



# INTEGRATING SOCIAL AND HEALTH CARE SERVICES FOR HIV-INFECTED INDIVIDUALS

*Review of Experience and Best Practices in the Baltic Sea Region*

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## ACRONYMS

<b>ART</b>	Anti-Retroviral Treatment
<b>CDPC</b>	Center for Disease Prevention and Control (Latvia)
<b>CSW</b>	Commercial Sex Workers
<b>ECDC</b>	European Center for Disease Prevention and Control
<b>GARPR</b>	Global AIDS Response Progress Reporting
<b>GFTAM</b>	Global Fund to Fight AIDS, Tuberculosis, and Malaria
<b>HCFC</b>	Social Help Centers for Families and Children
<b>IDU</b>	Injecting Drug User
<b>MARPs</b>	Most At-Risk Populations
<b>MDR</b>	Multi-Drug Resistant
<b>MSM</b>	Men Who Have Sex with Men
<b>NDPHS</b>	Northern Dimension in Public Health and Social Well-Being
<b>NGO</b>	Non-Government Organization
<b>OI</b>	Opportunistic Infections
<b>OST</b>	Opioid Substitution Therapy
<b>PLWH</b>	People Living with HIV
<b>SAA</b>	Social Assistance Agreement
<b>SRH</b>	Sexual and Reproductive Health
<b>TB</b>	Tuberculosis
<b>VCT</b>	Voluntary Counseling and Testing
<b>WHO</b>	World Health Organization
<b>XDR</b>	Extensive Drug Resistant

## EXECUTIVE SUMMARY

The following is a review of experiences and best practices in integrating social and health care services for PLWH in the NDPHS' countries. Its data-collection methods include (a) review of secondary data and background documents; (b) semi-structured interviews with key informants; (c) survey of national stakeholders-members of the NDPHS' Expert Group on HIV/AIDS and Associated Infections. The document highlights examples of successful cooperation among medical and non-medical institutions in this respect, identifies challenges and provides recommendations as to how to ensure that they address PLWH's needs to the extent possible.

Review of socio-demographic characteristics of PLWH in the NDPHS' countries suggests that they are likely to be interested in getting a range of social services, starting from assistance with employment to psychological counseling and child care. While social groups driving the HIV epidemic vary from country to country, most of them tend to belong to the disadvantaged segments of society. While males constitute the majority among HIV patients, in countries such as Estonia, Latvia, Norway, Russia and Sweden women account for about one-third of PLWH. Also noteworthy is that the absolute majority of registered HIV cases – from 81.0% in Poland to 85.8% in Lithuania – are below 40 years of age. These people need to secure stable sources of income for years to come.

Responses to the HIV epidemics in the Baltic Sea regions tend to follow the UNAIDS-recommended “Three Ones” principles, with national coordinating authority established, action framework adopted and country-level M&E system being put in place. However, in Russia the Federal Government disbanded its HIV coordinating structure in July 2012 and the absence of the national strategy to respond to HIV/AIDS was one of the highlights of the discussion held at the Chamber of Public in March 2012.

As to specific forms of integrated social and medical services for PLWH in the NDPHS' countries, the results of the survey conducted among members of the NDPHS' Expert Group on HIV/AIDS and associated infections suggest that sites providing these services in integrated fashion have been set up, practically, in every country of the region. Typically, it is *psychological and social support* that PLWH receive in combination with ART. Psychological counseling is available for PLWH in Estonia, Finland, Latvia, Norway, Poland, Russia and Sweden. Quite often it is provided by social workers at the HIV treatment clinics and/or as a part of case management so that psychological counseling tends to be supplemented by provision of references to health insurance agency, employment office, education department and housing authority.

There are numerous examples of government agencies providing financial support to NGOs who deliver social services to PLWH. For example, in Latvia there are 18 *HIV counseling points* that provide medical and social services to MARPs and PLWH. Their range of services includes psychological counseling, referrals to medical specialists and social workers, as well as OST. At the same time, PLWH are not always involved in evaluating quality of the services they receive.

