these should be specified, and can include sexual, health-seeking, and/or drug avoidance, or safer drug-using behaviors).</p> <p>Health care providers showing improved client-provider interactions, and/or delivering more comprehensive package of services to youth according to defined needs.</p>	<p>For example: By project month Z, z% of youth reached by intervention, show:</p> <ul style="list-style-type: none"> ▪ delay of onset of sexual relations ▪ reduction in number of sexual partners ▪ increase in use of condoms ▪ increase in self referrals for diagnosis and treatment of STD. <p>For example: By project month Z, z% of health care providers reached by intervention, show:</p> <ul style="list-style-type: none"> ▪ improved youth-provider interactions according to agreed standards ▪ increased provision of a wider range of services, to meet needs as previously defined. 	<p>The project needs a baseline of information gathered from target youth at the start of the project, to show this kind of change. The same survey is then carried out at the end of the project.</p> <p>Individual project results at this level can be shown to contribute to overall changes documented in local BSS.</p>
<p>Results Stage 3</p> <p>Project identifies and addresses key selected determinants of behaviors mentioned above.</p> <p>Project provides improved access to quality STD diagnosis and treatment, and training to health providers to improve youth-provider interaction.</p>	<p>For example: By month Y, y% of youth participating in [#activities listed in stage 4 below] report and/or show through tests/observation increased [knowledge, awareness, motivation and/or skills, related to risk reduction behaviors].</p> <p>By month Y, # service provider sites have STD treatment and diagnosis capacity, and y% of providers receive training and follow up in improved youth-provider interactions according to agreed standards.</p>	<p>Quality of results, such as building motivation and skills through group work, can be specified by making reference to an attached set of activity objectives/indicators and standard levels to be achieved by participants.</p>
<p>Activities Stage 4</p> <p>Project activities ensure that the products and services (in 3 above) are developed.</p>	<p>Refer to project work plan. Indicators show that # activities have been carried out by an agreed deadline, to an agreed standard (where necessary).</p>	

Individual youth projects need to stand up and be counted, but this can only be done with a clear evaluation plan linked to the project model and, where possible, to the planning frameworks of ECR.

Each indicator should be as specific as possible, stating its timeframe, quantity and quality. If the future

funding of a program depends upon an evaluation, it is worth reaching agreement on the methods and language to be used with the donors. If sustained and increasing youth participation is also fundamental, the youth's own suggestions for measuring success should also be incorporated into the project evaluation plan.

had attended a number of AIDS awareness workshops, but the organization felt that, to be effective change agents, the youth leaders needed to “discover who they are, what role they can play in society, and what they think about their own, and their society’s, future.”

ZWA youth work camp leaders (mostly male, ages 20 to 25, with ordinary levels of education) were based in provinces all over the country and involved in coordinating international and local volunteer work teams for selected rural development projects. The majority were otherwise unemployed. H. Hughes, then GTZ’s reproductive health advisor, developed a training focus for the work camp leaders, to carry out sexual health counseling as an integral part of their existing work—and to experience this counseling approach for themselves, as part of their training as behavior change agents.

The curriculum focused on developing primary level co-counseling skills and consisted of three five-day workshops, held over six months. During the time between workshops, participants were involved in ZWA work camps as well as their own district initiatives. Course content included:

- Primary-level counseling skills development (about 75 percent of course focus)
- Improved learning around sexual relationships, including human sexuality and gender interaction
- Basic knowledge of STD/HIV/AIDS and family planning
- Teaching and group leadership skills development
- Facilitation of key stages in participatory community problem solving
- Awareness of local resources and service delivery points, for referrals

Fifteen of the 18 work camp leaders completed the training, including a follow-up evaluation workshop. A key focus in evaluating the training impact was the degree to which trainees internalized the training and underwent personal change. Few sexual health promoters can be successful in effecting change in others without first internalizing a change process for themselves. In general, the course significantly raised awareness with regard to personal responsibility. Ninety percent of the participants stated that they had changed their own sexual behaviors, and nearly all demonstrated that their feelings about their own behaviors had become prominent.

There was consistent evidence from the community evaluation questionnaires and the youth counselors’ log books that most of what the training participants had gained for themselves was being gained for others. The young counselors had, to varying degrees, acquired the skills to provide other young people with an opportunity to explore values, feelings and behaviors; develop coping strategies; and make timely self-referrals, particularly for STD treatment and diagnosis. The development of basic listening and reflection skills also enabled these young peer counselors to branch out more effectively into the facilitation of broader community mobilization.

CASE STUDIES

ASHE: COMBINING ARTS WITH PEER EDUCATION, JAMAICA

In Kingston, Jamaica, where the realities of life can be harsh for young people and it is difficult to secure any job, let alone a fulfilling job, the high rate of STDs in many communities is most certainly a secondary concern. They have many more pressing worries in their lives than STDs, including HIV. Beyond their basic life needs there are also personal needs, such as the belief in a future in which they can follow their dreams and be professionally fulfilled.

When young people work as STD/HIV peer educators in prevention programs they are usually asked to work as volunteers. They are rarely able to meet their survival requirements this way. Their work as peer educators can go some distance toward providing them with a sense of pride and self-fulfillment, but most are not able to cultivate their activities into a full-time career.

The Ashe Performing Arts Ensemble and Academy is a dynamic nongovernmental organization that gives young people the chance to follow their dreams and helps them to meet their basic life needs. The young adults who form the Ashe Ensemble are full-time, paid performers—actors, singers, dancers, musicians, technicians—who perform around Jamaica and throughout the Caribbean, presenting a variety of cultural and pop shows.

In addition to their cultural programs, Ashe has become a leader in the Caribbean in behavior change communication (BCC). Since 1994, Ashe has been creating and performing theatrical pieces on issues related to STD/HIV, adolescent reproductive health, drug prevention, environmental protection and violence prevention. These pieces are performed for students, teachers, health providers, communities and politicians. Every ensemble player and academy student is trained through a rigorous peer education program. Before, during and after performances, they are sent out into audiences and communities to meet in small groups or one-on-one to discuss the topics being addressed. Performers make ideal peer educators since their profession trains them in the communica-

tion and interpersonal skills necessary to make talented health educators. The strongest ensemble members are also trained as trainers, paid to work with teachers, guidance counselors and youth leaders throughout Jamaica in using the performing arts to teach family life education and peer education skills, rather than traditional “chalk and talk” methods.

Because these young people are fulfilled financially and professionally, their lifespan as peer educators continues beyond the normal one- to two-year timeline. It is not uncommon to find Ashe peer educators who have been active—making weekly peer education contacts—for more than six or seven years. Ashe’s approach to peer education has the potential to transfer to other organizations around the world.

Organizations interested in using this model must be committed to a holistic approach to peer education. This means they must recognize the diverse needs of young people and seek ways to fulfill them before they can expect their peer educators to make years-long commitments to their work. Organizations must also provide opportunities for advancement, income generation and education. The young people trained in these programs will then be free to concentrate on STD/HIV and help their peers meet the challenges of the sexual world.

COMMUNITY COUNSELORS IN SEXUAL HEALTH: ZIMBABWE WORK CAMPS ASSOCIATION

In December 1996, the national coordinator of the Zimbabwe Work Camps Association (ZWA), a youth volunteer service providing manual labor to community building and agro-forestry projects, approached an international development cooperation agency (GTZ, Germany) for assistance in developing a youth AIDS prevention strategy. ZWA’s work camp leaders

RELEVANT CHAPTERS

- Chapter 8 *Reducing HIV Risk in Sex Workers, Their Clients and Partners*
- Chapter 11 *Reaching Men Who Have Sex with Men*
- Chapter 22 *HIV Risk Reduction in Injection Drug Users*
- Chapter 23 *Counseling, Testing and Psychosocial Support*

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C H A P T E R

8

*Reducing HIV
Risk in Sex
Workers,
Their Clients
and Partners*

BEA VUYLSTEKE
SMARAJIT JANA



Reducing HIV Risk in Sex Workers, Their Clients and Partners

INTRODUCTION

Because of high infection rates and large numbers of sexual partners, sex workers have been considered a core group for the transmission of HIV and other sexually transmitted diseases (STDs). In addition, men who have both commercial and non-commercial sex partners play a major role in bringing HIV infection into the general population. These “bridge” populations may be as important as core groups in direct prevention programs. The regular partners, or non-commercial partners of sex workers, are another important core group.

There is increasing evidence now that targeted programs to reduce transmission of HIV infection within core groups are feasible, effective and have led to successful risk reduction and decreased levels of infection. This chapter focuses on prevention of HIV in female sex workers, their clients and partners. Male and transgender sex workers, whose numbers are small in most developing countries, are not dealt with separately.

STATE-OF-THE-ART APPROACHES, STRATEGIES AND EXPERIENCE

There is no single, universal model for providing prevention activities to sex workers, their clients and partners. The content of the intervention package itself, and the strategies to deliver that package, have to be adapted to different situations.

THE INTERVENTION PACKAGE

Many projects have found that HIV prevention activities among sex workers, their clients and partners, are most effective when the intervention package contains at least three key elements:

- Information and behavior change messages
- Condoms and other barrier methods
- Sexual health services

S U C C E S S F U L S T R A T E G I E S

Intervention packages will be delivered more efficiently if a combination of strategies is used. Strategies that have been successful in a number of targeted interventions all over the world include:

- Use of informal contacts, key informants and “leaders” to access the population
- Peer health promotion and education
- Outreach activities
- Condom social marketing and distribution
- Accessible sexual health services

C O M M U N I T Y I N V O L V E M E N T A N D N E T W O R K I N G

If intervention programs targeting core groups are to succeed, they must be undertaken in full partnership with the targeted population. The success and sustainability of projects also depends on involving a range of people who influence commercial sex activity, either directly or indirectly. Networking of projects targeting sex workers is also important for sharing information about effective approaches and materials between organizations that provide services to sex workers, their clients and partners.

P O L I C Y I S S U E S

Political approaches to prostitution have an impact on, and are frequently inseparable from, control programs.

S P E C I A L A P P R O A C H E S T O P R E V E N T I O N P R O J E C T S

Three special approaches dealing with specific problems of HIV prevention and care in sex workers are discussed:

- Income-generating projects
- Care and support for HIV-infected sex workers
- Overlapping risks of injecting drug use and commercial sex

L E S S O N S L E A R N E D A N D R E C O M M E N D A T I O N S

A number of lessons learned and recommendations are presented, which support targeted interventions to reduce transmission of HIV in sex workers, their clients and partners.

FUTURE CHALLENGES

Some specific future challenges in preventing HIV infection in sex workers, their clients and partners can be identified. These include issues related to:

- Access to the most difficult-to-reach groups
- Female-controlled methods
- Designing prevention projects for partners of sex workers
- Income-generating projects
- Care and support for sex workers with HIV/AIDS

CASE STUDIES

HIV/STD PREVENTION IN FEMALE SEX WORKERS IN ABIDJAN, CÔTE D'IVOIRE

In Abidjan, Côte d'Ivoire, intervention activities were initiated by the Ministry of Health's *Projet de Prévention et de Prise en charge des femmes libres et leurs Partenaires* (PPP). The activities included mobilizing community leaders, providing health education in group sessions in or near sex work sites, and peer education. These activities have contributed to an increase in condom use and a decline in prevalence of HIV infection and other STDs. This integrated approach may serve as an intervention model for similar populations elsewhere in the region.

HIV/AIDS PREVENTION STRATEGIES AMONG FEMALE SEX WORKERS: CENTRO DE ORIENTACIÓN E INVESTIGACIÓN INTEGRAL (COIN) DOMINICAN REPUBLIC

In response to rising HIV prevalence rates among sex workers, the NGO COIN in 1989 began *Avancemos*, its first full-scale HIV prevention intervention using peer education. COIN is also in the process of forming a micro-credit cooperative to assist sex workers to develop their own businesses and savings as well as developing HIV and violence prevention interventions for the growing number of Dominican female sex workers working outside the country.

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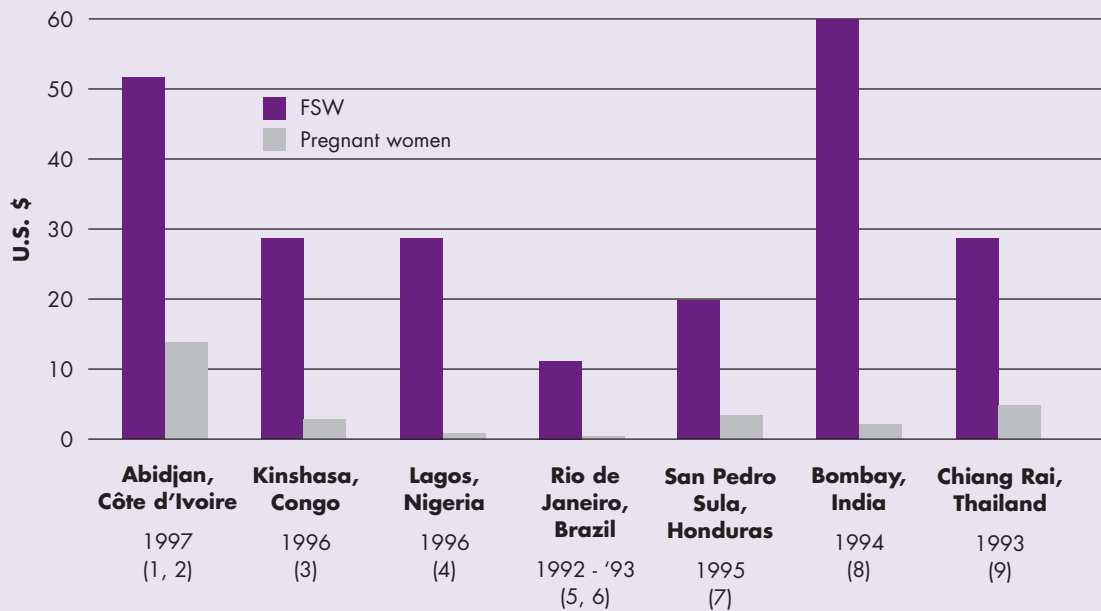
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I N T R O D U C T I O N

Since the beginning of the AIDS epidemic, sex workers in developing countries have been one of the groups most vulnerable to HIV infection due to their large numbers and rapid change of sexual partners. High rates of other sexually transmitted diseases (STDs) and sexual practices such as dry sex or sex during menses further increase the probability of HIV transmission in sex workers. Sex workers also are often in a poor position to negotiate safe sex because of social, economic, cultural and legal factors. Figure 1 compares data on HIV prevalence among female sex workers with data from pregnant women in the same city and in different developing countries. In some cities, such as Lagos, Rio de Janeiro and Bombay, the HIV prevalence of female sex workers was found to be more than 20 times higher than among pregnant women.

Because of high infection rates and large numbers of sexual partners, sex workers have been considered a core group for HIV transmission.¹ In addition, men who have both commercial and non-commercial sex partners play a major role in bringing HIV infection into the general population. These “bridge” populations may be as important as core groups in direct prevention programs.² Military personnel, long-distance truck drivers and migrant workers are easily identified as potential clients for commercial sex and targets for prevention activities. But in many developing countries, male purchase of commercial sex is a social norm, and married men purchase sexual services on a regular basis. In Zimbabwe, 38 percent of male students and 25 percent of working-class men reported having had sex with a commercial sex worker.³

Figure 1
**PREVALENCE OF HIV IN FEMALE SEX WORKERS (FSW)
 AND PREGNANT WOMEN, IN DIFFERENT CITIES IN
 DEVELOPING COUNTRIES**



Another important core group are the regular partners, or non-commercial partners, of sex workers. In a study among “lovers” of female sex workers in Bangladesh, 32 percent of them reported sex with other sex workers, and 28 percent reported another sexual partner, apart from their wife.⁴ Because of the important role of core groups in HIV dynamics, programs to reduce transmission of HIV infection within these groups could have a considerable effect in slowing the spread of the HIV epidemic, at a relatively low cost.⁵ It is sometimes stated that core groups are less important for HIV control in situations where the HIV prevalence is already high and has spread into the general population. But high prevalence does not change the basic epidemiologic principle that the core group accounts for a disproportionate amount of HIV transmission.⁶

There is increasing evidence now that targeted programs to reduce transmission of HIV infection within core groups are feasible and effective. Targeted interventions have led to successful risk reduction and decreased levels of infection. Reported condom use with the last client in Abidjan, Côte d'Ivoire, increased from 63 percent in 1991 to 91 percent in 1997.⁷ The Thai 100 Percent Condom Program has been associated with an increase in condom use among sex workers, from 14 percent to 94 percent.⁸

It should be stressed that there are important underlying principles for successful projects, including non-discrimination and respect for human rights. Prejudice, violence, arrest and harassment and compulsory testing for STD and HIV further stigmatize sex workers and jeopardize the successful implementation of prevention programs. (Issues related to human rights and HIV/AIDS are discussed in more detail in Chapter 27.)

This chapter focuses on prevention of HIV in female sex workers, their clients and partners. Male and transgender sex workers, whose numbers are small in most developing countries, are not dealt with separately.

STATE-OF-THE-ART APPROACHES, STRATEGIES AND EXPERIENCE

There is no single, universal model for providing prevention activities to sex workers, their clients and partners. Not only the content of the intervention package itself, but also the strategies to deliver that package have to be adapted to the different situations. The following sections will examine the components and “tools” of an intervention package; selected strategies and “best practices” for delivering the package; community involvement and networking; and policy issues. Finally, some special approaches to targeted interventions are discussed.

THE INTERVENTION PACKAGE

Many projects have found that HIV prevention activities among sex workers, their clients and partners are most effective when the intervention package contains at least three key elements:

- Information and behavior change messages
- Condoms and other barrier methods
- Sexual health services

Information and behavior change messages

The goal of sex work-related STD/HIV prevention messages is to reduce the health risk, and in particular the risk of STD/HIV infection, associated with sex work. Basic knowledge of HIV transmission and the protective role of condoms is usually high among sex workers in most developing countries with a mature HIV epidemic. Behavior change messages should therefore focus on:

- Alternative safe sex practices
- Use and conservation of male and female condoms
- Lubricants
- Symptoms of STDs
- Health-seeking issues
- Clarification of misunderstandings about unsafe traditional practices or beliefs

Creative tools can be helpful in conveying information and behavior change messages. In Brazil, for example, a survey among female sex workers collected all their questions on HIV and STDs. The questions and their answers were compiled in a booklet and distributed among sex workers.⁹ Other innovative behavior change message tools developed to target sex workers in different countries include videos, comic strips, pictorial flip-charts and WalkMan and cassette tape sets.¹⁰⁻¹³

Improving skills related to condom use and partner negotiation is essential to putting the preventive messages into practice. These skills include strategies to reduce accidental or deliberate condom breakage, and alternative methods for applying condoms (such as using the mouth) that are more acceptable for clients. Different communication and negotiation skills are needed with the non-commercial partners of sex workers. There is often a pattern of condom use by level of intimacy and familiarity. For example, while 100 percent of the sex workers surveyed in the Dominican Republic reported condom use with a new client, only 89 percent actually used a condom with repeat clients and only 29 percent with a long-term partner.¹⁴ In a similar survey in Cambodia, there was 89 percent consistent condom use with a client, 75 percent with a regular client and 42 percent with a “sweetheart.”¹⁵ When female sex workers in Abidjan were asked why they did not use condoms with their partner, 49 percent said that they trusted him, 17 percent wanted a child from him, 17 percent said they loved him and 10 percent said the partner refused to use a condom.⁷

Targeted information and behavior change messages are also needed to decrease ignorance, misinformation and condom resistance among the clients of sex workers. In Abidjan, a survey was conducted among 526 clients of female sex workers.¹⁶ Although the level of general knowledge about HIV was high, 36 percent of the clients believed that HIV could be transmitted by witchcraft and 61 percent believed that it could be transmitted through mosquito bites. One of the most common reasons reported for not using a condom was that they were “not used to it.” If both sex worker and client are fully informed about sexual health they are more likely to have safe sex.

Condoms and other barrier methods

The male condom is currently the only effective, widely available HIV/STD prevention method. Access to condoms is therefore essential to effective preventive behavior among sex workers, their clients and partners. Sex workers with many clients per day may complain of vaginal irritation and pain when using condoms. Water-based lubricants not only prevent these problems, but also decrease condom breakage. To increase their availability, water-based lubricants are being sold at a subsidized price in a sex worker clinic in Abidjan. More than 30,000 units (5 ml) were sold in 1998.¹⁷

Use of the male condom depends primarily upon the cooperation of the male sex partner. Effective methods under the control of women that allow them to protect themselves or reduce risks are urgently needed for female sex workers. In Thailand, a group of sex workers were given the option of using the female condom if clients refused or were not able to use male condoms. Another group was instructed to use male condoms consistently. The proportion of unprotected sexual acts was reduced by 17 percent in the group that had the female condom option. There was also a 24 percent reduction in the incidence rate of STDs in this group.¹⁸ This study shows that offering female sex workers an additional choice may result in better protection.

Other female-controlled methods should be tested for efficacy and acceptability. Some clinical trials with vaginal spermicides resulted in significant reductions in STD rates, but their protective effect against HIV is still being studied.¹⁹ Diaphragms have many potential advantages: they can be re-used, require no waiting time after insertion, fit nearly all women and may require no negotiation. But they leave a portion of the vagina unprotected and their effect on microbes, including HIV, that can be transmitted through sites other than the cervix, needs further study.²⁰

Sexual health services

Now that it is clear that STDs facilitate HIV transmission, prompt STD treatment has become a key strategy for HIV prevention. High STD infection rates have been reported in sex workers and their clients. Good quality STD care not only results in immediate health benefits, but also has the potential to slow down the HIV epidemic.²¹ Table 1 summarizes the effect of some targeted interventions on STD infections. Decreased levels of infection were observed not only in the targeted population itself, but also in the bridge population (miners in South Africa), and even in the general population (military conscripts in Thailand).

Given the prominent role of core groups in the epidemiology of STDs, diagnostic algorithms need to be highly sensitive to enable treatment of as many infections as possible. STD symptoms in male clients and partners can be efficiently managed using simple algorithms based on a syndromic approach. The diagnosis and prompt treatment of STDs in female sex workers are complicated by the large proportion of asymptomatic infections, the absence of a simple, valid and rapid screening test for cervical infections, and the problem of adapting risk assessment diagnostic algorithms to this high-risk population. Algorithms for STD case management in female sex workers have been validated in different settings and successfully implemented.^{22,23} These include guidelines for monthly STD check-ups, presumptive treatment at first visit and adapted risk evaluation. (Chapter 15 provides further details on specific diagnostic strategies.)

There may also be considerable need for other reproductive health services for sex workers, such as family planning services. Only 17 percent of the sex workers in Vietnam used contraceptives²⁴ and 13 percent of the female sex workers in Abidjan used hormonal contraceptives.²⁵ Sixty-two percent of the sex workers interviewed in Abidjan expressed their wish to receive family planning services in a confidential sex worker clinic. The need for family planning services is also evidenced by the high number of abortions among sex workers. The reported abortion rate was 37

Table 1

DECREASED INFECTION RATES FOLLOWING TARGETED INTERVENTIONS FOR SEX WORKERS AND THEIR CLIENTS

Site	Intervention	Outcome	Ref
Female sex workers (FSW)			
Zaire (RDC)	BCC, condom promotion, monthly STD screening/treatment	In FSW: HIV incidence 12/100PY—4/100PY	17
Côte d'Ivoire	BCC, condom promotion, monthly STD screening/treatment	In FSW: HIV incidence 16/100PY—5/100PY	18
Thailand	BCC, condom promotion (100 percent condom campaign)	In military conscripts: HIV incidence 2.5/100PY—0.5/100PY; STD incidence: tenfold decrease.	19
India	BCC, condom promotion	In FSW, Intervention vs. Control: HIV incidence 5/100PY vs. 16/100PY; syphilis incidence 8/100PY vs. 22/100PY; Hepatitis B incidence: 3/100PY vs. 11/100PY	20
Zimbabwe	BCC, monthly STD check-up	In FSW: vaginal infection 40 percent—9 percent; syphilis 35 percent—4 percent In miners: decreased visits to STD clinics.	21
South Africa	BCC, condom promotion, monthly presumptive treatment for bacterial STD	In FSW: Gc/Ct infection 25 percent—10 percent; genital ulcers 10 percent—4 percent In miners: Gc/Ct infection 11 percent—6 percent; genital ulcers 6 percent—1 percent; visits to STD clinic decreased.	22
Bolivia	BCC, condom promotion, improved STD care	In FSW: Prevalence Gc 26 percent—10 percent; syphilis 15 percent—9 percent; genital ulcers 6 percent—1 percent	23
Truck drivers			
Kenya	BCC, condom promotion, STD diagnosis and treatment	In truck drivers: Incidence Gc: 15/100PY—5/100PY; NGU: 10/100PY—2/100PY; genital ulcers 9/100PY—2/100PY	24

percent in Abidjan, 40 percent in Brazil, and 35 percent of the women in the Gambia had terminated a pregnancy in the past five years.²⁵⁻²⁷ It therefore seems logical to integrate family planning services into health services for female sex workers. But it should be stressed that promotion of hormonal contraceptives should always be done in combination with an enhanced condom promotion program to avoid a decrease in condom use when a safe non-barrier contraceptive method is used. (Dual protection is further

discussed in Chapter 17.) In addition to reproductive health services, other services may be provided including general health services, legal assistance, reference to welfare services and training programs. These services will contribute to increasing the acceptability of the prevention messages.

Three components, one package

Combining the three key elements—information and behavior change messages, condoms and other barrier methods and sexual health services—in one package will result in a better, more effective HIV prevention intervention. In South Africa, for example, condom sales remained low among high-risk women in a mining community, even after the introduction of a condom social marketing program within the community. The women said they were tired of receiving condom messages while other health issues were ignored.²⁸ Condom use started to increase when STD services were offered. In Peru an STD control program for female sex workers was inadequate because it did not address the behavioral and condom use components sufficiently.²⁹

SUCCESSFUL STRATEGIES

There is no single “best practice” approach to delivering the HIV prevention package to sex workers, their clients and partners. Intervention packages will be delivered in a more efficient way if a combination of strategies is used. Strategies that have been successful in a number of targeted interventions all over the world include:

- Use of informal contacts, key informants and “leaders” to access the population
- Peer health promotion and education
- Outreach activities
- Condom social marketing and distribution
- Accessible sexual health services
- Use of informal contacts and key informants to access the population

Sex workers, their partners and clients are generally a very mobile and hard-to-reach population. Some commercial sex environments are very closed and contact with them is extremely difficult, such as when legal or cultural conditions force sex workers to operate in secret. The multiple forms of sex work

(clandestine, registered, occasional, under the guise of small business, for paying school fees, etc.) add to the complexity of the phenomenon. Because of these difficulties, the task of accessing sex workers may be difficult but by no means impossible. Initial entry into the sex worker community should be made through informal contacts and the use of key informants.³⁰ It is usually possible at this stage to establish the existence of communication networks, informal groupings and leadership patterns. For example, Family Health International’s AIDS Control and Prevention (AID-SCAP) Project in Senegal used registered female sex workers to approach clandestine sex workers.³¹ In Vietnam and China, female sex workers were approached through “education centers,” where they are sent for several months if they are arrested.²⁴

The same strategy can be used to reach clients and partners of sex workers if they belong to an easily identified high-risk group. Contacts in truck companies may facilitate access to long distance truck drivers, for example, and were used in truck driver projects in Tanzania and Kenya.^{32,33} In Brazil, the Santos Port Authority was approached to reach the workers of the large port of São Paulo.³⁴ Miners in South Africa were reached through the health authorities of the mining companies.³⁵ But most often, clients of sex workers do not form a visible, coherent social grouping. To reach them, strategies for reaching the general sexually active male population should be used, including mass media, social marketing, billboards and general health services. Innovative approaches can be effective, such as in Lagos, Nigeria, where mobile health educators approached urban commuting workers stuck in traffic jams.³⁶

Peer health promotion and education

The use of peer educators has been recognized as an effective strategy for reaching targeted populations with behavior change and condom promotion messages. Peer education involves the sharing of information about attitudes and behavior among same-community members. In the context of sex work, peer health educators are persons who have worked or are still active as sex workers and are thus able to communicate more easily with their peers. Clients and partners, including truck drivers and military personnel, may be more receptive to prevention messages given by their own peers. But peer educators require considerable training and supervision to gain credibility and full acceptability by their peers. In Zimbabwe, informal leaders among the sex workers were recruited and trained as peer educators. They attended three-hour meetings held each week throughout the year, through which they were trained in STD and HIV information, educational and counseling techniques, condom promotion and community mobilization.³⁰ In Kenya, each peer educator was responsible for a group of approximately 20 peers within her catchment area, and they became resource persons, STD and AIDS educators, promoters and distributors of condoms.³⁰ The experience of sex workers as peer educators can enhance their credibility, especially where sex workers are suspicious about contact with officials. But there may be some difficulties with using peer educators, especially in situations in which there are significant tensions and rivalries in the sex industry. In Honduras, for example, peer educators promoting condom use were often met with suspicion by sex workers who feared they were trying to steal clients, because many clients were willing to pay more for unprotected sex.³⁷

Outreach activities

Outreach is the term used when activities or services are taken to sex workers or their clients. For behavior change messages, outreach is often through face-to-face interviews or group education sessions in the workplace or home, informal meeting places or local community venues. A team of fieldworkers in a project in Madagascar goes twice a week, at night, to sex worker worksites.³⁸ The team's outreach activities include discussing HIV prevention, distributing condoms, and providing free tickets for check-ups at the local STD clinic. The same project designed a specially equipped mini-bus with audio-visual material. The bus travels around the capital, leaving informational leaflets and distributing condoms at bus-stops.³⁸ The AIDSCAP project in the Dominican Republic used provocative theater techniques, carried out in brothels, bars, areas surrounding active businesses and busy commercial sex zones.³⁹ Another theater group is being used for the same purpose in Kinshasa, Democratic Republic of Congo (RD Congo).⁴⁰

Services outreach may be effected through mobile clinics. STD services and condom promotion and distribution to high-risk women were provided at a mobile clinic located near meeting places for miners and sex workers in a mining community in South Africa.⁴¹ In Cotonou, Benin, a study demonstrated the feasibility of the outreach methodology for contacting male clients and non-paying sexual partners of female sex workers directly onsite at prostitution venues for HIV prevention activities.⁴² Male clients in the company of a female sex worker were approached individually by an outreach worker who, with the aid of the sex worker, explained the purpose of the study to the client and asked him if he would like to participate. No payment was offered to the clients, though they were offered a free leucocyte esterase dipstick (LED) test and a physical examination for STDs, as well as free STD treatment when appropriate. Each participant also received individual preventive counseling and free condoms.⁴²

Condom social marketing versus free condoms

Condoms should be promoted continually and made accessible and affordable. In theory, condoms should be given free to highly vulnerable populations. The distribution of free condoms can also help outreach workers gain access to sex businesses or provide an incentive to sex workers to attend an STD clinic or an educational session. But in most developing countries, health promotion projects do not have a steady supply of free condoms. Social marketing, or selling condoms and lubricants at subsidized prices, is usually more sustainable than supplying free condoms. Social marketing programs for condoms are one of the most successful HIV interventions in developing countries. Non-traditional outlets located near sex worker work-sites increase the availability of condoms. Social marketing of condoms and distribution of condoms to the targeted population through multiple approaches—free, targeted distribution, community-based distribution programs, health facilities and other commercial outlets such as pharmacies and village stores—should complement each other to achieve a maximum availability of condoms. In Abidjan, for example, a survey among sex workers revealed various condom outlets, including the sex worker clinic, pharmacies, small stores, ambulant vendors, market places, hotels and brothels.²⁵

Access to sexual health services

Sex workers often have no access to good quality services. Among female sex workers who reported a history of STDs in Vietnam, 46 percent used self-treatment, 27 percent did not receive treatment and only 27 percent had access to health services.²⁴ Even when they are available, there are a number of reasons for poor utilization of services, such as stigma, inconvenient hours of operation and economic, language or other cultural barriers. Different projects have tried to increase the accessibility of services by promoting sex-worker-only clinics. In Abidjan, the *Projet RETRO-CI* set up a confidential clinic for female sex workers called the *Clinique de Confiance*. For reasons

of confidentiality, the clinic is located in a discreet place in a popular area in town, and does not advertise itself as a clinic. It offers free STD treatment, HIV counseling and testing, and condom promotion to sex workers and their regular partners.⁴³ In Bombay, India, a sex-worker-only clinic was established in each red-light area to provide basic health care services and referrals.⁴⁴ Other projects have tried to improve the quality and access of existing health facilities. In Rio de Janeiro, Brazil, sex workers received a card with a list of public health care facilities that provide good quality STD care. Clinics made this list if they had available STD drugs and their physicians had received training in STD care.⁴⁵

The question of whether it is better to set up special services for high-risk populations or to integrate STD services into primary health care remains unanswered. A Tanzanian study evaluated different approaches to STD services for women working at truck stops.⁴⁶ Service utilization was lowest in one site with insufficient drug supplies. The sites where services were offered outside health facilities or at times other than normal clinic hours had higher rates of utilization than those where STD services were integrated into established health services.⁴⁶ In the République du Congo (Kinshasa), attendance of sex workers at a specialized clinic dropped dramatically when the clinic was opened to the general population.⁴⁷ These data indicate that specialized services for sex workers could provide them with additional safe and confidential options for sexual health services. Specialized services may also offer better opportunities for targeted educational sessions and regular screening activities. A regular visit by the sex worker will enhance the relationship of trust with health care workers and provide a forum for prevention messages.

COMMUNITY INVOLVEMENT AND NETWORKING

If intervention programs targeting core groups are to succeed, they must be undertaken in full partnership with the targeted population. In Calcutta, India, for instance, peer educators were represented in several forums, such as the steering committee, participatory council, field committee and NGO AIDS coalition. The aim was to facilitate community ownership and eventually hand it over to the community.¹² Community involvement is especially important to understand and address the needs of sex workers. These needs may have little to do with HIV/STD prevention, but taking them into account helps to enhance the credibility and acceptance of the intervention.

The success and sustainability of projects also depend on involving a range of people who influence commercial sex activity, either directly or indirectly. In Bali, Indonesia, a behavior intervention project included education of female sex workers, education programs for pimps and a media campaign targeting clients of low-price sex workers.⁴⁸ In Bombay, madams and brothel managers were also included in a number of interventions including condom promotion and health education activities.⁴⁴

Networking of projects targeting sex workers is important for sharing information about effective approaches and materials among organizations that provide services to sex workers, their clients and partners. Networking is also important for advocacy at the international and regional levels. The Network of Sex Work Projects (NSWP), for instance, is an international network consisting of sex workers and organizations that provide services to sex workers. The NSWP aims to provide practical information and opportunities for information sharing among organizations that provide services to sex workers; raise awareness of the health and welfare needs of sex workers; advocate at the international level for policies and actions which further the human rights of sex workers; develop and maintain links between sex workers, service providers and relevant international agencies; and facilitate opportunities for the voices of sex workers to be heard in international forums in which ideas about commercial sex are exchanged.

POLICY ISSUES

Political approaches to prostitution have an impact on, and are frequently inseparable from, control programs.⁴⁹ Some countries have laws that prohibit and criminalize sex work. The effects of such laws include sex workers operating in secret, frequent arrest and abuse by the police, contact with other criminal activities and difficulty accessing organizations that provide services to sex workers. Other countries continue to make compulsory registration and health checks a working requirement. But the most vulnerable sex workers tend to work illegally without access to health care.⁴⁹ In Dakar, Senegal, unregistered sex workers were more likely to be infected with gonorrhea, trichomonas and syphilis than were registered sex workers.⁵⁰ In Vietnam and China, prostitution is considered illegal and a “social evil.” Female sex workers are sent to “education centers” for several months if they are arrested in their workplaces.²⁴ Repression exacerbates the problem since sex workers are further marginalized from health services and prevention interventions in the attempt to evade legal restrictions on their work.

SPECIAL APPROACHES TO PREVENTION PROJECTS

Three special approaches dealing with specific problems of HIV prevention and care in sex workers are discussed here:

- Income-generating projects
- Care and support for HIV-infected sex workers
- Overlapping risks of injection drug use and commercial sex

INCOME-GENERATING PROJECTS

All over the world, poverty and lack of alternative options are associated with prostitution. Because of economic considerations, some sex workers still have sex with men who refuse to use a condom. In many situations, clients offer to pay more for sex without a condom. In South Africa, the price of sex without a condom was four times the price of one with a condom.⁵¹ In a study in Abidjan, female sex workers were asked at what point they gave up arguing with a client who did not want to use a condom. Of these, 71 percent said they never gave up, but 20 percent said they stopped arguing when they “needed the money.”⁷

To help women stop working in the commercial sex industry, some projects give sex workers vocational training, help them obtain hawker/vendor licenses, provide small enterprise management advice, help them establish cooperative ventures or offer them loans to start small businesses. Many of these projects, however, lack clear goals and realistic expectations of what sex workers might achieve. Compared to commercial sex, few other jobs offer the same advantages for women, including ease of entry, a ready market and higher earnings than any other job these women could find.³⁰ A study in Thailand found that HIV and STD infection rates decreased after the women left sex work but were still substantial, indicating the women’s continued risk of infection even after leaving the industry.⁵²

But sex workers who do not rely on sex work as their only source of income are in a better position to negotiate safe sex. Projects may attempt to provide sex workers with income from other part-time work as a bulwark against inadequate or unreliable income. This could give sex workers some independence from clients and might help women, especially those who earn insufficient income from clients, to reject those who refuse to use condoms.³ Further research is needed to assess the effectiveness of such projects.

CARE AND SUPPORT FOR SEX WORKERS WITH HIV/AIDS

In most countries, a large number of sex workers have already been infected at an early stage of the epidemic. Health structures where first line STD case management is offered to sex workers usually have limited facilities to treat opportunistic infections. Sex workers should be referred to specialized clinics that offer good, affordable services in a non-stigmatizing environment. But in most settings these services are scarce. The access to antiretroviral therapy (ART) for sex workers in developing countries, where only a wealthy few can afford such treatment, is even more complicated. But the lack of antiretroviral (ARV) therapy should not be an excuse for not offering care and support to sex workers infected with HIV.

Health services for female sex workers should include cotrimoxazole prophylaxis of opportunistic infections in the minimum package of care as soon as the first symptoms of infection appear. Sex workers have needs that should be addressed regarding HIV testing and counseling, information and education if they are HIV positive; advice on care and support; access to people living with HIV/AIDS groups; and planning for their future.

In the Dominican Republic, a peer educator who was found to be HIV positive formed her own AIDS support group.⁵³ In the Biryogo health center in Kigali, Rwanda, a Service Social SIDA (AIDS social service) was started in 1989 because of increasing numbers of AIDS patients, many of them sex workers. The services provided include pre- and post-test counseling, home visits, monthly meetings for HIV-positive

people, weekly information sessions and a tontines pour les prostituées (savings bank for sex workers).⁵⁴ (Voluntary counseling and testing (VCT) and management of HIV disease and its complications are discussed further in Chapters 23 and 25 respectively.)

OVERLAPPING RISKS OF INJECTION DRUG USE AND COMMERCIAL SEX

Drug use, especially intravenous drug use, has been documented in female CSWs in several countries. Most of the research has been focused on female sex workers so the extent of this problem among male sex workers is unknown. For example, 3.5 percent of a sample of sex workers in the city of São Paulo,⁵⁵ 90 percent of sex workers in St. Petersburg, Russia⁵⁶ and 84 percent of street sex workers in Melbourne, Australia, had a history of injection drugs.⁵⁷ These overlapping risk behaviors—commercial sex work and injection drug use—increase the risk of HIV infection and amplify the potential spread of the virus in communities.

Interventions with CSWs who are also injection drug users (IDUs) require the simultaneous implementation of prevention strategies from two separate disciplines: harm reduction for IDUs (see Chapter 22) and sexual transmission reduction, using condoms, behavior change and STD care (See Chapters 6, 12, and 15). Unfortunately, most harm reduction programs fail to adequately address their clients' risk of HIV infection through sexual transmission and do not explicitly address commercial sex issues. Similarly, most sex worker interventions do not address their risk of HIV through injection drug use. Interventions are further complicated by the fact that while many women IDUs may engage in commercial sex for income they do not necessarily identify themselves as CSWs, and therefore would not be easily accessed by CSW intervention projects. In settings where intravenous drug use is common, harm reduction projects should explicitly look for and address the additional vulnerabilities in IDUs who engage in commercial sex.

LESSONS LEARNED AND RECOMMENDATIONS

- Targeted interventions to reduce transmission of HIV in sex workers, their clients and partners are a feasible and efficient use of resources in all stages of the HIV epidemic.
- A combination in one package of information and behavior change messages, condoms and other barrier methods and sexual health services will result in more effective HIV prevention.
- New approaches are needed to increase condom use with repeat clients and regular partners.
- Offering female sex workers additional choices of preventive methods will result in better protection.
- Condom social marketing and free distribution of condoms should complement one another.
- Specialized services for sex workers could provide them with additional safe and confidential options for sexual health services and behavior change education.
- Income-generating projects often have unrealistic goals.

FUTURE CHALLENGES

Making prevention interventions among sex workers, their clients and partners work successfully is in itself a major challenge in HIV prevention. But some specific challenges for the future can be identified:

- **Access to the most difficult-to-reach groups.** Adolescents, young girls living with their parents, unregistered sex workers and part-time sex workers are some of the most difficult groups to reach. Many of them have a hidden life as a sex worker, which complicates their access to prevention activities. Efforts should be made to reach these women since they are highly vulnerable to HIV/STD infection.

- **Female-initiated methods.** Effective methods under the control of women that allow them to protect themselves or reduce risks are urgently needed for female sex workers. Existing, effective methods—such as male and female condoms—should be made available and promoted among female sex workers. New methods, such as vaginal microbicides, should be tested for efficiency, feasibility and acceptability.
- **Designing prevention projects for partners of sex workers.** Many projects report low levels of condom use between sex workers and their non-paying partners. Because these relationships are of unknown stability and fidelity, they may also constitute a considerable HIV risk. The challenge is twofold: to reach the partners of sex workers and design an adapted prevention intervention for them.
- **Income-generating projects.** Operations research is needed to assess the effectiveness of income-generating projects. At present very little is known about the extent to which other part-time work might affect the sexual behavior of sex workers.
- **Care and support for sex workers with HIV/AIDS.** In the future, more and more projects will be confronted with the growing problem of sex workers with HIV/AIDS. Experience from small-scale pilot projects should be disseminated and guidelines developed for the care and support of sex workers with HIV/AIDS.

CASE STUDIES

HIV/STD PREVENTION IN FEMALE SEX WORKERS IN ABIDJAN, CÔTE D’IVOIRE

In Abidjan, female sex workers and their clients appear to have played a central role in the HIV epidemic. In 1990 the HIV prevalence rate among female sex workers was very high (69 percent), and sexual contact with female sex workers was common among men in Abidjan. In response to this dramatic situation, geographical mapping of the sites where FSW lived and where they recruited clients was undertaken in 1991. Also in 1991, a baseline community-based interview survey (CBIS) was conducted on the socio-demographic characteristics of sex workers, their knowledge of HIV/STD transmission, condom access and use and their access to STD treatment services.

Based on this situation analysis, intervention activities were initiated by the Ministry of Health’s *Projet de Prévention et de Prise en charge des femmes libres et leurs Partenaires* (PPP). The activities included mobilizing community leaders, providing health education in group sessions in or near sex work worksites and peer education. PPP’s activities were extended from three districts in 1991 to all 10 districts in 1994. The group health education sessions were conducted in bars, hotels and other sex work worksites by PPP staff, including health educators and social workers using slides, video films and drawings as audiovisual support. Peer education was conducted by sex workers and former sex workers trained in communication techniques and in STD/HIV prevention. The peer educators used a picture album as an STD/HIV/AIDS education tool and a wooden penis model to demonstrate condom use.

Clinique de Confiance, a clinic open only to FSW and their stable sex partners, started its activities in 1992. Operated by *Projet RETRO-CI* (a collaborative HIV/AIDS research project of the Centers for Disease Control and Prevention, Ivorian Ministry of Health

and the Institute of Tropical Medicine, Antwerp, Belgium), the *Clinique de Confiance* offers free group health education, diagnosis and treatment for STDs, HIV counseling and testing and condoms. During PPP's peer education activities and group health education sessions, information was routinely given about the STD/HIV services that *Clinique de Confiance* offers to FSW. Follow-up CBIS were conducted in 1993, 1995 and 1997.

There were major shifts in both the CBIS and at *Clinique de Confiance* in the country of origin of FSW. There have been fewer Ghanaian women and more Ivoirian and Nigerian women in recent years, and FSW have also tended to be involved in sex work for shorter periods of time and to charge more for sexual intercourse.

In the CBIS, reported condom use with the last client increased from 63 percent in 1991, to 91 percent in 1997. The proportion of women who had visited *Clinique de Confiance* increased from nine percent in 1993 to 37 percent in 1997, and these women were more likely to report having used a condom with their last client, compared with women who had not attended the clinic (e.g., 87 percent versus 72 percent in 1995). FSW who attended *Clinique de Confiance* for the first time reported increased, consistent condom use with all clients during the last working day between 1992 and 1998, from 20 percent to 78 percent. There were corresponding, significant declines in the prevalence of HIV infection from 89 to 32 percent, and of gonorrhea from 33 percent to 11 percent.

In Abidjan, community-based and clinic-based prevention activities targeting FSW were strengthened through collaboration. These activities have contributed to an increase in condom use and a decline in HIV and other STD prevalence rates. This integrated approach may serve as an intervention model in similar populations elsewhere in the region.

This case study was written by Peter D. Ghys (Projet RETRO-CI, Abidjan, Côte d'Ivoire and Institute of Tropical Medicine, Antwerp, Belgium) and Michel Ayokoin (program manager of the PPP project, Abidjan, Côte d'Ivoire).

HIV/AIDS PREVENTION STRATEGIES AMONG FEMALE SEX WORKERS: CENTRO DE ORIENTACIÓN E INVESTIGACIÓN INTEGRAL (COIN) DOMINICAN REPUBLIC

The number of female sex workers in the Dominican Republic has been conservatively estimated at 60,000 women. It is also estimated that another 30,000 Dominican women work in commercial sex settings outside the country. Of the women working in the commercial sex industry in the Dominican Republic, an estimated 80 percent work out of sex establishments such as bars, discos and brothels, and an estimated 20 percent work from the street. Female sex work occurs throughout the country and is particularly prevalent in larger cities and tourist areas.

Commercial sex and sex tourism are important elements that have historically contributed to the growth of HIV prevalence in the Dominican Republic. HIV median point prevalence from Ministry of Health sentinel surveillance sites among female sex workers rose from 3.3 percent in 1991 to 7 percent in 1995. While the average HIV prevalence rate among female sex workers in Santo Domingo has remained relatively stable at approximately six percent to seven percent over the last few years (1996 to 1998), prevalence rates in other areas of the country have continued to increase as high as 10 percent in specific sites.

In response, the NGO *Centro de Orientación e Investigación Integral* (COIN) was founded in 1987. In 1989 it began its first full-scale HIV prevention intervention in the commercial sex industry of Santo Domingo, the capital of the Dominican Republic. The intervention was called *Avancemos* and continues to this day in Santo Domingo and several other regions

of the country where there are significant numbers of sex workers. The basis of the intervention is a strategy of “education among equals,” or peer education. Sex workers educate each other about HIV/STD prevention techniques such as condom use and negotiation skills, as well as other related issues such as self-esteem, gender and sexuality, human and occupational rights and reproductive health.

The *Avancemos* intervention uses two types of peer educators or health messengers: leaders and volunteers. The health messenger leaders are sex workers or former sex workers who receive advanced training on how to educate and mobilize current workers, their clients and sex establishment owners and managers regarding HIV/AIDS/STD prevention and care. They use a variety of different approaches such as group workshops, individual counseling and street theater. The health messenger volunteers are current sex workers who reinforce on a daily basis the leaders’ educational messages with their peers in the sex establishment environment. Professionally trained educational staff from COIN provide training and supervision to the health messenger leaders.

Through the *Avancemos* project, several innovative educational materials—such as comic strips, posters, brochures and music spots for sex establishment disc jockeys—have been designed by and for sex workers, their clients and sex establishment owners and managers. In addition to educational techniques and materials, COIN also facilitates and implements condom social marketing and mobile clinical STD services. The peer educator/health messengers serve as the critical links to these other project services by selling condoms within the sex establishments and motivating and referring sex workers to their monthly STD check-ups in either COIN’s mobile clinic or local government STD clinics.

As a result of COIN’s programming, several other NGOs have been formed that now provide both HIV prevention programming and care for people living with HIV/AIDS. One such organization is *Movimiento de Mujeres Unidos* (MODEMU), a national union of female sex workers led by many of

the health messenger leaders and volunteers empowered and inspired by the *Avancemos* project.

MODEMU’s mission is to protect and promote sex workers’ legal, health and economic rights and development. The organization is also in the process of forming a micro-credit cooperative to assist sex workers in developing their own businesses and savings, as well as developing HIV and violence prevention interventions for the growing number of Dominican female sex workers working outside of the country.

Using this integrated approach, COIN’s efforts have had an important influence on the adoption of HIV-related protective sexual behavior among female sex workers in the Dominican Republic. For example, knowledge, attitude and practice (KAP) surveys, conducted between 1990 and 1996 in COIN’s area of intervention in Santo Domingo, showed that consistent condom use between bar-based sex workers and their new clients rose from 67 percent (1990) to 73 percent (1992) to 93 percent (1996). Less dramatic increases in condom use were seen between bar-based sex workers and their regular clients: 32 percent (1990) to 49 percent (1992) to 50 percent (1996). In a 1999 survey of female sex workers from both bars and brothels in Santo Domingo, 92 percent reported always using condoms with their new clients and 58 percent with their “friends of trust” (*amigos de confianza*) or regular clients in the last three months. Seventeen percent reported using a condom the last time they had sex with their husbands. More than half of sex workers in the survey sample reported having some sort of regular partner such as a friend of trust or a husband.

Seeking to fill these gaps in condom use, COIN became interested in successful condom promotion strategies used by other countries in commercial sex settings. In 1996 AIDSCAP supported COIN in conducting formative qualitative research to test the feasibility of adapting the Thai 100 percent condom program to the Dominican context. The Thai program mandates condom use in all commercial sex acts, access to condoms in sex establishments and regular STD screenings for sex workers via government policy and regulation. The burden of compliance with these policies and regulations lies with the establishment owners and managers who can be sanctioned by the government for their noncompliance.

The formative research revealed support on the part of study participants—including sex establishment owners and managers, sex workers, their clients and regular partners—for the creation and implementation of policies and rules to promote and monitor condom use within the sex industry. But one of the most important barriers to condom use found in the study was again related to issues of trust and intimacy among sex workers and their regular clients and other steady partners. Based on the results of this formative research, a 100 percent condom use intervention trial, sponsored by the Population Council/U.S. Agency for International Development (USAID), is currently underway and will test an adapted version of the Thai condom program. This adapted model will address both the environmental and structural determinants of condom use in the Dominican context, as well as the relational and cultural dynamics of trust and intimacy among sex workers and their regular partners. The ongoing intervention research will be implemented by COIN in Santo Domingo and CEPROSH, an NGO in Puerto Plata, together with the National Program for the Control of Sexually Transmitted Disease and AIDS (PROCETS) and the Dominican Ministry of Public Health (SESPAS). The current intervention model seeks to combine the empowerment-based learning and solidarity of COIN's Avancemos project with critical policy and regulatory mechanisms documented by the Thai 100 percent condom program, but adapted for the Dominican context.

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RELEVANT CHAPTERS

- Chapter 12 *Social Marketing for HIV/AIDS Prevention*
- Chapter 15 *Issues in STD Control for Special Groups*
- Chapter 17 *Reducing HIV Infection in Women and Providing Family Planning Services to Women at Risk*
- Chapter 22 *Risk Reduction in Injection Drug Users*
- Chapter 23 *Counseling, Testing and Psychosocial Support*
- Chapter 25 *Management of HIV Disease and Its Complications in Resource-Constrained Settings*
- Chapter 27 *HIV/AIDS, Health and Human Rights*

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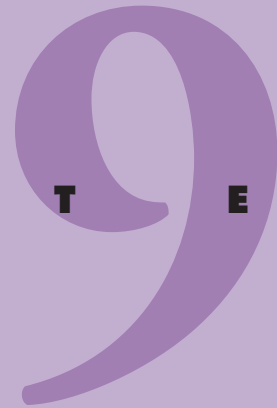
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C H A P T E R



*HIV/AIDS
Programs in
Private Sector
Businesses*

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HIV/AIDS Programs in Private Sector Businesses

INTRODUCTION

It is clear that if national efforts to prevent the spread of HIV/AIDS are to be effective and sustainable, they must be multisectoral in nature and include the involvement of private sector businesses. To date, the business response has been mixed, and most businesses in developing countries have not yet developed or sustained comprehensive workplace programs, nor have they made substantive contributions to national prevention initiatives.

This chapter will focus on key steps needed to more fully engage the business sector in HIV/AIDS prevention and care programs. The steps are straightforward: awareness of the problem and its implications for businesses; appreciation of prevention interventions; involvement and support of management and workers in defining appropriate policies for the workplace; and implementation and monitoring of both policies and programs.

THE BUSINESS MOTIVATION FOR HIV/AIDS PREVENTION

A 1997 UNAIDS survey on corporate responses to HIV/AIDS, conducted at 203 companies, found that the major motives for corporate action were: (1) The welfare of infected employees; (2) Prevention, to safeguard investments in staff and training; and (3) Avoidance of legal problems. Since then, additional studies have provided a more comprehensive picture of private sector concerns regarding HIV/AIDS in the workplace. For example, companies want to know how HIV/AIDS affects their productivity and profits, and what are the costs involved in typical prevention and care programs.

REQUISITES FOR ENGAGING BUSINESSES IN HIV/AIDS

Experiences from several countries point to the key factors that contribute to effective workplace programs and policies. These factors are discussed below.

GETTING AND SUSTAINING MANAGEMENT COMMITMENT

The establishment of a successful and sustainable HIV/AIDS workplace program is contingent upon genuine support from the upper-management team. To gain management commitment, two aspects of the epidemic need to be identified and, where possible, quantified: the costs of HIV/AIDS and the costs of HIV/AIDS prevention.

EFFICACY OF WORKPLACE PROGRAMS AND POLICIES

Workplace prevention programs and policies that are sustained, flexible and sensitive have been shown to work. Examples of effective programs (counseling, condom distribution) and policies (clear guidelines on illness, accommodation, testing, benefits) are needed to demonstrate to companies that such approaches are feasible and will offer returns.

OPPORTUNITIES FOR PROGRAM MANAGERS

It is possible to work directly with business managers and employee representatives to develop and sustain workplace programs and policies. Several steps will strengthen the process. These are outlined below.

ASSURING THAT RELEVANT POLICIES COMPLEMENT PREVENTION PROGRAMS

The integration of prevention and care policies, along with a workplace program on HIV/AIDS as part of a company's standard employee benefits package, is a key strategy to achieve sustainability of the program. It can also lead to unexpected spin-offs.

STRENGTHENING MANAGEMENT AND STAFF CAPACITY TO ADDRESS HIV/AIDS

Companies seeking to reduce the impact of the epidemic on their employees have tried to improve the ability of staff at all levels to reduce HIV/AIDS risk, and make prevention and care a more integral part of their operations.

IDENTIFYING CONCERNED BUSINESS LEADERS

As a select number of companies develop workplace programs and policies, their management staff can start to influence peers at other companies. Example, endorsement and guidance are likely to be as important as outside factors in drawing more companies into the prevention network.

OFFERING CLEAR, PRACTICAL ADVICE

Many companies continue to seek guidance on how to develop prevention programs and policies that will serve their employees while also assuring the profitable continuation of business. There are several resources that can aid companies in developing policies and programs and monitoring their effectiveness.

PROMOTING BUSINESS PARTNERSHIPS

HIV/AIDS program managers have numerous opportunities to promote partnerships with and among businesses. Depending upon the needs and resources available, partnerships can take numerous forms, including:

- Collaboration
- Networking
- Community alliances
- Consultation

FUTURE CHALLENGES

Working with businesses to stem the HIV/AIDS epidemic is one part of a larger multisectoral response. Many business managers are aware that the epidemic threatens the flow of commerce and profits. For these reasons there are mutual needs and interests in building an HIV/AIDS prevention partnership with business.

CASE STUDY

FORD MOTOR COMPANY, SOUTH AFRICA

Ford Motor Company of Southern Africa developed a comprehensive HIV prevention program to focus on communication, education, testing and community involvement. The program was extended to employees, contract workers, pensioners and their families, and has reached more than 12,000 people since 1999. This activity is providing an important link to workplace and community-based prevention programs.

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It is clear that if national efforts to prevent the spread of HIV/AIDS are to be effective and sustainable, they must be multisectoral in nature and include the involvement of private sector businesses. As managers of workplaces in resource-constrained environments, the business community has a critical role to play and can use company resources, creativity, organizational structures, access to communities and investment decisions to aid national AIDS prevention initiatives.

I N T R O D U C T I O N

To date, the business response to the epidemic has been mixed. A number of large corporations have adopted policies to guide management and workers who face difficult decisions relating to HIV/AIDS in the workplace. Some companies have implemented—often with outside help—prevention interventions for employees and occasionally the surrounding community. But most businesses in developing countries have not yet developed or sustained comprehensive workplace programs, nor have they made substantive contributions to national prevention initiatives.

This chapter will focus on key steps needed to more fully engage the business sector in HIV/AIDS prevention and care programs. The steps are straightforward: awareness of the problem and its implications for businesses; appreciation of prevention interventions; involvement and support of management and workers in defining appropriate policies for the workplace; and implementation and monitoring of both policies and programs.

THE BUSINESS MOTIVATION FOR HIV/AIDS PREVENTION

A 1997 UNAIDS survey on corporate responses to HIV/AIDS, conducted at 203 companies, found that the major motives for corporate action were: (1) The welfare of infected employees; (2) Prevention, to safeguard investments in staff and training; and (3) Avoidance of legal problems.¹ Additional studies since then have provided a more comprehensive picture of private sector concerns regarding HIV/AIDS in the workplace. For example, companies want to know how HIV/AIDS affects their productivity and profits, and what are the costs involved in typical prevention and care programs.² Some business leaders are cautious about accepting government-published epidemiological data because they have not witnessed a major epidemic within their establishment; others are skeptical of the efficacy of prevention programs.³ In addition, some companies worry about losing competitive advantage in the marketplace if they invest their own resources in HIV/AIDS prevention and care policies and programs—rather than investments in what is deemed more productive activities, such as new equipment or staff training—without similar investment by competing companies, such as has occurred in South Africa. This is why HIV/AIDS program managers seeking new or expanded partnerships with private sector businesses will need to provide sound economic/financial data on the impact of the epidemic on a foundation of good epidemiological data, credible examples of effective prevention interventions and their costs and flexible plans and technical expertise to design appropriate programs and policies.

MAJOR FACTORS IN ECONOMIC COST OF HIV/AIDS TO A BUSINESS

- Disruption of production due to:
 - Sick leave
 - Absenteeism
 - Funeral attendance
- Health insurance and/or medical care
- Recruitment and training
- Death benefits

REQUISITES FOR ENGAGING BUSINESSES IN HIV/AIDS

Experiences from several countries point to the key factors that contribute to effective workplace programs and policies. These factors are discussed below.

GETTING AND SUSTAINING MANAGEMENT COMMITMENT

The establishment of a successful and sustainable HIV/AIDS workplace program is contingent upon genuine support from the upper-management team. The challenge lies in being able to advocate for HIV/AIDS as a management issue in the workplace and in the communities in which workers live. To be successful, HIV/AIDS prevention efforts should involve not only workers at the shop-floor level, but executives as well. In this regard, non-profit organizations working with businesses must also include managers in their target groups. Management commitment must be seen as including but extending beyond corporate philanthropy and compassionate responses such as donations and fundraisers. Sustaining HIV/AIDS programs must be viewed as a means to achieve overall effective human resource management, assured through business ownership of the problem.^{4,5}

As noted earlier, business managers are concerned about the financial cost of HIV/AIDS to their operations, and the cost of investing in HIV/AIDS prevention and care. This is why gaining management commitment requires identifying and, where possible, quantifying these two aspects of the epidemic.

The costs of HIV/AIDS

As the virus tends to infect sexually active employees in their prime working ages (20 to 45 years old), it can reduce work performance and productivity. Experienced personnel with special skills, years of training and institutional memory are difficult and costly to replace. Increased absenteeism and labor turnover likewise add to the costs of running a company. And the impact felt is not simply from the loss of the most skilled workers. A flower estate in Kenya reported high HIV/AIDS-related absenteeism among its unskilled workers and subsequent losses in

productivity.⁶ A trucking firm in Zimbabwe reported higher costs associated with less experienced drivers who had more accidents.⁷

In the absence of clear policies understood by both management and employees, there can be confusion, lowered morale and work disruptions. In fact, a mere rumor that an employee(s) may be infected with HIV can lead to workplace conflict and reduced productivity. For example, employees in a large canning factory in Thailand went on a two-hour strike because they refused to work with a colleague they thought was HIV positive.

SHELL COMPANY, THAILAND

In 1992, as the AIDS epidemic worsened in Thailand, the Shell Company of Thailand established a comprehensive, non-discriminatory HIV/AIDS policy that is still in place. The policy provides counseling, syringes and needles where health facilities are sub-standard, medical confidentiality and education to all new expatriate and permanent staff.

With support from the United Nations Children's Fund (UNICEF), Shell in 1997 launched the Peer Education at the Pump Project (PEPP). The project provided education for fuel attendants at Shell petrol stations, the majority of whom are youth considered at high risk for HIV infection. The project contributes to AIDS awareness among youth and will reach a much wider audience through their peers in the workplace as well as through other friends and relatives outside of the pump. At least 800 youths were trained in peer counseling through the project.

Responsibilities to their customers, employees and society are mandated by a body of general principles governing how each Shell company conducts its affairs. These principles guide the company as it responds to the epidemic. Shell recognizes the opportunity to use the experience gained in one country or region to help others elsewhere.

The costs of HIV/AIDS prevention

Nearly two decades of prevention efforts make it possible to gauge the costs to companies of implementing HIV/AIDS policies and programs. To help demonstrate costs and potential savings, either general or sector-specific costs can be presented to companies. In Kenya, for example, research conducted by FHI found that in several businesses absenteeism due to HIV-related illnesses and medical and death benefits were the major costs to be expected. Total losses due to HIV/AIDS among employees were estimated to reach as high as 20 percent of profits by 2005 for some businesses. In contrast, comprehensive prevention programs—education, STD treatment and condom distribution—for these companies were likely to cost two percent or less of business profits by 2005. Some of the benefits, such as improvements in worker morale, cannot be quantified but are no less important to companies.⁸

EFFICACY OF WORKPLACE PROGRAMS AND POLICIES

Workplace prevention programs and policies that are sustained, flexible and sensitive have been shown to work. Likewise, prevention interventions in communities outside company gates where employees live and maintain their social lives have generated numerous examples of what works. Businesses are often reluctant to initiate workplace programs because of inadequate knowledge or the belief that it is not their role as an employer to do so. But it is not enough just to tell business managers that prevention can work. Examples of effective programs (counseling, condom distribution) and policies (clear guidelines on illness, accommodation, testing, benefits) are needed to demonstrate to companies that such approaches are feasible and will offer returns.

OPPORTUNITIES FOR PROGRAM MANAGERS

Once these requisites exist, it is possible to work directly with business managers and employee representatives to develop and sustain workplace programs and policies. Several steps will strengthen the process. These are outlined below.

ASSURING THAT RELEVANT POLICIES COMPLEMENT PREVENTION PROGRAMS

Businesses implementing workplace programs often do so without developing workplace policies. A workplace HIV/AIDS policy outlines exactly how the company will handle HIV in the workplace, what the company program entails, how it is administered and to what benefits an HIV-infected employee is entitled. The integration of prevention and care policies, along with a workplace program on HIV/AIDS, as part of a company's standard employee benefits package, is a key strategy to achieve sustainability of the program. It can also lead to unexpected spin-offs.

For example, since 1994 the Regent Hotel in Bangkok has integrated new employee orientations—approximately three, held every two months—to include at least one 30-minute session on the topic of AIDS. Employees also participate in seminars on HIV/AIDS education and prevention, living with HIV-positive people and trained HIV/AIDS leadership. This initiative led in 1996 to staff participation in a project to reduce the vulnerability of young northern Thai women to the sex industry. Under the project, five young women receive vocational training—including English language, hotel and life skills training—for five months per year. The hotel covers the costs of food, uniforms and per diems. The Regent was the first hotel to initiate such a project containing an AIDS training component. Effective peer influence by the general manager led an adjacent hotel, the Grand Hyatt, to *better* the Regent by offering an AIDS training project and hiring all the young women who finished it.

STRENGTHENING MANAGEMENT AND STAFF CAPACITY TO ADDRESS HIV/AIDS

During the first decade of the epidemic, many businesses considered an occasional AIDS awareness talk to be sufficient for employees. More recently, companies that seek to reduce the impact of the epidemic on their employees have tried to improve the ability of staff at all levels to reduce HIV/AIDS risk and make prevention and care a more integral part of company operations. Broadly speaking, these management strategies include mainstreaming HIV/AIDS prevention into the workplace, minimizing the costs of mainstreaming and monitoring the impact on staff attitudes and behavior. Mainstreaming is not simply offering an occasional HIV/AIDS prevention lecture for employees; rather, it entails changes in policies and sensitivity to situations that increase risk for employees. A hotel personnel officer in Bangkok reported: “As I become an effective manager of HIV/AIDS, I become a better personnel manager. Prevention is an ongoing process.” The officer added, “Our ‘Employee of the Month’ could celebrate his honor by treating his friends to a night out on the town,” noting that the night on the town might typically include commercial sex. So alternatives for celebrating were offered.

A number of companies in southern Africa have assigned a full- or part-time person to coordinate HIV/AIDS workplace programs. Other companies, such as Barclays Bank in Botswana have set up a Health and HIV/AIDS advisory committee, composed of management and staff representatives, to deal with issues that arise. Still other companies have included HIV/AIDS policies and programs in their training for human resource and other managers, to more effectively reduce the impact of the epidemic on company resources.⁹

OLD MUTUAL, SOUTH AFRICA

Old Mutual is an international financial services group. In the early 1980s, Old Mutual became involved in a variety of AIDS education initiatives, both internally as well as in the community. The company provides an advice service called OMUCARE, whereby people who are HIV positive can obtain much-needed financial advice, including access to life cover.

As part of the company's commitment to the broader community in which it operates, Old Mutual maintains a multifaceted HIV/AIDS program with six full-time staff. The program is aimed at school-going teenagers of all racial and cultural groups throughout the country. It motivates peer group leaders not only to be active AIDS ambassadors in their schools and communities, but also to assist HIV/AIDS service organizations.

EFFECTIVE HIV/AIDS PROGRAMS AND POLICIES WILL:

- Be integrated into organizational structure
- Minimize work disruptions and financial burdens to both the company and employees
- Reduce fear and discrimination
- Contribute to higher staff morale and a positive corporate image

IDENTIFYING CONCERNED BUSINESS LEADERS

As a select number of companies develop workplace programs and policies, their management staff can start to influence peers at other companies. Example, endorsement and guidance are likely to be as important as outside factors in drawing more companies into the prevention network.

OFFERING CLEAR, PRACTICAL ADVICE

Many companies continue to seek guidance on how to develop prevention programs and policies that will serve their employees while also assuring the profitable continuation of business. Although most businesses have employee welfare policies, they have little or no experience with HIV/AIDS in the workplace, and some may find themselves overwhelmed by the dynamics of HIV. Fortunately, there are several resources that can aid companies in developing policies and programs and monitoring their effectiveness. For example, the *Private Sector AIDS Policy* developed by FHI is an extensive how-to guide that can be used by companies or groups advising companies. Its step-by-step approach is adaptable to the needs of large- and medium-sized companies.¹⁰ The *AIDS Briefs* are another resource. They provide an overview of the impact of HIV/AIDS on various business sectors and list appropriate questions for working with those sectors to strengthen prevention and care responses.¹¹

In one joint-venture company in Vietnam, Haiha-Kotobuki Confectionary, the benefits of HIV/AIDS prevention programs are clear. The program increased staff knowledge of HIV and maintenance of good health, which led to a higher quality of life. Staff involvement in the program at all levels increased their own work group management and motivational skills. These activities as a whole led directly to improved human resource management of the company. As a result of the program, managers and supervisors are better able to interact and comprehend staff perceptions and behavior in relation to HIV/AIDS and other workplace issues, and have become more adept at managing and reducing higher risk behaviors.

HAIHA-KOTOBUKI JOINT VENTURE CO., LTD., VIETNAM

The Haiha-Kotobuki joint venture became involved with the Vietnam Chamber of Commerce and Industry (VCCI), CARE International and the National AIDS Committee (NAC) in a project to promote business partnerships to assist the government of Vietnam's efforts to prevent and control HIV and AIDS. The project attempts to do this by:

- Increasing knowledge and awareness of the risk of HIV/AIDS and skills for protection within the business community;
- Piloting a model of HIV/AIDS education within the workplace; and
- Developing policy with recommendations to encourage domestic and foreign companies to contribute to HIV/AIDS programs in their workplace.

Top management support was needed for such an initiative. VCCI identified a high-ranking and highly committed Vietnamese member of the

Haiha-Kotobuki joint venture. A large number of company staff also were willing to be involved and trained in emerging social issues that impinge upon their business. Corporate leadership meant corporate responsibility in matters related to their staff, their families and the wider community.

One major activity undertaken by Haiha-Kotobuki was the development of an HIV/AIDS workplace policy. The policy assists managers and workers in taking the initiative to protect themselves, their families and the community against HIV/AIDS, as well as providing care and support for PLHA in the company. Haiha-Kotobuki identified six categories of importance: implementation of prevention programs; testing; confidentiality; preventing discrimination; flexible work conditions for HIV-positive staff; and responsibility for HIV-positive staff. Staff who may be infected with HIV are treated equally and have access to all company benefits, including holiday allowance, social and health insurance, emergency support and free lunch in the company cafeteria.

There are other value-added benefits of a company's commitment to staff and their families. One major benefit, according to the deputy director, is corporate public relations: "Instilling public trust in a company's quality products and the procedures involved in providing the product to the public is vital to our success."¹² For Haiha-Kotobuki this means not only higher company profits but, more importantly, influencing other companies to undertake similar programs that benefit staff and their families.

PROMOTING BUSINESS PARTNERSHIPS

HIV/AIDS program managers have numerous opportunities to promote partnerships with and among businesses. Depending upon the needs and available resources, partnerships can take numerous forms, including collaboration as implementing partners, networking, alliances with communities and consultation. Both persuasion and directives can be used to influence business behavior.

COLLABORATION

The partnership American International Assurance (Thailand), established with CARE International through its AIDS prevention project in the Samut Prakarn Province in Thailand, was designed to protect the company's financial interests while seeking to reduce the incidence of HIV infection.¹ The company worked with CARE to create an AIDS information network and prevention programs targeting industrial factory workers in the province. In the long run, HIV prevention will directly benefit the insurance industry's business and underline its long-term commitment to Thai society.

American International Assurance's long-term involvement with AIDS initiatives since 1992 led to senior management's decision to go beyond community donations and corporate philanthropy. The company set out to integrate HIV/AIDS initiatives into its business operations, thereby assuring sustainability and demonstrating long-term corporate responsibility. With this goal, the company developed the idea of promoting prevention and non-discriminatory workplace programs among its policyholders. This will be undertaken by developing an evaluation and accreditation scheme which rewards companies that undertake effective HIV/AIDS workplace programs with a rate reduction in their group life insurance policy. Existing government and NGO networks will provide technical capacity to achieve this, thereby strengthening partnerships between the three sectors.

Collaboration can lead to cost-sharing between businesses and implementing agencies. In Tanzania, a union-led intervention negotiated with managers to share the cost of workplace prevention interventions. Once the program was underway, several companies were reluctant to contribute their agreed-upon share, but the formal pre-agreement provided a lever to eventually obtain the companies' contributions.¹³ Other cost-sharing arrangements usually have been in the form of in-kind contributions by companies, primarily covering salaries of peer educators during their training or allowing employees to attend prevention education sessions during business hours. But prevention programs initiated by external groups have encouraged

larger companies to step up and absorb the cost of onsite STD treatment. In Kenya and Zimbabwe, several managers reported that they would continue to support condom distribution within the workplace, even if external funding ended. From the business perspective, cost-sharing also exists in the form of the government taxes.³

NETWORKING

Established in 1993 as a link between the private and public sectors, the Thailand Business Coalition on AIDS (TBCA) works with businesses to create AIDS-supportive work environments by providing HIV/AIDS education and prevention seminars and promoting the adoption of appropriate HIV/AIDS workplace policies. TBCA remains one of the first fully staffed, full-time organizations addressing business and AIDS. It has also assisted in developing the Malaysian Business Coalition on AIDS, the South African Business Council on AIDS, the Zambian Business Coalition on AIDS, the Botswana Business Coalition on AIDS and the FICCI-UNAIDS Business Coalition Program on AIDS.

The Foreign Investors Chamber of Commerce and Industry (FICCI) of Bangladesh has sought to prevent the kind of impact that AIDS is having in neighboring India and Nepal. With limited government budgets and a large population base of semi-skilled and unskilled workers, HIV prevention now has clear economic benefits for low-prevalence Bangladesh. FICCI is working in partnership with UNAIDS to launch an extensive HIV/AIDS prevention campaign involving seminars for human resource managers, safe blood drives and raising general awareness. Through several high-level advocacy meetings and the *Declaration on Responding to HIV/AIDS*, the FICCI has reached out to the business community to implement intervention programs.

FICCI, BANGLADESH

In response to HIV/AIDS in Bangladesh, the business community has formed a coalition to confront the potential epidemic in the community and the workplace. Various activities have already taken place through the joint efforts of the Foreign Investor's Chamber of Commerce and Industry (FICCI) and donor agencies. Preventive measures including information, education and communication (IEC) and counseling are among them. Three stages were developed to implement HIV/AIDS workplace programs. The first phase consisted of raising the awareness and advocacy of the employers, managers and employees. The second phase involved developing appropriate IEC materials. During this phase a trainer's manual was formulated, tested and finalized, then used to train manager supervisors and trade union leaders at the enterprise level. In the third phase, factories were visited to open discussion among the workers, whose suggested solutions were recorded. During these discussions, proper management of HIV was prioritized, including safe blood, STD treatment and condom use. The initiative was launched with the support of the top management.

In 1998, FICCI and UNAIDS conducted a seminar on the business response to HIV/AIDS. This was the first large-scale effort to raise AIDS as an area of critical concern for business. The seminar was followed by a human resource manager training workshop, facilitated by the Thailand Business Coalition on AIDS with assistance from local resource associates.

COMMUNITY ALLIANCES

Working with community and activist groups offers two major benefits: insight into the effectiveness of workplace responses to the epidemic and a concerned constituency for advocacy. Since the early stages of the epidemic in Brazil, close collaboration between HIV/AIDS activists and state and federal government officials has been instrumental in defining the direction of prevention and care programs and generating resources, including some corporate resources. More recently, that alliance has been especially important in assuring effective distribution, at reasonable cost, of generic AIDS drugs produced by the private sector.¹⁴

CONSULTATION

Ongoing dialogue with the business community offers project managers opportunities to engage in a variety of emerging issues related to HIV/AIDS and business. Among these issues are the cost and availability of HIV/AIDS drugs, including palliative drugs; the availability of adequate labor to serve business needs; and aligning business projects with national and local HIV/AIDS prevention. Brazilian program managers and businesses have been involved for several years in drug-related discussions and negotiations. Private sector representatives also form part of a broad coalition to limit taxation on female condoms by pressuring the government to include condoms as essential commodities.¹⁵

WORKER'S SOLE CENTRAL (CUT), BRAZIL

Since the early 1990s, HIV/AIDS/STD prevention programs in Brazil have collaborated with the Worker's Sole Central (CUT), a national trade union organization. Workers from the construction and steel sectors of CUT have been involved in the training program and taken information, advice and condoms back to co-workers. Other CUT workers from large companies such as Ford and Volkswagen and petroleum-producing companies have been trained as workplace actors for HIV/AIDS/STD prevention programs. The training included a series of methodologies using participatory approaches. As a result, a series of HIV/AIDS/STD prevention activities was developed at the industry ground level.

The Worker's Sole Central has been deeply engaged as part of a broad national coalition to exempt condoms from taxation and in the campaign to include condoms as a part of the subsidy for low-income workers.

The labor needs of businesses are already apparent in some countries or sectors. Barclays Bank (Zambia) considered closing several branch offices because of trained personnel shortages. In Zimbabwe, businesses are considering substituting machines for people if they cannot find sufficient workers.³ The experiences of companies in resolving staffing issues offer examples that program managers can use to persuade other companies to address HIV/AIDS. For example, Zimbabwe's government-business-labor forum for discussion of common issues related to HIV/AIDS is one way for program managers to be closely involved in addressing these issues while learning and sharing information relevant to other situations.⁹ Likewise, as the relationship between major construction projects and HIV vulnerability is more clearly identified, program managers will have opportunities (if not the responsibility) to assess the impact of such projects on workers and local communities.^{16,17}

FUTURE CHALLENGES

Working with businesses to stem the HIV/AIDS epidemic is one part of a larger multisectoral response. One major difference in working with businesses is their emphasis on commerce and financial profits. While these differences have limited the involvement of the private sector in HIV/AIDS prevention and care, many business managers are aware that the epidemic threatens the flow of commerce and profits. Thus there are mutual needs and interests in building an HIV/AIDS prevention partnership with business. This chapter has identified a number of points to strengthen the role of businesses in the partnership, including:

- Demonstrating that prevention can work and can be cost effective.
- Opening and maintaining effective communication with businesses at regional and country levels.
- Designing strategies to achieve sustainability through regular monitoring and assessment of the impact of programs.

CASE STUDY

FORD MOTOR COMPANY, SOUTH AFRICA

South Africa currently has more than 4.5 million HIV-infected individuals, more than any other country, with approximately 1,500 new infections per day. South Africa has the largest and most developed economy in sub-Saharan Africa and generates 45 percent of sub-Saharan Africa's gross domestic product. It is precisely because South Africa has a relatively sophisticated formal economic system that its economic performance is so vulnerable to the potential effects of the epidemic.

One example of a business response to HIV/AIDS is that of Ford Motor Company of Southern Africa (Ford-SA). The HIV/AIDS workplace program was developed during the second quarter of 1999, and is led by a steering committee chaired by the CEO of Ford-SA with cross-functional representation of management and employees.

LESSONS LEARNED FROM THE THAILAND BUSINESS COALITION ON AIDS¹⁸

- Approach businesses in a non-confrontational, non-threatening way.
- Use relevant and persuasive case studies to illustrate the importance of HIV/AIDS workplace policies and programs.
- Meet early on with high-level corporate staff to obtain their endorsement.
- Do not highlight existing laws unless they are inherently useful and conducive to businesses trying to manage HIV/AIDS issues in an effective, PLHA-supportive manner.
- Mainstreaming, monitoring and minimizing the impact of HIV/AIDS provide clear benefits to business.
- HIV/AIDS cost-benefit data from other businesses, though important, may have limited use for another company. Encourage companies to develop such data for themselves.

The company developed a comprehensive HIV prevention program to focus on communication, education, testing and community involvement. Two HIV/AIDS program coordinators were hired from within Ford-SA to lead this initiative. In August 1999 the program concluded and published a Ford-SA policy statement on HIV/AIDS, which is laminated and hangs on walls throughout the plant and in the restrooms. Forty peer educators, 20 at each plant, were trained and wear red ribbons to be easily identified. They conduct their training at the workplace, during the workday. The program also promoted alignment of benefit programs, offering additional coverage when positive HIV/AIDS status is declared to medical schemes.

The program is extended to employees, contract workers, pensioners and their families, and has reached more than 12,000 people. The company provides leadership on HIV/AIDS within the South African auto industry by serving as a resource for the industry and hosting an HIV/AIDS conference with other employers. The steering committee believes that employees no longer hesitate to engage in open discussion on the topic of HIV/AIDS, with more and more seeking advice and clarity. As a direct result of Ford's efforts, General Motors requested a briefing on the global epidemiology of HIV/AIDS and is currently following up on plans to implement a similar workplace program in their own South Africa plant.

The two Ford plants in South Africa, in Pretoria and Port Elizabeth, stopped production for an afternoon so the CEO could introduce the program and demonstrate his support for HIV/AIDS education in the workplace. This was an extremely powerful means of engaging the company and its management, since managerial support is of the utmost importance when implementing such programs.

Since April 1999, Ford also has ensured maximum access to free condoms, with a 400 percent increase in the volume dispensed onsite. Condom dispensers are located in all the facility restrooms and are fully stocked at all times. Approximately 10,000 condoms are distributed each month.

In addition to workplace education programs, policies and family days, there are also community-based activities funded through Ford Motor Company-USA (Ford-USA) and the Centers for Disease Control and Prevention (CDC) Foundation. These activities complement the workplace programs by providing outreach and education to the communities in which the Ford employees reside. One example is the Life Skills Program in Port Elizabeth. Life Skills will work in

40 schools with sixth-grade students and aims to provide an understanding and awareness of HIV/AIDS, prevent transmission of HIV/STDs, create a support structure in communities for persons infected with HIV, protect and promote the rights of persons infected with HIV and reduce the personal, social and economic impact of HIV infection.

The CDC, with financial support from USAID, is implementing an important adjunct activity in the Ford-SA program in South Africa. The three major labor federations of South Africa—Congress of South African Trade Unions (COSATU), Federation of Unions of South Africa (FEDUSA) and National Council of Trade Unions (NACTU)—have developed HIV/AIDS in the workplace programs for their constituency. This activity is providing an important link to workplace and community-based prevention programs at Ford and Ford-SA. The workers receive training through their union leaders, the training is then reinforced in the workplace, and, with support from Ford-USA grants to the CDC Foundation, the information is reinforced in community planning in the workers' townships (See Life Skills program above).

This case study was written by Victor Barnes and Jennifer Newberger, Division of HIV/AIDS Prevention/ Intervention Research and Support (DHAP/IRS), Centers for Disease Control and Prevention (CDC).

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C H A P T E R

10

*Programs for
Mobile
Populations
and Their
Partners*

IVAN WOLFFERS
THOMAS M. PAINTER



Programs for Mobile Populations and Their Partners

INTRODUCTION

The relationship between population mobility and the spread of HIV/AIDS has received increased attention, particularly in developing areas of the world. Much of the mobility associated with increased risk of HIV/STDs is driven by economic reasons, but increasing numbers of people worldwide are forced into movement as refugees due to civil wars and international conflicts. This chapter provides an overview of selected prevention interventions for mobile populations, identifies principal lessons learned from these experiences and makes recommendations for future prevention actions.

POPULATION MOBILITY, HIV/AIDS/STD RISKS AND PREVENTION INTERVENTIONS

Although population mobility is a global phenomenon, useful data on mobility are scarce in developing countries. Data are also limited on HIV seroprevalence levels among mobile groups considered at high risk of HIV/STDs.

AN OVERVIEW OF SELECTED PREVENTION INTERVENTIONS

Many international donors in the 1990s began to appreciate that livelihood mobility can be an important factor in HIV risk and the spread of HIV. Consequently, HIV/AIDS prevention and care interventions among mobile populations in resource-constrained areas of the world have proliferated, but their impact has rarely been evaluated.

A CLOSER LOOK AT INTERVENTIONS IN WEST AFRICA AND SOUTHEAST ASIA

INTERVENTION STRATEGIES

West African and Southeast Asian interventions have tried to develop stronger linkages between improved access by target groups to prevention information and support for their efforts to engage in protective actions against HIV infection. Their strategies include:

- Supporting protective actions against HIV infection
- Getting the right prevention messages to the right people
- Following up carefully and adequately staffing

INTERVENTION IMPACTS

While reports of increased levels of HIV/AIDS awareness and knowledge—and, occasionally, HIV protective actions—are common to prevention interventions in many places, West African and Southeast Asian interventions highlight two challenges to HIV prevention among mobile populations and populations in resource-constrained settings:

- Misconceptions about how HIV is transmitted and prevented, and denial of the reality of AIDS are common.
- Time, persistence and financial resources are needed to create conditions for people to change, reinforce and sustain their behavior.

KEY CONCEPTS FOR PREVENTION INTERVENTIONS

VULNERABILITY TO HIV INFECTION

A combination of social, physical and emotional factors can make mobile populations highly vulnerable to HIV/STD infection.

RISKS OF HIV AND STD INFECTION

The HIV/STD risk situations faced by migrants are shaped by economic forces and labor policies. Mobile populations move because they have to, and the emergence and high incidence of STDs is closely linked to migration.

HUMAN RIGHTS OF MOBILE POPULATIONS

There is considerable evidence that the rights of mobile populations are vulnerable to abuse. Improving the conditions of mobile populations, including their human rights, can decrease their vulnerability over the long term.

ADDITIONAL CONSIDERATIONS FOR INTERVENTIONS

GENDER ISSUES

Gender issues need more attention as increasing numbers of people on the move are women. HIV/AIDS prevention interventions for these women need to focus on their vulnerability and rights as well as on their risk behaviors.

TRAFFICKING OF GIRLS FOR PROSTITUTION

About one million women and children are sold yearly to the sex industry. As youth is in high demand in the sex industry, an unknown but high percentage of those trafficked are adolescents and children. Dependence, high mobility, gender and age make these children very vulnerable to HIV/AIDS and other reproductive health problems.

ADAPTED INTERVENTIONS

Interventions need to be adapted to specific target groups and settings as people engaging in mobile livelihood strategies differ not only in terms of the specific types of income-earning activities they pursue, but also in the degree to which they are mobile.

IMPORTANT STAGES IN PROCESSES OF POPULATION MOBILITY

The development of prevention interventions needs to be based on solid understanding of major stages in the processes of population mobility and the relationship between these stages and the risks of HIV infection faced by people on the move and their sexual partners. These stages are:

- Pre-departure
- Transit
- Initial adaptation in destination areas
- Successful adaptation
- Return

LESSONS LEARNED AND RECOMMENDATIONS

Lessons learned are identified from this multi-stage review, and for each lesson listed, recommendations are made for future interventions.

A FRAMEWORK FOR IDENTIFYING PREVENTION OPPORTUNITIES

A framework is proposed for identifying opportunities for prevention interventions in relation to the key concepts and major stages of population mobility described.

CHALLENGES TO FUTURE PREVENTION INTERVENTIONS FOR MOBILE POPULATIONS

Challenges are identified for future HIV/AIDS prevention among mobile populations in resource-constrained settings.

CASE STUDY

The Coordination of Action Research on AIDS and Migration (CARAM) in Asia provides an example of a multi-country HIV/AIDS prevention intervention for mobile populations.

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I N T R O D U C T I O N

The relationship between population mobility and the spread of disease has been noted by epidemiologists, public health workers and social scientists.¹ Since the 1980s, this relationship has received increased attention as a factor in the spread of HIV/AIDS throughout different parts of the world.²⁻⁹ Mobility via road, rail, water and air transport and on foot in the case of refugees, contributes to the spread of HIV across areas within countries, across international borders, and across larger economic regions that include several countries and continents. Mobility in itself, however, does not spread HIV and STDs. These infections are disseminated through a combination of population mobility and patterns of high-risk sexual contacts by people on the move and their sexual partners in settings at different points in their travels: home communities, transit points and destinations.

Much of the mobility associated with increased risk of HIV/STDs is driven by economic factors, which involve people moving between areas having greater and lesser constraints on the resources they need for their livelihoods.¹⁰⁻¹³ In addition, increasing numbers of people worldwide are forced into movement as refugees due to civil wars and international conflicts. In both instances, mobility often involves people traveling between areas where HIV seroprevalence rates and the risks of HIV infection are significantly different. This is illustrated by recent data from West Africa. Figures 1 and 2 below show major patterns of two-way migration between originating and destination areas in countries having marked differences in the burden of AIDS and levels of HIV-1 seroprevalence.

What kinds of livelihoods are found among mobile populations or people on the move? Migrants are included, although this term as it is often used can mask considerable diversity. A closer inspection of this category reveals important differences in how often migrants travel and return home, how far they travel, what they do in destination areas and whether or not they are documented. These differences shape situations of HIV/STD risk faced by mobile populations. Itinerant traders and hawkers who may also be migrants are

included, as are sex workers (sometimes referred to as commercial sex workers (CSWs), mine workers, soldiers, long-distance truckers, bus drivers and their helpers, railroad crews, fishermen and boat crews, pastoralists and refugees.

While tourists and more affluent business travelers are of interest to international HIV/AIDS prevention, these groups are less typical in resource-constrained settings and will not be considered here.

This chapter provides an overview of selected prevention interventions for mobile populations, identifies principal lessons learned from these experiences and makes recommendations for future prevention actions. It begins by outlining the state of data and research on population mobility and HIV/AIDS in resource-constrained areas.

The chapter then provides an overview of prevention interventions for mobile populations, based largely on information from program documentation and presentations made at several international HIV/AIDS conferences. This is followed by a more in-depth review of a smaller number of prevention interventions in West Africa and Southeast Asia. Next, three important concepts are presented—vulnerability, risk and human rights—that need to be addressed by HIV/AIDS prevention interventions for mobile populations. The importance of addressing gender-related issues and specific target groups is also emphasized. The chapter then examines several key stages in the processes of population mobility (also referred to as the migratory process), highlights opportunities for prevention interventions at each stage and cites examples of interventions as appropriate. Lessons learned are identified from this multi-stage review, and for each lesson listed, recommendations are made for future interventions. A framework is then proposed for identifying opportunities for prevention interventions in relation to the key concepts and major stages of population mobility described. Challenges are identified for future HIV/AIDS prevention among mobile populations in resource-constrained settings. The chapter ends with additional details from a case study of a multi-country prevention intervention in Southeast Asia.

POPULATION MOBILITY, HIV/AIDS/STD RISKS AND PREVENTION INTERVENTIONS

AVAILABILITY OF INFORMATION ON POPULATION MOBILITY AND HIV/AIDS

While population mobility is a global phenomenon, useful data on mobility are scarce in developing countries. Data are also limited on HIV seroprevalence levels among mobile groups that are often considered at higher risk of infecting others or being infected by HIV/STDs. Nevertheless, some categories of mobile populations receive more attention than others. In 1998, for example, 22 (55 percent) of 40 countries in sub-Saharan Africa reporting to UNAIDS provided some (often spotty) seroprevalence data on sex workers. Only nine countries reported seroprevalence among truck drivers and military personnel, respectively, and one country in 40 provided data on “displaced pregnant women” and “war-displaced people.”¹⁴ No seroprevalence data were available on migrants, male or female, whether engaged in labor or trade at their destinations. Seroprevalence data from Asian countries reveal a similar emphasis on these same groups of people on the move.

Presentations at World AIDS conferences in 1996 (Vancouver) and 1998 (Geneva) highlighted the absence of a comprehensive view of the relationships between diverse forms of livelihood mobility in resource-constrained areas of the world, and the risks of HIV/STD infection faced by mobile populations and their sexual partners. Presentations at the World AIDS Conference in 2000 (Durban) revealed a growing interest in these issues. Few sociological studies in developing countries have examined the details of the relationship between different types of population mobility, particularly cross-border or transnational mobility, patterns of high-risk sexual behavior among mobile populations and their sexual partners and vulnerability to HIV and STDs.^{5,15,16} Studies often cover only single countries, based on perspectives from destination countries (such as the United States or European countries) or that concern internal migration (such as China or South Africa).

AN OVERVIEW OF SELECTED PREVENTION INTERVENTIONS

Interventions for HIV/AIDS prevention and care among mobile populations in resource-constrained areas of the world have proliferated since the 1990s, but their impact has rarely been evaluated. Intervention data are often limited to such process indicators as numbers of education sessions completed or condoms distributed. Before conclusions can be drawn about initial lessons learned—much less to make recommendations about state-of-the-art strategies—comprehensive and comparative analysis of the strengths and weaknesses of diverse interventions for mobile populations and the impacts of interventions must be done.

The information available provides a perspective on efforts to date. Much of it comes from unpublished project documents, presentations made at international conferences and symposia and, less often, from published works. The results from a preliminary assessment of 21 prevention interventions among mobile populations in 13 sub-Saharan African countries,^{17,18} an inventory of presentations at World AIDS conferences and Asian and African AIDS congresses, and an internal review of the Coordination of Action Research on AIDS and Migration (CARAM)-Asia program¹⁹ provide profiles of interventions for mobile populations.

Most interventions in sub-Saharan Africa are fairly recent and have been short-lived. Slightly more than half (52 percent) date from 1994 and operated for an average of three years. Similar observations about the start of interventions in other areas of the world reflect the fact that it was not until the 1990s that many international donors began to appreciate that livelihood mobility can be an important factor in the risk of HIV infection and spread HIV/AIDS.²⁰⁻²⁴

- Multiple-country or cross-border HIV/AIDS prevention interventions are rare despite widespread cross-border travel by mobile populations; only three cross-border interventions were identified in Africa^{23,25-28} and two in Southeast Asia.²⁹ This can be explained in part by the complexity of coordinating and implementing these programs within political and organizational frameworks where AIDS programs have always been national in scope. Organizational and financial resource requirements are great and, with some exceptions, most donor aid flows to national—not multi-country—interventions.
- Commercial sex workers and long-distance truckers and their crews receive the most attention by interventions, particularly single-country interventions. Diverse mobile target groups, ranging from dockworkers to boat crews, bar girls and market women to mine workers, are also included in single-country interventions, but far less often.
- Multiple-country interventions include migrants (men) as well as sex workers and truckers.
- The size of groups targeted and those effectively reached varies greatly. Target groups in sub-Saharan Africa ranged from 300 peer educators to 40,000 miners, truckers and forest industry workers. The size of “target groups effectively reached” ranged from 248 women, mostly sex workers, to 230,000 “people educated.” Nearly half of the interventions listed no target group numbers or accomplishments in terms of numbers of people reached.
- Outputs of interventions are diverse and range from creation of awareness and empowerment to numbers of condoms or handbills distributed and training sessions held.
- Very few interventions identified community-based forms of social support among mobile-population target groups, particularly in destination areas that may provide opportunities for local-level linkages for enhanced effectiveness.
- Interventions often use volunteer peer educators recruited from target groups; peer workers frequently complained about insufficient incentives for their work.

A CLOSER LOOK AT INTERVENTIONS IN WEST AFRICA AND SOUTHEAST ASIA

Selected interventions in West Africa and Southeast Asia provide insight into the accomplishments and challenges facing HIV prevention efforts among mobile populations. West African interventions focus on gold mine workers and sex workers in Ghana,³⁰ and migrant men from Niger and their sexual partners, including sex workers in Niger, in transit to Côte d’Ivoire and in their destination areas in Abidjan.³¹ CARE International implements both interventions with ministry of health partners. Interventions in Southeast Asia include programs implemented by the NGO Teneganita for Bangladeshi, Philippine and Indonesian migrant workers in Malaysia,³²⁻³⁴ and programs implemented by CARAM for rural populations moving to Phnom Penh and leaving Cambodia to work in Malaysia.^{35,36}

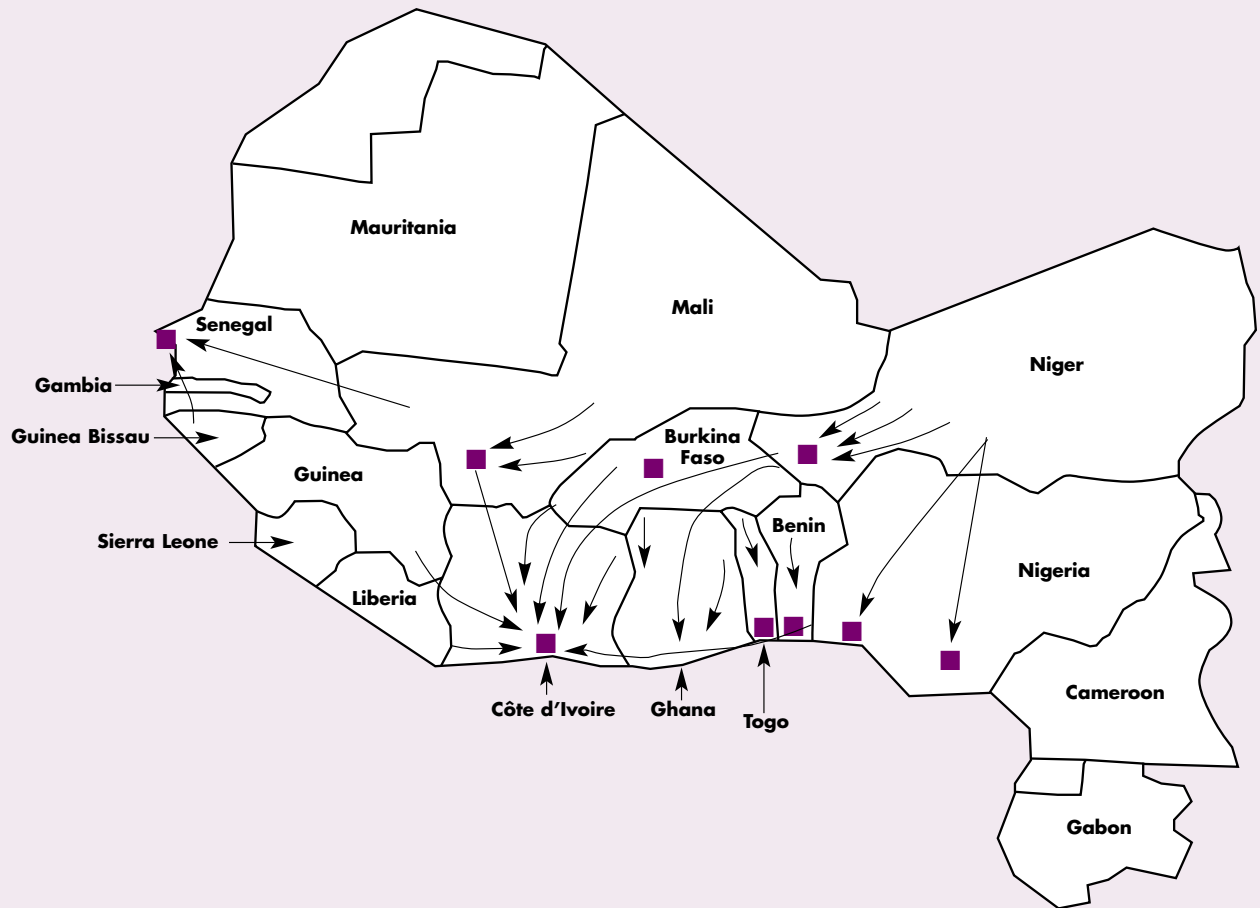
Intervention strategies

Support for protective actions against HIV infection

The Ghana and Niger interventions target both men and women, as do interventions with Bangladeshi and Indonesian migrant plantation and factory workers in Malaysia. Workers in Malaysia may live in compounds but they are free to come and go. Interventions with Philippine housemaids target women only because of their social isolation and limited ability to move outside the households where they work.

While most interventions target women alongside their male sexual partners, all interventions discovered that special efforts are needed to ensure that in practice women benefit as much as men. This requires that interventions address the gender-related constraints on power that women confront in everyday life, particularly in their sex lives, as they try to protect themselves and their sexual partners from HIV/STD infection. Target groups benefit broadly from improved prevention knowledge, but a major empowerment challenge for women consists of translating improved knowledge, awareness and concern into protective actions against HIV infection.

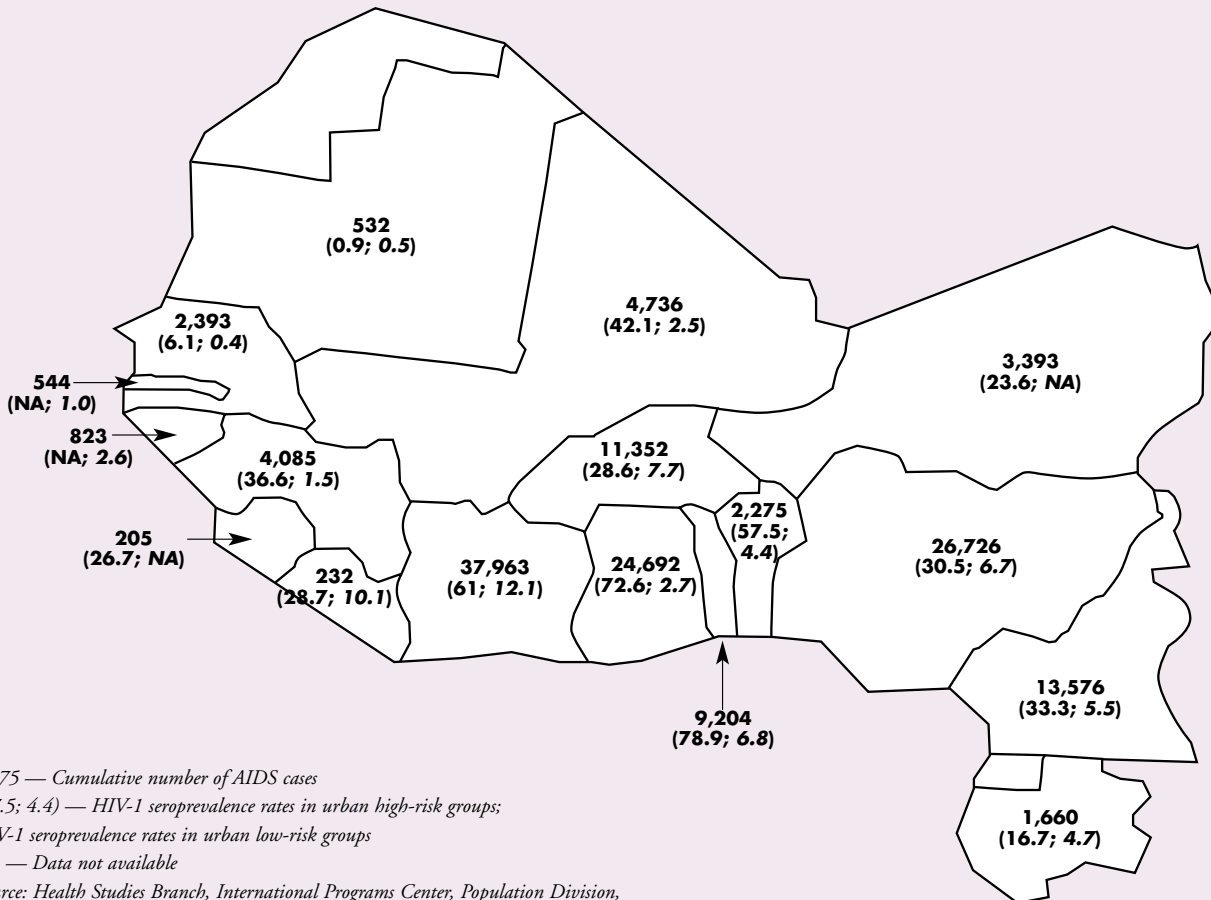
Figure 1
MAJOR MIGRATION FLOWS IN WEST AFRICA



Interventions in Ghana and Niger tried to work with mobile-population target groups in different ways to link prevention awareness and knowledge with such concrete protective actions as using condoms with sexual partners. The CARE-Ghana project trained public and private practitioners in syndromic STD treatment. Sub-district and district health officers, local drug sellers, and non-formal health practitioners were trained to recognize STD symptoms among miners and their sexual partners, provide counseling and make referrals for treatment. The CARE-Niger project developed a network of educators in the home communities of many migrants in the Tahoua district of Niger, one of the most impor-

tant areas for sending migrants to coastal areas, particularly Côte d'Ivoire. Educators were recruited from among migrants (particularly those identified as playing leadership roles among the migrant men), sex workers and Muslim religious leaders. Additional peer educators were recruited among migrants to provide prevention education at locations in Niamey's largest bus depot and at the Niger/Burkina Faso border. Community-based educators provided prevention information to migrants and their wives and sexual partners, while educators based at transit points provided additional information to the migrant men before their departure for Côte d'Ivoire.

Figure 2
**AIDS CASES & HIV-1 SEROPREVALENCE
 LEVELS IN WEST AFRICAN COUNTRIES**



2,275 — Cumulative number of AIDS cases
 (57.5; 4.4) — HIV-1 seroprevalence rates in urban high-risk groups;
 HIV-1 seroprevalence rates in urban low-risk groups
 NA — Data not available

Source: Health Studies Branch, International Programs Center, Population Division, U.S. Census Bureau. HIV/AIDS Surveillance Database, June 2000 Release, Washington, D.C.

CARE-Niger also planned to provide migrants with brochures containing information on STD treatment resources along with their Abidjan travel itineraries. Unfortunately, this innovative idea could not be implemented due to an interruption in project funding in early 1998.³⁷

The Malaysian NGO Teneganita worked with Bangladeshi male migrant workers, primarily assisting them with immigration documents. Based on the trust built in this way, extension workers from Teneganita

were invited into the compounds where migrants live. There they organized focus groups to discuss reproductive health, migrants' sexual needs and how to deal with STDs. The sessions often took place at night after workers returned from late shifts, and were conducted secretly because employers frequently objected to such interventions, fearing the organization of labor unrest. The men sometimes took Teneganita staff to nearby brothels so they could educate sex workers about HIV/STD prevention.

The CARAM Cambodia pre-departure program started with classes on reproductive health for female migrants leaving for Malaysia. This contributed to increased awareness of their situation, vulnerability and options. They were given contact information in Malaysia so they could continue these kinds of discussions in their destination areas.

Using different approaches for different results, the West African and Southeast Asian interventions have tried to develop stronger linkages between improved access by target groups to prevention information and support for their efforts to engage in protective actions against HIV infection. They have, for example, complemented standard safe sex messages by adding access to syndromic management and referrals for STD treatment (Ghana), and by providing contact information in their destination areas to female migrants in search of support on reproductive health issues (Cambodia).

Getting the right prevention messages to the right people

The CARE-Ghana intervention used an IEC strategy of audience segmentation, which involved peer educators recruited from among gold miners and sex workers who provided messages developed for specific age, religious and occupational target groups. This is an important IEC strategy that is often recommended but rarely used in programs for mobile populations in Africa.

The Teneganita intervention with migrant workers started with focus group discussions and selection of potential peer educators. Flyers and brochures from Bangladesh and Indonesia provided the basis for developing more educational materials in Malaysia. These were often more comprehensive and easier to read than locally available materials. The project also planned to develop materials based on the migrants' experiences.

The CARAM project in Cambodia aimed to add components to what began as a reproductive health education program. This was difficult, however, because the company that recruited housemaids for work in Malaysia was reluctant to raise issues related to HIV/AIDS/STD during pre-departure training for the young women. Government apathy was another challenge. When CARAM approached the Cambodian government about training housemaids, their response was that they considered it a private business matter, not a public concern. These kinds of difficulties reveal the importance of including a range of stakeholders in the development of pre-departure programs. The September 2000 Asian Summit on pre-departure, post-arrival and reintegration programs is an example of efforts to strengthen services in these areas. Officials representing health ministries, labor and immigration organizations worked with migrants, NGOs, recruiting agents, employers and physicians that test for HIV to prepare a regional plan and manual for service development and guidelines for national plans.³⁸

Careful follow-up and adequate staffing are important

The interventions reviewed illustrate the importance of following up activities at multiple levels. The CARE-Niger intervention was the first project in West Africa—and very possibly in sub-Saharan Africa—to attempt an intervention for mobile-population target groups in their home communities, at transit points, and in their destination areas 2,500 kilometers away in Abidjan, Côte d'Ivoire. Challenges to the project's success were compounded by the fact that CARE did not have offices in Côte d'Ivoire. As a result, follow-up of the migrant peer educators trained in Niger for work in Abidjan was insufficient, and they were left to work largely on their own.³¹

The lack of follow-up in Abidjan weakened the project's effectiveness and made it difficult to say what changes, if any, were occurring in patterns of HIV risk behaviors and risk prevention among migrants in destination areas. This is an important point because Abidjan was the setting of intensive, high-risk sexual

networking by many of the migrant men. Most migrants traveled without female companions to Abidjan, the epicenter of the West African HIV epidemic, where they spent three to nine months.¹⁶ Follow-up also suffered in Niger, where the small numbers of project staff were unable to ensure quality peer education at the numerous project sites in the migrants' home communities. If CARE—or any organization that implements multi-country HIV prevention interventions for mobile populations—can resolve these challenging follow-up requirements, it will be poised for more effective cross-border HIV prevention work in West Africa.

CARE-Ghana appears to have learned from the difficulties encountered by CARE-Niger. The Ghana intervention has more and better-trained staff, and gives greater emphasis to follow-up and support of all actions. The Ghana project also provides refresher courses to its intervention workers. Despite these successes, CARE-Ghana acknowledges that more follow-up, support and quality control are needed for its diverse HIV/AIDS/STD prevention actions.

After the forced repatriation in 1998 of thousands of Bangladeshi and Indonesian migrants in Malaysia, Teneganita's work in Malaysia seemed to be less effective. But Shisuk, the CARAM member in Bangladesh, together with the Welfare Association of Repatriated Bangladeshi Employees (WARBE), developed activities to assist returning migrants with the kinds of difficulties they commonly face, such as lost access to savings accounts and reintegrating themselves into their home communities. In this situation, follow-up through a multi-country network proved to be very useful.

These different experiences all highlight the importance of mobilizing adequate resources to address one of the more complex HIV/AIDS prevention challenges of our time: Protecting people on the move, their sexual partners and their families from HIV/AIDS/STD.

Intervention impacts

Evaluations have credited the CARE interventions in these two countries with significantly increasing HIV/AIDS awareness and knowledge among migrants and their sexual partners in Niger, and gold miners and their sexual partners in Ghana. Similar observations have been made among the migrant groups approached by Teneganita outreach workers.

Positive changes, albeit more modest, were also observed in self-reported reduction of HIV/STD risk behaviors, such as increased condom use, fewer sex partners and reduced contacts with sex workers. Of particular interest in Ghana, the sex workers who served large numbers of informal-sector gold miners reported a decline in their activities since the start of the project's education actions and condom promotions. As a result, the Ghana project is now engaged in a micro-credit program to assist sex workers in developing alternative lower-risk income-generating activities.

While reports of increased levels of HIV/AIDS awareness and knowledge—and, occasionally, HIV protective actions—are common to prevention interventions in many places, the West African and Southeast Asian interventions point to two challenges to HIV prevention among mobile populations and populations in resource-constrained settings.

First, despite efforts by national AIDS programs and interventions such as those considered here to increase HIV/AIDS awareness, levels of knowledge among the mobile target populations remained low. Misconceptions were common about how HIV is transmitted and prevented. Philippine housemaids in Malaysia were an exception. They were better educated and had access to Philippine newspapers containing more information about HIV/AIDS than the Malaysian press.³⁹ Denial of the reality of AIDS was also common. These areas of weakness indicate a continuing need for accurate information linked to community-based follow-up to better ensure the translation of awareness and knowledge into protective actions in resource-constrained settings.

Second, effecting sustainable behavior changes to reduce HIV/STD risk requires considerably more time and effort than increasing awareness and knowledge.

Time, persistence and financial resources are needed to create conditions that foster, reinforce and sustain behavior changes for HIV prevention. Empowerment and increased self-esteem are important contributing factors, particularly because people on the move often are obliged to pursue their livelihoods in settings that do not encourage them to do the right thing; that is, use their increased information and awareness for protection against HIV infection.

KEY CONCEPTS FOR PREVENTION INTERVENTIONS

The symposium “Mobile Populations and HIV” at the 12th International World AIDS Conference in Geneva in 1998 identified three linked concepts as key to effective HIV/AIDS prevention and care programs for mobile populations: vulnerability, risk and human rights. It is important to review their relevance for interventions with mobile populations.

- **Vulnerability** applies to many people on the move and is created by the precarious conditions that are typical of livelihood mobility in resource-constrained areas. Community-based interventions are needed to address issues related to migrants’ vulnerability.
- **Risk** applies to individual behavior and responsibility, and the opportunities and threats people face as they attempt to satisfy their needs. Interventions that focus on health education and individual behavior change are needed to address risk issues. Taking responsible action—doing the right thing to prevent HIV/STD infection—requires that people have the right to do so.
- **Human rights** are essential for programs with mobile populations, which should include advocacy and focus on improving pertinent policies. (HIV/AIDS and human rights are discussed in more detail in Chapter 27.)

Vulnerability to HIV infection

Mobile populations are often marginalized, which results in low self-esteem and short-term survival strategies. Most travel without their regular sexual partners but are at an age when sexual needs are often felt strongly. Mechanisms of social control in their home communities help to maintain patterns of sexual networking and behavior that fit more or less within boundaries of behavior shaped by shared values and social norms. The effectiveness of these norms may be attenuated in the new environments of destination areas. Studies by CARAM in several Southeast Asian countries indicate that migrants may lead parallel lives, using separate sets of rules for behaviors at home and in destinations. This facilitates the denial of certain high-risk behaviors.⁴⁰ These factors, combined with reduced access to HIV/AIDS prevention messages in their native languages and to health care facilities, contribute to increased risk of HIV/STDs for people on the move and their sexual partners.

Many governments show little or no concern for migrants’ problems in these difficult and risky circumstances. In some cases, governments prohibit relationships between migrants and local populations. People on the move are too often considered simply as a disposable source of labor that can be sent back home when the work is done. These factors increase the vulnerability of mobile populations to HIV infection.⁴¹ Focus on this increased vulnerability of migrants leads to interventions at the community level, such as the development of STD facilities and peer work to create greater HIV/AIDS awareness.

Risks of HIV/STD infection

The HIV/STD risk situations faced by migrants are shaped by economic forces and labor policies.^{5,16} Ironically, they result from efforts by people on the move to reduce or spread other kinds of risk they face as they pursue their livelihoods under resource-constrained circumstances.^{16,42}

Mobile populations move because they have to. The emergence and high incidence of STDs is closely linked to migration.^{43,44} It has been demonstrated that migration is an independent risk factor for acquiring HIV/AIDS in Southern Africa,^{4,45,46} where border towns that attract laborers and traders may contain large numbers of HIV-infected people.⁹ Data from the Philippines in 1992 revealed that 12 percent of HIV-infected people were infected overseas; data from 2000 indicate that the percentage has gone up to 24 percent.²⁹ Records from the central hospital in Niamey, Niger, showed that as early as 1991, when the estimated AIDS ratio was about two cases or less per 100,000 population, 70 percent of all AIDS cases had histories of migrating to the West African coast, particularly to Côte d'Ivoire (Figures 1 & 2). The Tahoua and Niamey districts, which are the home areas and major transit zones respectively for most of the country's migrants, accounted for 90 percent of all known AIDS cases.¹⁶

Education programs are needed that use languages understood by large numbers of mobile populations and that are also culturally sensitive in other ways. These programs need to give clear and accurate information to people on the move and their sexual partners about the risks they are running, stimulate them to adopt protective behaviors and avail themselves of health care facilities. Prevention education programs also must provide target groups with opportunities for interaction with information providers, questions, follow-up and clarification. Outreach activities by well-trained peer educators can contribute importantly

to these educational efforts, but as noted elsewhere in this chapter, particular care is needed to ensure continued effectiveness of peer education actions.

Human rights of mobile populations

Mobile populations face significant human rights issues that are closely related to the situation of increased vulnerability and risk. There is considerable evidence that the rights of mobile populations are subject to abuse. This is particularly true of people who travel without necessary immigration documents. Advocacy is needed to address human rights and policy regarding HIV screening of migrant workers and other mobile people, among other areas.

Much has been written about the portrayal of HIV/AIDS as a "hostile outsider."⁴⁷⁻⁵² For too long, authorities have considered migrants as HIV "carriers."⁵³ They are blamed for the spread of AIDS, and in some countries this has led to mandatory HIV testing of migrant workers, or testing under conditions in which they are not aware they are being screened for HIV. Since the onset of the Asian economic crisis in 1997, HIV testing has been a tool used by authorities for repatriating migrants, thereby reducing pressures on the national labor markets.⁵⁴ While mandatory testing of migrants interferes with human rights, current immigration policies too often serve narrowly defined national goals in ways that can raise serious ethical questions.^{55,56}

As noted earlier, mobility of people with HIV/STDs and other infectious diseases through geographic space is one factor that contributes to the spread of infection. It is very important, however, that national policies and programs for HIV/AIDS prevention focus on situations of risk and vulnerability faced by people on the move and their sexual partners, and on ways to improve prevention—rather than focusing on population mobility per se. Public health experts have been quick to understand these problems,⁵⁷ and have strongly warned against discrimination against mobile populations as they cross borders from one country to another in pursuit of their livelihoods.⁵⁸⁻⁶⁰ It is only by improving the conditions of mobile populations that their vulnerability can be decreased over the long term. This requires that their human rights be respected.

ADDITIONAL CONSIDERATIONS FOR INTERVENTIONS

Gender issues

Gender issues need more attention, as increasing numbers of people on the move are women, a fact that causes some to speak of a feminization of migration and population mobility. In 1997, for example, 60 percent of migrants from the Philippines and 80 percent of the migrants from Sri Lanka were female. More women are looking for opportunities in production, although they are often paid less than men. Large numbers of women on the move from resource-constrained areas of the world are also finding jobs as housemaids and entertainment workers in the service sectors of other countries. The migration of female entertainment workers has become a global phenomenon and many women also become involved in sex work.

Women and girls from Myanmar, Laos, Cambodia and China are brought to brothels in Thailand. The Thai Ministry of Public Health in 1997 estimated that 16 percent of sex workers in Thailand came from outside the country and that 90 percent of them came from Burma. An estimated 30,000 Burmese sex workers are active in Thailand, half of them infected with HIV. Thirty percent of sex workers in Cambodia are Vietnamese. Thai women and girls are brought to Japan and several European countries to work in the sex trade.⁶¹ In the Netherlands, more than 50 percent of the sex workers come from outside the European Union countries. Many female migrants reach their destination countries without immigration documentation, adding to their vulnerability to HIV infection. HIV/AIDS prevention interventions for these women need to focus on their vulnerability and rights, as well as on their risk behaviors.⁶²

Trafficking of girls for prostitution

It is difficult to determine where recruiting and voluntary migration stops, and where trafficking begins. This is especially true with regards to children. Is the voluntary decision of their parents to have their children “employed” by a recruiter also a voluntary decision of these children themselves? About one million women and children are sold yearly to the sex industry, a yearly trade worth an estimated US\$7 billion. As youth is in high demand in the sex industry, an unknown but high percentage of those trafficked are adolescents and children. In Vietnam, for example, parents sell children to entrepreneurs who use them for begging, sex work and drug dealing. Mothers in Hanoi rent their children for 20,000 duong (US\$2). There are an estimated 1,500 of these “rented” children. Some of the Vietnamese HIV-infected women identified by CARAM Cambodia were sent by their mothers to Cambodia at age 16 to contribute to the family income.

The ratio of child sex workers in Vietnam is believed to be steadily increasing: from 2.5 percent in 1989 to 11.42 percent in 1995. In recent years, MOLISA (Ministry of Labor, Invalids and Social Affairs) and UNICEF estimate that there were up to 200,000 sex workers with approximately 7 percent (UNICEF) to 10.5 percent (MOLISA) children. Depending on geographical area, child prostitution may vary from 5 percent to 20 percent, and is said to be more evident in the south than in the north. As there are many Vietnamese sex workers in Cambodia, it can be assumed that a corresponding percentage of Vietnamese sex workers in Cambodia are minors. Vietnam is just one example; in other poor countries we come across similar estimates. Approximately 200,000 Nepalese women and children are working in the sex industry in India. Few of them realize fully what awaits them at the moment they are recruited by agents that search rural villages for young girls. When traffickers found out that control in Bombay brothels was stepped up, they started to bring the trafficked girls to Madras, Calcutta or Pune.

Due to poverty in developing countries and high demand for these specific sex services in rich parts of the world, there is a steady increase in trafficking of female children. Hard data are difficult to get hold of, due to the criminal character of trafficking. In the Netherlands, for example, reports based on 93 police reports concerning minors in prostitution in 1998 estimated that there were between 1,000 and 1,500 child sex workers in the country. Of these, 300 to 400 are Nigerian girls. These girls are often transferred to other parts of Europe to work for some weeks, which makes it hard for authorities to get a clear picture of the situation. Dependence, high mobility, gender and age make these children very vulnerable to HIV/AIDS and other reproductive health problems.

Adapted interventions

Interventions need to be adapted to specific target groups and settings. People engaging in mobile livelihood strategies—described in the aggregate as mobile populations or people on the move—differ not only in terms of the specific types of income-earning activities they pursue, but also in the degree to which they are mobile. Migrant workers with labor contracts may spend several years in their destination sites, while individuals, particularly undocumented workers engaged in occasional labor or trade, may spend just a few weeks or months before returning home or moving to another location. Trafficked women may be transferred to different brothels every two or three weeks. Differing levels of mobility among these kinds of target groups affect the feasibility and effectiveness of HIV/AIDS prevention interventions.

The greater the degree of mobility, the more difficult it becomes to implement interventions. Development of satisfactory understanding of the risk situations faced by people on the move may be slowed, particularly when access to needed information or entrée to groups relies on recurrent contacts with the same people, such as key informants or influential

members of target groups. High levels of mobility can make it difficult to gain access to a critical mass of target group members and maintain contact with them for follow-up and assessment of intervention impacts. Problems related to limited access include small numbers of people contacted, severe constraints on their time and availability and limited interest and attention spans. When high levels of mobility affect intervention staff (such as peer educators), the tasks of training, supervising performance and providing quality control become particularly difficult.

Interventions with mobile populations need to concentrate on settings and the moments in livelihood mobility processes when target groups are physically accessible and reasonably attentive to well-prepared intervention content. These settings typically include their home communities prior to departure and following their return, transit areas inside and outside home countries and destination areas where they work, live and organize their sex lives. Both mobile populations and their spouses and other potential sexual partners should be targeted in each setting. Because so many people on the move travel to distant, often foreign destinations unaccompanied by regular sexual partners, and because the frequent opportunities for sexual networking are relatively free of the normative constraints that operate in their home communities, interventions should give particular attention to destination areas where migrants and others work, live and seek sexual satisfaction.

The next section reviews several major stages in the processes of livelihood mobility where needs and opportunities exist for HIV/AIDS/STD prevention.

IMPORTANT STAGES IN PROCESSES OF POPULATION MOBILITY

Prevention interventions need to be based on a solid understanding of the specific features of the settings in which mobile populations encounter HIV infection risks. Interventions also need to establish contact with mobile populations at key stages in what is described broadly as the migratory process. These stages include pre-departure, transit, initial adaptation to new settings, successful adaptation and return.

Pre-departure

Pre-departure is characterized by a combination of push and pull factors. Individuals may be pushed into mobile livelihood strategies by limited access to the real incomes they need for their well-being. Individuals, particularly younger people, may also be attracted to mobility because they seek a change of scene, greater freedom from the demands of life in their home communities or greater economic autonomy from parents.

During times of crisis or scarcity, migration may be seen as a survival strategy for families in some communities, leading to local traditions of migration. In the Philippines and in several Sahelian countries, for example, migration has been an acceptable survival strategy for much of this century and possibly longer.⁶³ In some instances, crisis situations such as drought and famine force younger family members, including daughters, to migrate to support their families.^{64,61}

Pre-departure interventions for communities of mobile populations should increase awareness about how mobility as a livelihood or survival strategy can create situations of high risk for contracting HIV and STDs. Although pre-departure programs need to provide information about reproductive health and

HIV/AIDS, experience reveals gaps in practice. In the Philippines, for example, HIV/AIDS information is not a standard component of mandatory one-day pre-departure orientations, despite a law requiring that this information be provided. Prospective migrants who have signed labor contracts are given information on airport procedures, government and NGO programs and services for migrant workers, and realities in the destination country—but HIV/AIDS prevention information is not regularly included.

Transit

This stage involves travel, border crossings during international travel and arrival at destinations. Travel can be time-consuming because migrants sometimes have to spend long periods at border crossings. Travel can be particularly risky for undocumented (described by some as illegal) travelers, as they can become easy targets for unscrupulous recruiting agents at border locations. Agents at the Thai-Burmese border, for example, offer very poor deals to women who have just been repatriated after being caught working illegally in Thailand. Offers of similarly disadvantageous arrangements have been observed among mobile populations elsewhere.

A range of interventions is possible in these settings. Interventions that focus on protecting migrants' human rights are particularly important. Prevention education interventions are also very important. Pharmacists and drug sellers can be trained to provide STD treatment when requested by people on the move who buy medications.

The Border Area HIV/AIDS Prevention Project (BAHAP) project, implemented by CARE International and funded by USAID, is an example of an intervention in cross-border areas to reduce the spread of HIV/AIDS in Southeast Asia. Using a "twin city" approach, participatory rapid assessments are first conducted to collect information about communities on either side of the Thai-Burmese, Thai-Cambodian, Cambodian-Vietnamese and Vietnamese-Lao borders. These assessments provide a picture of border activities. Risk profiles of HIV infection are prepared for the areas and interventions are developed. The project

team learned during the first year that border areas are not necessarily higher-risk relative to other places. Settings, including border-crossing areas, become places of higher risk for HIV and STDs because of conditions that are specific to a given locale and which must be satisfactorily understood for interventions to be effective.

Initial adaptation in destination areas

This is a time when migrants and other people on the move find their way in environments that may be new to them, develop social support networks and identify ways to satisfy their basic needs. This is also a time when they may be particularly vulnerable to situations in which sexual contacts expose them and their partners to HIV and STDs. Combined with pre-departure interventions for spouses and sexual partners in home areas, interventions at this stage need to focus on typical risk situations, encourage protective behaviors against HIV and STDs and address the conditions that increase vulnerability. This period may take months to years, depending on the education levels of mobile populations, cultural differences between home and destination countries and the degree to which mobile populations can benefit from social support structures created by earlier arrivals from the same country.

In areas where the migrants work and live, outreach work, peer-run programs and drop-in centers for those with health and other problems are useful interventions. Community building is essential, and protection and empowerment of women are important. Appropriate education about reproductive health is also essential and needs to be supported by family planning, abortion counseling, STD prevention and care, condom promotion, confidential HIV counseling and testing services and attention to migrants' rights.

The Transnational AIDS/STD Prevention among Migrant Prostitutes in Europe Project (TAMPEP) for migrant sex workers covers the Netherlands, Italy, Germany and Austria. It is a model intervention that

reaches 23 different groups of women and transgender individuals from Eastern Europe, Southeast Asia, Africa and Latin America. The project provides migrant sex workers with culturally appropriate HIV and STD education and resources, and aims to increase individual empowerment and responsibility. TAMPEP's methodology is based on the professional roles of cultural mediators and peer educators/peer supporters. Cultural mediators are field workers with the same cultural backgrounds as target group members. They support the intervention and facilitate the integration of immigrants within the scope of public health services.

There is a great need for HIV/AIDS/STD prevention and care programs for refugees. UNHCR and UNAIDS have developed policies, but very few interventions have been implemented due to a lack of resources. UNAIDS promotes a minimum HIV/AIDS prevention and care package for the acute stage of emergency situations. The package consists of (1) Ensuring a safe blood supply by testing transfused blood; (2) Avoiding HIV transmission from refugees to relief workers by taking universal medical precautions (washing hands thoroughly, using protective gloves, safe handling and disposal of needles, disinfecting medical instruments, etc.); (3) Providing free condoms; and (4) Providing basic HIV/AIDS information.

Relief agencies can initiate more comprehensive HIV/AIDS interventions after essential services are restored. The minimum package can be improved and community-based condom promotion should be undertaken. The need for STD control, and counseling and clinical care for people with HIV/AIDS should also be addressed.^{65,66} Because of the frequency of interactions between refugee and local populations, prevention interventions for refugees and internally displaced populations also need to include members of host and nearby communities. Special programs are needed in centers for refugees because their language and cultural differences may mean that they do not benefit from prevention information disseminated by national AIDS control programs. Translating national materials is a first step, but outreach work by trained members of refugee communities is also essential.

A rare example of an intervention among refugee populations underscores these more general remarks. Not long after a genocidal civil war in 1994 led hundreds of thousands of Rwandans to flee their country, a prevention program was initiated in camps for refugees at Benaco and three other sites in the Ngara District of Tanzania. Intervention components included community outreach education covering a range of HIV/STD prevention methods, condom distribution, syndromic STD management, home-based care for people with AIDS and psychosocial support, including support groups for women and younger people. CARE International in Tanzania implemented the program in partnership with several other organizations (Population Services International, John Snow, Inc., and the African Medical Research and Education Foundation), with funding from USAID through the AIDSCAP Project of Family Health International. Based on this experience, three requirements were identified for effective interventions with refugee populations: (1) Flexibility, creativity, cultural sensitivity, a good understanding of power relations among camp residents, and a great deal of patience; (2) Actions that address the increased vulnerability of women and youth; and (3) Good coordination of efforts by multiple relief agencies.⁶⁷

Successful adaptation

The amount of time needed for people on the move to successfully adapt to their destinations depends on several factors. These include individual factors (character, educational and cultural attributes); differences between countries and regions of origin and destinations (linguistic, religious and other cultural characteristics) and the ability of migrants and other people on the move to cope with and adjust to these differences; and the effects of relevant policies in destination areas and countries (national policies that isolate foreigners impede processes of adaptation while more liberal policies facilitate free movement and adaptation).

Successful adaptation in destination areas also depends on the presence or absence of social support networks that function to ease the transition from

being a new arrival to becoming a member of a resident expatriate community. Many of the larger cities in West Africa (such as Accra, Abidjan, Lomé and Lagos) have well-established communities of foreign-origin residents, some of which span several generations. Some neighborhoods in these cities have strong and long-standing linkages with specific communities in countries of origin. Thus, men and women of all ages who come and go as migrants, truckers and sex workers are potentially able to tap into these social support networks that may reproduce the structures found in home communities. These support networks can ease access to housing, jobs, information about local police practices, credit, assistance with repatriation in case of serious financial difficulties, illness or death and sexual contacts. In terms of facilitating access to sexual contacts, the process may not include attention to HIV/STD risk and prevention.

Community-based social support mechanisms like this, which embody shared concerns among members for the well-being of a community, may inadvertently contribute to members' increased risk of HIV/STDs. For many, particularly where older and more conservative male members occupy leadership positions, there may be neither interest in nor openness to incorporating knowledge about HIV prevention into existing value systems. This apparent lack of synchronization between shared beliefs and values and the relatively recent advent of HIV/AIDS may create a challenge to public health efforts among mobile populations in destination areas. Nevertheless, community-based structures like these offer opportunities to develop linkages with prevention interventions and a degree of cultural change that will support and possibly empower wider-spread HIV/AIDS awareness and risk reduction efforts by communities of mobile people.

A FRAMEWORK FOR IDENTIFYING PREVENTION OPPORTUNITIES

Our review identifies three concepts that are important for understanding the relationship between livelihood mobility and risks of contracting HIV/STDs on the one hand, and developing approaches toward HIV/AIDS/STD prevention on the other: vulnerability, risk and human rights. These concepts often characterize the situation of people on the move and require attention by prevention interventions. Each of these points can be addressed by complementary interventions at different stages in the migratory or livelihood mobility process as described above. The relationship of these concepts, stages and types of possible interventions are summarized in the matrix below. This framework suggests appropriate interventions for particular stages and settings. In practice, combinations of interventions are often needed, and in all cases attention must be given to advocacy.

	Vulnerability	Personal Risk	Human Rights
	Community-based interventions	Personal directed	Advocacy work interventions
Pre-departure	Awareness project for young people in areas with high migration.	Education on health and migrants.	Lobbying with policymakers on protection of migrants from exploitation by agents and middle-men.
Transit		Education and condom promotion in places where migrants stop or stay for a while.	
Initial adaptation	Awareness projects. Development of appropriate health/STD services.	Culturally sensitive health and STD/HIV education in own language.	Lobbying for the human rights of migrants in the receiving country. Networking with local labor unions.
Successful adaptation	Awareness of own identity in relation to sexuality.	Culturally sensitive educational material.	Asking special attention for problems of second generation migrants.
Return	Community work to support reintegration of returning migrants.	Education of friends and family of repatriating migrants on HIV/AIDS and mobility.	Influencing media to report appropriately on returning migrants and HIV/AIDS

Return

If and when migrants return to their home countries they need to reintegrate themselves, which may be difficult. In many cases, they have experienced personal and cultural changes while away, and their changed behaviors may lead to increased HIV/STD risk to them and their sexual partners at home. These kinds of situations also lend themselves to interventions.

Some programs are particularly concerned with returning migrants. With the help of the Bangladeshi NGO Shisuk (CARAM Bangladesh), the Welfare Association of Repatriated Bangladeshi Employees (WARBE) was founded to protect the rights of returned migrant workers. It also aims to create opportunities for discussion of sexuality, STDs and HIV/AIDS with returning migrants and their sexual partners. This is important because much of the Bangladeshi population believe that returning migrants brought the HIV epidemic home.

LESSONS LEARNED AND RECOMMENDATIONS

Our review of interventions has highlighted several important lessons. For each lesson identified, one or more recommendations are offered with a view toward the development of future interventions for mobile populations and their sexual partners in resource-constrained settings. Both the lessons and recommendations should be considered as one step in what must be a continuing process of examining prevention interventions. The process should include repeated assessments, analysis and dissemination of lessons learned from interventions, planning for more effective interventions, assessments, analysis and dissemination of lessons learned and so on.

1. The types of population mobility most often associated with increased risk of HIV infection are driven to a large extent by people's efforts to cope with the effects of uneven socioeconomic development. People are moving because they must do so for their livelihoods. Social disruption and war are also factors that play increasingly important roles in the kind of mobility that is associated with risk of HIV.

Recommendations: While no single intervention can address all the complex individual and broader socioeconomic factors associated with population mobility and HIV risk, it is necessary nevertheless for policymakers, international donors and intervention staff to remain keenly aware of the broader contexts of population mobility and HIV risk. A better balance is also needed between interventions that target individuals (such as behavior changes) and interventions that aim to modify broader structural, environmental issues that are associated with and possibly conducive to greater or lesser vulnerability and risk of HIV infection.

2. The relationship between specific forms of mobility and HIV risk situations is not well understood, in large part because so little detailed, qualitative analysis has been done.

Recommendations: More studies, especially qualitative studies that focus on particular problems or gaps in understanding the relationship between mobility and HIV risk, are needed to build on or complement existing work. Studies focused in this manner need to be linked with intervention

actions, particularly flexible pilot actions that increase understanding of both problems or issues and promising intervention outcomes.

3. Numerous prevention interventions have been undertaken with mobile populations but little is known about their methods, strengths and weaknesses, successes and failures and the results of their actions.

Recommendations: More assessments of interventions are needed to identify major lessons learned and develop a more solid foundation for future prevention work. Assessments should incorporate published and unpublished project documents and input from both program staff and members of target populations. The geographic focus should be national and regional, with comparative analysis insofar as possible. The results should be widely disseminated through regional workshops and satellite meetings at regional and world-level conferences.

4. Most HIV/AIDS prevention interventions for mobile populations operate within single countries, despite the fact that most population mobility entails travel across international borders, often to destinations that are culturally, economically and politically different from home communities.

Recommendations: More cross-border interventions are needed to address the particular situations of mobile populations and the prevention challenges and opportunities associated with these situations. In the event that cross-border interventions are not feasible, single-country interventions must be comprehensive in scope, covering home, transit and destination areas. Wherever mobility by nationals from a given country creates linkages to neighboring or more distant countries, and where livelihood mobility is associated with the risk and spread of HIV/STDs, single-country programs need to ensure high levels of coordination and collaboration with interventions in the other countries.

5. The multiple demands of working with mobile populations in single-country and cross-border interventions often make it difficult to ensure satisfactory follow-up, support and quality control when actions occur at multiple sites.

Recommendations: Interventions with multiple sites must ensure that adequate resources are available for high-quality actions at all sites. Strong follow-up and quality control are critically important for all actions, particularly those at sites in distant destination areas where people on the move are known to engage in high-risk sexual contacts. National and international organizations must mobilize greater resources for HIV/AIDS prevention among mobile populations and their sexual partners.

6. Responses by stakeholders other than mobile-population target groups can hinder the effectiveness of interventions.

Recommendations: Prevention interventions need to incorporate as many key stakeholders as feasible when identifying, planning, implementing and assessing actions. Insufficient attention to a range of stakeholders may result in reduced program effectiveness. In instances where stakeholders and potential partners are uncooperative or unresponsive, interventions need to work with those who are responsive and keep others informed as appropriate.

7. There is little evidence that interventions have identified or developed operational linkages with community-based forms of social support among mobile-population target groups.

Recommendations: HIV/STD prevention interventions need to identify and assess the role of community-based social support structures among mobile populations and, if appropriate, develop operational linkages with them. Doing so may help address the recurrent challenges of (a) increasing the degree to which target group communities appropriate, or take on as their own, the logic,

objectives and messages of prevention interventions, leading to a kind of normative, cultural change; and (b) sustaining protective intentions and actions against HIV infection.

8. Mobile populations may be marginalized and disenfranchised in destination areas and countries, perceived and treated in a hostile manner. Under conditions where there are negative perceptions in the absence of legal support for newcomers, mobile populations are particularly liable to suffer abuses of their rights.

Recommendations: Prevention interventions need to focus resources on protecting the rights of mobile populations whenever feasible, through specific actions and a focus on progressive policies in destination countries.

9. Most prevention interventions occur in social settings where people combine mobile livelihoods and high-risk sexual networking, such as truck stops, border crossings, major markets, truck (lorry) parks, bus depots, port areas and high-density urban settings. Some interventions also operate in the home communities of mobile populations. Outside home areas, the settings can be extremely difficult for prevention efforts. They are noisy, crowded places where a constant flow of people and vehicles often contributes to short attention spans and low levels of interest by target groups whose top priority is more often gaining their livelihoods than preventing HIV/STDs.

Recommendations: Interventions need to continue innovative efforts to work with mobile populations on their own terms, in the settings where they pursue their livelihoods and face HIV/STD risks. Use more formative or action research to better understand the social order and dynamics of these apparently chaotic places. Also use flexible pilot initiatives to assess innovative approaches for working with people on the move in these high-risk settings.

10. Interventions rely heavily on volunteer peer educators recruited from target groups. While this provides potentially privileged entrée to target groups, the frequent lack of satisfactory financial incentives leads to complaints and turnover of educators and occasional problems with peer educator performance.

Recommendations: Use incentives as needed on a case-by-case basis and do so appropriately to avoid making educators appear overly privileged relative to their counterparts, which contributes to isolation and reduced effectiveness. Select, train and retrain educators with a view to strong character and a good fit with their peers and the larger community. Consider using social mapping or simplified network analysis to assist with this. Identify existing forms of social support that occur among mobile populations and ensure that the work of peer educators fits with the objectives of these support structures, while seeking to increase their openness to increased and continuing concern for HIV/AIDS prevention and support of members' protective actions.

FUTURE CHALLENGES

Continued progress in HIV/AIDS/STD prevention among mobile populations in resource-constrained settings worldwide will depend on the ability of programs to address multiple challenges, including:

- Using creative approaches to deal with the complexities of HIV risk and transmission associated with livelihood mobility so that opportunities for innovative interventions can be identified. Avoid using overly routinized intervention approaches that do not encourage continued learning.
- Identifying and understanding community-based structures of social support among mobile populations and developing operational linkages with prevention interventions where feasible.
- Integrating representatives from mobile populations in identifying, designing, implementing and assessing interventions.
- Providing prevention messages and prevention support that are responsive to the diverse situations of mobile populations, and ensuring procedures to verify delivery, understanding and use of messages by target populations at all significant points along their travel itineraries.
- Integrating HIV/STD prevention messages and care within a broader range of reproductive and family health issues.
- Protecting and promoting the human rights of mobile people to empower them for protective actions against HIV/STD infection.
- Developing interventions that address structural and environmental factors as well as the individual behavioral factors associated with HIV/AIDS risk.
- Using multilateral support to develop immigration policies that are supportive of HIV/AIDS prevention interventions—for example, by ensuring the ratification of the 1990 UN Convention on the Protection of the Rights of all Migrant Workers and Members of their Families.
- Increasing the visibility of underprivileged mobile populations in the policies and programs of national and international HIV/AIDS prevention programs.
- Capturing and widely disseminating findings about successes and failures, difficulties and breakthroughs of current prevention interventions for the benefit of more effective future interventions, for replicating and scaling-up programs.

CASE STUDY

CARAM: PARTICIPATORY ACTION RESEARCH AS AN INTERVENTION FOR MIGRANTS

We have seen that multiple-country HIV/AIDS prevention interventions for mobile populations are infrequent. The Coordination of Action Research on AIDS and Migration (CARAM) in Asia, which has been referred to several times in this chapter, provides another example and will be described in greater detail here.*

CARAM is a partnership of seven NGOs in Bangladesh, Thailand, Malaysia, Cambodia, Vietnam, Indonesia and the Philippines for a regional program of action research on mobility and AIDS. CARAM has four objectives:

1. Do advocacy work to (a) demonstrate how migrants' working and living conditions increase their vulnerability to HIV and STDs at national and regional levels, and (b) improve their situations.
2. Develop grass-roots interventions for migrant populations to provide health/HIV/AIDS/STD education and increase their access to health facilities.
3. Develop action research models for the collection of data for advocacy work, and to develop and implement interventions for improved health education and access to health facilities.
4. Protect migrants' human rights.

The CARAM network disseminates information on its progress in research, interventions and advocacy in the newsletter CARAM News. CARAM's coordination center in Malaysia also organizes yearly workshops for partners and satellite symposia, booths and publicity at international conferences, including the World AIDS conferences and the International Congress on AIDS in Asia and the Pacific.

CARAM has developed a research methodology that emphasizes migrants' perspectives, to ensure that migrants' realities are described and understood in relationship to the HIV epidemics in Asia. The

research approach is participatory. Groups that should benefit from interventions based on the research are involved in setting priorities, identifying research objectives and providing analysis that will result in interventions. These groups or actors include the migrant populations, grassroots organizations that work with them and local health care workers and politicians.⁶⁸ The research is action-oriented in the sense that it must result in interventions that are also assessed by the approach. It uses a cyclical approach whereby problem statements lead to data collection, analysis and identification of potential solutions, which leads to further data on intervention impacts, analysis of data and so on. Quantitative and qualitative research methods are used to ensure satisfactory scientific quality. The CARAM program also involves a great deal of capacity building for NGOs, CBOs and other grassroots organizations. CARAM's research and interventions are closely linked with concerns about migrants' human rights and the need to improve their situations, which means that much of CARAM's action research produces materials for advocacy work.

The combined efforts of the country program in the CARAM network result in the following interventions for migrants:

- Pre-departure programs for prospective migrants to help them understand the conditions of the host country and teach them about sexuality and sexual health, specifically about HIV/AIDS.
- Follow-up in the host countries with (a) appropriate health education in the language of the migrants and fitting their daily realities, and (b) access to health care facilities (especially STD services). The care has to be affordable and culturally and socially significant.
- Reintegration programs for returned or repatriated migrants.

CARAM's participatory action research approach can be used by program managers to design culturally appropriate prevention and care interventions for

* For additional information about CARAM's experiences, consult its Web site <<http://www.geocities.com/ResearchTriangle/Facility/7747>> or <www.unaids.org/bestpractice/digest/files/empowering.html>. For more details on cross-border initiatives in West Africa described or cited earlier, see CARE International in Niger 1995, 1998, Kpognon 1997, PSI n.d., UNAIDS 1998. See UNAIDS 2000 for a particularly interesting and innovative example of action research supported by the UNAIDS regional HIV/AIDS prevention initiative in West Africa.

mobile populations. Research in the field of HIV/AIDS—concerning sexual behavior, hidden prejudices against foreigners, people with other sexual preferences and so on—makes the cooperation of those involved very important. People who are stigmatized and fear discrimination—or worse—are unlikely to share information with outsiders. Experience with participatory action research has shown that involving mobile populations in research and identifying possible interventions contribute greatly to the feasibility of resulting interventions.⁶⁹ Many anthropological research techniques, particularly Rapid Appraisal, reveal a top-down approach to data collection and analysis, often driven by the need of public health officials and health educators for information.

The steps used by Teneganita, the CARAM NGO partner in Malaysia, provide an example of how a participatory prevention program can be developed for mobile populations:

1. Outreach workers visit sites where migrants work and live. They are introduced by contacts of the migrants. In the case of established migrant communities, the contacts may occur via religious organizations (temples or churches), which provide opportunities for dialogue. It is important to realize, however, that members of religious organizations may not necessarily represent the broader migrant community. Outreach is more difficult with these kinds of contacts. Language can often be the most important barrier to effective outreach. Winning the confidence of target mobile populations can require considerable time because many of them, particularly people without immigration documents, may be suspicious of outsiders.
2. Outreach workers organize focus group sessions with migrants about HIV/AIDS and sexuality.
3. Sessions are taped and analyzed, using focus group discussion methodology. It is best to do the analysis together with migrants, but this can be difficult in practice because, as we have noted earlier, these people work hard and prefer to spend their free time in different ways. Results from the analysis should be presented soon to the migrants' community as a "reality check," to see whether they recognize themselves.
4. Session participants who are especially enthusiastic are invited to participate in the research. While this is a key element of the approach, it is sometimes difficult to identify potential participants because they may feel that the activity is not in their own interest. Cooperation from the community may be low if outreach workers show an interest only in HIV/AIDS-related issues, while migrants are primarily concerned with their documentation problems.
5. Selected participants are then trained. Training should be simple and focus on attitudes, cultural factors and differences and the relationship between HIV/AIDS risk and broader processes of development.⁷⁰
6. Short, concise questionnaires—20 questions at most—are developed to collect additional quantitative baseline information.

The same system can be used later for feeding back collected information and for HIV/AIDS/STDs education.

Maintaining a good relationship with migrants and other mobile populations is a key to success with this research approach. This differs from more conventional research where data collectors arrive in the community, get what they want, disappear to report to policymakers and donors and never return. Community participation is very important, although this can be difficult when authorities and employers are not supportive.

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C H A P

11

*Reaching Men
Who Have Sex
with Men*

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Reaching Men Who Have Sex with Men

INTRODUCTION

Few challenges in responding to HIV/ AIDS have proven to be as difficult as reaching and providing effective prevention and care services to men who have sex with men (MSM). Although homosexual and bisexual behaviors have been documented in all countries and cultures, widespread stigma and discrimination are associated with such practices. This has often made it difficult even to begin discussing the risk of HIV infection and the impact of AIDS among populations of MSM. One of the negative consequences of stigma and discrimination in many settings has been the relatively limited development of sexuality-based communities and community support structures. Many government agencies and international donors have almost completely failed to prioritize MSM in developing programmatic responses to the HIV/AIDS epidemic.

Fortunately, at least some local-level community and advocacy organizations have gradually emerged to respond to the epidemic in a range of resource-constrained settings, offering a growing understanding of the ways it is possible to reach MSM through prevention and care programs, and the key components that such programs ideally should include to be effective. This chapter briefly reviews programs designed for MSM in a range of resource-constrained settings to outline some of the ways these key components have been identified and the extent to which they are essential to effective program development.

STATE-OF-THE-ART APPROACHES, STRATEGIES AND EXPERIENCE

DEFINING THE MSM POPULATION

There is significant and growing evidence that MSM are an important population vulnerable to HIV infection everywhere in the world. In spite of growing levels of heterosexual transmission in Latin America, for example, HIV prevalence levels among populations of MSM have ranged from 20 percent to 35 percent in the major cities of a number of larger countries. HIV prevalence and incidence data for homosexually and bisexually active men are less readily available for countries in Asia and Africa. This is due in part to the fact that terms such as “homosexuality” and “gay” fail to adequately describe the diverse forms of traditional male-male sex that can be found in many African and Asian societies.

CONFRONTING A HISTORY OF DENIAL AND NEGLECT

The history of the HIV/AIDS pandemic has been marked by continued denial and neglect of the importance of prevention and care services for MSM, particularly on the part of official HIV/AIDS programs. This denial and neglect has unfortunately been widespread almost everywhere, but it has been most explicit in relation to the HIV/AIDS epidemics found in resource-constrained settings.

HIV/AIDS PREVENTION

EFFORTS AMONG MSM IN AFRICA

Only a small number of AIDS prevention programs or behavioral interventions directed at MSM have been developed in the sub-Saharan African region; the situation is only marginally better in northern Africa. Even on the basis of relatively unsystematic information, however, it is clear that in Africa, as in other parts of the world, nongovernmental AIDS-service organizations and gay and lesbian rights organizations have been largely responsible for the initiatives that do exist.

PREVENTION EFFORTS AMONG MSM IN ASIA

The situation in Asia is also marked by relative neglect of MSM as an important population for HIV/AIDS prevention programs. Fortunately, it is not characterized by the kind of almost absolute denial that still seems widespread throughout much of sub-Saharan Africa. In a number of South and Southeast Asian countries, important programs directed at MSM, and at the newly emerging gay communities found in many countries, have been initiated.

PREVENTION EFFORTS AMONG MSM IN LATIN AMERICA

As in Asia, small, nongovernmental, gay and AIDS activist organizations in Latin America typically have taken the lead in developing HIV prevention programs. For the most part these initiatives have been relatively small-scale, carried out without significant financial support and even, in some cases, in the face of official resistance. Nonetheless, by focusing on strategies such as street outreach, cultural activism and community-building and mobilization, important steps are being taken to redress the previous lack of attention to one of the most vulnerable population groups in virtually all of the countries in the region.

PREVENTION EFFORTS AMONG MSM IN THE CARIBBEAN

The Caribbean region has HIV prevalence rates second only to sub-Saharan Africa. It is important to examine the role of MSM in transmission as regionally there is widespread denial of MSM activity to the point that it is often disregarded or ignored as a mode of HIV transmission. Although the levels of HIV among MSM in the Caribbean are not completely known, there are strong indications that it is high.

LESSONS LEARNED AND RECOMMENDATIONS

It is clearly possible to provide a strong theoretical framework for the development of programs that should make it possible for policy makers and other stakeholders to design and implement meaningful programs even in the absence—or while awaiting the results—of more experimentally valid scientific research findings. If implemented urgently enough, these programs will surely save lives and reduce HIV/AIDS-related human suffering. A number of key principles emerge that can be defined as absolutely essential for the development of effective HIV/AIDS prevention and care programs for MSM.

FUTURE CHALLENGES

It is essential that programs for MSM remain deeply rooted in community structures and organizations precisely because these contexts provide the necessary vehicle for reaching isolated individuals and segments of the larger population group out of which they have grown. The task that remains for the future—everywhere in the world—is to recognize this fact and provide these communities and community-based organizations with the resources, structural and policy support and creative freedom necessary to do their work.

CASE STUDY

PREVENTIVE INTERVENTION AT PUBLIC SEX SITES IN SANTIAGO

The Chilean experience of an HIV/AIDS prevention program in public sex sites (PSS) will be of particular interest to countries where public sex, particularly sex between men, is more difficult to acknowledge or where homosexuality is more stigmatized.

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I N T R O D U C T I O N

Over the last two decades few challenges in responding to HIV/ AIDS have proven to be as difficult as reaching and providing effective prevention and care programs to men who have sex with men (MSM). There are multiple, complex reasons for this difficulty. Although homosexual and bisexual behaviors have been documented in all countries and cultures, widespread stigma and discrimination are often associated with such practices. This has made it difficult in many places even to begin to discuss the risk of HIV infection and the impact of AIDS among populations of MSM.¹

One of the negative consequences of stigma and discrimination in many settings has been the relatively limited development of sexuality-based communities and community support structures. Perhaps most worrisome, many government agencies and international donors have almost completely failed to prioritize MSM in developing programmatic responses to the HIV/AIDS epidemic. This has limited what might have been one of the most effective ways of overcoming the negative impact of widespread discrimination: the development of more effective health and welfare services, such as STD clinics specifically serving homosexually or bisexually active men, and human rights protection with an emphasis on sexual rights and the protection of sexual minorities.^{1,2}

Fortunately, at least some local-level community and advocacy organizations have gradually emerged to respond to the epidemic in a range of resource-constrained settings. They offer a growing understanding of the ways it is possible to reach MSM through prevention and care programs and the key components that such programs ideally should include to be

effective.¹ Unfortunately, these truly heroic efforts on the part of community-based organizations and frontline prevention workers have rarely been given adequate research attention in ways that might make possible a more systematic evaluation of their impact. A good deal of descriptive information is available, however, outlining the components of many programs. On the basis of such observational and descriptive case studies, it is possible to develop a strong theoretical model that synthesizes what would appear to be the key ingredients necessary for the design of meaningful HIV/AIDS prevention programs for MSM. Based on these accounts, it is apparent that at least five different elements must be present to reduce the risk of infection and guarantee responsible care and treatment for those who are already infected with HIV:

1. What might be described as “the democratization of information” is essential. While information alone is clearly not enough to ensure effective risk reduction,³ ensuring access to correct and current information about HIV and AIDS is nonetheless a necessary condition for the development of effective programs—especially for highly marginalized populations who are often excluded from the normal flow of information in mainstream social life.

2. To guarantee that information reaches the widest possible population of MSM—including those segments that are most hidden and marginalized—systematic outreach efforts aimed at connecting with these men, on their own terms and in their own social and sexual settings, consistently have been shown to be a key component of effective prevention and care.

3. To give consistency and long-term support to the democratization of information and the development of systematic outreach efforts, community mobilization and building must be a primary focus of AIDS-related programming. Effective responses to the epidemic can be sustained over time only within the context of increasingly strong and coherent community support structures.

4. Building stronger communities in turn must be linked to an ongoing process of collective and individual empowerment aimed at overcoming the discrimination, oppression and even violence that have consistently been associated with heightened vulnerability in the face of HIV and AIDS.

5. The defense of human rights has been identified as absolutely essential to developing a broader social climate capable of reinforcing risk reduction and guaranteeing access to care and treatment services. Defending human rights, particularly for highly stigmatized populations such as MSM, is necessary not only because it is ethically correct, but also because it is pragmatically necessary to bring individuals and communities into broader support structures capable of providing them with appropriate social, psychological and clinical services.

Taken together, these key components offer a framework within which to develop prevention and care programs capable of effectively reaching MSM. They combine to produce what has been identified as the single most important element in *all* HIV/AIDS prevention programs for *all* population groups: a supportive social environment in which it is possible to reach MSM and provide them with the information, skills, tools and

social mobilization necessary to respond effectively to the risk of HIV infection. While such programs to now have been relatively limited, the existence of this framework offers real hope that even with a reasonably small investment of human and financial resources, their scope and impact can be significantly extended in the future.

This chapter briefly reviews programs designed for MSM in a range of resource-constrained settings to outline some of the ways these key components have been identified and the extent to which they are essential for effective program development. It emphasizes the ways these components have emerged in relatively small-scale, community-based program development, and offers suggestions about the implications for scaling-up programs that will be able to reach a broader public in a range of different resource-constrained settings.

STATE-OF-THE-ART APPROACHES, STRATEGIES AND EXPERIENCE

DEFINING THE MSM POPULATION

There is significant and growing evidence that MSM are an important population vulnerable to HIV infection everywhere in the world.^{2,4} This has been true since the beginning of the epidemic among the populations of gay and bisexual men in the United States, Canada, Australia and in many of the countries of Western Europe, where HIV prevalence rates ranging from 20 percent to 50 percent were often reported during the 1980s.⁵ Much the same can be said of Latin American countries where, in spite of growing levels of heterosexual transmission in some countries, HIV prevalence levels among populations of MSM have ranged from 20 percent to 35 percent in the major cities of a number of larger countries such as Argentina, Brazil and Mexico, and from 5 percent to 10 percent in provincial areas and smaller countries such as Costa Rica.⁶

HIV prevalence and incidence data for homosexually and bisexually active men are less readily available for countries in Asia and Africa, where a clearly defined “gay” identity seems to be considerably less common than in the United States, Europe or even Latin America—and where the widespread denial of significant levels of sexual activity between men may also have resulted in a lack of research attention to these otherwise “hidden” populations.⁴ Throughout Asia, behavioral surveys of men have often reported high levels of bisexual behavior, and male-male sex has been responsible for an important percentage of the HIV infections reported among men. In a study of military conscripts in Thailand, for example, male-male sex was reported by only 7 percent of the sample, yet it was associated with 13 percent of the HIV infections in this population in 1995. While there has been strong denial of male homosexual behavior in sub-Saharan Africa over the years, social and behavioral studies by African researchers are increasingly calling this denial into question. They suggest that in many countries largely hidden homosexual practices may in fact be far more common than previously reported—and that levels of male-male HIV transmission may themselves be hidden in the HIV prevalence estimates for supposedly uniformly heterosexual men.⁷

Part of the problem here undoubtedly is due to the fact that terms such as “homosexuality” and “gay” fail to adequately describe the diverse forms of traditional male-male sex that can be found in many African and Asian societies.^{8,9} Closer study of the contexts within which male-male sex occurs—among adolescents or adults, as part of clan solidarity, in connection with spiritual and initiation activities—will in time reveal what many local people already know. Male-male sex does occur throughout the world, although only some forms are understood as being homosexual or “gay.”

CONFRONTING A HISTORY OF DENIAL AND NEGLECT

Even though there is significant evidence that MSM are an important population vulnerable to HIV infection, the history of the HIV/AIDS pandemic has nonetheless been marked by continued denial and neglect of the importance of prevention and care services for this population group—particularly on the part of official HIV/AIDS programs. This has unfortunately been widespread almost everywhere, though it has been most explicit in relation to the HIV/AIDS epidemics in resource-constrained settings. In fact, the lack of available data in some regions, particularly in Asia and Africa, is likely the result of official denial feeding into the limitation of HIV/AIDS research agendas.

The persistent denial of the importance of MSM has been clearly documented in a study by the Panos Institute in association with the Norwegian Red Cross.² The study included a targeted survey of national AIDS programs, AIDS service organizations and nongovernmental organizations involved in AIDS-related work and gay groups and individuals in countries around the world. The survey’s goal was to document both the extent of same-sex behavior but also, even more importantly, the kinds of programmatic and prevention responses that had been generated in

response to HIV vulnerability among MSM in the developing world. Data were collected from more than 40 national AIDS programs, more than 100 AIDS service organizations (ASOs) and NGOs, and more than 50 gay organizations in countries throughout Africa, Asia and Latin America. Unfortunately, only 25 percent of national AIDS programs list MSM as a target group for AIDS prevention campaigns. Only 9 percent report the development of programs for male sex workers—in contrast to 84 percent targeting heterosexual adults, 78 percent targeting adolescents or teenagers and 69 percent targeting female sex workers.²

These results were confirmed when national AIDS programs were asked not whether they specifically targeted prevention programs to MSM, but whether any AIDS-related services were available to MSM in their countries. Once again, a large majority, 74 percent, stated that no such services were available, while only 24 percent reported that some services were available. When asked what kinds of services were available, 23 percent said advice and counseling services; 18 percent said information and education programs; 16 percent said condom distribution; 12 percent said outreach work; and 9 percent said there were HIV testing and treatment services targeted to MSM.² These extremely limited AIDS-related services for MSM clearly reflect the almost complete lack of official attention to these populations in the international response to the HIV/AIDS pandemic, particularly in resource-constrained countries.

Given this history of denial and neglect on the part of most official governmental programs, the fact that at least some efforts have been developed and demonstrated important signs of success is a testament to the creativity of community-based organizations and activists in countries around the world. While these programs are often poorly documented and only rarely evaluated in any systematic way, they offer real hope concerning what is possible in terms of AIDS prevention programs for MSM in resource-constrained settings—particularly if more adequate sources of funding and political commitment can be generated on the part of governments and donors.³

HIV/AIDS PREVENTION EFFORTS AMONG MSM IN AFRICA

Only a small number of AIDS prevention programs or behavioral interventions directed at MSM have been developed in the sub-Saharan African region.^{2,3,10} The situation is only marginally better in northern Africa. The Association Marocaine de Lutte contre Le Sida, for example, has conducted outreach work with male sex workers in Casablanca and Marrakesh, aimed at raising HIV and AIDS awareness and promoting condom use.¹¹ While limited information has been collected on the sexual practices and self-perceptions of the men concerned, as well as on the number of contacts made and condoms distributed, information concerning the impact of this outreach work is not available.

But even on the basis of relatively unsystematic information, it appears that in Africa, as in other parts of the world, nongovernmental AIDS-service organizations (ASOs) and gay and lesbian rights organizations have been largely responsible for the initiatives that do exist. In the Panos Institute survey of prevention programs for MSM, only one national AIDS program (Mozambique) of the 20 surveyed reported any targeted prevention programs for MSM, though the extent of such programming is unclear. Likewise five percent of the 53 ASOs surveyed indicated they are developing at least some kind of service. But the few gay and lesbian organizations that exist in sub-Saharan Africa are the only ones that have explicitly prioritized work for MSM.² The Panos report also suggests that a number of gay organizations in Africa have taken leading roles in providing AIDS services to sex workers and prisoners.² In spite of these efforts, it is clear that much more must be done, and that there is still a pressing need in this context.

PREVENTION EFFORTS AMONG MSM IN ASIA

The situation in Asia is marked by relative neglect of MSM as an important population for HIV/AIDS prevention programs. Fortunately there is not the kind of almost absolute denial that still seems widespread throughout much of sub-Saharan Africa.³ In a number of South and Southeast Asian countries, important programs have been initiated which target MSM and the newly emerging gay communities in many countries. In India, for example, as in most other parts of Asia, small, emerging gay community and gay rights organizations have served as the point of departure for outreach activities aimed at reaching non gay-identified men and building a stronger sense of gay community among this population.

In spite of the possible difficulties and contradictions implicit in such a strategy, a number of organizations have initiated important efforts. In the early 1990s, for example, a nongovernmental group in Mumbai began to publish *Bombay Dost* (an Indian word meaning “friend”), a magazine targeting gay men and lesbians printed quarterly in English with a Hindi section. The group also started marketing condoms with Hindi- and English-language instructions on proper usage, and actively networked with other organizations throughout the country.¹² Since then the Humsafar Trust, also in Mumbai, has provided a wide range of AIDS-related information and services through printed materials, a library of resources, support groups and “street counselors” who can be accessed by leaving messages on a publicized voice mail system. They have also worked further among non-gay-identified MSM, including the “massage boys” of one of Mumbai’s beaches, in certain public sex environments and within several other sexual networks.

A range of other programs to promote the sexual health of MSM can also be found elsewhere in India. In Calcutta, for example, the Counsel Club has launched a gay magazine called *Pravartak* to reach substantial numbers of gay-identified middle-class men in Calcutta and surrounding areas, and there are plans to extend this work to meet the needs of non gay-identified MSM. In Lucknow, Friends India publishes a quarterly magazine called *Sacred Love*, whose articles promote HIV-related risk reduction.

Despite a number of preliminary studies documenting the complex and clandestine character of most same-sex relations in India, there have been relatively few other broad-based programs. A widespread denial of homosexual behavior as a key element in HIV transmission in India still seems to be a major problem, even among AIDS prevention workers.¹³ There are some notable exceptions to this trend in the work of the Community Action Network in Chennai (Madras) which has conducted a number of interventions among transgender and non-gay-identified sex workers in the city.¹⁴ Elsewhere in Tamil Nadu, the Praktiti sexual health project has worked with truck drivers to promote sexual risk reduction in relations with other men. In Cochin, in the state of Kerala, the Indian Council for the Prevention of AIDS has undertaken some limited sexual health promotion among local male-male sexual networks. But again, these interventions and activities have not been rigorously evaluated for their effectiveness in promoting risk reduction and reducing the number of new HIV infections.

Throughout much of Asia, as in India, there continue to be debates about how best to address the sexual health needs of MSM. In Bangladesh, for example, three contrasting frameworks of motivation and identity have been documented in relation to MSM: (1) Those among a few English-literate middle-class men for whom the term “gay” is an adequate self description; (2) Those for whom sexual identity is linked more closely to who is giving and who receiving in acts of penetration; and (3) Those for whom sexual access to other men is perceived as a matter of “discharge,” urgency and relief rather than a question of desire or longing.¹⁵ Also in Bangladesh, the Association

for Health and Social Development has been undertaking prevention work among students and members of the professional and middle classes in the manner of an activist gay-oriented group. The Bandhu (which means “friend”) Social Welfare Society has been offering education about HIV and AIDS, distributing condoms and facilitating access to STD treatment services among men who do not identify themselves as gay, but for whom the role taken in penetration is more salient.³

In Sri Lanka there have also been a small number of prevention projects and activities among MSM. “Companions on a Journey” is a gay group founded in 1994 to develop gay support networks, decriminalize homosexual behaviors, provide AIDS awareness and promote sexual health among gay men and those with emerging gay identities. The organization runs a drop-in center and has begun outreach work among male sexual networks, promoting community building and safer sex. While a number of other agencies have been involved in HIV prevention activities among male sex workers and their clients, much of this work has focused on relations with “foreign” tourists, leaving well-developed sexual-exchange networks among local men largely unexamined—and almost completely ignored in local service provision.³

Given Singapore’s strict legal regulations condemning homosexual behavior, the problem of reaching clandestine populations of MSM in the country has been especially difficult. As a result, at least one documented prevention program relied on outreach work as the key strategy for reaching men in settings associated with same-sex contacts. Wallet-sized invitations were distributed for events organized by the intervention team, where games and quizzes were conducted focusing on AIDS-related issues such as HIV testing, safer cruising and safer sex practices. A four-session risk reduction workshop was also organized. Over a two-year period, from 1990 through 1992, attendance at these events jumped from five to more than 200 participants, though evaluation of this work has been limited, as most participants have failed to respond to knowledge, attitudes and beliefs (KAB) surveys conducted by program staff.¹⁶

In the Philippines, the Library Foundation, a gay community organization, has sought to promote greater HIV/AIDS awareness among MSM. Beginning in the early 1990s, the foundation developed a series of eight weekend-long workshops on Healthy Interactions and Values in which 15 to 30 participants discuss HIV/AIDS, safer sex and the organization of homosexuality and gay life in the Philippines. The foundation conducted pre- and post-workshop surveys of participants, finding a 90 percent increase in AIDS awareness and a “high level” of behavior change among them.^{17,18} As this program was extended from 1992 to 1993, the Library Foundation reported an increasing sense of gay community developed through interpersonal networking and periodic social activities. The program focused increasingly on moving beyond HIV/AIDS information to address issues of empowerment and community mobilization.¹⁹ There has also been work among male sex workers in the Philippines to promote risk reduction, raise self-esteem and encourage greater awareness of HIV-related risks.²⁰ Targeted outreach work also has been carried out in the Philippines by the ReachOut AIDS Education Foundation in the only acknowledged gay bathhouse in Manila. Patrons of the bathhouse were given a KAB survey, and the results were used to develop a safer sex brochure, which was distributed together with condoms and lubricants. Safer sex seminars have also been organized for patrons, and initial results suggest an increased level of knowledge, improved personal risk assessment and increased condom use inside the bathhouse.²¹

In Vietnam, the Nguyen Friendship Society is reported to have carried out a range of educational, outreach and other activities—including condom distribution—to MSM in Ho Chi Minh City.²² Fashion events have been organized to promote AIDS awareness and enhance self-esteem among MSM. There are

reports of similarly innovative, but as yet unevaluated, outreach work among different groups of MSM in a range of locations in Indonesia, including Surubaya.²³

There seem to be a number of patterns in reviewing these reports from Asia. As in other parts of the world, the projects targeting MSM have almost always been conducted by small, nongovernmental, gay or gay-emergent organizations with limited staff and resources. Much of this work has focused on outreach activities that seek to reach MSM in settings where they congregate, socialize or meet sexual partners. A number of groups also have begun to initiate meetings and workshops aimed at involving men with AIDS prevention programs and organizations. As in the case of the Library Foundation in the Philippines, they are increasingly emphasizing notions of collective empowerment and building a stronger sense of gay community as a way of providing social support for risk reduction.³

PREVENTION EFFORTS AMONG MSM IN LATIN AMERICA

Many of the same approaches for AIDS prevention and intervention directed at MSM are being used in Latin America. As in Asia, small, nongovernmental, gay and AIDS activist organizations have tended to take the lead role in developing prevention programs. In Mexico, for example, gay rights organizations such as Colectivo Sol have undertaken a range of HIV prevention activities. A Todo Vapor, Colectivo Sol's project in the public steam baths of Mexico City, aims to inform patrons and bathhouse managers about STD and HIV transmission, safer sex practices and condom use. Condoms and water-based lubricants have been distributed as part of this work.¹

In Costa Rica, a well-developed gay subculture coexists with more traditional forms of homosexual and bisexual behavior—independent of a distinct “gay” identity. The Instituto Latinoamericano de Prevención y Educación (ILPES) has undertaken a wide range of prevention activities, including a telephone information line, holistic workshops in which sexual health concerns are addressed within the broader framework of self-understanding and self-esteem, work in prisons and outreach work in a

variety of locations, including male brothels. A recent evaluation of ILPES' workshops for gay men showed them to be effective in reducing the incidence of reported unprotected insertive and receptive sex.²⁴

A number of important programs have been developed in Peru.²⁵⁻²⁷ In collaboration with the Homosexual and Lesbian Movement in Lima, an educational intervention was initiated in 1988 for a cohort of 50 middle-class homosexual and bisexual men in Lima. The men in the cohort attended a program of three workshops that used group dynamics and audiovisual materials to provide information about HIV/AIDS and eroticizing safer sex practices. Evaluation documented a relatively high initial level of information about HIV/AIDS, as well as significant willingness to change risk behavior as a result of participation in the workshops.²⁴ This work was extended in the early 1990s through the work of the Via Libre Association in Lima. Following a survey on AIDS-related knowledge, attitudes, beliefs and practices, a three-and-a-half hour workshop was developed to improve HIV/STD risk perception, increase motivation and skills related to prevention and develop solidarity with people living with HIV/AIDS (PLHA). Pre- and post-workshop questionnaires were used to evaluate knowledge, attitudes and perceived skills. A follow-up survey was used to compare recent behavior with that of a non-interview control group, as well as to assess the accuracy of risk perception. The program was reported to have raised knowledge and decreased discrimination against PLHA, with a high percentage of the participants approving of the workshop methodology.²⁷

Brazil probably has the largest number and most varied range of projects. A number of important early activities, such as an AIDS hotline and free condoms, were developed in the mid- to late-1980s by a range of gay rights organizations, including Atobá in Rio de Janeiro and the Grupo Gay de Bahía (GGB) in

Salvador.²⁸ Like the projects in other parts of the developing world, these early initiatives for the most part were both poorly funded and relatively unsystematic due to their lack of resources.

One important exception to the relatively few small-scale intervention programs that have characterized the response to HIV/AIDS in most other developing countries has been the “Homosexualities Project” developed for MSM in Rio de Janeiro and São Paulo. The project sought to develop a range of activities and strategies designed to clarify the relationship between homosexuality and HIV/AIDS, and create a supportive social environment for risk-reducing behavioral change on the part of the emerging gay community. It aimed to address the stigma and discrimination related to homosexuality in Brazilian society, seeking to demystify homosexual behavior and develop a more realistic assessment among the population as a whole of the relationship between AIDS and homosexuality. Intervention methods included a range of outreach activities aimed at reaching MSM in the diverse sites in which work was carried out, and developing a range of cultural activities such as theater workshops, video and theater production and related cultural events.²⁹⁻³²

One of the most important elements of the Homosexualities Project in Brazil was the fact that it was developed in partnership among local AIDS-service organizations, gay activist groups and university research centers. Largely because of this partnership, it was possible to develop a set of ongoing research activities to monitor intervention activities through ethnographic observation and to monitor community impact through repeated surveys of sexual behavior and behavior change.^{12,32} These studies showed that between 1990 and 1995 there was a dramatic increase

in the perception of risk on the part of the men interviewed concerning their potential risk of HIV infection as well as in their belief that they could take positive action to avoid infection. Although the number of men reporting anal sex in the six months prior to the interview rose from 67.4 percent in 1990 to 76.3 percent in 1995, the proportion of unprotected anal sex fell from 54.1 percent in 1990 to 22.0 percent in 1995. The proportion of anal sex protected by condoms rose even more dramatically, more than doubling from 34.0 percent in 1990 to 68.7 percent in 1995.³²

An expanding number of interventions throughout Brazil in recent years have sought to address the needs of MSM, as well as men involved in sex work or in prison. AIDS-service organizations and gay groups—such as GAPA-Minas Gerais in Belo Horizonte, GAPA-Ceará in Fortaleza, GAPA-RS and Nuances in Porto Alegre, Grupo Dignidade in Curitiba, Atobá and the Grupo Arco-Íris in Rio de Janeiro, as well as GGB and GAPA-Bahía in Salvador—have all developed programs largely funded by the National AIDS Program of the Brazilian Ministry of Health.³¹ In a number of cases, special programs have been designed for behaviorally bisexual men, sex workers and men in prisons.³²⁻³⁴

Throughout the Latin American region, a growing number of HIV/AIDS and gay organizations have become increasingly involved in similar prevention activities. The Corporación Chilena de Prevención del Sida³⁵ and the Centro Lambda³⁶ in Santiago, Chile, for example, have developed a range of research and prevention activities directed at gay and bisexual men (see the case study below). As in Asia, these initiatives for the most part have been relatively small-scale—most frequently carried out without significant financial support, and in some cases, unfortunately, even in the face of official resistance. By focusing on strategies such as street outreach, cultural activism and community-building and mobilization, important steps are being taken to redress the previous lack of attention to one of the most vulnerable population groups in virtually all of the countries in the region.

PREVENTION EFFORTS AMONG MSM IN THE CARIBBEAN

The Caribbean region* has HIV prevalence rates second only to sub-Saharan Africa. By year-end 2000, UNAIDS estimates that an average of 2.3 percent of adults in the Caribbean were infected, 35 percent of them women.³⁷ Heterosexual contact was the primary mode of transmission and male-male sex a distant second. Up to five percent of the adult population in Haiti is HIV positive. The rates varied in countries such as Trinidad and Tobago (1.05 percent adult), Barbados (1.17 percent adult), Guyana (3.01 percent adult) and the Bahamas (4.13 percent adult).³⁸ The number of new AIDS cases in this region doubles every four to five years. Many cultural, social and behavioral factors and practices contribute to such high rates in the Caribbean, including early sexual initiation; acceptance and even encouragement of multiple sexual partners for males; low levels of condom use; substance abuse; denial that sexual activity occurs in prisons; and social norms that prevent open dialogue about sex with youth in schools.

While heterosexual contact is the primary mode of HIV transmission in the Caribbean, it is important to examine the role of male-male contact in transmission. There is widespread denial in the region of MSM activity, so it is often disregarded or ignored as a mode of HIV transmission. Homosexual behavior is illegal in most Caribbean countries (i.e., Barbados, Jamaica, and Trinidad and Tobago).³⁹ There are high levels of homophobia in the region and homosexuality is highly stigmatized by the general population as well as influential sources such as religious groups and politicians. Because of the stigma and fear of persecution and even prosecution, MSM are often not open about their sexual orientation. In fact, many MSM do not self-identify as homosexual or even bisexual. Research has shown that there are a significant number of men in the Caribbean region who have sex with men, and are not only openly involved in sexual relationships with women, but self-identify as being heterosexual.⁴⁰ This obviously has serious implications for prevention programs and makes it extremely diffi-

cult to target this group with effective communication interventions. These complex factors result in a lack of interventions targeting MSM.

An analysis of HIV data from this region reveals a high percentage of “other” listed as the mode of transmission. In conjunction with research this lends credence to the supposition that there are relatively high levels of MSM transmission in the Caribbean. The “probable exposure” category of the Pan American Health Organization (PAHO)/ World Health Organization (WHO) 1997 estimates of HIV cases in the English-speaking Caribbean suggests that 14.5 percent of all new exposures were attributable to male-male contact. More recent statistics report an average of 18 percent of cases listed as “unknown” across the region and as high as 35 percent in some countries.³⁹ Although the levels of HIV among MSM in the Caribbean are not completely known, there are strong indications that it is high. This comes mainly from the high percentage of those who claim “other” as their transmission mode and from health care practitioners who report a large number of young gay men dying from AIDS.⁴¹

Commercial sex in this region is complex and deserves mention and examination in the context of HIV/AIDS and MSM programming. There are various forms of heterosexual and homosexual prostitution in the Caribbean—street workers, bar workers and independent workers—as well as many types of sex tourism, such as casino girls, “sanky panky” (MSM), beach boys/“rent a dread” and female tourism workers. Among these are men and women who cater to both men and women in heterosexual and homosexual settings. Sentinel surveillance in the Dominican Republic for 1999 shows an HIV prevalence rate of 10 percent among commercial sex workers.^{42,43}

* This section refers mainly to the English-speaking Caribbean region, with some focus on the Spanish-speaking Dominican Republic.

HIV/AIDS interventions with MSM are further complicated by the existence of often complex sub-groups within the broad category of MSM. In the Dominican Republic, for example, there are four main sexual identity groups that may include MSM behavior: cross dressers, homosexuals, gigolos and bisexuals. These sub-groups need to be more fully understood and considered when creating prevention messages. It is extremely important to consider the role of MSM in society—their behavioral patterns and individual and group needs when planning prevention, care and support programs in the Caribbean. Programs need to foster openness, promote understanding and work towards eliminating stigma.⁴⁴ The most successful programs will understand and address the social and psychological factors behind MSM behaviors. Programs also will work to help men protect themselves in their sexual relations with other men, as well as with their female partners and future children. MSM interventions will be strengthened by working with the men on skills-building and self-esteem issues. Successful MSM programs have decreased vulnerability in this group. They become successful by having the backing of political leaders and other key stakeholders. Acceptance of MSM and successful interventions with MSM in the Caribbean region still have a long way to go, but MSM are an important constituency of HIV prevention planning and implementation, and can no longer be ignored by policy makers and program implementers.

LESSONS LEARNED AND RECOMMENDATIONS

In countries and cultures around the world, the types of small-scale, community-based programs described above have emerged to respond to the vulnerability of MSM in the face of HIV and AIDS. Given their limited scale, it is not surprising that such programs have not been enough to turn back the tide of the epidemic. Because they have almost never been systematically evaluated through the use of experimental or quasi-experimental research designs, the programs have not provided the kind of empirical information base that would ideally be available to programmers and policy makers in developing countries seeking replicable models of HIV/AIDS prevention programs for MSM. One of the most obvious conclusions from this review is that rigorous intervention and evaluation research on the structure, process and outcomes of prevention programs for MSM in developing countries are urgently needed.

In spite of these limitations, however, the descriptions we have reviewed above—they are largely based upon observational reports and case studies rather than experimental evaluation designs—nonetheless provide a clear sense of the issues that must be addressed. On the basis of such reports, it is clearly possible to provide a strong theoretical framework that will enable policy makers and other stakeholders to design and implement meaningful programs even in the absence—or while waiting for the results—of more experimentally valid scientific research findings. If they are implemented urgently enough, these programs will surely save lives and reduce HIV/AIDS-related human suffering.

First and foremost, the programs have demonstrated the fact that correct, up-to-date information about HIV/AIDS is necessary to prevention and care, which must be guaranteed to all population groups—especially those that have traditionally been marginalized and stigmatized in society. But the programs also have confirmed the fact that although access to information is necessary for responding effectively to the epidemic, it alone is not enough to ensure a successful response.

Beyond knowledge and information, or behavior change models based on notions of rational decision making, there are more intangible social, cultural, eco-

conomic and political issues of central importance. Above all else, perhaps, these programs demonstrate the importance of reaching out, building communities capable of providing community support structures, empowering MSM to take action on their own behalf, and ensuring their basic human rights and dignity—even in the face of persistent stigma and discrimination on the part of the wider society. In fact, a number of key principles emerge from this experience that can be considered as absolutely essential to the development of effective prevention and care programs. To be successful, such programs must recognize:

- The diversity of both identity and behavior among MSM, and their HIV prevention and sexual health needs.
- In many cultures concepts such as homosexuality, bisexuality or being “gay” may have little meaning, and even in societies that use such categories many MSM may not consider them to be relevant to their own identities or experiences.
- The value of gay community attachment for men who do identify as gay, and show confidence in their emerging sexual identity.
- The value of community outreach work in public sex environments, bars and other sites where men meet other men to have sex.
- The importance of mobilizing communities and developing community support structures to reach MSM and provide them with social and psychological support for adopting and sustaining safer sexual practices.
- The importance of collective and individual empowerment in the face of widespread stigma and discrimination as a key element of all intervention programs for MSM.
- The importance of defending basic human rights for MSM as part of broader efforts to develop a social climate capable of supporting the reduction of vulnerability to HIV/AIDS and other health risks.

Each of these principles is centrally important to creating a social context capable of reaching MSM. Ultimately it will only be possible to reduce the vulnerability of MSM to HIV and AIDS by linking all such principles together as part of a coherent program of mobilization and support.

FUTURE CHALLENGES

Recognizing the applicability and interdependence of such principles is the key challenge to the development of HIV/AIDS programs for MSM in resource-constrained settings—whether in the countries and cultures of the developing world or among the many poor and marginalized populations in the so-called developed countries. Such recognition will be possible only by building on the experience of highly localized community-based programs to scale-up existing activities with the goal of reaching larger and more isolated segments of the MSM population. Scaling-up, in turn, will require a serious investment in formative and evaluation research to ensure that programs meet the needs of communities and help reduce vulnerability and behavioral risk. It will also require ongoing commitment to providing the necessary resources for ensuring successful prevention. It helps very little to promote condom use, for example, if condoms are unavailable or inaccessible. (See Chapter 12 for information on condom social marketing strategies.)

Treating STDs as an important way of reducing HIV infection will be doomed to failure if health care services are unable to guarantee a nondiscriminatory environment for attending patients who are homosexually or bisexually active. (Chapter 15 discusses STD control among special populations.) Increasing the scale of program activities must never be confused with substituting their fundamental community base—or taking control of program activities out of the hands of community members in favor of professional staff or bureaucratic administrators from outside the community. It is essential that programs for MSM remain deeply rooted in community structures and community organizations precisely because these contexts provide the necessary vehicle for reaching isolated individuals and segments of the larger population. The task that remains everywhere in the world is to recognize this fact, and provide these communities and community-based organizations with the resources, structural and policy support and creative freedom they need to do their work.

CASE STUDY

PREVENTIVE INTERVENTION AT PUBLIC SEX SITES IN SANTIAGO

Sites where there is public sex between men have traditionally been the focus of AIDS prevention programs in Western gay communities. Such interventions have been less common in other countries where there is public sex, particularly between men, because it is more difficult to acknowledge or because homosexuality is more stigmatized. This makes the Chilean experience of an HIV/AIDS prevention program in public sex sites (PSS) of particular interest in this chapter.*

This program was implemented by the Corporación Chilena de Prevención de SIDA (Chilean AIDS Prevention Council [CChPS]). In the first phase, carried out in 1993 and 1994, CChPS assessed homosexual activity in public places to characterize the context and identify the intervention needs in these venues. This assessment was aimed at determining patterns of sexual behavior among homosexual and bisexual men who have sex in public places; their level of information about STD/HIV/AIDS; risk perception; attitudes and beliefs about their sexual activity; and the role of public sex in their affective and emotional life. Two types of spaces, namely open venues such as parks (“type 1”) and saunas (“type 2”) were targeted.

Of the 35 persons who were approached, 22 mostly middle- and upper-middle-class men agreed to have verbal contact in the locations studied, while another six participated in in-depth interviews. They ranged in age from 17 to 50, with an average between 21 and 30. Sixteen defined themselves as homosexual, three as heterosexual, two as bisexual and one did not specify. Twenty expressed their fear of contracting STD/HIV/AIDS. Ten reported practices posing high- or medium-risk for HIV/AIDS, and another 10 had less than basic information about the transmission and prevention of STD/HIV/AIDS. Twenty believed that preventive interventions were important in those places.

Information gathered in this first phase led to the conclusion that riskier situations occur in open spaces because the brevity of the encounter impedes the negotiation of safer practices. In contrast, saunas offer better conditions in which to negotiate safer practices. The men had a range of motives for seeking sex in these spaces. A few individuals who seem to seek anonymous sex to escape emotional abandonment are highly vulnerable and require the design of specific preventive interventions. A second group of individuals, who look for anonymous sex—sometimes under the influence of alcohol—are also highly vulnerable and have special intervention needs. A third group appear to seek casual sex for personal convenience. They seem to be less vulnerable and more receptive to prevention messages. It became clear that most individuals understood prevention to mean not doing things that they did not find exciting or amusing.

The second phase sought to implement and evaluate an intervention aimed at:

- Providing adequate sexual health information to the MSM population who use PSS, so it is possible to do realistic assessments of personal behavioral risks.
- Facilitating access to condoms and safer sex information.
- Generating common ground between the prevention program monitors and the users of public sex spaces so as to present prevention as a lifestyle applicable everywhere and in any situation, without giving up pleasure.

Both open spaces and saunas were targeted. CChPS devised a schedule of visits to the sites and reprinted educational materials. Intervention records, which would serve in monthly process evaluations and to measure the intervention impact, were revised and improved. A training workshop for new monitors was designed and applied in January 1996. Visits to PSS were made three times a week on the busiest days between May and July 1996, and the team held weekly meetings to evaluate program implementation and prepare evaluation reports.

* In preparing this case study, we would like to acknowledge information provided by Tim Frasca from the Corporación Chilena de Prevención de SIDA; Victor Parra, originator and chief investigator on the project; and Juan Carlos Silva and Juan Carlos Rios, the principal collaborators during the execution phase of the project.

Process information collected in the first semester of 1996 reveals that a total of 8,100 PSS users were observed, 64.5 percent of whom were reached and given educational materials and condoms. First-level contact—asking the monitor for information about STD/HIV/AIDS or CChPS—was made with 780 (9.6 percent) individuals. Second-level contacts—the individual talking about his sexuality, emotions and doubts about STD/HIV/AIDS—were made with 225 individuals (3.2 percent). Of the total population observed and interviewed at the PSS, 68 (0.31 percent) individuals phoned CChPS with more specific questions, and 79 (0.97 percent) visited CChPS to use its services.

Monthly qualitative and quantitative reports on the visits to the PSS were prepared so the impact of the intervention could be analyzed. Of the 225 contacted at a second level, 96.8 percent felt the intervention was very adequate, positive or very positive, and declared that the distribution of condoms at PSS was very important, since having them at hand might increase their use. On the downside, three percent were indifferent or reacted negatively to the intervention without stating their reasons.

This research experience is of particular value in the region because it has an adequate framework of development (i.e., a formal needs assessment), a focus on a usually neglected sex scene which should be a priority for prevention efforts and a well-documented process and impact evaluation. Another of the study's merits was its success in gaining access to subjects who are looking for the anonymity of the PSS in Chile, where homosexuality is illegal.

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Chapter 12 *Social Marketing for HIV/AIDS Prevention*

Chapter 15 *Issues in STD Control for Special Populations*

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C H A P T E R

12

*Social
Marketing:
Two Approaches
to HIV/AIDS
Prevention*

WILLIAM A. SMITH



Social Marketing: Two Approaches to HIV/AIDS Prevention

INTRODUCTION

There is no single, comprehensive solution to the problem of increasing HIV infection rates in many of the world's resource-constrained countries. But there are effective ways to reduce both the rates and the consequences of infection. In reviewing this list of prevention strategies, it is obvious that although condoms alone are not enough to prevent the spread of HIV/AIDS, they are an important part of any HIV prevention strategy.

This chapter focuses on lessons learned from the social marketing of condoms. It gives special attention to condom social marketing because of the important contribution to HIV prevention of promoting the distribution and sale of condoms among some of the world's most resource-constrained settings. The chapter also argues that the same social marketing approach can and should be applied to other critical HIV prevention behaviors. It provides arguments for the expansion of a social marketing methodology to address other critical aspects of HIV prevention.

STATE OF THE ART APPROACHES, STRATEGIES AND EXPERIENCE

The term "social marketing" has often been used as a label for programs that are really social communications or social advertising activities. Genuine social marketing focuses on both external (access to resources, new services and lower barriers) as well as internal (clever and persuasive messages) influences on behavior. One of the greatest strengths of condom social marketing programs has been their ability to increase access to reliable condoms among populations not served by the commercial sector.

Social marketing is characterized by five activities that constitute the basic project development process followed in the examples presented throughout this chapter. These are the characteristics that make social marketing so applicable to a broad range of HIV prevention behaviors and programs. These activities, which are described in this section, are:

- Ongoing, iterative research, planning, action, assessment and replanning
- Consumer research
- Audience segmentation
- Exchange
- Marketing mix

THE SOCIAL MARKETING OF CONDOMS FOR HIV PREVENTION

Condom social marketing took on special importance with the emergence of HIV/AIDS. A relatively difficult and unreliable method of contraception, the inherent deficiencies of condoms became challenges to be overcome, as there was no other viable product with the same potential to prevent HIV/AIDS. An early Swiss program provides a model of successful—and ongoing—condom social marketing, and demonstrates how monitoring and evaluation are used to constantly adjust a national program to the changing needs of the epidemic. The Appendix offers summaries of studies and lessons learned that represent the best information to date on the application and effectiveness of social marketing applied to the marketing and sale of condoms in resource-constrained countries, with a special focus on Africa.

THE SOCIAL MARKETING OF HIV PREVENTION SERVICES AND BEHAVIOR

HIV prevention requires more complex efforts than condom sales alone. An intervention framework is needed that is both systematic and adaptable to various cultures, one with a solid scientific base and which has shown its ability to absorb new theories as they arise. There is a similar situation with respect to HIV/AIDS medication in that both the drugs and information about proper compliance will have to be marketed.

Service and behavioral marketing refers to the application of social marketing to non-packaged products. Project examples are provided that demonstrate how social science has contributed to understanding the barriers and determinants of critical condom use behavior.

LESSONS LEARNED AND RECOMMENDATIONS

As developing countries move to address broader issues of HIV/AIDS prevention, social marketing with its rigorous systematic approach to understanding people and the cultural context in which they behave has much to contribute. A number of recommendations are provided.

FUTURE CHALLENGES

Future challenges to the effective use of social marketing in HIV/AIDS prevention include:

- Manpower development
- “Condom fatigue”
- Condom quality control
- The expansion of social marketing to the marketing of behaviors and categories other than condom sales

CASE STUDIES

This case study from the AIDSCAP program in Cameroon provides an example of how condom social marketing can be effectively integrated within a broader, more comprehensive program of HIV/AIDS prevention. This is perhaps one of the most important lessons to emerge over the years. Condom social marketing alone should be thought of as only one tool—albeit a very important one—for effective HIV/AIDS prevention.

Operations research on the Tsa Banana program in Botswana demonstrated that this adolescent social marketing intervention significantly improved adolescents’ beliefs regarding AIDS and preventive behavior within eight months after the start of the intervention. In particular the program increased awareness of the severity of HIV/AIDS, increased the beliefs that condoms and abstinence provide protection and demonstrated that it is not easy to convince males to use condoms.

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There is growing recognition that the HIV/AIDS pandemic is fostered by complicated cultural, social and behavioral factors. In this complex context, there is no single, comprehensive

solution to the problem of increasing HIV infection rates in many of the world's resource-constrained countries. But there are effective ways to reduce both the rates and consequences of infection, including:

I N T R O D U C T I O N

- Reducing an individual's number of sexual partners;
- Ensuring that all extramarital sex includes the proper use of a reliable condom;
- Providing counseling to HIV-positive married couples;
- Promoting early treatment of infants of HIV-positive mothers;
- Promoting proper feeding of infants of HIV-positive mothers;
- Reducing stigmatization and discrimination against HIV and persons living with HIV/AIDS (PLHA); and
- Ending gender inequalities that limit a woman's ability to protect herself from HIV/AIDS.

In addition to these direct actions, a number of indirect actions are believed to be important to successful HIV/AIDS prevention, including:

- Promoting national leadership that favors science-based HIV prevention;
- Promoting policies such as tax-free importation of condoms;
- Improving accurate information about HIV transmission;
- Reducing the number of harmful myths about HIV;
- Promoting social norms supportive of HIV prevention; and
- Increasing the self-efficacy of high-risk populations in using prevention effectively.

In reviewing this list of prevention strategies,* it is obvious that condoms alone are not enough to prevent the spread of HIV. But condoms are an important, perhaps essential, part of any HIV prevention strategy.

This chapter focuses on lessons learned from the social marketing of condoms. It also argues that the same social marketing approach can and should be applied to other critical HIV prevention behaviors. It provides arguments for the expansion of a social marketing methodology to address other critical aspects of HIV prevention. Some experts have tried to differentiate between condom social marketing and behavioral interventions—social marketing of non-condom prevention behaviors—but this distinction is semantically and programmatically misleading.

The fact is that both commercial marketing and social marketing have a long history of dealing with more than packaged products. *Service* marketing in the commercial sector and both *behavioral* and *advocacy* marketing in the social sector are well studied. The attempt to limit the lessons of social marketing to the promotion of packaged products denies HIV prevention the rich experience of success offered by the field of social marketing.

This chapter gives special attention to condom social marketing because of its important contribution to HIV prevention in promoting the distribution and sale of condoms among some of the world's most resource-constrained settings. But broader application of social marketing will be needed as the world moves to intensify its efforts on HIV/AIDS prevention.

* See Chapters 16, 16, 18, and 23 for more information on these prevention strategies.

STATE OF THE ART APPROACHES, STRATEGIES AND EXPERIENCE

DEFINING SOCIAL MARKETING

Social marketing has been in the literature since the 1970s, applied in various ways to promote childhood immunizations, diarrheal disease control, family planning, improved nutrition and diet and environmental behavior. Too often, however, the term “social marketing” has been used as a label for programs that are really social communications or social advertising activities. Media campaigns and clever slogans and messages characterize these narrower applications, and they often include sophisticated consumer research and targeted messages. This is why they are often confused with social marketing.

Genuine social marketing focuses on both external (access to resources, new services and lower barriers) as well as internal (clever and persuasive messages) influences on behavior. Social marketing is defined as: A program management process (implies sequenced action steps) designed to influence human behavior (not only knowledge or attitudes) through consumer-oriented decision making (marketing) leading to increased societal benefit.

The social marketing of condoms looks very much like the marketing of other frequently used consumer products. It is an integrated effort designed to make a seamless program of the choice of condom styles, the places where condoms are made available, the price charged for condoms and the promotion of condoms in a way that maximizes the consumer’s ability and willingness to purchase and use them. One of the greatest strengths of condom social marketing programs has been their ability to increase access to reliable condoms among populations not served by the commercial sector. Access is just one of the critical variables in a successful marketing program. The pricing of condoms to ensure that they have value and are also affordable is also critical. A choice of products has been shown to be useful, particularly as a condom market matures with customers who want both variety and reliability. Finally, the multiple ways of promoting condoms can be critical to success. What benefits do consumers care about? Which channels of communication do they use and trust? The answers to these questions constitute the primary thrust of a successful condom social marketing program.

A social marketing project includes five basic activities, which together constitute the project development process followed in the examples presented throughout this chapter. These characteristics make social marketing so applicable to a broad range of HIV prevention behaviors and programs. The process comprises these activities:

- Ongoing, iterative research, planning, action, assessment and replanning
- Consumer research
- Audience segmentation
- Exchange
- Marketing mix

Continual and iterative process of research, planning, action, assessment and replanning

Like many other program planning models, marketing uses a sequenced framework of assessment, planning, setting objectives, pre-testing, application, monitoring, reassessment and modification. Unlike some social planning models, there is fundamental recognition in marketing that this is a permanent cyclical process. No one at Coca-Cola would argue that marketing Coke is something you do, and once accomplished need do no more because everyone knows about and likes Coke. Selling Coke is something you have to do every day in ever-new ways to meet an ever-changing consumer. In many social programs, however, there is an assumption that behavior change is something to be “accomplished,” and once in place, behavior should sustain itself through some natural reward or the power of some cognitive process. This has led to a linear planning model that is inconsistent with behavior change.

People and communities change over time. There are very few “natural rewards” for many of the safer sex behaviors being promoted in HIV prevention

efforts. Safer sex behaviors face continual competition from unsafe behaviors, and people and communities need a permanent program of behavior change that aims to reinforce existing adopters of changed behavior, as well as helping people at high risk become new adopters. Social marketing provides a framework for programs to continually assess, plan and provide new support to meet the demands of those changes.

Consumer research

People and their behaviors are sufficiently complex to warrant a multi-faceted (qualitative plus quantitative) and iterative research process to identify and track changes in knowledge, attitudes and behavior that may influence the outcomes of interest to program managers. The key contribution of social marketing here has been *multifaceted research*, a skillful integration of qualitative and quantitative methods to produce practical answers to program design questions. Rather than asking what is not known about HIV prevention, market research is focused on answering such practical questions leading to program decisions, as:

- How are people different so that we can target their specific wants?
- What benefits do people care about in an HIV prevention product such as condoms?
- Where will people be most likely to get those products?
- What are the toughest barriers for them to deal with, and how can they be lowered?
- How important is the price of a condom to different users?
- What messages—language, metaphors, images—break through the clutter of other messages and resonate as authentic for them?

Audience segmentation

Although people and communities are different, they can be grouped in ways that maximize certain similarities that often go beyond risk behavior or demographics. Programs can take advantage of these meaningful similarities and develop specific interventions to address each “segment” identified. For example, all men who have numerous sexual partners are not alike. Some men with multiple partners may be condom users, while others are not. Some may see multiple partners as a lifestyle, while others may see it as related to being young and free for only a few years. Consumer research can help us make distinctions that are useful in reaching different subsets of this audience with greater precision and efficiency.

Exchange

People do things in exchange for benefits. This means that behavior change often involves a cost to individuals or audiences (giving up multiple sexual partners or time, for example); giving something up may require that a program manager offer some benefit to achieve a desired change (life-long commitment); and successful behavior change requires understanding that people value many things other than health or wealth in this process of exchange (identity as a man for some may mean having many sexual partners).

Marketing Mix

The concept of marketing mix is shaped by a belief that people’s behavior is influenced by four domains that they weigh against competing alternatives when choosing a behavior:

- **Product** (an idea, service or behavior that offers a benefit)
- **Price** (the financial, emotional, social and temporal costs of the product)
- **Place** (distribution channels through which the product is offered)
- **Promotion** (methods for motivating or encouraging individuals to use the product)

To be considered social marketing, a program must demonstrate serious consideration of all five basic activities outlined above. But the strategic consideration of the full “marketing mix” is what differentiates social marketing from the concept of traditional health education, social advertising or social communication.

THE SOCIAL MARKETING OF CONDOMS FOR HIV PREVENTION

Condom social marketing took on special importance with the emergence of HIV/AIDS. Male condoms had rarely been a preferred method of family planning; they are difficult to use, the unreliability of their use has been recognized for years and men tend to be less disciplined than women in effectively using a method. In the era of HIV/AIDS, however, these deficiencies became challenges to overcome, as there is only one other viable product, the female condom, with the same potential as condoms to prevent HIV/AIDS. But the female condom has yet to prove itself in a large-scale marketplace.

Among the world’s first and most successful HIV/AIDS social marketing programs was the Swiss Stop AIDS program. While Switzerland is certainly not a resource-constrained country, the Stop AIDS program was started by a small group of gay men who believed that if gay men were to use condoms they needed a specific branded condom (the *Hot Rubber*) with special appeal and distribution. Over time the program evolved into a national, government-supported effort with many phases. Stop AIDS demonstrates clearly how social marketing can be used to successfully promote a much wider range of prevention behaviors than condom promotion alone. It is an excellent example of how monitoring and evaluation are used to constantly adjust a national program to the changing needs of the epidemic.

THE STOP AIDS CAMPAIGN¹

The Stop AIDS campaign is one of the longest running and most carefully evaluated social marketing programs for AIDS prevention in the world. It was launched in 1987 as a national, multi-media campaign designed to increase condom use among Switzerland’s general population and targeted risk groups, reduce discrimination against individuals with HIV/AIDS, and increase solidarity between those living with HIV/AIDS and the rest of the population.

Its initial audience was gay men, but as the epidemic began to expand it reached out to a truly national audience. The campaign’s most important difference was to constantly measure not only condom use but changing attitudes toward the AIDS epidemic. One product was the condom, but another product was anti-discrimination and later needle exchange. The Swiss were convinced that as long as AIDS was feared, risky sex would remain underground. The price of prevention was lower than the price of high-risk behavior, because the price of prevention no longer included the fear of discovery. In addition to condom promotion and needle exchange being promoted on radio and TV, community groups were organized, a special *Hot Rubber* brand created for gay men, and new distribution points opened throughout the country for condoms and for counseling and testing.

Among the indicators of the Stop AIDS campaign’s success were:

- **Increased condom sales:** Between 1986 and 1990, condom sales increased by 80 percent (from 7.6 million to 15 million units).
- **Increased condom use:** Between 1987 and 1990 condom use among 17- to 30-year-olds increased from 8 percent to almost 50 percent. Condom use among 31- to 45-

continued

continued

year-olds also increased during that time (from 22 percent to 35 percent).

■ **Did not increase the number of partners:**

Between 1987 and 1989 the number of people that considered mutual faithfulness effective protection against HIV transmission had increased from 18 percent to 49 percent. In the 17- to 20-year-old age group, the number of those who had more than three partners actually decreased slightly.

An important element of the Stop AIDS campaign was its strategy of gradually phasing in different messages over a period of several years. This approach had the effect of allowing the population to slowly digest the information being presented while making subtle changes in attitude and behavior. Soon after the initial condom campaign, the media strategy began to include ads targeting the issues of needle sharing and faithfulness.

Condom social marketing in resource-constrained countries

Three international organizations have been particularly active in the application of condom social marketing to the problems of HIV/AIDS in resource-constrained countries. They are Population Services International (PSI), the Futures Group and Family Health International (FHI). The Appendix includes summaries of studies and lessons published by these organizations, which represent the best information to date on the application and effectiveness of social marketing applied to the marketing and sale of condoms in resource-constrained countries, with a special focus on Africa.

THE SOCIAL MARKETING OF HIV PREVENTION SERVICES AND BEHAVIOR

As indicated at the beginning of this chapter, HIV prevention requires more complex efforts than condom sales alone. What is needed is an intervention framework that is both systematic and adaptable to various cultures, has a solid science base and has been shown to absorb new theories as they arise. As drugs become available, both the treatments as well as proper compliance with them will need to be marketed. For example, HIV testing and counseling for married couples, proper feeding of infants with HIV-infected mothers and the proper treatment of HIV-infected pregnant women will also need to be marketed. (See Chapters 17, 18 and 23 for more information about preventing mother to-child-transmission of HIV and voluntary HIV counseling and testing.) Another example can be found in a recent study in Northern Thailand, which concluded that HIV-related tuberculosis (TB) sufferers did not seek treatment for TB because of stigma and a misguided belief that TB is not treatable.² This type of problem, as well as such issues as encouraging blood donorship and the social marketing of drugs for HIV and other sexually transmitted diseases (STDs), is an obvious case where social marketing can also be useful.

For many professionals, marketing still means manipulation. This attitude must evolve. Marketing is a systematic way to understand and then balance the needs of people against their wants and desires. When social marketing is successful it respects different cultures and finds within each one the positive forces that can support healthy behavior. And yet social marketing is bottom-line oriented: its goal is not empowerment, liberation or equity per se, but rather the reduction of morbidity and mortality. To effectively market complex and difficult prevention behaviors, a systematic process is needed which first establishes then maintains touch with different types of audience segmentation. Social marketing is such a process, uniquely focused on meeting the wants and needs of those segments.

Service and Behavioral Marketing refers to the application of social marketing to non-packaged products—services such as STD treatment and behaviors such as condom use versus condom sales, talking to partners about sex and condoms, delaying sexual initiation or adopting multiple safer sex behaviors. Many programs have found that behavioral science adds two new and rich dimensions to the social marketing framework: service marketing and behavioral marketing. As demonstrated in the examples below, even for behaviors like condom use versus condom purchase, social science has contributed enormously to understanding the barriers and determinants of this critical condom use behavior. For example, of all various possible determinants for condom use—after easy access has been assured—social norms, behavioral skills and self-efficacy seem the most promising starting points for investigation and intervention design.

Understanding Perceived Social Norms in the Caribbean helped set priorities in a behavioral social marketing project. An analysis of 1990 and 1991 national Knowledge, Attitudes, Beliefs and Practices (KABP) data in St. Vincent compared condom users and nonusers and found that users were significantly more likely to talk to their friends about condoms, believe that their friends use condoms and have their sex partner suggest using a condom.³ Similar results regarding the strong role of perceived social norms were found from analyses of St. Lucia KABP data.⁴ Supplemental focus group research with

sexually active youth revealed that they considered their parents to be obstacles to their own condom use. Focus groups with parents revealed that they did not approve of sexual activity among youth. While parents wanted their children to use protection if they were sexually active, they seldom discussed sex or expectations for behavioral protection with their children. In 1991, a two-phase “When You Can’t Protect Them Anymore...Condoms Can!” program was launched in St. Vincent and the Grenadines, St. Lucia and Grenada, using radio spots, call-in shows, a serial drama, a telephone hotline and public forums. Phase I targeted parents, encouraging them to talk with their teenagers about sexual responsibility and condoms. Phase II aimed at sexually active teens, using a “lifestyles” approach to sexual responsibility, and highlighting the options available to teens, including talking with friends, parents and partners. Tracking survey data from St. Vincent and the Grenadines showed significant changes in key attitudes and normative beliefs among those exposed to the campaign.⁵ Targeting focused scarce program resources on important and achievable goals.

Actual skill practice with condoms increased both perceived self-efficacy and reported condom use and was studied within the context of community implementation. Skill has been identified as a major factor potentially influencing behavior for a wide range of health behaviors, including condom use. Condom skills intervention studies conducted in the Dominican Republic, Trinidad and Tobago, St. Vincent and the Grenadines and Jamaica found that: (1) Physical skill and self-efficacy at putting on a condom can be increased by educational interventions administered in a face-to-face session as well as with an illustrated brochure; and (2) Physical skill and self-efficacy at putting on a condom was associated with increasing other determinants of condom use and with higher reported condom use.⁶

Combined norm and skill interventions increased condom use. The Academy for Educational Development (AED) conducted a field experiment in the Dominican Republic to examine the role of skills interventions in facilitating condom use. The study enabled comparison of the effectiveness of a skill intervention with interventions designed to influence social norms and perceived susceptibility. It included 300 sexually active men who worked in a sugar mill who were each randomly assigned to one of five study groups: control, susceptibility, norm, skills and combined norm and skills. An index of condom-protected sex acts was constructed to study behavioral changes. Results showed that condom use dropped in the control and susceptibility intervention groups. It increased relative to the control group in the individual norm and skills groups. Condom use increased most dramatically in the combined norm and skill group, along with measures of intentions and actual skill. This study, as well as a number of other studies conducted across cultural settings, led the project's principal investigator Dr. Susan Middlestadt to report, "I believe that in the domain of HIV prevention, there are two particularly promising intervention points: skills and social norms."⁷

As developing countries move to address broader issues of HIV/AIDS prevention, social marketing with its rigorous systematic approach to understanding people and the cultural context in which they behave have much to contribute.

LESSONS LEARNED AND RECOMMENDATIONS

- Condom social marketing should be considered an important element of any national program to prevent HIV/AIDS where condom access is low.
- In resource-constrained countries social marketing may be best organized and implemented by a private sector organization, rather than over-burdened governments.
- Governments can help promote effective condom social marketing through policy support to these programs in the form of tax-free importation of condoms, support for widespread advertising of condom products and the reduction of barriers to distribution.
- Free distribution of condoms should not be excluded in countries where there are successful condom social marketing programs. But free distribution should be organized to compliment, rather than compete with, condom social marketing.
- Pricing of condoms should be used to maximize sales, not to maximize the income of the social marketing organization. This may suggest the need for greater subsidies in poorer countries.
- Segmentation, distribution, pricing, advertising and branding are all critical elements of successful condom social marketing that should be resolved by country-specific consumer-based research, rather than the development of international norms or policies.
- Because consumers change over time and are influenced by more than a condom marketing program, successful condom social marketing programs should be free to monitor and change marketing tactics to meet the changing needs of consumers.
- Social marketing has more to contribute to the prevention of HIV/AIDS than just condom social marketing. Social marketing has already been successfully applied to the promotion of services and key prevention attitudes such as social norms and self-efficacy.

FUTURE CHALLENGES

Manpower development is important to the highly technical profession of condom social marketing. It is critical to train and prepare a growing cadre of specialists in marketing research, market management, product development, business management and social science.

Condom fatigue has already been noted in populations in the United States and Europe. There are not enough data to predict what will happen after several years of condom use on a large scale in the countries of Africa, for example. Fatigue has been combated by an ever-growing number of condom product improvements such as lubrication, color and ribbing. It is unclear whether such tactics will work or be accessible to most resource-constrained countries.

Condom quality control may become an important issue as the condom market expands. The U.S. market was flooded in the mid-1990s with cheap and less effective Asian condoms. Ensuring a supply of truly effective condoms for Africa will require regular vigilance.

The expansion of social marketing to the marketing of behaviors and categories other than condom sales will be resisted by professionals who still perceive social marketing as relating only to physical products. Further investments are needed to educate policy makers about the critical role played by condom social marketing and the possible value of expanding the use of social marketing to other HIV prevention needs.

CASE STUDIES

AIDSCAP PROGRAM IN CAMEROON*

The AIDS Control and Prevention (AIDSCAP) program in Cameroon (1992-1996) was designed to address unmet needs in HIV prevention. Available HIV prevalence information in 1992 indicated that Cameroon still had a relatively low HIV prevalence rate, estimated to be between 0.5 percent and 1 percent of the general population. But surveillance studies suggested that the epidemic was increasing rapidly among specific populations within Cameroon—specifically, urban youth, commercial sex workers (CSWs), sexually transmitted disease (STD) patients and the military.

The program focused on improving behavior change communication (BCC) for select targeted groups at higher risk of HIV and STDs, expanding condom availability and affordability through condom social marketing and assisting the Ministry of Public Health to establish a national STD control service. It was funded by the U.S. Agency for International Development (USAID) through a cooperative agreement with Family Health International (FHI).

AIDSCAP/Cameroon's primary responsibility was to build the capacity of the National AIDS Control Service (NACS) to design, implement, evaluate and sustain programs that prevent sexual transmission of HIV and STDs. The AIDSCAP program was implemented by government and nongovernmental organizations (NGOs) and operated at the national level and in geographically focused areas, addressing specific components of the Medium Term Plan of the National AIDS Control Program. The program actively collaborated with the World Health Organization (WHO) and the German Technical Cooperation (GTZ) on sentinel surveillance, and with GTZ on the development of national STD treatment guidelines and peer education activities. AIDSCAP's subcontractors, Population Services International (PSI) and the Institute of Tropical Medicine (ITM), were instrumental in implementing the condom and STD strategies in Cameroon.

** The materials for this case study were drawn from the Family Health International Web page, <www.fhi.org>, where additional information on condom social marketing is also available.*

National interventions included the condom social marketing program implemented by PSI, and support to the Ministry of Public Health for the national sentinel surveillance program and to develop national STD treatment guidelines. Geographically focused activities included interventions with CSWs and their clients, STD patients, university students, military, youth and truck drivers.

The AIDSCAP/Cameroon program focused on building capacity through three complementary and mutually reinforcing strategies: BCC, condom promotion and STD prevention. Below is an overview of these strategic approaches.

BCC strategy

The AIDSCAP/Cameroon BCC strategy included peer health education, community-based outreach programs, developing and distributing educational materials and alternative media such as theater. The heart of the Cameroon program was its pioneering behavior change interventions that have inspired the peer education models currently used around the world. Interventions with the military, university students, STD patients and CSWs and their clients were implemented by the NACS in collaboration with the ministries of defense, higher education and health. CARE/Canada and Save the Children-USA, two international NGOs, respectively implemented the in- and out-of-school youth project and a community-based intervention project in the East and Far North Provinces of the country. The BCC interventions focused on adoption of risk reduction behavior, including promotion of abstinence for young adults, fidelity for couples, partner reduction, condom use and treatment for STDs.

The projects used multiple, reinforcing communication channels and information, education and communication (IEC) activities. Specific approaches included interpersonal counseling and educational techniques, such as formal education sessions, drama, informal chats, one-on-one counseling and mass and traditional media. The projects also focused on building capacity for sustainability through training, developing and producing peer health educator manuals for CSWs, the armed forces, youth and university students. Over the course of the program, AIDSCAP/Cameroon trained more than 2,000 peer educators and leaders, who in turn educated more than 700,000 women, men and youth about HIV/AIDS prevention. More than 1.18 million educational materials that reinforced communication activities and behavior change, radio and television spots were produced and distributed.

Condom promotion

The BCC strategy was complemented and reinforced by the condom social marketing program. Condom programming was implemented by an AIDSCAP subcontractor, Population Services International (PSI). Under AIDSCAP, the condom social marketing program expanded countrywide to reach additional target group populations. As part of its strategy, PSI established officially recognized and supervised distributors in all major urban centers using specific marketing techniques and advertising to cover all of Cameroon's 10 provinces. More than 9,500 condom sales locations were established for Prudence condoms. The program also used peer educators, especially CSWs, to serve as condom sales agents in nontraditional venues while CSM sales staff supplied the more traditional commercial outlets. In Yaoundé alone, CSWs sold more than three million condoms. A number of CSWs were so successful as condom sales agents that they were able to leave the sex work profession. Over the life of the AIDSCAP project, the social marketing program sold more than 24 million condoms and distributed close to one million free ones.

STD prevention

When the AIDSCAP/Cameroon project began there was no national STD control program. AIDSCAP/Cameroon efforts, led by an AIDSCAP subcontractor, the Institute of Tropical Medicine (ITM), concentrated on supporting the NACP in the development of national STD guidelines. As a result of these efforts, a national STD control plan and standard diagnosis and treatment guidelines were adopted by the Ministry of Health. These guidelines were essential for effective and appropriate STD treatment as well as for promoting the rational, cost-effective use of antibiotics. As part of this initiative, AIDSCAP supported a collaborative study with the Centre Pasteur du Cameroun to investigate the sensitivity of gonorrhea to 10 antibiotics commonly used in Cameroon. The results of the study were used to validate the proposed treatment guidelines and assist caregivers in treating gonorrhea. In the final year of the project, the treatment guidelines were adopted and approved by the Ministry of Health for use in its decentralized training program. At the central level, a core group of 10 physician/trainers were trained in their use, followed by a decentralized training for 40 military prescribers. In addition, a pilot study on prepackaged urethritis treatment (MSTOP) to improve access to STD treatment was completed and evaluated.

Capacity building

With assistance from AIDSCAP, governmental and nongovernmental agencies strengthened their capacity over the course of the program to mobilize communities and individuals towards positive action in the fight against AIDS. They made significant progress in raising awareness about STDs and HIV/AIDS and creating a positive environment to support behavior change. Important technical and financial management skills for HIV prevention programming and implementation were transferred to the Ministry of Health and local NGOs.

Significant accomplishments were achieved over the life of the project, including:

- Increasing the capacity of the Ministry of Health to plan, manage and evaluate comprehensive STD/HIV/AIDS programs.
- Educating more than 700,000 men, women and youth about how to protect themselves from HIV/AIDS and STDs.
- Training more than 2,000 individuals working in professional and/or volunteer capacities to sustain HIV prevention activities in their communities.
- Distributing close to 25 million condoms, all but one million of which were sold through the condom social marketing system.
- Distributing more than one million educational and promotional materials that reinforce behavior change communication efforts and condom use.
- Developing and adopting national guidelines for STD diagnosis and treatment by the Ministry of Health.

The final country program evaluation was completed under a grant with Institut de Recherche et des Etudes de Comportement (IRESCO), a local research institute. IRESCO conducted the end-of-project knowledge, attitudes, beliefs and practices (KAPB) surveys among all the target groups. Analysis of baseline and post-intervention quantitative survey data suggests that knowledge about HIV/AIDS increased significantly in all target groups and that many of the target groups have adopted safer sexual behaviors such as increased condom use with a non-regular partner, reduced number of partners and/or seeking treatment for STDs. Specific documented outcomes include:

Increased knowledge of two correct methods of preventing HIV among all the target groups. One of the most dramatic increases was evidenced among youth in the Eastern Province. In 1993, only 37 percent were able to cite two correct methods of HIV prevention. By 1996, this had increased to 70 percent. Among both male and female university students, the proportion of respondents able to cite two correct ways of preventing HIV infection increased from 79 percent and 84 percent respectively, to 95 percent and 96 percent. Among clients of sex workers, knowledge of two correct HIV prevention methods increased from 50 percent in 1994 (unprompted) to 86 percent (prompted) in 1996. Knowledge about prevention methods also increased among CSWs from 40 percent (unprompted) in 1994 to 87 percent (prompted) in 1996.

Increased reported safer sexual behavior related to condom use among several target groups. Of the CSWs who reported having ever used a condom, the percentage rose steadily from 28.3 percent in 1988, to 88 percent in 1996. The percentage of clients who reported ever having used a condom also rose significantly, from 55.5 percent in 1990 to 81 percent in 1996. Consistent condom use by CSWs with non-regular clients increased from 52 percent in 1994 to 75 percent in 1996, and 63 percent with regular clients. The proportion of CSW clients who report using condoms during their last sexual encounter with a non-regular partner increased from 54 percent in 1992 to 97 percent in 1996. The percentage of female students reporting having ever used a condom increased significantly from 56 percent in 1993 to 85 percent in 1996. The percentage of men in the military reporting consistent condom use during the past 30 days with CSWs increased from 48 percent in 1993 to 59 percent in 1996.

Other risk reduction behaviors such as reduced number of partners were also evidenced in several target populations. The percentage of male students reporting more than one sexual partner in the last three months dropped from 53 percent to 36 percent between 1993 and 1996. In 1993, 18.6 percent of male university students reported having had sexual relations with an occasional partner during the 30 days preceding the survey, and by 1996 this figure had decreased significantly to 9.4 percent. Between 1993 and 1996, the percentage of male members of the military reporting more than two sex partners in the past three months dropped significantly from 47 percent to 37 percent. STD treatment-seeking behavior increased among several target groups. For example, the percentage of CSWs seeking STD care at a health care clinic rose from 34 percent in 1992 to 86 percent in 1996, and among their clients from 65 percent in 1992 to 84 percent in 1996. Among male university students in 1993, 72.6 percent reported seeking treatment for their most recent STD either at a health center, with a nurse, doctor or pharmacist, and in 1996 this percentage rose significantly to 85.7.

Many lessons were learned from the AIDSCAP interventions. Some of these are highlighted as major lessons learned from the overall project.

- Informal educational “chats” about relevant sexual issues and personal experiences with HIV/AIDS were an effective way to support behavior change among CSWs.
- Drama is a practical and accepted medium through which to reach people in bars and beer houses with educational messages.
- Prevention efforts should include “regular” partners of sex workers.
- Peer education projects need to explore innovative ways to motivate their volunteers.
- It is crucial to involve political and religious leaders in decision making to break cultural and religious barriers to AIDS prevention.
- It is critical to continue subsidizing condoms to achieve sustainable behavior change.
- Serious consideration should be given to subsidizing STD drugs as well.

THE TSA BANANA PROGRAM IN BOTSWANA

The Tsa Banana adolescent reproductive health program was designed to identify, develop and promote youth-friendly reproductive health information, products and outlets. The program was implemented in Lobatse from March 1995 through March 1996 by the Botswana Social Marketing Program/Population Services International (PSI). It included: (1) a communications campaign; (2) youth-oriented social marketing of condoms; (3) community outreach through peer sales educators; and (4) development of adolescent-friendly outlets. Peer educators taught adolescents condom negotiation skills, correct condom use and to “Abstain, Be Faithful and Condomize” (ABC).

Data were collected using a quasi-experimental control group research design. Pre- and post-intervention surveys were conducted in both the intervention location (Lobatse) and a comparison location (Francistown) by the Social Impact Assessment and Policy Analysis Corporation (SIAPAC)-Africa. A pre-intervention survey was conducted in mid-1994 among a random sample of 1,002 adolescents ages 13 to 18. A post-intervention survey was conducted among 2,396 adolescents in October 1995.

Analysis is based on the Health Belief Model (HBM), which attributes changes in individuals’ health behavior to their beliefs about: (1) the severity of the health threat; (2) their susceptibility to it; (3) the benefits/effectiveness of protective measures; (4) the barriers/negative implications of taking protective action; and (5) a trigger which leads individuals to act on these beliefs. HBM is suitable for intervention design and improvement because the components of the HBM model correspond with specific programmatic activities. Logistic regression analyses were used

Table 1
CHANGES IN ADOLESCENTS’ AIDS-RELATED BELIEFS (OBSERVED ONLY IN THE CONTROL LOCATION)

Desired Changes		Undesired Changes	
Males	Females	Males	Females
None	Hard to convince a partner to use condoms.	Shy about buying condoms in a public place or to obtain them from a health worker.	None

to estimate the change in the odds of expressing each health belief between the pre- and post-intervention surveys, after controlling for school enrollment, level of education and the respondent’s age.

By October 1995, 68 percent of females and 71 percent of male adolescents had heard of the Tsa Banana Program. Promotional items such as T-shirts, stickers and pamphlets had been seen by 59 percent of females and 64 percent of males, and more than 20 percent of males and females had heard about Tsa Banana condom demonstrations or had seen one. Nineteen percent of females and nine percent of males had attended or heard about the project launch, which consisted of an outdoor opening ceremony and a large promotional show.

Table 2
**CHANGES IN ADOLESCENTS’
 AIDS-RELATED BELIEFS (OBSERVED ONLY
 IN THE INTERVENTION LOCATION)**

Desired Changes		Undesired Changes	
Males	Females	Males	Females
People use condoms to avoid risks.	AIDS cannot be cured.	None	None
Hard to convince a partner to use a condom.	People use condoms to avoid risk.		
	People abstain to avoid risk.		
	Sex is good because it leads to marriage.		

IMPACT OF THE TSA BANANA PROGRAM ON HEALTH BELIEFS

Changes in health beliefs that occurred only in the comparison location (without the intervention) are shown in Table 1. All of the changes reported here were statistically significant. Females in the follow-up survey are 0.6 times as likely as women in the baseline survey to believe that it is hard to convince a partner to use a condom. At the same time, males were 2.2 times more likely to be shy about buying condoms in a public place, and 1.8 times more likely to be shy about obtaining them from a health worker. This is why in the absence of the intervention there were simultaneous desirable and undesirable changes.

Table 2 summarizes the changes in health beliefs that occurred in the intervention location but not in the control location. These changes can be attributed to the intervention. After the intervention, males were 1.5 times more likely than before to believe that people use condoms to avoid sexual risks, and only 0.7 times as likely to believe that it is hard to convince a partner to use a condom. Females were 2.7 times as likely as before the intervention to believe that AIDS cannot be cured, 3.4 times more likely to believe that people use condoms, 1.5 times more likely to believe people abstain, and only 0.2 times as likely to believe that sex is good because it can lead to marriage. No undesired changes occurred only in the intervention location. The fact that these positive changes were all achieved within the first eight months of the intervention testifies to the success of the Tsa Banana program.

Changes that occurred in the intervention as well as the control location are shown in Table 3. These are secular trends not attributable to the intervention. It is a desirable change for males to believe that sexually active people are at risk of HIV/AIDS, that people reduce risk by abstaining from sexual activity, that many of their friends use condoms and that they are less likely to believe that sex is good because it can lead to marriage.

But there is also evidence of undesired secular changes in beliefs. Females in both locations are more likely to feel shy about purchasing condoms in public and believe that women lose respect if they initiate condom use and that few of their friends use condoms. They are less likely to believe that people avoid casual and multiple partners to avoid risks. Among males, there is an increase in the belief that sex is good because it enhances one’s status.

While the positive impact of Tsa Banana is clear, the program was unable to effectively counter these undesirable changes, at least within the study’s short timeframe. But the Tsa Banana program may have been instrumental in countering the increased tendency of males (but not females) in the comparison community to feel shy about purchasing or otherwise obtaining condoms.

This operations research study demonstrates that the Tsa Banana program had a positive impact on several adolescent health beliefs. Within eight months, the intervention resulted in significant increases in the beliefs that AIDS cannot be cured (severity), people use condoms or abstain to protect themselves (benefits of protective action) and that it is easy to convince a partner to use condoms (barriers to protective action). In this short time span, however, the intervention was not able to effectively counter all of the undesirable secular trends taking place in the absence of the intervention. This research highlights the complexity of the factors that affect program impact. Males and females differ, both in their responses to the Tsa Banana campaign and in secular trends.

This research shows that intervention programs may need to counter undesirable changes. For example, the evidence that adolescents are increasingly shy about purchasing condoms and that females believe they lose respect if they initiate condom use suggests that the stigma associated with condom use is increasing. Growing awareness that condoms protect against the sexual risks involved in having casual and/or multiple partners may tend to stigmatize condoms through the association with high-risk behavior even as it increases the perception of the benefits of using them. This enhanced understanding of the complex factors that affect program impact will help program managers improve ongoing as well as future AIDS prevention programs.

This case study was written by Dominique Meekers, Guy Stallworthy and John Harris, Population Services International (PSI), Research Division. Data collection for this project was funded by the USAID Botswana Population Sector Assistance Cooperative Agreement No. 623-0249-A-00-3010-00, through the Africa Bureau, Health and Human Resources Division, USAID.

Table 3
CHANGES IN ADOLESCENTS' AIDS-RELATED BELIEFS (OBSERVED IN BOTH THE CONTROL AND INTERVENTION LOCATION)

Desired Changes		Undesired Changes	
Males	Females	Males	Females
Sexually active people risk AIDS.	None	Sex is good because it enhances status.	People avoid casual or multiple partners to reduce risk.
People abstain to avoid risk.			Few friends use condoms.
Few friends use condoms.			Shy about purchasing condoms in public.
Sex is good because it leads to marriage.			Women lose respect if they initiate condom use.

APPENDIX

A recent review of condom social marketing research and evaluation published by PSI (Summer 1999) provides important insights into the answers to several of the key questions posed at the beginning of this chapter.

THE IMPLICATIONS OF FREE AND COMMERCIAL DISTRIBUTION FOR CONDOM USE: EVIDENCE FROM CAMEROON⁸

This study used survey data to define how adolescents in urban Cameroon obtain condoms and whether the method of procurement—free from social marketing or other commercial sources—is related to actual use and continuation of use. Results of the study showed that condom marketing is more effective than free distribution at reaching sexually active adolescents. Of those who obtained free condoms, only 52 percent had ever used condoms, in contrast to 91 percent of those who bought social marketing

condoms and 84 percent of those who bought other commercial condoms. These differentials persist after controlling for other factors, providing empirical evidence for the assumption that fewer marketed condoms are wasted than those distributed free of charge. On the other hand, free distribution was more effective than marketing at reaching younger, sexually inexperienced adolescents. These results demonstrate the complementary relationship between social marketing and free distribution of condoms.

SEXUAL ACTIVITY AND CONDOM USE IN LUSAKA, ZAMBIA⁹

Based on data from a sample survey conducted in Lusaka in 1996 (n=806), this study showed that among women, there is a strong association between the advertising recall for the social marketing condom brand *Maximum* and condom use. This association was present even after controlling for education. After comparing this data with a 1990 WHO/Global Programme on AIDS (GPA) survey of Lusaka, results showed that there was a significant increase in the knowledge of condoms and a decrease in travel time to a source of condoms between 1990 and 1996. These findings indicate that condom marketing promotion and distribution campaigns have been successful in increasing the use of condoms in Lusaka. The 1996 data also shows that about 6 percent of women and 24 percent of men last had sex with a casual partner; and that overall, 17 percent of women and 24 percent of men used a condom during their most recent intercourse. Using multivariate regression analysis, the study also showed that women whose last intercourse was with a regular or casual partner were more likely to use a condom, as were women who recalled hearing a social marketing message advertising condoms. For men, condom use was higher for those who were younger, had higher than secondary education and had easy access to condoms. The study concluded that because of gender inequity, programs directed at men are more likely to succeed than those aimed at developing women's skills in negotiating condom use.

CHANGING ADOLESCENTS' BELIEFS ABOUT PROTECTIVE SEXUAL BEHAVIOR: THE BOTSWANA TSA BANANA PROGRAM¹⁰

This study examined the effect of the *Tsa Banana* adolescent reproductive health intervention—youth-oriented condom social marketing, peer sales educators, communications campaigns and development of adolescent-friendly outlets—on beliefs about protective sexual behavior. The study used a quasi-experimental research design, comprised of a before-and-after survey in the intervention location and in a control location. The analysis provides strong evidence that in just eight months the project had a positive impact on several health beliefs—including an increased awareness of the benefits of condom use and a reduction in important barriers to condom use, such as perceived difficulties in convincing partners to use condoms. The findings also indicate that several issues need further attention. For example, results in both the intervention and control location suggest that condom use is increasingly stigmatized among Tswana adolescents, which may partially offset program benefits. By examining negative secular trends as well as positive program effects, the study provided managers with a more complex understanding of the factors affecting program performance and identified issues to be stressed in subsequent communications.

AN EVALUATION OF THE EFFECTIVENESS OF TARGETED SOCIAL MARKETING TO PROMOTE ADOLESCENT AND YOUNG ADULT REPRODUCTIVE HEALTH IN CAMEROON¹¹

This study examines the effectiveness of a youth-targeted social marketing program for improving adolescent reproductive health in urban Cameroon. The PSI/Cameroon Social Marketing Program (PMSC) *Horizon Jeunes* program targeted adolescents and young adults for a period of 13 months using peer education, youth clubs, mass media promotion and behavior change communications.

Program effectiveness was examined using a quasi-experimental research design with a pre- and post-intervention survey in an intervention and control site. The results demonstrate that the intervention had a significant effect on several determinants of preventive behavior, including awareness of sexual risks, knowledge of family planning methods and discussion of sexuality and contraceptives, although the effect varied for men and women.

The intervention increased the proportion of women who reported using oral contraceptives and condoms for family planning. But there was no significant change in the proportion who used condoms during their last sexual intercourse, suggesting that condom use is not yet consistent. Among men, the intervention had a pronounced effect on the use of several family planning methods, including oral contraceptives, intrauterine devices (IUDs) and injectable contraceptives. Even though the intervention successfully increased the use of various family planning methods, there is no evidence that the intervention increased the use of condoms for STD prevention. The data show that while cost and availability are no longer important constraints to condom use among youths, many youths do not use condoms because they trust their partners or have had problems with condom use in the past.

THE PROMOTION OF SAFER SEX AMONG HIGH-RISK INDIVIDUALS IN MOZAMBIQUE¹²

Using data from a nationally representative sample of sexually active adults, this study examined the effectiveness of Mozambique's *JeitO* condom social marketing project in increasing safe sex practices among men and women at risk of contracting HIV. The study tested the hypothesis that exposure to program interventions (communications and access) increases condom use with non-regular partners. The population's exposure to the program was high and multivariate analyses showed that exposure to condom social marketing advertising, communications and knowledge of a condom source are associated with higher levels of condom use with non-regular partners.

Analyses of regional differences in condom use showed that knowledge and use of condoms with non-regular partners were higher than the national average in all four provinces where the project had been operating longer (18 months versus six months). Multivariate analyses also showed that the above-average level of condom use in the capital, Maputo, can be attributed to the higher socioeconomic status of this population. The above-average level of condom use in the Sofala and Manica provinces was partly due to their high levels of exposure to the program. These findings indicate that the *JeitO* project's behavior change communications and condom distribution were effective in encouraging safer sex practices among high-risk individuals.

AN EVALUATION OF THE EFFECTIVENESS OF TARGETED SOCIAL MARKETING TO PROMOTE ADOLESCENT REPRODUCTIVE HEALTH IN GUINEA¹³

This study examines the reach and impact of an adolescent reproductive health intervention in Guinea. During an eight-month period, the program used peer education and mass media to reach youths, as part of a larger nationwide social marketing program. The results indicated that even though short-term, youth-targeted social marketing programs may be able to improve reproductive health knowledge, significant behavior change requires a longer intervention. The results also showed that low-budget peer educator interventions by definition will have limited reach unless they are supplemented by intensive large-scale mass media activities.

Research conducted by the Futures Group also adds several important insights on regional message development, the importance of targeting women and the critical need to creatively distribute products.¹⁵

CROSS-COUNTRY STUDY OF CONDOM PROMOTION FOR AIDS PREVENTION¹⁴

The Futures Group completed a cross-country study examining approaches to condom promotion among groups with behaviors that put them at risk of contracting HIV/AIDS. The study sought to document the different techniques for condom promotion that the Futures Group has developed and implemented, as well as to evaluate the effectiveness of different interventions. It examined the results of two types of condom social marketing projects: those that integrated HIV/AIDS prevention strategies into existing family planning programs, and those that specifically developed condom social marketing activities with an HIV/AIDS focus.

The results of the study suggest that the different strategies implemented had varying levels of impact, but conclude that HIV/AIDS prevention messages can be effectively integrated into family planning programs. There is skepticism of this finding among several practitioners who have identified serious barriers to this integration. Agencies in countries where family planning is still politically controversial have not welcomed the addition of HIV/AIDS to their agenda. Audiences and benefits offered can be different, and the organizational branding of family planning versus AIDS can present a problem. One important finding of the study is the effectiveness of a general “protection” theme in promoting condoms for HIV/AIDS. This type of message escapes the political and religious backlash that frequently occurs in some conservative countries, and at the same time seems to clearly communicate an HIV/AIDS prevention message.

The Futures Group has used this approach successfully in marketing condoms for both HIV/AIDS and family planning in several sub-Saharan countries. In Malawi, for example, the research indicates that 94 percent of men interviewed were aware of the advertisements and that spontaneous recall of the HIV/AIDS prevention messages was high, despite the fact that HIV/AIDS is never directly mentioned in the advertising. Eighty-five percent found the theme of the advertisements appealing, and the same percentage said they were very likely to use condoms in the future. Current condom use among urban men increased from 28 percent before the campaign in 1991, to 60 percent in 1993 after the campaign. In addition, more men were using condoms “always” or “more than half the time” (65 percent versus 35 percent in 1991). The finding that the image of the condom had improved after the campaign was especially important. In 1993, men were significantly less likely to agree that condoms are used only for extramarital relations, that condoms are unreliable because they break and that condoms reduce sexual pleasure.

The study also examined the importance of addressing gender differences when promoting condom use. In Zimbabwe, the Futures Group designed

communication campaigns targeting women to increase the use of condoms within marriage or steady relationships. Since women's attitudes toward condoms and their condom negotiation skills are key factors in condom use, these advertisements encouraged women to ask their partners to use condoms. As with the Protector campaign for men (see below), the messages focused on general protection and avoided direct mention of HIV/AIDS. But research tests conducted before launch of the advertisements, showed that women clearly understood HIV/AIDS prevention from the messages.

MARKETING *PROTECTOR* CONDOMS IN AFRICA¹⁵

The Futures Group launched the *Protector* brand condom in eight countries in Africa using a regional branding and advertising strategy. The communications campaign is designed to: (1) Communicate a dual message of protection for both family planning and AIDS; (2) Convey the image of a high-quality product; (3) Associate product use with positive behavioral attributes; (4) Change the condom's image from negative to positive; and (5) Make the product more acceptable to use.

Both the *Protector* condom package graphics and the advertising campaign address these goals. The package shows a good-looking young African couple in order to associate the product with attractive and upscale adults. The campaign slogan "Be Wise. Always Wear Protector Condoms," promotes the benefits of using condoms as part of today's modern lifestyle. The package design and advertising campaign received more than 90 percent approval ratings in the market research in all eight countries. The Futures Group has found that combining a positive motivational message with aggressive, hard-hitting distribution/promotional strategies is the most successful approach to increasing condom use.

RELEVANT CHAPTERS

- Chapter 18 *Reducing the Risk of Mother-to-Child Transmission of HIV During Pregnancy and Delivery*
- Chapter 19 *Mother-to-Child Transmission of HIV Through Breastfeeding: Strategies for Prevention*
- Chapter 23 *Counseling, Testing and Psychosocial Support*

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C H A P T E R

13

*AIDS and
Developmental
Constraints*

BILL RAU



AIDS and Developmental Constraints

INTRODUCTION

Individual behaviors are recognized as the main reasons for risk of HIV/AIDS. In turn, individuals are shaped by the social, economic, political and cultural environments in which they live. This chapter examines some of the factors that open and close opportunities for children, adolescents, women and men in many developing countries, the contextual forces that place people in HIV-risk situations and exacerbate the impact of AIDS on households and communities. At first glance these structural factors may seem beyond the scope of program managers. But there are ways that programs can contribute to reshaping structural constraints.

THE STRUCTURAL CONTEXT OF HIV/AIDS

The long-term neglect, if not exploitation, of most rural and many urban areas by both colonial and post-independence governments has limited the opportunities for generating incomes and improving household and community life. The promises of development largely have either failed to materialize or been captured by national elites and international corporations. Given the steady stream of hardships faced by tens of millions of people over the past three decades, the impact of HIV/AIDS is viewed by lower income and dispossessed peoples as another socioeconomic constraint with which they and their countries must deal.

THE IMPACT ON WOMEN

Women have experienced the greatest losses and burdens associated with the economic and political crises, economic shocks, and structural constraints. Inequities in gender roles have run in parallel with inequities in income and assets. Among the ways in which structural shocks have affected women are:

- Breakdown of household regimes and attendant securities
- Loss of livelihood
- Loss of assets
- Survival sex

THE DISILLUSIONMENT OF YOUTH

There are well recognized multiple socioeconomic constraints on opportunities for young people in much of the developing world who are finishing school and entering the workforce. The system has not been working for many young people, and combined with the realities of the HIV/AIDS pandemic, this has led to growing disillusionment among young people.

LESSONS LEARNED FOR STRUCTURAL RESPONSES

Despite the pervasiveness of HIV/AIDS and its steady impact, communities, NGOs, local leaders and others offer numerous innovative and creative responses to the epidemic. Programmatic responses to the structural causes of HIV/AIDS can begin at three levels: institutional, programs/projects and community.

ADDRESSING CONSTRAINTS AT THE INSTITUTIONAL LEVEL

At the institutional level the goal is to assure that development institutions do the jobs they were established to do and serve the population designated in their mandates. There are two interrelated ways to address institutional constraints:

- Advocacy and oversight of policies and programs.
- Resource enhancement.

RESPONSES TO STRUCTURAL CONSTRAINTS AT THE PROGRAM LEVEL

The second level of structural response is in the area of programs and projects—designing and implementing projects to reduce risk. This second level can be seen as a link between institutions and communities.

COMMUNITIES AND STRUCTURAL CHANGE

Problem solving with communities incorporates a variety of lessons that have been learned over several decades of development programs and initiatives. The lessons illustrate the links between community-program-institution, and can be categorized as: ownership, process and resources.

CASE STUDY

CHIKANKATA HOSPITAL: EFFECTIVE FACILITATION WITH COMMUNITIES

A set of HIV/AIDS programs run by Chikankata hospital, in central Zambia, provides a good example of facilitation with communities. A home care program evolved into a community counseling program, promoting the transfer of responsibility for behavior change from the program implementers to the community.

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Individual behaviors are recognized as the main reasons for risk of HIV/AIDS. In turn, individuals are shaped by the social, economic, political and cultural environments in which they live. Their behaviors are sanctioned or condemned by society, and the choices they face in life are often determined by forces outside their control. For example, the quality of teachers at a primary school can determine literacy levels,

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livelihood options and problem-solving skills for girls and boys.

This chapter examines some of the factors that open and close opportunities for children, adolescents, women and men in many developing countries, the contextual forces that place people in HIV-risk situations and that exacerbate the impact of AIDS on households and communities. At first glance these structural factors may seem beyond the scope of program managers. But there are ways that programs can contribute to reshaping structural constraints.

THE STRUCTURAL CONTEXT OF HIV/AIDS

For many impoverished people, HIV/AIDS is only one of many problems and constraints that surround their lives.¹ The long-term neglect, if not exploitation, of most rural and many urban areas by both colonial and post-independence governments has limited the opportunities for generating incomes and improving household and community life. The wealth and benefits promised by development largely have either failed to materialize or been captured by national elites and international corporations.

Given the steady stream of hardships faced by tens of millions of people over the past three decades, the impact of HIV/AIDS is viewed by lower-income and dispossessed peoples as another socioeconomic constraint with which they and their countries must deal.^{2,3} Other constraints have included dramatic price increases for basic commodities, reduced value for export commodities, adoption of structural adjustment programs with rapid cost-of-living impacts, droughts, floods, wars and civil violence. Every country in eastern and southern Africa has been involved in or affected by warfare within the past two decades. Nearly all Latin American and sub-Saharan African countries have struck agreements with the World Bank and International Monetary Fund to impose fiscal constraints on government spending. These agreements often involved increased costs of agricultural production, new or increased fees at schools and health facilities, increased food prices and cutbacks in government employment. These constraints severely exacerbated income and gender inequalities and the already precarious living conditions of many people, making them more vulnerable to sexually transmitted diseases (STDs). And because the agreements were made from the late 1970s through the 1990s, they made national and local responses to the epidemic more difficult to sustain.⁴

Few of these constraints have been effectively analyzed to suggest direct correlations with individual vulnerability to HIV/AIDS—or to restructuring prevention and mitigation programs. But several researchers have argued that the structural adjustment-

type policy changes in the 1980s fostered situations that potentially promoted behaviors that place large numbers of people at increased risk of HIV infection.⁵⁻⁷ For example, attendance at STD clinics in Kenya dropped by as much as 60 percent after the World Bank directed the country to implement charges for STD clinic services.⁸ Similar decreases in clinic usage have been reported in Mozambique, the Congo, Ghana and Zimbabwe after user fees were either introduced or increased.⁹⁻¹¹ In the context of an emerging HIV/AIDS epidemic, the timing of these economic and social changes was key. The resources were unavailable at a time when national governments and local communities needed to invest in job creation, social stability, health and education.