The review also contains description of specific forms of integrated services provided to PLWH in the region and recommendations to promote delivery of these services:

1. To ensure optimal use of limited resources, provision of integrated social and medical services has to be premised on empirical assessment of the PLWH's needs and priorities. To minimize costs, needs assessment among PLWH can be conducted on the basis of existing institutions providing these services. Where possible, external agencies can be invited to direct these studies in an attempt to ensure unbiased answers from respondents.
2. Once PLWHs' needs for integrated social and medical services are identified, the respective planning exercise involving national stakeholders can be conducted. Its agenda will include identification of

financial resources required to reach the effective coverage with integrated services as well as their ranking in terms of their impact on the HIV epidemic and socioeconomic well-being of PLWH. Given that the amount of support provided by international donors for HIV-related programs is shrinking, a similar exercise can be conducted at the regional level to identify alternative funding sources for countries like Latvia or Russia where the exit of international agencies is unlikely to be compensated by the increase of funding from federal, regional or municipal budgets.

3. To promote provision of integrated services and to contribute to the reduction of stigmatization of PLWH, a review of policies regulating their provision and access to them in the Baltic Sea region can be conducted. The review has to address issues like limits on the number of medical services a patient can receive per day set by the National Insurance Funds in some countries. Also, it has to involve analysis of regulatory barriers for social groups like migrants to access medical and social services and to contain recommendations on how to remove or modify them in order to minimize stigmatization.
4. In light of substantial scale of the HIV/TB co-infection in the region and the emergence of MDR/XDR-resistant strains of TB, links among treatment services for HIV and TB have to be promoted. Depending on local conditions, this cooperation can be premised on either of the four models suggested by the WHO (2012), starting from entry via TB service and referral for HIV testing to TB and HIV services provided at a single facility (“one-stop service”). Introducing drug treatment and case management services in TB dispensaries is also a priority.
5. Given higher rates of TB observed in prisons, current and former inmates released into the community deserve special focus. To ensure continuity in treatment, links between medical services inside and outside of prison system have to be promoted, especially when it comes to sharing medical records on the to-be-released inmates. As considerable number of them end up getting settled in the area around prisons, NGOs/GOs offering social assistance to former inmates there should be supported.
6. Economically-disadvantaged status of many PLWH also suggests promoting professional training, career counseling and employment services among them. This is in addition to traditional forms of social assistance such as subsidized housing, transportation and child care provided to PLWHA.
7. Prevalence of emotional disorders requires expanding mental health, prevention of substance abuse and psychological support programs among PLWH in general and MSM in particular.
8. Discriminatory attitudes among service providers toward PLWH, as revealed by studies conducted in several countries of the region, makes it necessary to promote educational programs aimed at increasing familiarity with HIV transmission routes, HIV-related legislation among medical staff.
9. Assessment of quality of social and medical services provided to PLWH has to rely on formal instruments and be conducted on regular basis. It is also recommended to involve clients in assessing the quality of social and medical services they receive. This can be done through conducting surveys among them on regular basis or by soliciting feedback upon them getting the respective service.
10. In some countries, there are high turnover rates among policy-makers at the ministerial level resulting in inconsistencies in health and social welfare policies. This requires implementing regular advocacy campaigns aimed at promoting their support for provision of integrated services.

## 1. INTRODUCTION

National systems of medical and social services in the Baltic Sea countries accumulated rich experience in providing treatment, care and support for people living with HIV (PLWH) which in many respects remains unique and unsurpassed. The fact that some countries of this region, like Finland, feature lowest rates of HIV prevalence in the world (*Report on the Global AIDS Epidemic, 2010*) testifies to the effectiveness of their models of service delivery to those at risk of HIV infection or affected by the disease. Yet despite these achievements, dealing with HIV and its social ramifications still remains a challenge, as indicated by the recent increase in the number of registered HIV cases even in the low-prevalence countries of the region. Furthermore, the region also includes countries such as Estonia and Russia where HIV is estimated to affect over 1.0% of those 15-49 years of age, the fact that suggests that some of their previous HIV-related policies were ineffective and need to be updated (*Report on the Global AIDS Epidemic, 2010*).