Describing the relationship between HIV and economic change on the Shan State borders of Burma, Doug Porter argues, “It is more than coincidence that the HIV epidemic now coursing through these borders has arisen in tandem with economic deregulation and liberalization. And in large part, the pace and geographic spread of HIV infection is connected to larger, externally driven economic forces in ways similar to changing marketing networks, the organization of transport, or people’s movement.”¹²

Even activities often described as “development” have contributed to vulnerability. Workers at the Katse Dam construction site in Bokong, Lesotho, were found to have seroprevalence rates nearly seven times higher than people in nearby villages.¹³ In Mpumalanga, South Africa, HIV/AIDS and other STDs have increased dramatically, “thanks to a multi-million dollar infusion of cash to develop the area,” as another group of researchers put it. Infrastructure construction has not only attracted large numbers of men, but the wages they earn allow them

to offer rural women and schoolgirls money, food and clothing in exchange for sexual favors.¹⁴ Similar structural factors are well documented at the mines in South Africa, in port cities in Honduras and Brazil, and at the agricultural estates of Kenya.

THE IMPACT ON WOMEN

Women have experienced the greatest losses and burdens associated with the economic and political crises, economic shocks and structural constraints. Inequities in gender roles have run parallel with inequities in income and assets.¹⁵ Among the ways in which structural shocks have affected women are: breakdown of household regimes and attendant securities, loss of livelihood, loss of assets and survival sex.

Breakdown of household regimes and attendant securities

Decades of change in economic activity and gender relations have placed women in increasingly difficult situations.¹⁶ HIV/AIDS has accelerated the process and made “normal” sexual relations very risky. Women whose husbands have migrated for work are said to fear the return of the men, knowing they may be infected with HIV.¹⁷ Although poorly documented, the range and depth of women’s responsibilities have increased during the era of AIDS. More active caregiving for sick and dying relatives has been added to the existing workload.¹⁸ Children, beginning with girls, have been withdrawn from school to save on costs and add to labor within the household. Thus, HIV/AIDS is rapidly facilitating further differences along gender lines.

Loss of livelihood

Whether women receive remittances or “allowances” from men working away from home or earn income themselves, AIDS has made the availability of cash more problematic. In Malawi, women and men increasingly work on farms belonging to larger and/or wealthier farmers in order to earn income or in-kind payments, often neglecting production on their own holdings.¹⁹

Loss of assets

Although poorly documented, there are fairly substantial investments in medical care among many households affected by HIV/AIDS. These costs are actually disinvestments to the family and survivors. In Abidjan, Côte d’Ivoire, for example, families living with AIDS experience a monthly disavings of nearly 5,000 CFA francs. Household food security is often affected by HIV in negative ways.²⁰ In many parts of Africa, women lose all or most of the household assets following the death of a husband.

Survival sex

Low incomes, disinvestments and constrained cash flow all place economic pressures on women. Anecdotal evidence and some studies indicate that these pressures push a number of women into situations where sex is coerced in exchange for small cash or in-kind payments.²¹ Along the Thai-Burmese border, many of the sex workers are young women caught up in the “green harvest,” in which their work is a means to repay loans made to their families by money lenders who recruit young women for the sex industry. Most of the young women return home infected with HIV.^{22,23}

Taken together, these and existing education, employment, legal and other structural biases facing women add to the shocks that have disrupted social institutions over the past decades.

LESSONS LEARNED FOR STRUCTURAL RESPONSES

THE DISILLUSIONMENT OF YOUTH

The multiple socioeconomic constraints on opportunities for young people who are finishing school and entering the workforce are well recognized. The belief has eroded that life can be improved through rural enterprises. The long-established practice of migrating to employment centers also is failing to provide as much opportunity for employment as in the past. The system has not been working for many young people, who increasingly turn to alternative forms of income generation and social support. Richards writes: “HIV/AIDS cuts short the normal life expectancy, and already [c. 1999] young people in Tanzania make it clear that they have to work with the space [life-span] they will get. Life has to be lived to the full, but perhaps over 30 to 40 years rather than a normal three score years and ten.”²⁴ A study of young people in central Ghana uncovered similar fatalistic attitudes that may not be fully generalizable but reflect the situations in which many young people find themselves today. One observer notes, “Such attitudes to death in the era of AIDS point to apparent misunderstanding or lack of motivation for behavioral change in the existing socioeconomic circumstances.”²⁵ In other words, the attitude can be expressed as: “Why change my sexual behavior when I see little hope for improvement in life’s opportunities?” It seems that such attitudes are not simply statements of fatalism, but also of disillusionment and realism.

And yet there are “astonishingly vigorous responses to AIDS,” as reporter Mark Schoofs put it in his Pulitzer Prize-winning series on AIDS in Africa.²⁶ Despite the pervasiveness of HIV/AIDS and its steady impact, communities, NGOs, local leaders and others offer numerous innovative and creative responses to the epidemic. Programmatic responses to the structural causes of HIV/AIDS can begin at three levels: institutional, programs/projects and community.

ADDRESSING CONSTRAINTS AT THE INSTITUTIONAL LEVEL

At the institutional level, the goal is to assure that development institutions do the jobs they were established to do and serve the population designated in their mandates. Numerous studies have illustrated that, in fact, many government ministries and agencies do not fulfill their developmental mandate. Where institutions have functioned, they have played important roles in HIV/AIDS prevention and care programs. Thailand’s health care system, for example, was adapted to more fully diagnose and treat STDs. Likewise, a committed public health system in São Paulo State, Brazil, responded early and rapidly to HIV/AIDS, setting a pattern for the country as a whole.²⁷ There are two interrelated ways to address institutional constraints: (1) advocacy and oversight of policies, and (2) resource enhancement.

Advocacy and oversight of policies and programs

Governments and public and private institutions all need to be informed and pushed at times. Advocacy for policies, laws and programs—and for their implementation—have been essential in shaping the responses to HIV/AIDS in Brazil, South Africa, Kenya, and elsewhere. Advocacy in each of these countries has grown out of alliances among HIV/AIDS organizations, development, women’s and human rights groups, academics and concerned individuals both inside and

outside of institutions. In these and other instances, effective advocacy is the outcome of a process that is likely to include:

- Promotion of innovative and fairly specific options, backed by supporting information.
- Development of a long-term strategy for action, including organizing constituents, communicating with decision makers and negotiation.
- A core group (five to 20 people) to guide the process.

The role of program managers in the advocacy process can include:

- Acting as a link between affected groups and advocacy groups and decision makers.
- Generating information about the needs, interests and resources of affected groups, and of the strengths and constraints of programs and projects seen during implementation.
- Joining networks and coalitions, thereby adding strength and credibility to the advocacy efforts.
- Helping to inform and organize constituents and supporters, particularly among peers within their institutions.

Resource enhancement

The second approach to institutional change is resource enhancement through greater efficiencies or by adopting new ways to use existing resources. Efficiencies have been sought through integrating services—such as integrating STD diagnosis and treatment with other reproductive health services, expanding the skills of staff or bringing underutilized sectors, such as primary and secondary schools, into HIV/AIDS prevention and care. For example, the introduction of HIV/AIDS education into primary and secondary school curricula is increasingly accepted, despite opposition from some religious authorities, parents' groups and politicians. Where HIV/AIDS or broader reproductive health information has been integrated into school curricula, the results are often positive, at least in terms of student knowledge of sexuality and HIV/AIDS prevention and, to some extent, behavior change.²⁸

In Senegal, Thailand and Uganda, national HIV/AIDS programs have worked with religious communities and authorities to gain early acceptance for prevention. Rather than shunning or confronting religious groups—which has occurred in a number of donor-sponsored national programs—religious authorities are engaged because they are credible and influential leaders of public opinion and molders of cultural patterns.

Enhancement of resources has been achieved in Uganda through a blending of government (central and decentralized), private and community responses and responsibilities. As the impact of the epidemic has grown, the government has accepted co-responsibility with NGOs and households for providing prevention and care services. The government has acknowledged its own limitations and the strengths of communities and community-based NGOs.²⁹ It has not sought to shift its responsibilities to households by employing the rhetoric of household-coping mechanisms. The resources of each sector become complementary, rather than fragmented.

Integration of services or multisectoral responses has been described as “mainstreaming.” UNDP argues that mainstreaming does not mean adding HIV/AIDS promotion to existing functions—such as having agricultural extension workers promote HIV/AIDS awareness or distribute condoms. Rather it implies careful planning by ministries and organizations so that their functions take into account the environment within which HIV/AIDS prevention or mitigation can occur—such as designing agricultural programs to address the severe labor constraints in HIV/AIDS-affected households, or assuring that school curricula include practical reproductive health information for young people.

Responses to Structural Constraints at the Program Level

At the second level of structural response are programs and projects designed and implemented to reduce risk. This level can be seen as a link between institutions and communities. Besides implementing activities, programs have two roles in addressing structural factors of HIV/AIDS: (1) passing along information and (2) facilitating dialogue. Useful information can include reporting on the bureaucratic constraints to implementation of activities, timely evaluation of implementation that is not distorted to tell funders what they want to hear, descriptions of how communities are responding to prevention initiatives and how the epidemic is affecting communities. All of these points of information can be collected and reported through tools that exist within the HIV/AIDS or development communities. New perspectives are needed to provide information that will be useful to advocacy organizations and networks, other program managers who are searching for effective methods, concerned bureaucrats and decision makers and the media.

The second role is that of the facilitator who works formally and informally with communities and the networks with which the program is affiliated. Program staff are in a position to stimulate thinking and consideration of new ideas and approaches, share experiences from and across different programs and help groups look more closely at their existing skills and resources. It is likely that only a handful of program staff will have the sensitivity, patience, credibility and appreciation of local cultures and social systems to be effective facilitators with communities. To be effective they need the support of the program itself—a willingness to trust and respond to community input and take the time needed to build trust and confidence on both sides. Facilitation does not mean handing all decision making or resources to communities. Rather it is based on the premise of equal partners, each bringing valuable experiences and perspectives that can be merged to address prevailing issues.

COMMUNITIES AND STRUCTURAL CHANGE

The purpose of programs acting as facilitators with communities is that the latter have numerous strengths and abilities to identify, develop and implement initiatives for HIV/AIDS prevention, care and mitigation. In some cases, communities can identify problems and responses for themselves but may lack the resources to implement solutions. In other instances, facilitators can aid communities in identifying problems, options for response and needed resources. From an international public health perspective, community actions may appear too small, too scattered and too fragile to effectively contain the HIV/AIDS epidemic. The concerns have some validity when initiatives are viewed individually. But when considered collectively, the initiatives illuminate the factors that will strengthen the linkages between development and HIV/AIDS prevention and care.

Problem solving with communities incorporates a variety of lessons that have been learned over several decades of development programs and initiatives. The lessons illustrate the links between community-program-institution, and can be categorized as:

Ownership

- Local groups are able and willing to identify the prevailing problems and needs around which options and solutions can be discussed.
- Inclusion in identifying problems and options of affected people and groups—especially women and representatives of the numerous marginalized groups usually identified as core transmitters or high-risk groups, such as commercial sex workers, migrant workers, transport workers and uniformed services.

Figure 1

ADDRESSING STRUCTURAL CONSTRAINTS TO HIV/AIDS PREVENTION AND CARE: SOME LINKS

Institutions	Tools	Programs/Projects	Tools	Communities
Fulfilling Mandate	Advocacy	Implementation	Dialogue	Problem identification
Resource Enhancement	Networking	Evaluation	Surveys	Problem solving
Supportive policies/laws	Efficiencies	Information Sharing	Facilitation	Resources

The Table indicates some of the responsibilities of organizations and select tools available to program managers for assisting in achieving those responsibilities. The arrows indicate some of the links between organizations.

Process

- A timeframe long enough for groups to build trust, debate, test options and identify the range of available skills and resources.
- Facilitators—preferably though not necessarily from within communities—to stimulate discussion, offer new perspectives, link with external resources and keep a process moving.

Resources

- Identification and use of community resources (skills, economic).
- Selective and moderate insertion of external resources, as determined in close consultation with affected groups.
- A supportive economic, political and social environment that eases problem solving, rather than creating new problems or sustaining prevailing ones.

Approaches will vary because not all communities are alike. The diversity yields numerous insights and examples for testing programs on a larger scale, but it also makes developing and implementing prevention, care and mitigation programs more complex and time-consuming. Diversity also means that some

communities do not respond in a supportive way—stigma, fear and despair can be found in every country. But local leadership and supportive national policies and statements can help alter these perceptions, strengthen existing initiatives and offer fertile ground for new ones.

Household and community-level coping mechanisms in the face of adversity are now widely recognized and cited as attributes by many agencies outside of local communities. Coping mechanisms are among the resources and skills that communities bring to HIV/AIDS prevention and care. But in too many instances, the rhetoric about coping mechanisms has become an excuse for doing little or nothing to reduce the pressures on communities or even to work more closely with communities. Dialogue will illuminate how coping mechanisms serve households and communities. It will also demonstrate the limits to coping with multiple constraints.

As Figure 1 illustrates, organizations at various places in society have responsibilities toward the HIV/AIDS epidemic. Effectively addressing those responsibilities over time can contribute to both HIV/AIDS prevention as well as authentic development. A handful of the tools, none of them especially new, are available to organizations to stimulate new thinking and action. In turn, those tools become links between organizations.

The table indicates some of the responsibilities of organizations and select tools available to program managers for assisting in achieving those responsibilities. The arrows indicate some of the links between the organizations.

APPLYING LESSONS FOR STRUCTURAL CHANGE

Goal:

Assist development planners and public health officials in fitting HIV/AIDS into a wider development framework.

How?

Train planners in the socioeconomic realities of HIV/AIDS.

Develop multisectoral training activities for program planners and managers to learn from and with one another.

Develop the capacity to conduct HIV/AIDS impact assessments before undertaking large construction projects.

Require private sector industries to improve social conditions for workers and facilitate family solidarity.

There is a wealth of organizational and management experience within HIV/AIDS-affected households and communities—most of which are not known to, and thus are ignored by, “development” planners and HIV/AIDS specialists. These experiences are the building blocks for altering the environment that perpetuates poverty and susceptibility to HIV/AIDS.

How?

Integrate lessons learned about community initiatives and community development into training programs for program managers and their staff.

Recognize that the HIV/AIDS epidemic is at least two to three years ahead of national and interna-

tional responses. Thus, communities are living the daily realities well before most of us come to understand their situations. It is possible to move closer to the course of the epidemic by listening regularly to communities. Communities can more immediately suggest needs, concerns, options and solutions without the filtering processes that now inhibit transfer of those messages.

How?

Substantially increase community-based research by shifting research funding from the lengthy academic and medical studies to ones that use well-established participatory research methods. **As sentinel surveillance evolves** to include behavioral surveillance, the latter can evolve to include coping and innovation surveillance.

Adopt bureaucratic and procedural methods that treat HIV/AIDS as a crisis.

How?

Loosen—if not greatly abandon—donor agency reporting and financial management requirements for implementing agencies. This will shift more resources to field implementation.

Include significant HIV/AIDS prevention within the curricula for new recruits to government service and teacher training.

Include line items for HIV/AIDS prevention, care and mitigation in every sector and every project and program.

Shift 25 percent of existing international funding for HIV/AIDS from internal bureaucracies to field implementation.

CASE STUDY

CHIKANKATA HOSPITAL: EFFECTIVE FACILITATION WITH COMMUNITIES

A set of HIV/AIDS programs run by Chikankata hospital, in central Zambia, provides a good example of facilitation with communities. At the hospital a home care program evolved into a community counseling program. As the Chikankata staff explain, the program “promoted the transfer of responsibility for behavior change from the program implementers to the community.” From the beginning, “all the community members or participants are recognized as thinking, creative people with the capacity for action.”

Chikankata trained facilitators to be resource persons for communities, fitting into existing structures and not trying to create new ones or to work from a set agenda. One outcome was the abandonment of ritual cleansing through sexual intercourse with a surviving spouse by a brother of the diseased husband—a high-risk behavior. Another was the willingness of community members to take part in the direct care of people living with HIV/AIDS, a role formerly believed to belong to relatives.

Not surprisingly, the community counseling program stretched into other aspects of community life. School children and teachers were exposed to information about HIV/AIDS and sexual behavior. Teen pregnancies at the participating schools dropped, as did pregnancies among out-of-school young women.³⁰

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C H A P

T E R
14

*STD Case
Management in
Primary Health
Care Settings*

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STD Case Management in Primary Health Care Settings

INTRODUCTION

Sexually transmitted diseases (STD) impose an enormous burden of morbidity and mortality in many resource-constrained countries, both directly through their impact on reproductive and child health and indirectly, through their role in facilitating the sexual transmission of HIV. Because of this relationship with the HIV epidemic, there is now increased interest in STD control in resource-constrained countries.

The treatment of symptomatic STD is a key strategy for HIV prevention. The Joint United Nations Programme on AIDS (UNAIDS) and the World Health Organization (WHO) have recommended that high priority be given to the development of STD control programs. They further recommend that countries deliver high quality services with optimum coverage for STD-infected people using existing primary health care services, as well as expanding services to such other primary health care units as family planning and maternal and child health (FP/MCH) services.

This chapter reviews some of the concepts and practical aspects of STD case detection and management strategies that can be implemented at the level of primary health care, with special reference to resource-constrained environments.

STD PREVENTION AND CARE: CONCEPTUAL FRAMEWORKS

STD control programs should aim to reduce the rate of new (incident) STD through a combination of strategies, including behavior change, increased condom use and treatment of patients with STD.

STD prevention and care strategies have long been influenced by the transmission dynamics model. Other models have been developed to conceptualize the strategies needed to control STD—the epidemio-biological model and the operational model—which are described in this section.

PATIENT CASE MANAGEMENT STRATEGIES IN PRIMARY HEALTH CARE SETTINGS

Primary health care facilities may refer to health centers, dispensaries or hospitals at the district, regional or provincial level, and are often the first point of contact between patients and public health services. This section outlines general principles related to designing and providing STD case management in these settings.

STD DIAGNOSIS AND MANAGEMENT

While laboratory diagnosis is the STD diagnosis method of choice in many parts of the industrialized world, most health centers and dispensaries in resource-constrained countries do not have access to reliable laboratory facilities. Consequently, clinicians may use presumptive clinical diagnosis, a less reliable method. To address the limitations of both laboratory and presumptive clinical diagnosis in the management of STDs, the syndromic management approach was developed. These three approaches are discussed in this section.

STD CASE MANAGEMENT

The components of comprehensive STD case management described in this section include:

- History taking and examination
- Identification of the STD
- Antibiotic treatment for the STD
- Educating and counseling the patient
- Condom promotion and supply
- Partner notification and management
- Clinical follow-up

The section also discusses case finding and management of syphilis in pregnancy and the role of the private sector in STD case management.

ORGANIZATION OF STD CASE MANAGEMENT SERVICES

The integration of STD case management services at the clinical level is discussed in terms of outpatient departments and antenatal care, maternal and child health and family planning services. Detailed logistical considerations are presented, including equipment and consumables, STD drugs, personnel and time required and case reporting and surveillance. Other topics outlined in this section include:

- The role of the laboratory in STD case management
- Referral system and the role of the categorical STD clinics
- The role of district/regional personnel: training, supervision and monitoring

LESSONS LEARNED AND RECOMMENDATIONS

Key lessons learned since the start of the HIV epidemic relate to:

- STD diagnosis and treatment
- Key elements of STD case management
- Increased access to proper treatment through innovative approaches
- Case finding
- Importance of supervision and in-service training

FUTURE CHALLENGES

Challenges for effective STD control and for future research are presented. These include improving inappropriate STD services, addressing gender inequalities in sexual relationships, the lack of access of males to sexual health services and the urgent need for the development of rapid tests for gonorrhoea and chlamydial infection.

CASE STUDIES

DECENTRALIZED SYPHILIS SCREENING AND TREATMENT IMPROVES SYPHILIS DETECTION AND TREATMENT IN ANTENATAL CLINIC SETTINGS IN NAIROBI, KENYA

A decentralized syphilis screening and treatment pilot project was instituted in Nairobi in 1992. This project demonstrates the feasibility and cost effectiveness of congenital syphilis prevention and control decentralized to the clinic level, while highlighting several operational and logistical issues that must be addressed for optimal implementation.

MANAGEMENT OF SYMPTOMATIC WOMEN IN LOWER STD PREVALENCE SITUATIONS—EXPERIENCE FROM BANGLADESH

Appropriate case management strategies for women complaining of symptoms possibly related to infection in the reproductive tract were evaluated among a group of 465 women in rural Bangladesh. Results reflect the low prevalence of infections in these women and the difficulty of interpreting clinical signs that have a relatively low specificity. Levels of overtreatment were very high. Not only does this carry financial repercussions, but the social costs associated with women erroneously receiving a diagnosis of an STD are very high.

STD SYNDROME MANAGEMENT AT RURAL PRIMARY HEALTH CARE CLINICS IN NORTHERN TANZANIA

Between 1992 and 1994, a community-based clinical trial was conducted to test the impact of improved STD control on the incidence of HIV infections in adults from the communities in the Mwanza District of Tanzania. The study demonstrated that it is feasible to integrate effective STD services into the existing primary health care structure of a resource-constrained country. It also documented that syndromic management had several limitations.

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I N T R O D U C T I O N

Sexually transmitted diseases (STDs*) are caused by more than 30 different pathogens, including bacteria, viruses, protozoal agents, fungal agents and ecto-parasites. The various diseases are grouped together because sexual contact is epidemiologically important for their spread, though not necessarily the only mechanism through which the infections can be acquired. The World Health Organization (WHO)

estimates that there are approximately 340 million incident cases of the five main curable STDs (gonorrhea, chlamydial infection, syphilis, chancroid and trichomoniasis) every year, with 85 percent in resource-constrained countries.

STDs impose an enormous burden of morbidity and mortality in many resource-constrained countries, both directly through their impact on reproductive and child health, and indirectly through their role in facilitating the sexual transmission of HIV. It has been estimated that in urban populations in sub-Saharan Africa, for example, “classical” STDs—excluding HIV/AIDS—are responsible for some 17 percent of the total burden of disease in women of reproductive age. Yet it is only in recent years that they have been accorded any priority by national ministries of health or the international community.

The increased interest in STD control in resource-constrained countries is largely a result of the HIV epidemic. Earlier reports of an association between the classical STDs and HIV infection have now been supplemented by virological studies showing that current STDs increase levels of HIV in genital secretions.¹ It has been demonstrated that treatment of bacterial STDs can reduce HIV genital shedding in individual patients.² A community-randomized trial in the Mwanza Region of Tanzania further demonstrated that improved clinical services for STDs can significantly reduce the incidence of HIV infection in resource-constrained countries using a low technology, sustainable and cost-effective strategy.³

For these reasons, UNAIDS and WHO have recommended that high priority be given to the development of STD control programs and maintain that the treatment of symptomatic STD is a key strategy for HIV prevention. This is why they still recommend that countries deliver these services with optimum coverage for STD-infected people, using existing primary health care services and expanding services to other primary health care units such as family planning and maternal and child health (FP/MCH) services. Services for special groups often require establishing other services. (Chapter 15 discusses STD services for special groups.)

STD control programs have three main objectives: (1) Preventing the development of diseases, complications and sequelae; (2) Interrupting the transmission of sexually acquired infections; and (3) Reducing the risk of HIV infection.

These objectives can be achieved through prevention measures aimed at reducing STD incidence and prevalence by shortening the duration of infection and disease centered around STD case detection and management, thereby reducing the probability of complications, sequelae and disease transmission. Prevention measures are comprised of behavior change communication (BCC) activities aimed at reducing the level of individuals' exposure to STD.

This chapter reviews some of the concepts and practical aspects of STD case detection and management strategies that can be implemented at the level of primary health care. It offers special reference to resource-constrained environments, though most of the principles reviewed can equally apply to primary health care settings in both resource-constrained and industrialized countries.

** The term sexually transmitted disease (STD) is used throughout this chapter to describe sexually transmitted infections and the diseases, complications and sequelae that result. For example, a sexually transmitted infection, gonorrhea, results in a disease, cervicitis, which may lead to a complication, salpingitis. Permanently impaired fertility would be a sequelae.*

STD PREVENTION AND CARE: CONCEPTUAL FRAMEWORKS

STD control programs should aim to reduce the rate of new (incident) infections through a combination of strategies, including behavior change, increased condom use and treatment of patients with STD. The latter component of STD control programs aims to reduce the duration of an individual's infectiousness.

STD prevention and care strategies have long been influenced by the transmission dynamics model.⁴ The model expresses the transmission of an STD in terms of its basic reproductive number (R_0), which is to say the average number of new (or secondary) STD cases generated by an index (or primary) case in a defined population over a period of time. It has been demonstrated that R_0 is a function of the probability of transmission of the STD during sexual intercourse (B), the rate of partner change (C) and the duration of the infection (D) ($R_0 = B * C * D$). If $R_0 > 1$ —that is, if an index patient can infect more than one sexual partner per unit of time—the STD pathogen will spread (epidemic phase). If $R_0 < 1$, the transmission will eventually be interrupted.

Other models have been developed to conceptualize the strategies needed to control STD. The epidemiological-biological model maps out links between the different stages of an STD infection from “uninfected case” to “complications,” and identifies interventions at each stage (see Figure 1).

The operational model identifies the many different obstacles that patients with an STD have to overcome before they can be considered cured by health services (see Figure 2). At each step, a proportion of patients will drop out. Multiplying the proportions of patients taking each step provides an estimate of the cure rate achieved by the health services of interest. This model shows how in most resource-constrained

countries only a fraction of STD cases are successfully treated.^{5,6} In this way it clarifies the four main reasons for failure to control STDs:

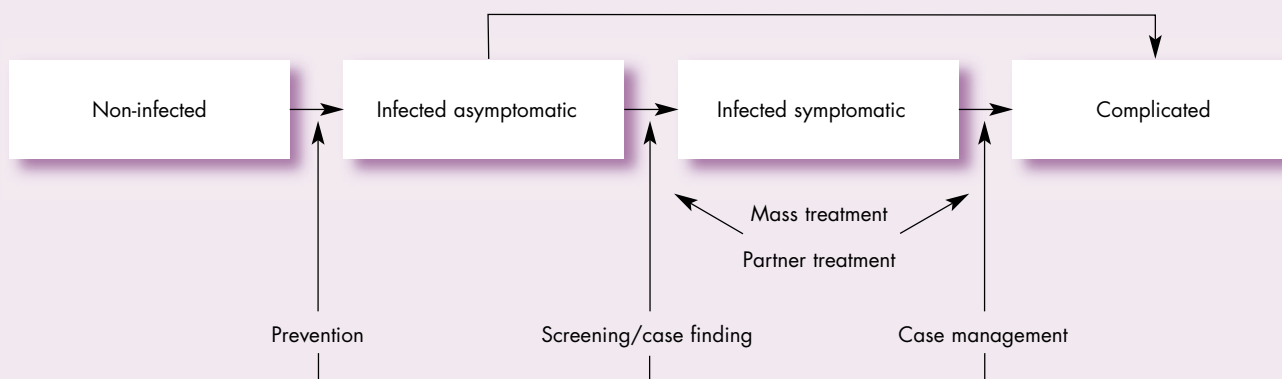
1. Failure to prevent unsafe sexual behavior
2. Failure of people with symptoms to access health services
3. Failure to identify and treat patients with symptoms
4. Failure of health services to provide adequate treatment

Each of these steps, in turn, suggests points for potential interventions. Starting from the bottom of the model, broad options for STD control include:

- Improving STD case management, including partner notification
- Improving STD treatment-seeking behavior
- Case finding or screening for neglected or asymptomatic STDs
- Mass treatment of the general population and/or presumptive treatment of high-risk groups
- Primary prevention (BCC strategies, condoms, microbicides, vaccines)

All these models highlight the fact that one of the cornerstones of STD control is prompt, effective and comprehensive treatment of all individuals with symptomatic infections.

Figure 1
**INTERVENTION STRATEGIES:
 EPIDEMIO-BIOLOGICAL MODEL**



PATIENT CASE MANAGEMENT STRATEGIES IN PRIMARY HEALTH CARE SETTINGS

Primary health care facilities usually refer to health centers or dispensaries expected to deliver integrated community health care—including curative and preventive services—and are often the first point of contact between patients and public health services. Many hospitals at the district, regional or provincial level also deliver primary health care in addition to their specialized care. For this reason many of the approaches described in this chapter would be applicable to these settings.

GENERAL PRINCIPLES

The **goals** of STD case management are to:

1. Provide appropriate antimicrobial treatment to cure and decrease infectivity.
2. Reduce risk-taking behavior.
3. Ensure that sexual partners are appropriately treated to break transmission and prevent complications.

The **components** of a comprehensive STD case management should include:

- Accurate diagnosis.
- Effective antimicrobial treatment of STDs.
- Education on:
 - The nature of infection
 - The mode of transmission of infection
 - Adherence to prescribed treatment
 - Risk reduction
 - Proper use of condoms
 - The need for all sexual partners to be treated
- Providing condoms and instructions on use.
- Providing information on partner treatment.
- Follow-up examination (if convenient to patient/service provider) to assess treatment outcome.

To ensure adequate coverage and maximum efficacy, STD case management should fulfill the following requirements:

- Ensure privacy and confidentiality for the patient.
- Ensure a good and caring staff attitude toward the patient.
- Provide accurate diagnosis.
- Provide treatment at the first visit with the health services.
- Provide rapid cure with effective drugs.
- Address issues of condom promotion, partner notification and education/counseling.
- Be adaptable for all levels of use.
- Be flexible for integration with other health services.

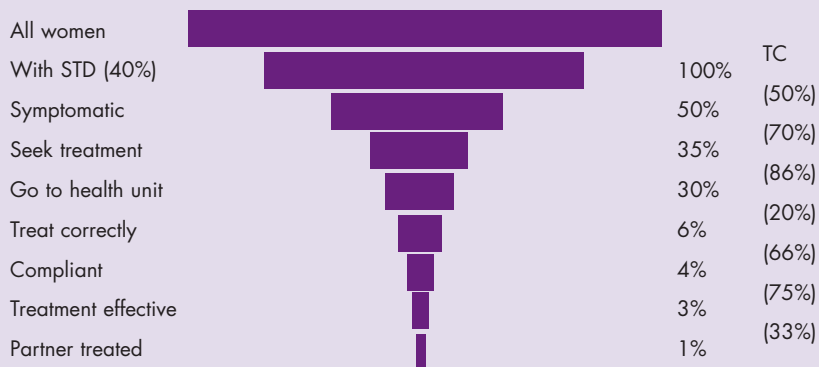
It is also important in designing STD services to know the factors that influence the patient's choice of facility, including:

- Accessibility:
 - Proximity to work or residence
 - Convenient opening hours
- Quality of services:
 - Efficiency of service delivery
 - Effectiveness of treatment
 - Competent and friendly staff
 - Availability of drugs
- Acceptability:
 - Non-stigmatizing
 - Non-judgmental staff attitudes
 - Affordable fees
 - Confidentiality

Surveys of health-seeking behavior in resource-constrained countries indicate that a substantial proportion of people, particularly men, with symptomatic

Figure 2

INTERVENTION STRATEGIES: OPERATIONAL MODEL OF STD MANAGEMENT (E.G., WOMEN IN AFRICA)



STD seek treatment in the informal or private sector—from traditional healers, unqualified practitioners, street drug vendors, pharmacists and private practitioners—and will attend formal public health services only after alternative treatments have failed.^{7,8} To improve access to information and appropriate treatment for these people, it is essential to have initiatives to enlist the support of private doctors, pharmacists, street (drug) vendors and traditional healers for sexual health promotion, enhancement of appropriate STD case management strategies and partner notification.

Table 1

ADVANTAGES AND DISADVANTAGES OF SYNDROMIC MANAGEMENT OF STDs

Advantages
Problem orientated (responds to patient's symptoms)
Highly sensitive and does not miss mixed infections
Treatment given at first visit
Provides opportunity and time for education and counseling
Avoids expensive laboratory tests
Avoids unnecessary return visit for laboratory results
Curtails referral to specialist centres
Can be implemented at primary health care level
Disadvantages
Overdiagnosis and overtreatment with the following consequences: <ul style="list-style-type: none"> ■ Increased drug costs ■ Possible side effects of multiple drug reactions ■ Changes in vaginal flora ■ Potential for increased drug resistance ■ Domestic violence
Requires (re)training of staff
Requires monitoring and updating
Possible resistance to its introduction from medical establishment
Still requires a referral system

STD DIAGNOSIS AND MANAGEMENT

LABORATORY, CLINICAL AND SYNDROMIC APPROACHES

The traditional method of STD diagnosis has been laboratory diagnosis to determine the etiological agent(s). This means demonstrating the presence of the STD pathogen(s) either directly, by microscopy, culture, antigen or other DNA-detection techniques or indirectly (e.g., by serology). While this is still the method of choice in many parts of the industrialized world, it is expensive in terms of diagnostics, infrastructure and maintenance. It also often results in

delays in diagnosis and treatment. And in fact most health centers and dispensaries in resource-constrained countries do not have access to reliable laboratory facilities. Consequently, clinicians either need to refer their patients to specialist centers, resulting in further delays, or attempt to make a presumptive clinical diagnosis by identifying particular clinical features. This method has often proven inaccurate or incomplete.⁹

WHO has developed and advocated the syndromic management approach to address the limitations of both etiological and presumptive clinical diagnosis in the management of STDs, particularly for patients who attend the first level of primary health care. STD-associated syndromes are easily identifiable groups of symptoms and clinical findings on which the health care providers can base their presumptive diagnosis. Management is simplified by using clinical algorithms or flowcharts, allowing time in the consultation to provide simple education messages, discuss partner notification and promote condoms. Antimicrobial treatment is provided at once to cover the majority of pathogens presumed responsible for the particular syndrome, in that specific geographical area.⁹

Table 1 summarizes the advantages and disadvantages of syndromic management of STDs.

Syndromic management is simple and lends itself to use in a variety of outlets such as STD clinics, primary health care facilities, pharmacies, FP/MCH services and private practitioners. The sensitivities and specificities* of the approach for the diagnosis and management of urethral discharge syndrome and genital ulcer syndrome in various settings have been very satisfactory. Its other advantages include cost effectiveness, diagnosis and treatment at first visit and increased patient satisfaction.¹⁰

* The sensitivity of a test is its ability to detect all cases to be found; a good test with a high sensitivity should not miss too many infections. The specificity of a test is its ability to correctly identify as "negatives" the individuals who are not infected. The positive predictive value is the correct prediction when a test is "positive" to actually find an infected case (by gold standard); conversely, the negative predictive value is the correct prediction when a test is "negative" to actually confirm that the individual is not infected.

Standardizing case management through syndromic management has the following benefits:

- It improves diagnosis and comprehensive case management.
- It simplifies drug ordering and management.
- It improves reporting and surveillance.
- It simplifies training and supervision.

But syndromic management also has two main limitations. First is the cost of overdiagnosis and treatment of patients with no infection or only one infection. This includes the direct costs of antimicrobials as well as the indirect costs in terms of adverse drug reactions, alterations in normal gut flora (such as increases in shigella infection) or vaginal flora (such as increases in candidiasis) and possible domestic violence. The second limitation is that since vaginal discharge is a poor indicator of cervical infection, the syndromic management approach has a low specificity and positive predictive value for detecting cervical infections in women presenting with vaginal discharge. Some sociodemographic and behavioral characteristics in an individual have been found to be predictive of the presence of cervical infections. WHO has recommended including such sociodemographic or behavioral factors, combined in a risk score, in the flowchart of vaginal discharge (see *Figure 3*).

This approach has been evaluated in several countries, but has yielded disappointing results.¹⁰ The evaluation found that risk factors and scores need to be setting-specific because there can be considerable variations within the same country; the performance of the flowcharts was not significantly improved; and risk score was found to be inadequate in societies where most women will not admit to extramarital or premarital sexual activity for fear of social sanctions.¹¹

It should be noted that the syndromic approach relies on people recognizing symptoms and presenting for treatment. Like laboratory-based diagnosis, syndromic management does not address the issue of asymptomatic or poorly symptomatic infections or poor treatment-seeking behavior. In these instances, additional case-finding strategies will be needed, such as partner referral, laboratory-based screening or presumptive treatment.

An important prerequisite for effective syndromic management is a well-functioning primary health care system, well-trained and supervised staff and a regular supply of effective drugs.

KEY ELEMENTS OF DEVELOPING SYNDROMIC CASE MANAGEMENT

It is important to define the main STD syndromes in any setting before developing management protocols. There are seven major syndromes:

- **Urethral discharge in men**—suspected urethritis, commonly due to *Neisseria gonorrhoeae* and/or *Chlamydia trachomatis* and/or non-gonococcal/non-chlamydial pathogens (such as *Mycoplasma* species) often referred to as “non-specific urethritis.”
- **Testicular pain and swelling**—suspected epididymo-orchitis in men due to *Neisseria gonorrhoeae* and/or *Chlamydia trachomatis* or non-specific urethritis pathogens.
- **Abnormal vaginal discharge**—predominantly caused by organisms causing vaginal infection, such as *Trichomonas vaginalis*, *Candida albicans* or bacterial vaginosis. *Neisseria gonorrhoeae* and *Chlamydia trachomatis*—which are of greater public health importance because of their complications—can cause a cervical discharge and consequently manifest as vaginal discharge. “Abnormal” discharge refers to a change in abundance, color, odor or consistency of genital secretions as perceived by the patient and confirmed by a trained health care worker as abnormal.
- **Lower abdominal pain in women**—suspected pelvic inflammatory disease (PID) due to *Neisseria gonorrhoeae* and/or *Chlamydia trachomatis* and/or anaerobic pathogens such as those commonly found in bacterial vaginosis.

Table 2

STEPS IN THE DESIGN AND DISTRIBUTION OF STD ALGORITHMS, THEIR IMPLEMENTATION AND REVISION

1. Flowchart development

- Stakeholders' involvement: STD/AIDS national program manager, national drug/pharmacy expert, consultant STD specialist, gynecologist, microbiologist, samples of users (health staff), supervisors (member of district management team), and consumers (patients' association, members of the community).
- Preliminary research: health care-seeking behavior patterns, sources of STD care, etiological pattern of syndromes, gonococcal antimicrobial susceptibility.
- Choice of drugs: efficacy, safety, cost.
- Drug system: procurement, storage, distribution channels.
- Design of algorithms.
- Pilot testing with users and with consumers.

2. Flowchart evaluation

- Validation—outcomes of the flowcharts are compared to gold-standard STD diagnosis of etiological agents supposed to be covered: calculate sensitivity, specificity, positive and negative predictive values, correct treatment rate, overtreatment rate.
- Feasibility (infrastructure and personnel required).
- Acceptability (by health care provider, by patients, by program managers).
- Cost:
 - Cost per patient.
 - Cost per case correctly treated (or cured).
 - Long-term costs.

3. Flowchart distribution

- Printing of flowcharts.
- Distribution.
- Storage/display.

4. Appropriate training of health care providers, pharmacists and policy makers

- Training manual.
- National trainers and quality insurance.
- Training of trainers at regional/district/local level.
- Supervision district/regional/national.
- Feedback mechanism.

5. Revisions

- Define constituency and frequency of revision workshops.
- Conduct necessary research in sentinel sites:
 - Etiological patterns.
 - Clinical efficacy.
 - Microbial efficacy.
 - Quality of care.
- Criteria for modifications.

6. Criteria for the choice of STD drugs

- >95% effective for the pathogens under consideration.
- Can treat more than one pathogen.
- Single dose, if possible.
- Not injectable, if possible.
- Few side effects.
- Can be safely administered during pregnancy or to lactating mothers.
- Children's formulation.
- Cost.
- Can be easily procured, transported and stored.

- **Genital ulcers**—caused by *Haemophilus ducreyi* (chancroid), *Treponema pallidum* (syphilis) or *Herpes simplex* virus (HSV) type-2 (sometimes also HSV type-1). Donovanosis (caused by the agent *Calymmatobacterium granulomatis*) may be important in such settings as South India, South Africa and Papua, New Guinea. Lymphogranuloma venereum (LGV—caused by special strains of *Chlamydia trachomatis* L1-L3 strains) produces only transient and mild ulcerations.
- **Inguinal bubo**—associated with chancroid (caused by *Haemophilus ducreyi*) or LGV (*Chlamydia trachomatis* L1-L3 strains).
- **Neonatal conjunctivitis (ophthalmia neonatorum)**—defined as conjunctival inflammation in the newborn occurring within 28 days of birth. Most cases occur within two weeks of life. Bacterial infection of the mother’s genital tract—mainly with *Neisseria gonorrhoeae* or *Chlamydia trachomatis*—is frequently the cause of the infection. If the mother is infected at the time of vaginal delivery, there is a 30 percent to 50 percent risk of transmission to the baby’s eyes.¹²

Management protocols can be developed after determining the syndromes and their common or important causative organisms. The following steps should be followed (see Table 2):

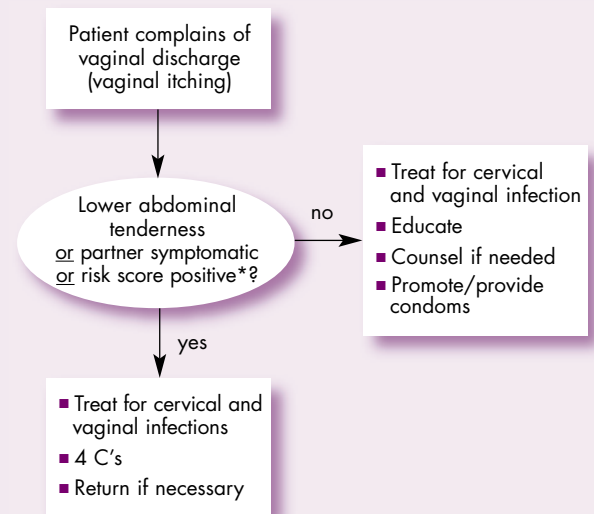
- Develop a flowchart.
- Evaluate the flowchart.
- Distribute the flowchart.
- Train health care providers, pharmacists and policy makers.

The establishment of flowcharts and the choice of drugs will be determined by laboratory-based findings. This is one of the areas in which laboratory facilities are required. It is possible to use information from a neighboring country or region in the first instance. If a country has no adequate laboratory capacity, a link with a regional or international laboratory should be made to determine the epidemiology of STDs in the local setting.

In the process of developing an STD flowchart it is important to involve the main stakeholders: experts in the field of STD or reproductive tract infections

Figure 3

FLOWCHART VAGINAL DISCHARGE (WITHOUT MICROSCOPE, USING RISK SCORE)



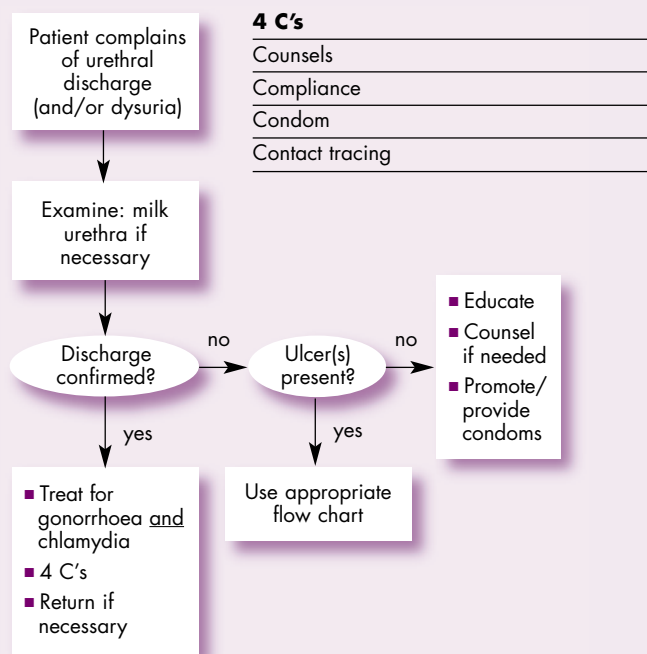
***Risk score = any 2 of:**

- Age <21
- Single
- >1 partner in last 3/12
- New partner in last 3/12

Source WHO, 1995

(national STD specialists, microbiologists, gynecologists, STD program managers) as well as representatives of those who use the flowcharts at all echelons of the health service (primary health care managers, hospital doctors, nurses, pharmacists, Essential Drug Program [EDP] managers, antenatal care [ANC]/MCH/FP managers). This helps to build consensus around the guidelines, ensure that recommendations are relevant for all levels of use and identify mechanisms for patient referral.

Figure 4
**FLOWCHART URETHRAL DISCHARGE
(WITHOUT MICROSCOPE)**



The flowcharts are simple step-by-step tools guiding the diagnosis and treatment. Depending on the level of use and the users' qualifications, a number of additional steps may be incorporated such as using a speculum or a simple laboratory test. Examples of STD flowcharts are displayed in Figures 3 to 5.

Generic names of drugs may appear on the flowcharts. These drugs should ideally be single dose and taken orally, at least 95 percent effective on targeted pathogens and without severe side effects. Suitable alternatives for pregnant or lactating women and dosages for children must be identified. Financial, administrative and procurement aspects must also be taken into consideration. (See Table 2.)

Finally, it is important to agree beforehand on when and how to modify STD flowcharts as this will influence the collection of important data on the etiological composition of syndromes, clinical (in vivo) and microbial (in vitro) efficacy of treatment and quality of care in selected sentinel sites at regular intervals.

WHO conducted and published a large review of the studies evaluating many of the WHO flowcharts in various settings.¹³ The authors concluded that “syndromic approach, utilizing currently available flowcharts, works well in the management of people with symptomatic urethritis, genital ulcer disease, and vaginitis, and [owing to] the lack of specific defining risk-factors and/or signs and symptoms, the syndromic management performs less well in the identification and management of women with cervicitis.” WHO recommended that further research be carried out to improve the identification and management of cervical infections—in particular to develop affordable, rapid and simple diagnostic tests.

As with many health interventions, a complex balance must be achieved between the sensitivity and specificity of the recommended flowcharts. Low sensitivity means that infected persons do not receive adequate care, are exposed to the possible sequelae of untreated infections and remain potentially infectious to others. Low specificity may result in high levels of overtreatment. The latter is problematic at both the health service provision and the individual levels. One option for program and policy makers is to articulate cost implications in terms of absolute cost and cost-effectiveness of the utilization of the flowcharts.

WHO recently concluded a cost analysis using a standardized cost tool to compare some of the recurrent program costs of syndromic management. This exercise looked at the evaluated flowcharts in their use for men and women. Basing the cost calculations on variable costs of drugs and supplies borne by the program and using cost per person and true case treated, it was possible to plot the results against the recorded prevalence of STD in the study. This exercise did not calculate the cost of treating possible sequelae of untreated disease. The prevalence of cervical infection in the studies ranged from 0.9 to 19.5 percent in symptomatic women.

This analysis demonstrated that the total cost per true case treated decreased as prevalence of infection increased. Using the recommended flowcharts in symptomatic women demonstrated that the overtreatment percentage significantly decreased as cervical infection prevalence increased. The cost per person ranged from US\$0.32 to US\$1.89. The total cost per true case treated ranged from US\$6.42 to over US\$100, depending on prevalence. The cost for men was considerably lower than for women. From a public health point of view, cost-effectiveness is achieved when the prevalence of cervical infection exceeds six percent. But the degree of overtreatment may have such adverse consequences as an accelerated emergence of drug resistance and high budgetary implications. Further cost and cost-effective analysis are needed to better guide programs in their decision making.

Figure 5
FLOWCHART GENITAL ULCERS

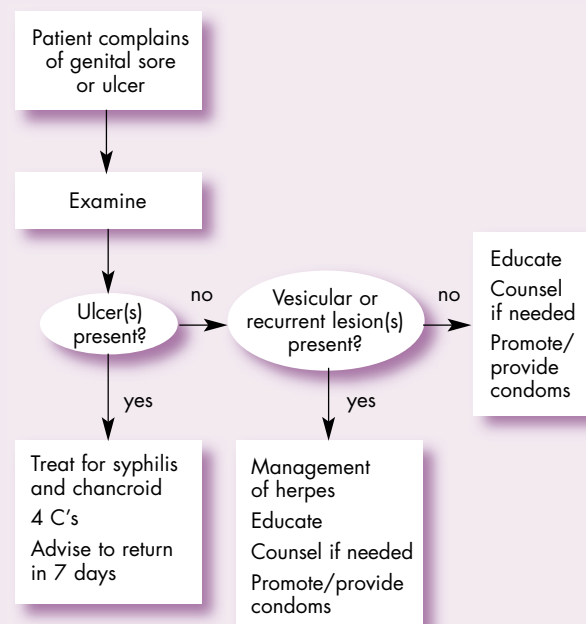


Table 3
**REQUIREMENTS AND COMPONENTS
 OF PROPER STD CASE MANAGEMENT**

Requirements
■ Appropriate diagnosis
■ Treat at first encounter
■ Rapid cure with effective drugs
■ Simplicity
■ Integration
■ Modifying risk behavior
■ Breaking the chain of transmission
Components
■ History taking and symptoms
■ Examination
■ Diagnosis
■ Treatment
■ “4 C’s”
■ Counseling
■ Compliance
■ Condoms
■ Contact(s)
■ Provide appointment for follow-up if necessary

STD CASE MANAGEMENT

DEFINITION

STD case management is the care of a person with an STD-related symptom, clinical sign (or syndrome) or with a positive test for one or more STDs. The components of comprehensive case management are shown in Table 3.

COMPREHENSIVE CASE MANAGEMENT OF STDs

History taking and examination

History taking is important for a number of reasons. If done properly, and if privacy is assured, the process of taking a history establishes a rapport between health care provider and patient. History can give early clues to the possible presence of an STD, traumatic lesions, previous treatments and allergies. A history will assess the patient’s risk behavior, duration of infection and will help identify the sexual partners who may have exposed the patient or have been exposed by him/her.

It is essential to examine the patient in good light and on an examination couch. Besides verifying the complaint, the exam also may uncover another condition of which the patient may not have been aware. For example, a mild urethritis and a genital ulcer may co-exist though the patient is aware of or reporting only one of the conditions. Table 4 details the elements of a good examination.

Identification of the STD

This can be done through syndromic diagnosis or laboratory testing, as discussed earlier. Clinical diagnosis tends to be unreliable, even in experienced hands.

Antibiotic treatment for the STD

Regardless of the means used for diagnosis, the availability and use of effective antibiotics is essential. Single-dose or short duration regimens are preferable. The drugs must be available at the first point of contact with an STD-infected patient and, if possible, the first dose should be taken in the presence of the health care worker (directly observed treatment). This is why STD drugs should be kept on hand—in a separate lockable box or cupboard—in the clinic room.

Ineffective or partially effective drugs actually result in increased treatment costs as patients repeatedly seek treatment for the same condition or its complications, or need to be referred to a higher level of care. Partially effective treatments may also lead to the rapid appearance of resistant strains of an organism and per-

Table 4

COMPONENTS OF A GOOD HISTORY TAKING AND PHYSICAL EXAMINATION*

Taking history from a patient with an STD	
<ul style="list-style-type: none"> Explore main symptoms and duration. 	
<ul style="list-style-type: none"> Take a sexual health history: when did the patient have sex, with whom, and in what manner (including use of condoms). 	
<ul style="list-style-type: none"> Past history of STD and treatment. 	
<ul style="list-style-type: none"> Prior treatment during this episode and history of allergy. 	
<ul style="list-style-type: none"> Help identify sexual partners who may have exposed / been exposed. 	
<ul style="list-style-type: none"> Ask women about menses, contraception and obstetric history. 	
Examination of women	Examination of men
<ul style="list-style-type: none"> Put patient at ease, and reclining on a couch. 	<ul style="list-style-type: none"> Put patient at ease, and if possible reclining on a couch.
<ul style="list-style-type: none"> Inspection of pubic hair, genitals, including separation of labia and inguinal lymph nodes. 	<ul style="list-style-type: none"> Inspection of pubic hair, genitals and inguinal lymph nodes.
	<ul style="list-style-type: none"> Retraction of foreskin in uncircumcised patients.
<ul style="list-style-type: none"> Abdominal and bimanual examination of the posterior urethra. 	<ul style="list-style-type: none"> If discharge not seen, massage ("milking").
<ul style="list-style-type: none"> Where speculum and lamp are available, a pelvic exam, allowing visualization of the cervix and vaginal walls. 	<ul style="list-style-type: none"> Palpation of testicles and epididymis.
<ul style="list-style-type: none"> Bi-manual examination. 	
<ul style="list-style-type: none"> Examine anus, rectum, mouth and skin when appropriate. 	<ul style="list-style-type: none"> Examine anus, rectum, mouth and skin when appropriate.

sistent sub-clinical infections. Drug choices should be clearly defined in terms of first line drugs, alternatives in case of allergies or other contraindications and treatment failures.

Educating and counseling the patient

There are compelling reasons to educate and counsel the STD patient. First, a person who has presented for STD care at a health center is at his/her most receptive phase for education about the nature of the infection, its consequences and risk reduction to prevent future infections. Second, if the patient is not educated he or she is at higher risk of becoming

re-infected and/or spreading the infection to his/her partners, thereby maintaining the chain of transmission. Finally, educating patients about the nature of their infection will enhance their cooperation with the health care worker's advice.

Counseling relates more to issues of anxiety and coping with the infection and its social consequences. (See Chapter 23 for a comprehensive look at HIV voluntary counseling and testing.) Counseling is important in discussing, identifying and dealing with issues causing stress or anxiety, such as:

- Informing the partner or spouse about the STD diagnosis.
- Learning about, and coming to terms with, worrisome complications, such as infertility.
- Coping with chronic/incurable infections, such as HIV, herpes genitalis and genital warts.

This is why it is important to take the opportunity to help patients assess their own risk for STD/HIV infection and enable

them to understand why they must adhere to treatment and advice, avoid re-exposure, reduce risk and consistently use condoms for risk-takers and respond to issues of partner notification. Counseling should also discuss any sense of guilt or blame—such as for passing on infection to a child or partner—and help reinforce the patient's own positive decisions and choices.

In a busy clinic there is often little time for a clinician to provide comprehensive health education. This may best be provided by a trained health educator, nurse or counselor, in a separate room during one-on-one discussions. It is important to reinforce key education messages by giving patients an information leaflet, which should be designed in a way and translated into languages that are easy to understand and relevant for them.

The following topics should be addressed during one or several sessions:

- Infectious nature of STDs
- Transmission through sexual intercourse
- Increased risks of infertility and other complications
- Importance of completing treatment, even after improvement
- Reasons for reporting back to the clinic
- Risk of re-infection by the partner and reason for sexual abstinence or using condoms while in treatment
- Advantages and necessity of treating sexual partner(s)
- How to use a partner referral slip (see section on partner notification)
- Reduction of number of partners and/or condom use as preventive measures

Other methods of reinforced education through group sessions or general education sessions through video have been tried in industrialized country settings, but they have not proven superior to individual counseling in achieving high partner notification rates and decreasing index patient re-infection rates.

Table 5

METHODS, PRINCIPLES AND FACTORS INFLUENCING THE CHOICE OF METHODS OF PARTNER NOTIFICATION

Method	Actions involved
Active partner notification	Initiation by the health care provider: telephone, visits.
Passive partner notification	Initiation by the index case consulting for the STD, using leaflet and other personal communication channels.
Contractual notification	Health care provider and patient agree on the strategy before hand: the patient will look for the sexual partners and if failing to have referred anyone after a certain period of time, the health care provider will actively look for the partners.

Principles of partner notification	Factors influencing the choice of methods
<ul style="list-style-type: none"> ■ No coercion ■ Confidentiality ■ Accessibility ■ No bad consequences for index case and/or their partners (e.g., danger of domestic violence) 	<ul style="list-style-type: none"> ■ Pathogens or syndromes to be targeted. ■ Available staff, their training and their role. ■ Number of contacts to trace (time, resources). ■ Distances/mobility/reliability of addresses. ■ Resources (finances, equipment, transport, time). ■ Literacy of the population. ■ Local health policy (e.g., mandatory notification). ■ Social and cultural factors.

It is important that health education on STDs is not restricted to patients with STD. Education efforts can be targeted to groups of patients attending health services for other reasons, such as general outpatient departments and ANC/MCH clinics. This strategy should encourage the patients' reporting of genital symptoms, should they occur. It will also increase acceptance of STD screening efforts in some groups, such as syphilis detection in pregnant women.

Messages given during these clinic sessions should be consistent with and reinforce education efforts in the general community, highlighting common symptoms and complications of untreated STDs, the need for prompt treatment and adequate protective measures. This approach may help alleviate the general stigma attached to STDs by making them a topic commonly discussed by health staff.

Condom promotion and supply

The STD consultation provides an opportunity to promote and supply condoms, as patients should be more receptive to understanding their usefulness in decreasing their future exposure to STD/HIV.

This activity has four components:

- Condom promotion
- Condom demonstration
- Condom supply
- Advice on further condom supply

First, patients must be told about the importance of condoms and their contribution to further limiting exposure to STD and HIV. The health care worker should explain how condoms work, how they should be used and properly disposed of, and discuss any cultural, social or mythical obstacles the patient may have about them. The health care worker should then demonstrate proper condom use using a penis model.

Condom use will require some negotiating skills with sexual partners. Such skills should ideally be taught by a trained counselor, but this may not be possible at the first visit and may require further visits or referral to other groups.

The clinic should supply a few free condoms. The health care worker should indicate where condoms can be acquired, either at the clinic or at various distribution points in the community. The health care worker should be aware of and mention to the patient any commercial outlets that sell condoms or any social marketing programs. (Examples of such programs and of their effectiveness are provided in Chapter 12.)

Partner notification and management

Contacting or notifying sexual partners of STD patients, persuading them to present themselves to a site offering STD services and treating them—promptly and effectively—is an essential part of any STD control program, and an integral part of comprehensive STD management.

Partner notification is intended to:

- Notify partners at risk to protect the uninfected and decrease transmission among the infected.
- Avoid re-infection of the index case and interrupt the chain of transmission to the community.
- Reduce the asymptomatic STD reservoir in the population.

Table 5 summarizes the principles of partner notification, methodology and the factors influencing the choice of methods.

It is important to pay attention to the social and cultural acceptability of partner notification to avoid ethical and practical problems that may result in undesirable outcomes, especially for women who may be rejected or physically harmed. This is especially crucial because the lack of specificity of genital symptoms in women makes it difficult to distinguish between common vaginal or endogenous infections—which often are not sexually acquired and therefore would not warrant treatment of the partner(s)—and sexually acquired cervical infections for which treatment of the partner(s) should be required. Clearly, then, without a specific etiological diagnosis—when using the clinical or syndromic approaches—it is important to exercise caution before initiating contact tracing with female index patients.

Health care workers need to be properly trained in undertaking partner notification in a sensitive and confidential way, since many patients may resent attending public health services in the first place because they fear being told to bring in their sexual partners. Partner notification should not be compulsory, nor should treatment of the index case be delayed until partners are brought forward.

Partners who present to the health services should be treated presumptively with a predefined treatment corresponding to that of the index case, targeting the

CASE FINDING AND MANAGEMENT OF SYPHILIS IN PREGNANCY

same pathogens, and no time should be wasted in trying to identify the etiology of the disease. This can be done simply by indicating the index patient's diagnosis—usually through a coded number—on the partner slip. This code should correspond to a standard prescription. Syndromic diagnosis and management lend themselves well to this sort of approach.

It is also important to take a rapid history from the contact to determine the course of action, possible allergies to treatment and to identify potential secondary contact(s) to be notified and treated. Take time to educate and counsel the contact, particularly on the need to complete treatment, even in the absence of symptoms, and to use condoms—just as for the index case. In the case of the partner or spouse of a woman with vaginal discharge, the health care worker should cautiously explain that infections diagnosed in their female partner may not necessarily be sexually transmitted, but may be caused by other agents, and that from a public health point of view it is necessary to administer treatment.

Clinical follow-up

Although it may be logistically difficult for patients in some settings, they should be encouraged to return for follow-up, particularly if symptoms persist. During this follow-up visit they may be restarted on the initial treatment if compliance seems to have been a problem, receive alternative treatment if failure of first-line treatment is suspected or be referred to another level of care if second-line drugs are not available. They may also be referred if the case seems too complicated to handle at the particular level of care or a different expert opinion is warranted—such as for surgical assessment or suspected cancer. Explicit referral guidelines should be defined for each level of care.

Case finding refers to the testing for STDs in individuals seeking health care for reasons other than STD. It is important because of the asymptomatic nature of many infections, particularly in women, and of the serious complications resulting from untreated infections.

Syphilis infection during pregnancy is a serious condition with a dramatic effect on pregnancy outcome. If untreated, it has been estimated that between 30 percent and 60 percent of pregnant women with syphilis will experience adverse pregnancy outcomes such as fetal death (spontaneous abortion or stillbirth), prematurity or congenital abnormalities. Syphilis prevalence rates between 3 percent and 19 percent have been reported in pregnant women from resource-constrained countries, and are increasing rapidly in many of the former Soviet Union republics.

DIAGNOSIS AND MANAGEMENT

Pregnant women may occasionally present with clinical features of primary or secondary stages of syphilis—though the patients themselves may frequently overlook these conditions. Health staff working at antenatal clinics should thus be trained in recognizing the early clinical stages of syphilis, by performing a simple systemic clinical examination involving an inspection of the vulva for any ulcers (primary stage) or characteristic lesions of condylomata lata (secondary stage), and an inspection of skin and other mucosa for any skin rash on the body, palms and soles, or around the mouth or neck—the most common places to find secondary syphilis. Genital ulcers should be treated syndromically—including treatment for syphilis—while suspect skin lesions should either be referred to experienced clinicians, confirmed by a laboratory test or treated on the spot without further testing.

Testing for syphilis should be incorporated into routine antenatal services based on the use of non-specific treponemal antigen agglutination tests such as the rapid plasma reagin (RPR) test or venereal diseases research laboratory (VDRL) test. Treatment of women

ROLE OF THE PRIVATE SECTOR IN STD CASE MANAGEMENT

with a positive serology—and of their sexual partners—should follow the national recommended guidelines for the management of serologically diagnosed syphilis.

Case finding and treatment of maternal syphilis clinics in antenatal clinics has been shown to be feasible, inexpensive and highly cost-effective, as demonstrated in a pilot program in Nairobi, Kenya.¹⁴

Despite such encouraging results, many national congenital syphilis control programs in resource-constrained countries remain inefficient for several reasons:

- Late attendance at antenatal clinics
- Logistical constraints, including shortages of laboratory equipment and supplies, drugs and transport facilities
- Lack of well-trained and motivated staff
- Poor follow-up for results and partner notification rates
- Lack of priority by public health decision makers

(For a detailed discussion of HIV risk reduction in women before, during and following pregnancy, see Chapters 17 and 18.)

The role of the private sector in STD case management in many resource-constrained countries can no longer be ignored. (For a detailed account of private sector involvement in HIV prevention, see Chapter 9.) Research on the treatment-seeking behavior of STD patients in many countries has shown that a great proportion of patients may attend private or informal services exclusively or prior to enlisting public health services. There are, however, indications that the management of STD patients in the informal or private sector is less than optimal, as allopathic practitioners may not use adequate drugs, suitable drug regimens or may not provide proper education and counseling, while traditional healers and herbalists may use remedies with no proven antimicrobial efficacy.

There have been attempts to enroll support from the private sector in providing syndromic case management and partner notification in various countries such as Nepal, Cameroon, Uganda and Peru.¹⁵⁻¹⁸ Among the approaches suggested are preferential subsidy of the private market price of certain essential drugs to encourage rational drug use and reduce the significant mark-ups applied to pharmaceuticals; establishing drug shop/pharmacy associations to maintain uniform prices; using generic antimicrobials; and pre-packaging treatment courses.

Social marketing of a sealed pre-packaged treatment for male urethral discharge—“MSTOP,” containing the full treatment course, condoms, referral slips and an instruction sheet—was not very successful in Cameroon,¹⁶ mainly because of resistance by the local medical establishment, and because packets were opened and drugs sold separately. A few years later, however, a similar concept (“Clear Seven”) was well accepted in Uganda by both patients and private health care providers as it was found to be convenient, more effective and cheaper than the usual treatment. But the reduction of profit margins due to low prices was seen as a disadvantage.¹⁷ Currently there are no pre-packaged treatment kits for genital ulcers or genital discharge in women, but a pilot study with encouraging preliminary results is underway in South Africa.¹⁹

ORGANIZATION OF STD CASE MANAGEMENT SERVICES

ORGANIZATION OF STD CASE MANAGEMENT AT THE CLINIC LEVEL: INTEGRATED SERVICES

Integration with outpatient work

Specialized (categorical) STD clinics are expensive to run, inaccessible to most rural populations and often stigmatizing for patients. This is why it is more desirable to integrate STD case management in the general medical outpatient department (OPD). The syndromic approach also allows many cadres of health personnel to be trained to diagnose and treat patients during their daily routine.

Depending on local conditions, STD patients may be identified through a private interview in the general OPD of a busy clinic and internally referred to a different room where examination, treatment and counseling can be provided. In this context, “integrated STD care” means integration within the health facility. It presupposes that all staff working at OPD have at least been sensitized to the syndromic approach and can correctly identify suspected STD cases, and are able to refer—even if not all are involved in treatment. Enough privacy must be provided at this level to allow patients to be honest about their symptoms. Specialized hours of operation and easily identifiable room or staff should be avoided to avoid stigmatization of services.

In less busy clinics, assuming that privacy can be ensured—only one patient at a time in the room, doors closed and screens separating the examination couch—it is possible to manage STD patients within the general flow of patients. In this context, “integrated STD care” means that the health care provider is able to identify and manage STD patients all by him/herself, and sometimes deliver counseling and supervise on-spot treatment. It assumes that all health care providers have been trained in STD case management. Often tasks can be shared, with one staff member taking charge of the diagnosis and prescription while another oversees the delivery of drugs, condoms, counseling and so on.

To improve efficiency of comprehensive case management, pre-packaged treatment packs—containing all necessary syndromic treatment as well as education

leaflets and partner notification cards—were introduced in the Hlabisa district of Kwa-Zulu Natal in South Africa.²⁰ Compared to health care workers trained in providing standard syndromic management without treatment packs, those using them were more likely to provide correct management (88 percent versus 55 percent), had more time for proper counseling (88 percent versus 46 percent) and displayed better attitudes towards patients.²¹

Integration of STD case detection and management with ANC/MCH or FP planning services

Within this setting, well-trained and sensitive staff can always look for symptoms and perform a physical examination. But this strategy may not be useful because of the frequent asymptomatic nature of cervical infections and the poor specificity of clinical signs. Case finding on the basis of a risk assessment, even in the absence of symptoms, also has not been proven useful in many populations.

Logistical considerations—equipment and consumables

Some basic equipment, consumables and drugs for diagnosis and treatment of STDs are essential. A regular supply must be maintained to provide quality, timely STD services and to maintain the clients' confidence in the reliability of services. Essential clinical infrastructure, STD equipment and consumables and BCC materials are listed in Table 6.

In some primary health care settings, it may be possible to perform speculum examination, which will allow for visualization of the cervix and collection of vaginal specimens to identify vaginal infections.

Table 6

ESSENTIAL INFRASTRUCTURE, EQUIPMENT AND CONSUMABLES FOR STD CARE AT PRIMARY HEALTH CARE LEVEL

Components

Infrastructure

- Privacy (screen, separate room)
- Examination couch
- Source of light (lamp or torchlight)

Equipment

- Sterilization equipment if specula are to be used (e.g., sterilizers or stoves);
- Basin (for soaking specula)
- Penis model in order to demonstrate the use of condoms

Clinic supplies

- Gloves
- Cotton
- Disinfectant
- Condoms

Additional supplies where possible:

- Specula (different sizes)
- Sponge-holder forceps
- Swabs
- Slides
- Coverslips
- pH paper
- KOH solution

BCC materials, flowcharts, records and forms

- Educational leaflets
- Education posters
- Other IEC material (eg. flipcharts)
- STD treatment flowcharts/guidelines
- Partner notification slips
- Appointment sheets
- HIS forms
- Monthly tally sheets
- STD record sheets or log book

STD drugs

Oral, single-dose STD treatment regimens are ideal because they improve adherence to the drug regimen and reduce the risk of developing antimicrobial resistance. But they cannot always be provided because they are usually more expensive. Appropriate monitoring of efficacy should be arranged through the reference clinic and laboratory, and some primary health care sites should participate in the information gathering.

It is important to maintain the supply of drugs and regularly check for expiration dates, etc. In general, drugs need to be kept in closed containers away from heat, frost and light. A locked room, cupboard or box is preferable.

Primary health care clinics may receive centrally organized drug kits, such as those sent at regular intervals by the Essential Drug Program (EDP). The kit often contains standard quantities of the various drugs needed to treat the most common clinical conditions. In this case, it is important that two things happen: (1) The STD program officials must link with the EDP officials to include the specific drugs they need; and (2) The district teams must make sure the kits reach peripheral health units.

District teams are increasingly being given responsibility for drug management, according to their needs. Drugs will be ordered from either a fixed budget or a revolving fund. District teams should be trained to estimate drug needs based, for example, on retrospective analysis (of the most recent one to three months) of drug prescription. Using standardized flowcharts and prescriptions can facilitate these estimates and predictions.

Personnel and time required

Even in high STD prevalence areas, the number of new STD patients presenting will rarely exceed a handful per day. There may be more in urban areas once good services have been established and become well known to the population. It should be possible to allocate at least 10 to 15 minutes per STD patient—enough time to take a correct history, perform a brief examination, provide basic explanations, take treatment action and make necessary notes in registers—all of which are indispensable elements of professional care. Realistically, however, more time would be required to conduct proper education and counseling. For this reason it is suggested that in busy outpatient clinics a dedicated counselor have this role. At least two clinicians at each outpatient clinic should be trained in STD case management to cover for absences.

Additional time for health education will be required when STD care is provided at ANC/MCH or FP clinics. The most practical way to provide this is to have a health care worker hold a 10- to 15-minute education session with small groups of women. The additional contact time for the clinical procedure ranges from three minutes for a healthy woman to 10 minutes if an infection is diagnosed or suspected. Again, most of the time required for educating and counseling the individual patient may be delegated to another staff member who serves as a health educator, and this person should receive the necessary training.

CASE REPORTING AND SURVEILLANCE

Health care workers are accustomed to keeping patient register books, filling in tally sheets and/or producing monthly reports. The amount of paperwork is often enormous and yet, unfortunately, health care workers rarely receive the necessary feedback on the data they collect. But health unit data can provide useful information for the district health management team as well as health care workers themselves.

Case reporting and surveillance can be organized in the following ways:

- Through the routine health information system (HIS) which tracks the main consultation diagnoses for each health unit. This often requires a redesign of the HIS forms to capture the syndrome diagnosis categories. Summarized reports, consisting of weekly or monthly tally sheets, will provide the number and distribution of STD syndromes treated by age group and sex.

- Selected sentinel sites may be asked to keep a separate patient register book for STDs. Depending upon their capacity, these sites could carry a number of activities in relation to the national STD surveillance system, such as antenatal syphilis (and HIV) sentinel surveillance, monitoring of STD cure rates and participation in gonococcal resistance monitoring. Only absolutely essential data should be collected, such as patient name or identification number, sex, age, residence, syndromic diagnosis and the treatment given and whether condoms were provided. A separate column should be used to enter such follow-up data as date of return, clinical observation and partners treated. These registers can form the basis of discussions with the supervisor at their regular visits. Some simple data can be extracted from them and analyzed by the health care worker alone or with the supervisor. Such monitoring indicators can become targets to attain and act as a motivating factor.

THE ROLE OF THE LABORATORY IN STD CASE MANAGEMENT

There are two levels on which to conceptualize the role of the laboratory in STD control:

- The clinical level, where the laboratory can be used to aid diagnosis, screening and case finding.
- The public health level, where the laboratory can contribute to the development and validation of national STD case management guidelines, and can assist in the necessary epidemiological and microbiological monitoring.

The ideal diagnostic or screening test should be accurate, inexpensive, simple, rapid, based on convenient culturally acceptable samples, stable under adverse conditions and functionally packaged. Highly specific tests are required for diagnosis to avoid overtreatment. High sensitivity and specificity are required for screening and case finding activities. Since the advent of molecular diagnostic techniques, very few of the old “gold standard” tests have remained cost-effective options. But the newer, more sensitive and more expensive techniques have become further out of the reach of laboratories in resource-constrained countries. Simpler STD diagnostic techniques are being devel-

Table 7

ROLE OF THE LABORATORY IN STD CASE MANAGEMENT

	Peripheral/primary health care level	Intermediate/district level	National/reference level
Clinical activities			
Diagnosis	<ul style="list-style-type: none"> (Optional—Simple tests for vaginal infections: pH, KOH, wet mount microscopy). 	<ul style="list-style-type: none"> Microscopic diagnosis of vaginal infections. (Optional—Diagnosis of gonorrhoea: microscopy (men) and possibly culture). 	<ul style="list-style-type: none"> Culture: <i>N gonorrhoeae</i>, <i>H ducreyi</i>. Chlamydia EIA. (Optional—PCR or LCR).
Case Finding	<ul style="list-style-type: none"> RPR/VDRL. 	<ul style="list-style-type: none"> RPR/VDRL. Confirmatory tests for syphilis (TPHA). 	<ul style="list-style-type: none"> RPR/VDRL. Confirmatory tests for syphilis (TPHA).
Public health activities			
Contribution to STD guidelines	<ul style="list-style-type: none"> Clinical efficacy of algorithms (in selected sentinel sites). 	<ul style="list-style-type: none"> Participating in aetiological/algorithm validation studies. 	<ul style="list-style-type: none"> Conducting/coordinating aetiological studies. Evaluation of algorithms.
Epidemiological and microbiological monitoring	<ul style="list-style-type: none"> Syphilis rates in ANC. 	<ul style="list-style-type: none"> District/regional level syphilis statistics. Quality control of peripheral syphilis testing. Antimicrobial susceptibility of <i>N gonorrhoeae</i> (disk diffusion). 	<ul style="list-style-type: none"> National level syphilis statistics. Quality control of syphilis testing. Monitoring antimicrobial susceptibility of <i>N gonorrhoeae</i> and <i>H ducreyi</i> (MIC or E-test). Guiding choice of drugs to be included in essential drug list. Training, supervision, quality control schemes.

oped, but even they do not dispense with the need for basic equipment and maintenance, a regular supply of reagents, the presence of properly trained and supervised staff and regular quality control.

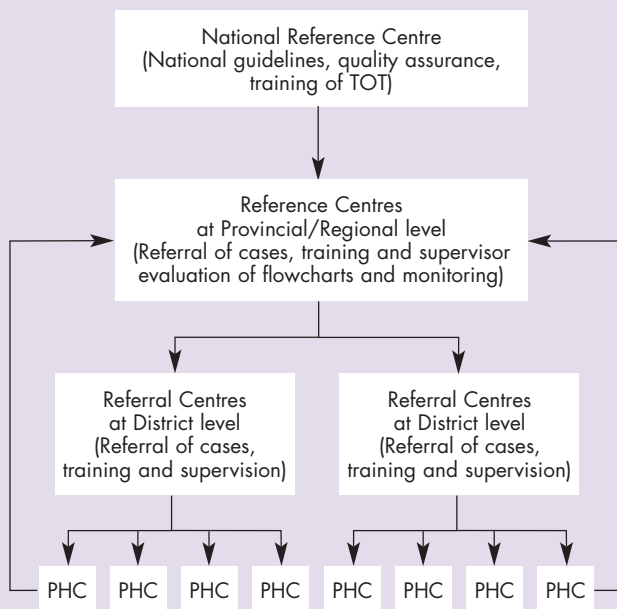
A few recent reviews have summarized the available information on the validity, feasibility and cost of existing tests for STDs.^{22,23} Table 7 provides suggestions on using laboratory services at various levels.

REFERRAL SYSTEM AND THE ROLE OF THE CATEGORICAL STD CLINICS

Even where routine STD care is integrated with general health services, a proportion of patients will still require referral to more specialized services. This form of secondary care can be provided at clinics staffed with clinicians experienced in STD case management. Efforts should be made to strengthen referral services at intermediate health care levels, such as district hospitals (or equivalent) and gynecological outpatient departments. STD services can be organized as described in Figure 6.

Figure 6

ORGANOGRAM OF STD SERVICES



A few categorical STD clinics can also support this network. At the regional or provincial level, one STD clinic could act as a reference center.

The reference categorical clinic should fulfill several roles:

- Serve as a referral center for complicated STD cases.
- Organize STD training (and elements of supervision).
- Monitor the epidemiology of STD and contribute to establishing and revising national guidelines.

In addition to its function as a referral center for primary health care or intermediate echelon clinics, the reference center is also responsible for training health care workers, either clinicians or laboratory attendants.

The third role of a reference center is to monitor the epidemiology of STD by looking at:

- The pattern of STD etiologies
- The pattern of resistance of *Neisseria gonorrhoeae*, or, in some settings, *Haemophilus ducreyi*
- Clinical and microbiological cure rates
- The pattern of service usage
- Quality of care

At the national level, a National Reference STD Center also should be responsible for developing and reviewing the national STD management guidelines, ensuring the development of STD training curricula for various staff cadres and organizing “training of trainers” (TOT), developing and coordinating the STD research agenda and maintaining quality assurance schemes for laboratory or clinical care. A number of peripheral reference centers can assist the National Reference Center in its tasks.

THE ROLE OF DISTRICT/REGIONAL PERSONNEL: TRAINING, SUPERVISION AND MONITORING

Although integrated with the daily routine of patient management, STD control efforts may depend to some extent on vertical services. The first level of vertical services may be found at the district or regional level where specialized staff will provide technical and policy support to staff from the periphery units. These staff must provide regular input in terms of training, support and monitoring of primary health care workers, in addition to organizing district-level STD control activities. Without these essential elements, STD control efforts may collapse.

Training

Training is an integral part of health care program management and focuses on developing human resources in a way that supports the program policies, activities and outcomes. Training also improves staff professionalism and morale.

Basic training and continuing education are both essential for quality STD care. The health care worker should understand the strategy into which the primary health care services fit. The STD treatment protocols—

which should be developed with representatives of service providers—should be relevant to the health problems associated with STD and appropriate to the setting. A health care provider needs to understand the rationale behind a particular protocol if he or she is to adhere to it. Once this is achieved the knowledge base needs to be strengthened.

A training program for health care workers can be planned based on the concept described above. Training needs can be identified after the strategy for STD prevention and care is outlined at the national level—at the state or provincial level in the case of larger or federal countries. Training needs can be identified once the protocols are developed and services are in place. It is important that the training involves appropriate cadres.

Among the important considerations in designing STD training are:

- Structure and content with an emphasis on both knowledge and skills:
 - Comprehensive case management
 - Use of flowcharts
 - Counseling
 - Case reporting
 - Drug ordering
- Training materials:
 - Trainers' manual
 - Teaching aids
 - Participants' manual
- Choice of participants—train those who do the job
- Choice of trainers—staff who can potentially supervise participants
- Duration of training—a few days to a few weeks

- Methodology:
 - Self-directed teaching
 - More participatory methodology rather than didactic
 - Use of case studies and problem-solving exercises
 - Practical training at a clinic in conditions similar to routine work
- Evaluation of training:
 - Knowledge gain of participants
 - Rating of the training by participants
- Plan refresher courses

Supervision

Supervision is one of the most important aspects of assessing performance and outputs. It ensures competence through observation, discussion, support and guidance. Effective supervision will require a checklist based on the importance of items needed to achieve the set targets. This may include the number of patients seen and treated correctly, availability of drugs, availability and accessibility of condoms and the ability of health care workers to improvise correctly in times of shortages or adverse reactions—such as whether or not a health care worker is able to give an appropriate alternative syphilis treatment to a pregnant woman who is allergic to penicillin.

It is the role of the national STD program team to help the peripheral units to identify indicators and set realistic targets. Supervision, however, should be the responsibility of the district or regional management. This will serve to inform the district of the prevailing constraints and how to remedy them. The national management should conduct periodic monitoring and supervisory visits together with the district team. This will give an incentive to district management and staff alike.

Supervision should be regular and routine, but not too frequent. A monthly supervisory visit can initially be set, then subsequently decreased or increased depending on the problems encountered. Such visits

Table 8
STD MONITORING INDICATORS

Syndromes

- Male and female genital discharge syndromes (M-GDS, F-GDS),
- Male and female genital ulcer syndrome (M-GUS, F-GUS),
- PID (optional) *
- Ophthalmia neonatorum (optional) *

* depending on extent of problem locally

STD monitoring indicators

- Trends in STD patients attendance over time (quarterly)
- Rates of follow-up visits; rates of completed follow-ups (until final out come is determined)
- Outcomes of treatment per syndrome (quarterly or overall) (see below)
- Partner notification rates
- Condom acceptance rates

Quality of STD care

WHO prevention indicators (PI) 6 & 7

- PI 6: Proportion of STI patients treated in an appropriate way (according to national/regional standards)
- PI 7: Proportion of STI patients receiving basic advice on condoms and on partner notification

PI 6 criteria

1) History taking

- Ask questions about STD
- Ask about symptoms
- Ask about duration
- Ask about recent sexual contacts

2) Examination

- For all patients: examine
- For all patients: undress (lie down)
- For male patients: milk urethra
- For male patients: retract foreskin
- For female patients: external genitalia
- For female patients: bimanual palpation
- For female patients: speculum exam

PI 7 criteria

- Condom advice given
- Partner notification advice given

Methods

- Interviews and focus group discussions with staff and patients
- Observations of STD patients management at clinics
- STD patients exit interviews
- "Mystery/dummy" patients visits

should focus on problem solving, reviewing difficult cases and praising good work. Traditional issues related to case reporting, drug utilization, stock management and ordering also need to be addressed.

Monitoring, evaluation and feedback with clinic staff

District supervisors are responsible for collecting and compiling data from all primary health care clinics in their district. As much as possible, the recording of such data should be integrated within the general primary health care information system. Some health units, however, may be selected to monitor important data such as clinical cure rates or partner treatment rates. District personnel should assist the health care worker in completing the monitoring forms. Quarterly data can be generated by compiling forms from several health units, and this information should then be reported to higher levels to compile national statistics. It should also go to the peripheral units that helped to generate the data. Marked differences between health units should be discussed in detail and—if necessary—advice for improvement given. Examples of useful STD monitoring indicators are provided in Table 8.

Ad-hoc surveys of the quality of STD case management using the WHO Prevention indicators (PI) 6 and 7 may also prove useful as complements to the supervision reports. Several methods for collecting these indicators have been described.¹⁰

LESSONS LEARNED AND RECOMMENDATIONS

Since the beginning of the HIV epidemic, STD control has assumed greater importance because of the close interrelationship between STDs and HIV, which share the same principles of control. As the Mwanza trial demonstrated, improved management of symptomatic STDs will decrease HIV transmission.

Here are the key lessons learned over the years:

STD diagnosis and treatment

- Etiological approach by laboratory test is preferable but not practicable everywhere and may incur delays in initiating treatment.
- Syndromic approach is recommended for the management of patients with:
 - Urethral discharge
 - Genital ulcer
 - Inguinal bubo
 - Vaginal discharge (for vaginal infections)
- Diagnosis and management of cervicitis caused by *Neisseria gonorrhoeae* or *Chlamydia trachomatis* in women is complicated.
- Risk-assessment strategies to discriminate between cervical and vaginal infections need to be carefully evaluated and adapted to local conditions; the existing WHO suggested score could be used as a basis for this work.
- Developing affordable, rapid and simple diagnostic tests for *Neisseria gonorrhoeae* and *Chlamydia trachomatis* infections is a top priority.
- A number of highly prevalent but neglected infections—such as genital herpes and bacterial vaginosis (BV)—can easily be diagnosed and/or included in management flowcharts with the aid of such simple tests as the pH paper and “whiff test” which detects a fishy amine odor from vaginal fluid when mixed with 10 percent potassium hydroxide (KOH) and indicates BV.

Key elements of STD case management

- Use flowcharts for syndromic diagnosis and case management.
- Integrate it with general outpatient services.
- Use the opportunity for health education.
- It is important and difficult to ensure proper counseling.
- Partner notification is likely to be more effective if index patient is indeed symptomatic.
- Be aware of the potential danger of domestic violence after partner notification.
- Provide all components of treatment at the same place and avoid referrals.

Increase access to proper treatment through innovative approaches

- Involve the private sector, both allopathic and traditional.
- Offer workplace-based STD services.
- Provide pre-packaged treatment kits for urethritis.

Case finding

- Provide onsite syphilis testing for syphilis during pregnancy.

Importance of supervision and in-service training

- Regularly monitor the quality of STD services by auditing cure rates, prevention indicators PI6 and PI7 and patient and staff satisfaction.
- Provide a continuum between prevention and care through BCC by encouraging STD treatment-seeking behavior and prevention messages.

FUTURE CHALLENGES

CHALLENGES FOR EFFECTIVE STD CONTROL

Improving inappropriate STD services requires:

- Training and re-orientating health care providers to be non-judgmental and adopt positive attitudes towards patients with STD.
- Ensuring the availability of services that offer private consultation and examination.
- Ensuring that effective drugs are consistently available at the patient's first clinical encounter point.
- Maintaining a consistent supply of condoms.
- Better, simpler and cheaper diagnostic tests for STD, and defining their utilization for case finding or management.
- Providing sustainable strategies to detect and treat STDs in women, adolescents and high-risk populations.
- Addressing gender inequalities, the lack of male responsibility in sexual relationships and the lack of access for males to dedicated sexual health services.
- Influencing societal norms ("shame"), education and information.
- Addressing structural issues and capacity in resource-constrained countries.
- Addressing policy issues, political will and neglect.
- Addressing economics, poverty, instability and migration.

CHALLENGES FOR FUTURE RESEARCH

Research needs:

- Integrate services, including analyses of barriers, conditions of success and maintenance of quality of care.
- Develop rapid tests for *Neisseria gonorrhoeae/Chlamydia trachomatis* and evaluation.
- Evaluate the role of endogenous infections in pathology.
- Determine the role and strategy for controlling such endogenous infections as BV or for targeted prophylactic treatment in pregnant women.
- Determine the role of asymptomatic versus symptomatic infection in maintaining the prevalence of STD and HIV in a community.
- Assess the role of single mass treatment or selective periodic presumptive treatment in controlling STD prevalence at the population level.

CASE STUDIES

DECENTRALIZED SYPHILIS SCREENING AND TREATMENT IMPROVES SYPHILIS DETECTION AND TREATMENT IN ANTENATAL CLINIC SETTINGS IN NAIROBI, KENYA

In the early 1990s, syphilis control in antenatal clinics (ANC) in Nairobi, Kenya, was a centralized system whereby women had blood taken for syphilis serology at the first ANC visit. The blood was transported to a central laboratory for testing and results were returned to the clinic in two to four weeks. Women found to have reactive serology were referred to a specific clinic within the city. This system was not very effective—fewer than 60 percent of pregnant women had blood specimens taken at their first visit. Of these, 87 percent had their syphilis test results recorded on their ANC records, but only 9.1 percent of syphilis seroreactive women received adequate treatment. In response to the low level of effectiveness documented in this centralized system, a decentralized syphilis screening and treatment pilot project was instituted in Nairobi in 1992. Components of this decentralized, clinic-based model of onsite diagnosis and treatment of maternal/partner syphilis included:

- Laboratory support:
 - An ANC nurse performed syphilis serology
 - Quality control procedures were established with monthly feedback to ANC staff.
- Diagnostic and treatment supplies provided to the ANC clinics.
- Training of ANC nurses in:
 - Performance of the RPR card test
 - Treatment of seroreactive women
 - Counseling patients
 - Partner referral
 - Supervision and monitoring

Over the 12 months of this pilot project, 13,131 pregnant women were tested for syphilis. Eighty-seven percent of the seroreactive women were treated

at their first ANC visit. A total of 86 percent of the women were counseled about the importance of sexual partner treatment. While about 50 percent of the partners of seroreactive women were treated at the same clinic as the index case, it is unknown how many women actually notified their partners. It cost an estimated US\$26.00 per case treated, and US\$48 per congenital syphilis case averted.

This pilot project demonstrates the feasibility and cost effectiveness of congenital syphilis prevention and control decentralized to the clinic level. But several operational and logistical issues must be addressed for optimal implementation:

- There must be a mechanism for ongoing supportive supervision to maintain a quality program, staff motivation and morale.
- ANC clinic staff need high quality training.
- The clinics need adequate and continuous supplies of diagnostic equipment, diagnostics, reagents and drugs.
- There has to be quality assurance of the onsite laboratory testing.

This project was implemented by the University of Nairobi, Nairobi, Kenya; Institute of Tropical Medicine, Antwerp, Belgium; University of Ghent, Brussels, Belgium; University of Manitoba, Winnipeg, Canada; and the Nairobi City Council, Nairobi, Kenya, with support from MotherCare/John Snow International, the Commission of the European Communities and the sub-program Science and Technology for Development, the Commission of the European Communities.

MANAGEMENT OF SYMPTOMATIC WOMEN IN LOWER STD PREVALENCE SITUATIONS—EXPERIENCE FROM BANGLADESH

Appropriate case management strategies for women who were complaining of symptoms possibly related to infection in the reproductive tract were evaluated among a group of 465 women in rural Bangladesh.²⁴ Among women seeking care at the primary health care level, their presenting complaints were established then correlated against both the clinical findings and diagnoses made by trained health care providers (trained in syndromic management) and against laboratory results. The drug costs were also calculated for treating women according to the recommended algorithms for use at primary health care level.

Most women (95 percent) presented with complaints of an abnormal vaginal discharge. This is consistent with surveys from other areas of the world, indicating that this is one of the most common reasons that women seek health care. A smaller number had complaints of vaginal itching, lower abdominal pain or painful intercourse. Health care workers diagnosed eight cases of cervical infection, 164 cases of vaginal infection and three cases of genital ulcer disease. Since all health care workers had been trained in the syndromic management of symptomatic women, the women were treated according to standard algorithms.

But laboratory diagnosis revealed that a reproductive tract infection was responsible for the symptoms in fewer than 40 percent of these women. Thirty-two percent had bacterial vaginosis (Nugent's criteria on Gram Stain) or candida (wet preparation); 1.5 percent had trichomonas (wet preparation and culture); and 1.1 percent had either gonorrhoea (culture) or chlamydial infection (urine polymerase chain reaction). Fewer than one percent of women had evidence of current,

active syphilis infection (rapid plasma reagin [RPR] and treponema pallidum hemagglutination [TPHA] tests). The correlation between the health care workers' diagnoses and the presence of laboratory diagnoses were zero percent for cervical infection and genital ulcer disease, and just under 30 percent for each of the endogenous infections.

These results reflect the low prevalence of infections in these women and the difficulty in interpreting clinical signs that have a relatively low specificity. This combination of factors resulted in high levels of overtreatment. In fact, the WHO recommended algorithm shows that more than 90 percent of drug costs went to overtreatment. Not only does overtreatment carry financial repercussions in this community, but erroneous STD diagnoses carry a high social cost for women.

When most women presenting for care do not show evidence of infection on laboratory diagnosis, it is clear that other reasons for their self-perceived symptoms need to be elucidated. It may be that other, more appropriate interventions are necessary to improve the quality of care for these women. For example, it remains to be seen whether they are misinterpreting as abnormal what are in fact normal variations in their vaginal discharge. Further qualitative investigations among these women may highlight the reasons they seek care and what they perceive as normal or abnormal.

In the meantime, it is important for policy makers and program managers to be aware that the epidemiology of these infections in resource-constrained countries is not entirely homogeneous. Extrapolation of results and attendant interventions from one area to another without evaluations of appropriateness and effectiveness can result in the application of inappropriate interventions in some areas. It is therefore recommended that before designing programs, the epidemiology and prevalence of the infections being targeted should be ascertained and approaches modified based on these data as well as the clinical setting in which they will be used.

This case study was written by Dr. Sara Hawkes, Population Council/India. The research was supported by the UK Department for International Development and

the International Centre for Diarrhoeal Disease Research, Bangladesh (ICDDR-B), Centre for Health and Population Research. Contributors to the study were from ICDDR-B, London School of Hygiene and Tropical Medicine in London and the Laboratory Centre for Disease Control in Winnipeg.

STD SYNDROME MANAGEMENT AT RURAL PRIMARY HEALTH CARE CLINICS IN NORTHERN TANZANIA

A community-based randomized trial was conducted between 1992 and 1994 to test the impact of improved STD control on the incidence of HIV infections in adults living in 12 rural communities in northern Tanzania.²⁵ The study, done in the Mwanza region, showed that improved STD control resulted in a 38 percent reduction of new HIV infections compared to communities where there was no improved STD control. The study also reduced the level of some STDs in the communities where STD control was improved. In particular, the prevalence of symptomatic urethritis in men was reduced by 50 percent, and that of active syphilis by 30 percent.^{25,26} Several lessons were learned during this trial about STD control, which will be reviewed in this case study.^{27,28}

Design elements of the STD intervention used in this study are applicable to any STD service development, including:

- **Integration:** STD control was integrated into the existing primary health care structure using the existing staff and health facilities. STD case management services were part of routine care—no special clinic hours were organized for STD care. Partner referral was done through the use of contact cards. Patients were asked to return for follow-up visits. Training, supervision and drug supply logistics were initially organized centrally through the regional program office. Subsequently, responsibility for training, supervision and logistics was decentralized to the district teams.

- **Training:** A training curriculum and book were designed. Health care workers were trained in comprehensive STD case management using the syndromic case management approach.
- **Supervision and ongoing in-service training:** Participating health units were supervised every two months at the beginning of the intervention. This frequency was subsequently reduced to every three months as health workers gained proficiency in the approach.
- **Drug supply and logistics:** Drugs for STD case management were supplied to the health units based on consumption, which was crosschecked against patient register books.
- **STD reference center:** A reference center was established in Mwanza town to: (1) monitor the etiologies of STD syndromes; (2) monitor the effectiveness of syndrome algorithms in use; (3) monitor the antibiotic susceptibility of *Neisseria gonorrhoeae*; and (4) train health care providers for the rural health units.

Five sources of data were used to evaluate operational performance of the program: (1) A survey of register books to collect data on patients presenting with STDs and reproductive tract infections (RTIs) to rural health units with improved STD services; (2) A survey of register books from health units in communities without improved services; (3) A survey of register books from referral clinics, (4) A home-based study of STD patients who did not return to the intervention health units for follow-up; and (5) A cross-sectional survey of reported STD treatment-seeking behavior in a random cohort of 8,845 adults served by rural health units.

During the two years of the Mwanza trial, 12,895 STD syndromes were treated at the 25 intervention health units. The most common syndromes were urethral discharge (67 percent) and genital ulcers (26 percent) in men and vaginal discharge (50 percent), lower abdominal tenderness (33 percent) and genital ulcers (13 percent) in women. Clinical treatment effectiveness was high in patients from whom complete follow-up data were available, reaching between 81 percent and 98 percent after first-line treatment and 97 percent–99 percent after first-, second- and third-line treatment. Only 26 percent of patients referred to higher levels of health care had presented to their referral institutions.

During the trial period, data from the cohort showed that 12.8 percent of men and 8.6 percent of women in the intervention communities experienced at least one STD syndrome. Use of the improved health units by symptomatic STD patients in these communities was estimated at between 50 percent and 75 percent, based on various approaches. Attendance at intervention units increased by 53 percent during the first six months of the intervention. The average attendance rate thereafter was about 25 percent higher than in comparison communities.

Home visits to 367 non-returners revealed that 89 percent had been free of symptoms after treatment, but 28 percent became symptomatic again within three months of treatment. One hundred percent of these patients reported that they had received treatment, but only 74 percent had been examined, 57 percent had been given health education and 30 percent were offered condoms. Patients did not fully recall which treatment they had been given, but possibly only 63 percent had been treated exactly according to guidelines.

This study demonstrated that it is feasible to integrate effective STD care services into the existing primary health care structure of a resource-constrained country. Improved services attract more patients, but additional educational efforts are needed to further improve treatment-seeking behavior. Furthermore, clear treatment guidelines, a reliable drug supply system and regular supervision are critical. All efforts

should be made to treat patients without delay at the point of first encounter, as referral to higher levels of care led to a high number of drop-outs. The syndromic approach to STD control should be supported by at least one reference clinic and laboratory per country to ensure monitoring of prevalent etiologies, the development of bacterial resistance and the effectiveness of the syndromic algorithms in use.

The program also documented that syndromic management had several limitations: (1) There was no impact on asymptomatic infections, which were highly prevalent in this population among both men and women; (2) There was no impact on STD prevalence among pregnant women living in the same communities; and (3) Despite emphasis on counseling services during the training of primary health care workers, there was a limited impact on condom acceptance and a modest but improved effect on partner notification in these rural areas. The program also identified the need to target more vulnerable population groups who are not reached by a general service approach; namely, young people and pregnant women.

This case study is based on the work of H Grosskurth, P Mayaud, D Mabey, R Hayes, and colleagues in Mwanza at the African Medical and Research Foundation (AMREF), National Institute for Medical Research (NIMR), Regional Medical Office (RMO) and Municipal Office of Health in Mwanza, as well as the National AIDS Control Programme (NACP) and Ministry of Health in Dar Es Salaam. The program was supported by the European Commission of the European Union (DG VIII and DG XII), the Overseas Development Agency (now Department of International Development [DFID]) of the United Kingdom and the Centre for International Migration (CIM) from the Federal Republic of Germany, with additional input on specific studies from WHO/GPA and AMREF Austria.

RELEVANT CHAPTERS

- Chapter 9 *HIV/AIDS Programs in Private Sector Businesses*
- Chapter 12 *Social Marketing for HIV Prevention*
- Chapter 15 *Issues in STD Control for Special Groups*
- Chapter 17 *Reducing HIV Infection in Women and Providing Family Planning Services to Women at Risk*
- Chapter 18 *Reducing the Risk of Mother-to-Child Transmission of HIV During Pregnancy and Delivery*
- Chapter 23 *Counseling, Testing and Psychosocial Support*

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C H A P T E R

15

*Issues in STD
Control for
Special Groups*

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Issues in STD Control for Special Groups

INTRODUCTION

In any society, most transmission of sexually transmitted infection (STI) occurs within a relatively small segment of the population characterized by high rates of sexual partner change. Vulnerability to infection based on high levels of exposure, combined with frequent opportunities to transmit infection to others, make effective prevention and treatment strategies for such groups a priority.

Reaching the most vulnerable individuals with effective services is not always a simple task. Sex workers and others with the greatest number of sexual partners are often socially marginalized, discriminated against and may be the last persons reached by traditional health care services. In addition, standard diagnostic approaches are often not sensitive enough to detect most infections.

To meet these challenges, new strategies are being developed and evaluated. This chapter reviews such targeted strategies, with emphasis on those approaches that seek to reduce the incidence and prevalence of sexually transmitted disease (STD) as an HIV prevention strategy.

CHARACTERIZING CORE POPULATIONS

This section is organized around the concept of differential vulnerability to infection that characterizes core groups, as defined by high rates of sexual partner change. Intervention strategies will be presented under two main categories, those for “sex providers” and those for actual or potential “sex clients.”

Youth require separate consideration because rates of partner change and STDs are higher among adolescents and young adults compared to older age groups, an epidemiologic condition that justifies targeted interventions. Youth also present an important opportunity in that effective prevention efforts directed to those who are just beginning sexual activity can protect an emerging generation.

To maximize impact, targeted approaches to STD control require attention to:

- Outreach—how to reach the target group.
- Service delivery—how to set up and provide services.
- STD management strategies—how to detect and treat STDs.

OUTREACH—HOW TO REACH THE TARGET GROUP

The most critical step in implementing effective targeted interventions is, arguably, reaching the core group and convincing individuals of the value of the intervention. Peer education has been used effectively to organize target groups, raise awareness about STD and other health issues and promote preventive behavior and use of curative services.

SERVICE DELIVERY—HOW TO SET UP AND PROVIDE SERVICES

Two important issues to consider in setting up or adapting curative services are accessibility and acceptability. Accessibility is influenced by such factors as distance to services as well as convenience of hours of operation. Acceptability issues include respect for privacy and confidentiality, non-judgmental attitudes of health care staff and perceived competence of care providers.

STD MANAGEMENT STRATEGIES—HOW TO DETECT AND TREAT STD

STD management strategies will need to be sensitive enough to identify the majority of people infected, while avoiding over-treatment where possible. While these objectives are the same as for general population STD services, core groups justify more aggressive approaches.

STRATEGIES FOR HIGH-RISK WOMEN

Accurately detecting STDs in women presents many difficulties. Advantages and disadvantages of several approaches are discussed for:

- Syndrome management
- Screening
- Presumptive treatment

STRATEGIES FOR HIGH-RISK MEN

Strategies for detecting STD in male core groups have been based on the assumption that most men with STD have symptoms and will eventually seek care. Treatment of symptomatic men seeking care at public or private sector clinics should be based on national STD case management guidelines.

LESSONS LEARNED AND RECOMMENDATIONS

By extending appropriate services to vulnerable populations with high rates of partner change, targeted programs can reduce STD rates where such reductions will have the greatest impact on community transmission. Experience from widely different settings over the last few decades has demonstrated that directing services for prevention and treatment to persons with the greatest number of sexual partners is both feasible and effective.

FUTURE CHALLENGES

While there are examples of successful STD interventions for vulnerable populations, many are localized demonstration projects with limited scope and impact, and few combine outreach and prevention with effective STD screening and/or treatment. Some specific areas for further research are outlined.

CASE STUDIES

PERIODIC SCREENING AND TREATMENT OF SEX WORKERS IN BOLIVIA

An STD screening program for sex workers in La Paz was strengthened to include more thorough examinations and behavior change interventions, leading to increased sex worker participation in the program and significant benefits.

PERIODIC PRESUMPTIVE TREATMENT OF WOMEN AT HIGH RISK IN SOUTH AFRICA

A project to bring preventive and curative services to women at high risk in a South African mining community has led to decreased STD rates both for the women attending the clinic and the miners living in the area.

BRIDGE GROUPS: STD SCREENING FOR HIGH-RISK MEN IN KENYA

Male “bridge” groups who work away from home facilitate the spread of HIV and other STDs from high to low prevalence areas. As a result of this combined behavioral/clinical intervention, the program documented a decrease in reported sex worker contact and a reduction of STD incidence among truck drivers in Mombassa.

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I N T R O D U C T I O N

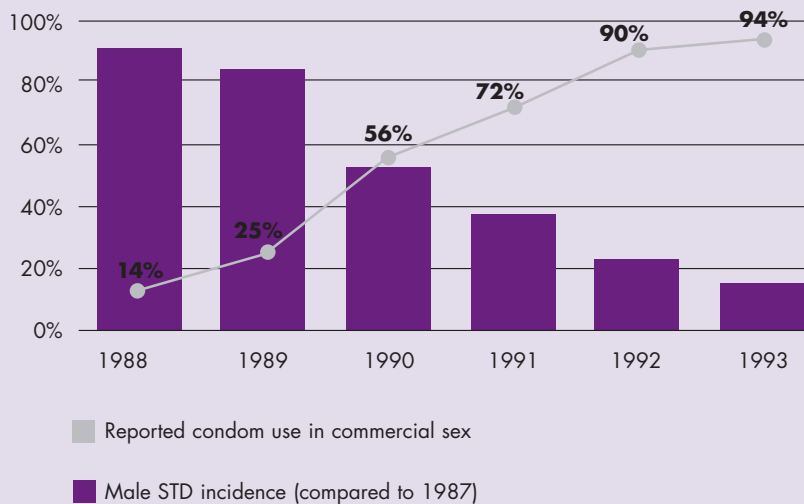
In any society, most transmission of sexually transmitted infection (STI) occurs within a relatively small segment of the population characterized by high rates of sexual partner change. Vulnerability to infection based on high levels of exposure, combined with frequent opportunities to transmit infection to others, make effective prevention and treatment strategies for such groups a priority. There is now ample evidence

that such strategies can have a large impact on STD transmission, even in areas where STD prevalence is already high in the general population. Perhaps the best example illustrating the potential of such targeted approaches comes from Thailand, where focusing prevention efforts on the commercial sex industry resulted in decreases in STD incidence of more than 80 percent and significantly reduced HIV transmission.¹

Targeting is not limited to situations such as those in Thailand, where brothels are easily identified. Even in less formal high-risk settings where promotion of condom use is a more long-term behavioral change process, targeted strategies can be applied to achieve rapid control of curable STDs, thereby reducing morbidity and slowing HIV transmission. Such short-term gains can have a large impact on the ultimate magnitude of a sexually transmitted epidemic.

But reaching the most vulnerable individuals with effective services is not always a simple task. Sex workers and others with the greatest number of sexual partners are often socially marginalized, discriminated against and—most significantly for control efforts—may be the last persons reached by traditional health care services. Even where access to preventive and curative care is good, standard diagnostic approaches are often not

Figure 1
THAI CONDOM AND STD RATES



sensitive enough to detect most infections. For core groups with high rates of partner change, each infection missed is likely to generate multiple threads of secondary infection in the community.

To meet these challenges, new strategies are being developed and evaluated. Peer education has been shown to be a powerful approach to outreach that emphasizes empowerment of vulnerable high-risk groups and encourages group solidarity and adoption of positive group norms. Special clinical services, ranging from targeted screening to presumptive treatment, address the unique needs of these core populations. This chapter reviews such targeted strategies, with emphasis on those approaches that seek to reduce STD incidence and prevalence as an HIV prevention strategy.

CHARACTERIZING CORE POPULATIONS

In addressing services and strategies for special groups, this section is organized around the concept of differential vulnerability to infection that characterizes core groups. Core groups are defined by high rates of sexual partner change: It is this high level of exposure that largely determines an individual's risk of acquiring and transmitting STDs.

At the population level, STDs maintain themselves within sexual networks with sufficient rates of partner change to produce at least enough new infections to sustain prevalence levels. The rate of partner change necessary to sustain an STD varies from pathogen to pathogen, with estimates ranging from four partners per year for gonorrhea to 15 for chancroid. Whatever the STD, however, a higher rate of sexual partner change means more opportunity for transmission—and determines the importance of the core population to STD control.

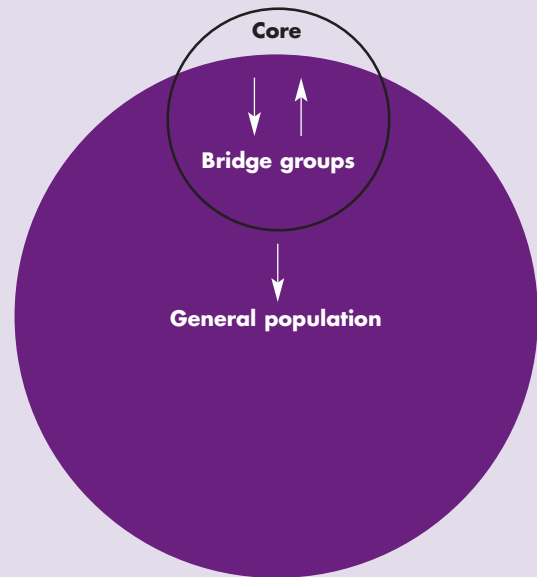
SEX WORKERS AND THEIR CLIENTS

Examples of important core groups are sex workers and their clients. This chapter presents intervention strategies under two main categories, those for “sex providers” (sex workers and others who may not identify with prostitution) and those for actual or potential “sex clients.” The nature of their work means that sex workers generally have the highest rates of partner change and are arguably the most important core group to target for STD control. Clients of sex workers form a larger, more heterogeneous group that is more difficult to identify and access. Certain male occupational groups—transport and migrant workers, military—may have frequent contact with sex workers, and will be discussed together as potential clients. Because male core groups also have contact with lower-risk women such as wives or girlfriends, they act as a bridge carrying infection from high-prevalence core groups to the general population so may be referred to as “bridge populations.”

The distinction between providers and clients in the context of commercial sex has practical application when considering intervention strategies. Sex workers are generally highly aware of the risks implicit in their profession and can often be identified and approached

Figure 2

A MODEL OF STD TRANSMISSION DYNAMICS (ADAPTED FROM THAILAND)

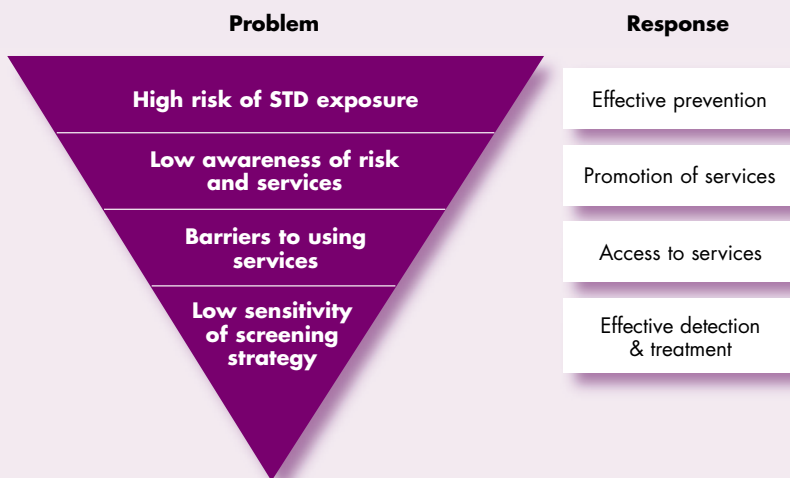


directly where they do business. Clients of sex workers, on the other hand, tend to be more secretive and are often more easily reached indirectly—through workplace programs, for example. Male core groups can also be reached “after the fact” through STD clinics or less formal sources of care, such as drug outlets.

Against this simplified view, it is important to recognize the diversity of high-risk sexual networks. Sex workers can be male or female, heterosexual, homosexual or bisexual, and compensation received in the form of money, drugs or less explicit forms of “support.” Despite differences, the person selling sex generally has more partners, more STD exposure and more opportunity to transmit infection to others—factors that make provision of effective STD services a priority. While strategies need to be adapted to specific circumstances, many of the principles outlined here may apply.

Figure 3

OBSTACLES TO STD CONTROL IN CORE GROUPS



OBSTACLES TO STD CONTROL IN CORE POPULATIONS

The first challenge is one of awareness. Not everyone in the core group recognizes that STDs are important problems and that something can be done to prevent or cure them. Secondly, even among those who are aware, many do not use services because of difficulty getting to them or because of negative attitudes of health care staff. Finally, ineffective clinical approaches may result in cure for only a minority of those who seek care. Unless these obstacles are addressed, STD control efforts will miss the majority of infections occurring within the

sexual networks where most transmission takes place.

To maximize impact, targeted approaches to STD control require attention to:

- **Outreach**—how to reach the target group.
- **Service delivery**—how to set up and provide services.
- **STD management strategies**—how to detect and treat STDs.

YOUTH

Youth require separate consideration. Rates of partner change and STDs are higher among adolescents and young adults compared to older age groups, an epidemiologic condition that justifies targeted interventions. Youth also present an important opportunity. Directing effective prevention efforts at those who are just beginning sexual activity can protect an emerging generation, even in areas with high adult HIV prevalence. But youth comprise a large and heterogeneous population that includes some very active individuals, others who are celibate and many who fall between these extremes. From a programmatic point of view, it may make more sense to widely promote high-quality, youth-friendly services and to target special services to especially vulnerable youth such as adolescent sex workers or street children.

Whatever the population, maximizing the impact of any intervention requires examination of the potential obstacles to STD control. These can be illustrated in a diagram that represents a core group with high STD exposure.

OUTREACH—HOW TO REACH THE TARGET GROUP

The most critical step in implementing effective targeted interventions is, arguably, reaching the core group and convincing individuals of the value of the intervention. Simply setting up services will not necessarily result in people using them. Involving members of core groups from the start in the design and implementation of services is a guiding principle. Members of the target population are in the best position to define aspects of service delivery that are important to those being served.

PEER EDUCATION

Peer education has been effectively used to organize groups of sex workers, raise awareness about STD and other health issues and promote preventive behavior and use of curative services. High levels of condom use and declining STD rates have been reported from longstanding peer programs in Zimbabwe and Kenya.² (The concept of peer education is discussed in more detail in Chapter 7.)

HUMAN RIGHTS

Sensitivity to human rights issues is paramount, especially in societies where sex work is illegal. Even where sex work has been legalized or decriminalized, however, issues such as police harassment or abuse by clients may be of more immediate concern to sex workers than health matters. Whatever the legal context, addressing the wider range of health and safety issues within a human rights framework will help to ensure active participation of such marginalized groups as sex workers. In Calcutta, India, sex workers have effectively addressed a range of social and public health issues, including high rates of STD exposure, as a community.³ (For further discussion of human rights, see Chapter 27.)

TARGETING MALE CORE POPULATIONS

Reaching male core populations involves different approaches. Condom promotion and prevention messages targeting male clients have been effectively implemented at bars and brothels. These range from informational—media messages emphasizing the importance of condom use in commercial sex—to

quasi-regulatory, such as “safe-house” rules mandating condom use. Because of clients’ concerns about anonymity, however, it may be difficult to organize curative services for males at places where sex work occurs.

Men who are at risk because of separation from their families—such as migrant workers or military personnel—can often be effectively targeted by working through employee health programs. Workplace health information campaigns and screening programs can be organized, and peer education among workers may be effective in disseminating prevention messages and promoting the use of curative services. Unions or other employee representatives should be consulted in designing and promoting services. In seeking to reduce risk among migrant workers, structural conditions should not be ignored. Providing family housing may be the most effective strategy for reducing STD transmission. (See Chapter 10.)

Core group men can also be reached after the fact by finding ways to better reach men seeking treatment for STD symptoms or concerned about possible exposure. Such men have long been considered a priority core population for such control activities as contact tracing. Improving care at STD or primary health care clinics is part of the strategy for effectively reaching them. But since men seek care for STDs from a variety of sources including pharmacies, traditional healers and drug vendors, innovative training programs and/or referral mechanisms may be needed to widen the catchment net. Direct social marketing of urethritis treatment has been proposed as a strategy for reaching symptomatic males who might not otherwise seek care.⁴

Whatever the strategy, efforts should be made to reach at least the most active core group populations in a given area. State-of-the-art STD services for migrant workers or military personnel will have little impact on STD rates unless quality preventive and curative services are also available to their commercial and casual sex partners.

SERVICE DELIVERY— HOW TO SET UP AND PROVIDE SERVICES

Once peer educators have been trained and are raising awareness about STDs and how to prevent them, the demand for curative services will likely increase. Two important issues to consider in setting up or adapting curative services are accessibility and acceptability. Accessibility is influenced by such factors as distance to services as well as convenience of hours of operation. For example, sex workers are unlikely to use services located far away and open only during hours when they are working or sleeping. Acceptability issues include respect for privacy and confidentiality, non-judgmental attitudes of health care staff and the perceived competence of care providers. Employees would be reluctant to use workplace clinical services if STDs are viewed as “self-inflicted” conditions that could jeopardize their employment. In general, the more accessible and acceptable the services, the more likely they will be used.

Improving access to STD services for sex workers may include arranging clinic sessions during convenient hours or organizing special clinics, onsite services in hotels or brothels or mobile clinics, and are discussed more fully in Chapter 8.

Workplace clinics are a logical focus for providing preventive and curative STD services, especially in industries that rely heavily on migrant labor. Where work conditions separate workers from their families, STDs should be considered occupational hazards requiring the same attention to preventive and curative services as, for example, silicosis in the mining industry. Programs may include a strong prevention emphasis as well as periodic screening—before workers return home on leave, for example—in addition to readily accessible, non-judgmental services for those with symptoms.

Improving STD care provided through non-clinic sources, such as pharmacies or traditional healers, often involves recognition, if not tacit acceptance, of roles outside accepted regulatory limits. Several options are possible once it is determined that a significant proportion of people bypass clinics in seeking

STD care, ranging from training and development of referral mechanisms to revising regulations governing the sale of antibiotics. Possible strategies include:

- Training pharmacists in national STD guidelines, ostensibly to ensure stocking of recommended drugs. Such training would also improve—without condoning—treatment dispensed without prescription.
- Training and developing referral mechanisms for a wide range of providers, including pharmacists and traditional healers. Awareness of STDs would be raised and cooperation sought in referring patients to clinics.
- Packaging syndrome-specific treatment doses (pre-packaged STD therapy) together with information, condoms and partner referral cards may help promote compliance with all elements of STD case management.
- Social marketing of STD drugs. The idea of direct sale of antibiotics to patients through a limited number and type of approved vendors should be carefully evaluated.

Similar strategies may help reach more adolescents and young adults with preventive and curative STD care. These may be built around school-based or special clinics designed to provide services in an accessible, non-judgmental manner, or focus on improving the quality of services provided by pharmacies or other sources already used by youth. Formative research and involvement of the target population in designing services will help ensure that the services are used.

STD MANAGEMENT STRATEGIES—HOW TO DETECT AND TREAT STDs

Once special services have been organized to meet increasing demand, decisions must be made about which strategies are appropriate for detecting and managing STDs. If outreach and peer education components are successful in reaching persons with the highest rate of partner change, and services are sufficiently accessible and acceptable to attract them, STD management strategies will need to be sensitive enough to identify the majority of people infected, while avoiding overtreatment where possible. While these objectives are the same as for general population STD services, the higher prevalence and incidence rates among core groups justify more aggressive approaches.

STRATEGIES FOR HIGH-RISK WOMEN

In general, tests—whether laboratory or risk-based—are more cost-effective, with higher positive predictive values or less overtreatment, for sex workers than for populations of women with low STD prevalence. Because of the potential for secondary transmission, sensitivity (the ability to detect infection when present) becomes a more important criterion when evaluating diagnostic and treatment strategies for core groups. Advantages and disadvantages of several approaches are discussed below:

- **Syndrome management**—Requires the presence of symptoms to identify infection. Standard risk assessment criteria used to guide the treatment of cervical infection (new partner, multiple partners) are universally present among sex workers. Risk assessment is thus essentially equivalent to presumptive treatment* for sex workers who develop symptoms. The weakness of using syndrome management alone is that most infections will be missed due to a high prevalence of asymptomatic disease.

- **Screening**—Many routine screening programs for sex workers are also limited by reliance on symptoms or clinical signs for identifying STDs (see text box). This has been supplemented in some places by serological tests for syphilis, cervical and/or vaginal microscopy, and in some cases routine gonorrhea culture and chlamydia assays. If affordable, regular laboratory screening of sex workers for the common curable STDs using sensitive tests would identify both symptomatic and asymptomatic STDs, and likely contribute to lower transmission rates.
- **Presumptive treatment**—Where screening is not feasible for cost or other reasons, presumptive treatment may be justified. The target population is presumed to have STDs, whether they have clinical symptoms or not and without screening. Because of high prevalence rates and frequent re-exposure, sex workers can be treated presumptively for the common curable STDs on a one-time or periodic basis. Such an approach may be an effective emergency measure to rapidly reduce high prevalence rates over the short term.

* Presumptive treatment of individuals or populations with a high likelihood of having disease is dependent not on the presence of symptoms or signs, nor on the results of laboratory tests, but on increased risk of exposure.

HOW EFFECTIVE ARE EXISTING PROGRAMS FOR SEX WORKERS?

Attempts to control or regulate prostitution have long been a focus of STD control efforts. Military forces have taken measures to ensure that “venereal diseases” do not compromise combat efficiency. Regulations restricting access to bars and nightclubs to women with “health cards” are common in port cities around the world. Even regulations requiring syphilis screening for food handlers may have had more to do with patterns of commercial sex than with a misunderstanding of how STDs are transmitted. Since such regulatory programs are still common, it is worth examining their strengths and weaknesses.

Typically, public health measures to regulate prostitution require periodic (weekly to monthly) examinations. They generally emphasize protecting the client or “society,” and enforcement is usually delegated to the police. When a woman is diagnosed as having an STD, her card is withdrawn pending a negative follow-up test. Women found “operating” with invalid cards are subject to arrest and/or (unofficial) harassment by police. STD prevention usually takes second place to treatment in such programs, and little effort is directed at the clients of sex workers.

A major weakness of such schemes is the approach employed to identify which women are actually infected with an STD. Diagnosis of infection is often based on symptoms or easily recognized clinical signs and supplemented by simple laboratory tests (microscopy, syphilis serology) where available. This approach has problems, including the facts that:

- Most STDs in women are asymptomatic, making disease less apparent.
- The most common clinical sign—vaginal discharge—is neither sensitive nor specific for STDs, so women with infection may have no signs, while those with discharge may have a non-sexually transmitted condition.
- Commonly available laboratory tests do not detect most STDs because of their low sensitivity.

Under such a system, several disincentives work to undermine cooperation on the part of the sex worker. Many women without STD are treated unnecessarily and have their cards confiscated, while a significant number of women with STD are given a clean bill of health—and a false sense of security. Not surprisingly, given the real consequences of reduced earning potential, many women—who do not succeed in circumventing registration in the first place—will resort to douching or self-treatment prior to their examinations in an effort to mask any sign of infection.

Despite these limitations, there is evidence that regulatory systems may have some effect on STD transmission, at least among registered sex workers. Syphilis, for which there is a simple screening test, has been maintained at low levels in port cities as diverse as Singapore, Mombassa and Dakar. It is clear, however, that such approaches often create two categories of sex work: a sanctioned, official one in which women have regular contact with health services, and a clandestine one in which women avoid all contact with the authorities. Numerous studies have documented higher rates of STD among clandestine compared to registered sex workers.

New strategies have evolved over the last few decades. In Europe, Australia, and elsewhere, sex workers’ rights are increasingly recognized and their participation sought in improving health and safety conditions for themselves and their clients. Prevention efforts are emphasized and near universal condom use in commercial sex encounters has become the norm in some countries. Decriminalization of sex work and the concept of “safe houses”—where mandatory condom use is enforced by brothel management—is promoted. In other places, peer education has been used successfully to organize sex workers and promote condom use, and more effective strategies for STD detection and treatment are beginning to be implemented. Intervention research is needed to better define the optimal combination of services that would reduce risk of disease acquisition and transmission among sex workers and their clients.

Most voluntary or regulated clinical services available to sex workers in poorer countries are limited to detection and treatment of symptomatic STD. A few successful programs employing screening and treatment or presumptive treatment have been described. Some have documented an impact on STD rates beyond the women themselves. In these experiences, intervals for screening or presumptive treatment vary from weekly (for gonorrhea cultures, for example) to monthly or longer (for presumptive treatment).

One of the first projects to take a comprehensive approach to STD prevention and care was the *Projet SIDA* (AIDS Project) in Kinshasa, Democratic Republic of Congo (DR Congo).^{5,6} Instead of coercing women into attending clinics, voluntary participation and use of prevention methods were promoted within networks of sex workers. Regular screening for curable STDs was conducted using sensitive laboratory tests. Over the life of the project, condom use increased and STD prevalence and HIV incidence decreased significantly. This approach has been successfully applied in other sites including Dakar, Senegal; Abidjan, Côte d'Ivoire; and La Paz, Bolivia. (See Case Studies.)

Despite the documented success of this approach in countries with limited resources, regular screening using sensitive (and expensive) laboratory tests has not been widely replicated beyond research settings. Attempts to develop less expensive algorithms for detection of STDs (primarily cervical infections) in sex workers, based on risk factors, clinical signs and microscopy have been reported from Benin,⁷ Côte d'Ivoire,⁸ Senegal⁹ and the Philippines.¹⁰ Results among populations of sex workers with gonorrhea/chlamydia prevalence rates of 20 percent to 35 percent suggest that such approaches work better than in general population women with lower STD rates. For example, a sensitivity of 86 percent and positive predictive value of 46 percent were demonstrated in Abidjan using diagnostic criteria of either clinical evidence of cervicitis on speculum exam, or cervical or vaginal gram stain with at least 10 leukocytes per high power field. While facilities for speculum exam and microscopy may not be universally

available, this approach is more feasible for widespread application than screening using cultures or ELISA technologies. Still, the limitations of this approach should be recognized—two-thirds of all women screened in the Abidjan study received treatment, and one in seven infections were missed.

Where accurate screening is not feasible or affordable, another alternative to laboratory-based screening is presumptive treatment of the common curable STDs. Several of the algorithm validation studies mentioned above suggested that presumptive treatment may be a more effective (100 percent sensitive) and cost-effective alternative when used either at a sex worker's first visit or on a periodic basis. This approach was applied in a South African mining community where sex workers received monthly treatment with azithromycin (one gram) as presumptive treatment for common STDs.¹¹ Rates of genital ulcers, gonorrhea, and chlamydia decreased among the women using the services, and there was a measurably significant impact on STD prevalence among local miners. (See Case Studies.)

As emergency measures to rapidly reduce community STD prevalence, intensive screening or presumptive treatment of sex workers may not be needed indefinitely. Once prevalence rates decrease, the justification for such measures diminishes. Maintenance programs that include vigorous promotion of barrier protection, syndrome management of symptomatic STDs and less frequent screening—or intermittent “morning after” emergency STD treatment—may be sufficient to maintain low rates.

While many of the details require further evaluation, the potential impact of targeted STD control interventions—to reduce prevalence rates in endemic areas or as outbreak control measures—has been demonstrated in diverse settings. Examples are summarized in Table 1.

Table 1

SELECT EXAMPLES OF SCREENING OF PRESUMPTIVE TREATMENT INTERVENTIONS

Location	Year	Target Population	Disease	Intervention/Results
Indonesia <i>ref. 16</i>	1957 to present	Sex workers	Syphilis	Periodic prophylactic penicillin reduced non-treponemal syphilis seroreactivity from 87% in 1957 to 1.5-4.2% in 1992 (some of this reduction likely due to yaws eradication campaign).
Olongapo, Philippines <i>ref. 17</i>	1967 -	Sex workers	Gonorrhea	Sustainable reductions among sex workers and servicemen with regular screening; transient additional reduction with addition of one-time selective mass treatment of SW.
Orange County, California USA <i>ref. 19</i>	1981	Sex workers, patients with ulcers and partners	Chancroid	Control of outbreak through neighborhood educational campaign, clinic referrals and presumptive treatment of sex workers, patients with ulcers and partners.
Winnipeg, Canada <i>ref. 20</i>	1987	Sex workers and contacts	Chancroid	Rapid control of outbreak through outreach to sex workers, presumptive treatment of ulcers and contact tracing.
La Paz, Bolivia <i>ref. 12</i>	1992 - 1995	Sex workers	Genital ulcers, gonorrhea, chlamydia	Reduced prevalence of GC, CT and genital ulcers among women following introduction of regular screening.
Mombasa, Kenya <i>ref. 14</i>	1993 - 1994	Truck drivers and assistants	Genital ulcers, gonorrhea, chlamydia	STD reductions following behavioral interventions and screening.
Free State, South Africa <i>ref. 10</i>	1996 - present	Women at high risk in mining community	Genital ulcers, gonorrhea, chlamydia	Significant reductions in GC, CT and genital ulcers among women; in area miners, GC/CT prevalence decreased by 43% and genital ulcers by 78% after 9 months.

STRATEGIES FOR HIGH-RISK MEN

Strategies for detection of STD in male core groups have been based on the assumption that most men with STD have symptoms and will eventually seek care. For this reason, little attention has been paid to identifying men with asymptomatic or minimally symptomatic disease. Education to raise awareness of STD symptoms and encourage use of health care services may help shorten the period during which men are infectious. Serologic syphilis testing and gonorrhea culture are effective screening tools where they are affordable. Although the sensitivity of some screening tests, such as leukocyte esterase dipstick (LED), is low, cost is also low, and periodic urine-based screening of high-risk male populations may be a cost-effective adjunct to other control measures. The high cost of more sensitive urine tests, such as ligase chain reaction (LCR) and polymerase chain reaction (PCR), currently makes their use prohibitive in most settings.

STD services appropriate to workplace or youth programs may include:

- Preventive education and condom promotion through peer educators and other channels.
- Syndrome management for symptomatic men at their worksites or in youth clinics.
- Screening for STD—examination, serologic testing for syphilis, gonorrhea culture, LED for urethritis—at routine occupational or school health exams and/or before going home on leave.

Treatment of symptomatic men seeking care at public or private sector clinics should be based on national STD case management guidelines. Informational sessions for pharmacists, traditional healers or drug vendors may be indicated. Experience from Nepal and elsewhere suggests that such training can improve the quality of STD treatment dispensed over the counter.¹² Whatever the source of treatment, pre-packaged STD treatment packs can help ensure compliance with national treatment guidelines and promote preventive aspects of care. Such packets may be suitable for broader sale directly to men in high-risk situations—for example, as a socially marketed product available through outlets in red light districts.

LESSONS LEARNED AND RECOMMENDATIONS

Targeted STD control interventions complement clinical services available to the general population. By extending appropriate services to vulnerable populations with high rates of partner change, targeted programs can reduce STD rates where such reductions will have the greatest impact on community transmission. Experience from widely different settings over the last few decades has demonstrated that directing services for prevention and treatment to persons with the greatest number of sexual partners is both feasible and effective (Table 1). General lessons drawn from successful programs include:

- Address the needs of the vulnerable population as a first priority. Broader public health objectives will be met only if services are also beneficial to the target population, and are perceived to be so.
- Principles of voluntary cooperation and respect for human rights are essential to the success of any effort involving socially marginalized groups. Programs attempting to “regulate” sex work must recognize the importance of gaining the support and participation of those involved. Otherwise, health or other regulations will likely be circumvented, leading to increases in higher risk “clandestine” activity.

Examples of possible components for targeted STD services for both vulnerable women and men are presented in Table 2.

HOW TO REACH THE TARGET GROUP

Representatives of the vulnerable population should be included from the beginning and have an active role in the design and implementation of services. Experience suggests that even the most vulnerable groups can be effectively engaged once trust is established.

Table 2
STD CLINICAL SERVICES FOR VULNERABLE GROUPS — POSSIBLE COMPONENTS

	Female core groups	Male core groups
Priority populations	Sex workers, other vulnerable women with multiple partners.	Clients of sex workers, STD patients, others (migrant workers).
Objective	Detect and treat as many infections as possible (maximize sensitivity). Frequency of examination/treatment should be based on exposure rates.	Emphasis on symptomatics, exploit opportunities for detection of asymptomatic infection.
Barrier promotion	Male condom, with female controlled backup method.	Male condom.
Treatment of symptomatics	Syndrome management (including presumptive treatment for cervical infection in symptomatic women).	Syndrome management at worksite clinics. Improved treatment at alternative sources of care (pharmacies, other). Social marketing of urethritis treatment.
Detection and treatment of asymptomatic	Screening for syphilis (q3-6 mo), gonorrhea culture/chlamydia assay (q1-4w.), trichomoniasis/bacterial vaginosis (q1-4w), cervical dysplasia (q1-2y)	Examination for inapparent infections (not noticed by patient). Lab screening: RPR, urine dipsticks (LED) for urethritis, gonorrhea culture, chlamydia assay where feasible.
OR		
Presumptive treatment of asymptomatic infections	Frequency 1-3 months (depending on exposure). Examination when symptoms appear or every 3-6 months with RPR and wet mount.	Possible uses in high risk populations (for example prior to migrant workers returning home on leave).
Other services	Contraception, referrals for other health problems, social services, legal advice.	Voluntary HIV counseling and testing.
Other program elements	Peer education, periodic monitoring of prevalence rates and antibiotic resistance.	Peer education, periodic monitoring of prevalence rates and antibiotic resistance.

Peer education is an effective strategy for reaching vulnerable population groups. In addition to promoting services, peer educators can positively influence group attitudes towards condom use and other aspects of preventive behavior and assist the group in improving unsafe conditions.

HOW TO SET UP AND PROVIDE SERVICES

- Special services for sex workers should address a wide range of sexual health needs in an accessible, nonjudgmental manner to maximize participation.
- Workplace and school-based clinics may provide opportunities for screening high-risk populations for STD, in addition to promoting prevention and making treatment available to those with symptoms.

- Community-based treatment strategies—including the involvement of pharmacists, traditional healers and others—can extend the reach of clinical services. Social marketing of STD treatment in high-risk settings may be an effective approach, especially for men.

HOW TO DETECT AND TREAT STDs

- Standard approaches to identifying and managing STDs perform poorly among high-risk populations because too many infections go undetected.
- Sensitive methods for STD detection are justified on the basis of public health as well as individual benefit. False-negative results multiplied by the number of exposed partners result in a large number of avoidable secondary infections.
- For similar reasons, presumptive treatment may be justified in situations where adequately sensitive tests for treatable STDs are unavailable or unaffordable.
- Prevalence and the rate of exposure to STD are two criteria for deciding frequency of screening or presumptive treatment. Strategies may change as STD prevalence declines.
- Program monitoring should include measures of STD prevalence and related behavior. Antibiotic susceptibility patterns of *N. gonorrhoea*—and others in certain regions—should be monitored to ensure continued effectiveness of treatment regimens.

Examples of specific strategies for routine detection/treatment of curable STDs in female sex workers are outlined in Table 3. Three examples requiring different levels of resources are described.

FUTURE CHALLENGES

While there are examples of successful STD interventions for vulnerable populations, many are localized demonstration projects with limited scope and impact, and few combine outreach and prevention with effective STD screening and/or treatment. Specific areas for further research include:

- What is the optimal screening strategy for different vulnerable groups? How often should sex workers, migrant workers or military personnel be screened? Which screening tests are sufficiently sensitive and cost-effective in each case?
- How long should presumptive treatment continue when it is used to rapidly reduce STD rates? How can lower STD rates be maintained once presumptive treatment is reduced or withdrawn?
- How can barrier method use be increased to high enough levels to maintain low STD rates? How can peer educators be most effective in promoting barrier methods?
- Does provision of STD screening and/or treatment services act synergistically to raise awareness and increase use of effective barrier protection? What can be done to minimize the risk that treatment will instill a false sense of security and undermine adoption of preventive measures?
- What is the role of screening for asymptomatic or minimally symptomatic infection among men working away from home?
- How can men who seek STD care outside the health system best be reached? Is there a role for innovative strategies such as community-based or socially marketed STD treatment?
- What is the risk of development of antibiotic resistance when aggressive treatment strategies are used to treat individuals with many sexual partners? Is this risk, if real, offset by decreases in STD prevalence?

Answers to such operational questions will help to refine and improve the quality of STD services for the people who need them most. Existing evidence already indicates, however, that well-implemented targeted interventions can have a dramatic impact on STD rates. Perhaps the main questions two decades into the AIDS epidemic are:

Table 3

STRATEGIES FOR STRENGTHENING PREVENTIVE AND CURATIVE STD SERVICES FOR SEX WORKERS (BY LEVEL OF AVAILABLE RESOURCES)

	Examination-based Screening	Laboratory-based Screening	Presumptive Treatment
Strategy	Examination and simple lab tests to detect a proportion of asymptomatic infections. Improved management of symptomatics.	Regular laboratory testing to detect asymptomatic infections. Improved management of symptomatics.	Periodic presumptive treatment of common curable STDs. Supplemental treatment where indicated for symptomatic patients.
Prevention	Condom with female controlled backup method (diaphragm?).	Condom with female controlled backup method (female condom/diaphragm?).	Condom with female controlled backup method (female condom/diaphragm?).
Resource Requirements	Low initial and recurrent.	High initial and recurrent.	Moderate to high recurrent.
Cost Effectiveness	Moderate (effectiveness limited by lower sensitivity).	High when averted secondary infections considered.	High when averted secondary infections considered.
Gonorrhea/Chlamydia	Syndrome management with presumptive treatment of cervical infections in women with symptoms of vaginal discharge. Treatment of asymptomatic women with signs of cervical inflammation or pelvic tenderness on exam (gram stain).	Gonorrhea culture + chlamydia ELISA (monthly*). Syndrome management with presumptive treatment of cervical infections in women with symptoms of vaginal discharge.	Presumptive treatment with azithromycin or alternative combination therapy (monthly*).
Syphilis	Syndrome management of genital ulcers. Speculum exam to detect unapparent ulcers. Syphilis screening (non-treponemal) q six months*.	Syndrome management of genital ulcers. Speculum exam to detect unapparent ulcers. Quantitative syphilis screening (RPR) q 3-6 months*.	Supplemental treatment (benzathine penicillin) for symptomatic genital ulcers (azithromycin may effectively treat incubating syphilis). Quantitative syphilis screening (RPR) q 3-6 months*.
Chancroid	Syndrome management of genital ulcers. Speculum exam to detect unapparent ulcers.	Syndrome management of genital ulcers. Speculum exam to detect unapparent ulcers.	(Covered by presumptive treatment).
Trichomonas/Bacterial Vaginosis	Syndrome management of women with symptomatic vaginal discharge using metronidazole. Microscopy where feasible.	Syndrome management of women with symptomatic vaginal discharge using metronidazole. Microscopy q one month*.	Supplemental treatment of women with symptomatic vaginal discharge using metronidazole. Microscopy or presumptive treatment with metronidazole q one month*.

*Illustrative intervals - should be adapted based on local incidence and prevalence rates.

- How much can effective core group interventions contribute to STD control? If they contribute significantly, how much of an impact will they have on HIV transmission?
- Is there a role for public health campaigns to reduce the prevalence of specific curable STDs, such as chancroid, that are particularly vulnerable and linked to HIV transmission? Is eradication a feasible objective for some STDs?
- How can comprehensive targeted interventions be scaled up to have an impact on a national level? Can successes such as Thailand's be replicated or adapted in other countries?

CASE STUDIES

PERIODIC SCREENING AND TREATMENT OF SEX WORKERS IN BOLIVIA¹³

Several studies have documented that screening programs for sex workers alone have little if any impact on STD transmission, especially when services are coercive, inadequately designed and poorly supported.¹⁴ This was the situation in La Paz, Bolivia, in the early 1990s. There, sex workers were required to attend weekly “check-ups”—usually limited to a brief history and external examination—and quarterly syphilis screening. Despite regulations, clinic attendance was poor and STD rates remained high.

This program was strengthened beginning in 1992 with quarterly “comprehensive” examinations that included a more thorough sexual and medical history, gynecologic examination with speculum, cervical gram stain, vaginal wet mount and syphilis serology. Gonorrhea culture and chlamydia test results were available at follow-up visits a week later. Perhaps most importantly, behavior change interventions were launched in the brothels to increase condom use and encourage use of the new services. As a result, sex worker participation in the program increased and significant benefits were documented. Between 1992 and 1995, reported condom use increased from 36 percent to 73 percent, while prevalence of gonorrhea declined from 25.8 percent to 9.9 percent, syphilis from 14.9 percent to 8.7 percent and genital ulcers from 5.7 percent to 1.3 percent.

The STD screening protocols used in this project included both clinical and laboratory criteria to identify STDs. Women with ulcers were treated for both syphilis and chancroid. Cervical infection was diagnosed on site if there were either clinical signs (mucopurulent discharge) or gram stain evidence of inflammation, and co-treatment was given to cover gonorrhea and chlamydia. Syphilis testing rapid plasma reagin (RPR) was performed on site.

Project staff attribute the observed decline in STD prevalence to the combination of increased condom use and improved STD detection and treatment, and hypothesize that the provision of curative services

contributed to the success of the condom promotion efforts. Other sites have also reported this synergy between preventive and curative components of sex worker programs.

Other projects that have reported positive outcomes for sex workers participating in periodic STD screening and treatment include DR Congo, Côte d’Ivoire, Senegal, Peru, Indonesia and the Philippines. Algorithms that combine one-time presumptive treatment with periodic screening are increasingly being employed.

PERIODIC PRESUMPTIVE TREATMENT OF WOMEN AT HIGH RISK IN SOUTH AFRICA¹¹

The women of Virginia, a mining community in South Africa’s Free State, call the project Lesedi, or “We have seen the light.” Once suspicious of the free diagnosis and treatment of STDs it offered—and of its connection with HIV prevention—they now embrace the project as their own. The project brings preventive and curative services to women at high risk in a South African mining community.

The project owes much of its popularity to a committed team of peer educators who were recruited from among early clinic attendees. Because sex work is covert and core groups are not easily identified in the mining communities, referrals to the clinic are generally by word of mouth. Besides promoting clinic attendance, peer educators advocate for consistent condom use and keep an eye out for newcomers to the community who may need referrals.

Once at the clinic, women receive additional prevention counseling as well as treatment for symptomatic STDs. The approach used to identify and treat

STDs at Lesedi is periodic presumptive treatment. A form of epidemiologic treatment similar to partner treatment, PPT is recommended based on the women's high likelihood of infection—half the women had one or more STDs at first visit. Women attending the Lesedi clinic initially receive one gram of azithromycin each month as presumptive treatment for gonorrhea, chlamydia, chancroid and incubating syphilis.

In evaluating this first phase of the intervention, STD rates were measured both for the women attending the clinic and miners living in the area. Among women using the services, STD prevalence was reduced by as much as 85 percent. Local miners screened nine months after the project began were found to have 43 percent fewer gonorrhea/chlamydia infections than before the intervention and 78 percent fewer genital ulcers. STD consultation rates at mine health services were also monitored. Miners living in hostels near the intervention had significantly lower rates of symptomatic STDs than those living farther away. In addition, self-reported condom use in commercial sex rose from negligible levels to as many as 30 percent of encounters after one year and up to 60 percent after three years. As STD prevalence decreased and condom use increased, the interval of PPT was increased. After three visits, women continue to attend monthly for counseling but the frequency of PPT is decreased to once every three months.

How important was presumptive treatment to this decline of STD prevalence? Data on STD rates during the first nine months were examined to determine the proportion of women who would have received treatment by the more conventional means of syndrome management. While two-thirds of women with STD at their first visit had symptoms that would have warranted syndromic treatment, only 15 percent were symptomatic at follow-up visits.

Other sex worker interventions using presumptive treatment are being evaluated in Cambodia, Côte d'Ivoire and the Philippines. Some are using one-time presumptive treatment at first visit—where STD prevalence is highest—to rapidly lower the prevalence followed by other interventions to maintain the reduced rates.

BRIDGE GROUPS: STD SCREENING FOR HIGH-RISK MEN IN KENYA¹⁵

Male bridge groups who work away from home facilitate the spread of HIV and other STDs from high- to low-prevalence areas. Truck drivers have been identified as an important male occupational group that, due to frequent and prolonged travel, are at high risk of acquiring STDs and transmitting them to regular and casual sex partners.

In Mombassa, an important Indian Ocean port and transport hub for eastern and central Africa, an intervention was implemented at the depots of six large trucking companies. Employees were offered risk-reduction counseling and STD screening at onsite clinics once every three months. At each visit the men received risk-reduction messages, reinforced condom promotion and a physical exam. Laboratory screening included syphilis and HIV serology, gram stain and culture for gonorrhea and antigen detection for chlamydia. They received their results at a follow-up visit a week later.

As a result of the combined behavioral/clinical intervention, the program documented a decrease in reported sex worker contact from 12 percent to 6 percent and a reduction of STD incidence from 34 to 10 per 100 person-years. There were substantial measurable decreases in genital ulcer disease, gonorrhea and non-gonococcal urethritis.

Less invasive and less expensive—but also less accurate—screening methods have been used to screen high-risk men in other places. Among South African miners, adding leukocyte esterase dipstick (LED) increased the sensitivity from 13 percent to 46 percent over an algorithm based on signs and symptoms alone.¹⁶ Other studies have shown that LED can help detect some asymptomatic infections, though at the cost of significant overtreatment. The more accurate DNA amplification tests that are increasingly used for screening adolescents in developed countries are currently unaffordable for most countries.

RELEVANT CHAPTERS

- Chapter 7 *Youth Intervention Programs*
- Chapter 8 *Reducing HIV Risk in Sex Workers, Their Clients and Partners*
- Chapter 10 *Programs for Mobile Populations and Their Partners*
- Chapter 27 *HIV/AIDS, Health and Human Rights*

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C H A P T E R

16

*STD Program
Management
and Evaluation*

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STD Program Management and Evaluation

INTRODUCTION

Despite the availability of curative treatment for bacterial, protozoal and fungal sexually transmitted infections (STIs), sexually transmitted diseases (STDs) caused by these infections remain a public health problem in both industrialized and resource-constrained countries. Many of the latter, in particular, still appear to have high endemic rates of infection.

This chapter addresses the need for a national program for the care and prevention of STD. It also emphasizes supervision and evaluation of such a program.

THE NATIONAL STD PROGRAM

In resource-constrained settings, an effective national STD program management structure can help establish and maintain prevention activities and ensure access to effective and acceptable services. This section describes the key elements in a national STD program that determines national policy and overall strategy, prepares an operational plan and implements or oversees support components with decentralized service delivery:

- Program structure
- Technical support
- Selection of program priorities
- Prioritization of support components
- Operational planning
- Resource mobilization

PERIPHERAL STD MANAGEMENT

Peripheral STD managers—who may be at the regional, provincial or even district level—implement the services and interventions. The roles of the central and peripheral STD programs must be carefully defined to avoid confusion of areas of responsibility and duplication of activities; their roles must be essentially complementary, not competitive. This section looks at issues related to local planning and implementation.

SUPERVISION, MONITORING AND EVALUATION

This section highlights areas of difference between various AIDS programs and indicates where coordination of activities is beneficial. Program managers – whether national or local – are responsible for supervision, monitoring and evaluation. If AIDS and STD programs are integrated or closely coordinated, joint planning of monitoring and evaluation is logical, as many of the activities are closely linked. Supervision has a more immediate relationship with implementation, as it is a routine, continuing activity that measures the immediate process and provides support and problem-solving.

SUMMARY AND RECOMMENDATIONS

Although many countries have formal national STD programs, lack of guidance on what constitutes the basis for an effective STD program has often hampered their success, especially in resource-constrained settings. This section summarizes a suitable package of activities for an STD care and prevention program and offers recommendations for developing such a program.

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I N T R O D U C T I O N

It is paradoxical that, in spite of available curative treatment for bacterial, protozoal and fungal sexually transmitted infections (STIs), the sexually transmitted diseases (STDs*) caused by these infections remain a public health problem in both industrialized and resource-constrained countries. In most industrialized countries, however, the rate of infection is low and often decreasing. In contrast, many resource-constrained countries still appear to have high endemic rates of infection.

Unlike the bacterial, protozoal and fungal STIs, transmission of viral STDs—including HIV—may be controllable only through behavior change: by reducing high-risk sexual activities, especially among those who are particularly vulnerable and at heightened risk due to frequent partner change.

Identifiable reasons for past failure to control curable STD and limit the spread of viral infections include the following:

Policy makers and planners have given low priority to allocating resources for STD control, often because STD is perceived to be associated with discreditable behavior, failure to appreciate the magnitude of the disease's complications and sequelae or failure to recognize the magnitude of the problem.

- Control efforts have concentrated on symptomatic patients (usually men), and failed to identify asymptomatic individuals (commonly women) until complications have manifested.
- Services have often been delivered through specialized treatment facilities, which provide inadequate coverage and are stigmatizing, particularly for women.

- Interventions have not been directed at those populations whose high-risk sexual behavior most influences continuing high rates of infection.
- Treatment strategies have focused on unrealistic requirements for definitive diagnosis rather than on practical decision making.
- Ineffective low-cost antibiotics have continued to be used for reasons of economy.
- There has been little emphasis on educational and other efforts to prevent infection.
- Academic interest in teaching and researching STDs is limited, and low professional status accorded health-care workers engaged in STD care and prevention activities.
- There has been an absence of authoritative guidance on a rational, practical and well-defined package of activities as a basis for prevention and control programs.

This chapter addresses the need for an organizational basis for a package of activities under the heading of a national program for the care and prevention of STD. Such a program must be closely linked to a national AIDS program, ideally with decentralization of many activities, including service delivery. Supervision and evaluation of an STD program are also emphasized.

** The term sexually transmitted disease (STD) is used throughout this chapter to describe sexually transmitted infections and the diseases, complications and sequelae that result. For example, a sexually transmitted infection, gonorrhoea, results in a disease, cervicitis, which may lead to a complication, salpingitis. Permanently impaired fertility would be a sequelae.*

THE NATIONAL STD PROGRAM

A national STD program that sets a national policy and overall strategy, prepares an operational plan and implements or oversees support components with decentralized service delivery can best address the problems listed in the introduction.

Most countries have some centrally managed STD activities; many have formalized these into a national program. A few countries, such as the United Kingdom, have no central program. In the UK, each geographic management unit is required to provide access to STD services; how this is to be done is not defined. This approach is probably only suitable for countries with well-developed and well-resourced health systems, as access to quality primary health-care services is particularly important.

In resource-constrained settings, an effective national STD program management structure can help set up and maintain prevention activities and ensure access to effective and acceptable STD services.

Program management is the organization and control of available human, material and financial resources to ensure their use in an effective and appropriate manner to achieve the program's objectives. In the case of STD, "political advocacy to ensure that resources are adequate" should be added.

NATIONAL STD PROGRAM STRUCTURE

The structure of a national STD program will depend on a country's general health care system, particularly its degree of decentralization. Experience has shown that decentralization of health programs is valuable, since it confers ownership of health services to the local authority and promotes efficient use of resources. If STD budgets are fully decentralized, however, there is a danger that resource allocation may be politicized. It is often difficult to justify allocation of limited funds to prevent and treat what are considered to be self-inflicted diseases associated with antiso-

cial and immoral behavior. This is particularly true when trying to provide non-judgmental quality services to such stigmatized groups as sex workers. (See Chapter 15 for in-depth discussion of STD control for special groups.)

Prevention activities for both conventional STD and HIV are similar and complementary; the audiences are identical. The programs should therefore be integrated or, if this is unacceptable, closely coordinated.¹ Primary prevention through behavior change communication (BCC) activities should not be duplicated, but should form a single component of the AIDS and STD programs.

The STD program can be an independent unit within the Ministry of Health, part of the National AIDS Program or part of a larger division such as communicable diseases. Probably the best situation would decentralize services to municipalities and local districts, with the STD and AIDS programs fully integrated. The National STD Program would assume the following responsibilities:

- Plan and oversee implementation of support components.
- Coordinate nongovernmental interventions and activities.
- Monitor and supervise implementation of decentralized STD service delivery.
- Coordinate with the AIDS program in the delivery of behavior change communication (BCC).
- Conduct evaluation of all STD activities.
- Coordinate STD surveillance.
- Effectively advocate for resources with planners and policy makers.

Whether integrated or not, the STD program should be headed by a full-time program manager with a public health background and appropriate technical support.

THE RELATIONSHIP BETWEEN AIDS AND STD

- The prime mode of transmission of HIV and other STD is sexual, although blood, blood products, donated organs or tissue are also transmission modes. An infected woman can also transmit infection to her fetus or newborn child.
- Many measures for preventing sexual transmission of HIV and other STD are the same, as are the target audiences for these interventions.
- STD clinical services are an important access point for people at high risk of both HIV and other STD, not only for diagnosis and treatment but also for education.
- There is a strong association between the occurrence of HIV infection and the presence of other STD, making early diagnosis and effective treatment of STD an important strategy for the prevention of HIV transmission.
- Trends in STD incidence and prevalence can be useful early indicators of changes in sexual behavior, and are easier to monitor than trends in HIV seroprevalence.

TECHNICAL SUPPORT TO THE NATIONAL STD PROGRAM

The STD program manager should have access to expertise in technical/scientific and policy-making issues related to STD control. Ideally, this will be provided by an STD technical advisory group, which will have, or may access, expertise in:

- Clinical care of STD
- Public health
- Women's issues
- Legal and human rights
- Laboratory medicine
- Epidemiology
- HIV/AIDS
- Behavioral sciences
- Health services planning and management at primary and secondary health care levels
- Training
- BCC
- Evaluation

The inclusion of academic and professional organizations, nongovernmental organizations (NGOs), and community groups whose members are most likely to access the services should be considered.

The technical advisory group should meet at regular intervals to review the components of the program, make suggestions for development and implementation priorities and advise on gaps or deficiencies.

One of the most important functions of the STD technical group is to establish a multidisciplinary approach that will encourage ownership of program components by the implementers. For example, the World Health Organization (WHO) recommendation that STD services should be integrated in first-level health care services will require the cooperation of several Ministry of Health programs, such as primary health care, family planning (FP), and maternal and child health care (MCH).

Situational assessment

Few countries have no STD program. One of the tasks of a national STD program manager is to review the existing program and develop or reorganize as necessary, taking into consideration the present situation and international "best practices."

The program manager should have a clear understanding of the existing situation in order to prioritize and design activities to remedy identified deficiencies. Longstanding STD programs may already have information on the availability of resources and program

MAKING OR UPDATING A SITUATIONAL ASSESSMENT

Objective

To understand the current STD status, and what can be done to improve it, the following must be assessed:

- The STD situation in the country or a particular area:
 - Epidemiology and clinical syndromes—STD pathogens and their antibiotic sensitivities, character and size of populations at greatest risk.
 - Existing services, public sector and private sector, including physicians, other health-care workers providing STD services, pharmacies and unqualified health care providers.
 - STD health care-seeking behavior among the general population and high-risk and vulnerable groups.
- The political, legal and social factors that may influence the national (or local) program:
 - Positive or negative political commitment.
 - Legal constraints:
 - Registration of sex workers and/or establishments
 - Availability of antibiotics without prescription
 - Reporting of STD patients by name
- The available resources:
 - Allocation of funds from the Ministry of Health (or local authority).
 - Available personnel.
 - Infrastructure, equipment, materials, consumables.

- Availability of and funding for drugs.
- Resources for study, operational research, curriculum development (university clinic, medical schools, social studies and educational institutions, etc.).
- Actual/potential additional resources (such as international agencies, donors, NGOs).
- Availability and commitment of other health care programs/services that can deliver STD care (such as reproductive health programs).

Means

- Key informant interviews:
 - Ministry, district and local officials.
 - Health care providers.
 - NGO staff.
 - General and target populations.
- Documents:
 - Reports, laws and regulations.
 - HIV/AIDS plans.
 - Health facility and laboratory records.
 - Publications and internal reports from local and national government offices, NGOs, donors and neighboring countries (areas).
 - Visits and observation.

Output

An up-to-date situational assessment is the basis for logical planning of STD care and prevention. It should look particularly at individuals, institutions and agencies focused on STDs and allied social problems that may provide commitment and leadership in developing services or the program in general.

activities, epidemiological data from case reporting, surveys and other operational research. Information on nongovernmental services and activities may also be available.

Situational data, however, must be reviewed at regular intervals to identify changing patterns and direct planning. The status quo cannot be accepted without periodic review. No matter how well-implemented existing activities may be, their relevance and adequacy must be assessed on a regular basis.

The central STD program is responsible for ensuring that the general situation is being assessed continuously, but peripheral authorities must also be encouraged to review their local situations and ensure that services are and remain appropriate.

Coordination of activities

The STD program must have a clear overview of the activities and interventions being undertaken. In resource-constrained settings it is very common for external agencies, donors, NGOs, etc. to help support the STD program. Their activities must be coordinated with each other and with the program requirements. Their support must be directed toward priority situations and avoid duplication.

Training in case management, advice on treatment and means of service delivery must be consistent with program policies. To achieve this, the program must ensure that there is a consensus on national STD case management guidelines and training curricula for staff at different levels of the health service.

COORDINATION OF ACTIVITIES REPUBLIC OF THE PHILIPPINES

Situational Assessment

Several NGOs with different sources of funding provided training to first-level health-care workers in STD case management using a syndromic approach:

- Flow charts used for training varied.
- Several training curricula were used.
- Treatments varied.
- Key informants reported having had several training courses with no consistent messages.

Solution

First

The National AIDS and STD Prevention and Control Program (NASPCP) contracted with an NGO to:

- Develop National STD Case Management Guidelines (NSCMG) based on available data, with assistance from the National STD Technical Group.
- Prepare a training curriculum based on the NSCMG.

The NSCMG and training curriculum were presented at a consensus workshop, discussed and agreed upon by all agencies providing STD services and training.

Second

- The NASPCP field-tested the guidelines and curriculum for feasibility.

Third

- The same NGO conducted a validation of the flow charts for vaginal discharge, and developed (and is currently validating) a variation to the flow chart.

Expected Outcomes

- Training is consistent between different agencies.
- Consistent service provided by first-level health-care workers (in primary health care, maternal and child health care and family planning) is consistent.
- A revised and validated flowchart for women will be available.

STD policy

A national STD policy should be developed, based on a situational assessment. This policy should outline principles that guide the strategy and approach of the local or national program. At a minimum it should indicate:

- Government commitment to addressing control of STDs
- Principles for the control strategy (for example, confidential, non-judgmental and non-stigmatizing service provision)
- Guidelines for service delivery (integration of STD services into the general health care system, promotion of services for women and for high-risk and vulnerable groups, etc.)
- Principles upon which training curricula will be based
- Logical and realistic goals for the national program

It is also useful to develop local (regional or provincial) STD policies that emphasize commitment to the general principles of the national policy and provide greater detail on local implementation. Such local policies create a greater sense of ownership and commitment.

Vertical versus horizontal systems

The National STD Program will decide which system of STD services will be promoted. Options include vertical programs and horizontal programs, or a combination of the two.

Vertical STD programs provide services through categorical STD clinics. Although these clinics can deliver quality STD care, access is often limited to the immediate geographic area and attending such clinics may be stigmatizing. In horizontal programs, STD services are delivered through the general health care system at the point where the individual first attends. Access is easy and services acceptable to the individual. Expertise is limited, however, and a referral service is necessary for those who fail to improve using the syndromic case management now widely promoted at first-level health care. (For in-depth discussion of the syndromic approach to STD care, see Chapter 14.)

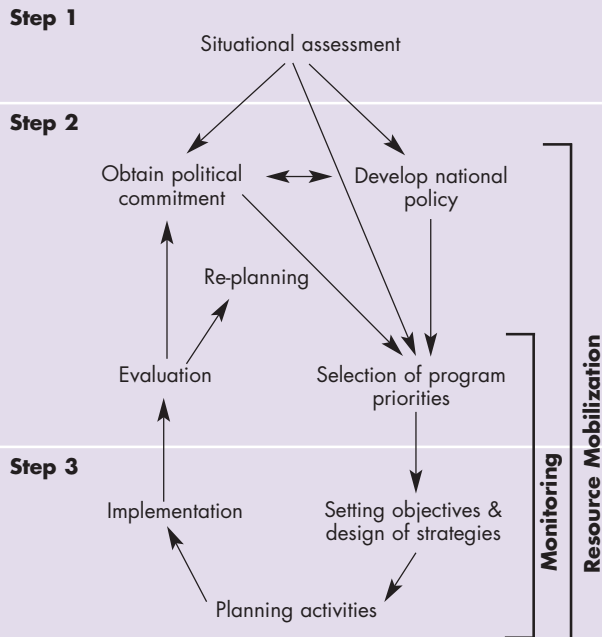
A reasonable compromise is the provision of routine STD case management through first-level health care, with referral services at categorical STD clinics or hospital outpatient departments (OPD), such as gynecology or dermatology, where expertise and laboratory support are available or can be made available.

Since most countries will have some categorical STD clinics, integrating STD services into the general health system may be opposed by influential venereologists who fear the reduction in their roles. The STD program should reassure them that their importance will actually increase with the development of better and more relevant referral services. It should be noted that the categorical clinic may be more acceptable to some marginalized groups—such as sex workers, who are unwilling to admit to their occupation in an integrated clinic, and migrant workers, who may have limited access to integrated services.

THE ROLE OF CATEGORICAL OR SPECIALIZED STD CLINICS

- Provision of STD care in urban settings for high-risk and vulnerable groups such as sex workers and their clients, migrants, transport workers and any other group with poor access to health care. (Note: sex workers and their clients, potential or actual, may not be willing to attend together. It may, therefore, be necessary to provide separate facilities or at least separate sessions.)
- Referral services from primary health care, hospital outpatients and private practice.
- Training of health care staff in appropriate STD case management (such as etiologically based STD services for gynecologists, syndrome-based services for primary health care).
- Performance of special studies necessary for the STD control program, such as antimicrobial susceptibility testing, prevalence of etiological agents within recognized syndromes and feasibility and validity of flow chart approaches.

Figure 1
STEPS IN PROGRAM PLANNING



Having determined—with the assistance of the national technical group—the type of system best suited to the situation, the program manager must identify steps to be taken for its implementation. These are outlined in Figure 1.

SELECTION OF PROGRAM PRIORITIES

Identification of priorities is an essential step in developing an operational plan for the implementation of the STD program. Available resources seldom, if ever, match optimal requirements. Decisions must be made on the work program—consistent with the accepted overall strategic plan—that can feasibly be undertaken with available human and financial resources, within the timeframe of the operational plan.

Priorities may include:

- Support activities (operational research, special studies, surveillance, development of guidelines, etc.)
- Routine STD services (STD case management integrated into the general health-care system including primary health care, MCH and FP)
- Specific service-delivery interventions based on the situational assessment data (clinics directed at particular target groups such as truckers along a highway, sex workers at truck stops, military and police camps and barracks, prisons, etc.)
- Specific BCC interventions, (such as promoting STD health care-seeking behavior)
- Services specifically directed at women (strengthened gynecology outpatient departments, etc.)

If the health system is fully decentralized, service delivery will be managed at the lowest level reached by decentralization. The national program then must provide guidance—not only for routine service delivery through the general health services, but also for specialized STD services such as those provided in categorical STD clinics or in gynecology or dermatology departments. The program will advocate provision of services, provide guidance on service delivery and clinical case management and training, and may arrange for STD-specific funds in the allocation of monies from the central government.

Although specific service interventions, such as for high-risk and vulnerable groups, may be initiated by the national program, these interventions will still require coordination with the local STD programs and activities.

BCC should be a joint function of the STD and AIDS programs. If they are integrated, STD/HIV/AIDS BCC will be implemented by an IEC unit. The STD program's role will be advisory.

PRIORITIZATION OF SUPPORT COMPONENTS

All of the following support components are essential to development and management of an STD program. An existing program will most likely already contain these elements, but they must be reviewed and updated from time to time. It is not possible to

implement them all at once; forward planning over two to five years is appropriate. Priority should be given to existing support functions that are least satisfactory or most needed for overall program strategy.

The support components are interrelated. For example, STD case-management guidance needs input from special studies/operational research/surveillance; training requires case management guidance.

Guidelines on STD case management

Clear guidance on STD case management within the capabilities of the non-specialist health care worker must be part of STD services in the general health system. National STD case management (NSCM) guidelines must be developed and agreed upon so that consistent quality care can be provided.

Training

Once NSCM guidelines are agreed upon, a training curriculum can be prepared and a training plan developed. The central program will develop and periodically review the curriculum; it will also support peripheral management in its implementation. In addition to clinical training, such curricula should emphasize communication skills, tolerant and non-judgmental attitudes, client confidentiality and gender sensitivity. STD specialists and other staff providing referral services must also be encouraged and enabled to remain up-to-date.

Operational research and surveillance

It is difficult to completely separate surveillance from special studies/operational research. Figure 2 indicates elements of both.

Other operational research may be identified that is unrelated to surveillance, but helpful to directing the program—such as a study of STD health care-seeking behavior in high-risk and vulnerable groups and determinants of such behavior. Some surveillance may link well with HIV surveillance activities, such as prevalence of serological markers for syphilis routinely obtained from specimens collected for HIV serosurveillance, and STD prevalence surveys periodically performed with HIV sentinel surveillance.

Laboratory services

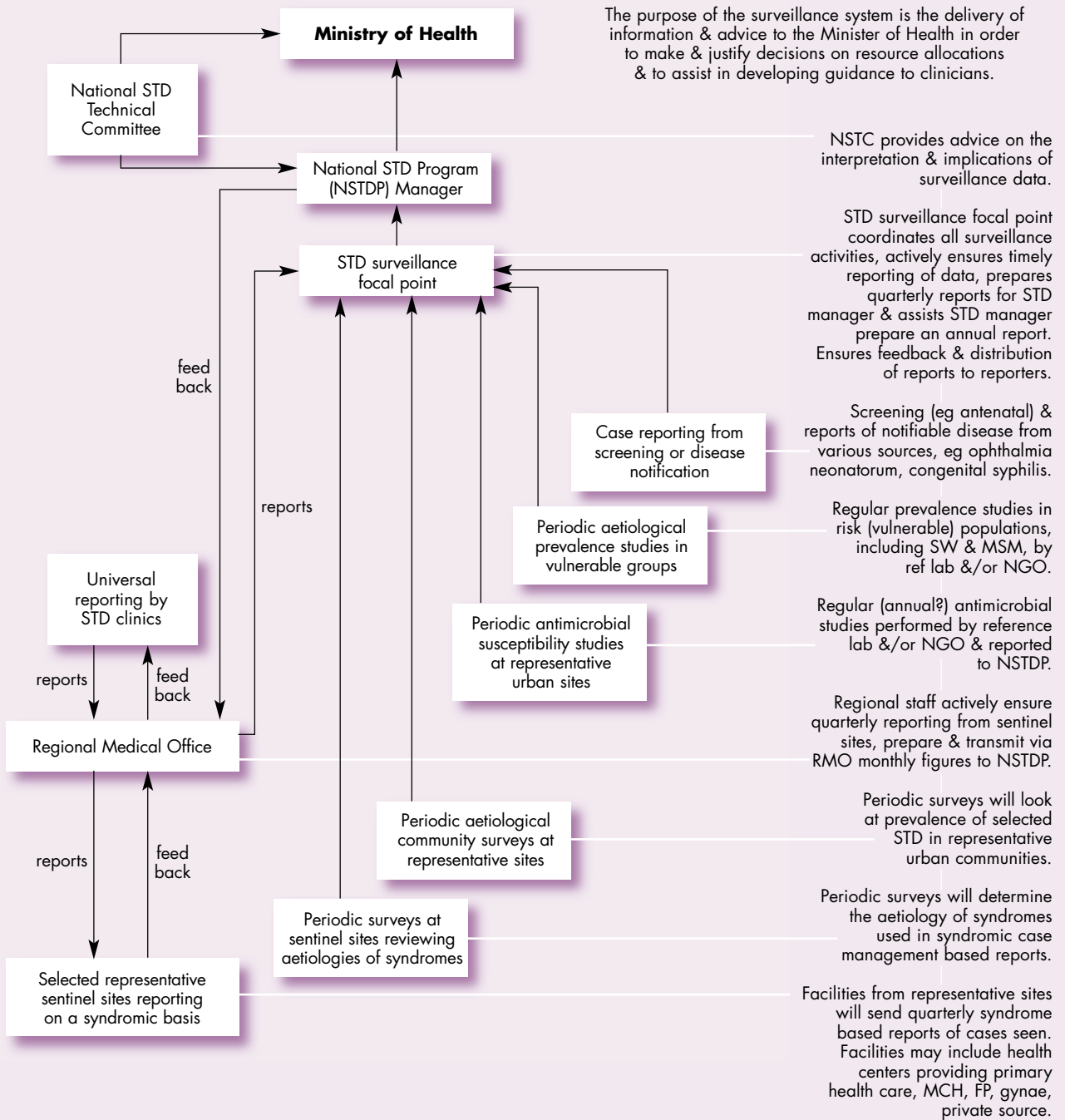
Laboratory support is rarely available—other than at tertiary or referral hospitals—in resource-constrained settings. Syndromic case management eliminates the need for laboratory investigations in STD diagnosis in all except the syndrome of vaginal discharge and, to a lesser extent, lower abdominal pain in women. Unfortunately, the syndromic approach to vaginal discharge cannot distinguish the difference between vaginitis and cervicitis, particularly in a low-prevalence situation. The need for laboratory support remains and must be addressed.

Identification and treatment of sex workers with gonococcal or chlamydial cervicitis is an essential part of STD control: Their vulnerability to infection, by reason of their multiple partners, results in further transmission to clients and thence to the general population. The probable higher prevalence of sexually acquired cervicitis in sex workers justifies a syndromic approach with treatment for vaginitis and cervicitis in symptomatic sex workers complaining of, or found to have, vaginal discharge. It cannot, however, even with the incorporation of clinical findings, reliably identify asymptomatic sex workers with gonococcal or chlamydial cervicitis; laboratory support is necessary.

The national program can help provide essential laboratory support by:

- Identifying sites where support is required and advocating its provision.
- Ensuring availability of necessary equipment in peripheral laboratories, categorical STD clinics, hospital laboratories serving OB/GYN departments, etc.
- Providing logistical management of reagents and consumables—the availability of these products is a major constraint to laboratory support.
- Providing seed funding or supplies to promote and enable development of laboratory cost recovery schemes.
- Providing curricula and training.

Figure 2
GENERIC SYSTEM OF SURVEILLANCE



Logistics

The program must ensure that effective STD drugs—recommended in the NSCMG—are included in the Essential Drugs List and available locally. Drug cost is a major constraint for many STD programs. The national program may help by bulk purchase, subsidies and promotion of cost recovery through drug revolving funds. It can support the availability of condoms in similar ways.

Maintenance and replacement of laboratory equipment, reagents, materials, consumables and other supplies are essential to the full delivery of STD services. These logistics must be addressed by both central and local management.

OPERATIONAL PLANNING

It is valuable to prepare a medium-term plan that outlines the expected strategy development over an extended period, usually five years. A more detailed plan is prepared for a two-year period, the first year fully developed with all activities for implementation defined (including time scale, responsibilities, implementing agency, cost and source of funding). The second year is less detailed, and can be revised if necessary.

The detailed operational plan cannot be finalized until the STD program policy is agreed upon, a clear understanding of the existing situation reached and activity priorities determined.

RESOURCE MOBILIZATION

The operational plan will have been developed with a realistic idea of resources available from the Ministry of Health and other sources, according to the situational assessment. Additional resource mobilization from national government, private sector and international partners is valuable for activities that need not be immediately sustainable, such as operational research and periodic surveillance surveys. Funds provided for service activities and ongoing interventions are usually time-limited and inherently difficult to sustain.

PERIPHERAL STD MANAGEMENT

The National STD Program is heavily involved in broad issues of overall planning, policy making, resource mobilization, coordination, etc., and much less with service and intervention implementation. This is the role of the peripheral STD managers, who may be at the regional, provincial or even district level. But principles that apply to the national program also apply to the local program, and local AIDS and STD programs and activities should be coordinated. This is best achieved by combining the roles of AIDS and STD managers. For example, when the AIDS program was integrated with the STD program in the Philippines, the local STD coordinators became the AIDS/STD coordinators.² The reverse happened when the STD program was developed in Lao People's Democratic Republic (PDR): each Provincial Committee for the Control of AIDS (PCCA) took on responsibility for local STD programs.³

The central and peripheral STD programs are essentially complementary, not competitive. Their roles should be carefully defined to avoid confusion in areas of responsibility and duplication of activities. For example, the peripheral program will be responsible for collecting case reporting data from its area and forwarding it—perhaps after local analysis—to the central program. There, the final data analysis will be made and put into the context of reports from other peripheral programs. The results—and any central decisions that have been made based on them—will be fed back to the peripheral programs, which will then meet with reporting facilities to discuss the results and plan necessary actions.

LOCAL PLANNING

Like the national program, the local program will make best use of its budget and resources by forward planning, using a work plan. The purpose of a work plan includes:

- Realistic planning of activities based on available resources.
- Coordinating STD, including HIV, activities with other programs and agencies:
 - The AIDS program, particularly STD/HIV IEC
 - The general health system within which STD services are integrated
 - Local and international NGO with STD interventions
- Measurement of achievements and identifying lessons learned.

Quantitative targets must be set to measure achievements in the work plan, and means of verification identified.

Preparing yearly work plans should be considered an essential management procedure. Successful and logical implementation depends on it. It is not usually possible to complete all the details required at the beginning of the year, so the work plan should be considered a dynamic document.

It is worth remembering that, as in all programs, time is a resource; its use must be properly planned. Program managers often have little control over the use of time by health-care providers, but should set an example with their own staff. This is particularly demonstrable in the organization of meetings, which should be well planned, run to time, achieve clear objectives and produce rapid feedback via written minutes.

IMPLEMENTATION

Sound management is critical for the success of public health activities, and is best undertaken by local staff who understand the community. Interventions directed at high-risk and vulnerable groups benefit from staff who are close to and sympathetic to the target population.

Human resources

In the public sector, staff are often poorly paid; their salaries may be insufficient to support a family. As a result, motivation is low, moonlighting is common and private practice thrives. Although it is not within the control of local management staff, the implications of poor remuneration must be kept in mind. Advocacy with the national program and donors, nongovernmental agencies and organizations may be helpful.

Higher salaries in nongovernmental projects and interventions draw good workers away from the public sector and make services even less sustainable. Linking nongovernmental projects with STD program activities may provide incentives, both in terms of salaries and working conditions.

CAMBODIAN HEALTH CARE WORKERS

Monthly salaries of health care workers: US\$15
Cost of living for a family of four: not less than US\$200 per month

UNAIDS, Japanese International Cooperation Agency and the European Union (EU) have now or in the past supplemented government health-care workers' salaries as a means of acknowledging their efforts and preventing defection of the best staff to nongovernmental employment.

Roles and responsibilities of management and service staff should be clearly defined to avoid duplication and resentment that can arise from misunderstandings.

Strengthening capability to perform work well and raising the capacity to do so are very important areas for program management. Training requirements should be very carefully evaluated. Long didactic workshops—beloved of donors because of their high visibility and by participants because of the per diems, break from routine and the recreational possibilities—are not necessarily the best way to instill knowledge, and are certainly not good at imparting practical skills. Short interactive workshops or onsite training/mentoring with an opportunity to put the theory into practice are better.

- In-service training is valuable if the expertise is available. This may take the form of:
 - Regular supervisors available to discuss problems, identify/correct misinterpretations
 - Short visits by skilled health-care staff or technicians to demonstrate correct methods
 - Exchanges between experienced and junior staff from different clinics

International training and experience are useful for motivational reasons and to introduce or enhance particular skills. Care must be taken, however, that international study is appropriate; for example, training in an area within the same geographic region and similar epidemiology may not have the same sophisticated structure or facilities.

INTERNATIONAL STUDY AND EXPERIENCE

Training - I

A project in support of STD services in one state in Nigeria provided training for six medical officers. These officers attended a three-month course that led to a diploma in venereology from the University of London.

Outcome - I

Two years later, only three officers remained at their original posts. All had considered the course excellent, but found most of what they had learned irrelevant to possible STD practice in their situation.⁴

Training - II

The Ministry of Health/EU STD Project in Lao PDR invited the director of the Thai Ministry of Public Health Venereal Disease (VD) Division to assess the training requirements for STD laboratory support. As a result, the chief of the bacteriology reference laboratory and laboratory staff in secondary and tertiary hospitals in the project pilot area worked in the laboratory of the Thai VD Division for six weeks. Theoretical input was also provided.

Outcome - II

Eighteen months later, etiological STD service is provided in the gynecology OPD and the Center for Dermatology and Venereology, supported by their hospital laboratory bacteriology reference center, provides quality control, supervision, a reference service, and in-service refresher training.⁵

Coordination of information

Regular, perhaps monthly, coordination meetings for a program area provide an opportunity to exchange information and experience, and lead to both problem recognition and solving. They help develop team spirit, commitment and loyalty.

To best coordinate information, it is important to include regular and timely feedback of the analysis from data collected by facilities and organizations in the program area. Workers lose interest in collecting data if they are not told why it is necessary, what it shows and what actions will follow. Some data—such as antimicrobial susceptibility of organisms—are only valuable if circulated quickly, before significant changes occur.

100% CONDOM PILOT PROJECT CAMBODIA

A key component of this pilot project has been monthly coordination meetings between partners with different agendas: the provincial government, police, health care providers and outreach workers to sex establishments and their sex workers.

Outcome

A successfully implemented project with strengthened STD services is being used by sex workers.

Material resources and logistics

The peripheral STD program manager should ensure that the equipment, materials, consumables, reagents and medical drugs are available as and when they are required. Logistical problems are common constraints on STD service provision.

Requirements are minimal for routine STD services integrated into first-level health care. Couches, a means for privacy, specula and sponge holders, gloves for vaginal examination, means of sterilization and sterile syringes and needles are all that is likely to be required—but the absence of any of these may be excuse enough for abandoning the services.

At referral clinics (such as categorical STD clinics, gynecology departments and dermatology OPD), requirements are slightly different but even more important: Laboratory support requires functioning apparatus (at least microscopes, candle jars, incubators, refrigerators, sterilizing equipment and voltage stabilizers), and enough glassware, consumables and reagents. The number of referral facilities is less important than the capability to provide consistent service.

Availability of appropriate drugs is a major problem in resource-constrained settings. Throughout the health system, drugs recommended for STDs should be those listed in the national STD case-management guidelines. But few health systems anywhere in the world can afford to provide free drugs for all. Peripheral program managers must seek ways to subsidize the more expensive drugs. Bulk buying for drug revolving funds can help, but will still leave many STD-infected individuals unable to afford the medicines. This is an area where help can usefully be sought from donors and international agencies, NGOs, etc. This may well be one-time funding, and not a continuing process, but it may be the only alternative.

Medical information system

A functioning and appropriate medical information system is necessary to implement the STD program; such a system is also necessary for monitoring and evaluation. Record keeping and reporting are vital functions for STD service provision and program management.

A dedicated computer and printer and access to telephone, facsimile and photocopying are no longer luxuries, but essential to proper program management. This should be factored into the work-plan budget. Again, this is an area where external funding can be sought without risk to sustainability—as long as funds are included for maintenance.

Transport

Without access to vehicles, monitoring and supervision will be poorly implemented. This is also an area where external support can be sought if transport facilities from the regional, provincial or district health offices are not available.

A NATIONAL STD PROGRAM LAO PDR

Problem

In a 1995 survey of countries and areas of the Western Pacific Regional Office of WHO, only Lao PDR was identified as being without some form of a national STD program.⁶ The National Committee for the Control of AIDS (NCCA) of the Ministry of Health recognized this as a major deficiency.

Solution

An international donor undertook a situational assessment and, based on its findings, contracted with the Ministry of Health to develop a national program.⁷

The project objectives were to:

- Strengthen the Ministry of Health's capacity and capability to manage a national STD program.
- Strengthen the public health care system to provide access to consistently acceptable, effective and affordable STD services.
- Establish support mechanisms for planning, monitoring and supervising a national STD care and prevention program.

Means

Implementation activities have included:

- Setting up a central STD management unit within the NCCA bureau, reporting to the NCCA manager.
- Convening a national STD technical advisory group (STAG).
- Developing a system for preparing annual operational plans.
- Developing a National STD Policy and Strategy at a multisectoral workshop and consensus meeting.⁸
- Developing a peripheral program management structure involving provincial committees for AIDS control.

- Developing national case management guidelines and a training curriculum for syndromic approach at a consensus workshop.
- Piloting routine STD service delivery in the general health-care system in two geographic areas (Vientiane and Savannakhet).
- Piloting referral services for women in the OB/GYN OPD in secondary and tertiary hospitals, and for men in a pre-existing but strengthened Center for Dermatology and Venereology, with support for an etiological approach.
- Strengthening a Center for Laboratory and Epidemiology to provide training/support/quality control to the referral hospital laboratories.
- Developing a National Policy and Strategy for STD Surveillance⁹:
 - i) Implementing regular reporting from sentinel sites and
 - ii) Conducting periodic surveys among:
 - High-risk and vulnerable groups in coordination with behavioral and HIV sentinel surveillance managed by WHO and other donors;
 - Antenatal clinic attendees by coordinating with the Maternal and Child Health Center and the Reproductive Health Research Unit of WHO in STD prevalence studies.
- Coordinating with CARE International, Lao PDR, in providing prevention activities for high-risk and vulnerable groups in the pilot areas.
- Formalizing a program of special studies and operational research including antimicrobial susceptibility.
- Instituting a system of routine supervision and monitoring of peripheral and referral STD services with plans for evaluation at regular intervals.

continued

continued

Constraints

- Support to the project is time-limited.
- Although sustainability has been built into all activities, it is still not certain that the Ministry of Health will be financially able to provide consumables, materials and reagents, or service and replace equipment as necessary.
- There is a lack of funding for extension of the referral services to a wider area.

Results

- A national central and peripheral STD program structure is in place with appropriate support activities.
- Access to STD care, using the syndromic approach, is available at all levels of the health system in the pilot areas, and is gradually being extended nationally through training.
- Access to acceptable STD referral services with etiological case management is available in the pilot areas.

Expected Outcomes

- Lower STD rates with improvement in the health of the community, particularly women and children; and
- Reduced risk of HIV transmission.

SUPERVISION, MONITORING AND EVALUATION

This section highlights the areas of difference between HIV/AIDS programs, and indicates where coordination of activities is beneficial. (The principles of monitoring and evaluation have been addressed in Chapter 5.)

Supervision, monitoring and evaluation are duties of program managers, whether national or local. If AIDS and STD programs are integrated or closely coordinated, joint planning of monitoring and evaluation is logical, because many of the activities are closely linked. Behavioral surveillance surveys (BSS), for instance, measure risk behaviors common to both. Serosurveillance of syphilis can be performed on the same specimen used for HIV sentinel surveillance and vice versa. STD periodic prevalence surveys (SPPS) can be undertaken at the same time as HIV surveillance surveys (HSS).

Supervision has a more immediate relationship with implementation: It is a routine activity that measures the immediate process and provides support and problem-solving. The national manager supervises broad aspects of the total STD program, including the local manager's performance, while the local manager supervises—through his staff—activities of service provision, etc.

SUPERVISION OF STD SERVICES

Supervision is particularly important in STD service delivery:

- Providers in health care centers may actually see few cases of STD; supervision supports them in recognizing and correctly managing cases.
- Categorical STD clinics benefit by supervision of approaches to high-risk and vulnerable groups and acceptability of service provision.
- Specialist services such as gynecology and dermatology providing STD referral services benefit from reminders of their capability and roles.
- STD drug revolving funds need careful supervision to prevent diversion of potent and expensive drugs into general use.
- Laboratories providing STD support benefit from supervision of logistics, services and laboratory investigation revolving funds.

It is both practical and convenient to develop checklists at each level of supervision. Monitoring and evaluating the extent to which STD control is being achieved provide essential information for further improvement of programs.

Indicators for STD prevention activities follow exactly those for the AIDS program. But indicators that verify the level of achievement of other STD operational objectives differ somewhat from those of the AIDS program. Selecting indicators and setting goals for the national and peripheral programs will be undertaken during program planning and re-planning, and should be consistent in central and local planning.

Indicators and goals for service components in individual projects will be determined at the planning stage. Both implementing agencies and stakeholders should be involved in this development process. It is particularly important that indicators and goals developed are consistent and complementary to national

goals and indicators, and those of the particular local program within which the project is to take place.

Individual projects should have a built-in framework for evaluation:

- Formative evaluation should be provided by the situational assessment already described, which determines the needs and resources available and priority of the intervention, and enables the appropriate goals and indicators to be determined.
- Continuous process evaluation can be a useful part of the supervision and monitoring activities, as well as of the traditional mid-term and final evaluation activities. Such evaluation allows fine-tuning and more serious re-planning as the project proceeds, if necessary.
- Effectiveness is most likely to be explored at a final evaluation and—if the project is reasonably long term—at mid-term evaluations. The most valuable method will be the estimation of change of prevalence and incidence of STD over the project life, which can be assumed to result from the project activities. This type of evaluation is only possible if there are baseline data.

EVALUATION RELATED TO STD ACTIVITIES

Whether in programs or projects, many factors must be considered in evaluating STD activities. These include quality of STD services provided, coverage, effectiveness evaluation and laboratory services.

Quality of STD services

Indicators for evaluating the quality of STD services are included as the first and second STD service indicators in the WHO/Joint United Nations Programme on HIV/AIDS (UNAIDS) evaluation criteria for HIV programs.^{10,11} Key questions to be addressed in monitoring service quality include:

- Are services providing quality care for men and women presenting with symptoms, signs or worries about STD?

- Are necessary drugs, diagnostics and other commodities available?
- Are services used effectively as an entry point for HIV and STD prevention?

The choice of methods described above depends on the local circumstances, available resources and acceptability to local health care providers. The following should be considered:

- Private practitioners may accept a brief interview, but not allow review of their records or observation of clinical sessions.
- Mystery client surveys may be viewed as intrusive and therefore ultimately counterproductive in standardizing high quality services.
- Inclusion of a limited set of quality indicators into ongoing monitoring systems may be most practical.
- A comprehensive approach may be to combine routine monitoring with periodic in-depth health facility reviews.

Confidentiality and respect for the individual must be strictly adhered to in the collection, storage and publication of data.

Coverage

As many persons as possible—particularly those in high-risk or vulnerable groups—should have access to STD services when they need them. Coverage must therefore be evaluated not only on the basis of availability of services, but also their uptake and reasons for non-utilization.

COMMONLY USED METHODS FOR EVALUATING QUALITY OF STD CASE MANAGEMENT¹²

Method	Advantages	Disadvantages
Provider interviews	<ul style="list-style-type: none"> ■ Commonly used method ■ Relatively easy ■ Permits evaluation of a range of knowledge and skills ■ Standardized protocols exist 	<ul style="list-style-type: none"> ■ Reporting bias (knowledge does not necessarily reflect actual practice).
Direct observation	<ul style="list-style-type: none"> ■ Commonly used method ■ Transparent ■ Standardized protocols exist 	<ul style="list-style-type: none"> ■ Logistically difficult and expensive. ■ Biases <ul style="list-style-type: none"> ● Need to select facilities with sufficient volume to permit observation. ● Providers' awareness of being evaluated.
Mystery patient/shopper	<ul style="list-style-type: none"> ■ May be less expensive than direct observation ■ Less likelihood of observation bias 	<ul style="list-style-type: none"> ■ Possible negative reactions of health-care workers to being observed without their knowledge. ■ Mystery patient/shopper does not have clinical signs that may affect management.
Record review	<ul style="list-style-type: none"> ■ Avoids observation bias ■ Less costly 	<ul style="list-style-type: none"> ■ Information in records can be limited and often inconsistent.
Patient exit interviews	<ul style="list-style-type: none"> ■ May be less expensive than direct observation ■ Less likelihood of observation bias 	<ul style="list-style-type: none"> ■ Recall biases (patients may not accurately remember details of clinical procedures or counseling messages).

Effectiveness evaluation

Evaluating the effectiveness of an STD care and prevention program requires determination of prevalence trends and incidence of STD and STD-related behaviors—including STD health care-seeking behaviors—condom use and sexual behavior. Sexual behavior and condom use can be measured as part of the National AIDS Program; it should be possible to incorporate STD health care-seeking behavior in program surveys.

The main elements of STD surveillance should be:

- Facility reports from a number of sentinel sites
 - A small number of geographic sites are selected as representative of the population as a whole, with reports strengthened to give consistent, reliable case information;

- As many facilities as possible within each site, both public and private sector, will be encouraged to report at regular intervals and should include primary health care, MCH, FP and secondary referral such as categorical STD clinics, OB/GYN departments and dermatology departments;
- Facilities should provide initial and refresher training, diagnostic support such as improved laboratory capability and administrative support;
- Data should be analyzed locally and/or centrally, with timely feedback to reporting facilities; and
- Case reporting should be based on syndromic case management as the lowest possible level where etiological diagnosis is available, reporting will allow conversion to syndromes in order to compare findings across all reporting sites.

Case reporting can only indicate the minimum number of STD cases occurring within a population. Trends in cases reported, however, can indicate the acceptability and quality of services provided and assist in advocacy and eventual resource allocation.

Surveys can spot such trends:

- Specific periodic surveys on community groups
 - Groups may include: high-risk and vulnerable groups likely to have high incidence of infection (sex workers, truck drivers, the military, migrants, etc.);
 - Antenatal clinic attendees usually considered as a surrogate for sexually active women in the general population;
 - General population—most difficult and expensive to undertake;
 - Frequency of performance of surveys will depend on the likelihood of changes in prevalence—in the absence of any outside influence such as known demographic change or specific STD intervention, every four to five years may be enough.

- Surveys to direct clinical guidance
 - Antimicrobial susceptibility studies; usually on *N. gonorrhoeae* and, where appropriate, on *H. ducreyii*; and
 - Studies to identify causative etiological agents in syndromes.

In practice, surveillance markers may be limited to a few common, curable STDs or identifiable syndromes.

Laboratory services

Consistent availability of laboratory support to STD services is rarely widely available in resource-constrained settings. It is, however, an essential requirement for reference and referral centers, and very desirable in facilities attended by women, such as OB/GYN departments and facilities where female sex workers present for care.

Coverage and quality of services should be carefully monitored. It is appropriate for the central referral laboratories to develop and provide a system of quality control. It is useful for academic institutions that can do so to periodically evaluate service provision and quality control. Such institutions may undertake this alone or share the responsibility with institutions from other countries (preferably in the same geographic region) with greater or more sophisticated laboratory resources.

SUMMARY AND RECOMMENDATIONS

- Although many countries have formal National STD Programs, an important constraint on their success in controlling STD—particularly in resource-constrained settings—has been the absence of guidance on what constitutes the basis for an effective program. This chapter outlines a suitable package of activities for an STD care and prevention program. It provides guidance on what a program should include to best organize and control available human, material and financial resources and ensure their use in an effective and appropriate manner.
- Within the constraints of an individual country's health care system it is recommended that there be a central STD program whose overall role is one of planning, coordination, advocacy, guidance and supervision. This central program should be complemented by peripheral (regional, provincial or district) programs that implement service delivery and interventions.
- National and peripheral STD programs should be integrated or at least closely coordinated with equivalent AIDS programs. Prevention messages for HIV and other STDs, target audiences and the facilitation of HIV transmission by many STDs argue for this approach.
- Prevention activities should be developed and implemented by the AIDS program. The STD program can provide input on messages specific to STD—for example, advice on STD health care-seeking behavior.
- STD programs should define the principles upon which an overall strategy is based. In this and other technical areas, a technical advisory group including epidemiological, medical, socio-cultural, training, BCC and evaluation expertise is recommended.
- Routine STD services should be delivered to the general population through the general health care system, so that access is easy and services are acceptable.
- Categorical STD clinics and specialist outpatient clinics, such as dermato-venereology, are of value in providing services to difficult-to-access groups such as sex workers, their clients and men who have sex with men.
- A regularly updated situational assessment will guide the program in developing and revising its operational plan and resource allocation.
- The program should ensure that interventions implemented by nongovernmental agencies and organizations are consistent with program policies. As much as possible, such interventions should complement the STD program and avoid duplication.
- To make the best use of available resources, an operational plan should be developed after prioritizing support activities (special studies, operational research, surveillance, clinical guidance, laboratory services, training, etc.), routine STD service delivery and service interventions targeted to specific high-risk and vulnerable groups and to women in general. This plan will consider input from nongovernmental sources to promote complementary services and prevent duplication of coverage.
- In developing operational plans, the central and peripheral programs should set quantitative targets to measure achievements; progress toward these targets should be identified.
- Staff management and implementation programs are critical to success. For the peripheral programs, local staff with knowledge of the area and trust of its communities and target populations is very desirable.
- Information should be shared between managers and implementing staff, particularly at a local level. Regular coordination meetings to exchange information and experience motivate and help to prevent or solve problems. Meetings should include timely feedback on analysis of reported data.
- Logistic failures are a common constraint on STD service delivery. It is a responsibility of the peripheral program to ensure that enough equipment, materials, consumables, reagents and drugs are available to implement the planned interventions and that activities are available when and where they are required.

- Cost-recovery schemes are recommended to increase the availability of drugs and laboratory investigations.
- Nongovernmental support can help purchase equipment such as vehicles and hardware for medical information systems. If possible, running costs and maintenance should accompany such donations. Support from nongovernmental sources for services is usually time-limited and runs the risk of being unsustainable.
- Supervision is a routine activity particularly important in STD service delivery. Each level of supervision should develop appropriate checklists.
- Evaluating the achievement of the central and peripheral STD program provides information for further planning and re-planning.
- Surveillance is an important element in STD service evaluation. If possible, it should be coordinated with the AIDS program surveillance activities to limit resource needs and avoid duplication of effort. Examples of coordination are syphilis serology combined with HIV sentinel surveillance and behavioral surveillance.
- STD surveillance should include:
 - Sentinel site reporting rather than universal case reporting;
 - Periodic prevalence surveys from high-risk and vulnerable groups, such as sex workers and identifiable groups of their potential clients;
 - Periodic prevalence surveys from groups believed to be representative of the general population—for example, pregnant women;
 - Periodic or continuous monitoring of antimicrobial susceptibility, e.g., *N gonorrhoeae*, *H ducreyii*; and
 - Behavioral surveillance including STD health care-seeking behavior.
- Evaluation specific to STD programs, as opposed to AIDS programs, should look at:
 - Quality of STD case management delivered
 - Are services providing acceptable and effective care?
 - Are drugs, diagnostics, etc. available?
 - Is appropriate STD/HIV prevention BCC provided at the clinical site?
 - Coverage
 - Availability of services, their uptake and reasons for nonutilization,
 - Effectiveness
 - Prevalence/incidence trends
 - Trends of STD health care-seeking behavior.
- Laboratory support for STD services is usually limited in resource-constrained settings. It is essential, however, in reference and referral centers and highly desirable where women are likely to attend with reproductive health problems. Evaluation of laboratory functioning should look at:
 - Coverage—is laboratory support consistently available? If it is inconsistent, what are the constraints (lack of skills, irregular availability of reagents, consumables, etc.)?
 - Quality of service including quality control by reference laboratories, national or international academic institutions.
- The STD program in reviewing projects funded and implemented by NGOs should ensure that evaluation forms an integral part of the project.

RELEVANT CHAPTERS

- Chapter 5 *Evaluation and Surveillance Approaches for HIV/AIDS Programs*
- Chapter 14 *STD Case Management in Primary Health Care Settings*
- Chapter 15 *Issues in STD Control for Special Groups*

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C H A P T E R

17

*Reducing HIV
Infection in
Women and
Providing
Family
Planning
Services to
Women at Risk*

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Reducing HIV Infection in Women and Providing Family Planning Services to Women at Risk

INTRODUCTION

In the last few years, the proportion of women among people living with HIV/AIDS (PLHA) has risen dramatically—and the number of infants who acquired HIV from their infected mothers has steadily increased. The first part of this chapter reviews a number of issues related to the primary prevention of HIV among women, with particular relevance to mother-to-child transmission (MTCT). The second part discusses the design and delivery of family planning services to women at risk and HIV-infected women. Information is also provided to guide contraceptive choice in these women.

PRIMARY PREVENTION AMONG WOMEN OF CHILDBEARING AGE

Women are more vulnerable than men to HIV infection because of biological, social and economic factors. Interventions directed at women at high risk of HIV can lead to substantial increases in condom use and corresponding decreases in HIV risk. However, evidence suggests that HIV prevention programs for women must move beyond providing information. Programs must help alter individual behavior by addressing broader gender-based barriers to change and developing necessary support systems.

MOVING BEYOND HIGH-RISK GROUPS

Targeted interventions for high-risk groups, such as female sex workers, may have the greatest impact on the rate of HIV spread, at least in the early phases of an epidemic. But women in a wide variety of situations and partnerships are at risk of HIV infection, and should be included in prevention programs.

REACHING ADOLESCENTS

High rates of teenage pregnancy and STDs indicate the extent of unprotected sexual activity among young people, and therefore their vulnerability to HIV/AIDS. An intensified effort is needed to reach adolescents with relevant services.

ADDRESSING THE NEEDS OF PREGNANT AND LACTATING WOMEN

Primary HIV infection during pregnancy and breastfeeding poses an increased threat of MTCT. HIV prevention interventions directed at pregnant and lactating women could make an important contribution to reducing MTCT.

EXPANDING ACCESS TO HIV COUNSELING AND TESTING

Expanded access to HIV counseling and testing could help seronegative persons accurately assess their own risk and develop an appropriate risk-reduction plan. Counseling and testing can also give seropositive persons the knowledge and support to prevent transmission to others—including infants—even before pregnancy is initiated.

EMPOWERING WOMEN

Widespread and sustained HIV-risk reduction among women will be realized only through action that addresses the gender-power imbalances and the social and economic factors that constrain behavior change.

FAMILY PLANNING FOR WOMEN AT RISK

Women at risk and HIV-infected women also need support and resources to prevent unintended pregnancies. In recent years, efforts have been made worldwide to expand and strengthen family planning services and deliver a broader range of services within a reproductive health approach. Some of the proposed changes should help reduce unintended pregnancies, thereby reducing the frequency of MTCT of HIV.

INCREASING ACCESS TO FAMILY PLANNING SERVICES

The large numbers of HIV-infected infants in Africa are a consequence of high fertility rates combined with high infection rates and low rates of contraception use. Family planning services must be rapidly expanded, with special attention to quality of care, contraceptive choice, equal access and relevance to women and young people in need.

DUAL PROTECTION

Decisions about contraceptives should reflect both the need to prevent STDs and the need to prevent unwanted pregnancies. To date, the methods most effective at preventing STDs—barrier methods—may not be the most effective contraceptives. Combining a barrier method with a more effective contraceptive can maximize the dual protective effect.

CONTRACEPTIVE SAFETY

Some contraceptive methods may even facilitate the acquisition, progression or transmission of STDs, including HIV. IUDs and hormonal contraceptives, for example, do not protect against STDs and may carry other risks.

THE SPECIAL NEEDS OF HIV-INFECTED WOMEN

Most HIV-infected women in the developing world are unaware of their serostatus. Increased availability of voluntary HIV counseling and testing would help them obtain essential care and support services and plan their futures. HIV-positive women should have access to appropriate family planning and reproductive health care counseling and services, so they can make—and act on—informed decisions concerning contraception, continuation or termination of pregnancy and prenatal practices to reduce perinatal transmission of HIV.

POTENTIAL IMPACT ON FERTILITY AMONG WOMEN AT RISK

Experience in Rwanda indicates that family planning services can significantly decrease the rate of unintended pregnancy among women at high risk of HIV. The effect of such services in reducing fertility among HIV-infected women is often limited, however. Many HIV-infected women desire more children, and few are willing to inform their partners about their status.

LESSONS LEARNED AND RECOMMENDATIONS

- Widening the choice for reducing the risk of MTCT of HIV will ensure that interventions consider the needs and rights of women for basic information and services.
- HIV prevention programs should be directed at a broader range of women at risk.
- HIV counseling and testing services can help women make more informed reproductive choices.
- More effort is needed to deal with the social and economic factors that increase women's vulnerability to HIV and address men's responsibility for both infection protection and contraception.
- The strengthening and convergence of health services that serve women of reproductive age may be a necessary foundation for interventions to prevent HIV among women and infants.
- The focus of family planning programs should be broadened to include other reproductive health concerns and other populations.
- Family-planning providers should more systematically consider the risk of STD, including HIV, in counseling women about their contraceptive choices.

- HIV-infected women should have access to appropriate family planning and reproductive health-care counseling and services.
- Operations research is required to develop and test modalities for dual protection in different settings.
- More research is needed to develop new or modified contraceptive and infection protection technologies that can expand the range of options for safer sex.
- More basic and epidemiological research is required to elucidate the association between contraception and acquisition or transmission of STD, including HIV.

CASE STUDIES

An innovative project in rural northeast Thailand demonstrates how community action can lessen cultural forces that put women at risk of HIV. In Tanzania, a school-based program was developed to protect schoolgirls from sexual exploitation by older boys and men, including teachers.

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I N T R O D U C T I O N

In the last few years, there have been marked changes in the pattern of HIV spread. The proportion of women among people living with HIV/AIDS (PLHA) has risen dramatically: In 1998, women accounted for 43 percent of all infected people. As these numbers grew, so did the number of infants who acquired HIV from their infected mothers. In 2000, an estimated 600,000 children under age 15 were newly infected with HIV.¹ These children most commonly acquired HIV from infected mothers during pregnancy, childbirth or breastfeeding.

There have been important advances in the development of approaches to reduce MTCT of HIV. The most effective interventions, however—including antiretroviral therapy and the provision of breast-milk substitutes—are not widely available in resource-poor settings where HIV infection is most prevalent and the risk of MTCT of greatest concern. Here, prevention of HIV infection among women of childbearing age and avoidance of unintended pregnancy among women at risk and HIV-infected women could greatly reduce HIV infection among infants.

The first part of this chapter reviews a number of issues related to the primary prevention of HIV among women, with particular relevance to MTCT. The second part discusses the design and delivery of family-planning services to women at risk and HIV-infected women. In addition, information is provided to guide these women's contraceptive choices.

PRIMARY PREVENTION AMONG WOMEN OF CHILDBEARING AGE

Women are more vulnerable than men are to HIV infection for many reasons.² In particular, women are biologically more susceptible to infection if exposed to HIV and other STDs. Women also are often socially, economically and sexually subordinate to men, increasing the likelihood of their exposure to risky practices such as coerced sex and restricting their ability to adopt HIV-preventive strategies. Thus, HIV prevention interventions should be gender specific.

Most interventions directed at women have been conducted among those at high risk of HIV, such as sex workers. Available data indicate that these programs can lead to substantial increases in condom use in commercial and casual sexual encounters and corresponding decreases in the risk of HIV infection.^{3,4} There is less experience with HIV prevention among women who are at risk for other reasons. But encouraging results have been found in peer-led small-group interventions that include training in social and sexual communication and assertiveness skills for disadvantaged women.^{5,6}

Mixed-sex group interventions bring women and men together, and can be an opportunity to open a dialogue and enhance communication skills.⁷ Community development projects that build upon women's capacity for informal organization and existing support networks also show promise. (See Case Studies.) These projects indicate that women can be mobilized around the issue of HIV prevention and provided with the skills and support they need to negotiate safer sex with their partners. Evidence strongly suggests that HIV prevention programs for women must move beyond providing information if they are to have the greatest impact on MTCT. Programs also must assist in individual behavior change by addressing broader gender-based barriers to change and developing necessary support systems.⁷

MOVING BEYOND HIGH-RISK GROUPS

Targeted interventions for high-risk groups, such as female sex workers, may have the greatest impact on the spread of HIV, especially in the early phases of an epidemic. Nevertheless, women in a wide variety of situations and partnerships are at risk of HIV infection and should be included in prevention programs. For example, many women in stable relationships are exposed to HIV infection not because of their own behavior, but because of their partners' behavior.⁸ In most settings, infected infants are born to women who do not belong to identified high-risk groups.

Women in stable relationships need to develop communication skills and strategies to protect themselves from infection. But for those interventions to be effective, they should involve the male sexual partners as well.

REACHING ADOLESCENTS

High rates of teenage pregnancy and STDs indicate the extent of unprotected sexual activity among young people, and therefore of their vulnerability to HIV/AIDS. More than half of all new HIV infections past infancy currently affect people under 25.⁹ But young people face many obstacles in accessing HIV prevention information and resources. An intensified effort is needed to reach adolescents with relevant services. The goal is to enable them to manage their sexual and reproductive lives in a responsible and informed way, and to protect themselves from sexual violence, unwanted pregnancies and STDs, including HIV.

Young people must be reached early, through programs for adolescents who are not yet sexually active. These should include school-based sexual health education programs (see Case Studies) as well as special programs for out-of-school adolescents to build their self-confidence, train them in communication skills and help them make informed and responsible choices regarding abstinence, delayed sexual initiation and consistent use of condoms. A major effort is required

to modify or reorganize reproductive health services so that young people can obtain STD and contraceptive services easily and in confidence. We must also change the policy environment to enhance the acceptability of adolescent HIV interventions.

ADDRESSING THE NEEDS OF PREGNANT AND LACTATING WOMEN

Primary HIV infection during pregnancy and breastfeeding poses an increased threat of MTCT. Since it is widely assumed that women who are pregnant or lactating are at lower risk of HIV infection because of prevalent cultural norms about sexual abstinence during pregnancy and in the first months after delivery, few purposive efforts have focused on preventing HIV during this period. In most settings, however, sexual intercourse is rarely interrupted for long around the period of childbirth, and women may be more susceptible if sexually exposed to HIV during pregnancy, though this has not been studied in any detail. The infant may also be at higher risk of HIV acquired by the mother during pregnancy or during breastfeeding.

HIV prevention interventions directed at pregnant and lactating women could make an important contribution to reducing MTCT. For many women, antenatal and obstetric services provide a rare opportunity for contact with a trained health worker who can provide advice and support regarding STD/HIV risk assessment and risk reduction, reproductive tract infection (RTI)/STD case finding and management and—if desired—HIV counseling and testing. Women and their partners may be more receptive to messages about safer sex at this time. Health workers also should pay particular attention to blood safety and the rational use of transfusions in the management of anemia and complications of pregnancy and delivery.

EXPANDING ACCESS TO HIV COUNSELING AND TESTING

The purpose of HIV counseling and testing in programs to reduce MTCT is often narrowly defined as the identification of infected women in antenatal settings. But greater access to HIV counseling and testing could also help in other ways: Knowledge of serostatus can help seronegative persons assess personal risk and develop an appropriate risk-reduction plan. It can also provide seropositive persons with the knowledge and support to prevent transmission to others, including infants, even before pregnancy is initiated. HIV counseling and testing may be particularly helpful to persons who are in stable relationships. Some evidence suggests that HIV counseling and testing directed at couples (as opposed to individuals) can lead to significant behavior change, especially in high-prevalence areas. Encouraging results have been found in serodiscordant couples,¹⁰ who are at greatest risk of producing HIV-infected infants. But since an important aim of HIV counseling and testing is to encourage informed decision making and behavior change, individuals must have ready access to resources and services that allow choices for action and support and maintain behavior change. These include access to condom supplies, family planning and other reproductive health services, RTI/STD treatment services and care and support services for HIV-affected persons. Linkages between these diverse but mutually supportive services should be considered. Expanded voluntary and counseling services (as they become available) will also improve access to care or support services for women.

FAMILY PLANNING FOR WOMEN AT RISK

EMPOWERING WOMEN

Prevention efforts for women are hampered because available methods for reducing HIV transmission remain under the control of men. Repeatedly, male resistance to condom use emerges as a major obstacle to interventions that seek to protect women. More study is needed to understand and reconcile the contrasting perspectives of men and women and to increase male responsibility in sexual issues, including HIV prevention. There have been few real attempts to involve men in this way.

At the same time, the increasing availability of female-initiated methods of protection—such as the female condom—shows some promise in strengthening women's ability to negotiate condom use. The development and evaluation of other methods of protection—such as vaginal microbicides, which ideally can be used without men's consent—is urgently needed.

Widespread and sustained HIV-risk reduction among women will ultimately be realized only through action that addresses the gender-power imbalances and the social and economic factors that restrict behavior change. Eventually, structural-level interventions—such as changes in laws and policies related to education, employment and marriage—will be required to change social norms regarding sexual behavior and create a supportive environment for more equitable decision making among men and women.

Women at risk and HIV-infected women also need support and resources to prevent unintended pregnancies. Efforts have been made in recent years to expand and strengthen family planning services to deliver a broader range of services within a reproductive health approach. Some of the proposed changes should help reduce the frequency of MTCT of HIV.

INCREASING ACCESS TO FAMILY PLANNING SERVICES

Contraceptive use remains low in much of the developing world, and may be especially low in settings where prevalence of HIV infection is high. The large numbers of HIV-infected infants in Africa are a consequence of high fertility rates combined with high infection rates. In such settings, many women want to delay or limit childbearing, and yet do not use contraception. There is an urgent need to address this unmet demand for family planning services. Rapid expansion of services with special attention to quality of care, contraceptive choice, equal access and relevance to women and young people is needed.

Particular attention should be paid to developing services that can reach groups such as adolescent girls and single women, who are especially vulnerable to both unintended pregnancy and HIV and other STDs, and yet remain underserved by traditional family planning programs and other reproductive and sexual health services. A strong case can also be made for increased male participation in family planning programs, in view of the major role of men in contraceptive decision making and the use of condoms.^{11,12}

The convergence and eventual integration of family planning services and other reproductive health services—including maternal and child health services and services for the prevention and treatment of RTI/STD—at the primary health-care level is receiving increasing attention. Evaluations of integrated services indicate, however, that many problems can arise in practice.¹³ A major effort is needed to train and support multipurpose health-care workers in delivering expanded services in AIDS-affected areas, assist them in discussing family planning and sexual health issues and dealing with the painful dilemmas that HIV infection raises for some of their clients.

Table 1
EFFECTS OF CONTRACEPTIVES ON BACTERIAL AND VIRAL RTI

Contraceptive methods	Bacterial RTI	Viral RTI
Condoms	Protective	Protective
Spermicides	Modestly protective against cervical gonorrhea and chlamydia	No evidence of protection In vivo
Diaphragms	Protective against cervical infection Associated with vaginal anaerobic overgrowth	Protective against cervical neoplasia
Hormonal	Associated with increased cervical chlamydia Protective against symptomatic PID, but not unrecognized endometritis	Not protective
IUD	Associated with PID in first month after insertion	Not protective
Fertility awareness	Not protective	Not protective

Source: *Cates*²⁰

DUAL PROTECTION

Family-planning providers have a special role to play in counseling people on responsible sexuality and providing them with the means to prevent HIV and other STDs, as well as unintended pregnancy. Providers should be able to discuss the connection between STD/HIV and contraceptive use, since the risk of infection is an important consideration in choosing a contraceptive (Table 1). Greater emphasis must be placed on barrier methods within the contraceptive choices offered in family planning programs. This will serve to encourage simultaneous contraceptive and disease protection (dual protection), and is particularly important in settings where HIV prevalence is high. Male and female condoms—if used consistently and correctly—can effectively prevent pregnancy^{14,15} and reduce transmission of STDs, including HIV.^{16,17} Other barrier methods (such as diaphragms, caps and vaginal sponges) may provide some protection against cervical infections when used with currently available spermicides, and are similar to male condoms in reducing typical pregnancy rates. However, they are less effective in preventing HIV transmission, since they cover the cervix, but not the vaginal wall.^{18,15} Recent

studies suggest that the use of nonoxynol-9 may actually increase the risk of HIV acquisition.¹⁹

Many family-planning providers downplay barrier methods, because they are less effective in typical situations of inconsistent use than other contraceptive options. On the other hand, contraceptives that are most effective in preventing pregnancy provide little, if any, protection against STDs. This leads providers to recommend a “dual method” approach, in which a highly effective contraceptive is used to prevent pregnancy, and condoms are also used during any act of intercourse with a risk of STD transmission. This places a greater

burden on both women and men, however, and is only sustainable among couples with a high level of motivation. Studies indicate that, in general, the more effective the primary contraceptive is in preventing pregnancy, the lower the level of consistent condom use.²¹ Other possible approaches to dual protection include the provision of emergency contraception as a back-up to condom use—in case of breakage, for example.

CONTRACEPTIVE SAFETY

Concerns about STD and HIV also demand greater attention to ensuring quality of care and safety in the delivery of family-planning services. Some contraceptive methods may actually facilitate the acquisition, progression or transmission of STDs, including HIV. For example, even though IUDs are considered to be among the most safe and effective contraceptives, they are associated with an increased risk of pelvic inflammatory disease (PID).²² Although the risk of PID among IUD users remains low, this method is not

Box 1

WHEN SHOULD WOMEN OR COUPLES BE ADVISED TO USE DUAL METHODS FOR PROTECTION AGAINST STDs AND PREGNANCY?

Decisions about contraceptives should reflect both the need to prevent STDs and the need to prevent unwanted pregnancies. To date, the methods most effective at preventing STDs—barrier methods—may not be the most effective contraceptives. Combining a barrier method with a more effective contraceptive can maximize the dual protective effect. But dual method use is relatively new, and is not appropriate for all clients. Deciding when to promote dual method use can be difficult, especially since it requires more counseling and places greater demands on each client. Providers have a responsibility to help clients choose which method or methods to use in light of this dilemma between pregnancy prevention and disease prevention. Providers will have to evaluate the dual needs of each client to assist him/her in making a safe and appropriate decision.

- A needs assessment can identify populations at risk and STD/HIV prevalence rates for a geo-

graphical area, thus helping providers understand STD/HIV risk their clients generally face.

- Clients who consider themselves or their partners at high risk of HIV and other STDs are good candidates for dual method use.
- Some clients may be able to achieve protection against both STDs and pregnancy using a barrier method alone. Motivated clients might safely use male condoms alone, because condoms are very effective at both disease and pregnancy prevention when used correctly and consistently.
- For women at risk of STDs who cannot persuade their male partners to use a male condom, the female condom or the diaphragm with spermicide can be used for both STD protection and contraception.
- Regardless of her history, a woman should always be informed if the contraceptive method she is using does NOT protect her against STDs. If she is ever in a situation where she suspects she may be at risk (for example, her partner has other sexual partners), she should immediately start using additional protection.

Source: Adapted from Cates²⁵

generally recommended to women who are at high risk of STD, since it does not protect against infection. Candidates for IUD insertions should be carefully screened for the presence of current genital infection and assessed for STD risk. IUDs should be inserted only when procedures for infection prevention and client follow-up are adequate. This requires that family-planning providers receive further training in screening, counseling and insertion techniques.

It remains unclear whether oral or injectable hormonal contraceptives increase a woman's susceptibility to STD—including HIV—or her infectivity to her partner if she is already infected. Some studies have found greater risk of cervical infections with chlamydia trachomatis among users of oral contracep-

tives than among non-users, though the risk of symptomatic PID may paradoxically be reduced.²⁰ The research conducted to date on the influence of hormonal contraceptives on HIV acquisition or transmission is inconclusive.^{23,24} Such methods are otherwise safe, effective and convenient and women should continue to use them. However, because hormonal contraception does not protect against STDs, women who are uncertain about their partners' infection status should also encourage them to use condoms for "dual method" protection against both unintended pregnancy and infection.

Table 2
CONTRACEPTION FOR THE HIV-INFECTED WOMAN

Method	Possible benefits	Possible drawbacks
Oral contraceptives	Good effectiveness with consistent use. Less blood loss and anemia risk.	Unclear interaction of steroids and immune function. Interaction with certain antibiotics, antiretrovirals, other drugs. Possible increased shedding of virus from cervix. No STD protection. No HIV protection for partner.
Norplant, Depo-Provera	Good low-maintenance effectiveness.	Unclear interaction of steroids and immune function. Possible increased shedding of virus from cervix. No STD protection. No HIV protection for partner.
IUD	Good low-maintenance effectiveness.	Risk of uterine infection secondary to insertion. No STD protection. No HIV protection for partner. Increased days of bleeding, possible anemia.
Diaphragm, cap, spermicides	Some STD protection.	Vulvovaginal irritation increases vulnerability to RTIs for some users. Requires good technique.
Male, female condom	Good STD protection HIV protection for partner.	Male condom requires partner cooperation; partner cooperation helpful with female condom. Requires good technique.
Surgical sterilization	Good low-maintenance efficacy for women who desire no more children.	No STD protection. No HIV protection for partner.

Source: Adapted from Guest³⁰

THE SPECIAL NEEDS OF HIV-INFECTED WOMEN

Most HIV-infected women in the developing world are unaware of their serostatus. Increased availability of voluntary HIV counseling and testing would correct this, and help them obtain essential care and

support services and plan their futures. This implies training and supporting more health workers at the primary health-care level in risk assessment and counseling techniques, and establishing linkages with HIV counseling and testing services. The use of rapid, simple and low-cost testing methods may help expand availability of such services soon.

Improving the standard of care for HIV-infected women and reducing widespread stigmatization and discrimination in health-care settings may help increase demand for HIV counseling and testing services. At the very least, women who are known to be HIV-positive should have access to appropriate family planning and reproductive health care so they can make and enact informed reproductive decisions concerning contraception, continuation of a pregnancy and prenatal practices to reduce perinatal transmission of HIV. Thorough and sensitive counseling regarding their reproductive choices is critical. The risk of HIV transmission to a partner or unborn baby should be discussed: Dual protection should be encouraged and information about available contraceptive methods provided.

Such counseling should take into consideration the complexities of the decision making process and support women's rights to determine their own reproductive future.

Limited and conflicting data are available to guide the choice of a contraceptive method for HIV-infected women. The goal is high contraceptive efficacy and low risk of HIV transmission. Method selection must also take into consideration potential risks associated with local genital irritation, interference with

menstrual bleeding patterns and drug interactions (Table 2). For example, antituberculosis drugs such as rifampin have been shown to increase metabolism of oral contraceptives and may decrease contraceptive efficacy.²⁶ IUD use by HIV-infected women has been discouraged by a WHO expert group and the International Planned Parenthood Federation, on the basis of theoretical concerns about pelvic infection and blood loss.^{27,28} But the risk of short-term IUD-related complications among HIV-infected women is similar to that among uninfected women in Kenya.²⁹ An IUD may be a safe method for appropriately selected HIV-infected women with continuing access to medical services. As mentioned above, some recent studies have raised concern that hormonal contraceptives may increase a woman's infectivity, perhaps through increased cervical viral shedding. More research is required to resolve this issue. Until further data are available, HIV-infected women who desire contraception should consider a combination of barrier and hormonal methods, tubal ligation or the IUD.

POTENTIAL IMPACT ON FERTILITY AMONG WOMEN AT RISK

In Rwanda, counseling and provision of contraceptives proved effective in preventing MTCT.³¹ At the time of the study, seroprevalence of HIV was 30 percent among urban women; contraceptive use was low (three percent to four percent), and there was great concern about the risk of perinatal HIV transmission. An intervention that increased access to and information about hormonal contraceptive methods led to increased contraceptive use and decreased fertility among a cohort of women with high levels of HIV infection. These women had previously received HIV counseling and testing, which had led to high rate of condom use but a continued high rate of pregnancy.

Overall, the enhanced family-planning services led to greater use of hormonal contraception (from 16 percent to 24 percent), a shift to longer-lasting hormonal methods and a decrease in attrition among users. The increase in the rate of contraceptive use was observed equally among HIV-positive and HIV-negative women. Nine percent of HIV-positive women became pregnant in the year after the intervention was initiated, compared to 22 percent in a prior 12-month period when contraceptives were not provided at the study site. The corresponding proportions for HIV-negative women were 20 percent after the intervention compared with 30 percent before the intervention.

The greater reduction in incident pregnancy among HIV-positive women compared with HIV-negative women—despite similar contraceptive use rates—suggests that other factors (such as progression of HIV infection) may have influenced the fertility outcome. This experience nevertheless indicates that the provision of family planning services can significantly decrease the rate of unintended pregnancy among HIV-positive women. In general, however, such services do little to reduce fertility among HIV-infected women. Many HIV-infected women desire more children and few are willing to inform their partners about their status.^{32,33}

LESSONS LEARNED AND RECOMMENDATIONS

- Widening the choice for reducing the risk of MTCT of HIV requires more attention to preventing HIV infection among women in the first place and providing better reproductive health services, including family planning, to women at risk. This will ensure that interventions to prevent MTCT consider the needs and rights of women for basic information and services.
- HIV prevention programs should be directed at a broader range of women at risk, including adolescent girls and young women, women in stable relationships and pregnant and lactating women.
- HIV counseling and testing services can help women make more informed reproductive choices. Couples counseling seems to be particularly effective. Linkages should be established between HIV counseling and testing services and family planning and other reproductive health services to enable and support behaviors that can reduce MTCT.
- More effort is needed to deal with the social and economic factors that increase women's vulnerability to HIV, and to increase male responsibility for both infection protection and contraception.
- Strengthening and convergence of health services that serve women of reproductive age may be a necessary beginning for interventions to prevent HIV among women and infants. Such efforts should integrate maternal and child health, family planning, and RTI/STD services at the primary health-care level.
- Family planning programs must be broadened to include other reproductive health concerns—including STDs and HIV/AIDS—and reach other populations, such as adolescents and young women.
- In particular, family-planning providers should more systematically consider the risk of STD, including HIV, in counseling women about their contraceptive choices.
- HIV-infected women should have access to appropriate family-planning and reproductive health-care services, including sensitive counseling about reproductive choices.
- Operations research is required to develop and test modalities for dual protection in different settings. This should include studies of user perspectives to better understand the priorities that people attach to preventing pregnancy and infection, how these priorities change over time and over relationships and how people perceive and apply messages about dual protection.
- More research is needed to develop new or modified contraceptive and infection protection technologies that can expand the range of options for safer sex. Additional female-controlled methods, such as vaginal microbicides (which are effective against STD/HIV and do not require male cooperation or consent) are of highest priority.
- More basic and epidemiological research is required to elucidate the association between contraception and acquisition or transmission of STD, including HIV.

CASE STUDIES

TOWARDS REDUCING THE SPREAD OF HIV IN NORTHEASTERN THAI VILLAGES: EVALUATION OF A VILLAGE-BASED INTERVENTION³⁴

This innovative project in rural northeast Thailand demonstrated how cultural forces that put women at risk of HIV can be lessened through community action. Project activities included village-level meetings to mobilize and involve community leaders and change agents, an audio-drama and other participatory communications activities at village level. This intervention aimed to change prevailing community norms about sexual behavior and HIV/AIDS risk. The program increased communications between men and women about condom use and HIV/AIDS. In particular, married, monogamous women were able to tell their husbands not to visit sex workers or to encourage them to use condoms in commercial sex encounters and discuss ways to ensure that HIV is not transmitted between them, thus breaking the “norm of discretion and silence.” Condom use in marriage did not increase, however, and continued to be reported predominantly for contraceptive purposes.

PROTECTING SCHOOL GIRLS AGAINST SEXUAL EXPLOITATION: A GUARDIAN PROGRAM IN MWANZA, TANZANIA³⁵

A school-based program was developed in Tanzania following reports of sexual exploitation of girls by older boys and men, including teachers. Female teachers were trained to serve as guardians in all primary schools in two districts of Mwanza region. Their role was to help children in cases of sexual violence and harassment and to act as counselors on sexual health problems. An assessment of the implementation of the program found that about half of the girls in the highest three classes of the primary schools had had sex. The median age at first intercourse was 15 years. Sexual exploitation of schoolgirls by schoolboys, young men and teachers was common, and cases of sexual violence and harassment were reported from all 62 schools in the study.

The guardian program was well accepted, and generated considerable public debate on the issue of sexual violence. This has served to bring the problem into the open and make sexual abuse by teachers more difficult than in the past. But most guardians were opposed to any sexual activity by schoolgirls, a belief in keeping with social norms of the region. Nearly all guardians said that should a schoolgirl approach her with questions about sex, pregnancy or condoms, the guardian would not answer the question other than to encourage the girl to remain abstinent.

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C H A P T E R

18

*Reducing the
Risk of Mother-
to-Child
Transmission
of HIV During
Pregnancy and
Delivery*

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Reducing the Risk of Mother-to-Child Transmission of HIV During Pregnancy and Delivery

INTRODUCTION

More than five million children under age 15 have acquired HIV since the AIDS epidemic began, and almost four million of them have already died of AIDS. The vast majority of infected children acquire the virus from their mothers. Although Africa accounts for only 10 percent of the world's population, to date close to nine-tenths of all HIV-infected babies have been born in that region. The Joint United Nations Programme on HIV/AIDS (UNAIDS) believes that by 2010, AIDS may have increased mortality of children under age five by more than 100 percent in regions most affected by the virus.

HIV-1 perinatal transmission rates, in the absence of any intervention, range from 25 percent to 40 percent in developing countries, and 15 to 25 percent in developed countries. Although several factors could explain this difference, HIV postnatal transmission through breastfeeding is currently considered to play a major role in the higher rates observed in developing countries. Therefore it is assumed that 15 to 25 percent of infants born to HIV-positive women are infected during pregnancy or delivery. This chapter focuses on the risk of transmission from a pregnant HIV-positive woman to her child in the womb and during labor/delivery.

WHEN DOES TRANSMISSION OCCUR?

Not taking into account postnatal transmission through breastfeeding, HIV perinatal transmission can occur both during pregnancy (in utero) and during labor/delivery (intrapartum). Sequential PCR tests and viral cultures performed in children born to HIV-infected mothers have suggested that a substantial proportion of HIV vertical transmission occurs late in pregnancy (around the time of delivery) and during intrapartum.

RISK FACTORS FOR MTCT OF HIV DURING PREGNANCY AND DELIVERY

The risk of MTCT of HIV is multifactorial, influenced by the characteristics of the virus, the mother, the process of delivery and the neonate.

MATERNAL FACTORS

Maternal factors for MTCT of HIV include:

- Stage of maternal HIV disease
- Maternal nutritional status
- Disruption of placental barrier integrity by chorioamnionitis
- Sexually transmitted disease (STD) during pregnancy

OBSTETRICAL FACTORS

Both vaginal delivery and being the first-born of twins have been found to be associated with higher risk of MTCT of HIV compared to, respectively, C-section delivery and being the second-born twin. Other obstetric factors found to be associated with higher transmission rates are:

- Pre-term delivery
- Hemorrhage during labor
- Bloody amniotic fluid
- Invasive procedures during pregnancy or labor

FACTORS RELATED TO THE CHILD

Genetic characteristics of the fetus have been suspected as potential risk factors for transmission.

VIRAL FACTORS

MTCT rates of HIV-1 are higher than that of HIV-2.

**OPTIONS (EFFICACY PROVEN OR UNDER STUDY)
FOR PREVENTING MTCT OF HIV DURING
PREGNANCY AND DELIVERY**

Advances in understanding the timing of, and risk factors for, HIV perinatal transmission have been of great importance in designing, evaluating and implementing interventions to reduce MTCT of HIV. Options that have been proven to be effective or still under evaluation involve:

- Antiretroviral therapy (ART)
- Mode of delivery
- Vaginal disinfection
- Vitamin A supplementation in HIV-infected pregnant women
- Immunologic interventions
- Passive immunization
- Active immunization (vaccines)

**ISSUES TO CONSIDER WHEN PLANNING
MTCT INTERVENTIONS**

Strategies to reduce MTCT of HIV should involve:

- Effective primary prevention programs and family planning services
- Adequate and functioning antenatal care programs
- Access to confidential voluntary counseling and testing (VCT)
- Follow-up care for mother and infant
- Regulation and supply of antiretroviral drugs and breastmilk substitutes

LESSONS LEARNED AND RECOMMENDATIONS

Introducing antiretroviral (ARV) therapy and/or replacement feeding options to reduce MTCT of HIV is a complex process. Costs and benefits need to be carefully assessed. A summary of the key issues for consideration in policy making, and ways in which the strategy might be tailored to suit local conditions are proposed.

FUTURE CHALLENGES

It appears likely that MTCT interventions will come into much wider use in the near future. The most important challenge is to ensure that basic HIV/AIDS and reproductive health services are ready to integrate the new interventions, which will entail the following issues:

- Rising need for VCT services
- Reorganization of pre-, peri- and postnatal care and family planning
- Making decisions about infant feeding
- Remaining questions about ARV therapy, infant feeding, and MTCT
- Care for orphans

CASE STUDIES

Two case studies identify areas of concerns and offer recommendations for preventing MTCT of HIV.

BOTSWANA GEARS UP TO PREVENT MTCT OF HIV

The first population-based MTCT pilot project in Africa was launched in Botswana, offering VCT to all pregnant women in government health facilities, oral ZDV to HIV-positive women starting at 34 weeks of pregnancy and during labor and ZDV syrup to babies born to HIV-positive mothers. Several issues of concern were identified and recommendations made.

THAILAND: SPREADING THE BENEFITS OF RESEARCH

A program to reduce MTCT of HIV using a short-course of ZDV was launched in a Thai province hit hard by the epidemic. The program has been incorporated into routine mother and child health care, and has identified key conditions for success.

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More than five million children under age 15 have acquired HIV since the AIDS epidemic began, and almost four million of them have already died of AIDS. The vast majority of infected children acquire the virus from their mothers.¹

Although Africa accounts for only 10 percent of the world's population, to date close to nine-tenths of all HIV-infected babies have been born in

I N T R O D U C T I O N

that region, largely as a consequence of high fertility rates

combined with very high infection rates. In urban centers in southern Africa, for example, HIV infection rates of 20 to 30 percent are common among pregnant women tested anonymously at antenatal clinics. Rates of 50 percent have been recorded in parts of Zimbabwe, and over 40 percent in Botswana. According to data from the Joint United Nations Programme on HIV/AIDS, there are very few places outside sub-Saharan Africa where the prevalence of HIV infection among pregnant women has reached even 10 percent, let alone the extremely high figures seen in this region. This is partly because the epidemic in other badly affected countries—such as India and Southeast Asian countries—is younger and less advanced than in sub-Saharan Africa, so there is no room for complacency. AIDS threatens to reverse years of steady progress in child survival achieved through such measures as the promotion of breastfeeding, immunization and oral rehydration. UNAIDS believes that by 2010, AIDS may have increased mortality of children under age five by more than 100 percent in regions most affected by the virus.

HIV-1 perinatal transmission rates, in the absence of any intervention, range from 25 percent to 40 percent in developing countries, and 15 to 25 percent in developed countries. Differences between developing and developed countries in mother-to-child (MTCT) HIV transmission rates were presumed to be due to differences in methodological procedures. However, recently it was shown that even when using standardized methods of calculation, these rates remained higher in developing countries.² Although several factors could explain this difference, HIV postnatal transmission through breastfeeding is currently considered to play a major role in the higher rates observed in developing countries. Therefore it is assumed that 15 percent to 25 percent of infants born to HIV-positive women are infected during pregnancy or delivery.

While means of reducing the pediatric HIV/AIDS epidemic through HIV prevention among women and through providing family planning options are developed in Chapter 18, this chapter focuses on the risk of transmission from a pregnant HIV-positive women to her child in the womb and during labor/delivery. Information relative to postnatal-transmission (during breastfeeding) is detailed in Chapter 19.

WHEN DOES TRANSMISSION OCCUR?

Results from virological testing of abortion products, sequential polymerase chain reactions (PCR) among children born to HIV-infected women and clinical findings have shed light on the timing of MTCT of HIV. Not taking into account postnatal transmission, HIV perinatal transmission can occur both during pregnancy (in utero) and during labor/delivery (intrapartum). Sequential PCR tests and viral cultures performed in children born to HIV-infected mothers have suggested that a substantial proportion of HIV vertical transmission occurs late in pregnancy (around the time of delivery) and during intrapartum. A study conducted among breastfeeding women in Zaire estimated the proportions of infection attributable to in utero, intrapartum/early postpartum, and late postpartum transmissions at 23 percent, 65 percent and 12 percent respectively.³ These estimates were supported by data from non-breastfed infants: two-thirds of the infected infants are assumed to be infected intrapartum, and 95 percent of the remaining infants are considered infected in late pregnancy (last two months).

RISK FACTORS FOR MTCT OF HIV DURING PREGNANCY AND DELIVERY

The risk of MCTC of HIV is multifactorial, influenced by the characteristics of the virus, the mother, the process of delivery and the neonate.

MATERNAL FACTORS

Stage of maternal HIV disease

Factors related to stage of maternal HIV disease represent the major determinants of HIV perinatal transmission. Many studies found higher risk of transmission associated with advanced maternal HIV disease. High levels of maternal plasma viral load have been shown to be associated with higher risk of MTCT of HIV. However, transmission can occur at any level of maternal viral load.⁴ Maternal primary infection, characterized by a transient high viral load, has also been found to be risk factor for MTCT of HIV.⁵

Maternal nutritional status

Nutritional deficiencies, particularly vitamin A deficiency, have been suggested as an important risk factor in developing countries.⁶ Vitamin A deficiency is common among African women who are pregnant and infected with HIV. In a study conducted in Malawi, 58 percent of HIV-infected pregnant women enrolled into the study were deficient in vitamin A.⁶

Other maternal factors

Other maternal factors involved in HIV perinatal transmission are disruption of placental barrier integrity by chorioamnionitis and sexually transmitted diseases (STDs) during pregnancy.⁷ Additionally, other maternal factors have been associated with transmission including maternal smoking, illicit drug use and multiple sexual partners during pregnancy.⁸

Obstetrical factors

Both vaginal delivery and being the first-born of twins have been found to be associated with higher risk of MTCT of HIV.⁹ Data from recent studies corroborate the hypothesis that cesarean section delivery performed prior to labor and rupture of membranes is associated with lower risk of transmission.^{10,11} In general, differences observed in the risk of transmission between vaginal and elective cesarean section deliveries

OPTIONS FOR PREVENTING MTCT OF HIV DURING PREGNANCY AND DELIVERY

are considered to be due to the greater exposure of the fetus to cervicovaginal secretions or maternal blood during vaginal deliveries. In vaginal deliveries, the first-born twin, by passing through the birth canal first, in effect mechanically cleans it, and thus reduces the risk for the second-born twin.

Other obstetric factors found to be associated with higher transmission rates are pre-term delivery, hemorrhage during labor, bloody amniotic fluid and interventions and invasive procedures during pregnancy or labor, such as amniocentesis, needling procedures, amniocentesis, amniocentesis, fetal scalp electrodes and episiotomy.¹² In addition, a duration of ruptured membranes exceeding four hours has been consistently and significantly associated with higher risk of transmission. The most probable mechanism involved in the association between premature membrane rupture and vertical transmission is the high risk of ascending HIV infection through greater exposure to maternal cervicovaginal secretions.

FACTORS RELATED TO THE CHILD

Genetic characteristics of the fetus have been suspected as potential risk factors for transmission. For example, a mutation in a gene coding for a cellular receptor for HIV (CCR5) has been found associated with a decreased risk of transmission.¹³

Multiple studies indicate that maternal HIV infection is associated with elevated rates of adverse pregnancy outcome including stillbirth, prematurity and low birthweight.¹⁴ Data from some studies indicate that maternal HIV infection can be responsible for intrauterine growth retardation.

VIRAL FACTORS

Data from prospective studies have found that MTCT rates of HIV-1 are higher than that of HIV-2.¹⁵ It has been suggested that transmissibility may vary between HIV subtypes, with possible increased transmission with sub-type E or C, but data are yet inconclusive.

Advances in understanding the timing of, and risk factors for, HIV perinatal transmission have been of great importance in designing, evaluating and implementing interventions to reduce MTCT of HIV. Since 1994, the scientific progress made and the increasing availability of various preventive options enable dramatic decreases in the risk of transmission, to below two percent.¹¹

ANTIRETROVIRAL THERAPY (ART)

The rationale for administering antiretroviral drugs to HIV-infected pregnant women and their newborns is the decrease of maternal viral load and the inhibition of viral replication in the newborn. In 1994, results from the ACTG076 clinical trial conducted in the United States and France brought the first breakthrough in the field of MTCT of HIV. This clinical trial found that by administering zidovudine (ZDV) orally from the second trimester of pregnancy, intravenously during labor to HIV-infected mothers and by giving their non-breastfed newborns ZDV during their first six weeks of life, the risk of perinatal transmission of HIV could be reduced by two-thirds, from 25.5 percent (placebo group) to 8.3 percent (treatment group).¹⁶ The widespread implementation of the ACTG076 regimen has resulted in a striking decline in the risk of HIV perinatal transmission in the United States and Europe.

For resource-poor countries, implementation of the ACTG076 regimen was impossible due to its complexity, prohibitive cost and other logistical obstacles. Therefore, shorter, simpler (less frequent dosing and oral administration only) and less costly regimens targeting the time of maximal risk of transmission (late pregnancy and labor) have been designed and evaluated.

Short-course oral ZDV regimens starting at 36 or 38 weeks gestational age (300mg twice daily) were evaluated in Thailand¹⁷ among non-breastfeeding women, and in Côte d'Ivoire and Burkina Faso in West Africa among breastfeeding women.^{18,19} Other trials evaluated the safety and effectiveness of even shorter regimens starting as late as onset of labor and consisting of a two-week combination of ZDV and lamivudine (3TC)²⁰ or nevirapine (NVP), administered at a single dose to the mother at onset of labor and a single dose to the child within 72 hours of life.²¹

All short regimens of proven efficacy, with transmission risk by age four to six weeks reduced by one-third to one-half (corresponding to transmission rates between 8 percent and 15 percent), are described in Table 1. To date, it is very difficult to differentiate these regimens in terms of efficacy. However, each regimen has advantages and disadvantages with respect to potential toxicity, concerns for future treatment options, practicality and feasibility for implementation. For example, NVP is the most practical and least costly regimen (US\$4) but one single dose is able to select viral resistance.²² Where antiretroviral (ARV) therapy is available for long-term treatment, it is as yet unclear which could be the impact of such resistance selection on long-term treatment options for the mother.

MODE OF DELIVERY AND VAGINAL DISINFECTION

Cesarean section delivery

A European prospective randomized study and a meta-analysis of 15 studies^{10,11} evidenced a significant protective effect of elective cesarean section (transmission rate of 1.8 percent in the European study) compared to vaginal delivery (10.5 percent). Elective cesarean section is increasingly offered in combination with ZDV prophylaxis to HIV-infected pregnant women in developed countries. However, cesarean section delivery presents some important limitations for developing countries. In resource-poor settings, cesarean section is associated with high rates of mater-

nal morbidity and mortality.²³ In addition, the relative cost of cesarean section and the lack of adequate equipment in these settings are some other important issues to be considered.

Prenatal and intrapartum management of HIV-infected women

Since invasive procedures such as amnioscopy, fetal scalp electrodes, episiotomy and prevention of premature membranes rupture have been found to be associated with a high risk of HIV transmission, such procedures should be avoided when possible during prenatal and intrapartum management of HIV-infected women.

Vaginal disinfection

It was hypothesized that the disinfection of the birth canal with an antiseptic or virucidal solution prior to vaginal delivery could prevent MTCT of HIV at low cost. In addition, vaginal disinfection with chlorhexidine during labor was found to be effective in reducing neonatal morbidity associated with vaginal colonization by group B streptococci.²⁴ Unfortunately, no significant reduction of HIV transmission was found in two studies conducted in Malawi and Kenya that assessed the efficacy of birth canal disinfection using a 0.25 percent solution of chlorhexidine. However, the results from the Malawian study showed a reduction in the transmission risk when membranes were ruptured more than four hours before delivery, and a reduction in both morbidity and mortality due to neonatal sepsis.²⁵

Table 1

PERINATAL HIV-I TRANSMISSION CLINICAL TRIALS OF ANTIRETROVIRALS

NO BREASTFEEDING								
Study	Antepartum	Intrapartum	Postpartum		Transmission rates		Percent	Percent reduction
			Mother	Infant	Active	Placebo		
THAI CDC	300mg 2 times daily starting at 36 weeks	300mg Q3h	None	None	9.4 percent	18.9 percent	50 percent	0.008
MIXED BREASTFEEDING ²								
Study	Antepartum	Intrapartum	Postpartum		Transmission rates		Percent	Percent reduction
			Mother	Infant	Active	Placebo		
PETRA (ZDV/3TC)								
(A)	2 times daily starting at 36 weeks	every 3h (3TC Q12h)	1 week (Q12h)	1 week (Q12h)	7.8 percent	16.5 percent	53 percent (at 6 weeks)	0.001
(B)	None	Same	Same	Same	10.2 percent		37 percent	0.02
BREASTFEEDING								
Study	Antepartum	Intrapartum	Postpartum		Transmission rates		Percent	Percent reduction
			Mother	Infant	Active	Placebo		
ABIDJAN CDC	300mg 2 times daily starting at 36 weeks	300mg Q3h	None	None	12.2 percent	21.7 percent	44 percent (at 4 weeks)	0.05
ABIDJAN ANRS	300mg 2 times daily starting at 36 weeks	300mg Q3h twice daily, 1wk	300mg	None	14.8 percent	21.7 percent	32 percent (at 6 weeks)	NA
KAMPALA NIH	200mg within 72 hours	None	2mg/kg		11.9 percent	21.3 percent ³	44 percent (at 6-8 weeks)	0.003

Note:

All regimen dosing refers to zidovudine (ZDV), except the PETRA study, which administered ZDV/ lamivudine (3TC), and the Kampala study, which administered nevirapine (NVP).

Polymerase chain reaction (PCR) is a very sensitive HIV-diagnostic test that becomes positive very rapidly after infection. By four to six weeks of age, all infants infected during pregnancy, labor or delivery will have positive PCR while few infants infected through early breastfeeding will already be PCR+. PCR at age four to six weeks is thus the most useful test to study transmission that occurs during pregnancy and labor/delivery. Trial results are thus given at four to six weeks postpartum. Transmission rates at later ages and the impact of breastfeeding on the efficacy of antiretroviral therapies are developed in Chapter 19.

² Mixed breastfeeding, including full breastfeeding, early weaning and no breastfeeding.

³ NVP was not compared to placebo but to a very short ZDV regimen from labor to one week postpartum.

VITAMIN A SUPPLEMENTATION IN HIV-INFECTED PREGNANT WOMEN

Based on studies that found a significant association between maternal vitamin A deficiency during pregnancy and HIV perinatal transmission, several placebo-controlled trials have been carried out in Africa (Malawi, Zimbabwe, Tanzania and South Africa). These trials were assessing the efficacy of vitamin A alone or in combination with other micronutrients in reducing perinatal transmission of HIV. Results now available from two of these studies have found no significant effect of vitamin A supplementation in the risk of HIV perinatal transmission. However, the study in Tanzania found that multivitamin supplementation significantly decreased the risk of low birthweight, severe pre-term birth and small size for gestational age at birth.^{26,27}

IMMUNOLOGIC INTERVENTIONS

Passive immunization

The use of polyclonal antibodies may exert its effect by decreasing the infectivity of maternal blood, preventing infection of the placental barrier and by transferring a broad range of neutralizing antibodies to the fetus during late pregnancy and at delivery. Two trials have been initiated, the first in the United States (ACTG protocol 185) and the second in Uganda. The ACTG 185 study was stopped because of unexpected low rates of transmission (4.7 percent in the HIV immunoglobulin [HIVIG] group versus 4.8 percent in the placebo group) due to the concurrent routine use of ZDV by women.²⁸ A Phase III Ugandan trial assessing the efficacy of HIVIG when added to NVP is currently underway.