Also of importance is the growing number of tuberculosis (TB) patients among PLWH including those who develop drug-resistant forms of TB. As most of these patients come from the socially-disadvantaged groups of population, ensuring their effective treatment requires close coordination between medical and social services in the respective countries. This requirement is reinforced by socio-demographic characteristics of PLWH most of whom are of working age and/or migrant status so that the outcome of their treatment very much depends on their being integrated into broader society through employment, participation into various social activities of the country-host, and maintaining stability of their families. Effective responding to these recent trends in the development of the HIV epidemic in the Baltic Sea region calls for promoting integration of medical and social welfare services, with the ultimate objective of their being not only evidence-based, accessible, patient-centred, and safe but also ensuring support for PLWH at different stages along the continuum of care.

As a reflection of these priorities, NDPHS Expert Group on HIV/AIDS and Associated Infections commissioned a review of evidence-based experiences and best practices in integrating social and health care services for PLWH in the respective countries. Developing this Review is in line with the following cooperative action included in the health sub-area of the Priority Area 12 of the EU Strategy for the Baltic Sea Region Action Plan: Health: “Contain the spread of HIV/AIDS and tuberculosis through partnerships and international collaboration in prompt and quality care for all, focusing on Tuberculosis/HIV co-infection and ensuring early diagnosis of HIV infections, providing access to treatment and strengthening interventions to reduce vulnerability especially for Injecting Drug Users (IDU), prisoners, etc”. Among expected outcomes of this exercise are policy recommendations on improving coverage of most-at-risk groups to be shared with countries-partners. The funding for conducting this review is provided by *DG Regio*.

## **2. METHODOLOGY**

### **2.1. DATA COLLECTION METHODS**

This review is premised on a combination of data-collection methods including (a) *review of secondary data and background documents*; (b) *semi-structured interviews with key informants*; c) *survey of national stakeholders-members of the NDPHS Expert Group on HIV/AIDS and Associated Infections*.

#### **(a) Review of Secondary Data and Background Documents**

Most of statistical data as well as references to coordination mechanisms and HIV response strategies come from Progress Reports submitted by the respective countries within the framework of the Global AIDS Response Progress Reporting (GARPR) in 2012. In cases of Norway and Russia who did not submit Country Progress Reports in 2012, the HIV statistics come from the respective documents submitted in 2010 as well as from the 2011 Information Bulletin published by the Federal AIDS Center in Russia. Also included in the review were publications on epidemiological trends in Europe produced by the European Center for Disease Prevention and Control and Prevention (ECDC) as well as case studies and projects' overviews developed by GO/NGO-partners from the Baltic Sea countries. For a complete list of References, please see Annex A.

#### **(b) Semi-Structured Interviews with Key Informant**

In July and September of 2012 interviews with key informants were conducted in Latvia, Poland and Russia during site visits to these countries. Interviews were premised on the selected items from the questionnaire developed for survey of members of the NDPHS Expert Group on HIV/AIDS and Associated Infections. The staff of national/regional institutions in charge of policy implementation on HIV-related issues nominated stakeholders and arranged interviews with them. Typically, among interviewees were representatives of medical institutions, social services and NGOs providing treatment, care and support for PLWH. Some of them were selected based on the references made by respondents in survey of national stakeholders. The complete list of persons interviewed is included in Annex B. In Annex C one can find outlines summarizing findings from respective site visits.

#### **(c) Survey of Members of the NDPHS Expert Group on HIV/AIDS and Associated Infections**

With inputs from the Lead Partner, the instrument focused on the availability of integrated medical and social services for PLWH, their range, organizational arrangements and funding was developed and distributed among members of the NDPHS Expert Group on HIV/AIDS and associated infections, both in English and Russian. The instrument also included requests to respondents to identify challenges in providing integrated services as well as possible ways to address them. A copy of the questionnaire is available for review in Annex D. Representatives from 9 countries completed the instrument, with their responses being presented in the respective sections of this report. Due to the non-representative nature of this sample, we did not submit the collected data for statistical analysis, using them instead to triangulate information collected from other data sources or to select key informants in the respective countries.