Active immunization (vaccines)

Based on data from some studies, and experience from other viral infections, it has been suggested that humoral and cell-mediated protective immunity could be achieved in newborns through active immunization. Several Phase I trials are ongoing or planned. The active immunization of newborns is targeted at prevention of postnatal transmission during breastfeeding, and would likely be combined with ARV therapy to prevent transmission during pregnancy and delivery.

ISSUES TO CONSIDER WHEN PLANNING MTCT INTERVENTIONS

EFFECTIVE PRIMARY PREVENTION PROGRAMS AND FAMILY PLANNING SERVICES

The first priority in any strategy to reduce MTCT of HIV is to prevent women of childbearing age from becoming infected with the virus in the first place.

In the AIDS era, family planning services have a special role to play in counseling people about responsible sexuality and providing them with the means to prevent STDs/HIV and unwanted pregnancy. HIV-positive women need appropriate advice on contraception and pregnancy. In developing countries, breastfeeding is an important means of regulating fertility. Additional family planning services should be made available for HIV-positive women who choose not to breastfeed.

The issues of preventing HIV infection in women and providing family planning options are fully developed in Chapter 17.

ADEQUATE AND FUNCTIONING ANTENATAL CARE

Programs to reduce MTCT can only be established where there is a properly functioning primary health care system, with efficient and accessible maternal and child health services. For MTCT prevention to be most effective, it is important that women be encouraged, through education and information programs, to attend antenatal clinics as early as possible in pregnancy. Even with a regimen as simple as NVP, women need to come early enough to be counseled, offered an HIV test, tested and receive test results. For peripartum care in general—and HIV VCT in particular—to be acceptable, maternal and child health care (MCH) staff need to care for women with empathy and confidentiality.

ACCESS TO CONFIDENTIAL VOLUNTARY COUNSELING AND TESTING (VCT)

Any ARV intervention will require the identification of HIV-positive women to allow them access to the intervention. VCT is thus the cornerstone of an HIV care service for pregnant women, and should be established or strengthened concurrently if ARV interventions to reduce MTCT are proposed. And yet in the developing countries where 95 percent of mother-to-child infections take place, there are very few counseling and testing services that allow a woman to find out her HIV status.

VCT for HIV provides benefits beyond preventing transmission from mother to child. These services have been shown to contribute to an increase in safe behavior at the individual level, and are likely also to reduce the ignorance, fear and stigma associated with HIV infection in the population at large. HIV counseling and testing in relation to pregnancy and other reproductive health services may prove a valuable entry point for provision of VCT to the wider community of healthy and asymptomatic women and their partners. Some reproductive health settings such as STD clinics, pediatric services and family planning clinics may provide an opportunity to offer testing to potential mothers and fathers of further children, while antenatal services will allow testing to be offered to women already pregnant and their partners.

Voluntary HIV testing of pregnant women must be confidential and undertaken with informed consent and access to ongoing counseling. Whenever possible, partners should also be counseled and offered VCT. Up to 25 percent of couples in some developing countries have been found to have sero-discordant HIV results. For sero-discordant couples, advice about preventing HIV transmission through safer sex has been shown to significantly reduce the rate of transmission to the uninfected partner. In addition, women alone

will often be unable to take decisions with financial implications for the family, such as infant feeding decisions. Furthermore, measures to reduce MTCT of HIV, especially the avoidance of breastfeeding, make it virtually impossible for HIV-positive women to keep their infection a secret from their families and people in the wider community.

VCT is further discussed in Chapter 23.

FOLLOW-UP CARE FOR MOTHER AND INFANT

A guiding principle for policy makers and planners is that interventions to reduce MTCT should be part of the broader strategy to prevent the spread of HIV and other STDs, to promote maternal and child health and to care for HIV-positive women and their families.

Postpartum care for HIV-positive women should include continued counseling about infant and young child feeding, advice on prevention of HIV transmission to sexual partners, access to and provision of family planning and emotional and medical support for the mother and the family. Infections in HIV-positive women may be more common in the postpartum period, and women should be told about the signs and symptoms of these infections in order to seek care early.

A QUESTION OF ETHICS

Introducing antiretroviral programs for the prevention of MTCT of HIV in countries where antiretroviral drugs are not available for the treatment of HIV-positive people more generally has raised sometimes heated debate about ethical implications. It is a key principle of health care that any measure taken be in the interests of the mother and baby as a pair, and the question asked is this: If a mother's access to antiretroviral therapy (ART) is limited to the period of pregnancy and labor, does this amount to treating the mother for the sake of her baby alone?

In fact, the question is based on an erroneous perception, for ARV therapy used for the purpose of preventing MTCT of HIV is not really a treatment, but a "vaccine" for the infant. A useful analogy is the rubella vaccine given to pregnant women to protect their offspring from the ill effects of maternal infection. Rubella vaccination does not meet with ethical objections, despite the fact that it, too, could be seen as treating the mother for the sake of the baby.

The issue of ARV therapy for HIV-infected people must be considered separately from the issue of ARV therapy for prevention of MTCT of HIV. It requires debate and policy decisions outside the scope of MTCT policy making. However, it is a point of principle when adopting antiretroviral drugs/replacement feeding (ART/RF) that HIV-positive pregnant women must be assured of the best possible care available in their countries. In some places, antiretroviral drugs will be available for therapy and prenatal VCT may help women to access antiretroviral combinations; in others, such treatment will simply not be feasible.

REGULATION AND SUPPLY OF ANTIRETROVIRAL DRUGS AND BREASTMILK SUBSTITUTES

If provided through the program, a system for distribution and supply of both antiretroviral drugs and breastmilk substitutes must be organized. Both of these products have high resale values and may be misappropriated for other uses. Regular supply, secure storage, distribution and accounting need to be ensured.³⁰

There is a risk of spillover of artificial feeding to infants of uninfected mothers. If breastmilk substitutes are provided, strict controls must be in place and it must be distributed according to the provisions of the International Code of Marketing of Breastmilk Substitutes.³¹ This topic is further discussed in Chapter 19.

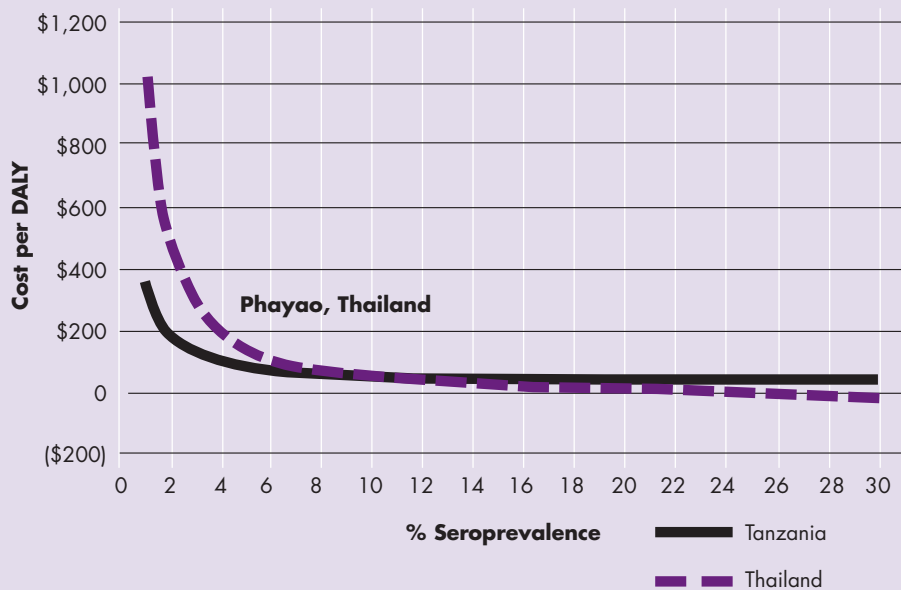
ARE THE INTERVENTIONS AFFORDABLE AND COST-EFFECTIVE?

Short-course ARV treatment should be evaluated with regard to the required investment in drugs and the supportive infrastructure as well as the expected benefit to woman, child and community health care. Today, the antiretroviral drugs needed for one HIV-positive pregnant woman plus infant formula for six months can be obtained for US\$100 or even less. In communities with a 40 per 1,000 birth rate, a 15 percent prevalence of HIV infection among pregnant women, and 10 percent of HIV-positive women knowing their HIV serological status (and accepting the intervention), the cost per capita of the intervention (ART and infant formula) would be US\$0.06 ($US\$100 \times 40/1000 \times 0.15 \times 0.10 = US\0.06). This assumes that the infrastructure does not need to be upgraded and that VCT is accessible independently of MTCT programs. This calculation does not take into account savings of medical and other expenditures to care for HIV-positive infants, which can be substantial. In fact, in most situations it more than compensates for the cost of the intervention.

Clearly, there will be initial costs to introduce ARV therapy for reducing MTCT transmission of HIV infection in health care systems that do not meet the

LESSONS LEARNED AND RECOMMENDATIONS

Figure 1
COST-EFFECTIVENESS BY HIV SEROPREVALENCE



Marseille E, Kahn J, Saba J. 1998

requirements described above, as these systems will have to be upgraded. In particular, if the costs of routinely offering VCT are to be supported by MTCT prevention programs, the cost of the program will greatly increase and the cost-effectiveness will vary according to the HIV prevalence in the area: The lower the prevalence, the more it will cost to identify one HIV-positive pregnant woman. Models show that where there is greater than 5 percent to 10 percent HIV prevalence, cost-effectiveness will remain quite stable, but below 5 percent to 10 percent prevalence, cost-effectiveness of the intervention rapidly decreases.²⁹ In such cases, targeted screening strategies will lead to better cost-effectiveness.

Introducing ARV therapy and/or replacement feeding options to reduce MTCT of HIV is a complex process. Costs and benefits need to be carefully assessed. Policy makers need to decide what kind of program is feasible and most appropriate for their countries, and whether or not to test models of the strategy in pilot projects before introducing it more widely.²⁹

Below is a summary of the key issues for consideration in policy making, and ways in which the strategy might be tailored to suit local conditions are proposed. The following issues need consideration:

- HIV seroprevalence rates in the country or community will determine the costs of inaction and the relative cost-effectiveness of different screening strategies.
- Attitudes towards HIV in the country or community will determine the risk of discrimination against women found to be infected with HIV, the likelihood of infringement of their rights, and the expected acceptability of the intervention.
- The risks associated with replacement feeding will determine whether or not the intervention can be introduced on a large scale immediately, or whether pilot projects will initially be needed so that lessons can be learned about how to make replacement feeding safer.
- The state of the existing health system and MCH services (including family planning) will determine the expenditure of effort and resources required to strengthen them sufficiently to support the new program.
- The maturity of the epidemic and level of social support that has developed to cope with it will determine how big a burden will be imposed upon the MTCT programs by increased demand for health care and counseling.

Table 2
**COMBINATION OF SERVICES APPROPRIATE
 TO DIFFERENT CIRCUMSTANCES**

		LOCAL HIV PREVALENCE	
		< 5 percent	> 5 percent
Minimal resource constraints (e.g., in industrialized countries)		Routine antenatal VCT Long ARV/RF	Routine antenatal VCT Long ARV/RF
Resource constrained +	<ul style="list-style-type: none"> ■ Local health system meets requirements ■ Low risk associated with RF and VCT 	Known HIV+/ Targeted antenatal VCT Short ARV/RF	Routine antenatal VCT Short ARV/RF
Resource constrained and/or	<ul style="list-style-type: none"> ■ Local health system does not meet requirements ■ Unknown risks associated with RF 	Known HIV+/ Targeted antenatal VCT Short ARV/RF	Pilot introduction of routine antenatal VCT + short ARV/RF (ARV/RF to be offered also to known HIV + women Prepare health system

Key: VCT = voluntary counseling and testing; ART/RF = antiretroviral drug therapy and/or replacement feeding.

DEFINITIONS

1. *Local health system meets requirements*
Access to adequate Mother-and-Child Health services including antenatal, delivery, postnatal and family planning services and continuing medical and psychosocial support for mother and child.
2. *Short ARV*
Short antiretroviral regimen such as one-month ZDV (Thai trial), two doses NVP (HIVNET012) or two weeks ZDV/3TC (PETRA).
3. *Long ARV*
Other regimens including ACTG 076 and regimens using a combination of antiretroviral drugs and antiretrovirals for the neonate as well as the mother.
4. *Known HIV positive*
Women who present for antenatal care having already been tested for HIV outside the maternal health services, and found to be infected.
5. *Targeted antenatal VCT*
VCT offered to pregnant women and their partners in communities (geographical or social networks) where HIV prevalence is particularly high.
6. *Routine antenatal VCT*
VCT offered to all women attending antenatal services and their partners as a matter of course.
7. *Pilot introduction of VCT and ARV/RF*
Introduction of the full strategy in a selected number of sites, and careful monitoring and evaluation of the processes and their impact, with particular attention to replacement feeding.
8. *Prepare the health system*
Where the health system does not meet the requirements for the successful introduction of the strategy, careful preparation is needed for voluntary counseling and testing, mother-and-child health services, and medical and support services for HIV-positive women and their children.

- The wider benefits to society will have to be taken into account when balancing costs and benefits of the intervention.
- Available financing for MTCT interventions and associated services will be a major consideration in decision making.

These factors will vary a great deal from one place to another. Table 2 proposes a decision-making process to assist policy makers who wish to consider adopting an ARV/RF strategy that is suited to their situation, and that reflects the local HIV prevalence rate, available resources, health system performance and expected risks associated with replacement feeding.

In many places it will be a good strategy to introduce VCT and ARV therapy and/or RF in a limited way in pilot programs, so that lessons can be learned about how best to operate the new service before it is introduced more widely. This is especially important in places where stigmatization of people with HIV/AIDS is common, and where there is uncertainty about the safety of RF or the acceptability of VCT. Pilot sites should be selected on the basis of having good basic health services already in place (or opportunities to strengthen it) and efficient referral systems.

FUTURE CHALLENGES

The progress of research on HIV prevention through antiretroviral drugs and other interventions strongly suggests that MTCT interventions will come into much wider use in the near future. The most important challenge is to ensure that basic HIV/AIDS and reproductive health services are ready to integrate the new interventions.

RIISING NEED FOR VCT SERVICES

As interventions become more widespread, HIV-infected women will have to know their HIV status in order to benefit from them. Therefore, VCT services will be required on larger scale than is currently available in most countries. This implies an expansion of VCT in general and within prenatal programs. However, the counseling component of VCT is often seen as being time consuming, adding to already heavy workloads, difficult and emotionally draining. Quality, costs and acceptance of different models of counseling interventions need to be tested.

The decision to take an HIV test is never an easy one. The acceptability of VCT will likely be related to the quality of the services (confidential, non-coercive, non-judgmental, etc.), the level of tolerance vis-à-vis HIV-positive people, and the availability of psychological support and care services for HIV-positive women. Acceptance of HIV testing and ARV therapy in developing countries needs further study. In reports from some countries, clinic attenders were found to be very willing to find out their HIV status. However in other settings, although antenatal attenders consented to testing, a substantial proportion did not return for their results or for post-test counseling.

STIGMA AND DISCRIMINATION

In many countries today, women are still facing the risks of stigma and discrimination. It is therefore essential to the safety and acceptability of MTCT interventions that effective steps are taken to combat rejection of people with HIV/AIDS. Where women fear discrimination and violence if they are identified as HIV-infected, they will be reluctant or completely unable to take advantage of opportunities offered to protect their infants from infection. Special attention should be paid in particular to developing positive and non-judgmental health staff attitudes towards HIV/AIDS. In places where stigmatization of HIV-infected people is a serious problem, it would be advisable to introduce VCT in a pilot site where the risks can be carefully monitored and strategies for dealing with stigma and discrimination tested.

REORGANIZATION OF PRE-, PERI- AND POSTNATAL CARE AND FAMILY PLANNING

Some 40 percent of the world's female population lack access to adequate antenatal care. In sub-Saharan Africa, less than half of all births are attended by professional health staff, with proportions well below this being reported from individual African countries as well as from parts of Asia. This represents a huge challenge for those committed to seeing that mothers and babies everywhere benefit from advances made in science and technology.

Expanding access to counseling, testing, family planning services and antenatal and postnatal care—along with adapting obstetrical practices and introducing ARV therapy—will have a heavy impact on clinical facilities. All aspects of providing and monitoring

treatment for mothers and children will have to be planned and implemented. Prenatal care will be the first area affected but, since infants born to HIV-infected mothers will need extra care themselves, postnatal settings will also come under pressure. HIV testing and the monitoring of HIV infection and ARV therapy will also impose extra work on laboratories. Family planning services for HIV-positive women—especially for those choosing not to breastfeed—will need strengthening.

MAKING DECISIONS ABOUT INFANT FEEDING

In developing countries, prolonged breastfeeding is heavily promoted for all children because it is a cheap, natural means of providing adequate nutrition and protection against many childhood diseases, with birth spacing as a secondary benefit. In comparison, the cost of infant formula, along with the clean water and fuel needed to prepare it, is often beyond the means of poor families in developing countries. Furthermore, when incorrectly used, feeding with infant formula may lead to severe malnutrition and fatal infectious diseases. Even safely used it may lead to stigma and rejection for women who find they are infected with HIV and, after counseling, decide not to breastfeed—a visible act in most developing countries. The choice of feeding method can thus be a difficult dilemma for an HIV-positive mother and health caregivers who will have difficulty understanding that breastfeeding may not be always the best option.

CASE STUDIES

REMAINING QUESTIONS ABOUT ARV THERAPY, INFANT FEEDING AND MTCT

The efficacy of short-course ARV therapy in preventing HIV transmission from an HIV-positive mother to her child is now well established. However, as for any effective treatment, ZDV, 3TC, and NVP can induce rare but severe toxic effects. In addition, NVP-resistant virus can be selected after a single dose of NVP. The potential implications of temporary selection of resistant virus for subsequent pregnancies or future therapeutic options for the mother, should they become available, is unknown.

Studies are still needed to assess the risks and benefits of exclusive breastfeeding associated with early and complete cessation of breastfeeding, and to examine ways to reduce transmission while continuing breastfeeding through, for example, prescription of anti-retroviral drugs during a reduced period of breastfeeding. Chapter 19 discusses further the challenges of reducing HIV risk to infants after delivery.

CARE FOR ORPHANS

Around the world, already over 11 million children have lost their mothers—and often their fathers—before they reached age 15. Although some of these children are or will be infected with HIV and others will not, all will need care and support as they grow up. In many countries the extended family is the traditional social security system which looks after orphans and affected families. But this system is already being pushed to the breaking point in the worst affected communities—long before the full impact of AIDS has been felt. Preventing MTCT of HIV may increase the number of HIV-uninfected children that are orphaned and need social support. However, it is important to recognize that in the absence of preventive interventions, more HIV-positive children will be born and require not only support but medical care. (This challenge is more fully explored in Chapter 26.)

BOTSWANA GEARS UP TO PREVENT MTCT OF HIV

The Botswanan Prevention of Mother-to-Child Transmission (MTCT) of HIV Program was launched in Gaborone and Francistown in April 1999.³² Through the program, VCT was offered to all pregnant women in government health facilities, oral ZDV was provided to HIV-positive women starting at 34 weeks of pregnancy and during labor, and ZDV syrup was given to babies born to HIV-positive mothers. The intervention also included infant-feeding counseling and provision of infant formula to women who opted not to breastfeed. In the first eight months of the program, over 4,000 of 7,000 antenatal clinic (ANC) clients had been counseled, of which 46 percent were tested for HIV and 41 percent were found positive. By January 2000, 221 women and 367 infants had received ZDV. A program review was completed in January 2000 to recommend the advisability of scaling-up the program.

In general, the program was found to be functioning well for this stage of a pilot project. It is the first population-based MTCT pilot project in Africa and received a high level of commitment from the Botswana government. The program is being integrated into ANC services, which are of a high standard.

Despite the general well functioning of the program, several issues of concern were identified and the following recommendations were made:

- More effort needs to be put into developing an adequate information, education and communication (IEC) strategy, so that women and their partners and families know more about the program before reaching the clinic.
- Communities need to be mobilized through a variety of efforts to support HIV-positive women and their families.

- To increase coverage with pre-test counseling, counseling skills among health care workers should be more widespread. The counseling sessions should be streamlined and made more routine.
- For more women to benefit from the full ZDV regimen, they must be encouraged to enter into the program at an earlier stage of their pregnancy, while at the same time NVP could be considered for HIV-positive women who attend too late for ZDV.
- Guidelines on infant feeding need to be clearer, and women who opt to formula feed need follow-up support.

After weighing the pros and cons, the program review team concluded that scaling-up was advisable. However, some preconditions were suggested, including the implementation of the above recommendations.

THAILAND: SPREADING THE BENEFITS OF RESEARCH

In July 1997, Thailand introduced a program in the northern province of Phayao to reduce MTCT of HIV using a short-course of ZDV.³³ The relatively poor province, home to 517,000 people, is particularly hard hit by the epidemic, with some 5.5 percent of pregnant women infected with HIV at the start of the intervention. Today, ARV therapy courses are offered through seven public hospitals—the most peripheral level of the health service with the facilities and capacity to handle the new service. The vast majority of pregnant women in Phayao attend antenatal clinics, where VCT has been available since 1993. At the start of the program, all pregnant women were offered counseling and testing on their first antenatal visit and told about the new measures to reduce the risk of MTCT of HIV. Virtually all who were offered an HIV test accepted, and by the end of 1997, close to 68 percent of those who were HIV positive had been enrolled in the program. Breastmilk substitutes are supplied to all participants, and are free of charge for one year to those with little income.

Despite the inconvenience for women of having to attend a hospital throughout pregnancy rather than a local health center, and the possibility that this would identify those with HIV and expose them to stigma and discrimination, the treatment has had a 90 percent compliance rate. The program has been incorporated into routine mother and child health care, and requires two days of extra training for laboratory technicians and three days for hospital-based counselors. It was set up with very little external assistance and is run by the Ministry of Public Health at an additional cost of just US\$0.13 per capita per year—or less than one percent of public health expenditure in Thailand. It has identified key conditions for success as:

- An uninterrupted supply of key resources such as HIV tests, ZDV and laboratory supplies
- Accessibility of services to all in the target population
- Acceptability of services to target population
- Continuity of care, and compliance
- High quality of service
- Free and informed choice about participating, and self-reliance in adhering to regimen
- Equity of coverage, with special effort made to reach groups who may remain excluded

RELEVANT CHAPTERS

- Chapter 17 *Reducing HIV Infection in Women and Providing Family Planning Services to Women at Risk*
- Chapter 19 *Mother-to-Child Transmission of HIV Through Breastfeeding: Strategies for Prevention*
- Chapter 23 *Counseling, Testing and Psychological Support*
- Chapter 26 *Orphans and Other Vulnerable Children: Approaches to Care and Protection Programs*

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C H A P T E R

19

*Mother-
to-Child
Transmission of
HIV Through
Breastfeeding:
Strategies for
Prevention*

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Mother-to-Child Transmission of HIV Through Breastfeeding: Strategies for Prevention

INTRODUCTION

The rapid expansion of the AIDS epidemic in resource-constrained settings, greater understanding of HIV transmission through breastmilk and increasing child mortality have forced the problem of mother-to-child transmission (MTCT) to the top of the international health policy agenda. MTCT can take place during pregnancy, during delivery and in the postnatal period through breastfeeding. Although fewer than half the babies born to HIV-infected women acquire HIV, increasing HIV prevalence among pregnant women has resulted in a very rapid increase in the number of HIV-infected children.

Breastfeeding can offer many benefits. For infants, breastfeeding provides adequate nutrition and protective anti-infective agents during the first six months of life. For mothers, breastfeeding facilitates uterine contraction, protects against excessive blood loss and delays the return of normal menstruation—the last conserves iron and contributes to child spacing. This chapter focuses on breastfeeding practices and alternatives, and examines some of the socioeconomic factors that determine whether mothers choose to breastfeed.

MAGNITUDE OF BREASTMILK TRANSMISSION OF HIV

Breastmilk transmission of HIV has been documented among infants of newly infected women and among women with established infections. According to the best available estimate, one out of seven children breastfed by an HIV-infected mother will become infected through breastfeeding.

Infants of HIV-infected women are at risk as long as they breastfeed. While there are limited data on the correlates of breastmilk transmission of HIV, prematurity, age at weaning and infant immune responses are believed to modify risk.

WEIGHING RISKS AND BENEFITS OF PREVENTION OF BREASTMILK TRANSMISSION OF HIV

Replacement feeding prevents breastmilk transmission of HIV. However, in resource-constrained settings the infant-feeding decision should be based on the balance between the risk of HIV transmission if the mother does breastfeed and the risk of death due to artificial feeding if she does not. Not breastfeeding can result in social stigmatization, economic hardship and early return of fertility. Women must be aware of all risks in order to make an informed decision.

PREVENTION OF BREASTMILK TRANSMISSION OF HIV

The most effective way of preventing breastmilk transmission of HIV while ensuring that babies enjoy the benefits of breastfeeding is to protect women of child-bearing age from HIV infection. HIV-infected women should be assisted with counseling and accessible family planning services to limit fertility and interventions to prevent breastmilk transmission of HIV through breastfeeding. These interventions include strategies to replace or shorten the duration of breastfeeding and reduce the infant's vulnerability to infection.

Prevention of breastmilk transmission of HIV can be achieved through the implementation of a seven-step program. Each step is outlined with accompanying practice points.

- Step 1: Good nutrition during pregnancy and the postnatal period
- Step 2: Good breastfeeding technique instruction
- Step 3: Reduction of infant's vulnerability to infection
- Step 4: Voluntary Counseling and Testing (VCT)
- Step 5a: Risk-reduction counseling for HIV-negative women
- Step 5b: Counseling for HIV-positive women
- Step 6: Antiretroviral Therapy (ART) to reduce MTCT
- Step 7: Infant-feeding options for HIV-positive women

Topics covered under Step 7, which was adapted from UNICEF/UNAIDS/WHO, include:

- Breastmilk substitutes
- Modifications of breastfeeding
- Safer breastfeeding
- Micronutrient supplementation
- Avoidance of dehydration

- Unsuitable replacement feeds
- Complementary feeding and weaning
- Family planning services
- Ethical considerations
- Spillover

**PREPARING THE HEALTH CARE SYSTEM
FOR PREVENTION STRATEGIES**

Health care systems must be prepared before implementing a program to prevent HIV transmission through breastfeeding. Health workers should be skilled in HIV counseling and testing, prevention of MTCT, lactation management and promotion of good breastfeeding techniques, standard midwifery procedures, management of antiretroviral therapy (ART) interventions, replacement feeding, nutrition counseling and family planning for HIV-infected couples. The health care system should also be strengthened to provide a continuum of care to manage the mother-infant pair.

**COST-EFFECTIVENESS OF STRATEGIES TO
PREVENT BREASTMILK TRANSMISSION OF HIV IN
RESOURCE-CONSTRAINED SETTINGS**

The high cost of infant-feeding options other than breastfeeding can be a major difficulty in resource-constrained communities. Any evaluation of cost-effectiveness must involve the definition of “effectiveness” and how it is measured. Although replacement feeding may not pay for itself in health care savings and may not compare favorably with other child survival strategies in cost-effectiveness analysis, there is a strong moral and ethical obligation to use all known strategies to prevent MTCT through breastfeeding.

POLICY CONSIDERATIONS

The International Code of Marketing of Breastmilk Substitutes and subsequent related World Health Assembly resolutions (which place restrictions on the ways in which the formula industry can market breastmilk substitutes) have helped reduce the impact of commercial marketing on breastfeeding. Although violations of the code continue, the WHA code and resolutions remain more relevant than ever in the context of HIV/AIDS, where there is a clear medical need for breastmilk substitutes.

LESSONS LEARNED AND FUTURE DIRECTIONS

Careful monitoring of programs to prevent MTCT in resource-constrained settings provides an opportunity to answer a number of important programmatic questions:

- How can health care workers best provide the information that HIV-positive mothers need to make infant-feeding decisions and best support these women in carrying out their decisions?
- How can such infant-feeding counseling and services be provided while minimizing their potential negative impacts?
- What is the risk of HIV transmission through breastfeeding under different conditions?
- What factors modify this risk?
- What is the risk of death due to artificial feeding under the same conditions?

CONCLUSION

The risk of MTCT through breastfeeding presents a huge challenge for HIV-infected women who must decide how to feed their infants, for the health care workers who counsel them and for the decision makers who must provide appropriate policy guidelines and resources. Research and pilot studies are planned or currently underway to provide better understanding and more effective solutions.

CASE STUDIES

Two case studies provide examples of interventions to prevent MTCT in resource-constrained settings.

THAI PROGRAM TO AVOID BREASTFEEDING IN HIV-INFECTED WOMEN

Thailand recently implemented several large regional programs of short-course ziduvodine (ZDV) treatment and avoidance of breastfeeding. With monitoring, these programs may provide more specific information about the acceptability and risks of HIV-infected women avoiding breastfeeding in a variety of settings.

THE ZAMBIAN NDOLA DEMONSTRATION PROJECT

A demonstration project is being implemented to introduce VCT and improved infant-feeding counseling into antenatal care and community services in a low-income area. The project aims to reduce MTCT by encouraging pregnant women and their partners to be tested for HIV and providing counseling on HIV prevention, improved care and nutrition during pregnancy and delivery and infant-feeding options for HIV-positive and uninfected mothers.

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The rapid expansion of the AIDS epidemic in resource-constrained settings, greater understanding of the magnitude of breastmilk transmission of HIV and increasing child mortality have forced the problem of mother-to-child transmission (MTCT) of HIV* to the top of the international health policy agenda. MTCT can take place during pregnancy or delivery and in the postnatal period through breastfeeding.¹

I N T R O D U C T I O N

Although fewer than half the babies born to HIV-infected women acquire HIV, increasing HIV prevalence among pregnant women has resulted in a very rapid increase in the number of HIV-infected children. The Joint United Nations Programme on HIV/AIDS (UNAIDS) estimates that about 600,000 children under age 15 were newly infected with HIV in the year 2000. Ninety percent of them acquired infection from their mothers – and 90 percent of these infected children live in sub-Saharan Africa.²

Breastfeeding can offer many benefits to both mother and infant. Exclusive breastfeeding (no other fluids and foods) provides infants with adequate nutrition for the first six months of life. Giving babies any other food during this early stage displaces breastmilk without increasing calorie intake and exposes the infants to pathogens that may cause diarrhea and other illnesses. Breastmilk has many protective anti-infective agents including macrophages, different types of lymphocytes, immunoglobulins, lipids and a variety of soluble factors such as lactoferrin.³⁻⁵ Breastfed babies have fewer and less severe episodes of diarrhea, pneumonia or other infections. In the developing world, where the leading causes of infant morbidity and mortality are infectious diseases, breastfeeding provides significant

protection to the young infant.⁶⁻¹⁰ Breastfeeding also helps babies and their mothers develop a close and loving relationship, enhancing mental and emotional development.⁴

Breastfeeding is also beneficial to the mother. In the immediate post-delivery period, the hormone oxytocin, which is produced as a result of stimulation of the nipples during suckling, facilitates uterine contraction and thus protects the mother from excessive blood loss. Exclusive breastfeeding delays the return of normal menstruation after delivery, which conserves iron and contributes to child spacing—thus reducing reproductive stress, maternal depletion and maternal mortality.

This chapter focuses on breastfeeding practices and alternatives, and examines some of the socioeconomic factors that may determine whether mothers choose to breastfeed. A seven-step program to prevent breastmilk transmission of HIV is provided.

** In this chapter « HIV » is used to mean HIV-1.*

MAGNITUDE OF BREASTMILK TRANSMISSION OF HIV

BREASTMILK TRANSMISSION OF HIV IN NEWLY INFECTED WOMEN

Breastmilk transmission of HIV has been documented among infants of newly infected women,¹¹⁻¹⁵ who carry very high viral loads before they develop HIV-specific immune responses. These women have an especially high risk of HIV transmission through breastfeeding: A metaanalysis based on four published studies estimated this risk to be 29 percent (95 percent confidence interval [CI]: 16 to 42 percent).¹⁶

BREASTMILK TRANSMISSION OF HIV AMONG WOMEN WITH ESTABLISHED INFECTION

Women with established HIV infections also transmit HIV through breastfeeding.¹⁷⁻¹⁹ The best available estimate of the risk of breastmilk transmission is based on an analysis of the results of six studies. This metaanalysis estimated the additional risk of breastmilk transmission of HIV to be 14 percent (95 percent CI: 7 to 22 percent).¹⁸ That is, one out of seven children breastfed by an HIV-infected mother will become infected through breastfeeding. In a more recent study from Kenya,²⁰ the transmission rate among infants randomly assigned to be breastfed was 37 percent versus 21 percent among infants assigned to be formula-fed, a risk difference of 16 percent. The investigators considered that this difference underestimated the risk, because 30 percent of infants in the formula-fed group actually received some breastmilk and may therefore have been infected through breastfeeding. Although the estimates remain imprecise, experts conclude that one-quarter to one-half of all MTCT among breastfed infants may be attributed to breastfeeding.²¹

A common problem in interpreting these data has been a lack of precise definition of the breastfeeding pattern. Experts have long suggested that truly exclusive breastfeeding (no other fluids or foods) may be safer than the usual pattern of non-exclusive breastfeeding or “mixed feeding.” They speculate that the addition of other foods and fluids to the breastmilk diet increases the risk of gut infections or physical trauma, thus increasing vulnerability to transmission. Previous studies that compared transmission among

“mixed fed” and “exclusively breastfed” babies used different definitions of these terms, and did not produce statistically significant results.^{18,22} In Brazil, transmission was higher among breastfed infants whose mothers reported early mixed feeding, but this trend was not statistically significant.²³ But in a more recent South African study,²⁴ infants exclusively breastfed for at least three months had significantly lower rates of infection at age three months (19.4 percent) than breastfed infants who had also received other foods or fluids (26.1 percent). In fact, the transmission risk among exclusively breastfed infants was not statistically different from that among formula-fed infants (19.4 percent). These results offer hope that promotion of exclusive breastfeeding among mothers who choose to breastfeed may be a feasible and effective option for reducing the risk of MTCT.

TIMING OF BREASTMILK TRANSMISSION OF HIV

Infants of HIV-infected women are at risk of breastmilk transmission as long as they are breastfeeding. Some studies have used time to the first positive polymerase chain reaction (PCR) to determine when, during the postnatal period, breastmilk transmission of HIV takes place. But it is not possible to differentiate transmission during late pregnancy, delivery and the early postnatal period. These studies therefore only reported rates of late postnatal transmission, defined in different ways by each study.

Late postnatal transmission of HIV refers to babies who initially are found to be uninfected, but who become infected following exposure to breastmilk. There is considerable variation in the published literature in the rate of late postnatal transmission. This is not surprising, as different periods of observation, definitions and laboratory methods were used to ascertain infection status. In a pooled analysis of data from 2,807 children from four cohorts in industrialized and

non-industrialized countries, the overall rate of late postnatal transmission (first positive PCR after 2.5 months) was estimated to be five percent, with an estimated risk of 3.2 infections per 100 child-years of breastfeeding follow-up (95 percent CI: 3.1 to 3.8 percent).²⁵ Malawi reported transmission rates of 0.7 percent per person-month during age one month to five months, 0.6 percent from age six months to 11 months, 0.3 percent from age 12 months to 17 months and 0.2 percent from age 18 months to 23 months.²⁶ These rates suggest declining risk with age. But such age-related variations in transmission are difficult to ascribe solely to the age of the infant, as feeding practices typically also change over this period. Beginning very early in infancy, other liquids and foods are introduced in ever-increasing amounts, which may reduce the amount of breastmilk consumed, thus reducing exposure, or may contribute to disruption of the integrity of the gut, thus increasing vulnerability to infection. As these studies did not measure such feeding mode effects, it is difficult to distinguish the real cause of any observed age-related variation in transmission rates. In Kenya, although risk of transmission of HIV per day of breastfeeding was about twice as great in the first four months as later in infancy (0.00042/d before versus 0.00026/d after four months), the risk of HIV transmission per liter of breast milk consumed did not vary with age. Rather, as children grew, they consumed less breastmilk and therefore the risk of breastfeeding transmission was reduced.²⁷

CORRELATES OF BREASTMILK TRANSMISSION OF HIV

There are limited data on the correlates of breastmilk transmission of HIV. A number of factors are thought to be involved, and the relationships are complex. Cell-associated and cell-free HIV virus is found in as much as 70 percent of breastmilk samples from infected women.²⁸⁻³⁰ One study that compared the

prevalence and concentration of HIV in mature milk and colostrum found more virus in mature milk.²⁹ But the presence of HIV in breastmilk does not automatically result in breastmilk transmission; there is a complex interaction with anti-infective factors in breastmilk.³¹⁻³⁴ One study in Rwanda suggested that the presence of HIV-specific immunoglobulin M (IgM), an antibody found in breastmilk, may protect against infection.²⁸ Cracked nipples and mastitis are also risk factors for breastmilk transmission of HIV.^{35,36} A baby's age and immune status are also important in this relationship, and there are ongoing studies to determine how prematurity, age at weaning and infant immune responses modify the risk.

WEIGHING RISKS AND BENEFITS OF PREVENTION OF BREASTMILK TRANSMISSION OF HIV

Replacement feeding prevents breastmilk transmission of HIV. But in resource-constrained settings the infant-feeding decision must include consideration of the risk of HIV transmission if the mother does breastfeed and the risk of death due to artificial feeding if she does not. A number of published studies use simulation models to weigh these risks,³⁷⁻⁴³ the features and results of which have been reviewed recently.⁴⁴ The models all reach the same conclusion: Where there is a high level of infectious disease mortality in childhood, breastfeeding is safer for infants of HIV-positive mothers than artificial feeding, despite the risk of transmission through breastfeeding. Where the baseline infant mortality is less than about 80 per 1,000 live births and the risk of death due to artificial feeding is less than 2.5 times the risk of death of exclusively breastfed infants, infants of HIV-positive mothers are generally safer when fed artificially. When the mother's status is not known and she is living under conditions of poverty and poor hygiene, breastfeeding is virtually always favored.

These analyses generally compare risks during an entire infancy. But the decision to initiate breastfeeding may be made on the basis of a risk assessment covering just the first few weeks or months. The additional risk of death due to artificial feeding is reduced as the infant ages, whereas the risk of transmission is

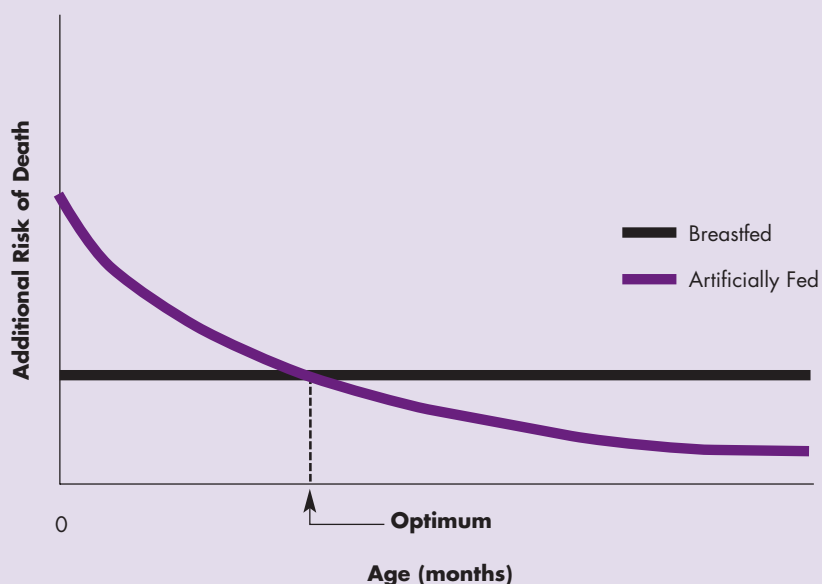
assumed to be relatively constant as long as the infant is breastfed. This situation is illustrated in Figure 1. As the infant matures and the risk of death due to artificial feeding is reduced, the balance of risks may shift to favor an alternative diet. The optimal time to stop breastfeeding would vary with the situation, depending on the shape and location of the replacement diet risk curve, which are unknown.

It is tempting to conclude from the risk analysis that mothers in resource-constrained settings should be advised to breastfeed despite the risk of transmission. This was the basis of earlier infant feeding guidelines.⁴⁵ The rapid expansion of the epidemic in resource-constrained settings, greater understanding of the magnitude of breastmilk transmission and increasing child mortality have challenged the old policy that provides prescriptive advice based on access to resources. In 1997, a new policy on infant feeding was formulated that promotes and supports breastfeeding for infants of women without HIV infection or of unknown status, and the right of a woman infected with HIV who is informed of her serostatus to choose an infant-feeding strategy based on full information about the risks and benefits of each alternative.⁴⁶ This principle of informed choice presents practical difficulties for health workers, who must tailor the information they provide to mothers based on the risks and benefits of each available infant-feeding option. In most cases this information is specific to the community and the household. It therefore requires some assessment of the mother's particular situation (hygiene and sanitation in the home, reliability of supply of ingredients for breast-

Figure 1

SCHEMATIC ILLUSTRATION OF THE CHANGING BALANCE OF ADDITIONAL RISK OF DEATH DUE TO ARTIFICIAL FEEDING VS. THE RISK OF MTCT OF HIV THROUGH BREASTFEEDING

The age at which the risk of death due to artificial feeding falls below the risk of transmission would be the optimal age to stop breastfeeding.



milk substitutes, reliability of income, etc.).⁴⁷ A rapid method for assessing infant feeding options at the community level is described in the case study from Zambia.

In addition to the health risks to the infant, there are other dangers that the mother must consider. Preliminary evidence from Kenya suggests that breastfeeding may jeopardize the infected mother's own health.⁴⁸ Not breastfeeding can result in social stigmatization, economic hardship and early return of fertility. Women should be aware of all known risks in order to make an informed decision.

PREVENTION OF BREASTMILK TRANSMISSION OF HIV

The most effective way of preventing breastmilk transmission of HIV while ensuring that babies enjoy the benefits of breastfeeding is to protect women of child-bearing age from HIV infection. HIV-infected women should be assisted with counseling and friendly and accessible family planning services to limit fertility. Interventions to prevent breastmilk transmission of HIV through breastfeeding should be available to infected mothers. These interventions include strategies to replace or shorten the duration of breastfeeding and, at the same time, reduce the infant's vulnerability to infection.

Prevention of breastmilk transmission of HIV can be achieved through the implementation of a seven-step program. The first four steps are general interventions that can be implemented in all health facilities and will improve the well-being of all women and their children. The last three steps are specific interventions for the HIV-infected woman.

STEP 1: ENSURE GOOD NUTRITION DURING PREGNANCY AND THE POSTNATAL PERIOD

Vitamin A deficiency and anemia are common in HIV-infected women. Both these deficiencies are associated with MTCT.^{40, 50} Iron deficiency is also associated with low birth weight and prematurity, both of which are risk factors for infant HIV infection.⁵¹⁻⁵⁴ Vitamin A deficiency in immunosuppressed women is associated with a significant increase in breastmilk HIV²⁹ and with increased mortality in HIV-infected adults.^{55, 56} This may be because serum Vitamin A levels are reduced as HIV progresses. Vitamin A supplementation resulted in a 63 percent reduction in mortality among HIV-infected children over 24 months of follow-up.⁵⁷ It has not, however, resulted in reduced MTCT.⁵⁸

Use of multiple micronutrient supplements in pregnancy reduces prematurity and low birth-weight and ensures adequate stores of iron in babies. In one randomized clinical trial in Malawi, giving multiple micronutrients (but not vitamin A alone) to HIV-infected pregnant women resulted in a 44 percent reduction in low birth-weight, a 39 percent reduction in prematurity and improved maternal hemoglobin and CD4 counts after delivery.⁵⁹ The role of micronutrient supplementation in prevention of MTCT has not yet been fully evaluated. Maternal iron status and hemoglobin concentration may also be improved through prevention and control of malaria during pregnancy.

Practice points

- Women should be counseled to consume a nutritious diet throughout pregnancy and lactation. The advice should be based on locally available foods.
- All pregnant women's diets should be supplemented with iron, folic acid, zinc and other micronutrients. Protocols for supplementation should follow national policy and availability.
- Malaria should be prevented through chemoprophylaxis and other avoidance and control measures.
- Women should be given high-dose vitamin A following delivery.

STEP 2: INSTRUCT ON GOOD BREASTFEEDING TECHNIQUE

Cracked nipples, mastitis and breast abscess significantly increase the risk of breastmilk transmission of HIV.^{35, 36} Cracked nipples can be caused by poor suckling technique, particularly latching onto the nipple rather than the areola. Candida infection and use of abrasive creams and soaps on the breasts may also cause cracked nipples. It is very painful to suckle an infant on cracked nipples, which puts a woman at risk of breast engorgement because of inadequate emptying of the breasts from infrequent feeding or avoidance of feeding. If poorly treated, breast engorgement may progress to mastitis.⁹

Practice points

- Instruct all women in good breastfeeding technique.
- Mothers in high HIV prevalence areas who do not know their HIV status should avoid breastfeeding from breasts with cracked nipples, mastitis or an abscess.
- If both breasts are affected, the woman should be encouraged to express breastmilk and pasteurize or boil it.
- If one breast is affected, express and discard breastmilk from the affected breast to avoid engorgement while continuing to feed from the unaffected breast.
- Treat the underlying condition appropriately.

STEP 3: REDUCE AN INFANT'S VULNERABILITY TO INFECTION

The infant risk factors for HIV transmission are less well-evaluated. But it is generally accepted that the following factors affect an infant's vulnerability to breastmilk transmission of HIV:

- Integrity of the infant gut epithelium: This can be compromised by vigorous suction at birth, poor nutritional status or oral lesions caused by candida infection.
- Duration of breastfeeding: Longer exposure is associated with a higher risk of infection.
- Colostrum versus mature milk: HIV is found in both the cell-free and cellular components of breastmilk. There is no evidence that colostrum is more infectious than mature milk.
- Mixed feeding versus exclusive breastfeeding: The lower rate of infection among infants exclusively breastfed for at least three months compared with infants who also received other liquids or food by this time suggests that exclusive breastfeeding is protective.²⁴

Practice points (for mothers who are HIV-negative or of unknown status)

- Exclusively breastfeed infants for the first six months, then gradually introduce and increase the quantity of nutritious complementary foods while maintaining frequent breastfeeding.
- Do not deny infants colostrum.
- Avoid mixed feeding in the first six months because it puts an infant at risk of enteric infections, which could increase vulnerability to HIV infection when exposed to breastmilk from an infected mother.
- Treat both mother and infant for candida infection as soon as it appears in either of them.

STEP 4: VOLUNTARY COUNSELING AND TESTING (VCT)

All pregnant women should be counseled about HIV/AIDS, MTCT and the benefits of knowing one's HIV status, after which confidential and voluntary testing should be available.

Practice points

- Counsel all women about HIV/AIDS and MTCT.
- Promote and provide voluntary and confidential HIV testing.

STEP 5A: RISK REDUCTION COUNSELING FOR HIV-NEGATIVE WOMEN

HIV negative women should be counseled on risk reduction. A number of studies have documented a high incidence of HIV seroconversion in the year after delivery.^{60, 61} Seroconversion during pregnancy and the postnatal period is associated with a high risk of MTCT.

- HIV-negative women should be counseled on ways to reduce their risks of infection, especially during pregnancy and lactation.
- HIV-negative women and women of unknown HIV status should be counseled to exclusively breastfeed their infants for the first six months (see Step 3).

STEP 5B: COUNSELING HIV-POSITIVE WOMEN

- Counsel and support women to accept their HIV status.
- Review different modes of HIV transmission (sexual, blood-borne and MTCT) and how to prevent them.
- Review the risks of MTCT with the woman, particularly transmission through breastfeeding.
- Counsel women on ART options for their own health and to prevent MTCT (see Step 6).
- Counsel HIV-infected women on options for preventing breastmilk transmission of HIV and associated costs and risks (see Step 7).

STEP 6: ANTIRETROVIRAL THERAPY (ART) TO REDUCE MTCT

A number of ART regimens of varying cost, complexity and efficacy have been shown to reduce the risk of MTCT for non-breastfed infants. To date, five clinical trials have tested ART regimens in breastfed infants. Since these regimens provide ART only during the perinatal period, it is not surprising that, with continued breastfeeding, efficacy is reduced over time. Still, for the four trials that have reported long-term (12-month to 24-month) efficacy, ART reduced MTCT by 21 percent to 35 percent.⁶²

Despite efforts to reduce costs and simplify ART regimens, most remain unaffordable to public health services in poor countries. An exception is nevirapine (NVP).⁶³ A single dose given to the mother during labor and to the infant during the first 72 hours after delivery costs only US\$4 per treatment and reduces MTCT among breastfed infants by 35 percent by 12 months; results are comparable to an equivalent treatment with zidovudine (ZDV).⁶⁴ In comparison with a

placebo and with longer-term postpartum treatment, NVP would likely be even more effective. Although concerns about the development of drug resistance to NVP have so far limited its use to research and pilot studies,⁶² it was recently recommended for wider use.⁶⁵

Practice point

- Women infected with HIV should be supported to make an informed choice about ART.

STEP 7: INFANT-FEEDING OPTIONS FOR HIV-POSITIVE WOMEN*

Withholding breastmilk is the most effective method of preventing breastmilk transmission of HIV. Alternatives include breastmilk substitutes or modifications of breastfeeding. For the mother who chooses to breastfeed, there are strategies that can be used to make breastfeeding safer.

- Breastmilk substitutes. These include commercial infant formula, home-prepared formulas based on animal milks or whole animal milk.
- Modifications of breastfeeding. These include heat-treated breastmilk and wet nursing.
- Safer breastfeeding. Strategies for making breastfeeding safer include breastfeeding exclusively, providing nutritional support to the mother, using good breastfeeding technique, treating breast problems and stopping breastfeeding early.

Practice points

Breastmilk substitutes

Commercial infant formula should be considered an option by HIV-positive women when:

- The family has reliable access to sufficient formula for at least six months. (Feeding an infant for six months requires an average of 20kg powdered formula [44 450g tins]).
- The family has the additional resources—water, fuel, skills and time—to prepare and feed the formula hygienically and according to instructions.
- Home-prepared formula is a reasonable option by an HIV-positive woman when:
- Commercial infant formula is not readily available or is too expensive for the family.

**This section was adapted from UNICEF/UNAIDS/WHO48*

- Supplies of animal milk or other milks are reliable and the family can afford it—about half a liter per day—for at least six months.
- The family has the additional resources to make the necessary modifications and feed the formula safely.

Unmodified cow's milk could be considered as an option for an HIV-positive woman when:

- Commercial infant formula is not available or is too expensive.
- There is a reliable supply of cow's milk, but the family lacks the resources to modify cow's milk to make home-prepared formula.

All of these alternatives carry additional risks of infection and malnutrition and therefore require early case management of illness and careful growth monitoring.

MODIFICATIONS OF BREASTFEEDING

The mother's own breastmilk can be expressed, boiled, cooled and fed by cup. This takes advantage of the nutritional superiority of breastmilk, while the heat kills any virus that may infect the infant. The process requires time, resources and support however, so it may not be a practical long-term option. Mothers with breast problems that increase the probability of infection can use heat treatment in the short-term while receiving treatment.

Wet-nursing is also an option if an uninfected woman is willing and able to provide this service for as long as needed. The wet nurse should be counseled as per Steps 1 to 3 above.

SAFER BREASTFEEDING

Counseling on safe breastfeeding should be provided for the HIV-positive woman who chooses to breastfeed. The mother should breastfeed exclusively, consume adequate amounts of a nutritious diet (including supplements if available), use good breastfeeding technique to prevent breast problems, seek

treatment for breast problems and candida if they occur and practice safe sex (see Steps 1, 2, 3 and 5a). She should also be counseled on how and when to safely introduce an alternative diet.

Shortened duration of breastfeeding reduces an infant's exposure to the virus. In addition, the risks of artificial feeding are reduced as the infant gets older. At some point, there will be less risk of death due to artificial feeding than risk of HIV infection through breastfeeding (Figure 1). In terms of HIV-free survival, this is the best time to switch to artificial feeding. The exact timing cannot be known for certain, but will depend on the situation and the mother's ability to provide an alternative diet that is both affordable and safe.

MICRONUTRIENT SUPPLEMENTATION

Animal milks are deficient in essential micronutrients. Commercially prepared infant formula is fortified with these micronutrients, but babies fed home formulas and whole animal milks need micronutrient supplements. If micronutrient supplements are not available, complementary foods rich in iron, zinc, vitamin A and folic acid should be introduced by age four months.

AVOIDING DEHYDRATION

Non-breastfed infants are at increased risk of diarrheal disease and severe dehydration. Mothers and health workers may need to provide extra water (that has been boiled and cooled) during diarrheal episodes. Risk of dehydration is particularly high if the infant under age six months receives unmodified cow's milk, due to its higher concentration of solutes.

UNSUITABLE REPLACEMENT FEEDS

Some types of milks and foods are not recommended as replacement feeds for infants under age six months, and may cause harm. These include skimmed milk, sweetened condensed milk, fruit juices, sugar-water, dilute cereal gruel and milk products such as yoghurt and other acid milks.

COMPLEMENTARY FEEDING AND WEANING

By age six months, babies need additional food to meet their nutritional requirements. During weaning, milk continues to be an important component of the diet, providing one-half or more of the infant's nutritional requirements between ages 6 months and 12 months, and up to one-third between ages 12 months and 24 months. An infant who is not breastfed needs replacement feeding that provides all required nutrients including fats, carbohydrates, proteins, vitamins and minerals. Health workers should familiarize themselves with locally available foods and their nutritional value in order to provide appropriate nutritional counseling.

FAMILY PLANNING SERVICES

Fertility returns earlier among women who are not breastfeeding, because they do not have the benefit of lactational amenorrhea. Women who opt for replacement feeding need counseling and provision of appropriate contraceptive methods within four to six weeks of delivery.

ETHICAL CONSIDERATIONS

Replacement feeding in a population that traditionally breastfeeds is difficult and potentially stigmatizing. These difficulties should be discussed with the client when the replacement feeding option is considered. HIV-infected women and their partners should make the informed choice on infant feeding.

There are concerns that MTCT prevention does not address the health needs of the HIV-infected woman herself. ART has been shown to improve the health and longevity of HIV-infected individuals, but is not readily available in resource-constrained settings.

But affordable non-ART interventions have also been shown to be beneficial. These include isoniazid and cotrimoxazole prophylaxis, good nutrition, prompt and effective treatment of opportunistic infections and ongoing counseling and support. In most of sub-Saharan Africa, care of HIV-infected individuals has been reactive; managed pro-active treatment has not yet developed. Antenatal VCT provides a new opportunity for introducing managed care to improve the well-being and survival of HIV-infected adults. Improved survival of mothers and fathers postpones the time when children become orphans.

SPILLOVER

The effect of information about the risk of HIV transmission through breastfeeding on the infant-feeding practices of mothers who are HIV-negative or who do not know their status (but who suspect that they are infected) is termed “spillover.” Mothers wanting to protect their infants from HIV transmission may use breastmilk substitutes inappropriately, endangering the health and survival of infants not at risk of HIV infection. Spillover may be minimized by ensuring that:

- Information for mothers on this subject—from all sources—is complete, accurate and unbiased.
- There is easy and affordable access to VCT (to minimize the number of mothers who do not know their status).
- Breastfeeding is actively promoted and protected among the general population through efforts such as the Baby-Friendly Hospital Initiative and strict enforcement of the International Code of Marketing of Breastmilk Substitutes.

PREPARING THE HEALTH CARE SYSTEM FOR PREVENTION STRATEGIES

Health care systems must be prepared before implementing a program to prevent HIV transmission through breastfeeding. Health workers require knowledge and skills to provide the new services effectively. They should be skilled in HIV counseling and testing, MTCT prevention, lactation management and promotion of good breastfeeding techniques, standard midwifery procedures, management of ART interventions, replacement feeding, nutrition counseling and family planning for HIV-infected couples. The health care system should also be strengthened to provide a continuum of care to manage the mother-infant pair. This should include development of appropriate follow-up health care to reduce risks associated with replacement feeding and establishment of a support network in the family and community.

Interventions to prevent postnatal transmission of HIV should be monitored to document their impact on infant morbidity and mortality of exposed children. Breastfeeding trends among HIV-negative women and those of unknown status should also be monitored.

COST-EFFECTIVENESS OF STRATEGIES TO PREVENT BREASTMILK TRANSMISSION OF HIV IN RESOURCE-CONSTRAINED SETTINGS

Apart from the safety of artificial feeding, the high cost of infant-feeding options other than breastfeeding is a major deterrent in resource-constrained communities. For households unable to afford continued supplies of ingredients for replacement feeding, provision of free or subsidized supplies has been suggested. This is one component of a series of pilot projects sponsored by international agencies.⁶⁶ Although some middle-income countries with relatively low HIV prevalence—such as Thailand (see case study) and Brazil—have provided free formula to HIV-positive mothers, the high cost of such a strategy has raised questions about cost-effectiveness and affordability, especially in

low-income countries with higher HIV prevalence. In many countries where HIV prevalence is high, per capita health expenditure is less than US\$10 per year, and frequent shortages of even the most basic medical supplies are reported. The cost of any intervention to reduce MTCT after delivery may need to be justified on the basis of cost-effectiveness.

An important part of the decision making depends on how “effectiveness” is measured. If cases of infections averted are used, this ignores the risks to infant health and survival of not breastfeeding. Some broader measure of net health benefit—such as lives, DALYs or QALYs** saved—is therefore preferred. If the risk of death due to artificial feeding is actually greater than the risk of transmission—as may be true in many situations (see “Weighing the Risks and Benefits of Prevention of Breastmilk Transmission of HIV” above)—then any discussion of cost-effectiveness is meaningless. Assuming that an alternative infant-feeding strategy would increase HIV-free survival, cost-effectiveness studies that provide information on the cost per life saved or per DALY gained allow these strategies to be compared with competing child survival investments.

Many studies of the cost-effectiveness of efforts to prevent MTCT using ART have been published,⁶⁶⁻⁷³ but only one examined infant-feeding alternatives.⁷³ No studies in a recent review of published and unpublished MTCT cost-effectiveness studies examine the cost-effectiveness of alternatives to breastfeeding.⁷⁴ The only published study of the cost-effectiveness of alternative infant-feeding strategies to prevent MTCT⁷³ estimates that in South Africa, screening and providing formula to HIV-positive mothers would cost US\$331 per year of life saved, even after accounting for the savings to the health care system in reduced costs of caring for HIV-infected infants. Screening and recommending (but not providing) formula would cost US\$200 per year of life saved. The cost-effectiveness of adding formula to an existing antiretroviral strategy would be an estimated US\$910 per year of life saved.

*** The DALY (disability-adjusted life year) and QALY (quality-adjusted life year) have become the “common currency” of cost-effectiveness studies because, unlike specific outcomes such as HIV transmissions averted, they allow a broad range of health interventions to be compared. The DALY and QALY use criteria related to the severity of a condition or disability to quantify the burden of disease for non-fatal as well as fatal conditions. They also allow an adjustment for the duration of life affected.*

These costs do not compare favorably with other important child health interventions, most of which cost less than US\$100 per DALY saved.⁷⁵

Although replacement feeding may not pay for itself in health care savings and may not compare favorably with other child survival strategies in cost-effectiveness analysis, there is a strong moral and ethical obligation to use all known strategies to prevent MTCT through breastfeeding. In particular, it is important to provide HIV-positive mothers with information on the risks associated with different infant-feeding strategies and to support these women in whatever infant-feeding strategy they choose. The issue for the mother is less one of cost-effectiveness than of affordability. Although hygienically prepared infant formula may be the preferred replacement feeding option for mothers who choose not to breastfeed, cost considerations may favor less expensive alternatives. The challenge is to find affordable alternatives that are safer than breastfeeding.

POLICY CONSIDERATIONS

The International Code of Marketing of Breastmilk Substitutes and subsequent related World Health Assembly resolutions place restrictions on the ways in which the formula industry can market breastmilk substitutes such as infant formula. Although the code has been instrumental in reducing the impact of commercial marketing on breastfeeding, violations continue.^{76,77} In one study, 10 percent of all mothers interviewed and a quarter of all facilities visited had received free samples of milk, bottles or teats—none of them for research purposes.⁷⁸ These violations are not isolated occurrences, but reflect what appears to be a systematic strategy involving multiple violations. In the context of HIV/AIDS—where there is a clear medical need for breastmilk substitutes—the code is even more relevant. It presents no obstacle to the use of breastmilk substitutes by HIV-positive mothers, but protects all mothers from promotional activities and misinformation, ensuring that the information they receive on the risks and benefits of different infant-feeding methods is accurate and unbiased.

LESSONS LEARNED AND FUTURE DIRECTIONS

Experience is accumulating on interventions to prevent MTCT in resource-constrained settings. The case studies included here provide two examples; there are many other pilot projects being sponsored by UN agencies.⁷⁹ Early data from these and other initiatives suggest that even if free formula is supplied, acceptance is still relatively poor. In the first half-year of operation in Côte d'Ivoire, for example, only half the HIV-positive mothers offered free formula accepted it.⁸⁰ In a similar trial project in a peri-urban district in South Africa, although nine out of 10 mothers accepted the offer of free formula, only 64 percent of the calculated requirements of these infants was actually distributed.⁸¹ The reasons for these shortfalls are not well understood and are being investigated. As these and other efforts to provide alternatives to breastfeeding are implemented, the impact on infant-feeding practices must be carefully monitored—not only the practices of HIV-positive mothers, but also those of mothers who are HIV-negative or who do not know their status. Careful monitoring of these programs also provides an opportunity to answer a number of important programmatic questions including:

- How can health care workers best provide the information that HIV-positive mothers need to make infant-feeding decisions, and best support these women in carrying out their decisions?
- How can such infant-feeding counseling and services be provided while minimizing the potential negative impacts (stigmatization of mothers who choose not to breastfeed, shorter birth intervals, illness and mortality due to artificial feeding, spillover, high cost of breastmilk substitutes)?

Other important research questions requiring urgent answers include:

- What is the risk of HIV transmission through breastfeeding under different conditions?
- What factors modify this risk (exclusive versus mixed feeding, maternal nutritional status, ART, infant age, etc.)?
- What is the risk of death due to artificial feeding under the same conditions?

CONCLUSION

The risk of MTCT through breastfeeding presents a huge challenge for HIV-infected women who must decide how to feed their infants, for health care workers who counsel them and for decision makers who must provide appropriate policy guidelines and resources. The guidance provided here is intended to help direct these efforts, but it is hampered by uncertainty. As the many research and pilot studies planned or already underway provide better understanding and more effective solutions, policy and practice must keep pace with these developments.

CASE STUDIES

THAI PROGRAM TO AVOID BREASTFEEDING BY HIV-INFECTED WOMEN

Thailand (population 60 million) since 1988 has experienced a rapidly developing HIV epidemic. In 1996, national HIV seroprevalence was 2 percent among the one million women giving birth annually; it is 1.8 percent as of the this book's publication. Since the early 1990s, the Thai Ministry of Public Health (MOPH) has recommended that HIV-infected women avoid breastfeeding. Before the recent introduction of short-course ZDV, this was the main intervention offered to reduce transmission risk. As part of routine antenatal HIV counseling, pregnant women learn about the risk of postpartum HIV transmission through breastfeeding. Although breastfeeding in general is actively promoted through the Baby-Friendly Hospitals Initiative, women who test HIV-positive are counseled during pregnancy (if identified during antenatal care) or immediately postpartum (a relatively small number identified at delivery) to avoid breastfeeding. During the typical two- to three-day postpartum stay, nurses instruct HIV-infected women how to prepare and use formula.

The Department of Health (DOH, MOPH) is responsible for distributing free infant formula to women who cannot afford to purchase it themselves. The DOH budget has been increased to support regional health promotion offices—which procure formula at a discount of approximately 20 percent through annual negotiations with international

manufacturers, within the guidelines of the Code of Marketing of Breastmilk Substitutes. Although UNICEF generally recommends cup feeding, bottle feeding is preferred in Thailand. A one-year supply of formula costs approximately US\$200 to \$250 (about four to five times the cost of short-course ZDV). The DOH program originally anticipated providing two years of formula for the poorest 10 percent to 20 percent of HIV-infected women. In 1998, target duration was changed to one year in order to provide a higher level of coverage. In fact, an estimated 70 percent of HIV-infected delivering women in many regions of the country receive free formula, although coverage may only be partial after six months and is commonly given for 12 to 18 months.

Despite the recent economic crisis, the program has been able to expand, but the need for support has also increased. Jurisdictions and hospitals not covered by the DOH (such as Bangkok regional, university, military and private hospitals) rely on their own funding and donations to provide formula. Most hospitals distribute tins as originally packaged by the manufacturer. UNICEF recently completed a detailed review of formula feeding among HIV-infected mothers in Thailand.⁸² While raising concerns about gaps in coverage and the potential for inappropriate and inconsistent supply and feeding practices, the report concluded that the program was generally well-conceived and well-accepted.

Although the impact of formula feeding among HIV-infected women has not been formally evaluated, the work at two large Bangkok hospitals over the past seven years suggests extremely high acceptance (nearly 100 percent), no indications of increased infant morbidity or mortality, no adverse impact on baby-friendly practices and few problems with stigmatization. Because bottle feeding, early mixed feeding and early weaning are relatively common in Bangkok, bottle feeding does not necessarily indicate HIV infection. Women who do not want to tell others about their

HIV status commonly say they are not breastfeeding because of hepatitis A. But more systematic data from both rural and urban settings are needed to assess coverage, acceptability and possible adverse effects.

Thailand recently implemented several large regional programs of short-course ZDV treatment and avoidance of breastfeeding. This combined strategy can reduce transmission risk by 50 percent to an absolute rate of less than 10 percent. With monitoring, these programs may provide more specific information about the acceptability and risks of HIV-infected women avoiding breastfeeding in a variety of settings.

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THE NDOLA DEMONSTRATION PROJECT

The Ndola District Health Management Team (N-DHMT), in collaboration with the National Food and Nutrition Commission and the LINKAGES Project of USAID is implementing a demonstration project to introduce HIV voluntary counseling and testing (VCT) and improved infant-feeding counseling into antenatal care and community services in a low-income area of Ndola, Zambia.⁸⁵

The project aims to reduce MTCT by encouraging pregnant women and their partners to be tested for HIV, providing counseling on HIV prevention, improved care and nutrition during pregnancy and

delivery; and infant-feeding options for HIV-positive and uninfected mothers. Antiretroviral drugs are not being offered, due to concerns about cost and sustainability. Hope Humana, a local NGO already involved in HIV/AIDS testing, counseling and support, is training and providing technical assistance to the N-DHMT on all aspects of the HIV testing, counseling and linking services with the community. The USAID HORIZONS Project is providing technical assistance with operations research.

To ensure that the project meets the needs of the local population, project designers carried out assessments of the health clinics' capacity and antenatal, delivery and postnatal care procedures. Community groups, organizations and services that can support project interventions were also surveyed and assessed. In addition, the designers carried out a rapid, formative research study to identify feasible and appropriate infant-feeding recommendations for HIV-positive women.

The formative research study (carried out over two months at a cost of less than US\$3,000) included focus group discussions, key informant interviews, market surveys, household observations, cooking demonstrations and trials of improved practices. These trials solicited feedback from caregivers, health providers and other community members about different practices recommended by UNAIDS/UNICEF/WHO in their guidelines on HIV and infant feeding. The feasibility and best ways to encourage practices such as cup feeding, boiling water, preparing infant formula or diluted and sweetened cow's milk, expressing breastmilk and enriching local recipes for young children were among the subjects discussed and tested with people in their homes.

Findings from the formative research were used to develop strategies for training health providers and counseling mothers, caregivers and other family members about HIV and infant feeding. Specific messages for counseling HIV-positive women on modified breastfeeding and safe replacement feeding options and counseling uninfected women about appropriate infant-feeding practices have been developed.

This case study was written by Ellen G. Piwoz, Academy for Educational Development, Washington, DC.

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C H A P T E R

20

*Ensuring the
Safety of Blood
and Blood
Products*

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Ensuring the Safety of Blood and Blood Products

INTRODUCTION

Blood transfusions have life-saving benefits—but they also carry risks. The HIV/AIDS pandemic has brought particular attention to the inherent dangers of blood and the importance of preventing transfusion-transmitted infections. Although an HIV screening test has been available since 1985, an estimated 5 percent to 10 percent of all HIV infections worldwide are transmitted by transfusion of contaminated blood and blood products. Yet prevention of transfusion-transmitted HIV infection is both achievable and cost-effective. This chapter outlines some of the challenges to a safe and adequate blood supply and the appropriate use of blood, as well as strategies that have been implemented to address them.

STATE-OF-THE-ART APPROACHES

ESTABLISHING A NATIONAL BLOOD TRANSFUSION SERVICE

A well-organized blood transfusion service (BTS) is a necessary part of any safe and effective use of blood and blood products. A national BTS service must be developed within the framework of the country's health care infrastructure—with government commitment and support—and recognition of the service as a separate unit with an adequate budget, management team and trained staff.

SAFE BLOOD DONORS

Safety considerations must be built into every stage of the blood collection process: testing, storing, distribution and transfusion. Multiple successful strategies have been developed to improve selection and retention of safe donor populations and minimize risk through donor deferral. These strategies involve:

- Recruitment of volunteer non-remunerated blood donors
- Deferral of donors who report risk behaviors
- Protection of donors' health

EFFECTIVE BLOOD-TESTING STRATEGIES

Testing all blood donations for HIV and other infectious agents is the cornerstone of programs to reduce transmission of infectious diseases by blood transfusion. Basic components in effective blood-testing strategies include:

- Selection of testing strategies appropriate for local conditions
- Training and supervision
- Quality management and forward planning

APPROPRIATE USE OF BLOOD

Despite the high prevalence of severe anemia in many resource-poor countries, use of blood could be substantially reduced, thus decreasing unnecessary risks and increasing availability of blood to those in need.

Appropriate use can be improved through:

- Development and implementation of national, regional or hospital transfusion guidelines
- Emphasis on clinical and hematologic assessment of patients prior to transfusion
- Education of health care providers on the appropriate use of blood and alternatives to blood use

USE OF BLOOD COMPONENTS AND BLOOD SUBSTITUTES

Decisions related to the provision of whole blood, blood components or plasma derivatives must consider cost, safety and efficacy. Blood products should be prescribed appropriately—and only when they are likely to offer a major benefit to the patient. Blood product options include:

- Alternatives to transfusion (such as saline)
- Whole blood or red cells
- Plasma
- Platelets

PREVENTION OF SEVERE ANEMIA

The most effective and inexpensive way to prevent anemia-associated mortality and exposure to the risks of blood transfusion is to prevent severe anemia. In resource-poor areas, increased attention to nutritional deficiencies as well as prevention and early effective treatment of malaria could greatly reduce both transfusions and anemia-related mortality.

MANAGEMENT OF BLOOD TRANSFUSION SERVICES

Ultimately, safety and availability of the blood supply relies on strong quality management to ensure an adequate and reliable supply. Program planning and management of blood banks must anticipate the clinical demand for blood and the financial, human and technical resources needed to meet requirements.

PROCUREMENT, EFFECTIVE PURCHASING, QUALITY ASSURANCE AND FORWARD PLANNING

Strong business management of the BTS is critical to its success. Various procurement strategies could greatly reduce costs incurred by transfusion services. To ensure a safe blood supply, managers must anticipate demand and prevent shortages of personnel, equipment and supplies. A clear and publicly supported delineation of health priorities will help guide planning and expenditures.

TRAINING AND RETAINING EFFECTIVE STAFF

Where the blood system is a public service—in both industrialized and developing countries—low pay levels often lead to serious problems in recruiting and retaining high quality professional staff. It may be necessary to accept a continued high training overhead and identify (and provide) incentives to keep trained and experienced staff.

LESSONS LEARNED AND RECOMMENDATIONS

- **Reduce unnecessary transfusions by effective clinical use of blood.** Transfusion has the potential for acute or delayed complications and transmission of infection. Minimize unnecessary transfusions through the effective clinical use of blood and blood products; the appropriate use of simple alternatives to transfusion (which are safer and most cost-effective) can lessen the risks associated with transfusion.
- **Educate, motivate, recruit and retain low-risk blood donors.** High priority should be given to the elimination of family/replacement and paid blood-donor systems, since these are associated with significantly more transfusion-transmitted infections. Recruitment and retention of voluntary non-remunerated blood donors from low-risk populations are the foundation of a safe and adequate blood supply.
- **Screen all donated blood for infectious agents.** The blood transfusion service should develop and maintain a national strategy for screening donated blood and blood products for infectious diseases, using the most appropriate and effective tests; and good laboratory practice in all areas of blood grouping, compatibility testing, component preparation, storage and transportation of blood products.

FUTURE CHALLENGES

Transfusion technology continues to evolve in the developed world, leading to higher costs—often with only marginal gains in safety. The rising cost of transfusion support makes it important for any national health plan to critically weigh investment in expensive new technology against other health priorities.

CONCLUSIONS

Securing national commitment and dedicated resources is vital to the safety of a country's blood supply. Blood banking and testing, donor selection, personnel training, effective management, anemia prevention and improving the appropriate use of blood and blood alternatives are interrelated and will require coordinated programs to be successful. Major gains in blood safety and availability can be achieved at any level of the health care system.

CASE STUDIES

Many countries, often with limited resources, have made great progress toward securing a safe and adequate blood supply. These case studies explore factors that may have contributed to their success:

- Establishment of a national BTS in Zimbabwe
- Targeted blood safety initiatives in Kenya based on results of rapid assessments
- Education, recruitment and retention of safe blood donors in Thailand and Uganda
- Improved appropriate use of blood in Tanzania
- Prevention of severe anemia in Vietnam

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I N T R O D U C T I O N

Originally an emergency life-saving procedure for severe hemorrhage, transfusion of blood and blood products became a routine procedure during World War II. The technique rapidly spread throughout the world, and was soon an essential component of standard medical care, particularly in trauma, surgery, obstetrics and hematology. But blood transfusions carry their own risks: They can trans-

mit hepatitis viruses, bacterial infections and—in endemic areas—parasitic infections such as Chagas disease and malaria. The HIV/AIDS pandemic has brought new attention to these risks and the importance of preventing transfusion-transmitted infections.

In industrialized countries, the dramatic reduction of HIV transmission by blood transfusion is one of the greatest success stories in the battle against AIDS. Sensitive HIV-screening tests, recruitment and retention of low-risk donors and more conservative use of blood have resulted in far fewer transfusion-transmitted HIV infections. But there are still challenges to a safe blood supply in many resource-restricted countries. Although a screening test has been available since 1985, 5 percent to 10 percent of all HIV infections worldwide are probably transmitted by transfusion of contaminated blood and blood products. The global inequity that exists in the area of blood safety has led WHO to give high priority to the provision of a safe blood supply worldwide. The WHO Director General made blood safety the theme of World Health Day 2000 when she announced, “Despite all the technological marvels that humanity is experiencing, a reliable and safe blood supply is still out of the reach for untold millions of people around the world.”¹

Lack of test kits because of inadequate resources is rarely the sole limiting factor in securing a safe blood supply. Providing enough blood—collected from low-risk donors, appropriately screened for infectious diseases in a controlled environment and stored and distributed for appropriate clinical use—requires a complex and often expensive health service delivery system. It is a system that is difficult to attain where resources, technology and trained personnel are scarce. Nonetheless, many resource-constrained countries have made important gains. This chapter outlines some of the challenges to a safe and adequate blood supply and its appropriate use, and some of the strategies that have been implemented to address these problems.

STATE-OF-THE-ART APPROACHES

ESTABLISHING A NATIONAL BLOOD TRANSFUSION SERVICE

WHO has given important emphasis to the establishment of a well-organized blood transfusion service (BTS) as a fundamental component for the safe and effective use of blood and blood products.²

Governments must ensure a safe and adequate supply of blood. This responsibility may be delegated to a nonprofit, nongovernmental organization, but the BTS must be developed within the framework of the country's health care infrastructure. The BTS requires government commitment and support, and recognition of the service as a separate unit with an adequate budget, management team and trained staff.

WHO outlines activities that are important in establishing a blood transfusion service. These include:

- Formalization of government commitment and support
- Development of a national blood policy and plan
- Development of necessary legislation/regulation for the BTS
- Formation of an organization with responsibility and authority for the BTS
- Formation of a BTS management committee;
- Appointment of a medical director
- Appointment of a quality manager
- Appointment, if necessary, of a specialist BTS advisory group
- Appointment and training of staff experienced in every key aspect of the BTS
- Development and implementation of a budgeting and finance system to ensure a sustainable blood program through cost recovery and/or annual budget allocation
- Establishment of a national quality system, including guidelines, standard operating procedures (SOPs), accurate records and monitoring and evaluation²

The development of national policy and guidelines demonstrates a cohesive approach to blood safety and galvanizes public support for transfusion services.

These guidelines define a standard of patient care, increase awareness of transfusion issues among health care providers and contain budget requirements for transfusion services.³

SAFE BLOOD DONORS

Safety considerations must be built into every stage of the process of blood collection, testing, storing, distribution and transfusion. The first step in the process is the collection of blood from low-risk donors, which serves multiple purposes in terms of safety, efficiency and cost-effectiveness: Collection of blood from low-risk donors minimizes many adverse consequences of subsequent errors in laboratory testing, errors in record keeping, or lack of sensitivity in laboratory testing—including failure to detect recently infected persons who are in the “window period.” Blood from HIV-positive persons increases costs to the blood transfusion service for collecting and screening donations that are later discarded. Targeting collection of blood from low-risk donors and deferring high-risk donors increases the proportion of collected blood that will be available for clinical use, thus improving efficiency of blood collection and screening. Multiple successful strategies have been developed to improve selection and retention of safe donor populations and minimize risk through donor deferral.

Volunteer non-remunerated blood donors

An important, internationally accepted strategy is for all blood to be collected from voluntary non-remunerated donors, that is, persons who donate blood for altruistic reasons and who receive no material reward for donation. Financial and technical limitations have forced hospitals and blood banks in many countries to rely on patients' families to provide or replace blood donations. Many areas still use paid donors. But a number of states have demonstrated that voluntary donation can be established in different cultures.

Why has voluntary non-remunerated donation been emphasized?

Safety: The volunteer donor has no economic incentive to conceal behavior or clinical symptoms that may indicate a risk to the patient (such as intravenous drug use). Multiple published studies from around the world have demonstrated that paid donors and family donors are at increased risk of HIV and hepatitis compared with volunteer donors. Paid donors may often present as family donors when family members are unwilling to donate or concerned about HIV testing and confidentiality. Persons who are motivated to sell their blood frequently engage in high-risk behaviors such as unsafe sexual practices or drug use or may place themselves at risk by donating too frequently.⁴

Ethical considerations: In many cultures, it is questionable or unacceptable to condone a system that potentially or actually exploits the health of some individuals (usually the poor who sell their blood when they do not have other employment options) to benefit the health of others.

Reliability of supply: Dependence on patients' family members to provide or replace blood for clinical use limits the ability to maintain a true blood bank; blood is not stored, tested in a controlled environment or available for emergency use.

Impact on the appropriate use of blood: Blood cannot be used appropriately if it is collected from patients' families. Health care providers cannot easily modify their transfusion plans if the family has gone to the trouble and expense of providing a donor. By the time a donor is identified, patients may be transfused late (when transfusion is unlikely to benefit them) and blood is not available for those who need it emergently.

The decision to convert to a blood supply that relies exclusively on volunteer donors is challenging for any policy maker, since it carries the risk of severe short-term shortages. Important management, training and resource issues must be addressed for this transition to occur successfully. Education and mobilization of volunteer donors requires specialized training and interpersonal skills. Blood collection campaigns often demand substantial resources for transportation, personnel, equipment, refrigeration and a reliable supply of electricity and consumables, such as blood bags and reagents.

Donor recruitment and deferral

Given the high prevalence of HIV among the general population of blood donors in many areas, a number of countries have revisited the issue of identifying low-risk blood donors—an idea traditionally considered problematic where heterosexual transmission is the primary mode of HIV infection.

By modifying their strategies for donor recruitment, many areas have reduced the prevalence of HIV in their donor populations. For example, as discussed above, elimination of paid donors has lowered HIV seroprevalence in the donor pool.^{5,6} In Tanzania and Kenya, seroprevalence among donations of secondary school students was nearly half that of donations collected from patients' family members.^{7,8} In Côte d'Ivoire, deferral of male donors with a history of contact with a female sex worker in the past five years would remove 73 percent of HIV-positive donors and 25 percent of seronegative donors.⁹ In Thailand, deferring male donors who were 21- to 30 years old and who had a reactive serological test for syphilis would remove seven percent of HIV-seropositive blood donors and only 1.5 percent of seronegative donors.¹⁰

Profiles of low- and high-risk donors vary by country and by region. Development of donor deferral strategies can be developed through epidemiological evaluation of donor information and test results collected through routine blood bank practices. Safer donor populations can be identified through examination of local patterns of infections, risk groups and risk behaviors. Understanding the epidemiology of a given disease in the population—and of asymptomatic infectious carriers in the community—may help define criteria for donor recruitment or deferral. Relevant donor characteristics might include age, gender, reported behavior, marital status and medical history. Understanding risk factors for incidence (such as recent infections) may also help guide efforts to reduce the risk of collecting blood from recently infected donors who may be in the “window period.” Retention of low-risk donors has been an important strategy to improve safety of the donor pool in both high- and low-risk settings. Taken together, this information may help guide donor motivation and recruitment, mass media campaigns and deferral criteria used in donor screening interviews.

Protecting the health of blood donors

There are numerous reports of donors acquiring HIV and other infections as a result of having their blood or plasma collected. This may reflect an inadequate or negligent approach to donor selection and testing, use of contaminated collection equipment or reuse of disposables. Collection of whole blood is generally restricted by national policy to three or four times per year; more frequent removal of blood can deplete iron stores. Iron deficiency anemia is a special risk if the individual’s diet is inadequate or where malaria and hookworm are common. Economically disadvantaged persons, who may seek income from selling their blood, may be at particular risk.

EFFECTIVE BLOOD-TESTING STRATEGIES

Testing of all blood donations for HIV and other infectious agents is the cornerstone of programs to reduce transmission of infectious diseases by blood transfusion. Well-implemented blood-testing programs have consistently been shown to reduce the incidence of transfusion-transmitted HIV and hepatitis to extremely low levels. Testing of blood donations for HIV has also been shown to be a cost-effective strategy compared with other HIV prevention interventions.^{11, 12}

Selection of testing strategies

The selection of testing strategies appropriate for individual settings is a critical component of an effective blood safety program. Effective screening test systems—including reagents, equipment and basic quality control materials—are available for HIV, HTLV, hepatitis B, hepatitis C and syphilis. Test systems for other transfusion-transmissible agents, such as CMV, Chagas disease and malaria, are also available.

For example, HIV enzyme immunosorbent assays (EIAs) are designed for large-scale testing. This method requires equipment, refrigeration, clean water, steady power supply and well-trained staff. “Rapid tests” tend to be technically simpler to perform, allow a single sample to be tested quickly and do not require laboratory equipment. Studies have demonstrated that, although performance varies considerably between assays, many commercially available rapid tests are as sensitive as EIA, and when different assays are combined in various testing algorithms, specificity is no less than that of an EIA-Western blot algorithm. Utilization of rapid tests rather than EIA could be important where small numbers of units are being tested, in hospitals that rely on family members to provide blood for immediate transfusion or where the necessary infrastructure for more sophisticated testing is not available. If the volume of blood testing is small (fewer than approximately 90 tests per day), rapid tests are more cost-effective than EIA.

It cannot be overemphasized that availability of test kits per se is not the only issue; it is critical that the kits be appropriate for the setting where they are being used.

BLOOD COLLECTION

Blood is collected by venesection; a sterile, disposable plastic pack should always be used. The blood collection pack contains a sterile solution that prevents clotting and provides nutrients to maintain the function of the red cells during storage. The volume taken from an individual at a single collection is generally 450 ml or—mainly in Asian countries—200-250 ml. The product is referred to as “whole blood,” and can be stored for three to five weeks at 2°-6°C; exact shelf life depends on the formulation of the storage solution. During storage, function of the red cells and some of the plasma proteins is maintained; however, other constituents (platelets and coagulation factors V and VIII) lose their activity.

Whole blood and blood components

In many countries, it is normal practice to separate the collected blood by centrifugation, followed by transfer to connected sterile plastic packs. This provides red blood cells, plasma and platelets. These are referred to as “blood components,” and are generally prepared locally in hospital blood banks or regional blood centers. Most countries do not treat these components as licensed pharmaceuticals, although various forms of regulation and certification of quality may exist.

Plasmapheresis and plasma derivatives

Plasma may also be collected from an individual by plasmapheresis: the plasma is removed, and the red cells returned to the donor. In many countries, frequent plasma collections from an individ-

ual are permitted (USFDA regulations permit up to 50 liters per year; Council of Europe guidance, up to 15 liters per year). Plasmapheresis is widely used to obtain plasma for bulk processing. Commercial concerns pay “donors” for each collection. The raw material for the majority of the world supply of plasma derivatives is obtained from these paid individuals (see below).

Although plasmapheresis does not deplete the donor’s red cell and iron reserves, it can remove four to five kg of protein from the body every year. In well-regulated institutions, the donor’s plasma albumin levels are monitored. But it should be considered whether this level of protein loss is acceptable among low-income individuals likely to have an inadequate diet.

Plasma derivatives are prepared by industrial-scale manufacturing processes from large volumes of plasma. Typically, a single production run would start with a tank of 20,000 liters of plasma, containing 40,000 individual plasma collections.²³

- These products’ safety depends on the consistent application of rigorous quality control systems governing the donors, the plasma itself and every aspect of the production process.
- Plasma derivatives are subject to regulation and licensing as pharmaceuticals in most countries. The whole supply process should consequently be subject to the same rigorous regulation as other licensed drugs.

A facility to produce plasma derivatives of good quality requires a substantial and continuing investment program.

Training and supervision

If HIV testing is to be performed accurately and effectively, laboratory, blood bank and supervisory personnel must be well-trained and technically proficient.^{13, 14, 15} Quality assurance programs and regulatory oversight are often ignored as vital components of a successful blood transfusion service.

In a multicenter study in east Africa, samples from blood donations screened by hospital blood banks were retested at a reference laboratory. Although all hospitals had test kits, 30 percent of donations found HIV-positive by the reference laboratory had not been removed from the blood supply by routine hospital screening. Many factors contributed to transfusion risk, including poor recordkeeping and lack of standardized reporting systems. In addition; breaks in the cold chain occurred during transport of test kits; blood was collected from relatives for immediate use when rapid tests were not available; and one hospital did not screen donations from mothers to their infants because of the erroneous assumption that all mothers and infants had the same HIV-infection status.¹⁴ The challenges faced by these hospitals are not uncharacteristic of those found throughout the region.

National quality systems must be established that include guidelines, standard operating procedures (SOPs), training, accurate recordkeeping, monitoring and evaluation. Establishment of centralized testing centers facilitates these activities. Expertise may not exist in smaller settings and control is difficult to ensure. However, centralized systems may have trouble providing adequate blood supplies to small or remote hospitals. Centralized systems are also difficult to implement in countries such as India, where transfusion services are operated by governmental, volunteer and commercial establishments. In these situations, standardized processes and centralized quality assurance programs have been recommended.

The effectiveness of a blood-testing program depends entirely on good quality management and an adequate and reliable supply of appropriate reagents. Multiple challenges face the quality and reliability of testing:

- If the quality or supply of test reagents is inconsistent, accurate universal testing of all blood donations cannot be achieved.

- Quality of blood-testing supplies may be poor or have a short shelf-life when delivered.
- Test reagents must be stored correctly or they may be unreliable.
- Ensuring quality control, training and oversight is difficult in decentralized settings where individual hospitals—particularly smaller ones—are responsible for blood testing. Even if testing is performed in a technically correct way, record keeping and stock management may be irregular.
- If a supply of banked blood is not available, blood may be collected from patients' relatives for emergent transfusion. Under these conditions, it is difficult to maintain standardized testing methods. Even if testing can be done, it is more prone to error than if it were conducted in a more controlled environment.

The establishment of blood banks that collect blood from volunteer donors—and test and store donations in a regulated and standardized fashion—greatly increases the chance that testing will be done correctly, minimizes errors and improves blood availability.

APPROPRIATE USE OF BLOOD AND BLOOD COMPONENTS

Awareness of the risks of transfusion has led clinicians and patients in many countries to move toward a more conservative use of blood and blood products. Published studies have shown that the use of blood can be minimized in many clinical situations without harming the patient. There are often wide variations in transfusion practices (such as in elective surgical treatment), suggesting that blood use could be decreased without detriment to patient care. Evaluation of patients who refused transfusion on religious grounds has demonstrated that even those requiring major surgery can often be managed safely without transfusion.

Blood transfusions are used frequently in many developing country settings, with primary indications varying considerably by geographic area. In many areas of Asia and Latin America—particularly in referral hospitals—surgical patients are the leading users of blood. In sub-Saharan Africa, transfusion is often used in the treatment of severe chronic anemia—primarily the malaria-associated anemia prevalent among young children—and frequent complications of pregnancy, nutritional deficiencies and narrow child-spacing among women of reproductive age. Studies in the Democratic Republic of Congo, Kenya, Tanzania, and Côte d’Ivoire have reported that 17 percent to 26 percent of hospitalized children were transfused.^{17, 18, 19, 20} Despite the high incidence of severe anemia, many studies have demonstrated that blood use could be substantially reduced, thus decreasing the risk of transfusion-transmitted diseases and improving availability of blood to those in need.

Transfusion guidelines

Many countries have developed and implemented national or local transfusion guidelines. These guidelines define a standard of patient care, increase awareness of blood safety issues among health care providers and help contain costs.³ Transfusion guidelines can be developed through literature review and consensus of expert committees. Involvement of clinicians from the major disciplines, administrators and policy makers will help broaden acceptance and implementation of the guidelines. Various studies have demonstrated that adherence to such guidelines could reduce transfusions by as much as 13 percent to 39 percent.^{21, 22, 23}

But guidelines alone are not usually enough to modify clinical practice. One study in Tanzania demonstrated that compliance with transfusion guidelines required repeated clinic meetings and supervision by medical staff.²⁴ Many hospitals use transfusion boards or committees to oversee education, training and monitoring of clinical practices.

Patient assessment

Many clinical reports and national guidelines emphasize the importance of both hematologic and clinical criteria for transfusion; this is supported by clinical experience and various research studies.

One prospective study among Kenyan children found that they had improved survival if they had both hemoglobin below 5.0 g/dl and clinical evidence of cardio-respiratory distress. In this area of Kenya, the blood bank relied on family blood donations; more than 40 percent of transfusions were delayed two or more days while waiting for blood donors or testing. Children who received these late transfusions had the same probability of survival as those who survived at least two days, but were not transfused.¹⁷

These studies emphasize the importance of both clinical and laboratory assessment of patients, as well as the importance of decreasing reliance on replacement blood donations. To achieve this, adequate laboratory support must be provided for monitoring hemoglobin or hematocrit. Hematologic assessment must be available to patients before transfusion and those presenting for well-child care or antenatal care to prevent development of severe anemia. Management issues arise if equipment is available, but the laboratory is not adequately staffed or is closed at night or during weekends. Laboratory testing is needed for accurate assessment of anemia, as clinical assessment by evaluation of pallor of the conjunctiva, oral mucosa and palmar creases does not accurately measure the severity of anemia.

APPROPRIATE USE OF BLOOD COMPONENTS AND BLOOD SUBSTITUTES

Decisions related to the provision of whole blood, blood components or plasma derivatives must take into account cost, safety and efficacy. Moving from providing whole blood to providing blood components greatly increases the complexity and cost of a transfusion service. Plasma derivatives raise both cost and the potential for new risk, due to the large pools of donor plasma in these products.

Caution must be exercised where development of expensive methods to produce blood components and plasma derivatives may detract from efforts to implement more simple, affordable and technically appropriate interventions. Investment in the blood supply system may need to reflect a balance between the clinical needs of the population, the professional demands of the medical profession for specialized products and the wider health priorities of the country. Steps must be taken to ensure that the blood products are safe, available and used efficaciously. They should be prescribed appropriately—and only when they are likely to offer a major benefit to the patient.

Alternatives to transfusion

It must be remembered that patients can often be successfully managed without the use of blood. In acute blood loss, replacement of fluids with crystalloid (saline) or colloid solutions is the first line of treatment—and can be life-saving without the use of blood. In these situations, patients may need volume, not more red cells, to increase cardiac output, perfusion and tissue oxygenation. Transfusion of blood or blood components could often be prevented if saline or other alternative fluids were available and affordable, and if clinicians were educated in their use.

Preoperative hemodilution (when blood is collected from the surgical patient preoperatively and replaced with crystalloid) serves to expand and dilute

the patient's blood volume, thus decreasing the absolute amount of red cell loss if hemorrhage occurs. Other interventions that can help minimize transfusion include:

- Drugs that reduce bleeding in some types of major surgery.
- Iron preparations and erythropoietin, both of which can assist in rapid correction of anemia. Due to its cost, erythropoietin use should generally be restricted to carefully defined situations in which it offers substantial benefits.
- Equipment for the salvage of operative blood losses. Simple (but potentially unsafe) methods of salvaging patients' blood, for example during surgery for ectopic pregnancy, are used in some developing-country situations and may be life-saving.
- Sophisticated devices for blood salvage. Although used in industrialized countries, they are unsuitable in many settings. There is an urgent need for development and evaluation of appropriate technological solutions to provide safe and affordable blood-salvage systems for use in resource-poor settings.

Whole blood or red cells

Whole blood or red blood cells are the most commonly transfused blood components. The indication for whole blood or red cell transfusion is to correct a loss of red cells when the oxygen supply to the tissues falls below a critical level. As indicated above, replacement of blood volume should be achieved through the use of safer, cheaper fluids such as saline.

Plasma

Plasma tends to be the most misused of all blood components. Although there are many widely taught and practiced uses for plasma, there are actually very few clinically proven indications. The risk of transmitting viral infection to the recipient by plasma transfusion is similar to that of whole blood. Plasma should be used for the replacement of clotting factors, and not for volume expansion. In some areas, however, plasma may be the most readily available intravenous fluid and is therefore used for management of hypovolemia. In these settings, many patients are needlessly

MANAGEMENT OF BLOOD TRANSFUSION SERVICES

exposed to HIV, hepatitis and other infections as a result of clinically inappropriate use of plasma. Ensuring the availability of alternative intravenous fluids such as saline—priced to encourage their use and discourage the use of plasma—is one essential condition for reducing the unsafe use of plasma. Plasma availability can be limited by concentrating on the production of whole blood units rather than component therapy. Large-scale plasma collection is rational only if the transfusion system commits to supplying plasma of an appropriate quality as the source material for manufacture of licensed derivatives.

Platelets

Platelet preparations are needed primarily for patients with bone-marrow failure resulting from chemotherapy for malignant disorders. Modern leukemia management depends on substantial availability of platelets. Platelets can be produced by several methods; all are costly and require skilled staff and good quality control. Determining how platelets are to be produced requires a thorough analysis of costs and other demands on the blood service. Therefore, decisions on platelet production must be related to availability of other clinical resources required for effective treatment of malignant disorders and competing health priorities. It may be appropriate to concentrate production of platelets in regional blood centers that support large, specialist cancer and leukemia units.

PREVENTION OF SEVERE ANEMIA

The most effective and inexpensive way to reduce anemia-associated mortality and exposure to the risks of blood transfusion is to prevent severe anemia. Although transfusions save lives, they are given to patients late in the course of their illness, when risk of anemia-associated mortality is already too great. In resource-poor areas, increased attention to nutritional deficiencies, hookworm and malaria prevention and treatment could greatly lessen both transfusions and anemia-related mortality. Strengthened ties between clinical services, national BTSs and the primary health care system are needed to successfully reduce the need for transfusion.

Ultimately, the safety and availability of the blood supply relies on strong quality management to ensure an adequate and reliable supply of resources. Program planning and management of blood banks must anticipate the clinical demand for blood and the financial, human and technical resources needed to adequately meet supply needs. WHO has developed a program plan and training resource materials that are available to any government that wishes to develop an effective, safe and sustainable blood program.

Blood transfusion services can be an expensive component of the health care system. Each unit of blood costs an estimated US\$35 to US\$50 to collect, screen and store in a typical developing country. If other blood products are prepared or purchased, much higher costs are incurred. These costs must be anticipated and funding secured. Establishment of a blood transfusion service helps protect funds allocated to blood bank activities.

PROCUREMENT, EFFECTIVE PURCHASING, QUALITY ASSURANCE AND FORWARD PLANNING

Strong business management of the blood transfusion service is critical to its success. Various strategies can greatly reduce costs. Central procurement of supplies and equipment has many advantages. These include improved quality of purchased goods and greater oversight and quality assurance of supplies. Bulk purchasing invariably lowers costs: Multinational companies have complex pricing policies; experienced and well-trained managers who are knowledgeable about these practices can negotiate prices and significantly reduce costs.

When small purchases must be made at the periphery or individual centers, prices are higher; suppliers may not be legitimate and quality is difficult to ensure. But if centralized procurement and forward planning are weak, shortages may occur and individual blood collection centers must use these less efficient and more expensive procurement mechanisms.

To ensure a safe blood supply, managers must anticipate demand and prevent shortages of personnel, equipment and supplies. This requires a good assessment of clinical need based on caseload, relevant practice guidelines and seasonal variation in blood requirements. Strong accountability must be built in, centrally and peripherally. Frequent and reliable means of communication with the peripheral centers are necessary to anticipate their needs and prevent shortages.

Blood services, like many other parts of the health system, rely heavily on imported supplies. Consumable products (such as blood collection packs and virus screening test kits) constitute a large share of recurring costs. Devaluation of local currency can significantly jeopardize a program's ability to purchase needed supplies throughout the course of a year with a fixed annual budget. But currency devaluation is often difficult to anticipate. To reduce reliance on imported products and dependence on foreign currency, many countries have moved to local production of blood collection bags, test kits and saline. Local production, or importation of locally produced products from other low- or medium-income countries, requires important quality control measures and regulatory oversight. Pricing policies can also help improve the clinical use of blood. If saline and other blood alternatives are made widely available—and priced less than plasma, exposure to the risks of blood and overall operating costs can be reduced.

A clear and publicly supported delineation of health priorities will help guide planning and expenditures. General health-sector priorities, high-ranking

physicians and the interests of private industry are not always compatible. Physicians may want state-of-the-art treatments of relatively rare disorders that could drain precious resources from the more basic overall needs of the country. Industry may promote expensive technologies that are not technically relevant to the local setting. A well-organized service will take into account these competing interests and work from a clearly prioritized plan.

TRAINING AND RETAINING EFFECTIVE STAFF

Where the blood system is a public service—in both industrialized and developing countries—low pay levels frequently lead to serious problems in recruiting and retaining high quality professional staff. Both clinicians and technologists may leave after costly training or be forced to supplement their income through another job, either private practice or commercial employment. It may be necessary to accept a continued high training overhead and incentives to help retain those who are already trained and experienced.

LESSONS LEARNED AND RECOMMENDATIONS

Clinical use of blood

- National policy and guidelines on the clinical use of blood.
- Training of clinicians and BTS staff.
- Prevention, early diagnosis and treatment.
- Alternatives to transfusion (crystalloids and colloids).
- Effective clinical use of blood.
- Monitoring and evaluation.

Blood donors

- National blood donor program officer.
- Blood donor unit.
- Blood donor recruitment officer.
- Standard operating procedures.
- Training of staff in blood-donor unit.
- Low-risk donor populations.
- Educational materials.
- Register of voluntary non-remunerated blood donors.
- Donor selection, deferral, care and confidentiality.
- Donor notification and referral.
- Monitoring of transfusion-transmitted infections (TTIs).

Blood screening

- Technical officer.
- Screening strategies and protocols.
- Training of laboratory technical staff.
- Screening of all donated blood for TTIs.
- Good laboratory practice, including standard operating procedures.
- Continuity in screening.
- Effective blood cold chain.

Reduce unnecessary transfusions by effective clinical use of blood

- Effective clinical use of blood and blood products.
- Appropriate use of simple alternatives to transfusion.
- Important activities include:
 - Developing a national policy and guidelines on the clinical use of blood.
 - Training for all clinicians in the clinical use of blood.
 - Prevention, early diagnosis and treatment of conditions that could result in the need for transfusion.
 - Availability of intravenous replacement fluids (crystalloids and colloids) for the correction of hypovolaemia, and pharmaceuticals and devices to minimize the need for blood.
 - Effective clinical use of blood and blood products in accordance with national guidelines.
 - Monitoring and evaluation of the clinical use of blood.

Educate, motivate, recruit and retain low-risk blood donors

- High priority should be given to the elimination of family/replacement and paid blood donor systems.
- Voluntary non-remunerated blood donors from low-risk populations.
- Important activities include:
 - Appointment of an officer responsible for the national donor program.
 - Establishment of a BTS unit responsible for donor education, motivation, recruitment and retention.
 - Appointment of a designated blood donor recruitment officer.
 - Preparation of SOPs in accordance with BTS guidelines.
 - Training of staff in the blood donor unit.
 - Identification of donor populations at low risk of TTIs.
 - Development of educational materials.
 - Establishment of a register of voluntary non-remunerated blood donors.
 - Assurance of safe blood collection procedures, including donor selection and deferral, donor care and confidentiality.
 - Donor notification and referral for counseling.
 - Monitoring of TTIs in the donor population.

Screen all donated blood for infectious agents

- Develop and maintain a national strategy for the screening of donated blood and blood products.
- Use of appropriate and effective tests.
- Good laboratory practice in:
 - Blood grouping.
 - Compatibility testing.
 - Component preparation.
 - Storage.
 - Transportation.
- Important activities include:
 - Appointment of a designated technical officer.
 - Development of protocols for the testing, selection and evaluation of appropriate screening assays to be used at each site.
 - Training of BTS laboratory technical staff.
 - Screening of all donated blood for TTIs, including HIV, hepatitis viruses, syphilis and other infectious agents, such as Chagas disease.
 - Good laboratory practice, including preparation of SOPs in accordance with BTS guidelines.
 - Procurement, supply, central storage and distribution of reagents and materials to ensure continuity in screening at all sites.
 - Maintenance of an effective blood cold-chain for the storage and transportation of blood and blood.

FUTURE CHALLENGES

In developed countries, transfusion technology continues to evolve under pressure for more testing, more complex processing of blood components and increasingly strict regulation of plasma fractionation. This trend leads to steeply escalating costs—often yielding only marginal gains in safety or efficacy.

The same forces stimulate efforts to develop technologies that may substitute for blood products or reduce the need for them. Such technologies are:

- Autologous transfusion (pre-deposit donation, blood salvage)
- Antifibrinolytic drugs
- Erythropoietin
- Other growth factors (such as thrombopoietin, Granulocyte macrophage colony stimulating factor)
- Hemoglobin solutions as alternative oxygen carriers;
- Fluorocarbon solutions
- Coagulation factors produced by recombinant DNA technology

The rising cost of transfusion support makes it important—in any national health plan—to weigh investment against other health priorities, and to concentrate on meeting the most critical clinical needs with the simplest product that is effective.

New concerns about the possibility of transmissible encephalopathies (BSE, CJD, variant CJD) have led some countries to make radical changes in the use of donor blood or selection of donors. But it is still unknown if such agents can be transmitted by transfusion in humans.

CONCLUSIONS

A screening test to detect HIV-infected blood donations has been available since 1985, and has proven to be among the most cost-effective strategies to prevent HIV transmission.²⁵ But providing a safe blood supply remains a public health challenge in many countries. Blood banking and testing, donor selection, personnel training, effective management, anemia prevention and improvement in the appropriate use of blood and blood alternatives are interrelated, and will require comprehensive programs to be successful. Securing national commitment and resources dedicated to blood safety is the most formidable task—but it is vital to the safety of the nation's blood supply. That being said, major gains in blood safety and availability can be achieved at any level of the health care system. Following the suggestions listed above—at the local, regional or national level—can yield an affordable and effective method of HIV prevention.

CASE STUDIES

ENSURING SAFE BLOOD AND THE SAFE USE OF BLOOD

It is complicated and expensive to secure an adequate supply of blood from low-risk donors that is appropriately screened for infectious diseases in a controlled environment, safely stored and distributed for appropriate clinical use. Nonetheless, many countries, often with limited resources, have made great headway toward this end. These case studies will serve to explore the factors that may have contributed to these countries' successful endeavors.

ESTABLISHING A NATIONAL BLOOD TRANSFUSION SERVICE

A strong government commitment appears necessary for a safe and adequate blood supply. (Zimbabwe offers a good example of this. It established a blood transfusion service as a separate organizational unit.) Securing national commitment and developing a well-organized blood transfusion service provides the oversight and authority, budget and staff required to develop and implement a complicated and technically sophisticated health service. But obtaining national commitment is difficult to achieve. Success in this area seems to be linked to the ability to bring together all the stakeholders, from both public and private sectors, and move together in a concerted effort to effect the necessary political will.

Development of national policy and guidelines has helped many countries demonstrate a cohesive approach to blood safety and galvanize public support for transfusion services. Guidelines define a standard of patient care, increase the awareness of health care providers and contain budget requirements for transfusion services.³

BLOOD SCREENING

Screening for infectious agents is the cornerstone of programs to reduce transfusion transmission of HIV. Evaluations conducted in multiple countries have demonstrated that providing test kits to all sites that transfuse blood is just one of many important steps. Training, supervision, management and selection of test kits appropriate to the needs of each particular setting are all key elements in attaining a safe blood supply.

How does a country determine its needs and address them appropriately? One example is a rapid assessment conducted in Kenya, which has a decentralized system with blood collection and screening performed at individual hospitals. Specimens and test results were collected from blood screened at six hospitals; specimens were then retested at a reference laboratory. This relatively simple, focused assessment uncovered great—but correctable—problems with the screening system. For example, record keeping was performed in a non-standardized manner; rates of recording errors were high and results of testing sometimes could not be found. Labeling, storage and destruction of infected units were not performed according to standardized methods. One hospital did not perform HIV screening of donations from mothers to their children, under the erroneous assumption that both would have the same HIV serostatus. Breaks in the cold chain were often observed during the transport of test kits. Lack of supervision, oversight, accountability and regulatory authority allowed for substandard laboratory practices. For one month of the assessment, no test kits were available in the country; the assessment team had to provide them. Enzyme immunosorbent assays (EIAs) were often used in hospitals that had low levels of technical expertise and low volume of testing, adding to increased error rates and delays in transfusion. Taken together, this assessment found that one-third of HIV-positive donations were not removed from the blood supply by routine hospital screening.

Based on these results, the Kenyan Ministry of Health identified donor support for the purchase and distribution of rapid HIV test kits and developed a national training program to improve laboratory practices. Recently, additional funds have been earmarked for training and development of a standardized quality assurance program. In these ways, the assessment identified key areas that needed improvement and mobilized the resources and political commitment needed to address them.

EDUCATION, RECRUITMENT AND RETENTION OF SAFE BLOOD DONORS

Simple record reviews and evaluation of HIV sentinel surveillance data have demonstrated to a number of countries (including Kenya, Botswana, Uganda, Tanzania and Zimbabwe) that blood collected for directed or replacement donation by patients' families are at very high risk of HIV. In certain areas of Kenya, hospitals that relied primarily on blood collected from patients' friends and families discarded up to 20 percent of their blood supply because of reactive HIV serological test results. This is not only expensive and wasteful, it also increases the chance of an adverse outcome in the event of a laboratory error or an unscreened transfusion. Other Kenyan studies conducted with international research collaborators demonstrated that blood collected from family donors does not provide blood to patients when it is needed to improve survival. The researchers determined that an adequate safe supply required collection from low-risk donors, with infectious disease testing conducted in an unhurried and standardized manner. Only then could blood be available for immediate transfusion when needed to improve survival.

The elimination of paid donors in many areas, such as Thailand and parts of India, has reduced HIV seroprevalence in the donor pool. Zimbabwe and Uganda have put considerable resources into the education and recruitment of volunteer donors, primarily targeting younger donors with lower HIV seroprevalence. In these high-prevalence countries, HIV seroprevalence among blood donors has been brought down to below three percent. These achievements,

however, are only possible with substantial investment in donor education and recruitment. This is a specialized field, and often is not done well when left to technical staff, such as blood-bank technicians. In countries that have addressed donor recruitment effectively, media campaigns are conducted through radio, newspaper and public service announcements. Donor educators visit mobile collection sites before a blood campaign to improve understanding of and enthusiasm for donation. Cultural mores, taboos and fears related to blood loss and HIV testing are often addressed during these sessions.

Effective donor mobilization programs in Uganda and Zimbabwe have required dedicated funds, staff and managerial attention. Uganda's successful program has received substantial support from European partners. Efforts have been made to increase cost recovery, including provision of laboratory testing for voluntary HIV-counseling and testing sites. Increased national commitment may also decrease reliance on foreign donor support. Finally, operational research conducted in conjunction with policy and program development has helped identify safer donor populations in countries such as Côte d'Ivoire, Kenya and Tanzania.

IMPROVING THE APPROPRIATE USE OF BLOOD

Reducing the high rate of transfusion has been emphasized as a practical and cost-effective method for reducing transfusion-associated HIV transmission. A large number of countries have put together expert committees and, through literature review and consensus development, established national transfusion

guidelines. Studies in the Democratic Republic of Congo, Ghana and Tanzania have all demonstrated that adherence to these transfusion guidelines would reduce the number of transfusions by 13 percent to 39 percent.^{22, 23, 26, 27} In most countries in sub-Saharan Africa, prevention of unnecessary transfusions seems particularly important among children, who receive 50 percent to 67 percent of transfusions, and among women of childbearing age, who receive 8 percent to 27 percent of transfusions. In Tanzania, more than 75 percent of avoidable transfusions are among children under five years of age.

Tanzania found that clinical guideline development alone did not change clinical practices. The country therefore developed an effective program that relied on repeated clinic meetings and supervision by medical staff.²⁴

Many countries have included only hematologic criteria for transfusion guidelines. Prospective studies support guidelines that emphasize both hematologic and clinical criteria, particularly for transfusion of children with chronic anemia due to malaria and nutritional deficiencies. For example, research in Kenya demonstrated that transfusion was associated with increased survival of pediatric patients when given to children with hemoglobin below 5.0 g/dl who also had clinical evidence of cardio-respiratory compromise, and who were transfused within the first two days of admission. Those who did not have these clinical criteria, or who were transfused late due to blood shortages, showed no survival benefit. Similar results were found in a pilot study conducted in Tanzania.^{17, 19}

Despite the importance of clinical and laboratory assessment, many hospitals, even in major cities, do not always measure hemoglobin or hematocrit before transfusion. In Mama Yemo Hospital, a large hospital in the capital city of the Democratic Republic of the Congo, 24 percent of transfusion recipients did not have hemoglobin measured first.²⁸ Similarly, in the capital city of Côte d'Ivoire, half the transfusion recipients did not have hemoglobin or hematocrit

measured before transfusion, often because the laboratory was closed during nights and weekends. Simple interventions, such as improving the availability of inexpensive and technically simple methods to measure hemoglobin, have had important effects on improving the appropriate use of blood and compliance with national transfusion guidelines.

PREVENTION OF SEVERE ANEMIA

The most effective and inexpensive way to reduce anemia-associated mortality and exposure to the risks of blood transfusion is to prevent severe anemia. Although the procedure can save lives, Kenyan studies have demonstrated that transfusion is given to patients late in the course of their disease, when their risk of anemia-associated mortality is already too great.

Increased attention to nutrition, sanitation, the use of bed nets and early and effective treatment of malarial illness in endemic areas has a great impact on the use of blood and anemia-related mortality. In Vietnam, programs that led to widespread use of bed nets have resulted in a dramatic reduction of blood transfusions for the treatment of malaria-associated anemia. Early detection of anemia and use of effective antimalarials in chloroquine-resistant areas can also improve hematologic recovery. Strengthening ties between transfusion services and the primary health care systems is often overlooked as an important strategy to prevent the frequent need for transfusion.

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C H A P T E R

21

*Transmission
of HIV in
Health Care
Settings*

DENISE CARDO
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Transmission of HIV in Health Care Settings

INTRODUCTION

Transmission of HIV infection in health care settings is not a major mode of transmission, and contributes little to the spread of HIV in the general population. As a result, prevention of infection here will have a very limited impact on HIV spread in the general population. This is one reason for the low priority accorded health care settings in resource-constrained settings. But prevention of such transmission should be considered part of good quality health care; the subject deserves more attention than it has received so far.

This chapter examines the risks and prevention of HIV transmission in health care settings, except through blood transfusion. Similar to other blood-borne pathogens, HIV is more likely to be transmitted from patients to health care workers (HCWs) than from HCWs to patients. The effects of HCWs' anxiety on attitudes towards HIV-infected patients have been documented in several studies. Measures to prevent occupational HIV infection will not only prevent morbidity and mortality in a small number of HCWs, but can also improve patient care.

THE MAGNITUDE OF THE PROBLEM

OCCUPATIONAL INFECTIONS

Although HIV transmission from patient to HCW is infrequent in industrialized countries, the situation is different in countries with limited resources. While there are no direct measures of the magnitude of the problem there, the few estimates available give reason for concern. The prevalence of infection in the patient population, the nature and frequency of blood exposure and the likelihood of acquiring infection after a single blood exposure from an infected patient will determine the risk of occupational transmission of HIV.

OTHER HEALTH CARE-ASSOCIATED INFECTIONS

HIV transmission from patient to patient has been reported in hospitals, nursing homes and outpatient health care settings in the United States and other countries. Most transmissions have been associated with improper infection control practices. Since the onset of the AIDS epidemic, only two episodes of HIV transmission from an infected HCW to patients have been reported.

Procedures in the informal health sector that may be associated with transmission of HIV infection include: injections by drug peddlers and quacks, scarifications by traditional healers, circumcision of boys or men and female genital mutilation (FGM).

PREVENTION OF HIV INFECTION IN HEALTH CARE SETTINGS: EXPERIENCE FROM INDUSTRIALIZED COUNTRIES

Prevention of transmission of HIV in health care settings requires two levels of action:

- Prevention of blood exposures. Studies in the United States have shown that implementation of “Universal Precautions,” as recommended by the Centers for Disease Control (CDC) in 1987 and later replaced by “Standard Precautions,” has reduced the frequency of blood exposures among HCWs. This infection control strategy treats all blood as infectious, and uses various work practices and barrier materials appropriate to the patient interaction to avoid blood exposure.
- Postexposure prophylaxis. Based on current information about primary HIV infection, the use of antiretroviral agents for postexposure prophylaxis (PEP) is biologically plausible. The US Public Health Service recommends PEP after some occupational exposures to HIV, based on indirect evidence from animal and human studies.

PREVENTION OF HEALTH CARE-ASSOCIATED HIV INFECTIONS: EXPERIENCE FROM COUNTRIES WITH LIMITED RESOURCES

In countries with limited resources, preventing transmission of HIV infection in health care settings is generally not a high priority: often, basic measures to protect HCWs and patients are not taken. But standard precautions can reduce the incidence of blood exposures even in resource-constrained settings—and should be taken.

LESSONS LEARNED

The few data available suggest that the risk of occupational HIV infection in many resource-constrained settings is far from negligible. Health care workers must be involved in the planning of realistic interventions, and must receive continual training and supervision.

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I N T R O D U C T I O N

Transmission of HIV in health care settings occurs from patient to patient, from patient to health care worker (HCW) and from HCW to patient. Before blood screening for HIV, transmission of HIV to patients in health care settings was mainly associated with blood transfusion. This is now an extremely rare occurrence in industrialized countries—but in some resource-constrained settings, the risk for patients receiving a transfusion with HIV-infected blood may still be considerable.

Even so, these infections account for only a small proportion of the national toll. A study in Tanzania, for example, estimated that less than 0.4 percent of the total annual incidence of HIV infection was attributed to medical infections.¹ Prevention of transmission in health care settings will have a very limited impact on the rate of HIV spread in the general population. But there are other good reasons for allocating resources to prevention of patient-to-patient transmission and occupational infections. Avoidance of transmission from one patient to another is an integral part of quality curative care.

Ensuring the safety of health staff is also the responsibility of health services managers. The effect of HCWs' anxiety on attitudes towards HIV-infected patients has been documented in several studies. Measures to reduce occupational infection will not only prevent morbidity and mortality in a small number of HCWs, but will also improve patient care.

This chapter examines the risks and prevention of HIV transmission in health care settings, other than through blood transfusion. (Ensuring the safety of blood and blood products is addressed in Chapter 20.) Similar to other blood-borne pathogens, HIV is more likely to be transmitted from patients to HCWs than from HCWs to patients. Transmission between HCWs and patients most often is the result of a percutaneous injury (PI) to a HCW, whereas the majority of patient-to-patient transmissions have involved breaches in recommended infection control practices.

THE MAGNITUDE OF THE PROBLEM

OCCUPATIONAL INFECTIONS

Determinants of the risk of HIV transmission after occupational exposure

Prevalence of infection in the patient population, the nature and frequency of blood exposure and the likelihood of acquiring infection after a single blood exposure from an infected patient determine the risk of occupational transmission of HIV.

Prospective studies from several countries have estimated that the risk after occupational percutaneous exposure to HIV-infected blood is approximately 0.32 percent (95 percent confidence interval [CI]= 0.18 percent-0.46 percent),²⁻⁴ and after a mucous membrane exposure, 0.09 percent.⁵ The risk of transmission after skin exposure has not been precisely quantified, but is believed to be even smaller: No cases of HIV transmission after exposure to intact skin have been documented.⁶ The risk after exposure to fluids or tissues other than HIV-infected blood is also unknown.

Epidemiologic and laboratory studies suggest that a variety of factors may affect risk following an occupational exposure. A laboratory study demonstrated that less blood is transferred across membranes by a needle that passes through gloves, is of smaller gauge or is solid rather than hollow bore.⁷ A retrospective case-control study of HCWs who have had percutaneous exposure to HIV found that risk increased with exposure to a greater quantity of blood from the source patient (as indicated by a device visibly contaminated with the patient's blood), a procedure that involved a needle placed directly in a vein or artery or a deep injury.⁸ The risk was also greater for exposure to blood from patients with terminal illness—possibly reflecting the higher titer of HIV in blood late in the course of AIDS—or other factors, such as the presence of syncytia-inducing strains of HIV.

Occupational infections in industrialized countries

Since transmission of HIV in health care settings is infrequent and involves unusual routes of transmission, most cases in countries with a well-organized surveillance system are detected by studying HIV-infected persons who have no identified risk for infection. Several countries have a surveillance system for occupationally acquired HIV infections.

As of December 1999, CDC had received reports of 56 United States HCWs with documented HIV seroconversion temporally associated with an occupational exposure. CDC has also received reports of 136 HCWs with possible occupationally acquired HIV infections; each of these workers reported the infection was occupationally acquired and no other risk was identified. But transmission of infection after a specific exposure was not documented. Of the 56 documented episodes, 51 involved infected blood; one, visibly bloody body fluid; one, an unspecified fluid; and three, concentrated virus in a laboratory. Forty-nine exposures were percutaneous; five were mucocutaneous; and one was both percutaneous and mucocutaneous; the route of one exposure (to concentrated virus) is uncertain.⁹ The 49 percutaneous exposures involved hollow-bore needles (44), broken glass vials (two), scalpels (two) or an unknown sharp object (one).¹⁰

Table 1
**DOCUMENTED AND POSSIBLE CASES
 OF OCCUPATIONALLY
 ACQUIRED HIV INFECTION¹¹**

	Documented	Possible
United States	56	136
France	11	27
United Kingdom	4	9
Mexico		9
Italy	5	
Australia	4	
Spain	5	
South Africa	3	1
Germany	3	3
Belgium	2	1
Canada	1	2
Holland		2
Switzerland	2	
Denmark		1
Israel		1
Argentina	1	
Zambia	1	

Another 42 documented cases and 56 possible cases of occupationally acquired HIV infection were reported from other countries, including a few resource-constrained settings, as of September 1997 (Table 1). Forty of these 42 occurred after a percutaneous injury (PI); two after massive mucous membrane exposures.¹¹

Since HCWs do not usually report occupational exposures, these numbers are certainly low—only 10 percent to 60 percent of percutaneous exposures are probably reported in the United States.¹²

Occupational infections in countries with limited resources

There are no extensive data on HCWs infected through occupational exposure in countries with limited resources (Table 1), but some studies have attempted to estimate the incidence of these infections.