## 2.2.DEFINING “INTEGRATION OF HIV SERVICES”

Research literature contains numerous references to “integration of services” and “models for service provision” when it comes to HIV prevention, treatment, care and support (e.g., Janssen *et al*; *HIV Model of Care*). While discussing theoretical underpinnings of these models and, moreover, their relative strengths and weaknesses is beyond the scope of this review, it is important to note that their development tends to be motivated by the need to concentrate limited resources on those most in need of preventive and treatment services thereby maximizing cost-effectiveness of the response to HIV. Developing models of service provision also involves outlining roles and responsibilities of government and non-government sectors in providing HIV-related services to ensure their high quality and – more importantly - their ability to meet both the clinical and non-clinical needs of PLWH that are changing over time. Symptomatic in this respect is how the objective is defined in one of these modelling exercises: “to ensure support for PLWH at different stages along the continuum of care” (*HIV Model of Care*). More generally, Kodner and Spreeuwenberg define “integration” as “a series of methods and models at the financial, administrative, organizational, clinical and service levels aimed at ensuring interconnection and coordination within as well as between medical and social spheres. The objective of these models and methods is to improve the quality of medical care and one’s quality of life, contributing to the patient’s satisfaction and effectiveness of treatment, especially when it comes to people with complex and long-term problems that require involving several institutions, services and observing various parameters” (Kodner and Spreeuwenberg, 2002).

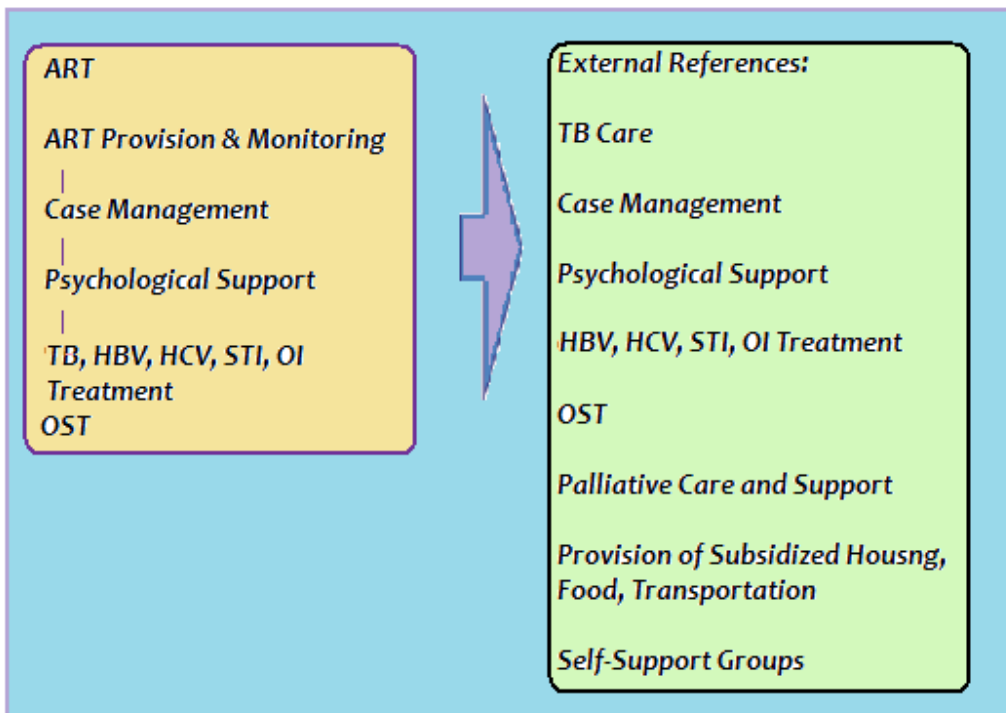
Keeping this objective in mind, one can state that the available empirical evidence indicates that integrated services can have a positive impact on client satisfaction, improve access to component services, reduce clinic-based HIV-related stigma, and that they are cost-effective (for review of respective studies see Church and Mayhew, 2009). However, at least with respect to integrating HIV and sexual and reproductive health (SRH) services, the same authors admit lack of controls and experimental design when integrated models are evaluated so that the available evidence related to their impact on health outcomes and cost-effectiveness needs to be strengthened (Mayhew, Church, Colombini, 2010). The challenges related to conducting respective evaluations are underscored by the fact that their own investigation of whether integrating HIV and SRH services is an effective model of health care for HIV patients through a comparative analysis of integrated and stand-alone HIV service delivery models was inconclusive. As they admit, due to a cross-sectional design with a very small sample of clinics, “we are not able to ascertain integration effectiveness with certainty” (Church *et al*, 2011).