A study in nine hospitals in Mwanza Region, Tanzania, found an average of five PIs per HCW per year.¹³ Estimating a 20 percent HIV prevalence among patients and a transmission probability of 0.25 percent, the incidence of HIV infection through occupational exposure would be 0.27 percent per year. When this study was conducted, the incidence of HIV infection in the general adult population was 0.95 percent in the rural areas and 1.2 percent in Mwanza town. Compared to these latter incidence rates, the incidence of occupationally acquired HIV infection among HCWs was far from negligible. A study in a Zambian hospital determined the risk to surgeons was 1.5 percent over five years. Yet surgeons at Katete Hospital had a parenteral exposure incidence of 0.7 percent per procedure—substantially lower than that found in industrialized countries (1.7 percent-5.6 percent).¹⁴ Table 2 summarizes two studies, one from Tanzania, the other from the United States, which used a similar methodology to estimate the annual risk of occupationally acquired HIV infection.^{14,15}

Although there are no direct measures of the magnitude of the problem in countries with limited resources, the few estimates available (such as those cited above) give reason for concern. HIV prevalence in many countries with limited resources is far greater than in industrialized countries. Rates among hospitalized patients of more than 20 percent are not at all exceptional. In addition to the study in Tanzania, research conducted in other countries (including Taiwan and Brazil) also shows a disturbingly high incidence of PIs, often due to insufficient staff training and equipment, such as inadequate containers for waste disposal.^{13,16}

As in the United States, most exposures to blood are not reported in these countries. A survey of 10,469 HCWs in 16 teaching hospitals in Taiwan found only 18 percent of sharp object injuries were reported.¹³

Table 2

	Tanzania	United States
Setting	9 hospitals in Mwanza Region	6 hospital emergency departments
Estimated HIV prevalence in patient population	20%	high: 4.1% – 8.9% low: 0.2% – 0.7%
Incidence of percutaneous injury per person per year	5	0.37
Annual risk of occupational HIV infection	0.27%	high: 0.026% low: 0.002%

OTHER HEALTH CARE-ASSOCIATED INFECTIONS

Patient-to-patient transmission

HIV transmission from patient to patient has been reported in hospitals, nursing homes and outpatient health care settings in the United States and other countries. These are usually associated with improper infection control practices.

The most dramatic reports have come from Eastern Europe. In the 1980s, between 8,000 and 10,000 Romanian children were infected with HIV through transfusion of unscreened blood or the use of contaminated hypodermic needles.¹⁷ Similar needles were also associated with the transmission of HIV to 41 hospitalized children in the Soviet Union.¹⁸ Three patients (two in the United States and one in the Netherlands) acquired HIV infection after being inadvertently injected with blood from an infected patient during nuclear medicine procedures.¹⁹

Hemodialysis centers have been implicated in several reported transmission incidents. Nine patients became infected in a dialysis center in Colombia between January 1992 and December 1993. Dialysers were reprocessed separately with five percent formaldehyde and labeled for use on the same patient. Access needles, however, were reprocessed by soaking in a common container with a low-level disinfectant,

with the potential for cross-contamination or use on another patient. Improperly reprocessed patient-care equipment (most probably the access needles) was the likely mechanism of transmission.²⁰ This outbreak was only discovered by accident; similar situations could have occurred elsewhere. Transmission during hemodialysis has been reported in at least three instances in Argentina with 11 to 30 infected patients in each episode; most of the episodes were not investigated.^{21,22} Lack of infection control measures during hemodialysis also caused HIV transmission in Egypt.²³

The only report of HIV transmission from patient to patient during a surgical procedure came from Australia, where five patients whose minor outpatient procedures were performed on the same day by an HIV-negative surgeon. These patients were subsequently found to be HIV-positive.²⁴ Four had no identifiable source of infection; the fifth patient had known risk factors for HIV, was subsequently found to be HIV-positive and is the probable source of infection. Although the mechanism of transmission was not identified, contamination of multidose medication vials was considered a possible vehicle for transmission in this outbreak.

In most cases, these transmissions could have been avoided through adherence to standard infection control practices, including aseptic technique, cleaning and disinfecting or sterilizing equipment between patients, safe injection practices and appropriate handling of single-use or single-patient-use devices and equipment.

HCW-to-patient transmission

Since the onset of the AIDS epidemic, only two episodes of HIV transmission from an infected HCW to patients have been reported, one in the United States (1990) and the other in France (1997).^{25, 26} The United States case involved six patients whose infections were linked epidemiologically and genetically to a dentist with AIDS.²⁵ Although the investigation indicated that HIV transmission occurred during office visits for dental care—and was most likely from dentist to patient rather than from patient to patient—the precise event resulting in transmission could not be determined.

The French incident involved an orthopedic surgeon whose HIV transmission to one patient was confirmed through genotypic analysis. Although the precise mechanism of transmission is unknown, the duration of the procedure (10 hours), procedure-related opportunities for PI to the HCW and possible high viral titer in the surgeon are hypothesized as contributing factors. No breaches in infection control were identified.²⁶

Retrospective investigations to assess the risk for HCW-to-patient transmission did not detect any transmission among 22,759 patients treated by 53 infected HCWs. Despite the limitations of retrospective studies, these data are consistent with other studies that show the risk from infected HCWs to patients is exceedingly low.²⁷

Transmission of HIV infection in the informal health sector

Procedures in the informal health sector that may be associated with transmission of HIV infection include:

- Injections by drug peddlers and quacks
- Scarifications by traditional healers
- Circumcision of boys or men
- Female genital mutilation (FGM)

A history of scarifications has been linked to increased risk in some studies, but not in others.^{28, 29} There are no hard data on the transmission risk of circumcision and FGM.

Nor has any increased risk due to occupational exposure been documented in traditional birth attendants (TBAs) in studies in Rwanda, Zambia and Uganda.^{30, 31} TBAs usually do not give injections and the risk of percutaneous injury should be minimal, but they do have frequent skin-blood contacts.

PREVENTION OF HIV INFECTION IN HEALTH CARE SETTINGS: EXPERIENCE FROM INDUSTRIALIZED COUNTRIES

Prevention of transmission of HIV in health care settings requires two levels of action:

- The first level (primary prevention) involves reducing PIs and other exposures to blood using a variety of strategies, including development of improved engineering controls (such as safer medical devices), work practices (such as technique changes to reduce handling of sharps) and personal protective equipment (such as gloves).
- The second level consists of prophylaxis of infection after an exposure, including treatment with one or more antiviral drugs.

PREVENTION OF BLOOD EXPOSURES

Studies in the United States have shown that implementation of the CDC's "Universal Precautions" and more recent "Standard Precautions" has reduced the frequency of blood exposures among HCWs.³²⁻³⁴ These precautions treat all blood as infectious, and employ various work practices (like not recapping needles) and barrier materials (gloves, gowns, face protection, etc.) appropriate to the patient interaction to avoid blood exposure.

Although several studies have reported fewer PIs when needles are not recapped and sharps disposal boxes are installed, a reduction in overall injury rates

has not been consistently observed.^{35,36} Injuries associated with disposal of the sharp are still frequent in all countries; location of sharps disposal containers, frequency of container replacement and education must be considered. In the United States, a continuing incidence of PIs despite implementation of these strategies suggests that additional preventive measures are needed—such as the use of devices with safety features. Studies have demonstrated the efficacy of some safety devices; however, they should not constitute the only prevention option.¹² Prevention of PIs among HCWs will also prevent transmission of HIV from infected HCWs to patients.

To prevent patient-to-patient transmission of HIV, the following are recommended:

- Standard infection control practices, including aseptic techniques
- Cleaning and disinfecting or sterilizing equipment between patients
- Safe injection practices
- Appropriate handling of single-use or single-patient-use devices and equipment

POST-EXPOSURE PROPHYLAXIS

Based on current information about primary HIV infection, post-exposure prophylaxis (PEP) with antiviral agents is considered biologically plausible. The US Public Health Service (PHS) recommends PEP after some occupational exposures to HIV, based on indirect evidence of PEP efficacy that includes data from animal and human studies.^{37,38} But assessing the efficacy of PEP through a prospective, placebo-controlled trial may not be possible because of the low rate of conversion. Data on perinatal transmission have shown that the protective effect of zidovudine (ZDV) is only partly explained by reduction of the HIV titer in maternal blood; ZDV may also have a direct protective effect on the fetus and/or the infant after exposure.^{39,40} In a case-control study among HCWs, PEP was associated with a decrease of approximately 81 percent in the risk of HIV seroconversion

Table 3

BASIC AND EXPANDED POST-EXPOSURE PROPHYLAXIS REGIMENS³³

Regimen category	Application	Drug regimen
Basic	Occupational HIV exposures for which there is a recognized transmission risk	Four weeks (28 days) of both zidovudine (ZDV) 600 mg qd in two or three divided doses and lamivudine (3TC) 150 mg BID
Expanded	Occupational HIV exposures where the nature of the exposure suggests an elevated risk for transmission (e.g., meets criteria for highest or increased transmission risk)	Basic regimen plus either indinavir 800 mg q8h (to be taken on an empty stomach and with increased fluid consumption, i.e., 48 oz/day) or nelfinavir 750 mg TID (with meals)

after percutaneous exposure to HIV-infected blood.⁸ Failure of ZDV PEP to prevent HIV infection after an occupational exposure has been reported in at least 21 instances worldwide.^{41,42}

Based on the PHS recommendations, most occupational HIV exposures will warrant only a two-drug regimen, using two nucleoside analogue reverse transcriptase inhibitors, usually ZDV and lamivudine (3TC). The addition of a third drug, usually a protease inhibitor (such as indinavir or nelfinavir), should be considered for exposures that pose an increased risk for transmission or when resistance to the other drugs is unknown or suspected (Table 3).³⁷ Although PEP with the above drugs has not been associated with serious adverse events, in several studies over 70 percent of HCWs experienced side effects such as nausea, headache or fatigue; approximately 50 percent of them stopped taking the drugs because of side effects.^{43,44}

If PEP is prescribed, it should be started as soon as possible (within hours of exposure). Although the optimum duration of PEP is unknown, four weeks appears protective in HCWs, and medication should probably be administered for that length of time. Exposed HCWs who choose to take PEP should be advised of the importance of completing the prescribed regimen. They should know the side effects of the drugs, what can be done to minimize these effects and how they will be clinically monitored for toxicity during the follow-up period.³⁷

Exposed HCWs should receive follow-up counseling, postexposure testing and medical evaluation, regardless of whether they receive PEP. HIV-antibody testing should be performed for at least six months (at six weeks, 12 weeks, and six months after exposure). Psychological prevention counseling of the worker and, in some cases, the worker's family is frequently beneficial.

PREVENTION OF HEALTH CARE-ASSOCIATED HIV INFECTIONS: EXPERIENCE FROM COUNTRIES WITH LIMITED RESOURCES

In countries with limited resources, preventing transmission of HIV in health care settings is generally not a high priority; even basic precautions to protect HCWs and patients may not be taken. There is a consensus for standard precautions; however, there is little documented experience showing how these precautions can best be taken in settings with limited resources and low staff motivation.

A survey conducted in nine hospitals in Mwanza, Tanzania, revealed lack of equipment and personal barrier commodities. The shortage of gloves was widespread and many procedures in labor rooms were conducted without them; reused gloves were the main source of protection in some areas.¹⁵ Only 37 percent of rooms in general wards and 89 percent of labor rooms had containers for sharps disposal.

The survey also revealed that exposures to blood were frequent. Approximately nine percent of 623 nurses and one percent of 118 physicians recalled having a needlestick during the week preceding the interview; 22 percent of nurses working in labor wards and 25 percent of those working in operating rooms had sustained a needlestick in the previous month; 50 percent had sustained a mucous membrane exposure in that period.

To prevent blood exposures, a comprehensive plan should be developed based on surveillance data from the institution (where, how and when exposures occur); measures should focus on the prevention of blood exposures associated with higher risks of transmission. This plan should include modification of procedures and work practices, elimination of unnecessary needles, use of devices with safety features, HCW education and safety promotion in the work environment. Any prevention program should include the implementation of barrier precautions (proper use of gloves, eye protection, etc.) and proper disposal of sharps. Several countries have adapted these recommendations to their circumstances, considering the limited resources available. Involvement of HCWs is fundamental to the success of a prevention plan.

But these personnel must have training and supervision. In a Ribeirao Preto, Brazil health care facility, HCWs were trained not to recap needles and sharps disposal containers were installed. Nevertheless, 64 percent of the needles in these containers were found to be recapped, showing the importance of continuing education to maintain safe work practices.⁴⁵

The Groupe d'Etude sur le Risque d'Exposition des Soignants in France (GERES) is working with a network of hospitals in Mali, Senegal and Côte d'Ivoire to reduce the risk of exposure to blood among HCWs.⁴⁶ The collaborative program will be implemented in several steps:

- Assessment of the risk of exposures to blood, including the incidence of PI and the circumstances in which PI occurs.
- Meetings with several groups (administrative staff, doctors, nurses, laboratory personnel) to discuss findings of the assessment and set priorities for intervention. A risk-reduction strategy will be defined that is adapted to the local needs and resources available.
- Implementation of the strategy, which will always include a training component.
- Setting up a surveillance system for exposures to blood that will allow evaluation of the program.

Despite the lack of financial resources or wide availability of antiretroviral drugs, several countries with limited resources have considered the use of PEP after occupational exposures to HIV. Although such a plan should not be the primary means to prevent occupationally acquired HIV infection, it has increased awareness of the problem and the need for preventive strategies. In countries with a high incidence of PIs and high prevalence of HIV, PEP use may become very difficult because of high costs and toxicity.

PEP should not be accepted as the only strategy for preventing occupationally acquired HIV infections in any institution. A program for postexposure management will fail if preventive strategies for blood exposures are not a priority. In a study conducted in Brazil, the direct costs associated with occupational exposures (such as follow-up testing and PEP drugs) was very high (US\$1,413.10).⁴⁷ These resources could be used to reduce exposures—the best way to prevent occupationally acquired HIV infections.

HCWs with occupational exposure to HIV should receive follow-up counseling, post exposure testing and medical evaluation, regardless of whether they receive PEP; measures to ensure absolute confidentiality must be in place. HIV testing should be available and free for HCWs and source patients. In addition, if an HCW is found to be HIV-infected at baseline, his/her rights (professional and other) should be protected.

Prevention of HIV transmission from patient to patient is a major challenge for countries with limited resources. Little has been done to evaluate approaches to be considered in these settings. Strategies to prevent transmission from patient to patient include:

- Promotion of basic infection control measures, such as cleaning and disinfection or sterilization of equipment.
- Safe injection practices, including avoidance of injectable drugs if alternative drugs are available that can be given per os.
- Appropriate reuse of devices/equipment.
- Appropriate handling of multidose vials.

Reuse of disposable syringes is not cost-effective and should be avoided; they are not manufactured for reuse and sterilizing methods may be inadequate. Reusable syringes and needles should be sterilized or boiled for at least 20 minutes. Chemical disinfection by soaking in high-level disinfectants must not be used for syringes and needles.

Training programs for TBAs include infection control. TBAs are usually taught how to boil their instruments (mainly scissors). Alternatively, the umbilical cord can be cut with a razor blade that is discarded after use. For instance, the Reproductive Health Kit for Emergency Situations provided by UNFPA contains single-edge razor blades to avoid accidental percutaneous injuries in birth attendants. It is also recommended that TBAs use gloves to conduct deliveries. Other traditional practitioners may also be trained in the prevention of HIV transmission in their practice.

Community awareness about the risks of traditional practices can be raised. Researchers of the Tanzania Netherlands Support Program on AIDS, for example, asked villagers in Mwanza Region, Tanzania to draw maps of their villages and indicate the places where HIV transmission was likely to occur. In some cases, the house of the traditional healer was highlighted and a rule was imposed on the traditional healer of one-patient one-razor blade.⁴⁸

More studies, preferably linked to action, must be undertaken to better understand the circumstances and possible preventive measures against HIV infection in health care settings in resource-constrained areas.

SUMMARY

Transmission of HIV infection in health care settings is not a major mode of transmission and contributes little to the spread of HIV in the general population. As a result, prevention of infection here will have limited impact on the rate of spread of HIV in the general population. This is one reason for the low priority accorded it in resource-constrained settings. But prevention here deserves more attention than it has received so far: It is part of good quality health care.

LESSONS LEARNED

- Prevention of HIV in health care settings in resource-constrained countries has so far received too little attention.
- The few data available suggest that the risk of occupational HIV infection in many resource-constrained settings is far from negligible.
- Addressing the problem of occupational risk may boost staff morale and improve the quality of patient care.
- The first priority should be prevention of exposure to infected body fluids.
- Involvement of health care workers in the planning of realistic interventions and continuous training and supervision is vital to the success of any prevention program.

RELEVANT CHAPTER

Chapter 20 *Ensuring the Safety of Blood and Blood Products*

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C H A P T E R

22

*HIV Risk
Reduction in
Injection
Drug Users*

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HIV Risk Reduction in Injection Drug Users

INTRODUCTION

There are an estimated 6 to 10 million injection drug users (IDUs) worldwide, and as many as 3.3 million of them are infected with HIV. Approximately 5 percent to 11 percent of AIDS cases globally are related to injection drug use (IDU). Sharing contaminated equipment and drug preparations are highly efficient means for transmitting HIV.

This chapter describes the methods used for assessing HIV/AIDS epidemics among IDUs, interventions available for preventing such epidemics and evidence for the effectiveness of these programs. It examines the feasibility and application of various projects in resource-constrained settings and their limitations. Finally, it offers guidance for policy makers on selecting priority interventions for communities where IDU is a significant factor in the spread of HIV.

MAGNITUDE OF THE PROBLEM

There have been explosive HIV epidemics among IDUs in a wide range of cities in the past 20 years; in some, HIV prevalence among IDUs has escalated from less than 5 percent to more than 40 percent in a 12-month period. The hepatitis C virus (HCV) has been an IDU infection far longer than has HIV, and where HIV prevalence has reached 40 percent or more, it is proving difficult to bring HCV epidemics under control.

Adolescents comprise an especially vulnerable population. This age group not only has the highest HIV incidence rates, it is also the age when drug use is often initiated.

STRATEGIES FOR HIV PREVENTION AMONG IDUS

There is evidence that effective interventions exist that can prevent HIV transmission at both individual and population levels. This part of the chapter is divided into three sections:

- Assessing for intervention
- Interventions to reduce individual risk behaviors
- Public health interventions to reduce the HIV risk environment

ASSESSING FOR INTERVENTION

The rapid spread of HIV associated with IDU demands assessment methods that are affordable, rapid, will result in immediate action, are easy to use and can monitor further developments. Rapid assessment and response (RAR) methods have been used widely in both developed and developing countries for planning HIV prevention strategies among drug-using populations. Utilization of behavioral surveillance surveys (BSS) also recognizes the importance of monitoring and tracking HIV risk behaviors as well as actual cases and HIV/AIDS spread.

INTERVENTIONS TO REDUCE INDIVIDUAL RISK BEHAVIORS

Different drug-using behaviors pose different risks for HIV transmission. At an individual level, interventions aim to change behavior to reduce HIV risks, with the ultimate goal of risk elimination. Specific interventions are:

- HIV information, education and communication (IEC) programs
- Risk-reduction counseling
- Voluntary counseling and HIV testing (VCT)
- Disinfection programs
- Needle-syringe programs
- Agonist pharmacotherapy programs
- HIV treatment and care

Each of these approaches is described in terms of its objectives, models of delivery, feasibility in resource-constrained settings, effectiveness and benefits, risks and limitations.

PUBLIC HEALTH INTERVENTIONS TO REDUCE THE RISK ENVIRONMENT

Although the strategies outlined above may reduce individual HIV risks, no single one can prevent or stop HIV epidemics among drug-using populations. Principles for preventing or stopping such epidemics are provided.

A public health response aims to bring all these principles together and support their implementation by:

- Promoting a “healthy public” policy and legislation
- Creating a safe and supportive environment for IDUs to adopt healthier behaviors
- Mobilizing IDUs and their communities to take action to reduce risks

- Making health and social services more responsive to the needs of IDUs
- Ensuring that members of the community have the necessary knowledge, skills and capacity to respond to the problem

LESSONS LEARNED AND RECOMMENDATIONS

A number of lessons learned and recommendations are provided, supporting the notion that specific actions can prevent, slow or even reverse HIV epidemics among IDUs in both developed and developing countries.

FUTURE CHALLENGES

The major challenge is in scaling-up HIV prevention programs to a reach and penetration that matches the scale of the IDU population, often when this is itself growing explosively. Countries or regions where this has been achieved are few; barriers to effective scaling-up are many.

CASE STUDIES

THE LIFESAVING AND LIFEGIVING SOCIETY (LALS), KATHMANDU, NEPAL

The LALS program initially distributed sterile needles and syringes purchased privately, then expanded to carry out a range of functions from primary health care and counseling to syringe exchange and condom distribution. LALS' experience illustrates both the effectiveness of these programs for their clients and the need to expand and reach the majority of IDUs in a country or region.

HY VONG CAFÉ—CAFÉ HOPE, HO CHI MINH CITY, VIETNAM

Hy Vong (“Hope”) Café in Ho Chi Minh City (HCMC) is Vietnam’s first needle-exchange café, having grown from the first needle-exchange program in Vietnam. Besides the needle exchange, the cafe provides condoms, information, tea or coffee, facilities for showering or washing clothes and a small STD clinic.

RAPID PROGRAM—MÉDECINS SANS FRONTIÈRES, RUSSIA

This project provides training and support for HIV/AIDS prevention among IDUs in the Russian Federation (RF). It focuses on the use of the World Health Organization’s *Rapid Assessment and Response Guide on IDU* and the *European Peer Support Manual*.

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Sharing contaminated injection equipment and drug preparations is a highly efficient means for transmitting HIV: As many as 3.3 million of the world's estimated 6 to 10 million IDUs are infected with HIV. Approximately 5 percent to 11 percent of AIDS cases globally are related to injection drug use (IDU).

Injection drug use has mirrored the explosive growth of the HIV epidemic. In 1992, 80 countries and territories reported IDU.

I N T R O D U C T I O N

Two years later, 134 countries and territories had documented IDU. Among them, 114 reported HIV infection associated with IDU, compared with only 52 in 1992. IDU is currently a major mode of HIV transmission in Eastern Europe and the Newly Independent States, Central Asia, East Asia, parts of South and Southeast Asia, North Africa, the Middle East, Southern Europe, North America and parts of South America. IDUs can also play a critical role in the spread of HIV into the general population through heterosexual transmission with sexual partners and through mother-to-child transmission (MTCT) from IDU mothers.

There is evidence from some developed countries—such as the United States—that IDU is decreasing and IDUs are becoming older. This can be attributed to increased drug purity (allowing for non-injected routes of administration) and increasing concern among drug users of the HIV risk. But evidence from many developing and transitional countries shows IDU there is increasing, and the average age of drug users is decreasing. In both developing and developed countries, IDU tends to be

more concentrated in marginalized and minority populations, particularly in urban areas. Nevertheless, it is seen across all social classes and non-urban settings. Prevention efforts must recognize the context (or risk environment) within which IDU occurs.

Despite the rapidly spreading dual epidemics of IDU and HIV, effective interventions can prevent, stop and even reverse epidemics among IDUs. This chapter describes the nature and extent of HIV/AIDS epidemics among IDUs, methods used for assessing such epidemics and associated risk behaviors and environments and interventions available for preventing such epidemics, with evidence of their effectiveness. The chapter discusses both public health interventions and those targeting individual behavior change; it examines the feasibility, application and limitations of each in resource-constrained settings. Finally, these pages offer guidance for policy makers on selecting priority interventions for those communities where IDU is a significant factor in the spread of HIV.

MAGNITUDE OF THE PROBLEM

HIV infection among IDUs can spread rapidly. Explosive epidemics have been witnessed in a wide range of cities in the past 20 years, starting with New York in 1979, followed by such cities as Edinburgh, Bangkok, Ho Chi Minh City, Odessa and, most recently, Moscow. In some cities, HIV prevalence has escalated from less than 5 percent to more than 40 percent in a 12-month period. At the same time, the epidemic has been prevented or controlled in many cities, such as Sydney and London. These cities tend to have four features in common:

- Comprehensive and multisectoral HIV prevention efforts, which were started early (often before HIV prevalence among IDUs reached five percent).
- Outreach services that provide broad coverage of interventions and establish trusting relationships between outreach workers and IDUs.
- Ready legal access to sterile injection equipment.
- Good access to drug dependence treatment services, particularly opioid agonist pharmacotherapy (such as methadone and buprenorphine).

ADOLESCENTS

In the past 15 years, we have learned much about IDU and associated HIV infection. But most studies focus on adult populations, with very limited information available on younger IDUs. Adolescence is a critical period; it is the age group with the highest HIV incidence rate and drug use is often begun then. Young IDUs tend to think and behave in ways that differ from their older counterparts and are treated differently within their communities. Specific interventions targeting adolescents should be considered (see Table 1).

HEPATITIS C (HCV)

The hepatitis C virus (HCV) has been an IDU infection far longer than has HIV—since the early 1970s at least, but probably longer. It is also more “infectious” than HIV: in general, smaller amounts of blood can transmit the virus from one IDU to another. HCV prevalence in most populations of IDUs around the world reached 50 percent or more well before the introduction of harm-reduction meas-

Table 1

DIFFERENCES BETWEEN YOUNG AND OLDER DRUG INJECTORS

Young injectors are more likely than older injectors to:

- Be less knowledgeable about HIV/AIDS and drug use.
- Be less inclined to identify themselves as being a drug user/drug injector.
- Deny they are at risk of HIV through both drug injection and sexual intercourse.
- Initiate their injecting through casual experimentation with wider drug use.
- Be intermittent (rather than regular) drug users and use (experiment with) a broader range of drugs.
- Be novices, with limited experience of injecting and contact with other injectors.
- Have a less developed network of drug-using peers.
- Inject in risky environments.
- Be females (although in most communities adolescent boys still outnumber adolescent girls).
- Have a less significant drug dependence and to be less damaged from their drug use.
- Have more frequent sex and more sexual partners.
- Have unclear sexual identities and more likely experiment with different sexual practices, including same-sex relationships.
- Be less aware of where and how to access prevention and treatment services, and more reluctant to use such services.
- Have less access to existing services, including restrictions because of their age.
- Be uninfected with HIV and hepatitis B and C.

ures for HIV. While there is evidence of HCV transmission through shared injection equipment other than needles and syringes (such as water, filters, cookers, spoons, etc.), shared reuse of contaminated needles and syringes is responsible for the majority of HCV transmissions between IDUs (and in other settings such as immunization). Bringing HCV epidemics under control in high HIV prevalence areas is proving difficult; these situations require far greater levels and consistency of safer behavior than do low-prevalence situations. But there is mounting evidence that programs for HIV prevention are slowly decreasing HCV incidence among the same populations.¹

STRATEGIES FOR HIV PREVENTION AMONG IDUS

The same interventions can prevent HIV transmission at both individual and population levels. This part of the chapter describes them in three sections:

- Assessing for intervention
- Interventions to reduce individual risk behaviors
- Public health interventions to reduce the HIV risk environment

ASSESSING FOR INTERVENTION

IDU patterns and associated HIV-risk behaviors are dynamic, varying between countries, populations and time. Such patterns are determined by a broad range of individual (knowledge, attitudes and behavior) and contextual (social, economic, cultural and political) factors that together establish the conditions for HIV spread. Because the mix varies among different populations and areas, prevention efforts must be tailored and responsive to each specific setting. The local situation must be understood and considered to ensure the most cost-effective, culturally acceptable and feasible interventions. The rapid spread of HIV associated with IDU demands assessment methods that are affordable, rapid, will result in immediate action, are easy to use and can be used to monitor further developments.

Rapid assessment and response (RAR) methods have been used widely in both developed and developing countries to plan prevention strategies among drug-using populations. These methods tend to have a number of features in common, including quick affordable assessment techniques, multiple indications and data sources and levels—individual, situational, social, etc. They involve the community in the assessment process, and complement other social science and epidemiological methods. The World Health Organization's *Rapid Assessment and Response Guide on IDU* is an example of a methodology that has been developed specifically to link situation assessment with development and implementation of appropriate and timely interventions.²

Despite their usefulness, rapid assessment methods have limitations. Developing a thorough understanding of the specific drug-using behaviors and their meanings or mapping drug-user networks may demand conventional social science research methods with a timeframe much longer than a few months. Likewise, large-scale surveys may be necessary to gather quantitative data for advocacy purposes, plan allocation of resources, design specific interventions, evaluate the effectiveness of strategies and monitor trends.

The use of behavioral surveillance surveys (BSS) also recognizes the importance of monitoring and tracking HIV risk behaviors as well as actual cases and spread of HIV/AIDS. BSS can act as an early warning system, predict the likelihood of HIV spread, gather behavioral information for program design, evaluate program effectiveness and help understand the role of changing behaviors in influencing HIV prevalence. Family Health International has produced a set of BSS guidelines that include key indicators for monitoring trends in HIV risk behaviors among IDUs and between different population groups.³

INTERVENTIONS TO REDUCE INDIVIDUAL RISK BEHAVIORS

Different drug-using behaviors pose different risks for HIV transmission. At an individual level, interventions aim to change behavior to reduce risks, with the ultimate goal of risk elimination. IDUs are in various stages of readiness to change their drug-using behaviors. But given the appropriate information and opportunity, they are likely to change both drug-using and sexual behaviors to protect themselves and their sexual and drug-using partners. Specific interventions for reducing HIV risk are:

- HIV information, education and communication (IEC) programs
- Risk reduction counseling
- Voluntary counseling and HIV testing (VCT)
- Disinfection programs
- Needle-syringe programs
- Agonist pharmacotherapy programs
- HIV treatment and care

Information, education and communication (IEC)

Objectives

HIV IEC programs should provide accurate information that will increase the IDUs' knowledge and modify their attitudes—which in turn will help them change their behaviors to reduce risks.

Description

IDUs obtain information on drug use and HIV/AIDS from many sources, including general awareness (mass media) campaigns, information campaigns specifically for IDUs, peer and drug-user networks, health professionals and outreach workers. Information may be provided in various forms, including posters, pamphlets, newsletters, videos and radio and television broadcasts. IEC materials may also target families and friends of IDUs and the general community. (See Chapter 12 for in-depth discussion of social marketing for HIV/AIDS prevention.)

Content of materials

The same principles for developing IEC materials for other populations are relevant to IDUs. Their involvement in this process is critical. IEC should cover the following areas where appropriate:

- Indiscriminate sharing of injection equipment
- Reducing the number of sharing partners and sharing occasions
- Risks of drug preparation techniques
- Risks of drug distribution techniques (front- or back-loading, etc.)
- Risks of sharing paraphernalia (filters, cookers, water)
- Needle and syringe cleaning/sterilization techniques
- Accessing sterile needles and syringes
- Safe disposal of contaminated injection equipment
- Alternatives to drug injection
- Available drug treatment services
- Overdose prevention and management

- Hepatitis B and C prevention
- Abscess and vein care
- Condom use and safer sex
- Contact details for health, welfare and other services

Models of delivery

Mass media campaigns can raise general awareness of HIV/AIDS among IDUs. But specific reference to them in such campaigns may increase stigmatization and public disapproval, and cannot usually provide the necessary (and often sensitive) messages required for IDUs. Furthermore, mass media campaigns tend to be very expensive and may not reach the most vulnerable groups.

Targeted information campaigns for IDUs, with explicit information on risk reduction strategies, are effective in reaching the most vulnerable IDUs and providing them with very practical information, including how to access treatment services. Local situation assessment is necessary to identify attitudes, knowledge and specific risk behaviors, target specific groups, determine the context of IDU, communication channels and local resources. Appropriate materials and messages can then be developed in collaboration with IDUs themselves.

Drug-user networks and peers are very good—and cost-effective—mechanisms for disseminating HIV-risk reduction information.

IDUs often come in contact with health care services. Workers should be trained in risk-reduction strategies, and able to provide accurate and nonjudgmental advice.

BEYOND APPEARANCES

A monthly newsletter on treatment and other issues for current and ex-drug users

Beyond Appearances, a simply formatted monthly newsletter, was launched in Delhi, India, in 1997, with the support of SHARAN, a non-governmental organization working with drug users and urban poor communities. The newsletter provides news and information to drug users on such issues as HIV and hepatitis risk-reduction strategies, maintaining health, drug dependence treatment, drug policy and human rights. The newsletter was developed based on experience in other countries, such as Australia, where drug-user organizations are very active in producing IEC materials.

Feasibility in resource-constrained settings

The development and dissemination of IEC materials on IDU and HIV is widespread; it exists in some form in most countries with significant levels of IDU. National policies or legislation may make it impossible for the government—and in some cases the nongovernmental sector—to produce explicit materials, as this may be construed as encouraging and abetting illegal behavior. But even in restrictive settings, informal materials, communication methods and networks can disseminate information and reach highly marginalized populations. Very simple and easily reproducible materials are likely to be just as effective as more expensive ones.

Effectiveness

Knowledge of HIV risks is enough to influence IDUs' behaviors, including: reducing the number of sharing partners and sharing occasions, selectively sharing partners and equipment, safely disposing of contaminated equipment, cleaning injection equipment, changing drug preparation and distribution methods, ensuring access to sterile equipment when needed and accessing treatment and other health services. Inaccurate information can result in useless prevention strategies.⁴

Benefits, risks and limitations

The development and provision of IEC materials is feasible and affordable in most resource-constrained settings. But targeting IDUs presents special problems: Although this group needs explicit information, such information may be offensive to the general population, resulting in community opposition. There may also be difficulties in presenting clear messages to IDUs because of high levels of illiteracy, language barriers (including the use of street-language) and diversity of drug-using practices.

Risk reduction counseling

Objectives

Risk reduction counseling aims to help individuals clarify their feelings and thinking, and better understand their behaviors and environment, so that they will protect themselves against the risks of IDU. Counseling also provides important psychosocial support to HIV-infected IDUs and helps them protect their health and reduce transmission to sexual and drug-using partners and children (the last, for pregnant and breastfeeding mothers). (See Chapters 18 and 19 for more information on reducing the risk of HIV transmission from mother to child.)

Description

Risk reduction counseling often includes:

- Accurate HIV/AIDS and drug use information
- Personal HIV risk assessment (making the individual aware of his/her specific behaviors and their associated risks)

- Behavioral skills training (how to use condoms and sterilize injection equipment, etc.)
- Problem solving (accessing help, dealing with crises and relationships, selecting appropriate prevention or treatment options, etc.)
- Stress management (to reduce stress or better cope with stressful situations)

Models of delivery

Counseling should be tailored to the needs of the individual client and sensitive to the setting within which he or she lives. Whatever the setting, non-directive and non-coercive counseling is more likely to be accepted. Approaches that encourage active decision making by IDUs themselves will more likely result in sustained behavior change.

Characteristics of the counselor strongly influence the effectiveness of counseling. Many resource-constrained settings cannot afford specialist HIV/AIDS or drug counselors; counseling often forms part of the general caseload of generalist health care providers or personnel providing a range of services through HIV/AIDS or drug treatment programs. Peer counselors—including current and former IDUs and members of drug-using networks—can effectively deliver relevant, acceptable and affordable counseling to difficult-to-reach IDUs. Training in basic risk reduction counseling should be given all health and other workers providing services to IDUs. Counselors should understand local drug use and HIV risk behaviors, know local resources and referral practices, be nonjudgmental and respect the confidentiality and other rights of IDUs, be accepted and trusted by the client population and recognize their own limitations.

The setting for counseling will also influence the effectiveness, acceptability and utilization of such services. Marginalization of IDUs, their fear of arrest or harassment and their inability to afford services may make it very difficult to access these individuals. Outreach approaches delivering counseling—often in association with other services such as the provision of injection equipment, condoms and primary health care—in settings where IDUs live and congregate are more effective than services offered through formal and traditional center-based programs.

Feasibility in resource-constrained settings

Many communities and services cannot afford dedicated HIV/AIDS and drug-use counselors. Nevertheless, the very nature of the encounter between health care workers and IDUs requires some degree of risk reduction counseling. Community health care workers and peer educators have been trained in risk reduction counseling—and have incorporated these skills into their daily work—in many resource-constrained countries, including Brazil, India, Kazakhstan, Malaysia, Myanmar, Nepal, Russia and Ukraine.

Effectiveness

IDUs have been shown to change both their drug- and sex-related HIV risk behaviors after participation in outreach-based interventions. They have reduced drug injection frequency and sharing of needles, syringes and other injection equipment and increased needle and syringe disinfection and condom use. They have also increased contact with and entry into drug treatment.⁵ Peer-outreach programs and social network interventions have proven cost-effective in reducing drug-related HIV risk practices.^{6,7}

Benefits, risks and limitations

Risk reduction counseling provides an opportunity to respond to the IDU's needs in a holistic and integrated fashion. Counseling can address factors influencing the IDU's behaviors and living circumstances. But the counselor must be trained and skilled in counseling approaches and familiar with the existing evidence for different strategies' effectiveness. There can be considerable harm if counselors provide IDUs with inaccurate information and inappropriate advice.

Counselors' personal beliefs and experiences may compromise their effectiveness. Moralizing over illegal drug use and urging abstinence from drug use as the only option are common problems. Clear guidelines should be established to ensure confidentiality and respect of IDUs' basic human rights. Counselors must be aware of their own rights and the law regarding advising on potentially illegal behaviors and associating with criminalized populations. In some communities, special attention must be given to securing the safety of health care workers, particularly those providing outreach services in drug-use environments.

Voluntary counseling and HIV testing (VCT)

Objectives

Knowledge of one's own HIV status allows, and can promote, modification of behaviors to prevent HIV transmission. Such knowledge can result in lifestyle modifications to improve general health, including seeking treatment for opportunistic infections. It also allows forward planning for families and partners and provides opportunities for prevention of vertical transmission from infected mother to child. (Chapter 23 provides a full range of information on voluntary counseling and testing strategies.)

Absolute confidentiality is critical in VCT. IDUs are already subject to stigmatization and discrimination; any breaches of confidentiality in HIV testing can have dire consequences—sometimes even leading to imprisonment and death.

Description

Professionals or trained and supported peers should be responsible for counseling. The process must not be simply a matter of information provision, but a much more active discussion—one that clarifies the meaning of a particular test result for a particular individual. Counseling for testing is not simply a matter of giving information, but a much more active process in which the individual considers possible

courses of action open to him or her. Very often, issues only become clear to clients with time, so post-test counseling must be available on an ongoing basis. Counseling after a negative test result is as important, in some ways, as counseling after a positive test result. Professionals or trained and supported peers should provide counseling.

Models of delivery

VCT is best integrated into existing programs for IDUs—including syringe programs, primary health care and drug treatment, if possible. With proper safeguards to ensure confidentiality, pre- and post-test counseling can be given in conjunction with other services; most staff—including peer and outreach needleworkers—can be trained to provide the VCT service.

Feasibility in resource-constrained settings

This integration requires training and ongoing support and debriefing of staff. It can be relatively expensive, but it is particularly important for programs in which clients otherwise would have no access to such testing.

Effectiveness

There is little evidence that VCT has a direct impact on decreasing HIV transmission. But there is growing evidence that infected IDUs who know their HIV status often act responsibly to reduce transmission and protect drug-using peers and sexual partners. IDUs who test negative, however, do not appear to change their behavior. In both New York City and Santos (Brazil), HIV-positive IDUs reported significant decreases in distributive sharing of injection equipment (passing on equipment to another IDU after using it).⁸ In New York City, HIV-negative IDUs were reluctant to change their sexual behaviors, whereas HIV-positive IDUs showed very significant reductions in sexual risk practices, and were protective of their sexual partners.⁹ These findings suggest that interventions should be targeted at HIV-positive IDUs, who should be mobilized to promote sexual risk reduction among their HIV-negative injecting peers. Testing did lead to one benefit for both HIV-positive and -negative IDUs: participation in primary health care and drug treatment.

Disinfection programs

Objectives

Anything that decreases the amount of infectious virus in used needles and syringes will lessen the probability of virus transmission. Disinfection programs aim to reduce the infectiousness of re-used injection equipment—particularly needles and syringes—for blood-borne viruses, especially HIV. This can be achieved by cleaning the needle and syringe to remove contaminated blood, disinfecting the needle and syringe with chemical disinfectants or sterilizing the needle and syringe with heat.

Description

While the only thing that guarantees sterilization is sufficient heat for a sufficient length of time, most disinfection programs promote the use of bleach. Many, if not most, programs in the United States rely on household bleach (sodium hypochlorite solutions) to disinfect needles and syringes before reuse. Bleach is effective at rapidly destroying most blood-borne viruses, including HIV. But bleach is not the only active chemical disinfectant available, and in many parts of the world, it is not as widely available as it is in most industrialized countries. Other chemicals that may provide some measure of protection include iodine, hydrogen peroxide, detergents and even (to some extent) strong alcohol.

Models of delivery

Bleach, and instruction in its use, is usually provided either by outreach workers for whom this is the major component of their job (“bleach and teach”), or as an ancillary approach by other programs, including needle-syringe and drug treatment programs or primary health care facilities. Bleach is provided either as a solution (often in small disposable bottles) or as a powder to be made into a solution on site before use. Disinfectants can be distributed by health care workers in a wide range of settings.

Bleach may be a firstline strategy in countries or other settings (such as prisons) where needle-syringe programs are not feasible. In other settings, bleach provides a backup or second-line alternative where sterile equipment is not available.

Feasibility in resource-constrained settings

Bleach or other chemical disinfectants are usually reasonably cheap and eminently feasible in resource-constrained settings. Their distribution also provides a key topic around which HIV prevention education can be pursued, and gives workers and clients an effective strategy if sterile equipment is unavailable. But chemical disinfectants are less effective than needle and syringe distribution.

Effectiveness

The evidence for effectiveness of disinfection programs in the prevention of HIV among IDUs is mixed, with some evaluations finding a protective effect and others not.¹⁰ In general, effectiveness relates more to the circumstances in which the bleach is distributed and used—and to how it is used—than to the programs themselves (see below). Messages to IDUs have often been confusing, proposing differing types of decontaminants and concentrations.¹¹ Disinfection programs are certainly not as effective as needle-syringe programs, and should not be seen as a satisfactory substitute. They are better viewed as a less effective alternative where needle-syringe programs are not possible, or as a second-line strategy to support needle-syringe programs.

Benefits, risks and limitations

While full-strength bleach or other chemical disinfectants efficiently kill HIV and most other blood-borne viruses in the laboratory, for a variety of reasons their effectiveness is diminished in the field. To disinfect properly, bleach must be strong enough and in contact with the virus long enough—at least 30 seconds in most situations. In the field, this requirement often is not understood or cannot be met because of situational pressures—the pressure to inject quickly to escape observation, for example. In addition, clotted blood protects viruses against the action

of chemical disinfectants. Rinsing used syringes immediately after use increases the effectiveness of disinfection programs by removing and diluting much of the blood before it can clot.

In some communities, IDUs are suspicious of bleach and other disinfectant agents and are reluctant to use them for fear of potential toxic effects. Education and counseling should address these fears and provide guidance on safe use of disinfectants.

ADEQUATE COVERAGE IS CRUCIAL FOR PROGRAM SUCCESS

Even evidence-based, culturally appropriate and well-accepted programs will have little impact on the epidemic if they are not implemented on a scale large enough to reach a critical number of IDUs. The example of LALS in Kathmandu demonstrates that a small needle-syringe program (reaching only 1,000 IDUs) may help slow the epidemic, but can do little to prevent an explosive epidemic once drug injection and HIV prevalence rises.

In the Russian Federation, HIV cases are rising exponentially, predominantly among IDUs. With an estimated 1.5 to 3.0 million IDUs in the country, the existing 35 needle-syringe programs reach only a small proportion of those at risk. As a matter of urgency, UNAIDS co-sponsors and other partners are planning to scale up needle-syringe programs in an effort to cover 60 percent of the IDU population throughout the country.

Needle-syringe programs

Objectives

Needle-syringe programs have several objectives, whose relative importance can be seen hierarchically:

- The primary roles of needle-syringe programs are to distribute sterile injection equipment to IDUs and remove used and potentially contaminated equipment from circulation, thereby removing the possibility of further intentional or accidental use.
- These roles relate primarily to needles and syringes, but can include other equipment—such as cookers/spoons, alcohol swabs and sterile water—and other materials such as condoms.
- Programs can also provide an opportunity to disseminate IEC materials about safer injection as well as information on sexual transmission.
- Needle-syringe programs can also become contact points for counseling, primary health care, referral of IDUs to other services and engagement with drug treatment services.

The primary tasks of distribution and disposal of injection equipment may be separate or connected activities: the commonest form of connection is exchange, where sterile equipment is provided in return for used equipment. But the need for exchange depends on circumstances, and other models have been developed.

These subsidiary roles should not interfere with the primary task of needle-syringe programs: to ensure that as many injections as possible take place with sterile injection equipment, thus breaking the chain of transmission of HIV and other blood-borne viruses.

An overarching objective of needle-syringe programs is to achieve sufficient reach and coverage to significantly affect epidemics or potential epidemics of blood-borne viruses among the IDU populations, and from them to their sexual partners and children. Such programs must therefore try to reach populations not otherwise in contact with any services, and to operate on a large enough scale to ensure that a high proportion of injections are carried out with sterile equipment. This scale depends primarily on the prevalence

of the blood-borne viruses—if the proportion of IDUs infected with HIV is high, coverage must be high; if prevalence is low, less coverage can still be effective. The goal, however, should always be to ensure that every injection is carried out with sterile equipment.

Description

The fundamental activities of needle-syringe programs revolve around contacting different groups and providing appropriate and accessible means for distribution and disposal of injection equipment. The actual methods by which these tasks are carried out will depend largely on the context within which the needle-syringe program operates (drug use and behaviors of drug users, cultural, legal and political situations and availability of resources). As a result, location, style of service delivery, hours of operation, staffing and other characteristics of the program vary widely around the world and even within a single country.

Models of delivery

Depending on context, very different models of service delivery have developed in various settings:

Needle-syringe services must be located close to where the drug users live or buy and use the drugs. IDUs tend to inject near their purchase site. The less deviation from their normal lives involved in collecting or disposing of equipment, the more likely IDUs are to use the needle-syringe service. Such access can be achieved by physically locating the program in these areas, or by outreach on foot or in vehicles.

Needles and syringes can be provided to IDUs in a range of ways. Sale at pharmacies or other facilities is common in many countries, and is sometimes promoted as an HIV prevention strategy. But in many situations, there are barriers that make it difficult for IDUs to access needles and syringes. They may be too expensive (even where unit costs seem very low, most IDUs inject at least daily and very regularly, resulting in rapidly mounting costs) or the IDUs may be subject to discrimination or harassment. Needle-syringe programs—whether exchange or distribution and disposal—are still necessary. The programs are also needed to provide sterile equipment to IDUs who, for

these or other reasons, cannot or will not access pharmacies. Vending machines also supply needles and syringes in a variety of settings (including prisons), providing anonymous access at all hours.

Needle-syringe programs may be fixed site—delivered from a stationary location such as a shop front, office or other health care or drug treatment facility—or they may be outreach or a mixture of the two. Outreach may be carried out on foot, with workers walking through scenes of drug dealing and/or using and making discreet exchange on the street or in vehicles—most commonly a van. This latter can work as a fixed site, providing services from the same locations regularly, or can move around to reach different groups of IDUs. Where laws permit, some needle exchange or distribution is done by prearranged delivery (by telephone order) by car or van, or even carried out through the mail.

Given the need to distribute or exchange as high a proportion of equipment as possible, different strategies have developed. In many circumstances, where needle-syringe programs are legal, exchanges are restricted by policy or law to one-for-one, where a single sterile needle and syringe can be provided for each used one returned. If these restrictions do not apply, and if the program can supply as much sterile equipment as is required, secondary exchange may become a large and actively promoted part of the program: Clients collect sterile equipment not only for themselves but also for distribution to other IDUs—in effect, working as unpaid peer outreach workers. The rationale for this style of program delivery is that it increases efficiency with less pressure on program staff and increases reach to populations who would not otherwise attend the needle-syringe program. Such services must be allied with greater efforts at disposal of used equipment (see below). Outreach needle and

syringe services can be provided by professional or peer staff. Both require intensive training and continuing support, as this work demands skill and can be extremely stressful.

To control epidemics of blood-borne viruses, sharing of injection equipment must be minimized or abolished. Prisons, juvenile correctional facilities and drug rehabilitation centers play special and often central roles in epidemics, but they are among the most difficult settings for needle-syringe programs, since sanctions against IDU in these institutions are so strong that provision of needles and syringes is usually impossible. Nevertheless, such programs do exist in some countries and special consideration must be given to this issue.

Feasibility in resource-constrained settings

Establishing a needle-syringe program can be difficult. While there have been demonstrations of their cost-effectiveness in preventing blood-borne virus transmission and eventual disease—especially AIDS—the benefits may be ignored, and only the cost considered. Where access to sterile equipment is difficult even in the orthodox medical setting, justification of expenditure on IDUs (usually among the most stigmatized and marginalized people in any community) can be difficult. The role of HIV epidemics among IDUs in promoting more general epidemics through sexual transmission to non-IDUs should be emphasized, as should any locally derived measures of cost-effectiveness.

In fact, if substantial populations of IDUs are at risk, needle-syringe programs are among the cheapest and most cost-effective of all HIV interventions. This is certainly the case when compared with drug treatment programs—and exchange is far more effective and rapid. Local production of needles and syringes in

most parts of the world means the equipment can be obtained relatively cheaply. Staff costs tend to be low. Proper disposal of collected used equipment (see below) is often one of the most significant costs.

In “mature” or “explosive” HIV epidemics among IDUs—when prevalence is already high or rapidly increasing—scaling-up programs to reach adequate coverage may appear expensive. But even in these situations, needle-syringe programs remain the most cost-effective HIV prevention strategy available.

These programs have been established not only in developed countries, but in a number of developing and transitional states as well, including Bangladesh, Belarus, Brazil, Bulgaria, India, Kazakhstan, Latvia, Nepal, the Philippines, Russian Federation, Thailand (including among remote hill-tribes communities), Ukraine and Vietnam.

The Open Society Institute has produced a detailed guide to establishing and operating needle-syringe programs, with particular focus on Central and Eastern Europe and the Newly Independent States.¹²

Disposal of used injection equipment

Collection and disposal of used injection equipment is very important. First, it eliminates the possibility for potentially infectious equipment being reused; and second, it removes a potential source of accidental transmission to non-IDUs, especially children. But such collection raises the problem of disposal, adding to the present medical-waste problem in most developing countries. Using landfill is dangerous and environmentally unsound; low-temperature incineration—all that is available in most settings—is similarly environmentally disastrous. High-temperature incineration, the method of choice, is usually unavailable or prohibitively expensive.

Effectiveness

Since the establishment of needle-syringe programs in the early 1980s, a number of studies in many parts of the world have attempted to measure these programs’ effectiveness in preventing HIV transmission and possible promotion of drug use. Several US government-funded reviews of this evidence have unanimously concluded that such programs are effective,

and do not lead to increases in the numbers of people injecting drugs.¹³⁻¹⁶ Furthermore, there is increasing evidence that such programs can be established in resource-constrained settings and very difficult environments.

Benefits, risks and limitations

Needle-syringe programs—whatever model they utilize—are the most effective and cost-effective method yet devised for preventing HIV transmission among IDUs, and from them to their sexual partners and children.

Such programs operate best when delivered in the context of other services, especially primary health care and drug treatment. But the absence or underdevelopment of such services should not preclude needle-syringe programs. This would simply allow further HIV transmission and increase future burdens on the health care and welfare systems. Providing sterile equipment to IDUs is extremely contentious in many countries. Here, other programs—especially outreach and drop-in centers providing information and education—should be implemented rapidly, while advocacy for needle-syringe programs continues. Community education—social marketing for “harm reduction”—is necessary at every stage of program development and implementation to achieve community understanding and support (or at least the absence of opposition). Promotion of the program’s role in removing potentially infectious used equipment from the environment, thereby lowering risks of accidental exposure to the general community, could increase support.

Some countries prohibit giving injection equipment to IDUs. HIV prevention programs must carefully assess the implications of such legislation, regulations and local policing to determine what services can be provided and their staff’s potential liability. Advocacy for changing restrictive legislation and attitudes of law enforcement professionals is often required before programs can be established.

Agonist pharmacotherapy programs

Objectives

Agonist pharmacotherapy treatment (drug substitution) usually has two aims: treatment of drug dependence and reduction of health risks and negative health consequences (such as HIV infection) by encouraging a transition from injection to non-injection drug use (under supervised prescribed treatment). Engagement and retention in drug dependence treatment also provides opportunities for risk counseling and advice, as well as management of other health and social problems.

Description

Agonist pharmacotherapy involves treating drug-dependent individuals with a drug that has a similar action to the drug they are dependent on, thereby preventing a withdrawal syndrome and craving. Most substitution programs rely on replacing an injected illicit drug (such as street heroin) with an oral legal drug (such as methadone). This is done under medical supervision, reducing the risks associated with injection—such as transmission of HIV, overdose and vein damage.

Oral methadone is the most widely used and rigorously evaluated form of treatment for opioid dependence. Although well established in certain areas of the United States for over two decades, it was not until the late 1980s that there was a dramatic expansion of methadone maintenance programs in other regions, such as Australia¹⁷ and Europe. All European Union countries now have such programs.¹⁸ Evidence of the effectiveness of methadone maintenance programs in preventing HIV infection and reducing risk behaviors has provided the rationale for such programs in many countries.

Methadone is not the only drug used in opioid agonist pharmacotherapy. Others include buprenorphine, levo-alpha-acetylmethadol (LAAM), morphine, codeine, diamorphine (heroin), pentazocine, ethyl morphine and tincture of opium. While most are given orally or sublingually, the substitute drug is sometimes given by injection, as in Switzerland’s heroin prescription program. Services using injection drugs aim to treat severely dependent and health-damaged IDUs who have failed on oral substitution programs.

Agonist pharmacotherapy is not widespread for other classes of drug dependence, such as amphetamine-type stimulants and cocaine.

Models of delivery

The United States' methadone programs were initially limited to dedicated specialist clinics often attached to major hospitals, with strict guidelines and regulations covering client eligibility, dosing regimes, monitoring of drug use (such as through urine testing), compulsory counseling and behavior codes. Typically, clients would be required to attend clinics daily for their prescribed dose of methadone under direct supervision, with limited choice of dose or other management.

Expansion of these programs and research on the effectiveness of different service delivery models led to considerable diversification in programs offered. Low-threshold programs that provide easier and quicker access to treatment slots have been set up. There has also been a move toward community-based and less expensive programs, involving methadone prescribing by general practitioners and other medical practitioners, dispensing through pharmacies and community health facilities, mobile dispensing vans and client-centered services with dosing schedules and other treatment negotiated between client and prescriber. Community-based models of opioid agonist pharmacotherapy have made such programs possible in resource-constrained communities, including urban slums in India and rural communities in Thailand.

Feasibility in resource-constrained settings

Despite the widespread expansion of agonist pharmacotherapy programs in many developed countries, it has been argued that such treatment approaches are not appropriate, feasible or affordable for developing countries. But a range of projects have been established in Asia, Latin America, Eastern Europe and the Newly Independent States—although the programs are often restricted to small-scale or pilot plans. For example, sublingual buprenorphine maintenance programs operate in India. Methadone maintenance programs have been introduced in Nepal, Vietnam, Thailand and a wide range of Central and Eastern European countries such as Latvia, Lithuania, Poland, Slovenia, Slovak Republic, Hungary, Bulgaria and the Former Yugoslav Republic of Macedonia. Hong Kong has a well-established and wide-scale low-threshold methadone maintenance program.

Many Asian and Central and Eastern European programs developed in response to dramatic increases in IDU and associated HIV-risk practices. Abstinence-based drug treatment programs were nonexistent, unaffordable or ineffective in preventing relapses to HIV-risk practices. Some substitution programs evolved from within the communities where IDUs live in response to community-identified needs: They were designed, implemented and managed by the communities themselves, often without government support or formal approval. These programs differ markedly from those in developed countries. Principles of community involvement and integration with primary health care services have made these programs feasible, acceptable and affordable—even in slum communities and remote tribal villages.

Effectiveness

Most research on the effectiveness of agonist pharmacotherapy has been limited to methadone treatment in developed countries; specific research in developing and transitional countries is needed to examine the cost-effectiveness of such programs. Methadone maintenance programs are associated with lower rates of HIV prevalence¹⁹ and risk reductions related to injec-

tion and sharing behaviors²⁰ for individuals during treatment. Other benefits include retention in treatment, reduction in criminal activity and improved social functioning.^{21,22} Comparative studies evaluating the effectiveness of different programs in reducing HIV risk behaviors have shown that more effective programs are characterized by: higher doses (above 50 to 60 mg daily), long-term maintenance as compared with detoxification to abstinence, better ancillary and supportive services and better staff-client relationships.^{17,23-25}

Benefits, risks and limitations

There is clear evidence that agonist pharmacotherapy can prevent HIV transmission among IDUs in a range of settings; as a treatment, it tends to be well accepted by IDUs. Many individuals have strong feelings about such programs, some viewing them as replacing one “addictive” drug with another and possibly prolonging the individual’s drug dependence. But if the primary goal is HIV-risk reduction and preventing relapse to IDU, agonist pharmacotherapy programs are more effective than abstinence-based programs.²⁰

A major limiting factor has been the relatively high cost of some substitute drugs, requiring funding assistance from international development agencies or client fees. Increasingly, generic drugs such as methadone and buprenorphine are being produced locally, which reduces costs and makes the drugs more affordable in resource-constrained communities.

Another major obstacle for many countries is the legal status of drugs used in substitution programs. For various reasons, drugs such as methadone are either unavailable or illegal in certain countries, or can be prescribed only for very specific purposes—not including the treatment of drug dependence.

HIV treatment and care

The rate of progression to AIDS for HIV-infected IDUs is the same as for other groups, but this population has special needs: There is a higher death rate among HIV-infected IDUs from causes unrelated to HIV infection, including pneumonia, liver disease (associated with HIV and hepatitis C and/or B co-infection), overdose and suicide. Female IDUs face other issues, especially around pregnancy, childbirth and breastfeeding. Weight loss and physical wasting can be worse for IDUs living with HIV because of malnutrition and poverty, in addition to the effects of some street drugs. Affected IDUs are at greater risk for infections related to injection drug use, including abscesses, septicemia, endocarditis and tuberculosis (TB). Co-infection with hepatitis C and/or B is extremely common.

IDUs living with HIV are often unable or unwilling to access HIV/AIDS treatments or general medical care because of inappropriately designed services, stigmatization, negative attitudes of medical and healthcare staff and poor healthcare experiences. Pain management is a problem for all IDUs and people living with HIV/AIDS (PLHA), but it is worse for those who fall into both categories: They usually have a very high tolerance for pain-control drugs.

Objectives

A number of objectives should be considered in HIV/AIDS management, including:

- Provision of quality care and treatment
- Integration of AIDS care and treatment services into general provision of health care, with HIV prevention programs
- Development of a continuum of care approach

Description

Medical care—both primary health care and especially support and treatment for HIV-related illness, can be carried out anywhere—in the home, the street, primary healthcare facilities, STI and other clinics, drug treatment centers and hospitals. In most situations, IDUs—and often their families—have poor or

little access to health care; comprehensive treatment for AIDS-related conditions or the HIV infection itself may not be available or affordable. Alternative strategies for providing care and support are needed to reach these often extremely marginalized people. At the same time, advocacy is required to improve acceptance of IDUs' health care needs by mainstream services and authorities.

Models of delivery

The most successful models for delivery of HIV services for IDUs are comprehensive: integrating this special care into harm reduction, primary care and access to drug treatment or detoxification and treatment. The optimum program integrates all these with good referral links to other health and welfare services, working from outreach in the home or streets through to hospital and hospice. Few such programs exist, especially in resource-constrained settings—where such an approach is unachievable even for much of the general population.

The most common and least expensive model provides primary health care by nurses or trained peer workers through outreach or drop-in services. Wound and abscess care, as well as minor opportunistic infections, TB, diarrhea and other HIV-related conditions can be treated in this way. Home-based supportive and medical care is a next step, involving families in the care of their HIV-infected members.

Feasibility in resource-constrained settings

Much of the current standard of medical treatment for HIV infection (highly active antiretroviral therapy [HAART]) and for the opportunistic infections and cancers of AIDS is far too expensive for resource-constrained settings. But a wide range of care and supportive medical strategies—such as treatment of skin infections and bacterial pneumonias (using cheap and available broad spectrum antibiotics), rehydration, TB

treatment and vaccination—can be delivered in resource-constrained settings. Infrastructure need not be complex for such service delivery.

Similarly, social support—PLHA networking or community mobilization for home-based care, for example—is fundamental in resource-constrained situations. This carries through to support for the dying—as important as care of the living—whether in community hospices or home.

PUBLIC HEALTH INTERVENTIONS TO REDUCE THE RISK ENVIRONMENT

Although prevention strategies outlined in the preceding sections may help reduce individual HIV risks, no single strategy can prevent or halt HIV epidemics among drug-using populations. Actions that, combined, can help include:

- Starting prevention interventions early in the epidemic (before HIV prevalence among IDUs exceeds five percent)
- Implementing multiple interventions and intervention strategies (legal, public health, social development, etc.) at multiple levels (individual, community, national, international)
- Establishing interventions in multiple settings (streets, drug-using venues, drug treatment services, health agencies, prisons, etc.)
- Targeting multiple risk behaviors (drug use, equipment and drug sharing, sexual behaviors)
- Providing access to multiple means for behavior change (risk reduction information, condoms, sterile injection equipment, HIV testing and counseling, drug treatment)
- Reducing obstacles to prevention and treatment services (making them affordable, convenient, user-friendly, confidential)
- Recognizing that populations at risk are in various stages of readiness to engage in an intervention; repeated opportunities to begin interventions are necessary²⁶

A public health response should bring all these elements together and support their implementation by:

- Promoting “healthy public” policy and legislation
- Creating a safe and supportive environment for IDUs to adopt healthier behaviors

- Mobilizing IDUs and their communities to take action to reduce HIV risks
- Making health and social services more responsive to the needs of IDUs
- Ensuring that community members have the necessary knowledge, skills and capacity to respond to the problem

Legislation and health policy

Objectives

Local, national and international policies, legislation and international treaties regarding illicit drug use and HIV/AIDS can significantly influence risk practices and prevention efforts. Where possible, policies and legislation should aid prevention efforts, enable IDUs to change their behaviors and promote an environment that minimizes HIV risks.

Description

A wide range of policies, legislation and international treaties influences IDU and HIV risk patterns in communities. Such policies and legislation are not limited to the health, HIV/AIDS or drug control sectors, but include such diverse areas as immigration, education, prisons, youth, housing and welfare. Careful analysis of different policies, legislation and regulations is needed to understand how they might affect behaviors and increase HIV vulnerability.

Many countries have policies and laws that present obstacles to effective prevention strategies, such as needle-syringe programs, outreach education, agonist pharmacotherapy and voluntary and confidential testing and counseling. Legislation and regulations that can hamper prevention efforts include: restrictive procedures, compulsory drug and STD treatment, required reporting and registration of illicit drug users, mandatory HIV testing and exclusion of protection for illegal drug users.

It may be necessary to change these existing laws and regulations to implement effective and comprehensive HIV prevention programs for IDUs. Legal expertise is needed to analyze such rules and recommend appropriate changes. More often than not,

strong arguments will be required to convince policy makers and legislators to make necessary changes, especially if such changes do not have the support of the community or relevant constituency.

Models of delivery

The complexities of HIV/AIDS and IDU require commitment and action across many different sectors. National HIV/AIDS, drug control and health policies—with mechanisms for coordinating policies and actions between different ministries and private and NGO sectors—are key features of many countries' response. Such intersectoral cooperation may work on a local level through district or community coordinating organizations to guide local actions. It is important to ensure that all such groups are fully informed about issues of HIV and IDU. Some mechanism should be established to ensure input from, or representation of, IDUs in any such process. For example, drug user organizations are represented on some government committees and in some cases are government-funded (such as the New South Wales Users and AIDS Association in Australia).

Feasibility in resource-constrained settings

Review and revision of policies, laws and regulations can be a lengthy process, requiring extensive consultation and consensus building. This is true in setting up intersectoral mechanisms to coordinate policies and programs. Nevertheless, increasing numbers of developing and transitional countries—such as Brazil, India and Ukraine—are establishing national or state policies that address HIV/AIDS among IDUs. The state of Manipur in India provides one example of how a state HIV strategy has made IDU its main priority. Furthermore, there are examples of legislative reform in such countries that specifically allow HIV prevention programs for IDUs (such as laws permitting needle and syringe exchange in Brazil).

Effectiveness

Although it is difficult to evaluate the impact of broad policies and specific legislation on HIV risk practices and transmission, there is evidence from a number of countries that a committed multisectoral response is the key to an effective HIV prevention strategy. Australia and the United Kingdom have tried this approach, and HIV epidemics among IDUs have been averted.^{27, 28}

Benefits, risks and limitations

Fear that such actions might undermine illicit drug control has prevented the widespread adoption and endorsement of various HIV prevention policies and strategies for IDUs. Many decision makers argue that strategies such as needle-syringe programs and risk reduction education may encourage illicit drug use, recruit new drug users or send the wrong message (particularly to young people). Similar arguments have been used against the promotion of condoms and sex education. There is no scientific evidence to justify such concerns. On the contrary, there is evidence that most HIV prevention strategies support drug control efforts; they encourage drug users to enter treatment and offer opportunities to disengage from criminalized activities.

Mobilizing drug users

Objectives

Recognizing the IDUs' isolation and fear of harassment or possible arrest, it is understandable that they do not trust traditional and mainstream services. Peer educators, outreach workers and networks can bring prevention services to the hardest-to-reach IDUs and help establish trust between them and health services.

Description

Involving current and ex-drug users in designing, promoting and delivering services is important for prevention programs. Three types of peer-led interventions may be considered:

First, peer outreach and education programs recruit and train current or ex-drug users to deliver HIV (and other health) interventions to drug users, both in- and out-of-treatment. Training is often similar to that for other HIV education outreach workers, although peer workers have the benefit of personal experience and may be perceived by IDUs as more trustworthy and credible.

Second, drug-user organizations offer a structured group of current and ex-drug users, along with other interested individuals, that can represent the interests of drug users, advocate on their behalf and support and implement HIV and other programs for drug users.

Third, drug-user network interventions take advantage of existing communities of drug users to disseminate information and interventions. Networks of IDUs provide excellent opportunities for outreach programs to influence peer group and social norms. Members of the network are provided with information and HIV training and are encouraged to disseminate this information as well as HIV prevention materials—such as condoms and sterile injection equipment—throughout their sexual and drug-using networks.

Feasibility in resource-constrained settings

All three types of peer-led approaches have been introduced into many different developing and transitional countries. There are difficulties where drug users are criminalized or registered and cannot be employed by HIV prevention agencies. Similarly, the formal organization of drug-user groups may not be permitted.

Effectiveness

Peer education programs among drug users have proven effective in reducing both risk behavior and infection rates,²⁹ while peer-based needle-syringe exchange programs have proven better at reaching new clients than programs conducted by non-peers.³⁰ Social network interventions using peers have been shown to

SELECTING PRIORITY INTERVENTIONS FOR COMMUNITIES WITH HIV EPIDEMICS AMONG IDUs

Assessment and Monitoring

- Implement rapid assessment to inform intervention development.
- In parallel, develop a sentinel surveillance system to monitor behaviors and HIV prevalence/incidence.

Advocacy

- Educate politicians, community leaders and other decision makers about the urgent need for specific interventions. Provide evidence and experience from other relevant countries (include study tours for key decision makers).

Policy and Legislation

- Negotiate with local authorities a pragmatic and flexible application of laws and regulations to lower barriers to assistance and enable IDUs to change their behaviors to reduce risks.
- In parallel, review existing laws and regulations that impede effective implementation of HIV prevention strategies.

Information and Education

- Develop IEC programs for IDUs, sex workers and other vulnerable populations, using peer networks.
- In parallel, develop public education campaigns to reduce stigmatization of IDUs.

Training

- Develop workforce of outreach workers skilled in working with IDUs.
- In parallel, provide training to relevant health professionals in contact with IDUs.

Service Provision

- Ensure access to sterile injection equipment, condoms, VCT and user-friendly STD prevention and treatment services.
- In parallel, develop drug dependence treatment services.

Prisons

- Provide training for prison staff and prisoners and negotiate broader interventions with prison authorities.

HIV/AIDS Care

- Ensure equitable access to treatment and care.

be better than professional outreach interventions in both reaching IDUs and providing HIV education at lower cost for both recruitment and training.³¹ Although drug-user organizations have been established in developing countries such as India, documentation of their work has largely been limited to developed countries such as Australia and the United States.³²

Determining Priorities

As described above, a broad range of interventions may be applied at different levels, ranging from those that target individual behaviors to those that focus on national policies and legislation. Given the possibilities and limited resources available, how do planners and decision makers select the best possible combination

of interventions? Feasibility, acceptability and effectiveness of individual interventions and strategic combinations largely depend on local conditions. The stage and nature of the HIV/AIDS epidemic in a community are also important factors. Clearly, selecting priorities and determining strategic approaches must be based on an understanding of the local situation—hence the need for good quality situation assessment before investing in interventions. Countries with very low HIV prevalence will have different priorities from those with concentrated epidemics among specific populations—such as IDUs or sex workers—or generalized epidemics.

LESSONS LEARNED AND RECOMMENDATIONS

- IDU and associated HIV/AIDS are spreading rapidly and now affect all regions of the world.
- Drug-use patterns and HIV risk practices are dynamic, differing between populations, geographically, over time and in different settings. Careful monitoring and detailed investigation of risk behaviors and contexts of drug use are necessary to prepare timely and effective interventions. Rapid assessment and response (RAR) and behavioral surveillance survey (BSS) methods have been developed for this purpose.
- Multiple behaviors put IDUs at risk of HIV infection, including: shared drug solutions, needles, syringes and other injection equipment; contamination of drug solutions during production or distribution; unprotected sex; and various skin-piercing procedures, such as tattooing. Interventions must address all potential risk behaviors.
- There is evidence that HIV epidemics among IDUs in both developed and developing countries can be prevented, slowed and even reversed through specific programs, including: community-based peer outreach, increased access to sterile injecting equipment and greater access to drug dependence treatment, particularly methadone.
- At the individual level, IDUs are more likely to change their drug-use behavior to reduce HIV risks than their sexual behavior, although HIV-infected IDUs do change their behavior to protect their sexual partners.
- Where effective action has been taken to stem HIV epidemics among IDUs, no single element has been found to be effective on its own. Comprehensive prevention programs, based on community development principles, operating in supportive environments that include access to social welfare and primary health care underlie successful approaches.
- The earlier it is implemented, the more effective and cheaper HIV prevention targeting IDUs will be. If possible, programs should begin before HIV is introduced into this population or begins to spread widely (i.e., before HIV prevalence among IDUs exceeds five percent).
- Information and education projects are most effective if they are targeted at drug users and those most vulnerable, provide explicit information and are developed with the involvement of IDUs themselves. Information campaigns on IDU for the general public can increase stigmatization of IDUs.
- Risk reduction counseling can be effective if it is delivered by peers through outreach, and involves natural drug-user social networks.
- HIV testing should be voluntary and confidential, with adequate pre- and post-test counseling provided by someone who understands IDU issues. Testing can assist in risk reduction counseling and referral for treatment.
- Disinfection programs have limited effectiveness, and should be promoted only as a second-line option when sterile injection equipment cannot be secured.
- Programs increasing the access of sterile needles and syringes are core components of an effective HIV prevention strategy. Peer programs are more effective than those using professional personnel. Pharmacy programs can be very effective in increasing availability of sterile injection equipment. Needle and syringe disposal programs must run in parallel with distribution programs.
- Methadone is the most effective drug dependence treatment for reducing HIV transmission among opioid users. Because of high relapse rates, abstinence-based drug dependence treatment has limited success.
- Many IDUs, particularly those involved in sex work, are at high risk of sexual transmission of HIV. Sexual risk reduction information/counseling, treatment of STDs and condoms should be components of HIV prevention programs.

- Infected IDUs should have equal access to HIV treatment and care. This may require services sensitive and responsive to their specific needs.
- Policy and law reform may be required in some communities and countries to enable specific prevention interventions for IDUs to be implemented.
- Drug users can be very effective in mobilizing action and providing prevention services—such as through drug-user organizations—for their peers.
- Behaviors, peer networks, HIV risks and intervention options of young drug injectors—including adolescents—often differ from those of older IDUs, and may require different prevention and treatment approaches.

FUTURE CHALLENGES

There is now much experience in implementing HIV prevention programs in many different settings. The major challenge is in expanding these programs to a reach and penetration that matches the scale of the drug injection population—often when this is itself growing, sometimes explosively. Countries or regions where such expansion has been achieved are few; barriers to effective scaling-up are many.

It has proven difficult to convince authorities to take action before HIV has begun to spread—when action is most likely to be effective. Opportunities to achieve this are rapidly disappearing, as IDU spreads to almost every country, rapidly followed by explosive HIV outbreaks.

Whereas drug injection is beginning at a younger age (often during adolescence) in many developing countries, most research and evaluation of interventions have been limited to adult populations. Priority attention must be given to investigating IDU among young people and identifying effective HIV prevention strategies for this population. Other particularly vulnerable and marginalized populations of IDUs, including prisoners, sex workers, those living in rural settings, indigenous and minority peoples and the homeless must also receive consideration.

CASE STUDIES

THE LIFESAVING AND LIFEGIVING SOCIETY (LALS), KATHMANDU, NEPAL

LALS began in 1991 when two volunteers noticed much unsafe injection occurring in the streets of Kathmandu, and began an outreach program distributing sterile injection equipment. IDU was a hidden phenomenon in Nepal at that time, despite estimates of 25,000 to 40,000 opioid users in the Kathmandu valley, about 10 percent of them IDUs. Ignorance about HIV/AIDS and other harms associated with IDU were the norm.

LALS initially distributed sterile needles and syringes purchased privately, overcame distrust among the IDUs and began to learn from them. With access to NGO funding, LALS established an office and staff of outreach workers. Discussions with community leaders and authorities helped defuse initial antagonism; the formation of a link with the Narcotic Division was extremely important in assuring LALS' survival and operations.

At its peak, LALS employed 24 full-time outreach workers—including peers, ex-IDUs, nurses and social workers—and carried out a range of functions from primary health care and counseling to syringe exchange and condom distribution. A review of the impact of LALS' activities from 1991 through 1994 found that although HIV was present, it was not spreading through LALS clients, who were reporting marked decreases in frequencies of risk behavior.

LALS operates as an NGO, with only enough funding to reach 1,000 IDUs, many intermittently. With growth of the IDU population, and a move to the injection of buprenorphine rather than heroin, an HIV epidemic exploded among Nepalese IDUs about five years ago. Those served by LALS were protected to some extent, but most Nepalese IDUs were not in touch with LALS. The organization's experience illustrates both the effectiveness of these programs and the need to expand them.

HY VONG CAFÉ—CAFÉ HOPE, HO CHI MINH CITY, VIETNAM

Hy Vong (“Hope”) Café in Ho Chi Minh City (HCMC) is Vietnam’s first needle-exchange café, having grown from the first needle-exchange program in Vietnam, which was started by the Save the Children Fund (UK). The HIV epidemic in Vietnam began and remains largely among IDUs (themselves a rapidly growing population) with a prevalence of 40 percent or more in many parts of Vietnam. The epidemic has lasted longest in HCMC, and it is here that the most innovative responses, like Café Hope, are operating. While government took a “hands-off” approach to the original needle-exchange program, Café Hope is now supported by the governments of both Canada and Vietnam.

Café Hope is a small building in an enclosed area of a park near the waterfront, itself enclosed by a wire fence. The Provincial AIDS Committee of HCMC, responsible for management of the café, has an agreement with the police not to target the park unduly or arrest IDUs simply for injection—it is, to all intents, a “safe injection park.” Needle exchange consists of one container with sterile needles and syringes and another for disposal, located at the front of the café. In addition to the needle exchange, the café provides condoms, information, tea or coffee, facilities for showering or washing clothes and a small STD clinic.

The café is run by experienced ex-IDU peer workers, who also talk with the customers, settle disputes and provide education and information. Open 10 hours a day, seven days a week, Café Hope is visited by about 350 people each day. Increasing numbers of these are commercial sex workers who also inject drugs—a population not only at major risk themselves, but also important vectors in the spread of the epidemic to other groups, especially their clients, and a prime target for interventions.

RAPID PROGRAM—MÉDECINS SANS FRONTIÈRES, RUSSIA

From September 1997 to January 2000, Médecins sans Frontières-Holland (MSF-H) provided training and support for HIV/AIDS prevention among IDUs in the Russian Federation (RF), focusing on the use of the World Health Organization’s *Rapid Assessment and Response Guide on IDU* and the *European Peer Support Manual*. As part of their training, participants carried out a rapid situation assessment (RSA) in their city or region, as a major step towards designing and implementing an effective program to prevent HIV transmission among IDUs.

To sustain prevention activities from the training program, MSF-H formed a strategic alliance—the Russian AIDS Prevention Initiative-Drugs (RAPID)—with the international organizations IHRD, Open Society Institute-Russia (OSI-R) and Médecins du Monde. RAPID participants who successfully completed a Rapid Situation Assessment in their city or region were invited to apply for technical assistance from international advisors and funding for harm reduction programs from OSI-R. The Ministry of Health of the Russian Federation, through its infectious diseases and narcology departments, had significant and practical input in advising and supporting the training program and selecting participants. MSF-H and UNAIDS also worked together on joint training efforts and in developing Russian educational material prior to the training course. UNAIDS—in the framework of a broader contract with the Trimbos Institute—enabled staff of this institute to participate in the design and delivery of the first three training courses.

As a result, 199 participants from 61 cities in 52 regions of RF attended the training; 61 rapid situation assessments were undertaken; and, by mid-2000, 35 HIV prevention programs had been started. This comprehensive training program—including two courses held three months apart, city visits and the program’s integration with further capacity development and funding activities—has had a greater practical impact than the many short training courses that have been offered on harm reduction and HIV prevention in

Eastern Europe and elsewhere. This type of training approach appears to influence attitudes and behaviors of participants as well as providing knowledge and skills. The training program has also stimulated collaboration between health, law enforcement and other administrative agencies at the city and regional level; Ministry of Health structures at the federal level; other governmental bodies and NGOs and international agencies working in RF.

The combination of rapid assessment and response methods with the type of training provided by the MSF-H program within a strategic framework—which also includes additional technical assistance and funding—appears to be effective in assisting countries in Eastern Europe respond to HIV among IDUs. The approach may also have application in other parts of Central and Eastern Europe and the Newly Independent States and countries in Asia, Africa and South America.

RELEVANT CHAPTERS

- Chapter 12 *Social Marketing for HIV Prevention*
- Chapter 18 *Reducing the Risk of Mother-to-Child Transmission of HIV During Pregnancy and Delivery*
- Chapter 19 *Mother-to-Child Transmission of HIV Through Breastfeeding: Strategies for Prevention*
- Chapter 23 *Counseling, Testing and Psychosocial Support*

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C H A P T E R

23

*Counseling,
Testing and
Psychosocial
Support*

RACHEL BAGGALEY
IGNATIUS KAYAWE
DAVID MILLER



Counseling, Testing and Psychosocial Support

INTRODUCTION

Voluntary counseling and testing (VCT) have become an integral part of HIV prevention and care programs in many industrialized and some developing countries. Besides recognizing the importance of VCT in reducing HIV transmission in those who test seronegative, VCT services have evolved to reflect the changing needs of communities and the changing possibilities in management, treatment and support for HIV-infected people. This chapter offers information on the role of VCT in HIV care and prevention programs as well as practical advice on setting up VCT services.

WHAT IS VOLUNTARY HIV/AIDS COUNSELING AND TESTING?

HIV counseling is defined as “Confidential dialogue between a person and a care provider aimed at enabling the person to cope with stress and make personal decisions related to HIV/AIDS. The counseling process includes an evaluation of personal risk of HIV transmission and facilitation of preventive behavior.”

For the person being tested, HIV testing has consequences that reach far beyond the diagnosis. It may have negative consequences in communities where HIV-infected people are stigmatized.

THE COUNSELING PROCESS

The VCT process begins with raising community awareness of the ways in which VCT is beneficial for HIV prevention and access to appropriate care and support. The process continues with pre-test, post-test and follow-up counseling, which can be adapted to the needs of the client(s).

THE TESTING PROCESS

The diagnosis of HIV has traditionally been made by detecting antibodies against HIV. A wide range of HIV antibody tests are available today, including ELISA-based tests and many newer, simple and rapid tests.

VCT MODELS

Different models of VCT are available, and choice will depend on the needs of the community, seroprevalence of HIV and maturity of the epidemic, attitudes and political and community commitment to VCT, available financing and existing VCT resources.

SETTING UP VCT SERVICES

VCT services will be greatly aided if the following factors are first assured:

- Political commitment and institutional ownership
- Identification of an implementation team
- Awareness of the problem and investment in skills development for health care workers
- Identification of existing resources
- Adequate long-term financing

ORGANIZATIONAL STEPS

The steps required in establishing VCT services include:

- Site choice
- Coordination
- Selecting and training staff
- Counselor monitoring and support
- Record keeping and confidentiality assurance
- Choice of testing strategy
- Organizing a distribution and supply system
- Adapting or developing quality assurance guidelines

COUNSELING FOR PARTICULAR NEEDS

Counseling can be tailored to certain groups with particular needs and issues. These issues should include:

- Prevention
- Premarital counseling and testing
- Couples counseling
- Counseling for children and families
- Adolescents
- Maternal-to-child-transmission (MTCT) interventions and antenatal infant-feeding options
- Tuberculosis preventive therapy (TBPT)
- Vulnerable groups (injection drug users, commercial sex workers and men who have sex with men)
- Bereavement
- Blood donation

INNOVATIVE APPROACHES

Some innovative approaches to VCT have shown success. These include:

- Group information/counseling
- People living with HIV/AIDS (PLHA) support groups
- Home testing

BARRIERS TO VCT

Although VCT is becoming increasingly available in developing and middle-income countries, many people are still to be tested. This is the result of barriers to VCT, which include:

- Stigma
- Gender inequalities
- Lack of perceived benefit

MONITORING AND EVALUATION

Most evaluations have sought to demonstrate that VCT reduces incidence of HIV infection and contributes to prevention efforts. Monitoring and evaluation pose special challenges, because confidentiality is critical. Many of the usual monitoring and evaluation techniques are therefore not applicable.

ETHICAL AND LEGAL CONSIDERATIONS

Ethical and legal considerations often arise around the issue of HIV testing. These include:

- Pre-employment/pre-education HIV testing
- Mandatory HIV testing
- HIV testing following rape
- Testing without counseling
- Discrimination
- Partner notification

LESSONS LEARNED

VCT services have a pivotal role to play as an entry point to HIV prevention and care. Lessons learned in VCT encompass:

- VCT models
- Counselor training
- Counseling content
- Testing methods
- Support services
- Involving hard-to-reach groups
- IEC, awareness and advocacy
- Funding

CASE STUDIES

UGANDA: AIDS INFORMATION CENTRE (AIC)

The AIC philosophy is that knowledge of one's own HIV infection status is an important intervention and prevention strategy. The organization provides rapid testing with same-day results, syndromic management of other STDs, initiatives to promote VCT and sustain behavior change and special services for couples with discordant HIV results.

MALAWI: MALAWI AIDS COUNSELING AND RESOURCE ORGANIZATION (MACRO)

In late January 2000, MACRO introduced onsite use of simple, rapid, whole-blood, finger-prick testing with immediate confirmation. A prevention counseling protocol was developed, and counselor training conducted for same-day counseling with same-day test results. These new procedures dramatically increased demand for services.

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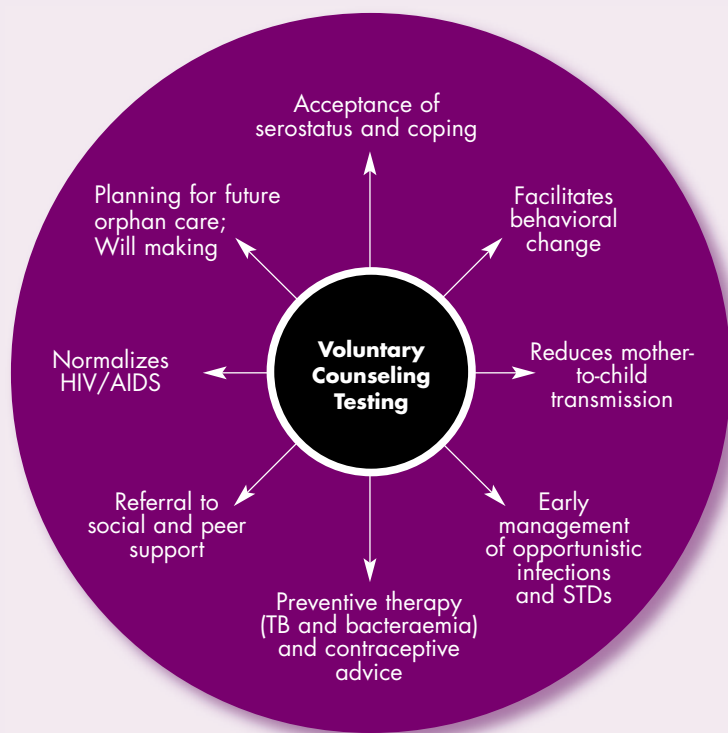
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I N T R O D U C T I O N

Voluntary counseling and testing (VCT) for HIV have become an integral part of HIV prevention and care programs in many industrialized and some developing countries. While recognizing the importance of VCT in reducing HIV transmission in those who test seronegative, VCT services have evolved and expanded to reflect the changing needs of communities and the changing possibilities in management, treatment and support for HIV-infected people.

The scope and challenges of VCT have changed over the past decade. VCT was initially used mainly to diagnose HIV infection in symptomatic people; testing was promoted as a component of HIV prevention. The development of antiretroviral treatment for people with HIV, less costly interventions to reduce the incidence of HIV-associated infections and relatively cheap and feasible methods to significantly reduce mother-to-child transmission (MTCT) of HIV have made the need to promote VCT for people with asymptomatic infection more compelling. Testing methods have also become simpler and cheaper, making VCT more feasible in many developing countries.

Figure 1
**VCT AS AN ENTRY POINT
FOR HIV PREVENTION AND CARE**



VCT services have a pivotal role to play as an entry point to HIV prevention and care. The advantages of this role are shown in Figure 1.

This chapter provides information on the role of VCT in HIV care and prevention programs and offers practical advice on setting up VCT services.

WHAT IS VOLUNTARY HIV/AIDS COUNSELING AND TESTING?

HIV counseling is defined as, “Confidential dialogue between a person and a care provider aimed at enabling the person to cope with stress and make personal decisions related to HIV/AIDS. The counseling process includes an evaluation of personal risk of HIV transmission and facilitation of preventive behavior.”¹

For the person being tested, the procedure has consequences that reach far beyond the diagnosis. Although there are many benefits to knowing one’s HIV status, testing may have negative consequences in communities where HIV-infected people are stigmatized. No one should be coerced into being tested. The decision to undergo HIV testing should be entirely voluntary.

Trust is one of the most important factors in the relationship between counselor and client. It enhances that relationship and improves the chances that the individual will act on the information provided. Given the possibility of discrimination, ostracism and personal recrimination that an individual diagnosed with HIV may face, it is all the more important that confidentiality be guaranteed. *Confidentiality forbids any reference to, or discussion about, a client, except within a professional relationship, and only then with the consent of the client.*

While some health workers are familiar with counseling clients about other issues such as treatment options, death and dying and/or family planning, many are not familiar with HIV/AIDS counseling and related matters. Even when health workers have been trained, professional understanding does not necessarily lead to an appropriate change of attitude or to professional behavior that guarantees confidentiality.^{2,3} Confidentiality must be guaranteed.

THE COUNSELING PROCESS

The VCT process begins with raising community awareness of how the testing is beneficial for HIV prevention and access to appropriate care and support. Without adequate community understanding, acceptance of VCT will probably be poor.

The process continues with pre-test, post-test and follow-up counseling, which can be adapted to the needs of the clients—whether an individual, a couple, a family and/or children. Counseling content and approach may vary considerably according to the group targeted: young people, gay men, drug users, sex workers, etc. Content and approaches may also reflect specifics of the context of the intervention. Examples include diagnostic HIV counseling (if testing is not available or desired) and counseling associated with specific interventions such as tuberculosis preventive therapy (TBPT) and interventions to prevent MTCT.

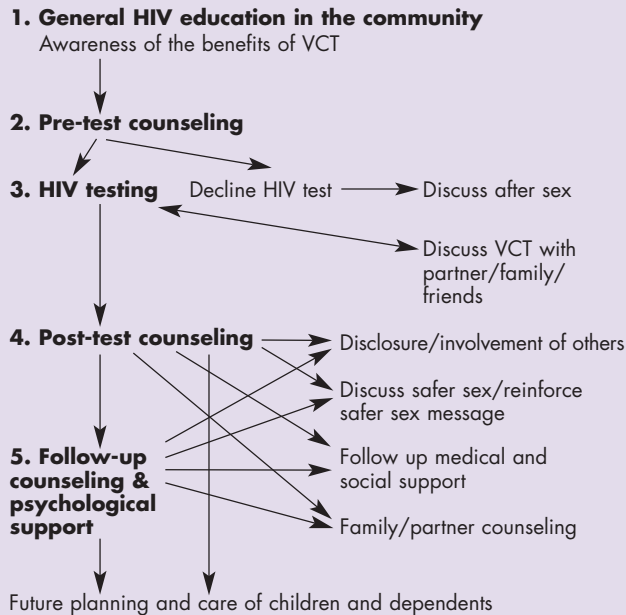
Good counseling practice contains certain core elements of content and quality that are important for all counseling sessions, as well as additional subjects that are important in specific circumstances and when specific interventions—such as MTCT and TBPT interventions—are available.

Establishing good rapport by showing respect and understanding will make problem solving easier in difficult circumstances. Reports have shown that the manner in which clients are informed of their HIV serostatus is very important in facilitating adjustment to news of HIV infection.^{4,5}

Important elements in good quality counseling include:

- Discretion and sensitivity to a nervous or embarrassed client
- Appropriate physical environment for comfort, privacy and confidentiality
- Good client reception, greeting and introduction
- Rapport, respect, interest and empathy
- Non-judgmental attitude
- Engagement of the client in conversation
- Active listening (non-verbal and verbal)
- Emotional warmth and support

Figure 2
THE VCT IMPLEMENTATION PROCESS



- Sensitivity to and accommodation for language difficulties
- Talking about sensitive issues plainly and in a manner appropriate to the culture, educational level and beliefs (spiritual and traditional) of the client
- Prioritizing issues to best use limited time and short contacts
- Techniques to overcome constraints such as time and privacy
- Appropriate management of client's distress or emotional reactions
- Flexibility to involve partner or significant other, when appropriate or requested

An outline of the key elements in pre- and post-test counseling is shown in Figure 2.⁶

PRE-TEST COUNSELING

During the pre-test session, the counselor will help the client decide whether or not to be tested for HIV. The following areas should be discussed:

- Reason for attending
- Knowledge about HIV and its transmission
- Misconceptions
- Assessment of personal risk profile
- The test itself (process, meaning of possible test results, window period, etc.)
- The meaning of seropositive and seronegative results and possible implications
- Coping with seropositive result
- Development of personal risk-reduction plan.
- Potential needs and available support
- Informed consent/dissent given freely

The client must be given adequate time to ask questions and digest new information. Where “same day” testing is used, clients should be given adequate time to think in the pre-test session.

Some people will defer testing at this stage and return later for the blood draw, after discussing the test with their partner, relatives or friends. If a client is not ready to undergo testing, he/she may wish to discuss VCT with his/her partner or family and return at a later date. When a client has a steady partner, he/she may prefer to return with the partner to be tested together. This approach is beneficial as it allows couples to make decisions together about safer sex.

POST-TEST COUNSELING

When simple/rapid tests are used, HIV test results may be available shortly after the specimen (blood, saliva or urine) is taken, or later on the same day. If testing is done at a central laboratory, clients may have to wait as long as two weeks for their test result.

If the client feels unprepared to receive his/her results, he/she should be given a future date to return. It may also be appropriate for him/her to bring a supportive friend or relative.

Whatever the result, post-test counseling should always be given. The two main objectives of the post-test counseling session are (1) support, and (2) prevention of HIV transmission. Post-test counseling accomplishes this through discussion of the result, sharing information and encouraging safer sex practices. Immediate plans, intentions and actions should be reviewed and follow-up plans discussed. In some circumstances, counseling sessions may last only 15 minutes. In view of the emotional consequences associated with giving an HIV test result, it may be necessary to allow up to 60 minutes for post-test counseling for some people.

Positive results

The following suggestions can aid counselors (either immediately at the post-test session or during follow-up counseling) when a result is seropositive:

- Give results simply, clearly and humanely.
- Allow time for the result to sink in.
- Discuss the meaning of the result for the client.
- Discuss the personal, family and social implications—including whom, if anyone, to tell.
- Deal with immediate emotional reactions.
- Check that adequate immediate support is available.

- Discuss follow-up care and support, which may include:
 - Ongoing counseling
 - Counseling of other family members and partners
 - Social support
 - Legal advice
 - Referral for screening and treatment of STDs
 - Family planning counseling
 - Special services for pregnant women
 - Medical referral, including TBPT
- Develop a personalized risk-reduction plan, including prevention of HIV transmission to partners who may be uninfected or untested, and use of safer sex practices (these areas may be dealt with in more depth during follow-up counseling).
- Identify options and resources.

Receiving a seropositive test result is often shocking and distressing. The client may be unable to take in large amounts of information at this time. To be supportive, the counselor should concentrate on showing empathy and conveying some measure of hope. The counselor must listen to—and hear—what the client is saying, and encourage him/her to voice his/her thoughts and worries. People's reaction to receiving a positive result will vary. Some may cry; others swear; some remain silent. The counselor may feel uncomfortable if the client starts crying, but can indicate that crying is alright by giving him/her some time to absorb the news. Sometimes, touching the client in a soothing manner can help, such as putting a hand on a client's shoulder for a moment.

The counselor should explore the client's immediate plans, and ensure that he/she will have adequate support. It is often very helpful to have a follow-up session after a few days, when the client has had time to reflect on the implications of the test result, and can discuss future plans, needs and follow-up.

Negative results

Although the client will be relieved to receive a negative test result, it is necessary to discuss repeating the test after three months if he/she has had unprotected sex in the three months before testing. This is the “window” period, during which a test may be negative, even though the client may have contracted HIV. It is also important to discuss sexual partners’ serostatus. If this is unknown or positive, he/she will still be at risk of HIV infection and discussion of safer sex is important. If the client has a steady sexual partner, the benefits of sharing results and testing the partner can be reviewed.

Intermediate/indeterminate results

Any serum that tests seropositive in the first test—but seronegative in the second test—should be retested using the two assays. Concordant results after repeat testing will indicate a positive or negative result. If the results of the two assays remain discordant, the serum is considered indeterminate. Fortunately, indeterminate results are rare. Serum from people with advanced immunosuppression and signs of disease occasionally will give an indeterminate result due to a decrease in antibodies. In these circumstances, a repeat test will usually be unnecessary and a presumed positive result can be given on clinical grounds.

If the person is asymptomatic and has an indeterminate result on initial screening, a second blood sample should be taken after two weeks or more. If the second result is also indeterminate, it should be tested with a confirmatory assay (Western Blot or similar assay). But if this result is also indeterminate, longer follow-up may be required at three, six, or 12 months. This will cover anyone who may have been in the window period. If the result remains indeterminate after one year, the person is considered to be seronegative.

The counselor must discuss the uncertainties associated with an indeterminate result with care and sensitivity. A follow-up plan must be made, explaining when the follow-up blood tests will be taken. Safer sex should be advised with all partners, regardless of their serostatus.

ONGOING COUNSELING AND PSYCHOSOCIAL SUPPORT SERVICES

Some people will require ongoing counseling and support upon learning their HIV status. In a Zambian study, fewer than 30 percent of people who tested seronegative received further counseling sessions, while more than 50 percent of those who tested seropositive sought further counseling.⁷

People turn to different sources for ongoing support after testing. Rather than confiding in their partners, women often turn to female relatives and men to male friends and relatives. Church-based and other religious groups provide spiritual support. This is important for many HIV-infected people in both developing and industrialized countries.⁸ In sub-Saharan Africa, many people seek the help of traditional healers, who can work closely with counselors and health workers in providing ongoing support and care for people with HIV.

For people who test seropositive in developing countries, the most commonly expressed concerns are medical.⁹ Even if asymptomatic, people worry about becoming ill and not having access to medical care. Many have seen HIV-infected friends or relatives suffer painful, undignified deaths, and fear this for themselves. VCT should therefore be linked with health care services such as palliative and home-based care services, and services providing social support. Other common concerns include the need for material support, especially for widows who care for orphans and sick dependents. The AIDS Support Organization (TASO) in Uganda found clients ranked the need for financial and material support higher than ongoing emotional support following VCT.¹⁰

THE TESTING PROCESS

The diagnosis of HIV has traditionally been made by detecting antibodies against HIV. A wide range of HIV antibody tests are available today, including ELISA-based tests and many newer, simple and rapid HIV tests.

ELISA TESTING

The most commonly used HIV-antibody testing method is the enzyme-linked immunosorbent assays (ELISA). The original ELISA tests used single recombinant antigens; with positive specimens usually confirmed using Western Blot technology, which is technically difficult, time-consuming and expensive. WHO has recommended testing strategies that show ELISA alone gives adequate sensitivity and specificity in high-prevalence areas.¹¹

ELISA tests were originally developed for blood screening, and these assays are suitable for batch testing (40 to 90 specimens per run, as many as several hundred specimens per day). This test has become routine in developed countries with centralized blood transfusion services, and has been gradually introduced in many developing countries for screening donated blood. But various elements are essential if ELISA is to perform accurately. Laboratory equipment such as pipettes, microtiter trays, incubators, washers and ELISA readers must be available. A constant supply of electricity and regularly maintained equipment are needed. Validity of the test results depends on skilled technicians who can, for example, pipette with accuracy, operate the equipment and prepare the necessary reagents. Storage at 2-8°C is needed, since ELISAs are vulnerable to temperature fluctuations. Reagents must attain 18-25°C for optimal reaction, but cannot be stored at this temperature, since their activity declines.

SIMPLE/RAPID TESTS

More recent advances in technology have led to the development of various rapid tests. Some use the same basic biochemistry, while others use simple agglutination techniques. Most come in a kit form that requires no other reagent or equipment and allows a single test to be performed (as opposed to batch testing). Because they are easy to use, staff can perform these new tests with minimal laboratory training. Some may also be stored at room temperature. Furthermore, their diagnostic performance is comparable with traditional ELISAs.

Advantages of using simple/rapid tests in VCT settings

Several evaluations¹² have demonstrated that simple/rapid tests perform similarly to ELISA tests. Errors in HIV antibody testing can be due to specifications in the tests, errors in the laboratory or clerical errors. Operational studies examining the use of simple/rapid tests in developing country settings—such as the AIDS Information Center (AIC) in Uganda—indicate that most errors are clerical and results of the simple/rapid tests are comparable to those of ELISA.¹³

Although the cost per individual simple/rapid test may appear higher than the cost per ELISA test kit, considerable savings can be achieved in situations where small numbers of tests are made. Often, many of the tests in the multiple ELISA test assays are not used and, when accurate costs are computed, the use of simple/rapid tests is more cost-effective.

Compared with the technically more difficult ELISA tests, the simple/rapid tests are easy to perform and interpret with less chance of error, thereby giving more accurate results overall. The majority of simple/rapid tests will give a preliminary result within a few minutes. Definitive results can also be obtained quickly if alternative simple/rapid tests are used for confirmation (see WHO testing strategies II and III).

All tests should be selected from the list of WHO recommended assays. They should also have been checked by a reputable national research laboratory to

determine performance under local conditions and on local sera. Based on these results, a testing strategy should be specified that clearly states the following:

- After testing with one rapid test, all samples testing negative shall be reported as negative.
- After testing with one rapid test, all those testing positive shall be subjected to a second and different rapid test.
- Those testing positive by the second test shall be reported as positive.
- Those testing negative by the second test (but positive by the first test) shall be subjected to a third test (the tie-breaker).

This strategy must be tested and proven accurate against a “gold standard.” Verification can be carried out by the national research institution. An example of this process was provided by the AIDS Information Center in Uganda.¹⁴

It is important to emphasize that although HIV antibody testing is highly sensitive and specific, all seropositive results from one test must be confirmed by an additional, different test.¹⁵

VCT MODELS

Different models of VCT are available; choice will depend on the needs of the community, HIV seroprevalence and stage of the epidemic, attitudes and political and community commitment to VCT, available financing and existing VCT resources.

Community acceptance of PLHA should also be factored into any decisions.

VCT SITES

VCT is being carried out in various settings in industrialized and developing countries, depending on needs and resources, including:

- Freestanding sites
- Hospital services
- NGOs within the hospital:
 - Integrated into general medical services as part of specialist medical care (STD, dermatology or chest clinic; antenatal and family planning services, etc.)
- Part of the continuum of care/home-based care (including palliative care services)
- Health center (urban or rural)
- Private sector (clinics and hospitals)
- Workplace clinics
- Legal requirements: pre-employment, pre-travel, pre-marital
- Youth and school health services
- Health services for vulnerable groups:
 - Sex workers
 - Prison populations
 - Refugees
 - Men who have sex with men
 - Children and orphans
- Self testing/home testing
- Research project/pilot project:
 - Associated with antenatal services and interventions
 - Associated with tuberculosis service and TB preventive therapy
- Blood transfusion services

SETTING UP VCT SERVICES

A conducive health system and an informed, supportive community are necessary to successfully implement VCT. Community and health system planning are as important as planning for the intervention itself. In setting up VCT services, the following steps lead to success:¹⁶

- **Ensure political commitment and institutional ownership.** If VCT interventions are being planned, there must be increased awareness about the benefits of knowing one's serostatus. It is also important that national policy and strategy plans support VCT. Institutions should authorize VCT as an integral part of service provision. In many areas, social mobilization efforts to educate the targeted populations have been shown to be a vital part of implementation; this requires political commitment.
- **Identify implementation team.** A team, or focal point, at the institutional or project level must be identified to develop any implementation, coordinate VCT development, ensure the acceptability of the service among health care staff and provide monitoring and evaluation of services once they are in place. The team may include members from a variety of disciplines, including administrative, VCT staff, spiritual leaders and counselors (such as the hospital pastor), health care staff already involved in counseling, community groups and NGOs assisting HIV care and support. PLHA will also be able to make an important contribution.
- **Raise awareness and invest in skills development for health care workers.** Even health care workers have a poor understanding of the benefits of VCT. They may be reluctant to undergo testing themselves, yet have personal and family worries about HIV.¹⁷ It is essential to provide appropriate training in general and specific counseling skills.
- **Identify existing resources.** When planning VCT services, it will be important to identify existing resources (including physical/infrastructure, personnel and financial resources and existing and support services). There is already a wide range of services in many areas with high HIV prevalence, but coordination and communication between them is often poor. It may be appropriate to use

the expertise gained from these existing services in planning a more widely available program. But if a completely new service is planned, the most appropriate models for the community's needs should be considered. It will also be important to have an inventory of support and care services for referral of seropositive people.

- **Securing adequate long-term financing.** If VCT services have been implemented and are found to be acceptable, demand will be created. Long-term funding must therefore be ensured before services are started. Estimates of the cost of VCT in developing countries range from US\$8 to US\$29 per client. In poorer countries heavily affected by HIV, it is unlikely that VCT will soon become affordable for all people, or that a significant proportion of the costs can be met by "cost recovery" initiatives. Subsidy schemes may therefore be necessary. In lower-prevalence or middle-income countries, such as those in South America and Asia, partial- or full-cost recovery may be an option. While studies show the main costs of VCT provision relate to labor and infrastructure, VCT has been shown to cost less per HIV and STD case averted than intervention strategies that do not include counseling.¹⁸

ORGANIZATIONAL STEPS

Choice of site

The choice of VCT site will depend on existing facilities and available resources.

Coordination

A system must be established to ensure coordination between VCT and HIV care and support services, so that each is informed of the other's needs and problems and confidential information-sharing about treatment is assured.

Selecting and training staff

Organization of training and ongoing counselor support must be arranged. Initial training courses typically last from one to two weeks. To manage psychological issues arising from VCT, counselors need courses that equip them with:

- Thorough knowledge of HIV/AIDS and information on how to get updates.
- Familiarity with the logic and content of pre-test and post-test counseling processes.
- Skills to break bad news, and contain the immediate and mid-term consequences.
- Ability to work with families in crisis.
- Discussion of “taboo” topics, such as sex, death and bereavement, anticipatory planning, etc.
- VCT management in the context of ongoing work.
- Ability to identify and manage psychological sequelae of risk recognition—anxiety, depression, suicidal thinking, grief, etc.
- Information for linking with local and national community resources in ongoing care and support.

Such courses may be intensive sessions or involve regular seminars on a part-time basis. Experience has shown that role-playing, active participation in discussion, feedback and case study examples are essential to assist trainee counselors in identifying and working through the key issues that arise in counseling management.

Counselor monitoring and support

Regular case monitoring or supervision in difficult situations and cases is critical to ensure counseling quality and identify needed training and support. Guidelines for evaluating VCT implementation, skills, content and level of supervision and counselor support have recently been successfully field-tested and published by UNAIDS.¹⁹

Work stress and burnout are inevitable among HIV/AIDS health workers of all disciplines in poor or resource-constrained areas, or when caseloads are very high and mounting. Under the same conditions, attrition of health staff is high.¹³ Access to supporting supervision and burnout prevention techniques are vital for the sake of the counselor and client.¹³

Record keeping and ensuring confidentiality

Clients may be seen by different counselors for pre- and post-test counseling and ongoing emotional and health care. A system must be in place to ensure that health care workers who need access to test results and case notes have it, while ensuring that confidentiality is not breached. Otherwise, clients’ needs may not be met. Adequate liaison and cross referral should be planned and encouraged between health care workers and counselors.

Choice of testing strategy

Consideration must be given to the most appropriate testing strategy—always ensuring that a quality-control system is in place. All seropositive tests are confirmed before a definitive result is given.

Organizing a distribution and supply system

A system for distribution and supply of both HIV test kits and reagents (if required) and consumables such as syringes, gloves, vacutainer bottles, disposable pipettes, etc., should be organized. Regular supply, secure storage, distribution and accounting must be ensured.

Record-keeping systems must be designed to ensure confidentiality of HIV-related data.

Adapting or developing guidelines on quality assurance

Guidelines to ensure the quality of the HIV testing strategy and the counseling content will need to be adapted for the particular setting.

COUNSELING FOR PARTICULAR NEEDS

COUNSELING FOR PREVENTION

VCT has been shown to help people change their sexual behavior to prevent HIV transmission.²⁰⁻²⁶ In some high-prevalence countries, people often assume that they must already be infected and therefore do not bother using safer sex practices. But even in these areas, the majority of people will test seronegative, presenting an important opportunity for counseling on safer sex and HIV prevention. In these cases, VCT can play an important role in the prevention of HIV transmission.

PREMARITAL COUNSELING AND TESTING

Several countries in Asia and sub-Saharan Africa have proposed that couples undergo VCT prior to marriage. A voluntary program already exists in some of these countries, and many church groups and religious organizations support premarital VCT. Premarital VCT can help in future planning and decision-making about having children. Those who test seropositive should not be discriminated against. Both partners should undergo testing voluntarily, understand the implications of the test and decide what they will do whatever the outcome.

COUPLES COUNSELING

Some countries have promoted counseling couples together to facilitate disclosure and safer sex behavior. Although this has been shown to be successful in reducing HIV transmission, counselors should be aware of barriers to couples counseling and worries about the fate of seropositive women. (Couples counseling is also discussed in the sections on MTCT and barriers to testing.)

Some people do not want to be tested with their partners and may not come forward for testing. While couples counseling should be encouraged, counseling approaches should be flexible and respectful of different needs.

TYPES OF COUPLES COUNSELING

- Premarital
- Couples counseling associated with MTCT and other interventions
- Married couples or regular partners
- Serodiscordant couples
- Same-sex couples

Disclosure of one's HIV status increases both practical and emotional support for those who test seropositive.²⁷ Sharing one's HIV status with one's sexual partner is important in order to make appropriate changes in sexual behavior to reduce HIV transmission. Revealing serostatus often takes time, and disclosure to spouses or partners can be problematic for a number of reasons—including fear of reprisals, stigma or loss of economic and emotional support. Special counseling and support are needed to explore these barriers to disclosure and facilitate communication between couples.

Many couples will have discordant results. This is often not understood; partners may believe that both should have the same result. Counseling discordant couples poses special challenges. These include assisting the couple to cope with their emotional reactions, helping them develop a plan to not only protect the seronegative partner, but also to help the HIV-positive partner live with the infection. Family planning must be discussed.

COUNSELING FOR CHILDREN AND FAMILIES

HIV testing of infants must be considered carefully, because diagnosis is difficult in children under 16 months, and there are implications for the mother and the rest of the family.

All children born to HIV-positive mothers will have maternal antibodies for HIV at birth. They will test seropositive using ELISA or simple/rapid testing, but are not necessarily HIV-infected. The mother's antibodies start to disappear when the baby is nine months to 15 months old. HIV antibody testing is therefore recommended after 16 months. Testing that identifies viral components (such as polymerase chain reaction [PCR] or viral culture) can detect HIV infection in an infant four to six weeks old. More than 90 percent of perinatally infected infants will have a positive DNA PCR by the time they are four weeks old, and by six months, PCR has a sensitivity of approximately 99 percent.^{28,29} But these techniques are expensive and difficult to perform; they require technical expertise and complex laboratory equipment. They are not widely available in developing countries, but may be available in the private sector or research institutions.

Counseling and testing children born to HIV-infected mothers

When known seropositive mothers are given interventions to prevent MTCT, up to 10 percent of children will be infected despite the intervention. (See Chapters 17 and 18 for in-depth discussion of MTCT.) In this situation, the mother will already know her seropositive status and may have already shared this with the baby's father. Even if a mother has received antenatal counseling, she may still need support to deal with many outstanding anxieties and problems. These issues may need to be addressed over the weeks and months following testing.

SPECIAL CONSIDERATION WHEN COUNSELING AND TESTING CHILDREN

- Future medical care of child
- Emotional support of the child, including dealing with his/her illness and parental illness or death
- Anxieties about other children in the family who may be infected
- What and when to tell the child
- What to tell siblings and other family members
- Coping with stigma and discrimination at school and in the community
- Future plans—what to do if the child's mother or father becomes ill or dies
- Provision for the child's future. Making a will and dealing with issues around "property grabbing"

Testing children as "index cases"

The possibility of infection in a child may be the first indication that HIV is a problem in the family. If an infant tests positive, his/her mother will almost always be infected too—and the father will probably also be infected. Siblings may also be infected, leading to worries for future children. If older children are found to be seropositive, there may be anxieties about child sexual abuse, especially if the mother is seronegative.

ADOLESCENTS

HIV-infected adolescents may have become infected during infancy or childhood, in a number of ways. Some children who were infected with HIV at birth or through breastfeeding survive into their teens. In countries where antiretroviral (ARV) therapy is available, some HIV-infected children have reached

adulthood and had children of their own. Other children may become infected through tainted blood products, surgical procedures, sexual abuse and incest. Many young people also begin sexual relationships with their peers—or older sexual partners—in their early teens. Young girls are particularly vulnerable to HIV infection: immaturity of their reproductive tract facilitates HIV transmission. In some settings, poverty necessitates exchanging sex for food or school requisites. (Chapter 26 focuses on care and protection programs for vulnerable children.)

A child (defined in most countries as younger than 15 years of age) or adolescent (less than 18 years) will usually require parental or guardian consent before testing. While legal requirements vary, counselors must protect the rights of adolescents by ensuring that they have freely agreed to VCT, fully understand the meaning of the HIV test and its implications and that appropriate post-test support will be available. Counseling adolescents poses particular challenges due to their age, the sensitive nature of adolescent sexuality and the need to guarantee voluntary informed consent. (See Chapter 7 for more information about youth intervention programs.)

In some sub-Saharan African countries where children and adolescents have been tested as part of an HIV prevention campaign or blood-donor recruitment, teachers have given consent. This practice may not be considered appropriate or ethical, and is not supported by UNAIDS. Wherever children test seropositive, they should not be discriminated against, either at school or at home, and should be given adequate ongoing emotional support.

SPECIAL CONSIDERATIONS WHEN COUNSELING AND TESTING ADOLESCENTS

- Parental consent may be required
- Diagnosis and treatment of other STDs
- Potential history of child sexual abuse
- Particular vulnerabilities and emotional needs of adolescents
- Stigma and discrimination at school and home
- Lack of support groups/services available for young people

MTCT INTERVENTIONS AND ANTENATAL INFANT-FEEDING OPTIONS

ARV interventions for preventing MTCT

Antiretroviral (ARV) therapy interventions are being implemented at pilot sites in many countries in sub-Saharan Africa, and are more widely in Asia and Latin America. If ARV is available, and if a pregnant woman must decide whether she needs it, she must first know and understand her HIV status. VCT is therefore considered an essential element of services for women in antenatal clinics.

Although pregnant women will require the same information as other people in pre- and post-test counseling sessions, additional areas must be explored. These special considerations include:

- **Disclosure.** Sharing results with the baby's father/her partner and close family members requires sensitive counseling. Interventions to reduce MTCT may involve changing infant-feeding methods that will make it difficult to conceal a seropositive status. Sharing HIV results during pregnancy should be encouraged if women have adequate emotional support.

- **Reinforcing safer sex messages to all women and their partners.** Even in high HIV-prevalence areas, the majority of women tested during pregnancy will be seronegative; this is an opportunity to reinforce safer sex messages. Women who become HIV infected during pregnancy or during breastfeeding are at increased risk of transmitting HIV to their babies, due to the high viral load associated with acute infection.³⁰
- **Promotion of couples counseling and testing.** Where MTCT interventions are available, antenatal testing should always be offered to couples. If women are tested alone, if their partners refuse to be involved in the VCT process, or if they feel unable to disclose their serostatus to their sexual partner, it becomes harder for women to take full advantage of the benefits of VCT. They will have difficulties making decisions about using safer sex practices, planning for their own and their families' futures, accessing care and support and making informed infant feeding choices. But most women do test alone in MTCT pilot projects, and disclosure to partners occurs infrequently. Testing women individually should be the exception (at the women's request), and not the rule. But the decision to test as a couple should always rest with the woman.

Infant feeding counseling

Thirty percent to 35 percent of MTCT occurs through breastfeeding. It is therefore important that even in settings where ARV interventions are not available for pregnant women—but where they have access to VCT—they be advised of all available infant-feeding options. Even in the highest prevalence areas, the majority of women will test seronegative. It will be important that the positive aspects of breastfeeding are reinforced to this group, and not diluted by the promotion of non-breastfeeding options. It also must be emphasized that, although they are seronegative at the time of testing, they may still be vulnerable to HIV if they do not know the serostatus of their partners (up to 25 percent of couples have discordant results) or if their partners have other sexual partners and do not

use condoms. If they become infected during the antenatal period or during breastfeeding, they have a high risk of passing the infection on to their infants. (See Chapter 19.)

The decision whether or not to be tested must always be informed and voluntary. Some women will choose not to know their status. This decision must be respected and supported. If a woman is unaware of her status, she should usually be encouraged to breastfeed her infant.

COUNSELING FOR TUBERCULOSIS PREVENTIVE THERAPY (TBPT)

In many countries, TB is the leading cause of death in people with AIDS. In countries where TB is common, many people will have been infected, sub-clinically, during childhood and adolescence. If they then become infected with HIV, a reactivation of this latent TB infection can occur causing clinical disease (active TB). It has been shown that tuberculosis preventive therapy (TBPT) can reduce the incidence of clinical TB in people with HIV by 50 percent.³¹ It is, however, important to screen people for clinical TB before TBPT is given. WHO and UNAIDS recommend that TBPT (with daily dose of isoniazid for six months) should be offered to HIV-positive people following VCT.³² Other preventive therapies can also be offered during the post-test counseling session, such as cotrimoxazole (Septrin/Bactrim) prophylaxis, which is routinely given to people with CD4+ counts of less than 200 in industrialized countries for prevention of pneumocystis carinii pneumonia (PCP). In developing countries, prophylactic administration of cotrimoxazole may prevent common bacterial infections in people with symptomatic HIV disease. Initial promising results from Côte d'Ivoire have shown that cotrimoxazole prophylaxis may reduce morbidity and mortality

in HIV-infected people.³³ Specific information about adherence to therapy and possible drug interactions and adverse effects should be discussed with clients during the post-test counseling session. (Chapter 25 provides information about management of HIV and its complications.)

VULNERABLE GROUPS

Injection drug users (IDUs)

HIV prevention and care for IDUs already infected is complicated by discrimination and marginalization of this group. Their VCT services are poorly developed, often with great resistance to testing because of fear of discrimination, a lack of voluntarism, and confidentiality. (See Chapter 22 for in-depth information about risk reduction in IDUs.)

PROBLEMS ASSOCIATED WITH VCT FOR IDUS

- Seen as a low priority and lack of political will
- Lack of acknowledgment of HIV as a problem among IDU population
- Lack of resources and services available
- Illegality of IV drug use
- “Hard to reach” population
- Psychosocial problems frequently associated with IDU
- Punitive rather than prevention and care approach to IDU
- Needs of IDUs in prisons ignored
- Mandatory testing before medical and psychosocial treatment or entry to prison

Commercial sex workers (CSWs)

In many countries, directing care and support to CSWs has been considered an important approach in HIV prevention. Offering VCT, STD screening and treatment, group discussions about prevention and free condoms for HIV-negative sex workers can help increase condom use and reduce the incidence of HIV and other STDs. (Chapter 8 focuses on reducing HIV risk in sex workers and their clients.)

SPECIAL CONSIDERATIONS WHEN OFFERING VCT TO CSWs

- Avoid blame and stigma among CSWs.
- Offer comprehensive STD as well as family planning services.
- Target clients of CSWs.
- Ensure ongoing support for HIV-positive CSWs.

Men who have sex with men (MSM)

VCT services for men who have sex with men (MSM) are well established in Europe and North America, but few services for these men are available in developing countries. In many resource-constrained countries, homosexuality is either not acknowledged or illegal; the need for VCT among MSM is therefore ignored. (See Chapter 11 for more information about HIV prevention activities targeting MSM.)

BEREAVEMENT COUNSELING

Counseling for partners and families following the death of a loved one is often overlooked in developing countries. The death of a person from AIDS may give rise to new problems for surviving friends and family members. Counseling can help the bereaved person to discuss and reflect on the changes brought about by loss, mourn appropriately and enable him/her to look to the future. Partners and parents of a child who dies from AIDS may have unresolved fears and concerns for themselves or other family members, and can be helped to make decisions about testing.

The process of grieving may last many months or years. But some people find that a single counseling session can clarify their thoughts and feelings, and reassure them that they are coping as best they can under the circumstances. This is particularly true for people who have other emotional supports, such as family, friends and church or spiritual support. For others, several sessions may be helpful. Some people never completely come to terms with a loss, particularly if it is the loss of a child. In high HIV-prevalence developing countries, grieving may be more difficult when there have been multiple losses of friends and relatives due to AIDS.

BLOOD DONOR COUNSELING

Counseling blood donors about HIV is different from VCT in other settings, because the first concern is safeguarding the blood supply. Furthermore, blood donation counseling is not ongoing; one pre-donation session is usually the rule. This session focuses on providing information; however, some personal risk questions should be asked. Given the limited time of these sessions, this requires tact and skill for the counselor. Some countries have established systems whereby blood donors who test seropositive may be referred for further VCT and needed care. But the practice of using blood-screening services to learn HIV serostatus should be discouraged.

INNOVATIVE APPROACHES

GROUP INFORMATION/COUNSELING

In situations with limited resources and few counselors, group counseling can increase the number of people having access to VCT. Group counseling can provide pre-test information to women in antenatal settings, couples and groups of people who seek services. This may be more aptly described as “group interaction,” where people learn details about HIV transmission, risks, testing and interventions, as “group education” rather than counseling. The counselor who leads the group session will need skills similar to those required for individual counseling, and will also need to cope with the complex dynamics that may arise in a group.

Although group work has been used successfully as part of pre-test preparation, it should not replace individual pre-test counseling; everyone undergoing an HIV test should have the opportunity to receive individual pre-test counseling. Informing patients of their test results and post-test counseling should always be conducted on an individual basis. It may be very difficult for individuals to discuss personal issues and fears in a group setting, and people may feel swayed by the opinion of the group and need time to discuss their own circumstances. Individual counseling should always be available to participants who wish it.

There are many examples of post-test groups where people gain mutual support from others’ VCT experiences. Again, this should not replace post-test and ongoing counseling—which should be available to all people following VCT.

PLHA SUPPORT GROUPS

People living with HIV/AIDS (PLHA) describe feeling empowered by support groups, and state that the group approach helps them to overcome fears that can accompany a seropositive result. Support groups offer a forum for problem solving in areas such as coping with stigma and discrimination, relationships, sexual concerns, care of partners with HIV and issues related to children and dependents. By sharing their experiences, group members can give each other new

perspectives. Some groups provide practical support and advice on income generation, legal issues and writing wills. For HIV-positive people in low-prevalence countries, where there is little understanding about HIV in the community, support groups can play an important role in overcoming feelings of isolation. These groups may or may not be facilitated by a trained counselor.

HOME TESTING

Several self-test kits are now available, allowing people to test themselves for HIV at home. Although there are advantages to using home collection and self-testing kits—they offer privacy and may provide a service for people who do not seek testing at VCT sites—they should be used with caution. Users must understand the need for a confirmatory test and be informed about the “window” period. Regulations must be in place to ensure their quality, and self-test kits should contain clear instructions and be easy to use.

There are also concerns that people using self-test kits receive no pre-test counseling or access to follow-up care and support, and that some may be coerced into testing.

But there are special groups who could benefit from home testing. These include health care workers who may be reluctant to be screened for HIV after occupational exposure because they fear they may already be infected, and people who may wish to self-test before mandatory testing for travel abroad or issuance of a work permit.

BARRIERS TO VCT

Although VCT is becoming increasingly available in developing and middle-income countries, many people are still greatly reluctant to be tested. This reluctance is the result of barriers to VCT, which are discussed below.

STIGMA

HIV is highly stigmatized in many countries, and HIV-infected people may experience social rejection and discrimination. In low-prevalence countries, or places where HIV is seen as a problem of marginalized groups, rejection by families or communities may be a common reaction. Fear of rejection or stigma is a common reason for declining testing. Linking testing with ongoing care and support services, as well as HIV education and awareness in the community, can reduce stigma and may contribute to wider acceptance of VCT. VCT may also be seen as an important way of overcoming stigma and—as more people become aware of their HIV serostatus—of normalizing the disease.

GENDER INEQUALITIES

In many countries, women worry that they would suffer shame and discrimination if they were known to be HIV-infected. Many women are particularly vulnerable, and risk violence, abandonment, rejection or even loss of their homes and children if their seropositive status becomes known. The need for protection and support of vulnerable women who test seropositive must be considered when developing VCT services.

LACK OF PERCEIVED BENEFIT

Lack of perceived benefit is another common barrier to testing. In poorer high-prevalence areas, many people do not want VCT. They may be afraid that little help will be available to them if they learn they are infected, and therefore it is better not to know their serostatus. Linking VCT with comprehensive care and support services and improving acceptance of the HIV-infected in the community can reduce this barrier to testing. Offering interventions to prevent MTCT once status is known is another major benefit of VCT.

MONITORING AND EVALUATION

Most evaluations of VCT have sought to demonstrate that VCT reduces incidence of HIV infection and contributes to prevention efforts. VCT efficacy reports have therefore largely concentrated on outcomes, such as the role of VCT in modifying sexual behavior.³³⁻³⁷ But VCT services in developing countries are often new interventions, with monitoring limited to attendance reports, coverage and return rates.

The quality of VCT counseling determines service outcome. Poor-quality counseling can result in misunderstanding and even resistance to change.

VCT monitoring and evaluation poses special challenges because confidentiality is a critical element; many of the usual assessment techniques are therefore not applicable. While some measures are presented in the box below, additional guidance on monitoring and evaluation of VCT can be found in recent UNAIDS guidelines cited in the reference list.

One critical difficulty with the evaluation of VCT is the complexity of variables influencing pre-test and post-test behavior. It may be unreasonable to expect that a few counseling sessions will significantly affect sexual behavior in the context of gender inequality and disempowerment. Future counseling evaluation strategies may need to be less linear if the added value of counseling in VCT is to be appropriately revealed.

OPERATIONAL MONITORING AND EVALUATION

In operational settings it is important to monitor and evaluate the services, both at an individual and community level.

OUTCOME MEASURES

Individual

- Reduction in cases of HIV transmission (either by direct sero-incidence studies or by proxy indicators, such as rates of STDs or sexual practices (condom use with regular and casual partners, number of partners, etc.)
- Partner/family disclosure
- Uptake of partner testing
- Uptake of care and support services by people testing seropositive
- Long-term follow-up of people undergoing testing and their families and children (social consequences of testing, long-term coping with HIV infection and future planning, use of safer sex practices over time, uptake of family planning and pregnancy rates, morbidity and mortality, etc.)

Societal/community responses

- Acceptance of HIV in the community and measure of stigma associated with HIV infection
- Attitudes toward VCT in the community

OPERATIONAL FACTORS

At the VCT Sites

- Uptake and acceptability of VCT
- Quality of counseling
- Reliability of testing strategy (including external quality control)
- Stress and burnout among counselors/health care workers

In the community

- Attitudes toward VCT in the community
- Uptake of VCT
- Availability and quality of community care and support services

EXAMPLES OF POSSIBLE INDICATORS

Numerator	Denominator
People accepting VCT.	All people invited for VCT.
People returning for test result.	All people tested.
People sharing result with partner.	All people receiving test result.
HIV-positive people accessing care and support services.	All HIV-positive people requiring services.

ETHICAL AND LEGAL CONSIDERATIONS

PRE-EMPLOYMENT/PRE-EDUCATION HIV TESTING

The intention and result of pre-employment testing is to exclude those who test seropositive. Such testing is, therefore, an abuse of human rights, but some employers continue to test job applicants or employees before sending them for further studies. Some countries insist on testing people before allowing them entry to take up a job or studies. Pre-employment testing is often carried out without adequate pre-test counseling and informed consent—sometimes without the knowledge of the person undergoing the medical examination, who may be unaware that his/her blood is being taken for HIV testing. (Chapter 27 explores issues related to HIV and human rights; Chapter 9 looks at HIV prevention in the workplace.)

MANDATORY HIV TESTING

Mandatory testing has been applied to many groups, including immigrants, migrant workers, refugees, prisoners, CSWs, IDUs, military recruits and pregnant women. Mandatory testing has no advantages over VCT, and several disadvantages.

DISADVANTAGES OF MANDATORY HIV TESTING

- Mandatory testing without informed consent or counseling does not help people change their sexual behavior to reduce HIV transmissions to others.
- Testing without counseling and follow-up support can be devastating for those who test seropositive. It may lead to depression and irresponsible actions, including violence to self and others.
- Mandatory testing may lead to a false sense of security. For example, it is illogical to require mandatory testing of surgical patients to “protect” health care staff, as universal precautions should be applied to all patients. In addition, patients who test seronegative may be in the “window” period.
- Insisting on testing new employees or military recruits will not insure that they are HIV free, as they may acquire HIV infection during their employment or military service. It would be better to use resources to offer care and support to those with HIV and provide comprehensive HIV prevention and education programs for employees.
- The need to provide evidence of a negative test result has led to anecdotal reports of health workers selling negative certificates to untested people.
- Mandatory testing in health care settings, such as antenatal clinics, may lead to mistrust by clients and discourage them from seeking health care.

HIV TESTING FOLLOWING RAPE

There is a more convincing argument for mandatory testing of rapists, as provision of ARV therapy to rape victims can prevent HIV transmission. But in the majority of cases it is impossible to test the rapist, as he is rarely apprehended. The rape victim should receive counseling in order to get tested for all STDs including HIV, and to determine pregnancy.

TESTING WITHOUT COUNSELING

There may be circumstances in which people specifically request or decline pre-test counseling—for example, when they have had previous tests, or say that they already have enough information. In these circumstances, people should not be refused testing and should receive post-test counseling.

DISCRIMINATION

An HIV seropositive test result has led to deportation, or incarceration in some countries. HIV testing may also be mandatory before receiving a visa or pursuing further studies (with a seropositive result precluding foreign travel and/or education). UNAIDS/WHO opposes mandatory testing under any circumstance.

PARTNER NOTIFICATION

India and several other countries now require that seropositive persons inform their partners of their status before marriage.³⁸ A resolution from the Southern African Development Community (SADC) Health Sectors meeting in April 1999 proposed that partner notification and notification of close family members of people with AIDS (although at this point not HIV) should be compulsory. Supporters argue that AIDS notification is necessary to create greater openness about HIV, and that it will protect sexual partners and caregivers from becoming infected with HIV. But this proposal has been criticized within sub-Saharan Africa and by international human rights and activist groups, who charge that it will limit people's rights to privacy and confidentiality. UNAIDS and its co-sponsors are currently developing policy options for governments considering broader notification strategies.

LESSONS LEARNED

VCT MODELS

All VCT models have both benefits and disadvantages. It is important to support existing VCT services and help health care structures include VCT among their services. Advantages of particular programs may be specific for individual sites, though some generalizations can be made. Cross-referral between VCT services should also be considered—for example, couples can be referred from MTCT interventions to free-standing sites for counseling together; symptomatic clients can be referred from free-standing VCTs to clinic-based services for appropriate medical interventions. Other VCT models such as peer and community counseling should also be considered.

TRAINING OF COUNSELORS

The type and length of training required to provide high-quality counseling is still under debate.

Counseling training programs may be as long as four weeks (the Kenya association of professional counselors) or as short as three days (some VCT programs associated with MTCT interventions argue that VCT training can be achieved in this time period.). Those who propose longer training maintain that counselors who receive inadequate training cannot handle the complex behavioral aspects of counseling that may lead to behavior change.

An alternative approach suggested is a cadre of “health educator/counselors” for routine pre- and post-test counseling and “expert counselors” to lend support with difficult cases and provide support and supervision.

There is, however, clear agreement that ongoing support, supervision and training are essential. Without these, staff motivation, morale and counseling quality will likely deteriorate.

It is also important to develop minimum standards of counselor training. In most VCT sites, monitoring and evaluation of counseling services consists of counting uptake and return rates—but more critical assessments are needed to monitor counseling quality. These standards may vary, depending on the backgrounds of trainees.

COUNSELING CONTENT

There should be a greater emphasis on client-centered counseling. The driving force behind VCT has been its usefulness as a determinant of effective medical interventions, such as MTCT. This focuses counseling on a particular aspect of VCT, and may lead to neglect of the clients' real needs and concerns.

HIV TESTING METHODS

New simple/rapid (S/R) technology should be embraced. S/R using finger prick whole blood allows testing anywhere, including home-based care. Algorithms using either initial testing of all samples with two S/R tests and a third as a tiebreaker, or initial screening and re-testing of all seropositives can be considered. All services employing S/R have reported an increase in demand and return rate, with satisfaction of both clients and counselors. Some individuals will still decline to be tested or defer testing after having their blood sample taken. This choice should be respected.

Saliva- and urine-based HIV tests are good alternatives to blood tests. Both fluids contain HIV antibodies, the presence of which allows for HIV detection. They do not require needles, so health care workers collecting the specimen are at very low risk of contracting HIV. These samples are also well suited for people who do not like having their blood drawn, people with difficult veins, hemophiliacs and those taking medications that affect coagulation. Although they are about as accurate as blood-based tests, saliva- and urine-based HIV tests are not yet widely used, in part because of their cost.

SUPPORT SERVICES

VCT services should allow referral for ongoing support. The following services could be considered:

- Emotional support/ongoing counseling
- Social support
- Medical support
- Pre-test and TB preventive therapy (TBPT)
- Cotrimoxazole
- Family planning
- Home-based care (HBC)
- Legal counseling/support
- Family counseling

INVOLVEMENT OF HARD-TO-REACH GROUPS

When developing VCT services, particular consideration should be given to providing accessible and appropriate services for groups such as:

- Men (in MTCT interventions)
- Adolescents
- Couples
- Sex workers and their clients
- Injection drug users (IDUs)

IEC, AWARENESS AND ADVOCACY

Although knowledge about HIV among most age groups in most communities is very good, there has been little emphasis on the benefits of VCT. Improved and appropriate advertising and awareness raising are needed. Special emphasis on messages for young people, couples, sex workers and their clients and other groups must be considered. The metaphors of HIV must also change, making the messages softer and more supportive. Stigma remains the most important challenge.

FUNDING ISSUES

Adequate long-term funding is essential to provide high quality service and maintain staff morale.

CASE STUDIES

“In countries where HIV prevalence is high and where there are numerous deaths attributed to AIDS, it is common for many to develop feelings of hopelessness and a misperception that behavior change is futile. In these settings, the power of positive behavior change messages may be reinforced by effective HIV counseling and testing services.”³⁹

UGANDA: AIDS INFORMATION CENTRE (AIC)

The HIV/AIDS epidemic arrived early in Uganda and hit the country hard. It came in the midst of devastation from civil strife and economic hardship. By the late 1980s, Uganda had the highest rates of infection in the world. Today, Uganda is recognized for its effective response to the epidemic. This success is thought to have resulted from several factors, among them: (1) An assertive and open response from the government; (2) Prevention programs implemented by both the government and NGOs; (3) An active role for PLHA; (4) Involvement of religious organizations; and (5) A sustained, high level of support by the donor community.⁴⁰ VCT was one of the early programs implemented.

Many Ugandans wanted to know their HIV serostatus after awareness campaigns began in 1986. At that time, few HIV testing services were available and even fewer provided counseling. This placed an enormous burden on the national blood bank, where individuals interested in knowing their serostatus went to donate blood. The blood bank was not equipped to provide counseling and support, and blood donated under these circumstances proved to be a costly misuse of the blood banking services.

Several organizations met and discussed the need for anonymous and voluntary counseling and testing. As a result, the AIDS Information Centre (AIC) opened in February 1990, with the philosophy that knowledge of one’s HIV infection status is an important intervention and prevention strategy.⁴¹

AIC originally offered well-planned VCT services with informed consent and a referral system for more comprehensive care and support. This referral system was developed in consultation with other NGOs, community-based organizations, hospital directors, PLHA organizations and various other service providers.

Today, AIC provides a wide range of services: VCT using rapid testing with same-day results, syndromic management of other sexually transmitted diseases (STDs), condom education and distribution, tuberculosis education and referral, family planning information, psychosocial and medical services through the post-test club, initiatives to promote VCT and sustain behavior change, food supplementation, peer support through the post-test club and special services for couples with discordant HIV results. In addition, AIC offers training for a variety of service needs, including integration of rapid testing with prevention counseling into other clinical services.

Since it began operations a little over a decade ago, the AIC has served more than 500,000 clients.

Lessons learned

- VCT services utilizing rapid test are feasible, cost beneficial and acceptable to clients and counselors.
- Rapid testing and counseling increase availability and demand for VCT services.
- Counseling should be prevention-focused and include risk-reduction planning.
- Ongoing support through a post-test club helps HIV-positive clients cope with infection and helps HIV-negative clients adopt and maintain safer behavior.
- Active referral systems can be established and maintained to provide additional support and care services by prevention and care partner organizations.
- Monitoring is essential to maintain quality control for counseling and testing services.
- VCT services should be part of a comprehensive HIV prevention program.
- When first establishing services, anonymity is important; confidentiality is always critical in assuring trust and creating demand.

- Integrating other services—such as treatment for STDs and education and referral for tuberculosis diagnosis and treatment—are feasible and well received by VCT clients.
- A computerized information management system is crucial for monitoring services and helps quality control and evaluation activities.

MALAWI: MALAWI AIDS COUNSELING AND RESOURCE ORGANIZATION (MACRO)

Perhaps fewer than 10 percent of African PLHA are aware of their infection. This lack of knowledge limits access of infected individuals to supportive care and prevention therapies, and is an important factor in the spread of AIDS. In Malawi, VCT has been available in Lilongwe since 1992 and in Blantyre since 1994 through the Malawi AIDS Counseling and Resource Organization (MACRO), an NGO supported by the Ministry of Health and donor organizations.

VCT use remained very low from 1992 to 1999. During 1999, 5,663 clients received VCT services—but only 69 percent received their test results and additional counseling. Thus, the problem of low utilization was compounded by a low rate of return for test results. Off-site testing in a central laboratory resulted in delays in receiving test results. These problems are not unique to Malawi or to Africa: In the United States, fewer than 70 percent of clients tested return for HIV test results in most settings.

In addition to these problems, supplies of test kits at the Malawi laboratory were inconsistent and inadequate. Even returning clients sometimes could not receive their results, because laboratories lacked enough supplies to conduct tests.

The Ministry of Health and MACRO, in collaboration with the U.S. Agency for International Development (USAID) and the Centers for Disease Control and Prevention (CDC), in late January 2000 introduced the onsite use of simple, rapid, whole-blood, finger-prick testing with immediate confirmation for HIV. A prevention counseling protocol was developed, and counselor training conducted for same-day counseling with same-day test results.

Almost overnight, demand for services increased dramatically. By the end of December 2000, testing increased fourfold to more than 21,400 clients. The number of clients receiving their test results and additional prevention counseling increased sixfold. More than 99 percent received their test results with additional prevention counseling.⁴²

Lessons learned

- An HIV rapid, whole-blood, two-different-test algorithm conducted onsite provides results equivalent to ELISA testing with confirmation conducted in a reference laboratory.
- This test algorithm provides confirmed results for both HIV-negative and HIV-positive clients on the same visit, eliminating the need to return two weeks later for test results and post-test counseling.
- Quality prevention counseling can be provided; both clients and counselors attest to the improved service delivery of the new strategy.
- HIV rapid testing with counseling promotes both prevention and earlier access to care and support.
- The test used in this algorithm is simple and rapid, requires no electricity to process, no refrigeration for storage, has a long shelf life and can be conducted by a trained counselor.
- A computerized information management system is crucial for monitoring services and aiding quality control and evaluation efforts.

This VCT strategy can dramatically increase access to and use of VCT services throughout Africa and the rest of the world—especially in rural areas—even in such developed countries as the United States.

SUMMARY

VCT serves as a cornerstone and vital entry point for early access to prevention, care and support services. Testing should not be considered or implemented as a separate program, but as a key component in a comprehensive HIV/AIDS prevention strategy.

The public health need for a rapid HIV testing algorithm with prevention counseling is as important in the United States and other developed countries as it is in Africa. VCT use must be increased for HIV prevention, care and treatment. But slow results cause low return rates, with their impact on care and treatment. The Uganda and Malawi VCT approach offers the rest of the world a successful strategy in our war against HIV/AIDS.

These case studies were written by Carl Campbell, Senior Public Health Advisor, Chief, Voluntary Counseling and Testing Activity, Global AIDS Program, Centers for Disease Control and Prevention.

RELEVANT CHAPTERS

- Chapter 7 *Youth Intervention Programs*
- Chapter 8 *Reducing HIV Risk in Sex Workers, Their Clients and Partners*
- Chapter 9 *HIV/AIDS Programs in Private Sector Businesses*
- Chapter 11 *Reaching Men Who Have Sex with Men*
- Chapter 18 *Reducing the Risk of Mother-to-Child Transmission of HIV During Pregnancy and Delivery*
- Chapter 19 *Mother-to-Child Transmission of HIV Through Breastfeeding: Strategies for Prevention*
- Chapter 22 *HIV Risk Reduction in Injection Drug Users (IDU)*
- Chapter 25 *Management of HIV Disease and Its Complications in Resource-Constrained Settings*
- Chapter 26 *Orphans and Other Vulnerable Children: Approaches to Care and Protection Programs*
- Chapter 27 *HIV/AIDS, Health and Human Rights*

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C H A P T E R

24

*Home Care
for People with
AIDS*

HELEN JACKSON
SANDRA ANDERSON



Home Care for People with AIDS

INTRODUCTION

Many people with AIDS are cared for at home—not necessarily because they wish that, but because the scale of the HIV/AIDS epidemic and the inadequacy of health budgets in developing countries require it.

At its best, supported home care allows patients to remain in familiar surroundings with loving family members during repeated illnesses and to die with peace and dignity. At its worst, home care is a euphemism for home neglect, with patients unable to gain access to, or discharged from, the health system and abandoned at home to die without support, hidden to avoid prevailing AIDS stigma. This chapter outlines HIV/AIDS care needs and the home care gap, explores the definition of home care and various home care models in development and discusses their drawbacks and advantages.

AN OVERVIEW OF THE CRISIS

As HIV/AIDS epidemics grow, the burden of coping with the patient falls increasingly on family members, who often have limited information, equipment and access to drugs and other necessities. As expenditures rise, families can quickly become impoverished—losing productive jobs, household and subsistence labor.

HIV/AIDS CARE NEEDS AND THE HOME CARE GAP

There is a huge—and growing—gap in HIV infection rates and AIDS deaths between rich and poor nations. Many countries have developed home care services through hospital outreach, both as new programs and as extensions of existing ones. But the number of people developing AIDS is growing more rapidly than the increase in services—a phenomenon that has led to what may be termed the “home care gap.”

HOME CARE MODELS

Different settings may require different models of home care, but it is essential that any model be cost-effective and sustainable, capable of being scaled-up to meet growing needs as the epidemic escalates and provide a basic minimum quality of care. There are five general models of home care, each with possible drawbacks and advantages:

- Hospital outreach
- AIDS service organization (ASO), non-governmental organization (NGO)
- Church-based
- Community-based
- People living with HIV/AIDS (PLHA) network

FINANCIAL COSTS AND CONSIDERATIONS

Developing countries are often forced to rely on home care because the governments cannot afford more sophisticated services. But home-based care also imposes considerable costs on patients, their caregivers and their families. Actual costs often are not monitored carefully, nor are the programs evaluated for cost-benefits and cost-effectiveness. It has been noted, however, that home care programs with many volunteers need not cost much more than programs working with few volunteers, and the scale of service and potential for sustainability are notably higher. In addition, community-based programs are substantially cheaper than institutional programs that rely on professional service providers.

CHARACTERISTICS OF QUALITY HOME CARE: LESSONS LEARNED

The basics of holistic AIDS management and optimal home care include: offering psychosocial and spiritual care, meeting nutritional needs, providing curative or palliative treatment of various conditions, keeping the patient as comfortable as possible and taking precautions to prevent the spread of HIV. In terminal care, the emphasis should be on palliative care, emotional support and future planning.

INTEGRATED AND INCLUSIVE SERVICES

Home care services should be available for all who need them, rather than for AIDS patients alone. An inclusive approach makes more rational use of resources and mainstreams the disease, rather than isolating AIDS as if it were qualitatively different from other terminal conditions.

FILLING THE GAP THROUGH PROGRAM EXPANSION

One phenomenon common to home care programs is the small proportion of patients served compared to the sheer numbers and needs related to HIV/AIDS. Coverage can be increased by encouraging direct referrals by community members to mobilized volunteers, and including a church coordinator to gain the support of church leaders.

COMBATING STIGMA

The involvement of large numbers of volunteers in home care visiting lessens the disease's stigma, a major factor driving the HIV epidemic.

PREVENTION OPPORTUNITIES

Home care provides opportunities for HIV awareness and prevention efforts in the community.

FUTURE PLANNING

Encouraging open family discussion about death helps patients and families plan for bereavement, inheritance and long-term childcare. It also eases the emotional strain of denial.

MALE AND YOUTH INVOLVEMENT

Home care generally means additional work for women of all ages. Efforts should be taken to make men aware of the women's workload and the importance of mutual support. Schools provide a valuable forum for sex education; they could also teach care roles for girls and boys.

SUPPORTING THE SPECIAL CARE ROLE OF GRANDMOTHERS AND THE ELDERLY

Caregiving responsibilities often fall to grandparents, and particularly to grandmothers. Programs can be developed to train and support grandparents as home caregivers.

COMMUNITY LINKS

Maximum family and community involvement is essential to ensure the necessary expansion of home care and the regular, routine availability of support within each home. Qualified people are needed to provide back-up in a well-structured support network. Health workers and volunteers should be able to call upon the formal health sector for assistance.

COOPERATION WITH TRADITIONAL HEALERS

Links with traditional healers should be viewed as additional conduits for care, not as competition. To be effective, traditional healers and families must be well informed about HIV/AIDS and know their own limitations.

SUPPORT FOR CAREGIVERS

Caregivers—whether they are program staff, family members or community volunteers—need support to maintain morale and work effectively.

DONOR RESOURCES AND COMMUNITY MOBILIZATION

Donors and other development agencies must make a fundamental change in the way they operate: helping communities care for their own members. NGOs and health services should support local initiatives and provide back-up professional support, training and monitoring.

FUTURE DIRECTION

It is essential to reorient home care towards broad, meaningful community mobilization and development, with the creation of effective democratic structures and true gender-sensitive grassroots participation. The harsh realities of poverty must be recognized, so home care programs can grow within a wider developmental context. Donors must find mechanisms to foster local development without establishing unsustainable structures that take responsibility and ownership away from communities.

CASE STUDIES

Case studies in Zimbabwe, Brazil and Cambodia provide examples of basic standards of home care and optimal services in low-resource settings and address issues of sustainability and coverage.

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I N T R O D U C T I O N

The scale of the HIV/AIDS epidemic and the inadequacy of health budgets in developing countries have forced many people with AIDS to be cared for at home. At its best, patients can remain in familiar surroundings with loving family members during repeated illnesses and die with peace and dignity. Competent home care staff make regular visits to assess patient needs and ensure appropriate nursing, medical, psychological and spiritual support—not just for the patient, but for the entire family. Staff help plan for future needs of children and other dependents, and the home care visits provide an opportunity for HIV education and prevention efforts with the family and wider community.

At its worst, home care is a euphemism for home neglect after patients have been discharged from or failed to gain access to the health system. They are abandoned at home to die without support, hidden to avoid prevailing AIDS stigma. Treatable opportunistic infections are neglected; even basic palliative care is absent. Family members and the community may be afraid and hostile. Some patients die of malnutrition and despair—perhaps even without a “home” in which to die.

What makes the difference between good home care and home neglect? Which approaches to home care are cost-effective and sustainable, able to reach the growing numbers of AIDS patients in countries with severe epidemics? What are the basic standards for home care? After outlining

care needs and the home care gap, this chapter explores the definition of home care and the various models in development, discussing their drawbacks and advantages. Following a description of the characteristics of quality home care, case studies from around the world are presented. It concludes with a look at future challenges and directions for home care practice.

OVERVIEW OF THE CRISIS

Early in the course of HIV/AIDS epidemics, end-stage disease is comparatively rare and handled similarly to other diseases, often not even diagnosed as AIDS. As the epidemic matures, the number of symptomatic people rises exponentially, with individuals exhibiting widely differing patterns of health and illness before they die. Depending on resources, they may be hospitalized several times, with intervening periods of comparatively good health; or they may be cared for at home, whether ambulatory or bedridden. Inevitably, as the epidemic grows, the demand increases for hospital beds. Patients with terminal disease are likely to be discharged to make room for others. The tendency also develops for health staff to withdraw costly treatments from patients they deem hopeless; many AIDS patients do not receive the drugs and other medication they need, even when they are available.

The burden of coping with the patient falls increasingly on family members, who often have limited information, equipment and access to drugs and other necessities. In many cases, home caregivers do not even know the patient's diagnosis, although they may suspect AIDS. The burden of care and death often multiplies within the family if, for example, both husband and wife die or young children fall ill.

AIDS is a major factor in the impoverishment of families as they lose productive, household and subsistence labor. Expenditures rise for health care, transportation to hospital and clinics and funerals. Many families resort to spending savings, selling productive assets, removing children—especially girls—from school and reducing their long-term security to finance the present crisis. (See Chapter 3 for in-depth discussion of the socioeconomic impact of HIV/AIDS.)

HIV/AIDS CARE NEEDS AND THE HOME CARE GAP

As the 20th century drew to a close, some 33.6 million men, women and children were living with HIV infection. Nearly 16.3 million more had died from AIDS since the epidemic began—3.6 million of them children under 15 years, another 6.2 million women. Along with Africa, parts of South and East Asia are beginning to be severely affected, with a serious epidemic emerging in the enormous populations of India and China. The need for care services as those infected progress to end-stage disease will be tremendous. Sub-Saharan Africa continues to bear the brunt of HIV and AIDS, with close to 70 percent of the global total of HIV-positive people.

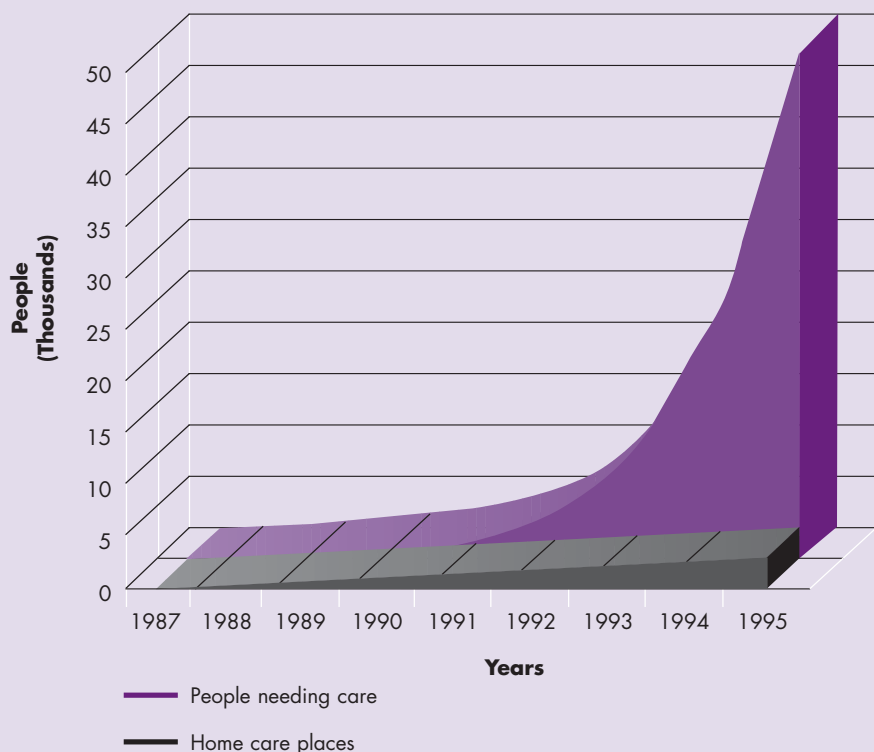
According to the Joint United Nations Programme on AIDS (UNAIDS) and World Health Organization (WHO), “Most will die in the next 10 years, joining the 13.7 million Africans already claimed by the epidemic and leaving behind shattered families and crippled prospects for development...Life expectancy at birth in southern Africa, which rose from 44 years in the early 1950s, to 59 in the early 1990s, is set to drop to just 45 between 2005 and 2010 because of AIDS...In short, the huge gap in HIV infection rates and AIDS deaths between rich and poor countries, and more particularly between Africa and the rest of the world, is likely to grow even larger in the next century.”¹

To face this dire situation, many countries have developed home care services through hospital outreach, both as new programs and as extensions of existing services. But the number of people developing AIDS is outpacing this massive increase in services—a phenomenon that has led to what may be termed the “home care gap.”

In Zimbabwe, as in many other countries, public health services cannot meet the demands of the increasing number of people with AIDS-related illnesses. There is a pressing need for cheap and cost-effective home-based care. Since 1990, the Family AIDS Caring Trust (FACT), Mutare, Zimbabwe, has operated such a program. It has expanded considerably to fill the gap

Figure 1
THE JUXTAPOSITION OF GROWTH IN HOME CARE SERVICE AND NUMBERS OF AIDS PATIENTS

The home care gap: regional estimates for a country in southern Africa.



Source: Wilson D, Sabatier R*, Foster G, Poster presentation to Community Home Based Care Conference, Montreal, May 1995.

by focusing on community mobilization, including: (1) Recruiting large numbers of community volunteers, (2) Promoting referral by the community and (3) Enlisting churches and church members.

Home care must meet all needs of patient and family in the home (as illustrated in Table 1) rather than in a formal health care setting.

The family's ability to meet these needs will depend on its financial situation, access to resources, time, knowledge and skills. The importance family members place on patient care—and their willingness to provide it—depends on culture, family relationships, religion and other factors. For example, a man may receive

* Renee Sabatier, the director of the Southern Africa AIDS Training Program (SAT), died suddenly in March 1999, a serious loss to the SAT program and its many partners throughout southern Africa and beyond.

better care than a woman, because of his status and command over resources.

The specific components of a home care program in one resource-constrained setting, Family AIDS Caring Trust (FACT), Mutare, Zimbabwe, include the following:

- Training family in infection control, nutrition and basic nursing
- Counseling clients and family members about HIV
- Pastoral support, prayer and Bible reading
- Linking patients with clinics for medical diagnosis and treatment
- Material assistance (food, soap, disinfectant, gloves)
- Advice concerning other sources of support (such as legal aid)
- Nursing services, (bathing patients, changing dressings, etc.)
- Home help in cleaning, washing, shopping
- Bereavement and orphan support visits

The FACT home care program was evaluated several years after its inception. The results revealed

that few of the people needing the service actually received it.

This was due to several factors:

- Stigma against HIV led to secretiveness and reluctance of clients to be visited.
- Churches were minimally involved.
- Most problems were social rather than medical.
- Visits were short and infrequent and focused on nursing needs.
- All clients interviewed claimed to be happy with the services received.

Table 1
CORE DIMENSIONS OF HOME CARE

Health
■ Nursing care.
■ Treatment of opportunistic infections.
■ Palliative care.
■ Nutritional requirements.
Material/Financial
■ Nursing aids and hygiene requirements.
■ Bedding.
■ Food (including food for visitors).
■ Transportation.
■ Funeral costs.
■ Schooling and other family needs.
Emotional, Spiritual, Social Support
■ For patient and family regarding loss, ill-health, stigma, blame, guilt, impending death.
■ For children, parents and caregivers coping with “burnout,” bereavement and loss.
Awareness and Prevention
■ Information on HIV transmission.
■ Information on care needs.
■ Openness about HIV serostatus.
■ Condoms.
■ Legal and human rights information and support (planning for inheritance, widows, orphans, etc.).

Home care should not be considered an alternative to hospital care. Instead, it should be part of an accessible, coordinated series of services, with each care setting more effective if complemented by well-functioning care at all other levels, from home to clinics to hospitals.

Home care—or home neglect—of dying patients has always existed in resource-constrained settings, including poor sectors of affluent populations. Now, with the added stress of HIV/AIDS on already inade-

quate health services—particularly in developing countries—home care is receiving renewed attention, with many countries experimenting with both new and older models.

MODELS OF HOME CARE

Different settings may require the development of different models of home care, but it is essential that any model be cost-effective and sustainable, capable of being scaled-up to meet growing needs as the epidemic escalates and provide a basic minimum quality of care.

Different criteria will predominate in rural and urban settings. For example, in scattered rural populations, mobile or hospital outreach services will entail disproportionate spending on travel and salaries, compared with expenditure on services of direct benefit to patients. In many urban areas, the high population density allows for greater coverage by mobile services, with relatively little time and finance wasted on transportation. If the population is fragmented and transient, there is no sense of community, making community mobilization for care difficult. In many rural areas, both on large-scale farms and in small-scale farming sectors, mining compounds and villages, there may be a strong sense of community that can be tapped to mobilize community care provision. Table 2 summarizes five general models of home care and identifies possible drawbacks and advantages.

Although not explicitly identified above, clinic outreach can become part of the continuum of health sector provisions. Governments must give greater importance to primary care; the current process of health reform in many countries—emphasizing decentralization to districts and localities—could support increased community outreach from clinics. But the

Table 2

DRAWBACKS AND ADVANTAGES OF VARIOUS HOME CARE MODELS*

Model Type	Possible drawbacks	Possible advantages
Hospital outreach	High cost of transportation and salaries that do not directly benefit patients, low coverage, inflexibility, low frequency of visits.	Easy monitoring and supervision, good link with supplies, access to professional staff, hospital referral facilitated.
AIDS service organization, nongovernmental organization	May have poor hospital links and little medical supply or expertise; may be costly.	May provide comprehensive support through community volunteers; accessible, innovative, flexible; may mobilize new resources.
Church-based	May moralize and increase stigma; eligibility may be limited; (see also “community based” category).	Addresses spiritual and social needs; uses existing sustainable network and volunteers; affordable for prevention and care.
Community-based	May have poor hospital links and little medical supply or expertise; may lack technical and supervisory input; little back-up in crises; may overburden women.	Uses existing networks and structures; affordable and acceptable; important for prevention; reduces stigma; can include other chronic health needs.
People living with HIV/AIDS (PLHA) network	Members may feel abandoned; unlikely to be integrated with other chronic or critical health needs; problematic as service providers die; (see also “community based” category).	Personal understanding; shared experience and learning; shared burden; may reduce stigma and create acceptance and openness; mobilizes preventive action; empowerment of self-help.

* Developed from Osborne, van Praag, and Jackson³

realities of constrained resources and declining health budgets in many settings make it less likely that additional services can be developed effectively from within the government health sector.

Besides economic constraints, most home care services seem to suffer from barriers related to stigma and accessing treatment. The AIDS Service Organization (TASO) in Uganda, created in 1987 to provide psychosocial support to people living with HIV/AIDS, has demonstrated a strong capacity to overcome four common problems that haunt AIDS care in most places and settings: “(1) Revealing one’s

HIV serostatus to relevant others, (2) Family and community acceptance of PWA, (3) Seeking early treatment and (4) Combining prevention and care.”⁴ Through counseling, medical care, home care and material support, TASO has affected change in people’s attitudes and lifestyles.

An evaluation of care provided to TASO clients noted that, particularly for home visits, “nurses should be more involved than the current situation where counselors make most home visits.” The evaluation team strongly recommended that TASO reassess the role of its nurses, and consider their potential to make a greater contribution to client care, including taking advantage of their nursing skills in patient assessment and equipping them with counseling skills.⁵

FINANCIAL CONSIDERATIONS AND COSTS

Intense poverty is a major obstruction to quality care in developing countries. For instance, patients may have special nutritional requirements—such as frequent small meals, easily digestible food and nutritious drinks and mineral and vitamin supplements. These may require extra money and time spent on food acquisition, preparation and feeding the patient—money and time that are then not available for other family members' food requirements or other needs. In one family visited by home care researchers in Zimbabwe,⁶ two visibly malnourished children watched while a huge plate of mealie meal and vegetables was toyed with by their dying 19-year-old brother and then thrown away as contaminated. Advice without access to the means to act on it is irrelevant and irresponsible; imaginative ways must be found to provide for basic needs.

The actual costs of home care often are not monitored carefully, however, nor are the programs evaluated for cost benefits and cost-effectiveness. This applies to costs to both service providers and the families themselves. Mobile outreach services tend to have high service providers' expenditures on transport and salaries, while community-based programs with volunteer support are likely to be much more cost-effective, with more financial resources going into services of direct benefit to recipients. For instance, the first home care programs in Uganda, Zambia and Zimbabwe were developed by hospitals; 75 percent of staff time was spent traveling to patients' homes in the rural areas.⁷ Strong financial and technical support from the Salvation Army enabled Chikankata Hospital in Zambia to develop extensive mobile outreach services.⁸ But a 1998 cost analysis⁹ found that the costs amounted to about US\$1,000 per client served, and the major budget item was transportation.

Home-based care also imposes considerable costs on patients, their caregivers and their families. These include financial, resources, time and opportunity costs. In 1994, four Zimbabwe home care programs

(two urban, two rural) were studied, and the estimated cost incurred by households in caring for a bedridden patient for three months was between US\$68 and US\$103.¹⁰ Home-based care is not necessarily a cheap alternative to the households and communities involved.

Nevertheless, it has been noted that the “costs of home care programs that involve large numbers of volunteers need not be much higher than for programs working with few volunteers, and the scale of service provision and potential for sustainability are notably higher. Community-based programs are substantially cheaper than programs that are institutionally based and rely on professional service providers.”¹¹ In one program, the cost per home care visit was reduced from US\$20 to US\$1, and the cost of the service per new client dropped from US\$338 to US\$30.¹¹

A literature review undertaken by the Southern Africa AIDS Information Dissemination Service (SAfAIDS) for UNAIDS⁷ found considerable process analysis of home care and other responses to the AIDS epidemic, but limited data on cost analysis. But more than cost-effectiveness analysis is needed. Both short- and long-term studies of the programs' effects are required, with a clear sense of impact indicators. These must include the impact of AIDS on other members of the household in addition to patient needs. For example, the extent to which long-term survival is jeopardized through withdrawing children from school to provide care, selling productive assets to meet patient needs or diversion of subsistence and productive labor to patient care.

CHARACTERISTICS OF QUALITY HOME CARE: LESSONS LEARNED

The basics of holistic AIDS management and optimal home care include: providing for psychosocial and spiritual aspects of care, meeting nutritional needs, providing curative or palliative treatment of various conditions, keeping the patient as comfortable as possible and taking precautions to prevent the spread of HIV. In terminal care, the emphasis should be on palliative care, emotional support and future planning.

Helping people live positively with HIV/AIDS is an important part of quality home care. It implies both encouraging hope and accepting reality. Sufficient communication between patients, caregivers and other family members is needed, so they can share their concerns, fears and emotions in a culturally appropriate way.

INTEGRATED AND INCLUSIVE SERVICES

Home care services should be available for all who need them, rather than for AIDS patients alone. An inclusive approach reduces the risk of stigma and avoids making a special case of an AIDS patient. It makes more rational use of resources and removes some of the disease's stigma, rather than isolating AIDS as if it were qualitatively different from other terminal conditions. Integrated services can make optimal use of existing resources and structures—which should be strengthened, rather than building unsustainable parallel structures. Referral systems linking homes and hospitals are essential to ensure that professional backup is available. Families must know when and where to seek care.

FILLING THE GAP THROUGH PROGRAM EXPANSION

One phenomenon common to home care programs is the few people served compared to the sheer numbers and needs related to HIV/AIDS home care. FACT redesigned their program in an attempt to increase coverage by encouraging direct referrals by community members to the large number of mobilized volunteers and by including a church coordinator to gain the support of church leaders, thus enabling committed church members to become involved in home care.

COMBATING STIGMA

FACT program experience showed that the involvement of large numbers of volunteers in home care visiting led to a reduction in stigma, a major factor driving the HIV epidemic. Community members observed that people perceived to be HIV-positive were being visited regularly. This led them to overcome their own concerns about confidentiality and stigmatization by accepting home visits for members of their own families.¹¹

PREVENTION OPPORTUNITIES

Home care provides opportunities for HIV awareness and prevention efforts in the community. Continuing the dichotomy between care and prevention is no longer a viable practical option,¹² as home care requires openness about the diagnosis and an enabling, non-stigmatizing environment. In addition, although many patients keep their diagnosis secret, home care encourages caregivers to keep informed in order to observe relevant HIV prevention measures.

FUTURE PLANNING

Some cultures avoid any discussion of death. This makes it difficult for patients and families to plan for bereavement, inheritance and long-term childcare, and creates the emotional strain of denial. Despite inherent difficulties and widespread taboos, breaking the silence has often been helpful, and many home care services try to encourage open family discussion about death. To safeguard widows and orphaned children from

potentially predatory relatives, it may be important to establish a will. It may also be necessary to discuss where the children will go if they cannot stay in the family home. These concerns should involve active engagement with other relatives in an attempt to prevent them contesting provisions made by the dying person, even if the legal rights of dependents are clear.

MALE AND YOUTH INVOLVEMENT

Home care generally means additional work for women of all ages. This burden might be lessened if men became aware of the workload of women and the importance of mutual support. Rather than drawing girls out of school to care for patients at home, it is very important to keep girls and boys in school, so they can become literate adults with greater earning potential. Schools also provide a valuable forum for sex education, which should help young people develop balanced and informed attitudes toward sexual behavior, sexual relations, contraception and prevention of sexually transmitted infections.

Schools can also provide a forum for developing care roles among both girls and boys. For example, children could be taught basic hygiene and nursing care, as well as the rudiments of counseling. This could be both rewarding and educational for the students, and could contribute to a valuable, sustainable, community home care service. To achieve such an outcome would, of course, require an intensive teacher-training program, and probably require nurses in the schools—at least part time—to initiate, support and monitor the training and service provision.

SUPPORTING THE SPECIAL CARE ROLE OF GRANDMOTHERS AND THE ELDERLY

In northern Thailand, the Sanpatong Home-Based Care Project noted that caregiving responsibilities often fall to grandparents, particularly grandmothers. This can be an unexpected and heavy burden on the elderly, especially if they have no previous knowledge of HIV/AIDS or basic home care techniques such as universal precautions. The project began a new activity to improve grandparents' ability to function as

home caregivers and to give them training, support and acknowledgement from neighbors. The Thai experience is common in many African countries where the elderly, especially women, become the major caregivers despite their own infirmities.

COMMUNITY LINKS

Maximum family and community involvement is essential to ensure expanding service provision and the regular, routine availability of support within each home. Qualified people are needed to provide back-up in a well-structured support network. Health workers and volunteers should be able to refer back to the formal health sector—both at the clinic level and, if necessary, the hospital. Low-cost community residential and respite centers in urban and rural areas might also be cost-effective and sustainable, reducing the burden on women in the home.¹³ Private nursing homes are being established in Harare, Zimbabwe, with the support of medical aid societies. These new facilities reduce the burden on women in the area and provide a more affordable, personal service than is currently provided in hospitals.

COOPERATION WITH TRADITIONAL HEALERS

In many countries, traditional healers provide remedies for pain and disease; these may have holistic importance beyond the medical value of modern health care. Links with traditional healers should be viewed as additional conduits for care, not as competition with modern care. To be effective, traditional healers must be well informed about HIV/AIDS and know their own limitations. Families must also be knowledgeable to avoid exploitation by unscrupulous healers promising unsubstantiated cures.

FUTURE DIRECTIONS

SUPPORT FOR CAREGIVERS

In many parts of the world, whole communities are becoming involved in HIV/AIDS-related care. Where this has happened, it is increasingly difficult for health care workers to distance themselves from the disease or for home care providers to gain support from an overburdened community.¹⁴ Caregivers—whether program staff, family members or community volunteers—need support to maintain their morale and work effectively. For example, volunteers for people with HIV/AIDS and TB in Zambia’s copperbelt receive appreciation, supervision and ongoing training. They also get technical and logistical support to help patients gain access to care, incentives such as mealie meal and loans for income-generating activities as well as a sympathetic ear from the Ndola Catholic Diocese.¹⁵

DONOR RESOURCES AND COMMUNITY MOBILIZATION

To better help HIV/AIDS patients, donors and other development agencies must make a fundamental shift in their operations, and support communities in caring for their own members. NGOs and similar health services should encourage local initiatives and provide back-up professional support, training and monitoring — without becoming the main direct service provider. They must develop skills in “caring for the caregivers” to sustain long-term voluntary support from the community. Finding ways to enhance activities and structures already in place and reducing the long-term costs to families (such as taking children out of school) will be more beneficial than well-meant but misplaced costly outreach programs providing professional services to a minority of the population.

Donors fear misuse of their funding and resources, poor accountability, nepotism and corruption. Community-based organizations need help to guard against misuse of resources. They need strategies that they themselves can monitor effectively and procedures that they can enforce when misuse occurs. Organization-based funding mechanisms are needed that allow donors to disperse small-scale grants with acceptable accounting processes. Umbrella networks and well-placed NGOs could potentially help the community develop these strategies and perhaps train them.

A reorientation of home care towards broad community mobilization and development is essential, with effective democratic structures and true gender-sensitive grassroots participation. The sheer size of the epidemic—especially in Africa and eventually in Asia—emphasizes the need to maximize community mobilization, with reliance on volunteers rather than direct-service professionals. In turn, management, training, supervision, monitoring and evaluation must be strengthened and consolidated. Home care requires more effective monitoring and cost-benefit analysis than has been achieved so far, as well as more research into community initiatives. Participatory rural appraisal techniques should identify priorities and existing responses. Support groups for PLHA should be fostered: They can promote effective self-help strategies, reduce stigma and demystify the epidemic.

The harsh realities of poverty and its attendant human suffering must be kept central in planners’ minds, so that home care programs are expanded within a wider developmental context. Donors must find mechanisms to foster local development without establishing unsustainable structures that take responsibility and ownership away from communities. It is tragic that a disaster on the scale of AIDS should force such a reversal in the basic tenets of community development.

CASE STUDIES: AFRICA, LATIN AMERICA AND ASIA

The following studies provide examples of basic standards of home care and optimal services in resource-constrained settings. They also address issues of sustainability and coverage.

CHIRUMHANZU HOME-BASED CARE PROJECT, ZIMBABWE¹⁶

Chirumhanzu District is a farming area in the central Midlands Province of Zimbabwe. The HIV epidemic has struck the area very hard. At St. Theresa's Hospital (the first-level referral centre in the District), just over half of the 253 inpatient deaths which occurred in 1997 were due to AIDS, and the numbers are increasing.

The Chirumhanzu Home-Based Care Project started in 1994. It grew out of an initiative of hospital health workers, including senior nurses, Dominican sisters and foreign doctors. Already concerned by overcrowded hospital wards, they were also aware of the wish of local AIDS patients to remain at home under the care of their families until and at the time of death. Since the project's inception, a variety of services have been created, including home care for over 200 PLHA. This care is provided primarily by family members under the supervision of home care volunteers. The project coordinator and hospital nursing staff oversee the volunteers.

The project has two main goals:

- Meet the needs of HIV-infected and affected people in their homes and with their families, if possible.
- Provide the necessary information, skills, care, materials and support.

To this end, Chirumhanzu has defined three central elements in its program:

- Home-based care for AIDS patients
- Support groups for HIV-positive people
- Awareness and prevention for general public and target groups

From the beginning, the project has taken a comprehensive approach to care that includes meeting medical, social and emotional needs. It promotes HIV awareness and prevention and encourages the local community to take greater responsibility in accepting and caring for its HIV-positive members. Chirumhanzu also encourages the participation of people infected or affected by the virus in all aspects of the project. This principle is important; it increases the profile of PLHA in the community in a positive way, and thus can serve to reduce stigmatization.

The project strongly supports and builds on African traditions of family support and mutual obligation, including consensus to designate a direct caregiver within each family. As project coordinator Etta Dendere puts it: "Family is the most important resource for our clients."

The first step of Chirumhanzu Home-Based Care Project involves identification of clients. This occurs mainly through hospital admissions or as a result of HIV testing. If diagnosed as HIV-positive, an individual undergoes counseling sessions that include assessment of individual needs and wishes. When a patient is ready to leave the hospital, letters confirming that the patient has been discharged for home care are sent to the patient's nearest clinic and the caregivers. A trained community-based caregiver volunteer follows up at home; each client is visited once a week. After each visit, the volunteer writes a report, which is used by the project coordinator at the hospital to decide whether a home visit by a qualified nurse is needed. The Ministry of Health provides most of the nursing materials and drugs used.

PLHA who are independently mobile and able receive self-care training in nutrition, hygiene and techniques such as caring for HIV-related skin problems. They also receive support training in "positive living"—for example, taking an optimistic attitude to life.

When a person needs a greater degree of care and has come to St. Theresa's Hospital for inpatient treatment, her or his family is asked to send a member over the age of 12 to take home-care training while the patient is in the hospital. This relative is usually a female (wife, mother, daughter or cousin). Only about

one in 10 of the caregiver relatives are male (father, husband or son). If coming from far away, the relative is given accommodation in a guesthouse operated by the hospital during the training. Like self-care patients, family caregivers receive training in nutrition, hygiene, oral rehydration and control of simple infections.

Most of the project's volunteer home caregivers are recruited through the district's church parish councils and other local religious organizations. Volunteers are usually themselves HIV-positive, although an increasing number are uninfected relatives of infected people. About 30 volunteers currently receive basic training in providing care to PLHA and supervising the care provided by family members. The project administrator and a qualified nurse supervise these volunteers. All volunteer caregivers meet monthly to discuss general problems and concerns.

Several women volunteers have taken on responsibility for prevention work. They visit popular meeting places where they teach about HIV/AIDS and sexually transmitted diseases, hand out pamphlets on these subjects and distribute condoms.

Volunteers receive some incentive—monthly “pocket money.” Since the actual sum of Z\$8 per month is only enough to buy a small item such as a bar of soap, most volunteers prefer to receive payment in an annual lump sum. Refresher workshops and monthly meetings at St. Theresa's are intended partly as a way of thanking and motivating volunteers by providing a good meal and social gathering.

Chirumhanzu has created a number of support groups in the district. Currently six groups of 12 to 22 people each meet once a week; members learn about the groups through hospital recommendation or by word-of-mouth. In addition to providing a forum for sharing and mutual support, the groups increase members' economic self-reliance by teaching skills such as sewing (by hand and machine), gardening and running a small business.

From the beginning, the project has made it a priority to work with local traditional leaders to gain trust and overcome stigma and ignorance about HIV/AIDS. The project's initial outreach to a village begins with an invitation to the village chiefs and their advisers to visit the hospital or clinic and meet with project staff. A video on home care and HIV/AIDS is shown during this visit. This is usually followed by a visit from the staff to the village, during which a public meeting may be held. This meeting may include a presentation about HIV/AIDS by the project's drama group and a talk by the project's nurse or coordinator.

Chirumhanzu's drama group has been its principal tool for awareness and prevention efforts. The group usually performs at village meetings when a nurse and coordinator are making these visits. They entertain the public with a skit, which also provides information on HIV/AIDS. The project recently started to organize local netball and football clubs for young people. Games between the clubs are used as occasions to deliver talks and show a video about HIV/AIDS.

Chirumhanzu sends the provincial medical director an annual report of its activities. Recently, the Zimbabwe government provided five bicycles for the program to help project members move around the area more effectively. In the 1994-95 period, the project received financing from UNICEF through the government. Since 1996, overseas donations have come from the Swiss SolidarMed, and from German parishes and private donors with the help of the Dominican Sisters.

PROJECT HOPE—PROJETO ESPERANÇA, SÃO PAULO, BRAZIL¹⁶

Project Hope was first in the state of São Paulo to provide home care services. An extension of the AIDS work undertaken by Sister Gabriela O'Connor, Project Hope began in 1988 when the local bishop gave his support and provided a small building in the working-class neighborhood of São Miguel. The initiative has been acknowledged as an important factor in sensitizing government health authorities to the feasibility of home care and challenging their original scepticism of this approach to AIDS care.

From the beginning, Project Hope's goal has been to improve the quality of life of PLHA by:

- Changing behaviors and attitudes of PLHA
- Involving the community

The motto "hand in hand with life" expresses the Project Hope philosophy of solidarity and positive living that pervades all their undertakings. The Project Hope home care approach is based on the following principles:

- The ideal environment and best therapy for a person infected with HIV is to be with his or her family.
- Families should be helped to accept the reality of living with HIV/AIDS.
- Infected individuals and their families should be helped to demand and fight for their rights as citizens.

São Miguel covers an area of about 7.5 square kilometers and is home to about 103,000 people, many of whom live in poverty. As of December 1997, the state of São Paulo had reported 65,350 AIDS cases, three-quarters of them men. Sexual transmission accounts for just under half of all cases, while almost one-third are the result of injection drug use. Mother-to-child transmission accounted for just under three percent of cases. Currently, Project Hope provides services to approximately 480 PLHA. Approximately 10 percent are seriously ill; 30 percent are asymptomatic and the remainder show some AIDS symptoms.

Project Hope is structured around four program areas:

- Health programs—including support and orientation for PLHA and their families, nursing care, occupational therapy and mutual-help groups for emotional and psychological support. Two professional nurses on staff provide care both at the project's centers and in patients' homes.
- Social programs—including a Campaign for Orphans.
- Educational programs—including training of volunteers, production of educational material and public talks aimed at specific groups such as students, young people and housewives.
- Fundraising efforts—seeking help from local donors and national and international agencies.

On average, the project assumes 183 new cases each year. Most often, initial contact is made by the PLHA or his or her family, although some introductions are arranged by the social services unit of the local hospital.

The first home visit is intended primarily to collect information, and is carried out by a nurse accompanied by a volunteer. The visit begins with a discussion of the PLHA's background and is followed by evaluation of his or her clinical condition. Finally, the social and economic situation is considered to determine the patient's needs. In approximately 90 percent of the cases attended by Project Hope, the families look after their PLHA.

Project Hope could not do its job without the voluntary contribution of time by a variety of people, who include:

- Seventy-four volunteers who work daily or weekly in the health programs
- Ninety-seven “godmothers” and “godfathers” who help with orphaned children
- Forty to 50 people who help sporadically with particular events such as fundraising bingos, raffles and bazaars

Volunteers are recruited in a variety of ways, including community radio campaigns, local newspaper articles, neighborhood associations and word-of-mouth. Candidates are asked about their background, motives and expectations. Interviewers describe the project and explain its objectives.

If both parties are satisfied, volunteers enter an orientation period, learning in greater detail about Project Hope’s activities and philosophy. After choosing a health program area in which to work, they start accompanying staff and more experienced volunteers on home visits—but strictly as observers. They are reminded that everything divulged during the visits is confidential.

An important component of the project is to find financial support for its activities. This work is carried out in several ways, including promoting fundraising events with the local community and identifying and maintaining relationships with local donors and supporting agencies both in Brazil and internationally.

The single most important strength of Project Hope has been its ability to improve the quality of life of PLHA. This is measured in terms of numbers of people visited, medical attention given, etc. But other indicators show success of a different kind. One of these has been the project’s ability to attract volunteers who do not have a direct “stake” in HIV/AIDS. In addition to people living with the virus and their relatives, the project has a number of volunteers who are not HIV-positive and have no family members living with the virus. This solidarity indicates success in the project’s participatory, community-based approach.

Project Hope’s internal evaluations reveal several weaknesses. One is the lack of professional management training within the organization. Another is difficulty in managing the relationship between paid and volunteer workers, which has occasionally led to misunderstandings or conflict.

HOME AND COMMUNITY CARE, PHNOM PENH, CAMBODIA¹⁷

The first cases of HIV infection in Cambodia were reported in 1991, at the peak of the AIDS epidemic in neighboring Thailand. Seven years later, the 1998 sentinel surveillance estimated HIV prevalence in Cambodian adults to be 2.8 percent—higher than Thailand’s 2.4 percent. The Cambodian prevalence rate is now 3.8 percent. Infection appears throughout the population, with 3.8 percent of married women in Phnom Penh recorded as HIV-positive. Contributing factors to both the speed and the spread of the epidemic include a well-established and largely unregulated commercial sex industry and a young, mobile population showing significant urban drift since the early 1990s. Inadequacies in the health system result in poor diagnosis and treatment of STDs, use of contaminated blood and a widespread lack of universal precautions by health workers. These combined to further fuel the spread of infection.

Despite a large-scale program of Health System Reform begun in 1991, unstable political conditions in 1997 led to a fall in state per-capita health spending of less than US\$1, stalling much of the progress made in the preceding few years. The burden presented by the estimated 18,000 currently living with AIDS is not yet widely appreciated. Not only are the country’s 8,000 hospital beds and drug supply woefully inadequate, but fear is causing health workers to refuse care

for HIV-positive patients. Studies on health-seeking behavior have shown that Cambodians are prepared to spend large amounts on health care—five times more than their richer Thai neighbors—but lack of access to quality care for PLHA is forcing patients and families deeper into poverty. Although an estimated US\$5.5 million of loan/donor money was allocated for spending on HIV/AIDS in 1998, less than three percent was available for care and support activities.

In an attempt to address the growing problem of HIV/AIDS care in Cambodia, WHO started a joint pilot project in Home and Community Care in 1997 in collaboration with the Ministry of Health and local and international NGOs. The project sought to develop ways to provide appropriate level support through government/NGO collaboration within the government policy of health reforms. Using the framework of WHO's Comprehensive Care Across the Continuum, eight home care teams were established across the city of Phnom Penh. Based in government health centers and working within their boundaries, the teams form a network of caregivers supporting patients and families at home. The primary focus is health care: At least two members of each five-person team are nurses. Social and emotional support are given high priority, as well as raising general awareness about HIV/AIDS within families and the community at large. Depending on the need, one or two members of the team may make several visits a week, during which they show the family how to manage symptoms simply and safely, and support both family and patient as best they can. Although they carry simple drugs and supplies and have some welfare funds, team members encourage the family to buy essential items if possible. Emphasis is placed on maintaining good hygiene and nutrition. The teams' activities may also include accompanying a newly diagnosed patient to a support group, educating monks concerned about contamination or negotiating treatment options with a traditional healer. Local volunteers assist the teams in their work—for example, in finding a particular house in Phnom Penh's urban sprawl, or providing liaison with community leaders.

Each team is made up of both government and NGO staff, all of whom operate under the same terms and conditions. The project is coordinated through a committee of members representing all partners, including the seven NGOs and the health-center managers. Monthly team activity reports are submitted to the committee for discussion. Representatives from the teams themselves meet weekly to exchange news, pass on referrals and provide mutual support. Senior health workers and NGO staff carry out onsite supervision. Hospital doctors support the teams with regular medical consultations at the homes of seriously ill patients unable or unwilling to go to hospital.

The practice of sharing resources helped both the NGOs and the government. Working on an equal footing towards a common goal enabled both "sides" to share their different skills and experiences and learn from each other. This has helped normalize relations between NGOs and government, which are sometimes strained. (Government staff members believe that the lion's share of resources go to NGOs, which often adopt conflicting and unsustainable approaches. NGOs, in turn, complain that corrupt and lazy staff members poorly manage government facilities.)

A new problem has emerged, however: Creating an equal team required supplementing the government staff salaries (normally between US\$8 and US\$15 per month) to a realistic level. The extent to which this creates a problem is something that needs further analysis. The civil servants' low salary is a constant source of frustration in Cambodia. Until it is addressed, salary supplementation will be difficult to avoid if the government is to be included in innovative projects.

Following the pilot year, WHO was replaced by Khana (Khmer HIV/AIDS NGO Alliance), the local linking organization of the International HIV/AIDS Alliance, as the provider of financial and technical program support. The teams have become more autonomous, although they continue to coordinate through the project committee. The project hub has shifted from WHO to the AIDS Care Unit of the Ministry of Health. Areas identified as needing improvement and development—such as the referral system, counseling and orphan care—will receive additional technical assistance from Khana. Care and support have become a high priority for NGOs working in HIV/AIDS in Cambodia, as the epidemic becomes increasingly visible. In addition to building capacity for the entire system of HIV care, there is a move to integrate care and support into prevention-focused programs.

The Ministry of Health welcomes the Phnom Penh project's coordinated approach, and is eager to expand it to the three provinces with approved voluntary testing centers. Long distances and poor communication between potential providers of care and support, both government and NGO, will present a new set of challenges for any expansion into rural Cambodia. Nevertheless, the Phnom Penh project is an interesting starting point for adapting to the differing circumstances around the country. It has shown that cooperative development of an HIV/AIDS model of HIV/AIDS care can reach acceptable compromises, even between partners with many and varied viewpoints.

The project was evaluated after one year, and effectiveness of such an approach debated. Teams had visited more than 1,000 families, although not all of these had members who were diagnosed HIV positive. Providing a community health care service focused on—but not exclusive to—HIV/AIDS prevented both teams and patients from acquiring an AIDS “label.” Patients and families, NGO and government partners, health staff and community leaders all reported a high level of satisfaction with the teams' activities, including their effect on community awareness of HIV transmission and prevention. The home care staff had grown in confidence and identified clear priorities for future services. Three new health centers requested home care teams, and an additional team was established in a health center where the caseload was already very high. Regular monitoring had assured that supply kits carried by the teams were adjusted according to need. The teams' experiences formed the basis of the final version of the Cambodian *AIDS Home Care Handbook*.

RELEVANT CHAPTER

Chapter 3 *Responding to the Socioeconomic Impact of HIV/AIDS*

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C H A P T E R

25

*Management
of HIV Disease
and Its
Complications
in Resource-
Constrained
Settings*

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Management of HIV Disease and its Complications in Resource-Constrained Settings

INTRODUCTION

The disease burden attributable to HIV infection will probably continue to increase for at least another decade. The impact of the disease is especially severe in the countries least equipped to deal with it: More than 90 percent of HIV-infected people live in resource-constrained settings.

This chapter focuses on providing health care for people living with HIV/AIDS (PLHA) in resource-constrained countries. Most health facilities in these areas lack the resources to offer high-quality medical care to the general public—much less meet the complex demands of HIV/AIDS-related morbidity and mortality. Antiretroviral treatments and other expensive diagnostics and treatments for HIV-related illnesses are rarely available or accessible. The challenge of improving PLHA's quality of life requires a more comprehensive or holistic approach—an approach that meets the medical, psychological and social needs of people and families living with HIV.

HEALTH CARE FOR PEOPLE INFECTED WITH HIV

Care for PLHA should cover all stages of HIV, from asymptomatic infection through end-stage disease, bereavement and care for survivors in the family. The composition and emphasis of such a comprehensive approach changes—as do the medical, psychological and social needs of PLHA and their families—between early-stage infection emphasis on counseling to help cope and change behavior and late-stage emphasis on palliation and social support. But at all stages medical interventions are needed to prevent or treat opportunistic infections and HIV-related illnesses.

CONTINUUM OF CARE

Providing the different elements of comprehensive care to complement and strengthen each other demands coordination and collaboration. This should include timely referrals between home or community and hospital (and vice versa) and effective discharge planning, as well as follow-up at each level to ensure a continuum of care.

CLINICAL GUIDELINES

Differences in clinical presentation and variations in the ability of health systems to diagnose and manage HIV-related illnesses mean that the clinical approach to medical problems of people infected with HIV varies from country to country. But there is a need for generic guidance, with updated information on diagnosis and management to help countries develop or update their national guidelines.

MANAGEMENT OF HIV-RELATED PROBLEMS

Managing the health problems of a person infected with HIV differs according to his/her degree of immune deficiency. Health problems with a relatively intact immune system include skin disorders such as herpes zoster, lymphadenopathy or pulmonary tuberculosis. At later stages of infection there are chronic diarrhea and serious opportunistic infections, wastage and neuropsychiatric disorders.

PROPHYLAXES FOR OPPORTUNISTIC INFECTIONS

Cotrimoxazole can significantly reduce hospitalization and mortality for symptomatic HIV-infected people. Studies have also shown that isoniazid (IHG) treatment is effective and feasible preventive TB therapy for PLHA in areas where TB is very common.

CLINICAL MANAGEMENT OF TB

An HIV-infected person is 10 times more likely to develop TB than an uninfected person. In resource-constrained countries, more than 30 percent of people infected with HIV will develop TB—and the disease can occur at any point in the course of the infection. The highest priority for TB control is the diagnosis of sputum smear-positive pulmonary TB cases. Early diagnosis and good adherence to treatment are the best ways to prevent further spread.

IMPROVING ACCESS TO ESSENTIAL DRUGS

Regular and adequate availability of essential drugs will ensure proper management of most opportunistic infections and HIV-related illnesses during both early and later palliative stages of disease.

INCREASING ACCESS TO ANTIRETROVIRAL DRUGS (ARVs)

Antiretroviral drugs (ARVs) are increasingly used in resource-constrained countries and even more in medium-income countries. The challenge is, therefore, how to use these medicines in the most efficient and safest manner. Guidelines are available to help countries with limited resources.

ARVs TO REDUCE TRANSMISSION OF HIV

Recent studies demonstrate that the concentration of HIV in blood—and by extension, genital secretions—determines the efficiency of the sexual transmission of HIV within discordant couples. These observations and extensive work with macaques suggest that ARV therapy can reduce transmission, although it is too early to be certain.

DIAGNOSIS AND MANAGEMENT OF HIV INFECTION IN CHILDREN

Without affordable antigenic tests, it remains difficult to diagnose HIV infection in infants. But clinical tools are available to build management capabilities to treat HIV-infected children.

HIV INFECTION IN WOMEN

The vast majority of women infected with HIV are of reproductive age, and are at particular risk of stigmatization, abandonment by their partner/family or becoming victims of violence. They are also less likely than men to receive early clinical care. Gynecological examination is essential as such symptoms may be the first sign of infection, allowing for comprehensive management. In making reproductive decisions, infected women should be given information and counseled about their pregnancy options, including contraception. During pregnancy, they should have a wide range of care services, including preventive therapies, interventions to prevent mother-to-child transmission (MTCT) of HIV and follow-up care and counseling.

HEALTH SECTOR REFORM AND HIV/AIDS

Many countries are introducing health reforms to improve the quality and effectiveness of services delivered at lower levels of the health care system. These countries have found that decentralizing authority and responsibility of service planning and provision has often led to better health care quality and effectiveness. The countries believe that the rapidly increasing number of people seeking care can be more effectively managed in the new, decentralized format.

FUTURE CHALLENGES

In recent years, progress in the treatment of PLHA has been made mainly in industrialized countries. The challenge now is to look at ways to introduce new treatment regimens into resource-constrained settings and maintain quality comprehensive care.

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HIV infection has risen from 22nd to fourth place as a cause of disease-adjusted life-years lost to disease in the last 10 years—and experts fear the disease burden attributable to HIV infection will continue to increase for at least another decade.¹

The impact of the disease is especially severe in the countries least equipped to deal with it: Ninety percent of HIV-infected people live in resource-constrained settings.

I N T R O D U C T I O N

Wherever HIV has emerged, communities and individual societies have mounted care and prevention efforts. While the adequacy of those responses and activities have frequently been less than optimal, the foundation has been laid for an integrated system of prevention and care services.

UNAIDS and WHO advocate supporting four major areas to advance care and support for PLHA: (1) Voluntary counseling and testing for HIV (VCT); (2) Access to health care; (3) Psychosocial support; and (4) Help for families affected by HIV.

This chapter focuses on the provision of health care for PLHA in resource-constrained countries, where most health facilities lack the resources needed to offer high-quality medical care to the general public—much less provide the complex treatment of HIV/AIDS-related morbidity and mortality.

Affected communities, in coordination with health facilities, have developed innovative approaches to meet the broad clinical, psychosocial and welfare needs of PLHA and their families through community-based programs.

In recent years, HIV/AIDS-related morbidity and mortality has declined more than 50 percent in industrialized countries—thanks largely to highly active antiretroviral treatment (HAART).¹ Prophylaxes against opportunistic infections and early detection and adequate treatment of these infections also helped the decline. Despite their high cost—more than US\$10,000/year—HAART regimens may reduce overall health-care costs for HIV-infected people in industrialized countries, because patients need less hospitalization and treatment of HIV-related complications and can return to their jobs. In addition to its dramatic effect on the clinical management of patients, HAART has improved PLHA's quality of life, offering a new perspective on living with HIV. The challenges are now focused on choosing the right antiretroviral drugs (ARVs), monitoring their side effects and efficacy (by viral load and CD4 lymphocyte testing), treatment counseling and support for patients to obtain maximum adherence with ARV drugs.^{2,3}

But in situations where HAART and other expensive diagnostics and treatments are not available or accessible, AIDS still has a devastating impact on patients and their family members. The challenge is to improve their quality of life. This requires a comprehensive, holistic approach. Patients with HIV/AIDS-related illnesses face many problems. Not only do they suffer from medical conditions such as diarrhea, fever, skin lesions, cough and weight loss but they also have many psychosocial and material needs. These include fear of loss of support from family members, friends, employers or the authorities if their serostatus becomes known; and income depletion due to increased spending on medical

needs, traditional practitioners and transportation. PLHA often express the need for spiritual support, household help and assistance in disclosing serostatus to a partner. Incomes are further depleted by despair-driven care seeking, which often leads to paying healers who make false claims. Listening to patients' needs and trying to address them is the key to improving their quality of care; it forms the basis of various community care responses, often at minimal expense. (See Chapter 3 for more information on the socioeconomic impact of HIV/AIDS and Chapter 23 for more information on psychosocial support.)

The absence of expensive treatments, including ARVs, should not be an excuse to neglect patients. Certainly, HIV-infected patients in resource-constrained settings should have access to ARVs, but they are not a panacea: Even when available, there are many obstacles to the safe and effective use of ARVs, especially if the health care infrastructure is very weak.^{4,5} When they are used, ARVs should be introduced progressively and in a supervised way, while at the same time strengthening the quality of health care to accommodate these new and complex interventions.

HEALTH CARE FOR PEOPLE INFECTED WITH HIV

HIV comprehensive care includes three basic components:

1. Counseling and testing for HIV infection.
2. Health care (including nursing, psychological and medical care).
3. Impact alleviation for HIV-affected families (social support).

Care for PLHA should cover all stages of HIV infection, from asymptomatic infection to end-stage disease, bereavement and care for family survivors.

Awareness of HIV serostatus allows for early access to HIV-specific health care services. Ideally, people should be informed of their serostatus through VCT provided in a confidential manner (the advantages, planning and implementation of which are discussed in Chapter 23). HIV care must respond to both medical and psychosocial needs. Various studies in developed and resource-constrained countries have shown that the needs of PLHA are comprehensive and interrelated. The needs might be clinical and concern HIV-related illnesses; they might be emotional and spiritual (such as coping with infection in a stigmatizing environment); or they might be social (maintaining a nutritional and economic balance when repeated health expenditures deplete family incomes, planning to secure basic support for survivors including orphans, etc.). These needs must be met if the goal is improvement of quality of life for PLHA.

The composition of and emphasis within such a comprehensive approach will change as the disease progresses. Early-stage infection requires emphasis on counseling and behavioral change; late-stage disease should emphasize palliation and social support. Medical interventions are needed at all stages to prevent or treat opportunistic infections and HIV-related illnesses.

CONTINUUM OF CARE

At all stages, the different elements of comprehensive care should complement and strengthen one another. For example, managing a clinical condition will be easier and more effective if worries about

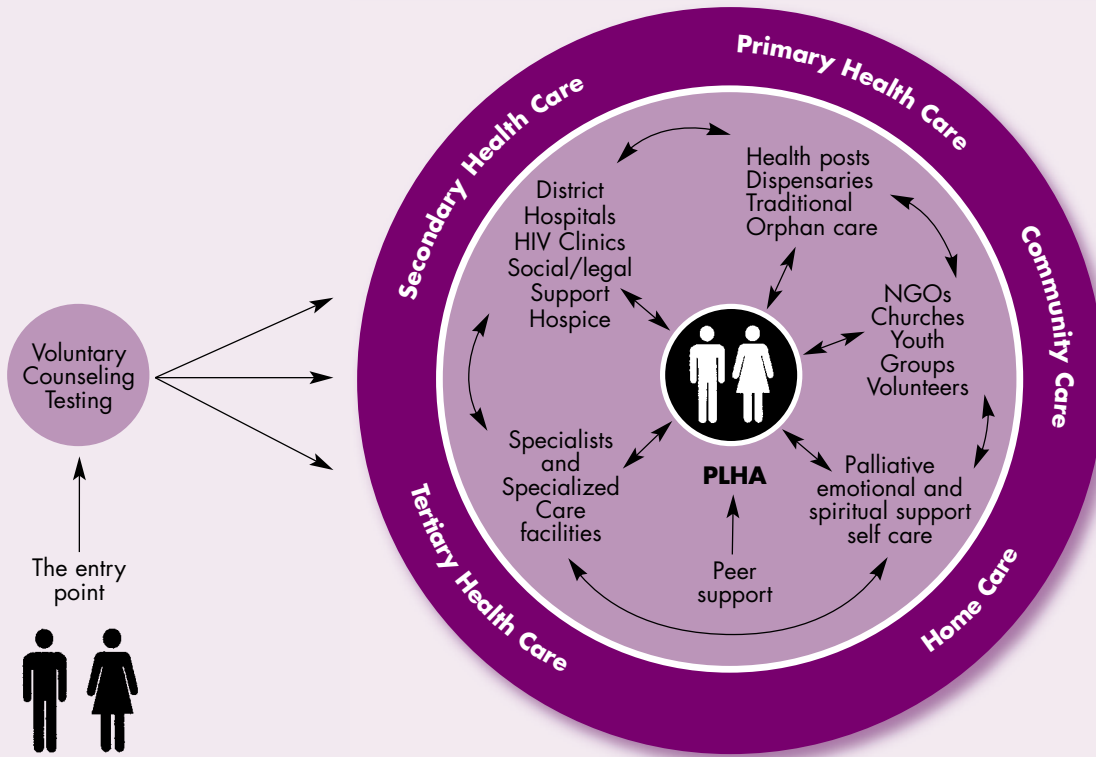
infecting a partner and planning for the family's future can be addressed through referral to counseling services that provide social or legal support.

The different elements of comprehensive care need not come from the same institution, but can be provided through networking with other services, institutions and projects in the community, including urban neighborhoods. Comprehensive care should include timely referrals between home or community and the hospital (and vice versa), effective discharge planning and follow-up at each level in order to ensure a continuum of care.

Functional and confidential referral systems must be in place to build on previous care efforts. Patients who have already disclosed their serostatus to one health care provider may not immediately disclose the fact that they are HIV-infected to a second. This is as important for medical referrals from a central hospital to a community health center as it is for psychosocial referrals between a counselor and a spiritual worker, or between a welfare officer and a home-based care program. Such coordination permits a continuum of care—from the institutional level to the community and home, as shown in Figure 1.⁶ A peer support group's ability to make these linkages, exchange information and offer emotional and moral support has been found to be essential all over the world.

To enter a care continuum, a diagnosis must be made in a way that promotes and encourages further care-seeking and support.

Figure 1
THE HIV/AIDS CONTINUUM OF CARE



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HIV/AIDS and Sexually Transmitted Diseases/WHO

CLINICAL GUIDELINES

The clinical spectrum of HIV infection differs from region to region.^{7,8} In resource-constrained countries, mycobacterium tuberculosis is a frequent complication of HIV infection. *Penicillium marneffi* infection is only seen in AIDS patients in certain parts of Southeast Asia. *Pneumocystis carinii* pneumonia (PCP), cytomegalovirus (CMV), retinitis and mycobacterium avium complex (MAC) infection are opportunistic infections often found in industrialized countries. Because of these differences in clinical

presentation—and because of resource-constrained health systems' limited ability to diagnose opportunistic diseases—the clinical approach to PLHA's medical problems differs in various parts of the world.

Health workers frequently have no choice but to use a syndromic approach in settings where the diagnostic infrastructure is underdeveloped and referrals for diagnostic work-ups would be difficult or impossible. In recognition of the need to deliver at least a minimum of health care in settings with severe diagnostic and therapeutic limitations, WHO in the early 1990s produced guidelines to care for people with clinically defined AIDS, based on different diagnostic and therapeutic capacity.⁹ The main problems covered in the guidelines are weight loss, fever, diarrhea,

pulmonary symptoms, neurological disorders and oral and skin disorders and pain. The guidelines are intended to be adapted to the disease presentation, disease stage, health infrastructure and resources available. In many countries, national guidelines have been established using the WHO guidelines as a template. But their use has varied widely; very few have been evaluated and recent developments in prevention and treatment of opportunistic infections have not been included. In addition, ARV therapy had not yet been fully developed when the guidelines were produced, and therefore was not mentioned. Separate guidance modules on the clinical, organizational, laboratory, regulatory and ethical aspects of ARV treatment have recently been developed by WHO and UNAIDS. An updated clinical guide on the safe and effective use of ARVs (with particular reference to resource-constrained settings) was published in September 2000 by WHO, the International AIDS Society (IAS) and UNAIDS.¹⁰

WHO has also produced a guide on treatment options for HIV/AIDS in its Model Prescription Information series, and UNAIDS has published a guide on the adaptation of clinical guidelines for care for PLHA. This chapter and the guides mentioned should encourage updates of currently available national guidelines. (See Recommended Reading for accessing these guides.)

Table 1

LIST OF CLINICAL CONDITIONS BY CLINICAL STAGE

Clinical Stage 1

1. Asymptomatic infection.
2. Persistent generalized lymphadenopathy.
3. Acute retroviral infection.

Performance scale 1: Asymptomatic, normal activity.

Clinical Stage 2

4. Unintentional weight loss < 10% of body weight.
5. Minor mucocutaneous manifestations (seborrheic dermatitis, prurigo, fungal nail infections, oropharyngeal ulcerations, angular cheilitis, etc.).
6. Herpes zoster within the previous five years.
7. Recurrent upper respiratory tract infections (such as bacterial sinusitis).

And/or performance scale 2: Symptomatic, but nearly fully ambulatory.

Clinical Stage 3

8. Unintentional weight loss > 10% of body weight.
9. Chronic diarrhea > one month.
10. Prolonged fever (intermittent or constant) > one month.
11. Oral candidiasis (erythematous or pseudomembranous).
12. Oral hairy leukoplakia.
13. Pulmonary TB (typical or atypical) within the previous year.
14. Severe bacterial infections (such as pneumonia, pyomyositis).
15. Vulvovaginal candidiasis, chronic (> one month) or poorly responsive to therapy.

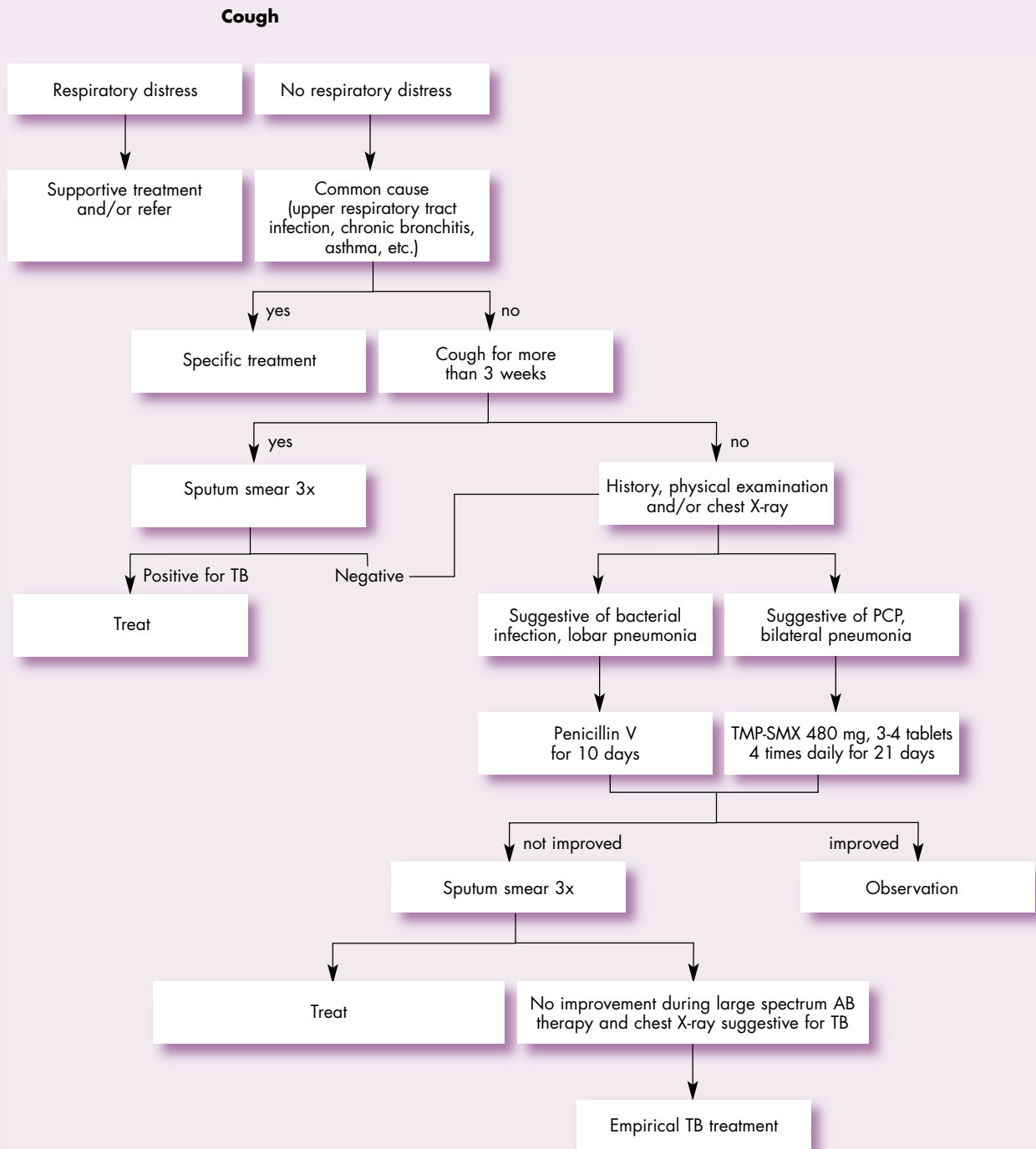
And/or performance scale 3: In bed < 50% of normal daytime, but > normal, during previous month.

Clinical Stage 4

16. HIV wasting syndrome.
17. *Pneumocystis carinii* pneumonia.
18. Toxoplasmosis of the brain.
19. Cryptosporidiosis with diarrhea > one month.
20. Isosporidiosis with diarrhea > one month.
21. Cryptococcosis, extrapulmonary.
22. Cytomegalovirus disease of an organ other than liver, spleen or lymph node.
23. Herpes simplex virus infection, mucocutaneous (> one month) or visceral (any duration).
24. Progressive multi-focal leukoencephalopathy.
25. Any disseminated endemic mycosis (histoplasmosis, coccidioidomycosis, etc.).
26. Candidiasis of the oesophagus, trachea, bronchi, or lungs.
27. Atypical mycobacteriosis, disseminated.
28. Non-typhoid salmonella septicaemia.
29. Extrapulmonary TB.
30. Lymphoma.
31. Kaposi's sarcoma.
32. HIV encephalopathy.

And/or performance scale 4: In bed > 50% of normal daytime during previous month.

Figure 2



MANAGEMENT OF HIV-RELATED PROBLEMS

Managing the health problems of a person infected with HIV depends largely on his/her degree of immune deficiency. In the early stages of infection, patient complaints will often be unrelated to the infection itself. In advanced stages, however, opportunistic infections or cancers are to be expected. Therefore, algorithmic flow charts for the diagnosis and treatment of PLHA health problems differ according to the stages of disease. Ideally, CD4 lymphocyte counts should be measured to determine a patient's degree of immune deficiency, but this is often impossible in resource-constrained settings. To classify patients in different stages of disease in settings where CD4 lymphocyte counts are not available, a clinical classification system has been proposed by WHO (Table 1).¹¹

Chronic diarrhea

Dehydration and weight loss can cause fast decline of the general condition. Before starting diagnostic procedures, a health care worker should determine whether a patient needs oral or parenteral rehydration. Recommendations about hygiene and nutrition should be given and potassium supplements considered.

Figure 3 provides an example of an algorithm for the management of chronic diarrhea (more than three loose stools per day for at least 30 days).

Fever

If the following clinical symptoms/signs are present, the patient should be referred immediately to a reference health facility: altered consciousness, convulsions, neck stiffness, shock and severe dyspnea. If these alarm symptoms/signs are not present, the following algorithm is proposed (Figure 4).

Cough

In the absence of respiratory distress, clinical management of a patient with HIV infection and cough can generally be done in a peripheral health center (Figure 2).

Figure 3

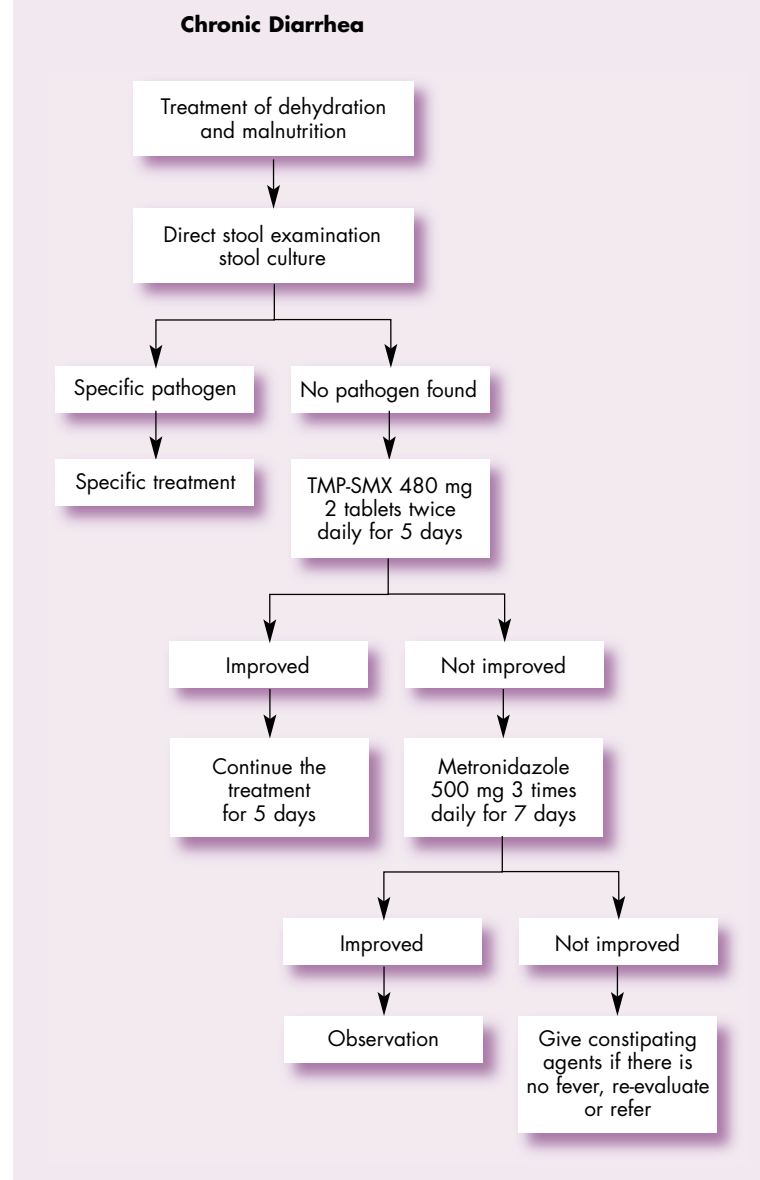
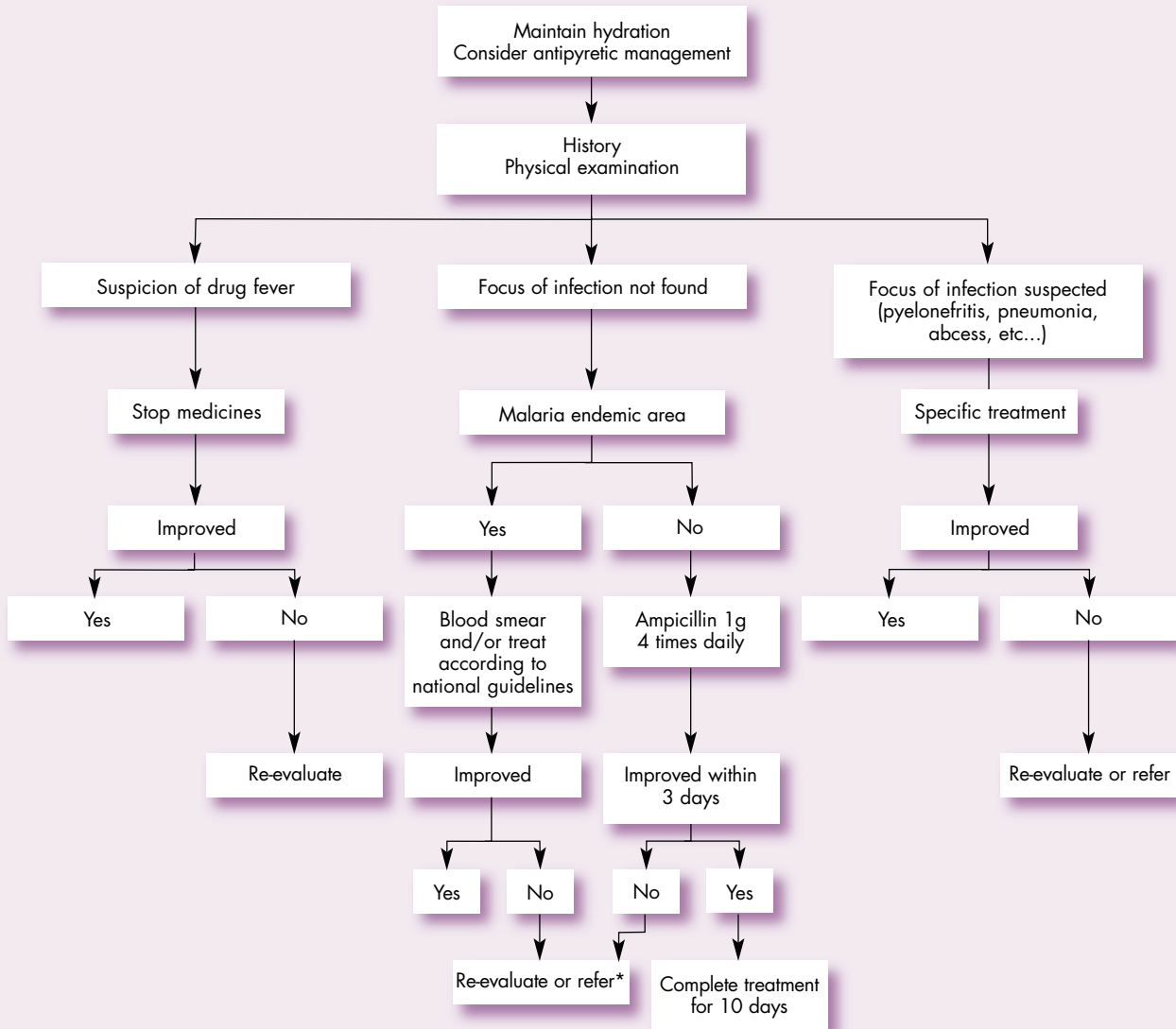


Figure 4

Fever



*Consider opportunistic infections, certainly if clinical signs/history are suggestive of immune deficiency (sputum smear, chest X-ray, fundoscopy, CSF examination...)

Headache

Headache is generally due to a common cause such as stress or sinusitis in HIV-infected people with good immune systems. The work-up of headache in a person with severe immune deficiency—certainly in the presence of other symptoms and signs (including a neurological deficit)—is much more complicated and may require referral to a reference center (Figure 5).

HIV-related skin diseases

Dermatological abnormalities are very often observed in people infected with HIV. Table 2 describes the treatment of some of these skin lesions.

PROPHYLAXES FOR OPPORTUNISTIC INFECTIONS

Two studies in Abidjan, Côte d'Ivoire, showed cotrimoxazole significantly reduced both hospitalizations and mortality from opportunistic infections. (In a study among TB patients, mortality was decreased by nearly 50 percent). Whether large-scale administration of cotrimoxazole in resource-constrained settings will be feasible and beneficial remains to be studied. Use of this drug should be watched to determine whether it leads to increased bacterial resistance.

(For information on TB prophylaxis, see the following section).

Pneumococcal vaccination did not protect against pneumococcal infections in a clinical trial in Uganda.

Figure 5

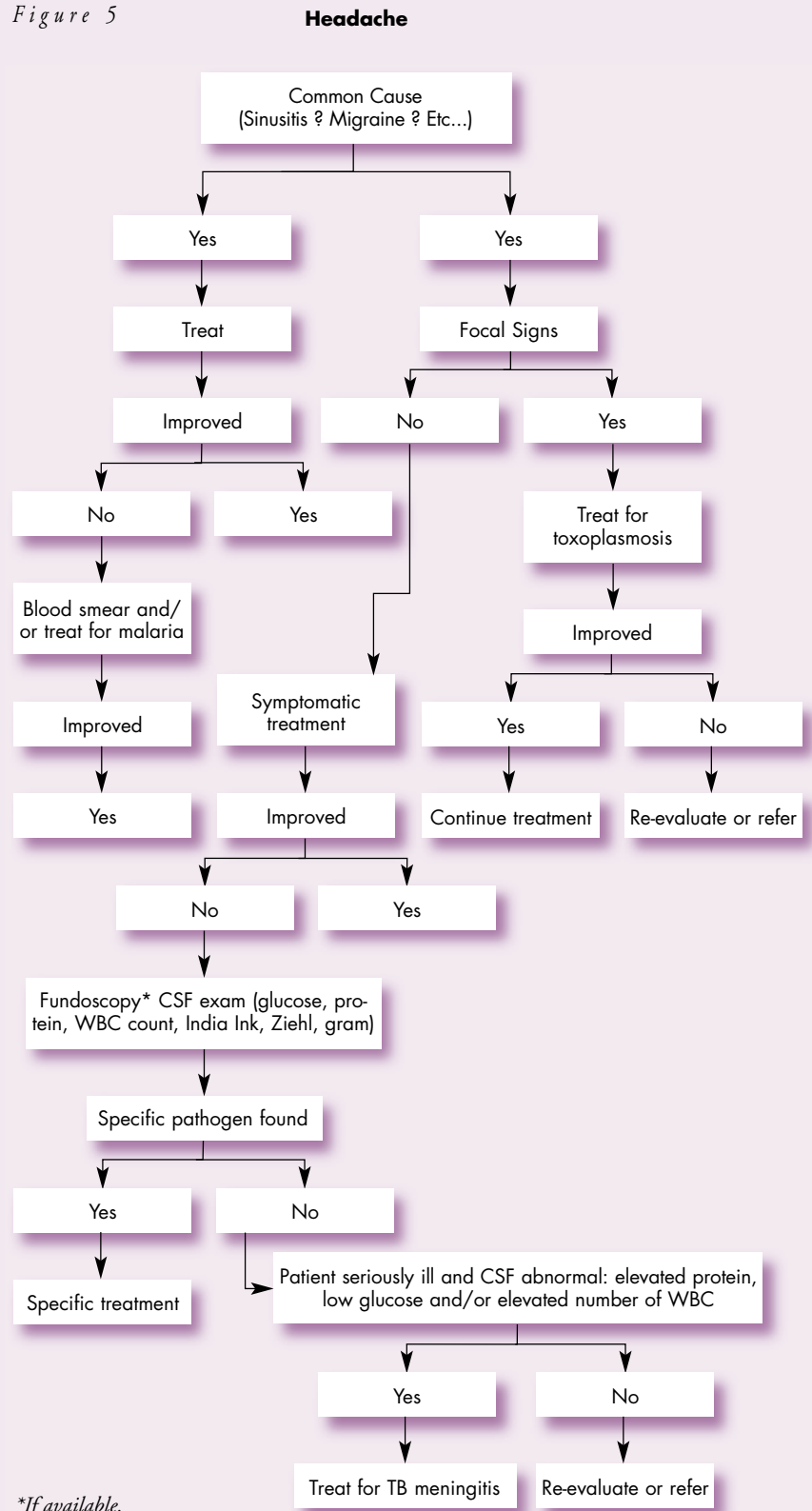


Table 2

Herpes zoster	Local lesion care/if available: acyclovir 10 mg/kg three times daily for seven days.
Herpes simplex	Local lesion care/if available: acyclovir 5 mg/kg three times daily for seven days.
Molluscum contagiosum	Prick each lesion with a needle and touch with phenol.
Condyloma acuminatum	Treat with podophyllin 20% solution, once or twice weekly until cleared.
Furunculosis, impetigo, pyoderma or folliculitis	Local lesion care/treat with penicillin for 10 days.
Hidradenitis suppurativa	Local lesion care/treat with tetracycline 500 mg twice daily for six weeks.
Pyomyositis	Surgical drainage and antibiotics.
Dermatophytosis	Treat with topical broad-spectrum antifungal.
Kaposi's sarcoma	Cryotherapy, intralesional therapy, surgical excision, radiotherapy, chemotherapy.
Drug eruptions	Withdraw drug/local lesion care.
Prurigo	Topical calamine lotion.
Seborrhoeic dermatitis or generalized erythroderma	Topical 1% hydrocortisone.
Psoriasis	Coal tar in salicylate ointment twice daily.
Scabies	Topical benzylbenzoate lotion 25% or ivermectin.

TB/HIV DUAL INFECTIONS

An HIV-infected person is 10 times more likely to develop TB than an uninfected person. In resource-constrained countries, more than 30 percent of people infected with HIV will develop TB, and it can occur at any point in the course of the infection. The clinical presentation of TB depends on the degree of immune deficiency. In patients in an early stage of HIV infection, TB presents in a manner similar to that in non-HIV-infected persons. In late-stage disease, disseminated TB is more common.

TB DIAGNOSIS

The highest priority for TB control is the diagnosis of sputum smear-positive pulmonary TB cases. Clinically, this diagnosis should be suspected in the presence of the following symptoms:

- Cough more than three weeks
- Sputum production
- Weight loss

Ideally, patients with symptoms suggestive of pulmonary TB should submit three sputum samples for microscopy: one on-the-spot sample, a second early-morning sample and a third on-the-spot sample. No chest X-ray pattern is absolutely typical for pulmonary TB.

Sputum smear-negative pulmonary TB

Such a diagnosis should be considered in a patient who continues to cough despite treatment with broad-spectrum antibiotics, and who has repeatedly negative sputum smears.

Extrapulmonary and disseminated TB

An increased incidence of extrapulmonary and disseminated TB is seen in PLHA. Diagnosis is made on clinical grounds or based on the result of a bacteriological or histological examination (such as a lymph node aspiration and a Ziehl coloration of the smear).

TB TREATMENT

Several treatment regimens can be followed for TB patients with and without HIV infection (Table 3). The regimen recommended depends on the patient treatment category. There is a standard code for TB treatment regimens. Each anti-TB drug has an abbreviation (shown in Table 3). A regimen consists of two phases. The number before the phase is the duration of that phase in months, and a number in subscript after a letter is the number of doses of that drug per week. If there is no number in subscript after a letter, treatment with that drug is daily.

TB/HIV co-infected patients should never be treated with thiacetazone because they are at higher risk of severe, sometimes fatal, allergic reactions (Steven Johnson syndrome). Hypersensitivity reactions

Table 3

RECOMMENDED TB TREATMENT REGIMENS

TB treatment category	TB treatment regimens	
	Initial phase	Continuation phase
■ New smear-positive PTB	2 HRZE(S)	6 HE
■ Seriously ill, extra-pulmonary or Smear-negative PTB	2 HRZE(S)	4 HR
Smear-positive PTB		
■ Relapse	2 HRZES/1 HRZE	5 H ₃ R ₃ E ₃
■ Treatment failure	2 HRZES/1HRZE	5 HRE
■ Return after default		
Not seriously ill, extra-pulmonary TB or smear-negative PTB	2 HRZ or 2 H ₃ R ₃ Z ₃	6 HE 2 HR/4H
Extrapulmonary TB	2 HRZ or 2 H ₃ R ₃ Z ₃	2 H ₃ R ₃ /4H
Chronic case (still sputum-positive after supervised re-treatment)	Refer to specialist center if second-line drugs available	

PTB: pulmonary TB, H= Isoniazid, R= Rifampicin, E= Ethambutol, Z= Pyrazinamide, S= Streptomycin

may occur with all anti-TB drugs and are particularly frequent in people infected with HIV. Patients with severe drug reactions should be referred to specialized TB centers.

In regions of high HIV-prevalence in resource-constrained countries—where needles and syringes are often inadequately sterilized—oral ethambutol should replace streptomycin injections.

Adherence to anti-TB treatment

Strict adherence to anti-TB treatment is essential to avoid the development of multiple drug-resistant TB. Ways to improve adherence:

1. Short course chemotherapy. By using more effective anti-TB drugs, TB treatment can be reduced to six months (see Table 3).
2. Direct observed therapy, short course (DOTS). Such treatment should be given as close to the patient's home as possible. A member of the health staff in a peripheral health facility, a trained local community member or a family member should supervise the therapy.

3. Treatment counseling by health care workers. Health care workers should explain how to take anti-TB drugs, their potential side effects and when patients must return for follow-up.
4. There should always be an adequate supply of anti-TB drugs in the health facility and patients should have easy access to them.

Monitoring TB treatment

TB patients should be monitored the same way, whether they are or are not infected with HIV. Recording the treatment results of sputum smear-positive pulmonary TB patients is vital to monitor patient cure rates and the effectiveness of the National TB Control Program.

Mortality of TB patients infected with HIV will be higher than mortality of non-HIV-infected TB patients: 20 percent of the TB/HIV co-infected patients will generally die within one year after starting TB treatment. This excess mortality is due partly to the TB itself, and partly to other HIV-related problems. Early mortality is often due to TB, while later deaths usually result from other HIV-associated causes.

HIV TESTING IN TB PATIENTS

It is impossible to diagnose HIV infection in a TB patient solely on the basis of clinical symptoms. HIV infection may be suggested by certain symptoms—such as severe weight loss, chronic diarrhea, persistent fever despite effective anti-TB treatment, a history of herpes zoster, a chronic papular pruritic eruption, oral

Table 4

DRUGS OF THE ESSENTIAL DRUG LIST FOR HIV/AIDS TREATMENT IN RESOURCE-CONSTRAINED SETTINGS

Acyclovir
Albendazole
Amphotericin B
Ampicillin or benzylpenicillin
Anti-TB drugs
Aspirin
Calamine Lotion
Calcium folinate
Ceftriaxone
Ciprofloxacin
Chloramphenicol (or other broad spectrum antibiotic)
Chlorpromazine
Clindamycin
Codeine phosphate
Cotrimoxazole
Daraprim
Dapsone
Diazepam
Flucytosine
Gentian Violet
Hydrocortisone cream
Ketoconazole
Metronidazole
Morphine
Multivitamins
Nystatin
Paracetamol
Pentamidine
Primaquine
Pyrimethamine
Sulfadiazine
Sulfadoxine/pyrimethamine
Trimethoprim

candidiasis, a persistent painful genital ulceration, anemia, leucopenia or thrombocytopenia. But a diagnosis of HIV infection can only be made and announced to a patient based on the result of an HIV test. Therefore, health care workers involved in TB care must be trained in HIV counseling (see Chapter 23). TB treatment centers in regions of high HIV prevalence may require additional staff to cope with the increased workload.

PREVENTION OF TB

Early diagnosis and treatment of sputum smear-positive TB patients and good adherence to TB treatment are the best ways to prevent the further spread of TB. By diagnosing TB early, patients can be treated in an outpatient setting. This avoids transmission in hospital wards. Ideally, wards where TB patients are treated should have large windows, sputum collection rooms, and microbiology laboratories. Doors should be kept closed and windows open.

Patients should be instructed to keep their mouths covered with their hands when coughing and to use sputum pots with lids. Patients with sputum smear-positive TB ideally should wear face masks when they are moved from one part of a hospital to another. But masks generally do not provide health care workers with effective protection against inhaling other people's infectious droplets. The exception is during a cough-inducing procedure, such as a bronchoscopy. If possible, sputum-positive TB patients should be admitted in a special room/ward separate from other patients, and patients should be admitted to a TB ward only after a diagnosis of TB has been confirmed.

TB PROPHYLAXIS IN HIV-INFECTED PEOPLE

Studies indicate that isoniazid (IHG) for six to nine months or rifampicin and pyrazinamide for three months can reduce the incidence of TB in PLHA when a positive skin test indicates they are already infected with mycobacterium TB.¹² This prophylaxis, however, has not been studied sufficiently to show reduced mortality, and it remains unknown how long its protective effect will last. Before starting TB

Table 5

MINIMUM REQUIREMENTS TO INTRODUCE ANTIRETROVIRALS (ARVs)

- Health care workers must have sufficient knowledge about ARV drugs. Patients should receive appropriate counseling. Advantages and disadvantages of ARV drugs should be discussed.
- Patients should be willing to adhere to the treatment regimen.
- ARVs should be stored in optimal conditions and distributed by trained staff.
- ARV treatment should be sustainable.
- It should be possible to diagnose and treat concomitant illnesses.
- There should be capacity to provide prophylaxis for opportunistic infections.
- A minimum of laboratory monitoring should be possible, including routine hematological and biochemical tests to detect side effects of drugs. CD4+ lymphocyte counts and viral load measurements are needed to decide whether to start ARV treatment in asymptomatic patients.

prophylaxis, it should be certain that the patient has no active TB. Therefore, an extensive clinical history and examination including a chest x-ray should be performed.

WHO and UNAIDS recommend that preventive therapy for TB should be included in the health care package of PLHA whenever possible.²

BCG VACCINATION AND HIV INFECTION

There have been some reports of disseminated Bacille Calmette Guerin (BCG) infection after BCG vaccination of HIV-infected children. In the majority of cases, however, BCG immunization has been shown to be safe. The advantages of BCG vaccination outweigh the possible disadvantages in countries where there is a high prevalence of TB. WHO therefore continues to recommend BCG vaccination of all children in these countries, except for children with symptoms of HIV/AIDS.

IMPROVING ACCESS TO ESSENTIAL DRUGS

Drugs are needed primarily for infectious complications that are easily diagnosable and treatable (at low cost), particularly those that may occur during relatively early stages of HIV infection—such as other sexually transmitted diseases (STDs), salmonella septicemia, bacterial pneumonia and TB. For some of these infections (TB and STDs), access to treatment—at low or no cost—is important to avoid their further spread. Symptomatic treatment should be available to treat diarrhea, fever and pain. UNAIDS and the WHO Action Program on Essential Drugs and Vaccines recently established a list of essential drugs for HIV/AIDS (Table 4). (See Chapter 4 for more information on managing essential drugs for HIV/AIDS patients.)

IMPROVING ACCESS TO ANTIRETROVIRAL DRUGS (ARVs)

Providing optimal ARV therapy to all persons for whom such treatment may be beneficial should be the goal. But in resource-constrained settings there are many obstacles to achieving this. Minimum requirements to introduce ARV drugs are shown in Table 5.

ARVs are increasingly used in resource-constrained countries and certainly in medium-income countries, such as those in South America. The issue is therefore how to use these ARV drugs in the most efficient and safest manner. Guidelines have been developed by WHO in collaboration with IAS and UNAIDS (see Recommended Reading). Countries with limited resources should establish a list of priorities for the use of ARV drugs. An example is given in Table 7.

WHAT SHOULD NOT BE DONE WITH ARV TREATMENT

- Start therapy in someone whose HIV diagnosis has not been confirmed.
- Begin when long-term provision cannot reasonably be guaranteed.
- Start in a patient not motivated to follow such treatment, or in a person who is unaware of his/her seropositivity.

Table 6
**LICENSED ANTIRETROVIRAL
 DRUGS AND COMMONLY USED REGIMENS
 FOR INITIATING TREATMENT**

Nucleoside Analogue Reverse Transcriptase Inhibitors (NRTI)	Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTI)
Zidovudine (ZDV)	Nevirapine
Didanosine (ddI)	Delavirdine
Zalcitabine (ddC)	Efavirenz
Lamivudine (3TC)	
Stavudine (d4T)	
Abacavir (ABC)	
Protease Inhibitors (PI)	
	Indinavir
	Ritonavir
	Saquinavir
	Nelfinavir
Commonly Used Regimens for Initiating Treatment	
	1 PI + 2NRTI (e.g., indinavir + ZDV + 3TC)
	1NNRTI + 2 NRTI (e.g., nevirapine + d4T + ddI)

- Prescribe ARV monotherapy, except for the prevention of perinatal HIV transmission and post-exposure prophylaxis (PEP).
- Start without laboratory monitoring. In resource-constrained settings, anemia with hemoglobin levels seven to eight grams per deciliter is relatively frequent. These patients may be particularly at risk for severe anemia during zidovudine and cotrimoxazole treatment. Chronic hepatitis caused by hepatitis B and C infections is also very common in resource-constrained countries; ARV drugs are all potentially hepatotoxic and should be prescribed with caution to these patients. If these drugs are given, liver

function should be monitored. In cases of renal insufficiency, dosage of certain ARV drugs such as stavudine and indinavir should be modified.

- Start without providing adequate information about how and when to take the drugs, potential side effects, interactions with other drugs, when to stop the drugs, etc.
- Provide treatment without the capacity to diagnose, treat or prevent opportunistic infections.
- Provide treatment unless patient's other needs, such as sufficient nutritional support, adequate home care, etc. can be met.
- Continue treatment despite serious side effects or possible irreversible damage.
- Strict adherence to treatment cannot be assured, since this is essential to avoid the development of resistance.

HOW TO IMPROVE ADHERENCE TO ARV TREATMENT

Treatment decisions should be made jointly by the patient and the clinician after careful discussion of:

- Advantages and disadvantages of ARV treatment
- Different treatment options
- Possible adverse reactions
- Cost of treatment
- Need for a long-term emotional and financial commitment

Choice of an ARV treatment regimen should take into account the lifestyle of the patient:

- Patients may accept a twice-daily, but not a three-times-daily, treatment regimen.
- Patients who eat at irregular time intervals may have problems adhering to certain ARV treatment regimens.

Once an ARV treatment regimen has been chosen, the following should be explained very carefully:

- How and when the drugs should be taken: Written information should be given the patient or a family member if they can read. Clearly illustrated materials should be given illiterate patients.
- Potential adverse reactions of such treatment and what to do about them.
- How and where the patient can get information about possible treatment problems.
- When the patient should return for follow-up visits, blood tests and other monitoring.
- Who will help the patient adhere to the treatment regimen—partner, another family member, a friend, a nurse.
- Where to get psychosocial support.

Patients should be able to consult regularly with a trained counselor to discuss all aspects of adherence. Communication skills of the doctor/counselor are very important. There should be a reliable, long-term and regular supply of ARV drugs that patients can easily access.

ARVs TO PREVENT TRANSMISSION OF HIV

Studies with macaques provide compelling evidence that ARV therapy can prevent acquisition of HIV. Animals provided ARVs before or after exposure can be protected from infection.^{13, 14} A single retrospective study suggests that ARVs can prevent acquisition of HIV after needlestick exposure.¹⁵ (See Chapter 21 for more information on HIV transmission in health care settings.)

The use of ARVs to prevent mother-to-child transmission (MTCT) of HIV emphasizes the power of biological prevention strategies. (See Chapters 18 and 19 for more information on ARV therapy to reduce MTCT of HIV.)

Recent work in Uganda¹⁶ and Zambia¹⁷ demonstrates that HIV concentration in blood—and by extension, genital secretions—determines the efficiency of sexual transmission in discordant couples.

Table 7
SUGGESTED PRIORITY TO BE ACCORDED TO ARV TREATMENT ACCORDING TO DISEASE STAGE

Disease stage (WHO stage 1-4)	
1. Acute HIV illness	No ARV drugs
Asymptomatic phase	No ARV drugs
2. Early symptomatic phase	No ARV drugs
3. Symptomatic phase, non-AIDS	ARV drugs*
4. AIDS	ARV drugs
5. Terminal AIDS	No ARV drugs

**It is strongly recommended that CD4 lymphocyte and, if available, viral load results should determine when ARV treatments are used. Where budgets are limited, it is probably best not to begin treatment too early, to assure continuation of this therapy once it has been started. A maximum beneficial impact on the quality of life of patients is expected in patients with CD4 lymphocyte counts < 200/mm³ and/or a viral load > 30,000-100,000 copies/ml plasma. With a small budget it is probably better to delay ARV treatment in TB patients because the TB treatment itself is complicated, and rifampicin cannot be given in association with certain ARV drugs (protease inhibitors). Ideally, tritherapy should always be considered because bitherapy will rapidly lead to drug resistance.*

These observations and extensive work with macaques¹³ suggest that ARV therapy can be used to reduce transmission of HIV. Such therapy could be used to prevent transmission from an infected person to his/her uninfected partner, or to prevent HIV acquisition through pre- or post-exposure ARV prophylaxis.

But there have been no studies of ARV sexual prophylaxis in humans, largely because of the difficulty in developing research strategies capable of proving the benefit of prophylaxis.¹⁸ Research that demonstrates the feasibility of prophylaxis does not prove that such prophylaxis works.

Table 8
**CLINICAL MARKERS OF
 PERINATALLY ACQUIRED HIV**

Strongly suggestive of HIV
<i>Pneumocystis carinii</i> pneumonitis
Non-suppurative parotitis
Esophageal candidiasis
Kaposi's sarcoma (rare)
Multi-dermatomal herpes zoster
Hyperglobulinaemia without obvious cause
Suggestive of HIV
Failure to thrive
Chronic diarrhea
Nephrotic syndrome
Persistent oral thrush
Cardiomyopathy
Frequent, slowly responsive bacterial infections
Immune thrombocytopenia
Extrapulmonary TB
Non-cavitary pulmonary TB
Suggestive of HIV in the context of known maternal infection
Extensive lymphadenopathy
Hepatosplenomegaly
Development delay
Drug eruptions
Finger clubbing
Generalized dermatitis
Prematurity

HIV INFECTION IN CHILDREN

DIAGNOSIS AND MANAGEMENT OF HIV INFECTION IN INFANTS

It is difficult to detect HIV infection in infants because they passively acquire HIV antibodies from their mothers. Maternal antibodies may last as long as 18 months, but uninfected children usually revert to a negative status before age nine to 10 months. A single negative HIV antibody test result can be considered diagnostic of absence of infection.

In better-equipped settings, diagnosis is made by HIV DNA PCR testing. This should be performed before the infant is 48 hours old, at age one to two months, and at age three to six months. HIV infection is diagnosed by two positive HIV virologic tests, performed on separate blood samples. In the absence of biological markers, clinical markers of perinatally acquired HIV infection should be used, as shown in Table 8.

MONITORING PEDIATRIC HIV INFECTION

Ideally, CD4 lymphocyte counts should be done. CD4 lymphocyte counts in healthy infants who are not infected with HIV are considerably higher than in uninfected adults, and slowly decline to adult levels by age six. Therefore, levels of CD4 lymphocyte counts in HIV-infected children are higher than in adults with the same stage of disease. When there is no access to CD4 lymphocyte counts or viral load during regular clinical check-ups, weight, growth and development should be monitored to determine whether treatments are effective.

MANAGEMENT OF OPPORTUNISTIC INFECTIONS

Frequent opportunistic infections in children include candida, tuberculosis (TB) and pneumocystis carinii pneumonia. In resource-constrained settings, pneumocystis carinii pneumonia seems to occur more frequently, and TB less frequently, in infected children than adults. Cryptococcal meningitis and cerebral toxoplasmosis also are less common in children than in adults. Children infected with HIV often present with recurrent ordinary bacterial infections.¹⁹

The United Nations Children's Fund (UNICEF) approach to Integrated Management of Childhood Illnesses (IMCI) provides a framework for managing common diseases and malnutrition. This approach could also be used as a basis for the treatment of infected children. WHO has also produced algorithms specifically for the management of medical problems of pediatric HIV/AIDS patients. Adequate nutritional support is essential, and vitamin A supplementation may be useful for children with persistent diarrhea.

PROPHYLAXIS AGAINST OPPORTUNISTIC INFECTIONS

Primary prophylaxis with cotrimoxazole has been proposed for all infants born to HIV-infected women from four weeks of age until their infection status is established. Cotrimoxazole prophylaxis may decrease pneumococcal and other bacterial infections, but may increase the risk of selecting resistant organisms. So far, however, the efficacy and cost-effectiveness of this strategy has not been evaluated in HIV-infected children in resource-constrained settings.

VACCINATIONS

Inactivated polio vaccine should be preferred over oral polio vaccine. Where the risk of measles is high—especially during hospital admission—measles vaccine should be given at six and nine months. In children with known symptomatic HIV infection, BCG and yellow fever vaccination are contraindicated. Otherwise, no changes in immunization schedules are indicated for children born to mothers who are suspected or known to be infected with HIV.¹⁹

HIV INFECTION IN WOMEN

Women are particularly vulnerable to HIV infection due to physiological, socioeconomic and (often) cultural factors. The vast majority of infected women are of reproductive age, and are at particular risk of stigmatization, abandonment by their partner/family or becoming victims of violence. One important response to discrimination has been the formation of self-help groups. Women infected with HIV generally have access to fewer resources than do men; increasing their economic independence is an important step toward enabling women to reduce infection risks for themselves and their families. Small credits and skills development can help them achieve independence. Legal assistance may be needed to protect the inheritance rights of widows.

GYNECOLOGICAL PROBLEMS

Gynecological symptoms may be the first sign of HIV infection in women. These include recurrent or persistent vaginal candidiasis, recurrent or persistent herpes simplex tubo-ovarian, genital ulcerations, genital ulcerations caused by ulcus Ducrey, syphilis, pelvic inflammatory disease (PID) (especially tubo-ovarian abscesses) and cervical dysplasia caused by human papillomavirus infection. Women infected with HIV are approximately 10 times more likely to develop cervical cancer than those not infected, and should be screened regularly for cervical abnormalities. In addition, infected women often suffer from infertility caused by other STDs. Women in late-stage disease frequently present with oligomenorrhoea or amenorrhoea.