Despite these methodological difficulties, the assumption that addressing related medical problems as well as non-clinical needs of PLWHs affects their HIV treatment outcomes has face value, as these services are focused on the same individual so that their outcomes can potentially reinforce one another. Accordingly, providing them in the integrated fashion promotes the timeliness of their delivery as well as coordination between them and allows to reduce transaction costs. Yet even with this proposition being accepted, the notion of “integration” has been applied to various forms of cooperation among medical and social welfare institutions, starting with one provider offering a full range of services (“room-level” or “provider-level” integration) as well as to clients being referred to a more specialized provider for within the same facility (“facility-level” integration) or to services provided by other organizations operating in the community (“community-level” integration). In

part, these differences in service configuration are reflective of variations in health care structures and capacities as well as in broader socio-political context that exist in the respective countries so that assessing their effectiveness in addressing PLWH's needs has to be done against this background. Furthermore, distinctions were also made between *active*, i.e.provider-driven and *responsive* (client-driven) (Maharaj & Cleland, 2005) as well as *functional* and *organisational* integration (Lush et al., 2001; Fleischman, 2006). Having completed a review of the respective literature, some scholars came to the conclusion that (1)“integration” has no consistent definition; (2) isolating the integration effect from other programmatic activities/interventions virtually impossible; and (3) isolation of the complex structure of health services & programmes inhibits measurement of specific models (Mayhew, Church and Colombini, 2011)

In light of these debates related to the conceptualization of “integrated services”, our approach is to premise the analysis on the minimal common denominator even if it means trading depth for breadth. In other words, by “*integration*” we mean referral systems through which medical and social services are offered in combination to the same set of PLWH. By “*services*” we mean both facility-based services or services provided through community workers. They can be provided in the same or different facilities in the coordinated fashion. Coordinating bodies may be government agencies, medical institutions as well as NGOs. Ultimately, their integration should be aimed at improving PLWH's access to treatment, care and support, increasing their quality and cost-effectiveness. Some of these services such as ART and treatment for OIs or ART and case management can be provided in the same medical facility. However, depending on the local context, medical institutions can also refer PLWH to external organizations for clinical services such as TB, hepatitis, OIs and STI treatment, as well as non-clinical ones including case management and psychological counseling.

**Figure 1. Integration of Medical and Social Services : Graphical Representation**



At the same time palliative care and community-based support including provision of subsidized housing, food, transportation and child care can be provided by non-medical organizations only. In Figure 1 we provide a tentative list of these services while highlighting the central role of referral mechanisms in our conceptualization of their being integrated.

### **2.3. LIMITATIONS**

While the non-random design of this review leads to inevitable **selection bias**, i.e. those respondents who choose to be interviewed or complete the survey might differ from those who do not in terms of their attitudes and perceptions, affiliation with government/non-government structures, socio-demographic characteristics and experience. Furthermore, since a number of questions raised during the interviews dealt with issues that took place in the past, there is a possibility of respondent **recall bias**. An additional complication is that some questions called upon the respondents to assess performance of their colleagues or people on whom they depend upon for the provision of services.

Overshadowing the impact of the possible sources of bias mentioned above is the **limited availability** of key stakeholders involved in the provision of medical and social to PLWH for interviewing. Understandably, implementing their direct responsibilities and – in case of NGOs, ensuring financial support for their services – leaves little time for these people to discuss service provision in theoretical format. Furthermore, most of data collection for this project took place during summer months, the period of holidays and vacations. Some of the organizations providing services relevant for this review do not cooperate with NDPHS directly so that getting feedback from them also turned out to be problematic as they perceived these requests as coming from “outsiders”. For example, the NGO *Aksept* in Norway provides such services as “open house,” i.e. a meeting place for PLWH and “outpatient department” offering individual and group counselling as well as alternative forms of therapy. While these services do appear highly relevant for this review, our attempts to contact these colleagues for details were not successful. Likewise there was limited feedback from organizations specializing on hepatitis or STI treatment or providing services for PLWH released from prisons. Given these limitations, the document does not claim to be a comprehensive review of social and medical services provided to PLWH in the NDPHS’ countries. Rather, it highlights examples of successful cooperation among medical and non-medical institutions in this respect, identifies challenges and provides recommendations as to how to ensure that they address PLWH’s needs to the extent possible.

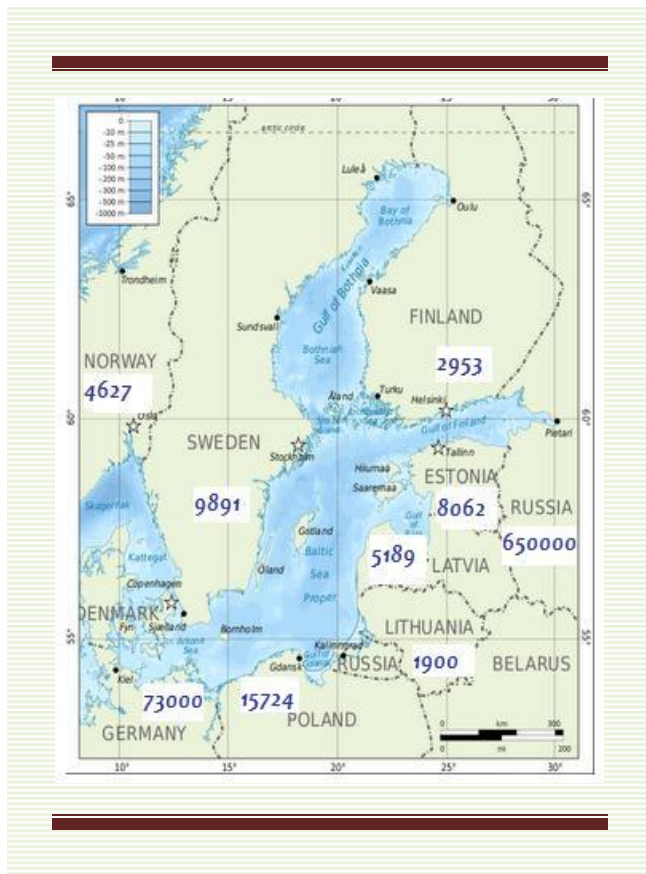
### 3. BACKGROUND: HIV TRENDS IN THE BALTIC SEA COUNTRIES

#### 3.1. NUMBER AND SOCIO-DEMOGRAPHIC PROFILE OF PLWH

There are a number of statistical measures one can rely on when describing the epidemiological situation in a specific country or region. Among them are *prevalence* rate or the proportion of people in a population who have a particular disease at a specified period of time and *incidence* rate that refers only to the new cases of disease registered over a certain period. While these measures capture the burden of chronic disease such as HIV in a population, they do not provide information as to how many patients need medical and social services, what their socio-demographic profile is and what specific HIV-related services they may require. Taking into account that the objective of this review is to describe experiences and best practices in integrating social and health care services for PLWH, it is more appropriate to premise the overview of the HIV situation in the Baltic Sea region on the number of officially registered HIV cases. As a rule, registration of HIV case involves collecting background information from the patient including his or her gender, age, employment status and place of residence. Based on this information, it is possible to make projections as to what type of medical and social support HIV patients may require in the short- and medium-term perspective. Furthermore, registration of HIV case by medical institution indicates that the respective patient is eligible for government or insurance coverage so that this statistics tends to be employed by government structures when allocating resources among treatment facilities, welfare institutions and NGOs providing services to PLWH.

**Figure 2. Cumulative Number of Registered HIV Cases in the Baltic Sea Countries**

Source: GARPR, 2012. Germany reported estimated number of HIV cases



In this respect the above-mentioned measure differs from the *estimates* of the number of HIV cases: while highlighting the extent to which the respective PLWHs' needs are unmet, the latter are rarely used as a basis for resource allocation with respect to HIV. Moreover, cross-country comparisons premised on the number of estimated cases can be problematic due to different methodologies being employed in the respective modelling exercises.