HIV INFECTION IN PREGNANCY

In making reproductive decisions, HIV-infected women should be provided with information and counseled about their pregnancy options. Contraceptive counseling should be offered to those who do not desire pregnancy. Condoms should be used, since the efficacy of hormonal contraceptives may be reduced by drugs such as rifampicin or protease inhibitors. Intrauterine contraceptive devices are

HEALTH SECTOR REFORM AND HIV/AIDS

not recommended because they are associated with an increased risk of PID, and also may cause endometriosis, increased menstrual bleeding and micro-abrasions on the penis (which may increase the risk of HIV transmission to an unprotected partner). The use of female condoms could be proposed if the sexual partner is not willing to use a male condom. Although there is *in vitro* evidence that some spermicidal agents act against HIV, their efficacy *in vivo* has not been established. Recent studies indicate that nonoxynol-9 may actually increase the risk of HIV acquisition, and is not recommended for prevention of HIV in women.

Where legally accepted, prenatal and safe abortion services should be available by referral. Pregnancy among HIV-infected women does not appear to increase maternal morbidity or mortality, but the following adverse pregnancy outcomes have been reported in women infected with HIV, particularly in women with advanced HIV disease: increased risk of fetal loss, intrauterine growth retardation, pre-term birth and low birth weight.

Many infected women refuse contraceptives for a variety of reasons: They have no access to them; they are unable to tell their partner they are HIV-infected (risk of violence, risk of abandonment); they are expected to become pregnant; or they want to become pregnant. With greater availability of ARV drugs, more infected women will probably consider becoming pregnant. If a partner is HIV-seronegative, artificial insemination could be proposed. (See Chapter 18 for antenatal intrapartum and postnatal management.)

In many resource-constrained settings, health care is changing: Reforms are being introduced to improve the quality and effectiveness of services delivered—often by transferring responsibility for planning and management of services and budgets to the district level. Health sector reform may also reduce the accountability and affordability of HIV/AIDS health services in the public sector. Privatization of health care is increasing, while cost constraints are limiting public sector services.

What does this mean for HIV/AIDS care? Most PLHA will have no choice but to continue to seek care through the public sector. But cost-sharing schemes may inadvertently disclose serostatus and, for those with few resources, further limit access to care. As the number of people seeking care is rapidly increasing, there is urgent need for decentralized services to cope with growing demand. The challenge remains to integrate HIV/AIDS comprehensive care into district and local services and ensure access to care across a continuum—from hospital to community to home. For the moment, too many patients are treated in large hospitals. Overcrowding in these health facilities means both PLHA and those with other diseases do not receive adequate care. Decentralization of care, with the involvement of district management teams knowledgeable about HIV/AIDS and guidelines for referral between services, will be needed (see Figure 1).

FUTURE CHALLENGES

Progress in the treatment of people infected with HIV has been made mainly in industrialized countries. The challenge now is to look at ways to introduce new treatment regimens into resource-constrained settings. A minimum package of HIV care should include simple diagnostic facilities and counseling, accurate information about HIV/AIDS, psychosocial support, symptomatic treatment, treatment for easily diagnosable and treatable conditions such as salmonella septicemia, bacterial pneumonia, TB, STDs and oral candidiasis, as well as palliative care.

There has been very little research into the biomedical and socioeconomic aspects of care and support for people infected with HIV in resource-constrained settings. Very few studies have evaluated the quality of care and the efficacy of clinical algorithms. A number of trials are underway to evaluate the efficacy of prophylaxes against opportunistic infections and the effect of ARV therapy in preventing perinatal transmission. Operational research is now needed to evaluate whether certain successful interventions can be implemented on a larger scale, outside research settings.

RELEVANT CHAPTERS

- Chapter 3 *Responding to the Socioeconomic Impact of HIV/AIDS*
- Chapter 4 *Improving Access to Drugs for People Living with HIV/AIDS*
- Chapter 18 *Reducing the Risk of Mother-to-Child Transmission of HIV During Pregnancy and Delivery*
- Chapter 19 *Mother-to-Child Transmission of HIV Through Breastfeeding: Strategies for Prevention*
- Chapter 21 *Transmission of HIV in Health Care Settings*
- Chapter 23 *Counseling, Testing and Psychosocial Support*

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C H A P T E R

26

*Orphans
and Other
Vulnerable
Children:
Approaches
to Care and
Protection
Programs*

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Orphans and Other Vulnerable Children: Approaches to Care and Protection Programs

INTRODUCTION

The 1997 World AIDS Day release of *Children on the Brink* represented a “wake-up call” to the effects of HIV/AIDS on children. Updated in 2000, the USAID report estimates that by 2010, at least 44 million children will have lost one or both parents to all causes in the 34 countries most severely affected by the AIDS pandemic. Of these 44 million orphans, 68 percent of their parents will die from AIDS. The orphan crisis is most acute in sub-Saharan Africa.

These devastating numbers present an unprecedented challenge to the governments, communities and families of heavily affected countries—and to the agencies and organizations that assist them. Development of large-scale systems for orphan management and protection is still evolving; it is not an area for which a large body of written materials is available. This chapter attempts to consolidate the existing knowledge in this very new, but critically important, field.

BACKGROUND

In countries heavily affected by HIV/AIDS, the proportion of children and young people under age 15 who are orphans is tripling or quadrupling. But orphaning is only one of the problems—although by far the largest and most pressing—faced by children in affected countries. Due to the pandemic, the prospects of children and young people today have also worsened in many other important ways. The pandemic is undermining two decades of hard-won gains in achieving the World Summit Goals for Children, and it will have other far-reaching consequences for social structure, economic development and human productivity.

PROGRAMMING AND POLICY MAKING FOR ORPHANS

Countries have struggled to develop policy review and systems of community care. But work has mostly been limited to running pilots and demonstrations in a few heavily affected areas—far short of the full-scale systems needed. A comprehensive nationwide program assessment must be an urgent priority in heavily affected countries.

STRATEGY DEVELOPMENT

STRATEGIC FOUNDATION

Systems of care and protection for children that incorporate substitute social mechanisms for care and mitigate additional suffering can be developed. The strategy should be an overarching multisectoral plan to meet the needs of large numbers of orphans and other children affected by HIV/AIDS over the next two to three decades.

STRATEGIC CAPACITY

Planning and development of a rational system of protection and care for children affected by HIV/AIDS must include four elements:

- Technical analysis
- Policy review
- Conceptual capacity
- Political support

PLANNING CONSIDERATIONS

Certain key planning considerations can guide strategy development. These will include:

- General considerations
- Situation analysis
- Linking prevention and care

DESIGN OF ORPHAN MANAGEMENT SYSTEMS

MANAGEMENT STRUCTURE

At least two levels of response are involved in “orphan management”: the macro (national and regional) and the micro (family and community).

DEVELOPING RATIONALIZED SYSTEMS OF CARE

Strategy and policy development can be linked with development of a managed, rational system of care and referral that supports community-based initiatives.

RESPONDING TO CHANGING SOCIAL CONDITIONS

Social welfare systems designed originally for relatively few numbers of vulnerable children who fell outside the systems of family care are now faced with serving very large numbers of children.

SYSTEM COMPONENTS AND LEVELS OF CARE

Countries faced with the prospect of developing a rationalized system of care and protection for vulnerable children must focus on at least three dimensions of the system: (1) Financial feasibility; (2) Availability of services; and (3) Personnel and acceptability.

TARGETING VULNERABLE CHILDREN

HIV/AIDS increases the number of vulnerable children—including orphans—because of the loss of parents, guardians and productive adults. The success of preventive interventions will be measured by the number of these children who are reached.

DATA DEVELOPMENT

ORPHAN ESTIMATES

Orphan estimates may come from one or several sources; estimates for a given country can vary widely. It is important to determine what types of orphans are being included in an estimate and to make careful comparison of orphan estimates.

DATA DEVELOPMENT

The information needed on children, caregivers and their families for a thorough situation analysis typically will be incomplete, limited, unavailable or outdated. Data sources include national censuses, demographic and health surveys (DHSs) and special surveys and registrations.

THE RESPONSE

CHILDREN

Children face many dangers due to the loss of their parents. And these losses are increasing as the AIDS epidemic worsens. Interventions must be targeted directly to children as well as families and communities.

FAMILIES

Family care is much more cost effective and acceptable than any kind of institutional care. But poor families need help, including psychosocial and material assistance and schemes to raise incomes and productivity.

COMMUNITIES

If individual families are too weak to provide care, AIDS-stricken communities view children as a village responsibility. These communities can benefit from organizational support in a variety of forms, including assistance in income-generating projects and increasing agricultural productivity.

GOVERNMENTS

Over the past decade, many sub-Saharan Africa governments have responded creatively and energetically to the needs of children, families and communities affected by HIV/AIDS, revising laws and creating new policies to protect children.

PRIVATE SECTOR

Some private sector enterprises have helped people living with HIV/AIDS (PLHA) and their dependents in a variety of ways, and have been involved in AIDS prevention activities ranging from the distribution of condoms to regular screening and treatment for STDs.

GOING TO SCALE

SHORT- AND LONG-TERM PROGRAMMING

In the short term, a national orphan program requires investment in a planning and monitoring system. In the long term, implementing agencies should integrate family and community support programs into health, education, agriculture, water and sanitation sectors.

MONITORING AND EVALUATION

A monitoring and evaluation plan for orphan programs will be similar to those for other child protection, health or education programs.

PROGRAM QUALITY AND DEVELOPMENT

A monitoring and evaluation plan should review the quality of existing programs to serve children, families and communities affected by HIV/AIDS.

FUNDRAISING

A funding plan can include local sources of support as well as external sources. A national development plan and strategy for orphans will be important in increasing funds from foreign donors and programs.

AIDS AND THE RIGHTS OF POOR COMMUNITIES

Economic adjustment programs have weakened social services, health services and public assistance schemes, leading governments to abrogate responsibility for family welfare to local governments and community charity. This leaves the most vulnerable—children, women, the elderly and the disabled—exposed, with weak or nonexistent safety nets and few resources.

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The 1997 World AIDS Day release of *Children on the Brink* alerted the world to the effects of HIV/AIDS on children.

Updated in 2000, the report, published by the U. S. Agency for International Development (USAID), estimates that by 2010, at least 44 million children will have lost one or both parents to all causes in the 34 countries most severely affected by the AIDS pandemic. Of these 44

I N T R O D U C T I O N

million orphans, 68 percent of their parents will die from

AIDS. The orphan crisis is most acute in sub-Saharan African countries where 20 percent to 35 percent of children under 15 have lost a mother, father or both parents. The scale and urgency of this unprecedented demographic event shows the massive impact the pandemic will have on children, families, societies and economies through the first third of the 21st century.¹

The large numbers of orphaned children present a tremendous challenge to governments, communities and families of heavily affected countries—and to the agencies and organizations that assist them. Large-scale systems for orphan management and protection are still in the early stages of development. There is not a large body of written materials available for guidance. Governments, communities and families must develop responses that rely on vision and experience, rather than technical data and tools. Fortunately, the essential elements of a long-term care strategy are already being developed in some countries. The fact that they are moving ahead demonstrates considerable courage—courage that often requires breaking through layers of denial regarding the epidemic in order to lay the groundwork for children’s future protection. This chapter attempts to consolidate existing knowledge in this very new but important field.

BACKGROUND

UNICEF was the first global organization to publish estimates of children orphaned by the AIDS epidemic. *Children and AIDS—An Impending Calamity*, the agency's 1988 study, covered 10 countries in central, eastern and southern Africa. It included the first multicountry estimates of AIDS orphans and the first estimates of the disease's impact on infant and child mortality presented to the international community.² The numbers were condemned even as they were being developed—and roundly criticized after they were made public—for vastly overstating the problems facing women and children. Unfortunately, many of these predictions have now been confirmed.

In heavily affected countries, the proportion of children and young people under age 15 who are orphans is tripling or quadrupling. Wherever seroprevalence is now close to or above 20 percent, the proportion of children orphaned will be as high as 30 percent by 2010. Pre-AIDS levels of orphaning in sub-Saharan Africa was about five percent.^{1,3} Not only are orphan levels extremely high and growing, but they will remain high through the first three decades of the 21st century, even if HIV incidence declines rapidly in the near future.

Orphaning is only one of the problems—although by far the largest and most pressing—faced by children in AIDS-affected countries. Prospects for children and young people have also worsened in many other important ways because of AIDS.⁴

The pandemic is undermining two decades of hard-won gains in achieving the World Summit Goals for Children, and it will have other far-reaching consequences for social structure, economic development and human productivity. Child mortality has already

CHILDREN AFFECTED BY HIV/AIDS

- Worsening mortality
- Increasing morbidity
- Living in families weakened by HIV/AIDS
- Living in communities weakened by HIV/AIDS
- Less social support
- Increasingly impoverished
- Declining access to health, education, and social services
- Children's fundamental human rights are threatened by:
 - Starvation, illness and death
 - Physical, sexual and emotional abuse
 - Exploitation as labor
 - Deprivation of adult care and protection

DISADVANTAGE OF A CENTRALIZED SYSTEM OF CARE

- Vulnerable children are too numerous for government to support or monitor directly.
- Public welfare benefits reach only a small proportion of vulnerable families and children affected by the epidemic.
- Centralized systems encourage dependency and are not sustainable over the long term.
- These approaches professionalize childcare unnecessarily, discrediting family and community programs.
- Centralization makes systems inelastic, inflexible to local needs, budget-driven instead of needs-driven and not tailored to local preferences.

PROGRAMMING AND POLICY MAKING FOR ORPHANS

increased drastically in countries with severe epidemics. The disease only adds to existing difficulties of children in heavily affected countries: The World Bank estimates that 30 percent of all children in sub-Saharan Africa are chronically malnourished. In most countries with severe epidemics, this proportion is between 40 percent and 50 percent. Only 63 percent of the region's children are immunized against tuberculosis; less than 50 percent against DTP, polio and measles.^{5,6} Effects such as these will continue to be felt well into this century.

Even children who are not directly affected are living in societies with poorer infrastructure and human resources. Access to health, education and social services decreases as wage earners fall sick and the disease draws off skilled personnel and resources. It is difficult even to factor in the grief, horror and resulting social pathology resulting from AIDS deaths.

Children suffer in the most basic ways when their caregivers die. The World Bank's study of AIDS-affected families in Kagera, Tanzania, shows that "childhood malnutrition is potentially one of the most severe and lasting consequences of a prime-age adult death . . . Among the poorer households, stunting . . . among children under age five is indeed substantially higher for orphans (51 percent) than [non-orphans] . . . the difference in the better-off households is even larger . . . Half of the children who have lost one or both parents are stunted, regardless of whether they live in a poorer household or a less-poor household."⁷

Countries, most notably Malawi and Zimbabwe, have struggled to develop intelligent policy review and systems of community care. But most efforts have been limited to pilot projects and demonstrations in a few heavily affected areas, falling short of full-scale systems design.

To encourage cross-country sharing and capacity development, UNICEF supports regular regional program consultations. The first consultation, held in 1998, identified a preliminary conceptual foundation for orphan programs based on services during the preceding 10 years. This conceptualization cited the disadvantages of a centralized system of care (see box) and noted that:

- Decentralized family and community-based responses are the most affordable and acceptable ways to care for orphans and children left vulnerable by HIV/AIDS. Centralized systems of care and institutional care should be a last resort.
- Community capacity and willingness to care for the children have been documented, but communities must have resources to sustain mechanisms of care.
- Partnerships with community-based organizations (NGOs, religious organizations, the private sector) are widespread and increase their viability.
- Coordination and strategy building are necessary at all levels and increase the viability of community-based responses.
- Approaches tested at the micro level can be replicated rapidly if appropriate.
- If included in government development plans, community-based programs can be stimulated and linked with a wider resource base.
- Expanding program responses—using a comprehensive nationwide program assessment—is an urgent priority in heavily affected countries.

STRATEGY DEVELOPMENT

STRATEGIC FOUNDATION

It is possible to develop systems of care and protection for children that incorporate substitute social mechanisms for care and mitigate additional suffering in heavily AIDS-affected countries—although it is not possible to eliminate increased death and morbidity. If a strategy is developed to accomplish this, some of the overall damage to the social and economic functioning of future generations may be averted.

This strategy should be an overarching, multisectoral plan to meet the needs of large numbers of orphans and other children affected by HIV/AIDS over the next two to three decades. It should cover gaps in services by geographic area or program type, building on data from a situation analysis. It should be linked with goal-setting for coverage of community-based programs and state safety nets (by age, location, vulnerability), and for the well-being of children and caregivers (measured by indicators like health, nutrition and school enrollment). Unfortunately, few countries have developed such a strategy.

STRATEGIC CAPACITY

Review of the data on children affected by AIDS, services and the lack of explicit strategies for support to family and community-based responses suggests that strategy development is required in four major areas: technical analysis, policy review, conceptual capacity and political support.

Technical analysis

Before beginning any national strategic planning exercise, national orphan estimates must be prepared, either by the Ministry of Planning/Economic Development or the Ministry of Health/National AIDS Control Program (NACP). A central ministry or central statistics bureau should also prepare estimates of population impact, in conjunction with planning or health agencies or the NACP. Since these numbers are highly political, formal estimates are often difficult to obtain; informal estimates can be used instead.

ADVANTAGE OF FAMILY- AND COMMUNITY-BASED APPROACH

- Encourages community self-reliance.
- Encourages voluntary and spontaneous links with HIV/AIDS prevention activities.
- Recognizes and builds on the reality that PLHA and affected children get most of their support from families and communities.
- Builds on natural family and community roles in protecting children and the elderly.
- Social workers and other professionals can focus on serving difficult cases, monitoring, training, and support.
- Delivers more benefits effectively and inexpensively.
- Fewer children fall through safety nets.
- Builds on African preference to keep children within their families and communities.

Ideally, each line ministry will complete a sectoral analysis, estimating the impact of the epidemic on loss of skilled personnel and the total client base for their services. In addition, line ministry planners should conduct a barrier analysis, brainstorming about other effects of the epidemic, preparing for orphan needs, and identifying policies and programs that limit access of AIDS-affected children to services (see box). For example, child-headed households may not be able to access free primary care, education or social welfare benefits because the household head is under age 18 or does not know what his or her entitlements are. While safety nets may be officially in place, they may be underfunded, understaffed by social welfare professionals or unknown to household heads.

STRATEGIC AND POLICY CONCERNS FOR A BARRIER ANALYSIS BY SECTOR

General

- Developing partnerships among all players
- Designing a large-scale system that is equitable, and builds on family and community initiative
- Protecting very young orphans
- Delivering services to households with elderly guardians and child-headed households
- Developing systems that are effective in rural areas

Health

- Linking prevention and care
- Monitoring health status of orphans and non-orphans to ensure equity
- Delivering appropriate care to HIV-positive children
- Providing replacement feeding and proper weaning for infants who have lost their mothers
- Assuring that health workers counsel family members on the special needs of orphans
- Strengthening community health services to provide special care and attention to orphans
- Linking home-based care with care for orphans

Social Welfare

- Developing family and community capacity to support orphaned children
- Providing ongoing organizational and psychosocial support to community care mechanisms
- Assuring needed social welfare benefits for the poor so orphans can be maintained within the family and community
- Educating caregivers and children to prevent abuse
- Developing community mechanisms to ensure child rights

Education

- Ensuring access to education as a protection and socialization mechanism
- Including HIV/AIDS education in curricula
- Providing alternative schooling in heavily impacted districts
- Replacing teachers who die from HIV/AIDS
- Considering Early Childhood Development centers

Women/Gender/Property

- Educating women about property and inheritance
- Educating community about child rights

Policy review

This assessment determines whether policies have considered the needs of orphans and other children left vulnerable by the epidemic. It can also help coordinate policies in different sectors so they have stronger synergistic effects. The assessment can also align policies so that they contribute more constructively to an enabling environment for children and families and encourage community-based responses. Many countries have partially completed comprehensive policy development for children as part of National Plans of Action for Children, stimulated by the World Summit for Children. Others have gone much further in codifying laws and developing child- and youth-friendly judicial and ombudsmen systems. A thorough policy review will include many areas (see box).

Conceptual capacity

The meaning of social welfare must be entirely redefined, moving from individual casework to community-driven development of mutual systems of support. At the national level, development of strategies and systems requires national policy makers to visualize and implement a system in a fresh and innovative way. Budgetary restrictions force many countries to explore this change.

To support expanded conceptual capacity at the local level, social-welfare training must increase the professionals' ability to train family and community

AREAS FOR POLICY REVIEW

Local Policy Review

- Allocation of land and other resources
- Communal gardens or shelters for children
- Sharing resources with the weaker and more vulnerable
- Use of local services by the poor or disenfranchised
- Participation of women and children in decision making
- Protection of women and children's property
- Credit associations and small business opportunities
- Widow inheritance and mistreatment of children
- Community responsibility for all vulnerable children
- Interventions with harsh or abusive guardians

National Policy Review

- Review of laws, policies and administration in all sectors to protect children's rights
- Children's access to resources without adults
- Increasing women's rights, entitlements and protection
- Recognizing legal maturity for women

- Definition of sexual maturity, age of marriage and defilement
- Entitlement and access of vulnerable children to health and education
- Budget restrictions, discrimination or insensitivity
- Inheritance and protection of property
- Adoption and fostering
- Paternal affiliation and responsibility
- Public education programs
- Grants or other fiscal support to maintain children
- Positive support for communities
- Support of NGOs and CBOs
- Responsibility of the private sector
- Tax breaks for large private-sector employers
- Employee rights, insurance and death benefits
- Targeting productive infrastructure to AIDS-affected communities
- Technical assistance to communities
- Support to increase productivity in agriculture or in small businesses
- Mechanisms to coordinate actors and partners
- Donors examine their policies

members. Commitment to family and community-based systems of care also implies “de-professionalization” and “demystification” of some social welfare, education and health roles. Coincident with trends in reduced provision of social services due to economic adjustment, the loss of professionals to HIV/AIDS-related causes also demands that communities provide their own services. Increased conceptual capacity at macro- and micro-levels can be encouraged through site visits between countries and through regular cross-border meetings of policy makers and innovative community-development personnel.

Political support

Advocacy and public education plans are critical to the success of a national strategy. Two audiences are important: the general public and opinion leaders and policy makers. For the general public, advocacy and education have been used by several countries to:

- Educate the public about the needs of vulnerable children and how to meet them.
- Increase adoption and fostering and overcome cultural constraints to both.
- Alert guardians to their entitlements.
- Encourage communities to care for families and children affected by AIDS.

- Educate service providers about government policy and the needs of orphaned children.
- Reduce stigma and discrimination against AIDS-affected families and children.
- Educate children about the needs of their peers and encourage their kindness and assistance.

Advocacy and education are also important to the development of comprehensive government strategies. Even in the most heavily affected countries, it is often important to educate policy makers and opinion leaders who are not in AIDS or public health work about the impact of the epidemic. It may be possible to work through the National AIDS Control Program or, in some countries, with ministries of planning, finance and development to better integrate AIDS into development planning. In many sectors, the presence of orphans will demand a change not only in the scale of service delivery, but in delivery mechanisms. Advocacy and public education plans may already be part of the National Plan of Action for Children. If not, this document can be revised to reflect the special needs of children orphaned by AIDS and other causes.

Because it involves children, the problem of orphaning can serve as an entry point for development of political and social commitment to change. Children orphaned by the epidemic who do not receive sufficient support from their families, communities or state will quickly become visible as street children, delinquents or children in trouble with the law. This can be one of the reasons governments, donors, NGOs and communities may find it easier to commit to programs for surviving children.

POLICY DEVELOPMENT IN MALAWI AND ZIMBABWE

Malawi's National Orphan Policy

Members of Malawi's National Orphan Task Force, with advisors from the Ugandan government and NGOs, developed the region's first "Policy Guidelines for the Care of Orphans in Malawi and Coordination of Assistance for Orphans" in 1992. The guidelines are simple and brief, so they can be used to provide program guidance to community groups:

- **Community-based approaches** to orphan care are primary. The government will coordinate service providers to support and enable communities.
- **Formal foster care** will be expanded as the second source of care.
- **Institutional care** is the last resort, although temporary care may be needed for children awaiting placement.
- Hospitals should **record next of kin** so relatives can be traced if children are abandoned.
- **Birth and death registration** should be revitalized to monitor orphans.
- Government will protect the **property rights of orphans** and these should be widely published.
- **Self-help groups** should be developed to assist families with counseling and other needs.
- **NGOs** are encouraged to set up systems of community-based care in consultation with the government.
- The **needs of all orphans** should be included regardless of the cause of death, religion or gender.
- The **National Orphan Task Force (NOTF)** will continuously plan, monitor and revise programs and policies.
- Government will solicit **donor support** for resources for capacity building.
- The Ministry of Women, Youth and Community Service is the **lead government body** on these issues.

ZIMBABWE'S NATIONAL ORPHAN POLICY

Zimbabwe's Department of Social Welfare in the Ministry of Public Service, Labor and Social Welfare is the key agency for implementing child welfare policy. Its services have been decentralized to all 58 districts. But most district offices have one social worker, resulting in unrealistic social worker-to-population ratios. After four years of advocacy by local leaders, Zimbabwe's government in 1995 worked with partners to draft a national policy on the care and protection of orphans, but it was delayed in Cabinet because it requires additional resources. Community-based care is universally accepted and promoted. The new policy emphasizes:

- Care and protection of orphans must comply with the Convention on the Rights of the Child and the African Charter on the Rights and Welfare of the Child.
- Institutional care is a final and temporary resort.
- Additional human and financial resources (subnational funds) are needed for orphans, as are budgetary increases to cover sustainable health and nutrition programs.
- Public awareness campaigns are needed on orphans' needs, capacity building in areas of children's rights and counseling for orphans and caregivers.
- Guidelines and legal framework are needed to ensure education for all children, including orphans.
- Government must protect the property rights of orphans by legislative changes and legal assistance in matters of intestate inheritance.
- The Department of Social Welfare will lead the coordination, implementation, monitoring and information-sharing under the program through the Child Welfare Forum at national and sub-national levels.
- Grassroots implementation is the responsibility of communities, local government, and NGOs.

PLANNING CONSIDERATIONS

General considerations

As planning continues, certain key considerations can guide strategy development. The problem of children affected by AIDS will probably last 20 to 30 years, so any strategy must have short- and long-term components. More children than have typically been provided for by social welfare systems in the past will need care. Any response must therefore be large-scale, community-based, systematic, integrated within existing infrastructure, low-cost and sustainable. As responses also involve care and protection for the most vulnerable children, they must include a good deal of oversight, monitoring and review.

It is possible to plan and develop a rational system of protection and care for children affected by HIV/AIDS because the number of children in need of care and protection will be large yet predictable. Inputs can be specified and planned. Orphan, family and community needs have been described by a large number of research studies (see "The Response"). Project impacts are measurable using standard indicators of well-being (see "Going to Scale"). Most importantly, the strategic orientation of any program should emphasize development, not charity. This will only be possible if communities have enough assistance before they reach a stage of exhaustion and burnout.

Situation analysis

A situation analysis preparatory to strategy development for children, families and communities affected by HIV/AIDS requires information on the numbers and proportion of children orphaned: their location, education, health and protection requirements by age and sex; their guardians' status and women's status generally; and distribution and nature of poverty in a

DESIGN OF ORPHAN MANAGEMENT SYSTEMS

MANAGEMENT STRUCTURE

There are at least two levels of response to “orphan management”: the macro (national and regional) and the micro (family and community) levels. In the past, microlevel responses have been viewed as the forerunner of macrolevel responses. While piloting a variety of responses in the early stages of program development may be helpful, enough is already known about the needs and advantages of family and community programs to state that they are the preferred mechanism for local management. It is more important now to specify roles, responsibilities and challenges at higher levels of the system.

As in any management system, concerns at the macrolevel are substantially and qualitatively different from those at the microlevel. Each level must be clearly separated and defined to develop a satisfactory management system (see box on roles and responsibilities). Three countries have accomplished this and are moving forward with strategic systems development: Malawi, Zimbabwe and South Africa.* They can serve as models for other countries. To determine whether there really is a management structure in place entails knowing not only that there is an existing structure, but that it is also functional.

In the “model” countries, strategy and policy development were coordinated by a central multisectoral body composed of responsible government and NGO (including church) actors. This central body is replicated at regional, district or provincial and local levels. The NGO community is a full partner with government in strategy development, as well as in providing social services (including health, education and social work) and community development activities. NGOs have a considerable network of services and collaborate to produce a coordinated, rationalized system of response to increase equity, access and availability on a geographic basis and improve program quality.

Following strategy development, coordinating bodies can also conduct policy review, coordinate service delivery, integrate their findings and activities into local development plans, monitor and evaluate program implementation, review program quality and provide training.

** Adverse political conditions in Zimbabwe have altered the response and halted expansion of the national orphan care system.*

country. Although the emphasis is on orphans, information on all vulnerable children is useful, including street children, physically and emotionally abused children, children experiencing exploitation of their labor and sexuality and children in trouble with the law. Estimates of these groups are often of uneven quality or nonexistent. In addition, children often move between these categories in response to stress and loss of a caregiver’s protection. Data on services and responses needed for planning purposes include the categories’ characteristics (community-based or institutional), location, sponsorship, networks and linkages and collaboration among providers. (The nature and sources of data needed are explored in the section “The Response.”)

Linking prevention and care

In the beginning of a strategy development exercise, participants must be challenged to link prevention and care by understanding the three principal ways to “prevent” orphans: (1) Reduce births and thereby reduce the numbers of children who could become orphans; (2) Prevent HIV transmission; and (3) Enable PLHA to live longer. When these connections are acknowledged, support for effective prevention and reduced stigma and discrimination must be built.

ROLES AND RESPONSIBILITIES IN NATIONAL SYSTEMS OF CARE FOR CHILDREN AFFECTED BY HIV/AIDS (MALAWI, SOUTH AFRICA AND ZIMBABWE)

Central, district, local government	NGOs, churches	Family and community
Leadership Stimulating collaboration Setting standards and guidelines using consultative process Monitoring community-based groups to ensure protection of children's rights Handling cases requiring legal procedures Helping communities obtain specialized resources	Training for families and communities Capacity building Material support Provision of institutional care Mobilization of resources required by communities	Provision of care Mobilization and coordination of resources Prevention of abuse, neglect Counseling for children, guardians Collective mutual support (labor, child care, credit, microenterprise farming and food security fund raising)

For example, in South Africa, the Children in Distress Project (CINDI), the Ministry of Population and Social Welfare's pilot program for orphan care in the KwaZulu-Natal Province, has a steering committee that coordinates local services provided by community-based organizations, NGOs, government social welfare officers, hospitals and home care agencies.⁸ Botswana's local development structure includes multisectoral child welfare committees organized through local government. But these have not been fully mobilized to provide assistance to orphans.

DEVELOPING RATIONALIZED SYSTEMS OF CARE

Strategy and policy development can be linked with development of a managed, rational system of care and referral that supports community-based initiatives. Such systems involve two essential ingredients:

- Recognition by government that it cannot manage the child protection and care requirements of all orphans and vulnerable children as a consequence of the AIDS epidemic.
- Commitment of all actors to cooperation and collaboration to support community development and capacity building to provide care and support services for families and children affected by HIV/AIDS.

The partners in these systems should acknowledge that formal social-welfare, health and education systems established through many years of experience before the epidemic may need to be fundamentally revised. Such recognition may not be easy for any of the partners because it involves reconsideration of their traditional roles and responsibilities in child protection.

RESPONDING TO CHANGING SOCIAL CONDITIONS

AIDS and other scourges have dramatically changed the situation of vulnerable children. In many countries, social welfare systems designed to address the needs of relatively few vulnerable children who fell outside the systems of family care are now faced with serving very large numbers of children. The types of systems needed and the conditions under which they must operate have also changed radically in a relatively short period of time.

SYSTEM COMPONENTS AND LEVELS OF CARE

Countries faced with the prospect of developing a rationalized system of care and protection for vulnerable children must recognize that at least three dimensions of the system are key: financial feasibility, availability of services and personnel and acceptability. To accomplish this, families and communities must be the foundation of the care system. While this has always been the case, fewer children were vulnerable in the past. Emphasis on families and communities also

Table 1
**MODELS AND OPTIONS IN A
 SYSTEM OF CARE FOR VULNERABLE CHILDREN***

Model/option	Responsible party	Percentage of vulnerable children	Input needed
Family-based care	Two biological parents One biological parent Extended family No parents/child-headed households Formal foster parents or adoptive parents	55 percent .5 percent to 1 percent (with formal adoption)	Free access to basic social services Psychosocial support and monitoring Government assessment and monitoring
Community care	Village committees Local government Volunteers Community-based organizations (CBOs) NGOs Religious organizations Private sector	35 percent	Management training Financial and material support Training in psychosocial counseling Child rights training Monitoring and evaluation Awareness raising Advocacy
Temporary shelters	Street children shelters Feeding centers Places of safety	5 percent	Management training Financial and material support Psychosocial counseling
Institutions	Orphanages, children's homes Hospices Hospitals Home-based care Remand homes Jails Boarding schools	5 percent	Facility construction, equipment Guidelines, policies, standards Awareness raising Fostering and out-placement Counseling Community visiting CRC training Government assessment Monitoring and evaluation Fundraising skills Networking and outreach services
System as a whole	Government and partners	100 percent	Legal and policy framework Conceptual base Referral networks, monitoring, identification

**This and the next table were developed in part during a workshop held at a meeting of UNICEF Child Protection Officers and counterparts from 15 countries in Nairobi in April 1999.*

increases acceptance. Surveys typically report the preference of families and communities for maintaining children within normal systems of social support.^{9, 10} But most also report that they need financial and material supports, including access to basic social services for their children, due to two factors: extreme underlying poverty and the need to provide for additional children within the same or a diminished resource base.

Some children will fall outside these two preferred sources of care, and must be provided for by institutions—including orphanages, children’s homes and remand centers. They will also need temporary shelters while in transit between one permanent form of care and another. For example, children leaving family-based care may receive support at a street children’s shelter or feeding center while they are rehabilitated for placement in another family or in a community-care program.

If the system explicitly includes these various facilities, emphasis and investment should be distributed according to the number of children needing each type of care. Referral mechanisms are needed to help children moving from one part of the system to another. Supporting family and community care is viewed as a “preventive” intervention, because it functions to maintain children in the most “normal” environments possible. If children are not taken into these levels of care, the system is not functioning well.

The following chart illustrates the approximate distribution of children in a typical care system in a developing country heavily impacted by HIV/AIDS. The estimated proportion of children in each type of care shown in the third column is somewhat arbitrary and will change as mortality from the AIDS pandemic advances. But even in a very advanced epidemic, approximately 55 percent of children will still be cared for within some form of family, while community organizations at some level of formal organization will care for another 35 percent. At any time, institutions

Table 2

MODELS AND OPTIONS IN A SYSTEM OF CARE FOR VULNERABLE CHILDREN

Model/option	Responsible party	Needs of vulnerable children percentage	Sector support needed
Social safety nets Poverty alleviation Child grants Disability grants, Pensions for elderly Free health care Free schools Employment training Income generation Credit schemes	Government and partners	Up to 10 percent of all children need grants. 100 percent need primary health care and primary school.	Ministry Support: Finance Social Welfare Health Education Labor, Education Labor Private sector

will provide care or at least shelter for no more than five percent of all children due to fiscal and physical constraints (that is, the number of places within institutions) while another five percent will be in transit, assisted by temporary forms of care.

TARGETING VULNERABLE CHILDREN

HIV/AIDS increases the number of vulnerable children—including orphans—because of the loss of parents, guardians and productive adults. The box below provides a preliminary conceptual framework in which to place children, not all of whom will be equally vulnerable. The vertical axis describes vulnerability as “high” or “low,” while the horizontal axis describes the number of children. The largest number of highly vulnerable children is in the upper lefthand corner, and includes very young orphans, orphans with disabilities, orphans with elderly guardians and children in female-headed and very poor households. Also highly vulnerable—and very visible because of that vulnerability—are HIV-positive children, street children, child sex workers and orphans in child-

NUMBER AND VULNERABILITY OF CHILDREN NEEDING CARE AND PROTECTION

		Number of Children	
		LOW	HIGH
Vulnerability	HIGH	Very young orphans Orphans with disabilities Orphans with elderly guardians Children in female-headed and poor households	HIV+ children Street children Child sex workers Orphans in child-headed households Children in under-funded State institutions
	LOW	Orphans in stable families of reasonable means	Children in stable two-parent families of reasonable means Children in well-resourced institutions

headed households. But these are fewer in number than children in the lefthand box. For example, while a great deal of concern is expressed for HIV-positive children, globally they represent only 1.7 percent of children affected by HIV/AIDS; orphans represent more than 98 percent of affected children. Children who are highly vulnerable are likely to need the strongest safety nets and protection. Children in poorly resourced institutions fall into this category because in many cases their basic rights are not protected.¹¹ Children who are less vulnerable are shown in the bottom row of the chart. They include orphans and children with both biological parents in stable families of reasonable means.

Children can move between boxes—levels of vulnerability—depending on changes in their life circumstances. But the AIDS pandemic is increasing the number of highly vulnerable children, those in the upper boxes. Success or failure of preventive interventions will be measured by the number of children in the upper right hand box, those who are most vulnerable.

DATA DEVELOPMENT

ORPHAN ESTIMATES

Orphan estimates may come from one or several sources, including a country's National AIDS Control Program (often assisted by UNAIDS), special studies or *Children on the Brink*. Estimates for a given country can vary widely, depending on whether they include:

- AIDS orphans or orphans due to all causes of parental death.
- Orphans who are maternal (mother dead), paternal (father dead) or double (both parents dead). Maternal and double orphans are estimated from maternal deaths; these are the most common statistics. But paternal orphans are often as numerous as maternal orphans, and in many cases are in fact double orphans because they have been abandoned or their mothers die soon after their fathers.
- Children under age 15 (the demographic cutoff) or children under age 18 (the legal cutoff in many sub-Saharan African countries).
- Orphan estimates also vary by time period. *Children on the Brink* includes the only projections of orphans through 2010.
- Orphan estimates can be cumulative (all orphans since the beginning of the epidemic) or represent totals at a given time.

It is important to determine what types of orphans are being included in an estimate and to make careful comparison of orphan estimates. They can then be presented to a national body or steering committee for review to establish official consensus.

WHY PATERNAL ORPHANS ARE VULNERABLE

- When a child's father dies in patrilineal groups, the child is in fact a double orphan because the mother is not living with the father, is sent away or leaves to remarry elsewhere.
- Often both parents are infected, which means that the child will eventually become a double orphan, that is, with both parents dead.
- Children over age five need the cash support most often provided by fathers for education and health care.
- The vulnerability of families and communities is related to the overall number of adults and children living, so that a community with large numbers of single or double orphans may have reduced productive capacity.

GATHERING DATA

The information needed for a thorough analysis of children, caregivers and their families typically will be incomplete. National data or estimates for orphans and other vulnerable children are usually limited, unavailable or outdated. Because these children were not numerous before the AIDS epidemic, they were not a major concern for governments and little effort was made to collect information about them. Data on the geographic distribution of vulnerable children and services are also quite limited.

Data on orphans have been collected in the national censuses of several countries, including Kenya, Uganda, Tanzania, Zimbabwe and Malawi. Censuses have the widest geographic scope of any data and 100 percent coverage, although their data are typically "thin": Details are sparse and household-level analysis has not been done. In addition, marginalized children or families, such as street children or homeless populations, may not be fully enumerated by census-takers. It is crucial to encourage officials to collect data on the orphan status of children during the next round of census taking.

Demographic and Health Surveys (DHS) are conducted in many countries every two to four years. Until recently, only households with women of child-bearing age (15 to 49 years) were included. This excluded many orphaned children who may have resided on their own or with elderly guardians. For this reason, DHS surveys taken before 1999 underestimate the proportion of orphaned children.

In 1999, DHS instruments and procedures were revised to include all households with children under age five, regardless of the presence of a caregiver or guardian. Surveys will now include households headed by children or elderly guardians. Health, immunization, nutrition, education and other data will also be collected on all children in the household. In the past, this information was collected only on biologically related children. DHS are not complete-count surveys, but their samples are usually nationally and regionally representative. Unfortunately, coverage of marginalized children and families may also be incomplete, for the same reasons that data are limited in the national censuses.

In some countries, special surveys or estimates were undertaken by universities or for poverty monitoring and alleviation. Several of these were quite extensive, and are now a valuable resource for data on children and families.¹² Expanding on these, UNICEF and its partners in 60 countries have collaborated on surveys of country progress toward World Summit Goals for Children. These Multi-Indicator Cluster Surveys (MICS) are "mini-DHSs," and should prove an invaluable update on children's status.

Registrations and enumerations of orphans and other vulnerable children collected by local authorities and communities can help mobilize communities for action. Community members are trained to collect, analyze and maintain their own data as the basis for targeting assistance to vulnerable children and families. Such information is usually more complete than census or DHS data, but is often highly variable and unreliable: Neighboring communities in Malawi

respectively reported 50 percent and 6 percent of their children to be orphaned, reflecting the communities' perception of vulnerability rather than demographic reality.

Malawi and Uganda both undertook national orphan registrations in the early 1990s, and both reported that their experience was problematic because:¹³

- Registrations were too costly to administer on a national basis.
- Registrations raised false expectations for assistance by communities.
- Numbers produced were wildly variable and unreliable as a basis for national orphan estimates.
- Registrations could not be maintained or updated because communities saw no advantage or result in doing so.

Both countries abandoned the effort, and now recommend registrations in small areas or pilot projects for specific assistance programs. They also recommend local registrations by village orphan committees rather than data collection by a regional or national authority.

Cost and quality data are vital in developing long-range plans and strategies—but such information is presently unavailable from most organizations except international NGOs, whose programs are relatively expensive to administer. Data on quality of services and their effectiveness can also be critical in choosing between alternative forms of care and developing strategies for improving long-term programming. Investment data describe the contribution of various sectors to orphan care. It is important to estimate the voluntary contributions of families and communities to appreciate and recognize their commitment, value their work and persuade policy makers to support their efforts. One way to do this is to estimate the cost of maintaining all orphans in institutions, or to estimate the cost of paying a substitute caregiver in the home, were it possible to hire one. These data should include both cash and in-kind contributions to fairly represent the balance of investments and evaluate their sustainability.

THE RESPONSE

CHILDREN

HIV/AIDS creates many demands and pressures on children and their families. Children are pressed into service to care for ill and dying parents and relatives. They are removed from school prematurely to help with household and farm chores, replacing adults who have succumbed to AIDS. They are pressured into sex to help pay school fees their families can no longer afford, or to help support younger brothers and sisters. Girls are married off at an early age to reduce pressure on their families. Sexual abuse is growing.^{11, 14}

Often, children are moved from relative to relative as fewer adults in the family attempt to care for an increasing number of orphans. Finally, when families exhaust their resources and coping capacity, children live on their own or on the street. As the epidemic progresses, more and more children are living without adult supervision of any kind, often struggling to take care of younger brothers and sisters. Sometimes, children deliberately choose this option to avoid separation from surviving brothers and sisters after their parents, aunts, uncles and older siblings die. These child-headed households are growing in number, and are especially vulnerable without support.

Despite their courage, children face many dangers. And they are increasing as the epidemic worsens. Escalating AIDS-related mortality has resulted in enormous demographic pressure on children and reduced protection through ordinary family and community mechanisms. This results in increased neglect, emotional and physical suffering and increased exploitation of child labor and sexuality. Most often, orphans say that they miss the love of their parents and family. Many are traumatized permanently by the loss of care and protection in ways that are very similar to the damage experienced by children in war or other violence.

CHILDREN

Responses

- Becoming household heads
- Making household decisions
- Supporting younger siblings
- Participating on community orphan committees

Dangers

- Children have to leave school
- Girls are marrying earlier
- Children are entering the labor force earlier and are often exploited
- Children, especially young girls, are sexually exploited

Interventions

- Enable children to stay in school
- Reduce labor demands on families
- Psychosocial care
- Allow sibling adoption
- Income generation and job counseling
- Adequate child protection and community supervision

KEY DETERMINANTS OF VARIATION IN ORPHAN NEEDS

- Age and sex of child
- Age of guardian
- Relationship of guardian to child
- Number of parents dead
- Proportion of children orphaned in the geographic area
- Inclusion/exclusion of orphaned children in family and community life
- Level of AIDS-related stigma and discrimination
- Access to health education, and social services and safety nets

Interventions must be targeted directly to children as well as families and communities, including programs to enable children to stay in school or allow working children to attend alternative schooling. Although children can be helped by interventions that reduce labor demands on families, they often also need their own income-generation and vocational training. Children must be given direct access to state grants and supports before they are 18 years of age. They should also be permitted, with appropriate supervision and limits, to adopt or foster their own siblings.

FAMILIES

Families in developing countries are anxious to do all they can to keep their children in the home and village environment. In country after country, families oppose the idea of orphanages because they remove children from the love and protection of their homes, from their property, villages and traditions, and place them in an artificial environment that is not conducive to long-term social development. Families are fostering children informally and formally, attempting to live up to their own and society's expectations. But as pressure increases, they are finding it more difficult to do so.

Studies in Malawi have shown that poor families need two things to continue caring for children:¹⁵

- Psychosocial help to deal with their own guilt, fear and grief and that of children who have lost their parents under very traumatic circumstances.
- Assistance to become more productive and innovative, so that fewer adult hands can support more children.

Families are asking for simple things: fertilizer, improved seed and access to water so they can improve and ensure the productivity of their fields. They are asking for help in starting micro-credit and micro-enterprise programs, so they can earn the income needed to feed, clothe and educate their children.

Family willingness to help children remains undaunted—if the family can surmount the problems of earning enough to do so.^{9,10} Financial allowances to foster families (such as those provided in developed countries) are being examined by governments as a way to assist those willing to take in orphaned and other vulnerable children. Financial support is usually nonexistent and social services—health, education, unemployment, social security—are often limited. In fact, most of the interventions needed by families are economic in nature, although psychosocial counseling helps families adjust to new members and additional burdens. Governments and donors must consider the cost of not supporting families when they consider the long-term cost of prevention and care programs. In the long run, family care is much more cost-effective and acceptable than institutional care of any kind.

COMMUNITIES

Spontaneous family and community responses are the most effective, affordable and least visible programs currently available to assist children and adults affected by HIV/AIDS. They share many common elements even in different countries and among people with different cultural traditions. Communities locate children and vulnerable families, organize committees to plan assistance, provide voluntary community services to the needy (day care, subsistence and commercial gardens, construction, shelter) and develop informal monitoring systems to ensure that children are not abused and guardians receive needed help. Even the poorest communities make small donations to support their most destitute neighbors. This is especially true in communities that receive external support.¹⁰

COMMUNITIES

Responses

- Child protection as community responsibility
- Orphan assistance committees
- Counseling and assisting guardians
- Programs by and for young people
- New channels of communication
- Fundraising and material support
- Voluntary vocational training
- Protecting widows and orphans' property

Dangers

- Burnout as more adults die or become ill
- Resources do not match demand
- Labor demands grow intolerable
- Communities refuse to assist more children

Interventions

- Organizational ideas, training
- Limited material supports
- Recognition as official partners
- Assistance in accessing resources
- Psychosocial counseling
- Data collection and monitoring systems
- Development of service networks
- Openness about HIV/AIDS

Communities where AIDS has taken a large toll view children as the responsibility of the village if individual families are too weak to provide effective care. Orphan committees intervene to help guardians who are having difficulties caring for children and provide counseling to help step- or foster-parents adjust to the needs and demands of unwanted additional children. These groups have proven to be more aware of children's needs and problems as a result of their new programs, and can articulate children's rights to protection. Orphan committees give children a forum to voice their problems and needs, and receive counseling and guidance. In some countries, children and young people participate in the orphan committees, contributing skills in record keeping, counseling and planning. Young people in anti-AIDS clubs "adopt" vulnerable children, giving them material and emotional assistance.

Communities view AIDS-related problems as problems in development, challenging them to work harder and more efficiently to improve productivity and organization so that more children can be cared for by fewer adults. Early childhood education is understood as a way to ensure the well-being of small children. Pooled labor and technical inputs increase agricultural productivity. Access to credit and microenterprise training can increase incomes through small-business development. Voluntary vocational training teaches such skills as tailoring and carpentry. These projects have many positive implications:

- Community power structures are changing, leaving more room for the participation of women and young people.
- Communities are seeking organizational innovations useful to other programs.
- Civil society becomes more open and stronger as communities are trained in self-governance and mutual assistance through these programs.
- Material and organizational support can sustain community responses.
- Changes in the community increase members' acceptance and use of development programs and agriculture, education, health and other services.

- As a consequence, the productivity of available labor increases.

But innovations are difficult to sustain as more children are orphaned, the burden of care increases and there is little access to resources and support. Helping the community by providing small items can make a big difference in the success of community-based programs over the long term. These may include giving a bicycle to a volunteer who travels long distances to visit AIDS patients or vulnerable children, or a length of garden hose to make watering communal gardens easier. Communities also benefit from organizational support in a variety of forms:

- Training in care-giving, community organization and income-generating activities increases the quality of services provided to children and the overall skill levels of their communities.
- Increased resources for income-generating activities and other communal projects can stimulate greater participation and benefit, and also ensure their sustainability.
- Inclusion in formal social-welfare systems for monitoring and referral will improve the quality of these services and help ensure that children and families in need of specialized support will not "fall through the cracks."
- Improvements in water and sanitation reduce labor demands on affected families and community members who want to help, thus giving them more time to do so.
- Expanded health and education services can increase access for orphans and their families and assure that these services are provided equitably to orphaned children.
- Service-delivery networks can provide communities with moral and material support, recognition and systematic monitoring.

GOVERNMENTS

Responses

- National orphan policies
- Law review and codification
- Expanded social services
- Public assistance and support
- Tighter sexual abuse laws
- Modernize adoption and fostering laws and support
- Educating the public to protect families and children

Dangers

- Denying the severity of the problem
- Viewing orphans as a special case
- Not mainstreaming assistance through health, education, and social welfare sectors
- Not protecting women's rights
- Not taking development implications seriously

Interventions

- Education about HIV/AIDS and social changes
- Advocacy for social service support
- Donor assistance to community and family support
- Knowledge of approaches in other countries
- Technical planning assistance

Many program and policy actions are needed to ensure that communities can sustain the burden, including:

- Income support to poor households with PLHA or orphans. While this is legally provided in many countries, budgetary constraints mean that few actually receive benefits.
- Increased funding for public assistance programs.
- Tax credits to individuals, households and businesses that provide care.

- Laws protecting the property of widows and orphans and promoting the writing of wills.
- Payment to semi-professional caregivers and community workers as part of the formal social-welfare system, so that their contributions are acknowledged and rewarded.
- Engaging men more directly at all levels in finding solutions and sharing responsibility for care and prevention.
- Combating stigma and discrimination against families and children affected by HIV/AIDS.

GOVERNMENTS

Over the past decade, many governments in sub-Saharan Africa have been responding creatively and energetically to assist children, families and communities affected by HIV/AIDS. Countries have revised a variety of laws and created new policies to protect children. Judicial systems have been more flexible for women and children defending their inheritance and property rights. Land tenure systems and property ownership have been opened to women in several countries. Uganda provides voluntary child advocates to help children redress exploitation. Zimbabwe, Malawi and Zambia support village committees to assist children. Most governments are reviewing assistance programs so children without guardians can directly access support. Botswana, Namibia, South Africa and Zambia are among the nations that provide public welfare assistance and support to adopting and foster families—but they are underfunded and coverage is extremely limited. In Zambia, for example, only two percent of the qualifying needy receive assistance.¹⁶

Government safety nets include:

- Adoption and fostering stipends to families caring for children up to the age of maturity (18 years in most countries).

PRIVATE SECTOR INITIATIVE— ZIMBABWE'S FARM ORPHAN SUPPORT TRUST

The Farm Orphan Support Trust (FOST) is a state-registered national program that solicits and facilitates support for children in especially difficult circumstances, particularly orphans, on commercial farms. The aim is to proactively increase the capacity of the farming community to respond to and care for the most vulnerable individuals in the emerging orphan crisis. Government resources are inadequate to cope with the magnitude of the problem, and children's institutes are already overwhelmed.

Two million people, 17 percent of the total population, live on commercial farms. Farm workers are multi-ethnic and families are often isolated from their extended family networks, which traditionally involve relationships of obligation and responsibility.

Agriculture is the most important productive sector in Zimbabwe's economy, and commercial farming is the largest single employer of labor. The Commercial Farmers' Union (CFU) is an umbrella organization representing large-scale agricultural producers. The CFU has had an active HIV/AIDS prevention program since 1986. In 1996, following initial research, situation analysis and a national seminar, FOST was formally launched with government approval and CFU logistic support.

The FOST executive committee has representation from farmers, both employer and employee unions, government, the university, churches and NGOs. The committee may call on further expertise where needed. The CFU also provides access to farmers and farm workers through its national structures.

FOST aims to keep sibling orphans together, within a family of the same culture and in a familiar environment. The development of foster-care schemes on farms involves using existing struc-

tures, such as farm development committees to: identify the need, create community awareness and select child care committees, train caregivers, establish monitoring channels, promote "community projects" and disseminate information. Farms individually register orphans and send duplicate details for computerized data-banking. This assists in relative tracing, advocacy and forward planning.

The program promotes five levels of care, in descending order of preference:

1. Within the extended family.
2. Placement in substitute families.
3. Small groups of orphans, living together, overseen by a carefully selected caregiver, employed by the farmer for that purpose.
4. Adolescent child-headed households with siblings remaining together, preferably in the family home, cared for by the eldest child, under the regular supervision and support of the Child Care Committee, the community and the field officer.
5. Orphanages, as a temporary place of care until an alternative solution can be found, particularly for babies and very young children.

Community acceptance of the responsibility for orphans is not the only key to sustainability; adequate support, provided by the combined efforts of the community, farmer, government and society in general are also necessary. Farm support—through the provision of accommodation, seed and land for cultivation, income generating projects and women's club self-help initiatives—is determined by both community motivation and farm viability. FOST is exploring innovative forms of funding from industry and commerce, as well as government support for free education and health care for orphans and tax credits for those involved in the scheme. The aim is not only to benefit the orphans, which may result in reverse discrimination, but to enrich the entire community.

- Public welfare assistance grants for needy and vulnerable families, including those caring for AIDS patients, single mothers, disabled persons and the elderly.
- Services through health, education and social welfare systems—including primary care for mothers, children and persons with infectious diseases; free schooling for all children or orphans; and stipends and material assistance through social welfare for needy children and families.

PRIVATE SECTOR

Private commercial farms in Zambia and Zimbabwe have provided support to PLHA and their dependents in a variety of innovative ways.^{16, 17} Commercial farmers are popularly villainized and used as political scapegoats in some countries—and some do exploit poorly regulated employment situations—but most are actually competent business people who recognize the effect of the epidemic on their labor force. In some cases, farmers have acted in the best interests of their employees against a government that is actively discriminating against farm employees as a way to reduce their legal responsibility. Tanzanian employers and those in neighboring countries, for example, have long been involved in AIDS prevention activities ranging from the distribution of condoms to regular screening and treatment for STDs. Unions act as a powerful force in many countries to raise sick pay and survivor benefits. In Botswana, the private sector (through the Rotary Club) assists communities with development of microcredit and microenterprise projects. Rotary International has considered fund-raising for orphans when their current campaign for polio ends.

GOING TO SCALE

SHORT- AND LONG-TERM PROGRAMMING

In the short term, a national orphan program requires investment in a planning and monitoring system. In the long term, implementing agencies should integrate family and community support programs into national health, education, agriculture, water and sanitation services.

Programming must be vertical and focused until the groundwork for long-term responses is laid. It may take five years or longer to pass through the initial organizing stage, because of decentralization and multisectoral involvement. Even then, a country may wish to maintain a national body for advocacy, ongoing monitoring and policy and program development.

The first step in widespread implementation of the services is reviewing the effectiveness of responses to the needs of orphans or other children left vulnerable by the epidemic. In countries where orphans are a significant minority of children, this will be especially critical. Over the long term (five to 10 years), implementing agencies can integrate family and community support programs into mainstream programs in health, education, agriculture, water and sanitation. All are key sectors determining a country's progress in meeting the goals for children and families.

MONITORING AND EVALUATION

Once a strategy is developed, a monitoring and evaluation plan can be devised. This would include several broad areas:

- Coverage of vulnerable populations by geographic area and sources of vulnerability. This includes child health and well-being, caregiver status and community status and changes over time. While there are indicators for the first two areas, little work has been done in the third.
- Performance of service providers, including the actions of organizations as well as their viability and sustainability, given a range of resource constraints.

- Outcomes or impact of programs for which baseline data will be needed. Indicators can be developed by category or vulnerability of children. Data will be needed to measure impact on both caregivers and children.

Process indicators measure the implementation of programs in terms of outputs (numbers of children served, services provided). These are needed in the early stages of program development to measure progress as well as functioning and sustainability of community organizations. Impact or outcome indicators measure the success of programs by their ability to support family and community survival, and maintenance of child well-being and health. These are essential to long-term program planning, and are needed to attract donor funding and private-sector support.

A monitoring and evaluation plan for orphan programs will be similar to those for other child protection, health or education programs. Basic indicators for child well-being may be the same as those used in other programs, but survey instruments should compare their values for orphans and non-orphans, children in foster homes versus children in parental care. It may be useful to evaluate maternal and paternal orphans separately because their problems will be different at different ages.

Because there will be more dependent children, all children's well-being may deteriorate as a result of pressure on families and communities due to more dependent children. Several heavily affected countries anticipate the possibility of emergency conditions in the next few years. For this reason, a monitoring plan should include:

- Establishing the overall situation of children and their caregivers using regular national sample surveys (poverty alleviation or DHS surveys might be ideal).
- Monitoring the performance of specific projects, especially pilot projects, before widespread implementation.

Increased numbers of vulnerable children—such as street children, working children or child-headed households—are indicators of the saturation of community coping.¹¹ Criteria are needed to determine the most vulnerable children and families within communities by poverty level and vulnerability of household or guardian. These criteria can be established by the community itself according to its capacity for assistance. Program planners may also wish to choose between communities needing assistance to identify specific vulnerable communities or targeting entire regions or areas.

PROGRAM QUALITY AND DEVELOPMENT

A monitoring and evaluation plan should also review the quality of programs in place to serve children, families and communities affected by HIV/AIDS. Questions asked could include the following:

- Are the programs sufficiently comprehensive?
- What other models could be encouraged, and how can models be expanded to meet new needs or provide new services?
- Is there periodic training for community committees and for family caregivers?
- What allowances are made for developing programming over time in response to changes in the epidemic?
- What are the material needs and supports?
- How do programs encourage innovation, including opportunities for communities to teach and talk with one another?

- What variation is there in response to differences in program setting (urban, periurban, rural, commercial and farm settings)?
- How are children's physical, socialization and psychosocial needs met?

Program development seeks to encourage change and innovation in programs that respond to changes in communities as AIDS mortality increases.

Communities will need assistance to ensure the sustainability of their programs, including:

- Working structures and networks
- Skills training
- Ownership of programs
- Awareness of program impact
- Close cooperation of government and NGOs with community-based organizations

FUNDRAISING

A funding plan can include indigenous sources of support as well as external sources. Indigenous sources of support include the government, communities, religious organizations, commercial- or private-sector organizations, community fundraising and small contributors of cash and in-kind goods and services. External sources of support include program-specific support from UN or multilateral donors, NGOs, bilateral donors, external funding to religious organizations or hospitals and World Bank AIDS sector loans.

Collaborative support and synergistic potential can be gained through coordination with donors supporting primary education, and health or agricultural programs. Orphan programs can build on programs developed in other sectors. For example, villagers in Malawi who had participated in a UNDP community development program were quicker to organize around the orphan issue in subsequent years. Programs in other sectors could be targeted at communities with large numbers of orphans. For example, a high-protein seed program organized by the World Food Program was targeted at heavily affected communities with good results.

National, district and local coordinating committees often stimulate local interest and contributions. In-kind contributions of goods and services are often as important as cash contributions and may be easier for groups or individuals to provide. Expanded donor funding in other sectors can be used to support mainstreamed services for orphans. For example, programs for early childhood education and development are especially important in supporting young orphans. A national development plan and strategy for orphans will be important in increasing funds from external donors and programs because it can articulate the scale of the problem, strategies being pursued to address it and the contributions of local communities and organizations.

AIDS AND THE RIGHTS OF POOR COMMUNITIES

As economic adjustments have weakened social services, health services and public assistance schemes, governments have abrogated responsibility for family welfare to local governments and community charity. Families and communities must respond as best they can, but the coverage and effectiveness of their efforts are not being systematically monitored or evaluated. This leaves the most vulnerable—children, women, the elderly and the disabled—exposed, with weak or nonexistent safety nets and no resources beyond their own creativity.

It is within this context that community volunteer groups are expected to function as social welfare systems—sometimes with little or no organizational inputs or reimbursements for services. They need training, continued development and hardware—such

as bicycles and water pumps—and capital for revolving credit and income-generating activities to support poor children and sick community members. It is important that program managers anticipate what such volunteer systems need and treat volunteers with sufficient respect.

Advocating community care for children orphaned and left vulnerable by the epidemic may have unanticipated negative consequences for women unless other gender inequities are addressed. In South Africa, community care for orphans is viewed as additional unpaid women's work, and the long-range justice of community care is questioned. Removing female orphans from school sooner than boys to provide care for the sick, childcare and other domestic work contributes to the gender inequities.

Poor communities should consider the following in establishing community-based care programs for vulnerable children:

- Operational or action-oriented research in selected countries to investigate the “bottom line” of caring—the point at which households willing to provide care for children are unable to do so given restrictions of time, money and other resources.
- Recognition that family systems may not be able to sustain themselves under the burden of adoption and fostering—not because they are unwilling, but because they are too impoverished.
- Recognition that communities are often willing and resourceful (albeit impoverished) partners. Communities may well be dependent because they are poor as a result of receiving too little national wealth and other resources, such as education, health care, water and sanitation, capital and credit.
- Acknowledgement of communities as viable delivery mechanisms for a range of social services.
- Appropriate support to sustain community development, including organizational training and material assistance, transportation and agriculture in all programming.

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C H A P T E R

27

*HIV/AIDS,
Health and
Human Rights*

SOFIA GRUSKIN
DANIEL TARANTOLA



HIV/AIDS, Health and Human Rights

INTRODUCTION

HIV continues to spread throughout the world, shadowed by increasing challenges to human rights both within countries and globally. An effective response to HIV/AIDS demands understanding the linkages between HIV/AIDS and international law and, in particular, international human-rights law.

Realization of human rights is critical to protecting the rights and dignity of those infected and affected by HIV/AIDS—and to decreasing the vulnerability of individuals everywhere. This chapter proposes an analytical structure and directions for reinforcing the ties between human rights and HIV/AIDS. It suggests that human rights can define the degree to which individuals are protected from HIV infection and, when infected, from denial of needed care and support.

RISK, RISK-TAKING BEHAVIORS AND RISK-REDUCTION STRATEGIES

The concept of risk is anchored in epidemiological terminology. In the initial response to HIV/AIDS, the notion of risk—particularly once it became measurable through sero-epidemiological methods—gave rise to short-term risk-reduction interventions. Most national and international responses to the pandemic still focus on short-term risk-reduction interventions. Too often, this has obscured the societal issues in which the risk of infection and the probability of acquiring appropriate care and support are deeply rooted.

VULNERABILITY TO HIV/AIDS AND VULNERABILITY REDUCTION

Not only must risk-reduction interventions be augmented, but more attention must be given to the concept of “vulnerability reduction.” HIV/AIDS vulnerability links the notion of risk to personal and collective factors that determine the likelihood of exposure through risk-taking behavior. Vulnerability is evidenced by the pandemic’s relentless focus on individuals, communities and nations that are marginalized or discriminated against for reasons of gender, age, race, sexual orientation, economic status or cultural, religious or political affiliation.

FROM VULNERABILITY REDUCTION TO HUMAN RIGHTS PROMOTION

Recognizing human rights in the design, implementation and evaluation of health policies and programs can help lead the way toward more effective action. Human rights provide a structure for identifying the civil, political, economic, social and cultural dimensions of life that are linked to—and often determinants of—health status.

GROWING UNDERSTANDING OF THE RELATIONSHIP BETWEEN HIV/AIDS AND HUMAN RIGHTS

Given the reality of violations that continue to plague people living with HIV/AIDS (PLHA), it is useful to consider the specific human rights responsibilities of governments. For every human right, governments have responsibilities at three levels: they must respect the right; they must protect the right; and they must fulfil the right.

HUMAN RIGHTS, RISK AND VULNERABILITY TO HIV/AIDS

A review of the historical steps toward recognition of the relationship between public health and human rights in the context of HIV/AIDS—and how its application has expanded as the understanding of the roots of and effective responses to the pandemic has progressed—may help provide a useful background to constructing a framework for action.

HIV/AIDS, PUBLIC HEALTH AND HUMAN RIGHTS IN PRACTICE

Human rights can provide a method of analysis and framework for action to help shape specific interventions that reduce the pandemic's impact on individuals and populations. An agenda for action can be created by recognizing the convergence of the three situations in which people live in a world with HIV/AIDS: infected, affected and vulnerable; and the three levels of government obligations that exist for every right: respect, protect and fulfil.

CONCLUSION

The course of the HIV/AIDS pandemic has shown that public health efforts to prevent and control its spread are more likely to succeed in public health terms if policies and programs promote and protect human rights. Policy makers, program managers and service providers must become more comfortable using human rights norms and standards to guide and limit their actions in all matters affecting the response to HIV/AIDS. Advocates must become more comfortable using international human rights law in holding these officials accountable when they fail to do so.

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HIV continues to spread throughout the world, shadowed by increasing challenges to human rights both within countries and globally. The virus hits certain population groups hardest: those who live on the fringes of society or who are assumed to be at risk of infection because of behaviors, race, ethnicity, sexual orientation, gender or whatever characteristics are stigmatized in a particular society. In

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most of the world, discrimination also jeopardizes equitable distribution of access to prevention and care products, including necessary drugs, and development of vaccines to respond to the specific needs of all populations, in both the north and the south.

An effective response to HIV/AIDS demands understanding the linkages between HIV/AIDS and international law – and, in particular, international human rights law. International law provides a critical framework for looking at HIV/AIDS because it applies to all nations at all stages of development, including resource-poor countries. As the number of PLHA continues to grow in areas with different economies, social structures and legal systems, HIV/AIDS-related human rights issues are not only expanding worldwide, but also becoming increasingly diverse. The catastrophic impact of AIDS on the lives of individuals and populations, however, falls disproportionately on the developing world.

Realization of human rights is critical to protecting the rights and dignity of those infected and affected by HIV/AIDS, and to reducing the vulnerability of individuals everywhere. This chapter proposes an analytical

structure and directions for reinforcing the linkages between human rights and HIV/AIDS, and suggests that the extent to which individuals enjoy their human rights defines the degree to which they are protected from HIV infection and, when infected, from denial of needed care and support. Finally, the chapter explores the relationship between HIV, public health and human rights, and proposes steps for analysis and action.

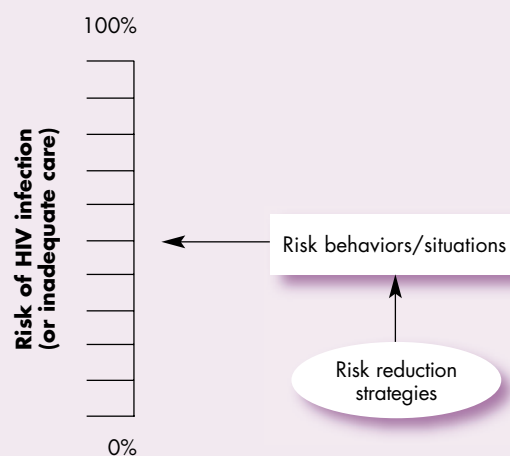
RISK, RISK-TAKING BEHAVIORS AND RISK-REDUCTION STRATEGIES

From an HIV/AIDS perspective, risk can be defined as the statistical probability that an individual will become infected with HIV. The concept can be extended to include the probability that an individual will acquire or die from other HIV-associated infections and diseases. Risk is commonly expressed as an HIV incidence rate, HIV seroprevalence rate or AIDS morbidity or mortality rate (Figure 1). As described elsewhere in this handbook, these rates are used to identify individual and collective risk of acquiring HIV infection, target prevention and care interventions and evaluate programs.

In the initial response to HIV/AIDS, the notion of risk—particularly once it became measurable through sero-epidemiological methods—gave rise to short-term risk-reduction interventions. These interventions relied on biomedical approaches—such as prevention and treatment of sexually transmitted infections (STIs); physical barriers against the transmission of viruses (condom promotion); attempts to influence individual decision making to adopt protective behaviors and practices (behavior change); and, in some cases, coercion (mandatory HIV testing).¹⁻³ From a care perspective, reducing morbidity and mortality risks involved access to care for prevention and treatment of opportunistic infections, other aspects of the physical and psychological consequences of HIV disease and, more recently, appropriate use of highly active antiretroviral therapies (HAART).⁴⁻⁶ These interventions have yielded significant short-term benefits: adoption of protective behaviors, decline in the incidence of HIV and other STIs and, particularly in economically affluent countries, longer quality life for PLHA.

To date, most national and international responses to the pandemic continue to focus on such short-term risk-reduction interventions. Too often, exclusive reliance on risk-reduction strategies has obscured the societal issues behind the risk of acquiring HIV infection and the probability of receiving appropriate care and support.⁷ Individuals, communities and national and international groups can effectively help reduce the impact of HIV through the use of appropriately designed and well-implemented prevention and care activities.⁸⁻¹⁰ Successful short-term risk-reduction interventions must be expanded considerably, adapted to local needs and replicated worldwide. But the empha-

Figure 1
HIV/AIDS RISK AND
RISK REDUCTION STRATEGIES



sis on short-term risk-reduction interventions must not come at the expense of medium- and long-term interventions.

These longer term interventions have been ignored, underfunded and even misconstrued as irresponsible and unnecessary diversions of scant HIV/AIDS resources across health and social programs, resulting in loss of direction, control and accountability.¹¹ An effective response to the pandemic will require greater attention to longer term risk-reduction interventions, including linking HIV/AIDS prevention, care and support work with other actions in the health and social sectors, as well as remodeling services to respond more effectively to growing needs.¹² Such changes might include integrating HIV prevention interventions with reproductive-health services, including HIV and sexual health education in primary and secondary school curricula or redesigning adolescent health services to better respond to young people's needs for advice, care and support. These strategies call for medium- and long-term commitment, investment and action within countries and at the global level.

VULNERABILITY TO HIV/AIDS AND VULNERABILITY REDUCTION

In some politically organized communities—particularly where individuals have access to adequate information, education and services—the incidence of HIV infection has begun to decline.¹³ But HIV continues to reach new populations and new geographic areas. It has become clear that risk-reduction strategies alone cannot stop the pandemic.¹³

Two important lessons have been learned in the past decade: (1) Behavior changes can seldom be effected exclusively by making available preventive information and services; and (2) The societal context within which people are born, raised and sexually initiated strongly influences the degree to which they are or will be likely to adopt or avoid risk-taking behaviors.^{14,15} The influence of these societal factors on individual and societal vulnerability to HIV/AIDS has been increasingly recognized in recent years.¹⁶⁻¹⁸

In generic terms, individual vulnerability can be defined as a lack of control over one's own destiny—in short, a lack of autonomy. In relation to HIV/AIDS, vulnerability links the notion of risk to personal and collective factors that determine the likelihood of exposure to HIV through risk-taking behavior.¹⁹⁻²⁰ The concept of vulnerability also includes the probability of being denied appropriate care and support once infection has occurred, because of insufficient access to quality health and social services—which, in turn, may be determined by civil, political, economic, social or cultural factors.

The degree of vulnerability and the capacity of an individual to reach the level of autonomy that could help reduce risk may be determined by three sets of factors: (1) The characteristics of an individual—such as sexual abuse in childhood, lack of information or skills; (2) The design and implementation of health and social services—for example, discrimination against population groups in access to health care

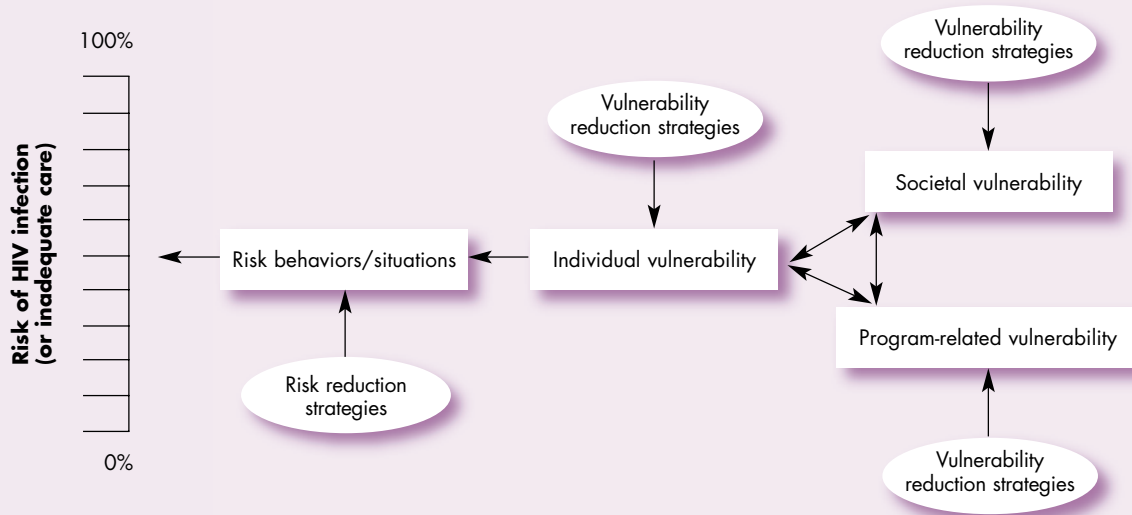
institutions or services; and (3) The implicit and explicit features of the society in which the individual is born and grows through adolescence and adulthood—such as history, beliefs, cultural norms, policies, laws and structures.²¹ These factors may act against or with one another. Societal norms, for example, may constrain health services for drug users; restrictions on girls' access to higher education may accentuate gender imbalances and increase women's vulnerability to HIV/AIDS; lack of information may reduce an individual's ability to claim access to quality care.

The pandemic has taught us that vulnerability to HIV/AIDS—as well as to other health issues such as violence, substance use, unwanted pregnancies and an array of other communicable or non-communicable diseases—is deeply rooted in discrimination and lack of respect for human rights and dignity.^{22, 23} The effects of this vulnerability are shown clearly by the pandemic's relentless focus on individuals, communities and nations that are marginalized or discriminated against for reasons of gender, age, race, sexual orientation, economic status or cultural, religious or political affiliation.

From this understanding emerges the need not only to augment risk-reduction interventions, but also to give far greater attention to the concept of “vulnerability reduction” (see Figure 2). Multiple interventions must attempt to lessen societal factors that increase individual and collective vulnerability to HIV/AIDS, while reinforcing factors with favorable effects.²⁴

It might be argued that, even if this approach is recognized as fundamental to an effective response to HIV/AIDS, it requires deep societal transformation involving a lengthy process of cultural, structural and environmental change. But like risk-reduction interventions, vulnerability reduction can also be implemented in the short term by modifying laws, policies, regulations or practices that discriminate against specific populations; promoting the norms and standards of human rights; and focusing existing human development schemes on the most vulnerable communities.

Figure 2
**HIV/AIDS RISK, VULNERABILITY
 AND REDUCTION STRATEGIES**



In the medium- and long-term, vulnerability reduction can be implemented by working to achieve gender equality in relation to power, education and employment, or by bridging the poverty gap.

Societal factors are not sufficiently considered in most public health interventions. Nor has much attention been paid either to long-term risk-reduction strategies or to vulnerability reduction in any form. Setting both short- and long-term goals for risk reduction and vulnerability reduction is a critical step in reducing the impact of HIV/AIDS, and one that may be manageable in the face of daunting, seemingly overwhelming challenges. The human rights framework has been found to be particularly useful in advancing both analysis and action.²⁵

FROM VULNERABILITY REDUCTION TO HUMAN RIGHTS PROMOTION

Human rights are governmental obligations towards individuals. Because these obligations include the protection of public health, they are relevant to the design, implementation and evaluation of health policies and programs.^{27,28} Thus, governments are responsible for instituting policies and programs that can reduce the spread and impact of HIV/AIDS. Recognizing human rights in the development of health policies and programs can help point the way toward more effective action. Human rights provide a structure for identifying the civil, political, economic, social and cultural dimensions of life that are linked to—and often act as determinants of—health status.²⁶

Examining public health through a human-rights lens means looking not only at the technical and operational aspects of public health interventions but also at the civil, political, economic, social and cultural factors that surround them. These factors may include, for example, gender relations, religious beliefs, homophobia or racism, which separately and together influence the extent to which individuals and communities can

Box 1

THE HUMAN RIGHTS DOCUMENTS AND HIV/AIDS

Human rights, broadly speaking, concern the relationship between individuals and the state. International human rights law defines what governments can, cannot and should do to or for us. For example, governments should not torture people, imprison them arbitrarily or invade their privacy. Governments should, however, ensure that all people in a society have shelter, food, medical care and basic education. The concept of human rights has a long history, but the modern human rights movement really dates back 50 years, when the promotion of human rights was set out as one of the purposes and principles of the newly created United Nations.

The key human rights document and the cornerstone of the modern human rights movement is the Universal Declaration of Human Rights (UDHR). It is a common aspirational document, by and for governments, about the rights that should exist for all people everywhere. The UDHR was adopted by the UN General Assembly on December 10, 1948. A number of international treaties further elaborate the rights set out in the UDHR. These documents—the International Covenant on Civil and Political Rights and the Covenant on Economic, Social, and Cultural Rights; the Convention on the Elimination of All Forms of Racial Discrimination; the Convention on the Elimination of All Forms of Discrimination Against Women; and the Convention on the Rights of the Child, describe legally binding obligations for the governments that agree to them.

These documents codify health and government responsibility for health in several ways. The right to the highest attainable standard of physical and mental health appears in one form or another in most of them. Even more importantly, nearly every article of every document can be understood to have clear implications for health and for HIV/AIDS. Everything—from the rights to information and association to the rights to social security or the benefits of scientific progress and its applications—has clear implications for HIV/AIDS and for public health generally.

None of these treaties specifically mentions HIV or the rights of individuals in the context of HIV/AIDS. The fact that all international human rights mechanisms responsible for monitoring government action have, nonetheless, expressed their commitment to exploring the implications of HIV/AIDS for governmental obligations may be critically important for bringing HIV/AIDS and human rights together in practical and concrete ways. In addition, governments have made political commitments at recent international conferences such as the Cairo International Conference on Population and Development and the UN Fourth World Conference on Women, stating their responsibility for ensuring the rights of individuals in the context of HIV/AIDS.²⁹ Finally, resolutions of the UN Commission on Human Rights and the 1998 International Guidelines on HIV/AIDS and Human Rights provide both advocates and policy makers with useful tools to ensure increased attention to both HIV/AIDS and human rights, and may help not only with advocacy efforts, but also policy and program design.³⁰

access services or make and effectuate free and informed decisions about their lives and, therefore, the extent of their vulnerability to HIV/AIDS.

Governments are responsible for promoting and protecting both public health and human rights. These responsibilities have been translated into a set of obligations under international law, which are enshrined in declarations, treaties and conventions. Using human rights concepts, one can look at the extent to which governments are respecting, protecting and fulfilling their obligations for all rights—civil, political, economic, social and cultural—and how these government actions influence the patterns of infection and what is being done about it.²⁶

GROWING UNDERSTANDING OF THE RELATIONSHIP BETWEEN HIV/AIDS AND HUMAN RIGHTS

Given the reality of violations that continue to occur in the context of HIV/AIDS, it is useful to consider again the specific human rights responsibilities of governments. Governments are responsible for not violating rights directly, as well as for ensuring the conditions that enable us to realize our rights as fully as possible. It is understood that governments have responsibilities for every human right at three levels: (1) They must respect the right; (2) They must protect the right; and (3) They must fulfil the right.³¹ As an illustration, consider governmental obligations in the context of HIV, using one right—the right to education:

- **Respecting the right** means that states cannot violate the right directly. This means that the right to education is violated if children are barred from attending school on the basis of their HIV status.
- **Protecting the right** means a state must prevent violations by non-state actors, and prescribe some sort of redress that people know about and have access to if a violation does occur. A state must ensure, for example, that extremist religious groups are not successful when they try to stop adolescents from accessing reproductive health education.

- **Fulfilling the right** means states must take all appropriate measures—legislative, administrative, budgetary, judicial and otherwise—towards fulfilling the right. If a state fails to provide essential HIV/AIDS prevention education in enough languages and media to be accessible to everyone in the population, this could be a violation of the right to education.

In most countries, resource and other constraints can make it impossible for a government to fulfil all rights immediately and completely. The mechanisms responsible for monitoring governmental compliance with human rights obligations recognize that, in practical terms, commitment to the right to basic education will require more than just passing a law. Financial resources, trained personnel, facilities, textbooks and a sustainable infrastructure are also needed. Therefore, realization of rights is generally understood to be a matter of steadily progressing towards a goal. This principle of “progressive realization” is fundamental to the achievement of human rights. It is especially critical for resource-poor countries; it also imposes an obligation on wealthier countries to engage in international assistance and cooperation.³²

Under certain conditions, human rights can be restricted for the benefit of national security, general welfare or public health.³³ This practice has been and continues to be applied by many public health officials—often too liberally—to the field of communicable disease control, including HIV/AIDS. Restrictions on the lives of individuals—such as limitations on

Box 2

RESTRICTION OF RIGHTS IN THE CONTEXT OF HIV/AIDS

Public-health workers can, under international human rights law, impose restrictions on human rights for the benefit of public health. While there are some rights—such as the right to be free from torture or from slavery—that are absolute and should never be taken away, most rights can be legitimately restricted in some circumstances—such as the need to interfere with freedom of movement when instituting quarantine or isolation for a serious communicable disease, such as Ebola fever or untreated tuberculosis. Simply stating that the action is necessary for public health, however, is not sufficient.

Several criteria must be met before governmental decisions are acceptable under international human rights law:

- The action must be taken in accordance with a national law.
- It must be in the interest of a legitimate objective.
- It must be strictly necessary to achieve this objective.
- It must be the least restrictive alternative.
- It cannot be imposed in an unreasonable or discriminatory way.

A human rights framework can help identify abusive public health actions, whether intentional or unintentional. For example, these criteria will show that an HIV prevention strategy consisting of police roundups and mandatory testing of sex workers raises obvious human rights concerns. More subtle violations may also come to light through this exercise, such as the impact of denial of the right to information on the rates of HIV infection in young people around the world.

freedom of movement through forced institutionalization, or requirements for the forced testing of certain groups—cannot be imposed without sufficient attention to the human rights implications of these actions. The process described below compels governmental authorities to apply a set of established criteria when considering human rights restrictions as a means to protect public health.

There are ongoing human rights violations around the world against women, men and children infected, affected and vulnerable to HIV/AIDS. Violations occur when, for example, infected people face marginalization and discrimination, as well as when their rights to privacy, health, education and social services are violated.^{34, 35} People are affected when their close or extended families, their communities and, more broadly, the structures and services that exist for their benefit are strained by the consequences of the AIDS pandemic and fail to provide them with the support and services they need. They are also affected when they face marginalization and stigmatization on the basis of perceived HIV status or when their rights—including rights to health services, education and social programs—are violated.^{36, 37} The effects of discrimination—particularly in the forms of racism, gender-based discrimination and homophobia—have exacerbated the impact of the pandemic on the lives of individuals and populations around the world. For example, the marginalization of certain communities has led to their neglect by state-controlled HIV/AIDS programs. This neglect has then increased vulnerability within these groups, causing them to suffer a disproportionate burden of HIV-related health issues. It has also resulted in a scarcity or absence of services for these infected and affected individuals.

HUMAN RIGHTS, RISK AND VULNERABILITY TO HIV/AIDS

A review of the historical steps toward recognition of the relationship between public health and human rights in the context of HIV/AIDS—and how its application has expanded as the understanding of the roots of and effective responses to the pandemic have progressed—may help provide a useful background for constructing a framework for action.

In the 1980s, the relationship of HIV/AIDS to human rights was only understood as it involved PLHA and the discrimination to which they were subjected.³⁸ For them, the concerns included HIV testing; restrictions on international travel; barriers to employment; access to education, medical care or health insurance and the many issues raised by named reporting, partner notification and confidentiality.

These are serious issues. And almost 20 years into the epidemic, they have not been resolved. In some ways, the situation has become even more complicated, as old issues emerge in new places or new and different ways. For example, in certain settings, access to employment was routinely denied to PLHA. Even where this situation has improved, infected individuals now run the risk of finding themselves excluded from workplace health insurance schemes—with considerable impact on their health and, therefore, their capacity to work. New issues with tremendous human rights implications have also been raised in recent years, including the large and growing disparities and inequities regarding access to anti-retroviral therapies and other forms of care, as well as the need to control tuberculosis within and beyond populations living with HIV/AIDS.³⁹

The 1980s were extremely important in defining some of the connections between HIV/AIDS and human rights. By the end of the decade, the call for human rights, compassion and solidarity with PLHA had been embodied in the first WHO global response to AIDS.⁴⁰ This approach was motivated not only by moral outrage but—even more importantly—by the recognition that protection of PLHA's human rights was a necessary element of a worldwide public-health response to the emerging epidemic. The implications of this call were far-reaching. By framing this public health strategy in human rights terms, it became anchored in international law, holding governments and intergovernmental organizations publicly accountable for their actions toward PLHA. The groundbreaking contribution of this era lies in the recognition of the applicability of international law to HIV/AIDS, and in the attention generated by this approach to the linkages between other health issues and human rights—and therefore to the ultimate responsibility and accountability of the state under international law for issues relating to health and well-being.⁴¹

This attention to the human rights of PLHA helped pave the way for increased understanding in the 1990s of the importance of human rights as a factor in determining vulnerability to HIV infection, the consequent risk of acquiring the infection and chances of accessing appropriate care and support. It is only very recently, however, that human rights have been recognized as directly relevant to every element of the risk/vulnerability paradigm. The linkage of human rights with HIV issues as understood within the risk/vulnerability paradigm, helps illustrate the relationship between HIV and human rights—with all the implications of this relationship for both advocacy and government action. A few selected examples, identifying some of the rights relevant to situations faced by people in the context of HIV/AIDS, help demonstrate this link. The impact of neglect or violations of the right to nondiscrimination should be understood as an important concern in each of the examples shown below.

HIV/AIDS, PUBLIC HEALTH AND HUMAN RIGHTS IN PRACTICE

Box 3

EXAMPLES OF HUMAN RIGHTS VIOLATIONS IN RELATION TO HIV/AIDS RISK AND VULNERABILITY

Human rights violations related to risk:

- Deliberate exclusion or forcible inclusion of people in HIV testing schemes implemented for surveillance or other purposes (right to security of person).
- Mandatory name reporting or disclosure of the HIV status of individuals without their consent (right to privacy).

Human rights violations related to risk-taking behaviors and risk reduction:

- Criminalization of certain behaviors (such as same-sex sexual activity), causing lack of access to suitable prevention and care programs and resulting in increased risk-taking behaviors (rights to association and equal protection).
- Restrictions on HIV/AIDS information available to certain populations (such as women or young people) resulting in people unknowingly engaging in risk-taking behaviors (right to information).

Human rights violations related to vulnerability and vulnerability reduction:

- Gender-based discrimination within a society resulting in women's increased vulnerability to HIV (rights to education, social security, equal pay for equal work and equal rights in marriage).
- Low-intensity and open conflicts resulting in population displacement, refugee flows and circumstances of extreme poverty and deprivation, in turn resulting in increased vulnerability to HIV in populations previously at low risk (rights to social services, to security of person, to share in scientific advancement and its benefits, to take part in government and to freedom from arbitrary interference with family and home).

Human rights are important to HIV/AIDS policies and programs because they can provide an analysis and framework for action to help shape specific interventions aimed at reducing the impact of the pandemic on the lives of individuals and populations. This approach requires studying international documents to determine the specific rights applicable to a given situation, and then considering how and to what extent risk behaviors and vulnerability are caused or exacerbated by insufficient realization of human rights.

An agenda for action can be created by recognizing the convergence of the three situations in which people live in a world with HIV/AIDS—infected, affected and vulnerable—and the three levels of government obligations that exist for every right—respect, protect and fulfil. This approach can incorporate human rights promotion and protection into the diversity of responses designed to bring the pandemic under control and mitigate its impact. Table 1 summarizes the three situations and three levels of obligation that should be considered when identifying specific needs and rights of individuals in the context of HIV/AIDS.

As a next step, HIV/AIDS policies and programs can be improved by a systematic review of how and to what extent interventions targeted at reducing risk or vulnerability respect human rights and benefit public health. This review will be a critical first step in assessing the validity, applicability and soundness of new and existing policies and programs, addressing their practical implications from both human rights and public health perspectives. In making decisions and taking action, governments are responsible for respecting, protecting and fulfilling human rights under international law, and for promoting and protecting public health. They are thus responsible for enacting and implementing policies and programs that comply with human rights and sound public health principles.

Table 1

GOVERNMENTAL OBLIGATIONS WITH RESPECT TO PEOPLE IN THE CONTEXT OF HIV/AIDS⁴²

	People infected with HIV	People affected by HIV/AIDS	People vulnerable to HIV/AIDS
Respect	Government must refrain from directly violating the human rights of PLHA on the basis of their HIV status.	Government must refrain from directly violating the rights of people affected by the HIV/AIDS pandemic.	Government must refrain from directly violating human rights that impact on vulnerability.
Protect	Government is responsible for preventing rights violations by non-state actors against PLHA and for prescribing some legal means of redress.	Government is responsible for preventing violations by non-state actors that would increase the burden of HIV/AIDS on affected people, and for prescribing some legal means of redress.	Government is responsible for preventing rights violations by non-state actors that may increase people's vulnerability to HIV/AIDS, and for prescribing some legal means of redress.
Fulfil	Government should take administrative, judicial and other actions towards realization of the rights of PLHA.	Government should take administrative, legislative, judicial and other actions towards realization of the rights of people affected by HIV/AIDS.	Government should take administrative, legislative, judicial and other actions towards the realization of the rights of people in order to minimize their vulnerability to HIV/AIDS.

The questions described in Box 4 can be used by policy makers and public health and other government officials to help develop, implement and evaluate more effective HIV/AIDS policies and programs, and by nongovernmental organizations and other concerned actors as an advocacy tool to hold governments accountable for compliance with their international legal obligations to promote and protect both public health and human rights.

Box 4

QUESTIONS TO BE ANSWERED WHEN DEVELOPING HIV/AIDS-RELATED POLICIES AND PROGRAMS

The following questions may serve as a starting point to help guide this analysis:^{43,44}

- What is the specific intended purpose of the policy or program?
- What are the ways and the extent to which the policy or program may positively or negatively affect public health?
- Using the international human rights documents for guidance, what and whose rights are affected positively and negatively by the policy or the program?
- Does the policy or program require restriction of human rights?
- If so, have the criteria/preconditions to restrict rights been met?
- Can health and other relevant structures and services effectively implement the policy or program?
- What systems of monitoring, evaluation, accountability and redress exist to ensure that the policy or program is progressing towards the intended effect, and adverse effects can be acted upon?

CONCLUSION

The challenges posed by HIV/AIDS are immense. The course of the HIV/AIDS pandemic has shown that public health efforts to prevent and control its spread are more likely to succeed in public health terms—such as lower HIV incidence, better quality of life for PLHA—if policies and programs promote and protect human rights. PLHA, their friends and relatives, their communities, national and international policy makers and decision makers, health professionals and the public at large all, to varying degrees, understand the fundamental linkages between HIV/AIDS and human rights. The importance of bringing HIV/AIDS policies and programs in line with international human rights law is generally acknowledged—but, unfortunately, rarely carried out in reality. Policy makers, program managers and service providers must become more comfortable using human rights norms and standards to guide and limit their actions in all matters affecting the response to HIV/AIDS. Advocates must become more comfortable using international human rights law in holding these officials accountable when they fail to do so.

In the short term, those concerned with HIV/AIDS must not only use the rhetoric of human rights, but also learn more about human rights concepts and procedures. This will require building information and education about human rights into awareness campaigns, as well as curricula for school education and professional training. It will also require information exchange and stronger cooperation between those working on health and those working on human rights. When people are sufficiently knowledgeable about human rights, they will be able to identify the issues for which the nexus between human rights and HIV/AIDS prevention and care is critical, and act accordingly.

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C H A P T E R

28

*Future
Challenges
in HIV
Prevention
and Care*

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Future Challenges in HIV Prevention and Care

INTRODUCTION

Our technological knowledge of HIV/AIDS and the epidemiology of AIDS, and our understanding of the behavior, risk and vulnerability of both individuals and populations have risen exponentially over the past 20 years. At this point, we have had certain successes and made some progress in some aspects of dealing with HIV/AIDS. But the HIV/AIDS pandemic continues its relentless global spread and devastation, and there is still a long way to go.

This chapter describes the challenges we face in the future, especially how to reduce the six million new HIV infections that occur globally every year; how to provide care for the 36 million people living with HIV/AIDS (PLHA); and how to provide support and protection for the millions of AIDS orphans and vulnerable children. It also highlights the need to improve the quality and scope of current activities, including improving the human rights of PLHA by reducing stigma and discrimination related to AIDS.

AN EXPANDED AND COMPREHENSIVE HIV/AIDS RESPONSE FOR GLOBAL IMPACT

Most HIV/AIDS interventions have been small in scale, reaching a minimal proportion of the populations at risk, and not comprehensive enough to meet prevention, care and support needs. To improve the impact of prevention and care programs, interventions must be scaled up to deliver an expanded and comprehensive HIV/AIDS response. This section focuses on the mobilization of resources needed to sustain organizational capacity adequate enough to effectively and rapidly deliver large-scale, comprehensive and sustained HIV/AIDS programs.

HIV/AIDS VACCINES: PROPHYLACTIC AND THERAPEUTIC APPLICATIONS

Development of an “ideal” vaccine has been elusive for three reasons: HIV infection and the human immune response are complex in nature; research and development are costly and time consuming; and human clinical trials involving a fatal infectious agent transmitted primarily by sexual behavior involve many ethical and legal issues. This section defines the ideal vaccine and focuses on the current challenges related to vaccine development, including ethical considerations and issues of cost-effectiveness.

ANTIRETROVIRAL DRUGS: ACCESS FOR THE MANAGEMENT OF HIV DISEASE IN RESOURCE-CONSTRAINED SETTINGS

Use of effective antiretroviral (ARV) therapies has significantly reduced morbidity and mortality among HIV-infected people in most industrialized countries. But because of the high cost and complexity of regimens, ARV therapy has been largely unavailable in resource-constrained countries, even though most of the world’s HIV and AIDS cases occur in these areas. This section explores the many considerations in providing ARV therapies, including the potential use of ARVs to prevent or reduce sexual transmission of HIV.

BARRIER METHODS: THE NEED FOR FEMALE-CONTROLLED METHODS

There is continuing need for more female-controlled methods of preventing transmission of HIV. This section looks at the female condom, an effective method that women can largely control, but for which there are several barriers to use, and the development of microbicides, which could play several roles in overall HIV prevention efforts.

MALE CIRCUMCISION: ITS ROLE IN PREVENTION

Research indicates that male circumcision may reduce HIV infection risk among men by as much as 50 percent. This section explores the role of male circumcision on transmission of HIV, including questions related to the biological basis for protection and concerns regarding the safety of circumcision in resource-constrained countries.

ORPHANS AND VULNERABLE CHILDREN: PROVIDING CARE AND PROTECTION

The large—and increasing—number of vulnerable children and those orphaned by AIDS presents an unprecedented challenge to governments, communities and families. This section raises the issues related to providing care, protection, education and job skills for orphans and vulnerable children in high HIV prevalence countries.

HUMAN RIGHTS: REDUCING STIGMA AND DISCRIMINATION

Stigma and discrimination against those who are infected have characterized the HIV pandemic. Widespread abuse of the human rights of marginalized populations also puts them at higher risk of HIV infection. This section outlines the challenges of improving human rights and reducing stigma and discrimination of PLHA.

CONCLUSION

This section underscores the numerous challenges that we need to overcome in controlling the spread of HIV and minimizing its destructive impact on resource-constrained countries.

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I N T R O D U C T I O N

The AIDS epidemic was first recognized in 1981, and HIV discovered in 1984. Since then, our technological knowledge of the virus and the epidemiology of the disease, and our understanding of the behavior, risk and vulnerability of both individuals and populations have risen exponentially. We have succeeded in decreasing the number of new HIV infections in several industrialized and a few resource-constrained countries, and HIV disease and mortality have been reduced by highly active antiretroviral therapy (HAART).

Despite this progress, however, the HIV/AIDS pandemic continues its relentless global spread and devastation, and we still have a long way to go.

This chapter describes the challenges we face in the future. The most pressing of these include how to reduce the six million new HIV infections that occur globally every year; how to provide care for the 36 million people living with HIV/AIDS (PLHA); and how to provide support and protection for the millions of AIDS orphans and vulnerable children (OVC). The sections that follow cover the urgent need to reduce HIV risk and vulnerability, especially in resource-constrained countries and marginalized communities, and highlight the need to improve the quality and scope of current activities, including hope for technological breakthroughs in prevention and treatment—especially for a vaccine and a cure. Finally, the chapter focuses on the worldwide need to improve human rights and reduce stigma and discrimination related to AIDS.

AN EXPANDED AND COMPREHENSIVE HIV/AIDS RESPONSE FOR GLOBAL IMPACT

We are currently hindered in slowing the HIV/AIDS pandemic because we are doing too little, too late and with inadequate resources. Most HIV/AIDS interventions are small in scale, reaching a minimal proportion of the populations at risk, and not comprehensive enough to meet prevention, care and support needs. Several obstacles have thwarted the development of large-scale programs. These include a lack of adequate financial resources, inadequate health infrastructure and technical and operational capacity and limited absorptive capacity.

To improve the impact of prevention and care programs, interventions need to be scaled up to deliver an expanded and comprehensive HIV/AIDS response (ECR). The aim of such a response is the mobilization of resources and organizational capacity adequate enough to effectively and rapidly deliver large-scale, comprehensive and sustained HIV/AIDS programs. A successful intervention ECR should result in:

- A substantial reduction in new HIV infections
- A substantial reduction in AIDS-related morbidity and mortality
- Improved quality of life for people infected and affected by HIV/AIDS
- Reduced HIV/AIDS stigma and discrimination
- Reduced impact of the epidemic, especially on children and other vulnerable groups

MOBILIZING RESOURCES

At least US\$7 – 10 billion a year is needed in the next decade to fight AIDS.¹ This level of funding would support an expanded and comprehensive HIV/AIDS prevention, care and support strategy, and would ensure the provision of low-cost HAART and treatment of opportunistic infections to PLHA. This resource commitment would be a remarkable bargain given the public health, developmental and security impact of the HIV/AIDS pandemic.*

Where will the required resources come from? Although, the full answer is unknown, HIV/AIDS continues to rise globally on the foreign policy agenda of major bilateral, multilateral and corporate private actors:²

- The U.S. government has increased its financial commitment to AIDS, and the U.S. Congress authorized the creation of the World Bank Trust for AIDS, with expected contributions from other industrialized countries.
- The Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Bank have established a Multi-Country HIV/AIDS Program (MAP) to expedite soft loans for community-level prevention, care and treatment programs.
- Several of the major pharmaceutical manufacturers have announced a number of initiatives to provide AIDS drugs and/or strengthen prevention, health-care access and patient management and treatment.
- The Bill and Melinda Gates Foundation and other foundations have provided funding for several AIDS programs in Africa.³

These contributions are helpful but are still too small in scale to make any substantial difference in slowing the pandemic and improving access and affordability of drugs for most PLHA in resource-constrained countries.

** For perspective, Europe is spending around \$5 billion in 2001 to fight mad cow disease, which has killed about 80 people so far, while AIDS has killed about 19 million people in Africa alone.*

HIV/AIDS VACCINES: PROPHYLACTIC AND THERAPEUTIC APPLICATIONS

Despite the successes of current interventions in controlling the global HIV pandemic, the best way to eliminate the virus as a major public health problem probably will be through preventive vaccination. But vaccination alone will not replace current biologic and behavioral interventions; use of a safe and effective vaccine will need to be incorporated into a comprehensive HIV prevention package.⁴ Development of the ideal vaccine has been elusive for three reasons: (1) HIV infection and the human immune response are complex in nature; (2) Research and development are costly and time consuming; and (3) Human clinical trials involving a fatal infectious agent transmitted primarily by sexual behavior raise many ethical and legal issues.

THE IDEAL VACCINE

The ideal vaccine must be safe, efficacious, affordable and accessible. These are simple concepts with complex definitions. Safety concerns, for example, include reversion to infectious HIV, oncogenic potential and immunosuppression in vaccinees. The vaccine must not produce adverse reactions when given to people infected with HIV. In addition, we will need to be able to differentiate seroconversion caused by vaccination from that caused by true HIV infection. Since it has not been possible to determine what constitutes immunologic protection against HIV, development of vaccine candidates has been hampered. We do not know the *in vitro* correlates of protection and, because there is no suitable animal model for HIV infection, clinical trials involving large numbers of human volunteers at risk for HIV infection will be needed to evaluate a preventive HIV vaccine.⁵

Determining the appropriate measure of efficacy has presented another challenge. Critical questions include whether we should develop, license and market a vaccine with relatively low protective efficacy (say, less than 60 percent); whether we should license a vaccine that only modifies the course of infection (reduces viral load) or hold out until we can develop a vaccine that induces sterilizing immunity (completely block HIV-1 infection); and whether we should use a vaccine that is only effective in limited parts of the world. HIV-1 has tremendous genetic diversity: The HIV-1 strains found worldwide are classified into at least 11 subtypes, or clades. The ideal vaccine should protect against all strains of HIV, and should also protect any population, regardless of nutritional status, race/ethnicity or route of HIV exposure.⁶

HIV vaccine development and testing has greatly accelerated over the past few years, and multiple activities are underway to find a practical and acceptable alternative to the “ideal” vaccine to provide HIV protection for those at highest risk. Currently, more than 50 HIV-1 vaccines are in development. More than a dozen of these have been tested in human volunteers,⁵ but only one has progressed to large-scale, phase III efficacy trials.

CHALLENGES IN VACCINE DEVELOPMENT

The challenges ahead are scientific, ethical/legal and financial. In the scientific arena, most current candidate vaccines are based on subtype-B strains, prevalent in the Americas and Western Europe. Candidate vaccines for other subtypes are being developed for less-developed countries, such as subtype-E for Thailand and subtype-C, the dominant subtype in southern Africa and India.⁴ It is possible that multiple subtypes share common protective epitopes. Also, genetic subtypes may not strictly correspond to immunotypes important for vaccine protection. More information is needed on the relative contributions of humoral and cell-mediated immunity, and protective immunity at mucosal surfaces where HIV infection takes place.

Ethical concerns

Ethical concerns surround a vaccine that may not be 100 percent efficacious. If people increased their risky behavior because of a false sense of vaccine-induced protection and this led to HIV infection, negative publicity would be rampant. Who would assume responsibility for providing care for these newly infected people? Obtaining informed consent is another complex issue, especially in resource-constrained countries. Education and counseling programs need to be in place to ensure that the vaccine does not instill a false sense of security and increased risk behavior.

A variety of ethical considerations stem from the need to test candidate vaccines in the populations most affected by HIV, often in resource-constrained countries. Such testing requires collaboration between scientists from the countries that developed the vaccine and scientists, public health officials and communities in the host country. As for the issue of informed consent, the potential imbalance between the resources and expectations of the sponsoring country (where the vaccine is developed) and that of the host country (where the vaccine will be tested) calls for both countries to collaborate in ensuring that host countries and communities participate fully in the development and testing of vaccines.⁷

Cost-effectiveness

Vaccines are among the most cost-effective health interventions,⁴ yet less than one percent of AIDS resources are devoted to vaccine development—primarily because the HIV vaccine market is not perceived to be lucrative. With the enormous costs involved in developing a new pharmaceutical agent,⁹ private industry needs incentives to pursue a product with 90 percent of its market in resource-constrained coun-

tries, where there are problems ensuring the product sells at low cost, is easy to give and remains stable in varying temperatures and storage conditions. Collaboration is essential to change the pharmaceutical industry's avoidance of an unprofitable market. Incentives can be provided through public-private alliances.

ANTIRETROVIRAL DRUGS: ACCESS FOR THE MANAGEMENT OF HIV DISEASE IN RESOURCE- CONSTRAINED SETTINGS

Use of effective antiretroviral drugs (ARVs) has significantly reduced morbidity and mortality among HIV-infected people in most industrialized countries. But because of the high cost and complexity of regimens, ARV therapy has been largely unavailable in resource-constrained countries, even though most of the world's HIV and AIDS cases occur in these areas. Lack of funding for ARV therapy is due in part to the many health care needs, such as diarrheal and childhood illnesses, malaria, tuberculosis (TB) and other respiratory diseases competing for limited resources.

CONSIDERATIONS IN PROVIDING ARV THERAPIES

In considering providing ARV therapies, health officials and policy makers must look at the social and economic costs and benefits of purchasing the drugs to treat people infected with HIV and/or AIDS. Benefits include potential reductions in hospitalization costs, increased productivity of the labor force, potential reductions in new infections due to lower viral loads and increased stability and longevity of families with fewer orphans. Costs include potential increases in overall treatment expenditures, possible “crowding out” of people with other illnesses and possible increases in new infections as people live longer and/or return to risky behaviors.¹⁰ Specific economic costs include patient management, record keeping, laboratory monitoring of CD4 and viral load counts and capacity building for the early diagnosis and treatment

of opportunistic infections. Even if patients pay the costs of their medical care, the public health system still must meet the costs of training, development and implementation of treatment guidelines and expanded access to laboratory diagnostics.¹¹

There is not likely to be a single answer to the question of whether ARV therapies are cost-effective for resource-constrained countries. Considerations beyond cost—such as the overall societal impact of massive human suffering and death—must also be taken into consideration. Alternatives to such treatment have not been assessed on the basis of cost-effectiveness basis either, so there is no opportunity for comparison of the costs and benefits of both types of interventions.¹²

Significant concerns remain that difficulties of compliance and continuity of supplies could result in a multi-resistant virus that would have devastating consequences worldwide, although the UNAIDS Drug Access Initiative pilot programs have generally shown good patient adherence.^{11,13} In addition, some have suggested that the limited provision of ARVs could cause conflict within communities between those who receive treatment and those who do not. A black market could develop from which ARVs could be obtained, but without a complete understanding of the possible dangers of taking them without appropriate medical support and follow-up.¹⁴

Should resource-constrained countries choose to make ARVs available, they will need to ensure that there is an adequate infrastructure that includes access to HIV counseling and testing; monitoring of treatment, side effects, compliance and drug resistance; and treatment for opportunistic infections and general health care. In addition, basics such as clean water are required in order to take the 20 to 30 tablets daily, and some medicines will require refrigeration. Maintaining such high-cost services will be a critical

issue for many countries. Some governments may choose to establish a hierarchy for ARV therapy—for example limiting it to pregnant women, health care providers who have had an occupational exposure and/or people with AIDS.¹⁵

For the near future, it is likely that the five main priorities in the resource-constrained world for controlling HIV infection for the majority of the population will be limited to behavioral prevention interventions, condom provision, integrated sexually transmitted disease (STD) treatment services, treatment of AIDS-related opportunistic infections and palliative care for infected individuals. These strategies will still be relatively expensive for resource-constrained nations.¹⁵ But strategies for greater access to lower-cost ARV therapies will be important to assist those countries most in need of reducing their burden of HIV/AIDS.

USE OF ARVs TO PREVENT OR REDUCE SEXUAL TRANSMISSION OF HIV

ARVs have been shown to reduce the concentration of HIV in blood,¹⁶ semen¹⁷ and female genital secretions.¹⁸ Thus, use of therapeutic doses of ARVs in people infected with HIV might also lead to reduced sexual transmission to uninfected others. Further research is required to validate this hypothesis. In addition, several obstacles must be overcome before widespread application of this option is possible. First, currently available ARVs are expensive and their availability only to those who can afford them limits their public health application and future impact. Expected dramatic reduction in costs will certainly increase access to ARVs and expand their potential to have a greater impact on HIV prevention, especially in high prevalence countries. Second, people taking ARVs may perceive themselves to be cured and/or incapable of transmitting HIV, and thereby revert to high-risk behaviors.¹⁹ Finally, it is important to consider that the prolonged use of ARVs for prevention may lead to the rapid development of resistant strains of HIV.

One potential future application is the widespread therapeutic use of subsidized ARVs among HIV-infected high-risk populations such as commercial sex

workers (CSWs) and injection drug users (IDUs). Such an application would result in the availability of ARVs for marginalized infected populations who would otherwise never have access to them, with the additional public health impact of reducing HIV transmission in those most at risk of transmitting the virus. It is debatable, however, whether policy makers in resource-constrained countries are likely to agree to subsidize ARVs for such populations if the cost of the drugs continues to be prohibitive. Another possible application is the use of prophylactic ARV therapy to reduce HIV transmission, especially in high-risk groups, without providing continuing therapeutic doses. This approach has clear ethical implications, though it could arguably be seen as not much different from the use of prophylactic ARV therapy in preventing the transmission of HIV from mother to child than not providing the mother with continuing therapy.

PROPHYLAXIS AFTER SEXUAL EXPOSURE TO HIV

Follow-up studies of post-exposure prevention (PEP) for HIV following needle stick injuries indicate that ARVs may reduce the risk of HIV infection after exposure. These studies beg the question, “Does the use of ARV for prophylaxis after sexual exposure have a future?” The current cost of the drugs, their toxicity and the likely low prevention efficacy makes PEP an unlikely large-scale public health intervention, even in the future. But selective use in special circumstances such as for victims of rape or condom failure in an HIV-discordant couple may be justified.

BARRIER METHODS: THE NEED FOR FEMALE- CONTROLLED METHODS

There is continuing need for more female-controlled methods of preventing transmission of HIV. Male condoms can provide highly effective protection, but many women, particularly in resource-constrained countries, face serious difficulties negotiating condom use by their male partners. The female condom, which became available in 1993, is an effective alternative that women can largely control, but there are significant barriers to its use by women in both resource-constrained and industrialized nations. Perhaps more promising, but generally expected to offer less overall efficacy than condoms, microbicides are in development. These will provide women with more control of the means of protection, which may be a critical factor in prevention practices in many areas.

THE FEMALE CONDOM

Studies indicate that a substantial barrier to female condom use is the cost involved.²⁰ Another significant drawback is the longer time and practice needed to become proficient and comfortable in its use. Other barriers to female condom use may include cultural proscriptions against touching the genitals or discomfort with this, refusal of male partners to support its use, concerns about diminished sexual pleasure and fears about safety and efficacy. A continuing challenge for intervention programs will be to help women maintain their motivation to continue practicing until use becomes routine.

MICROBICIDES

Microbicides are chemical products—usually in the form of a gel, cream or suppository—that, when applied topically to either the vagina or rectum, would prevent or decrease transmission of HIV. Microbicides can act in several ways to: directly kill the pathogen; prevent entry of the pathogen into the cell; or prevent the virus from replicating after it has entered the cell.²¹

Scientists are now seriously pursuing more than 40 products, including at least 15 that have been tested in animals and are now in human trials.

There was a fair amount of disappointment when a 2000 UNAIDS study showed that nonoxynol-9 (N-9), a widely used spermicide, not only did not provide protection against HIV but appeared to somewhat increase transmission risk. It is now thought that the frequent use of N-9 among trial participants may have led to vaginal micro-ulcerations, which in turn increased the likelihood of transmission.²² Despite the findings that N-9 is not a suitable microbicide candidate, microbicides are still seen as a key prevention tool to focus on in the immediate future.

Microbicides could play several roles in overall HIV prevention efforts—as an adjunct to condom use, to provide additional protection in case of condom failure or when condom use is not possible or desirable. They could also be promoted as an alternative protective method for people unable or unwilling to use condoms. While they might not be as effective as consistently used condoms, they could provide considerable protection.²¹ A distinct advantage is that microbicides are likely to be much easier for women to use, and some would even be imperceptible to sex partners, particularly if they can be applied well before intercourse occurs.²¹

BARRIERS TO MICROBICIDE DEVELOPMENT

Unfortunately, pharmaceutical companies, which are in the best position to bring a microbicide to market, have been relatively uninterested in investing in such research, primarily because of fears about liability for a product that gives an implied protection against a fatal disease. Other industry concerns include an uncertain regulatory environment and the belief that the microbicide market would not be sufficiently

lucrative. The public sector may need to take the lead in this area, encouraging microbicide development through research grants for product development and partnerships with small biotech companies to help evaluate their products.²¹

If microbicides become widely available, the public health message may need to shift from a narrow focus on condom use to a hierarchical message that emphasizes condom use but calls for less effective but helpful choices for those who are unable to use condoms with each sexual act. This harm reduction approach, similar to the prevention message for IDUs (“Don’t inject drugs, but if you do, use a clean syringe each time, and if you can’t do that, use bleach to clean your works”), recognizes that not everyone will be able to follow the “best” advice at all times, but that using even some preventive measures will help to reduce HIV transmission. It may be useful to begin examining the ways that a new female-controlled method could be introduced without undermining existing prevention efforts and messages.²¹

MALE CIRCUMCISION: ITS ROLE IN HIV PREVENTION

More than 40 studies conducted during the past two decades have examined the role of male circumcision on transmission of HIV, with most finding that the practice is associated with substantially lower rates of infection. These research results have led to an increasing interest in male circumcision as a prevention tool, particularly in sub-Saharan Africa, where most transmission is heterosexual and many areas have low rates of male circumcision. In fact, a meta-analysis of studies on male circumcision in this region indicated that the procedure might reduce HIV infection risk among men by as much as 50 percent.²³

Despite the strong and suggestive findings there is much to be considered regarding male circumcision as an HIV prevention intervention. The exact biological basis for protection is not clear at this point. Research indicates that the foreskin provides a warm, moist environment for the growth of bacteria and viruses and is susceptible to scratches and tears during intercourse, which can provide entry points for pathogens. In addition, the foreskin has a high density of Langerhans cells, which are a possible source of cell entry for HIV.²⁴⁻²⁶ Lack of circumcision also increases the chances of infection with other STDs, including chancroid, syphilis and genital herpes, which have been shown to enhance transmission of HIV.²⁴ Nevertheless, further studies of the biological mechanism for transmission are needed to better determine the role of circumcision in this process.

The age at circumcision also appears to be a factor for HIV transmission. In sub-Saharan Africa, there is a wide range in the age at which males are circumcised, extending from infancy to adulthood. In one study, males who were circumcised before puberty had a much lower rate of infection than men who were

circumcised after age 20.²⁴ Since many men at high risk of infection would be older than 20, more understanding of the role of age at circumcision is needed before widely offering this intervention.

There are other concerns regarding the safety of circumcision in resource-constrained countries, where many procedures are done by inexperienced or unskilled people or with unsterile tools. Another risk related to many traditional circumcisions are the rituals and customs surrounding the ceremony, such as extensive travel and parties and feasts that may be associated with increased alcohol consumption, increased sexual activity, reduced in condom use and other high-risk behaviors among community members. In fact, some men in Africa have expressed the belief that circumcision will protect them fully from infection and therefore take the place of condoms and other protective behaviors. Thus, unless male circumcision is accompanied by effective HIV prevention counseling, it could lead to more HIV infections instead of fewer.^{24,27} Another little-discussed ethical policy issue relates to promoting male circumcision in communities where female genital cutting exists, which might seriously undermine efforts to eliminate this practice for women.²⁴

Implementing an intervention that provides male circumcision will likely require additional public health infrastructure and extensive educational efforts not only for people at risk, but also for policy makers, prevention program officials, medical staff and others involved in health care services.

RESEARCH NEEDED

Most scientists agree that randomized controlled trials are needed to explore these issues. But such studies raise problematic ethical issues. The issue of informed consent, particularly for minors, and the appropriateness of behavioral messages that are provided in the context of circumcision must be addressed. In addition, there may be no justification for offering circumcision to men of an age at which little or no protective effect has been demonstrated.²⁴ Research on attitudes toward male circumcision in

high-risk populations as well as studies of the practice among populations that currently have high rates of circumcision would probably be valuable first steps in determining the role of male circumcision in HIV prevention.²⁴ In addition, epidemiological and clinical studies are needed that can address the biological mechanisms that may increase the susceptibility of uncircumcised men to HIV infection and whether it is possible to educate people about male circumcision without increasing high-risk behaviors among circumcised men.²⁷

ORPHANS AND VULNERABLE CHILDREN: PROVIDING CARE AND PROTECTION

The large number of vulnerable children and those orphaned by AIDS presents an unprecedented challenge to governments, communities and families. In sub-Saharan Africa, there have been an estimated 12 million orphans—and this number will grow to at least 44 million children by 2010.²⁸ In addition, several million children who are not yet orphaned are socially and economically vulnerable due to parental separation, loss of employment, discrimination and chronic ill health of one or both parents as a result of HIV/AIDS.

Many challenges must be overcome to care for and protect orphans and vulnerable children (OVC) in heavily affected countries:

- The explosive increase in the number of OVC will continue in countries with high HIV prevalence, even if HIV incidence levels decline rapidly in the near future. We therefore have the important task of providing and caring for the existing OVC affected by the epidemic and supporting even greater numbers in the future.
- The loss of large numbers of the most productive members of society worsens an already high dependency ratio. As a consequence, a small proportion of healthy and productive adults have to support a much larger proportion of dependents, mostly children.

- The impact of orphanhood may persist for a number of generations. Orphaned children are more likely to become uneducated, unskilled and impoverished adults. Their children in turn are more likely to be further marginalized in a continuing vicious cycle. Many orphaned children are even more likely to become street children, at risk and vulnerable to physical, sexual and emotional abuse, exploitation, starvation, ill health, crime and early death.
- Orphaned children may themselves be infected or at high risk and vulnerable to HIV as well as other infectious diseases, such as TB. These children often face widespread stigma and discrimination as a result of their parents' infections or their own.

Providing care, protection, education and job skills for these children poses one of the most pressing challenges facing high HIV prevalence countries in Africa. It will require substantial financial resources from both government and international agencies and the commitment and support of local organizations and communities. Equally important is reducing the number of new orphans. This can be accomplished by reducing the rate of new HIV infections in the population and prolonging the lives of adults living with HIV/AIDS with effective treatment for HIV disease and opportunistic infections.

Unless we succeed in both our prevention as well as care and support for children affected by the epidemic, there will continue to be millions of children and youth who are emotionally damaged, physically at risk, and vulnerable, disadvantaged, uneducated and without hope or opportunity.

HUMAN RIGHTS: REDUCING STIGMA AND DISCRIMINATION

Populations already on the fringes of society are pushed even further from societal support as a result of HIV/AIDS.²⁹ Stigma and discrimination against those who are infected have characterized the HIV pandemic. HIV-infected women are often physically abused, ostracized and blamed for the infection of their sexual partners. Widespread abuse of the human rights of marginalized populations also puts them at higher risk of HIV infection. These groups are already stigmatized because of their perceived antisocial behavior. They include CSWs, IDUs, men who have sex with men (MSM) and prisoners.

The stigma associated with HIV/AIDS is often a result of multiple factors such as the shame associated with having contracted the virus; the fear of how other people will react; the fear of being discriminated against; and the actual discrimination experienced by individuals.²⁹ The perception of stigma may be as important as the actual discrimination experienced by PLHA.

The abuse of human rights of individuals with HIV infection:

- Stifles open communication about HIV/AIDS and contributes to the continued spread of the epidemic
- Prevents PLHA from accessing voluntary counseling and testing (VCT) services
- Prevents PLHA from disclosing their HIV status to family, friends or colleagues and benefiting from their support
- Prevents PLHA from seeking or obtaining employment
- Prevents PLHA from accessing health care and other services

Reduction and eventual elimination of HIV/AIDS-related stigma and discrimination are therefore critical challenges for the prevention of the virus and for the care and support of those already infected.

CONCLUSION

HIV/AIDS is a devastating human tragedy that challenges the limits of our science, our compassion for those who are less fortunate, our social and economic priorities and the value we place on human life in this global village. We have identified numerous challenges that we need to overcome if the world is to succeed in controlling the spread of HIV and minimizing its destructive impact on resource-constrained countries. The most important of these challenges are:

- The mobilization of substantial resources to control the further spread of HIV and provide treatment and hope for those who are infected and affected by AIDS.
- The development of a vaccine and a cure; and the improvement of the human rights of those at risk and vulnerable to HIV, including the reduction of the stigma and discrimination faced by those infected and affected by AIDS.

How well we meet these challenges will determine whether HIV/AIDS becomes a controllable and curable disease—or the Black Death of the 22nd century that destroys the hope and future of many countries.

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