For these reasons, our description of the HIV situation in the Baltic Sea region relies on the number of registered HIV cases, as reported by the respective countries within the framework of the GARPR, 2012 (Figure 1). As already mentioned, the exceptions are Estonia, Norway and Russia for whom we used data from other publications on their HIV policies (Estonia:

[http://www.euro.who.int/data/assets/pdf\\_file/0020/1/55630/e96096.pdf](http://www.euro.who.int/data/assets/pdf_file/0020/1/55630/e96096.pdf);

Norway:<http://www.fhi.no/eway/>; Russia:

<http://www.oprf.ru/ru/press/news/2012/newsitem/1>

[7200?PHPSESSID=h2g7u1k4c76ub2c6ut1cjept11](#)). In terms of number of registered HIV cases, the most serious situation is in Russia where over 650,000 PLWH have been registered since the start of the epidemic in 1986. While the majority of these cases are registered outside of Russian regions bordering on the Baltic Sea, still Leningrad and Kaliningrad oblasts are listed among the most HIV-affected areas of Russia (Federal AIDS Center, 2011). As of May 2012, the number of PLWH registered in the city of St Petersburg alone stood at 49,942 (<http://hivrussia.ru/stat/2012.shtml>), far exceeding the respective number for some Baltic Sea countries of similar population size. The burden of this disease (8,062 registered cases) is also quite heavy in Estonia where most infections occur in north-eastern regions of the country and Tallinn, the capital city. In neighboring Latvia the majority of 5,187 HIV patients were also registered in the national capital Riga. Specifically, in 2011 close to 70% of new registrations occurred in this city. Sizeable PLWH communities emerged in Germany and Poland (73,000 and 15,724 registered HIV patients, respectively). Among Scandinavian countries, there is a significant number of PLWH in Sweden (total number of cases is 9,891 among them 5,800 lived in the country as of 2011), with over 70% of infections being registered among foreign-born residents of the country in 2010 and 2011. In Norway, too, the immigrants are listed among contributors to the rise of annual registrations of HIV cases, up from 150 cases in the 90s to almost 300 cases in 2008 (*UNGASS Country Progress Report, 2010*). As of January 1, 2011, 35.4% of the total number of HIV cases registered in this country were linked to heterosexual transmission that had occurred before the patient's arrival in Norway. While in Finland the size of PLWH community (2,953 diagnosed cases) is relatively modest, the impact of migration on the HIV epidemic is reported there as well.

In addition to the totals of PLWH registered in the respective countries, also of interest are trends in the number of annual registrations, groups that are at-risk of infection and their socio-demographic characteristics of HIV patients as these data point to the needs that PLWH are likely to have. In Table 1 below we indicate directions of these trends in 2010-2012 treating annual changes of less than 1% of the total number of HIV registrations in the country as "slight". Admittedly, in all Baltic Sea countries trends in annual registrations of HIV cases were subject to fluctuations over the past 10 years so that highlighting their direction in the past two years has limited predictive power. At the same time these fluctuations - that turn out to be in the upward direction in 4 out of 9 countries included in this review- suggest that in no Baltic Sea country the HIV epidemic is reversed. Furthermore, they also suggest that national HIV response can be effective only to a certain extent as even some Scandinavian countries experience the rise in HIV infections due to the arrival of immigrants from high-prevalence areas such as South-East Asia. Also to be noted is that the most significant increase is in Russia where 62,000 HIV cases (9.5% of their total number) were registered in 2011.

As to most-at-risk populations, their composition varies from country to country with MSM spearheading the trend in Scandinavia and Germany, while IDUs driving the epidemic in Estonia, Latvia, Lithuania and Russia. Blood-borne transmission through unsafe injections of drugs is also a factor in promoting the HIV epidemic, Germany, Finland, Norway and Sweden. At the same time in all Baltic Sea region countries heterosexual transmission is playing more and more prominent role in recent years, with Poland being the example of this trend. While



**Table 1: Overview of the HIV Epidemics in the Baltic Sea Countries**

COUNTRY	TREND IN ANNUAL REGISTRATION OF HIV CASES (2010/2012)	POPULATIONS AT RISK OF HIV INFECTION	MALE/FEMALE	
			%	%
<b>1. Estonia</b>	Slight decrease	IDUs and their sexual partners, CSWs	62	38
<b>2. Finland</b>	Slight decrease	MSM, IDUs, migrants	72	28
<b>3. Germany</b>	Slight increase	MSM, heterosexual transmission, migrants	81	19
<b>4. Latvia</b>	Slight increase	IDUs, heterosexual transmission, MSM	68	32
<b>5. Lithuania</b>	Slight increase	IDUs, heterosexual transmission, MSM	80	20
<b>6. Norway</b>	Slight decrease	MSM, heterosexual transmission (migrants), IDUs	67	33
<b>7. Poland</b>	Slight increase	MSM, heterosexual transmission, IDUs	75	25
<b>8. Russia</b>	Increase	IDUs, Heterosexual transmission, MSM	65	35
<b>9. Sweden</b>	Slight decrease	MSM, migrants, IDUs	61	39*

\*2010/2011 data

Source: GARRPs , 2012

pinpointing specific social groups that suffer the most as a result of heterosexual transmission of HIV is a challenge, the available data from Norway and Sweden suggest that migrants are particularly affected in this respect. In Germany, Finland, Norway and Sweden, at least, a half of them were actually infected in their home countries before arriving for permanent residence in Europe. In any case, their current migrant status implies that much like IDUs they are likely to belong to the disadvantaged social groups.

Reflecting the fact that for many years the HIV epidemic in the Baltic Sea countries was driven by IDUs and MSM, males constitute the majority among HIV patients across the board. At the same

time in countries such as Estonia, Latvia, Norway, Russia and Sweden women account for about one-third of PLWH. For example, in Estonia in early 2000s women accounted for 20% of new registrations, while in 2009 the respective number was 40%.

Also noteworthy is that the absolute majority among registered HIV cases – from 81.0% in Poland to 85.8% in Lithuania – are below 40 years of age. This means that these people either enter or are in the middle of their professional careers and family life. They are likely to have dependents and, therefore, need to secure stable sources of income for years to come. For this reason their interests and needs are likely to extend beyond those disease-related and include career counseling and professional training, family planning, psychological support and social assistance such as provision of subsidized housing, transportation, enrollment in food programs, etc.

Another indication of the need for providing integrated services to PLWH is the growing number of patients co-infected with HIV and TB. In Estonia the percentage of PLWH among TB patients went up from 7% in 2005 to 10% in 2010 while the share of MDR-TB cases also increased during this period. HIV/TB co-infection presents a serious problem in the Baltic provinces of Russia as well.

### **3.2. AVAILABILITY OF ANTI-RETROVIRAL TREATMENT (ART)**

ART is one of the most important medical services that allows PLWH to maintain their immune system and health in general. Also of relevance is that facilities providing ART tend to be points of contacts through which PLWH receive references to other health care and social services. In countries like Latvia and Poland staff of these facilities include social workers whose task is to promote patients' adherence to ART through ensuring that the latter receive psychological counseling, references to supporting medical services such as opioid substitution therapy (OST) programs and are provided with proper documents including health insurance or registration at the employment office. In other words, job responsibilities of social workers boil down to ensuring that medical and social services for PLWH are provided in integrated fashion. For these reasons the number of PLWH on ART is also indicative of the extent of their inclusion into broader network of medical and social services.

In general, ART in the Baltic Sea region is covered through public funds or national health insurance plans and provided at no cost to PLWH who have legal status in the respective country. However, ART coverage rates vary from country to country, with the highest being in Poland where this treatment is available to 100% of PLWH with appropriate clinical indications, Sweden (98%) and Germany (85-90%). On the other hand, in some countries the demand for ART outstrips the capacities of health care systems, with 66% of patients with advanced HIV infection receiving antiretroviral therapy in Lithuania and every third eligible patient getting this treatment in Estonia in 2008. Availability of ART is also affected by different definitions of the level of CD4 cell counts at which treatment should start in national treatment protocols and guidelines. While the respective Swedish or Finnish documents set it at 350, in Latvia it is only below 200 meaning that some of their PLWH who would have received ART if they were Swedish or Finnish legal residents are not eligible for it in their home country.

In Russia ART also is available to PLWH, with national estimates putting it at 96% of those at the

advanced stage of the disease (*2010 Country Progress Report*), with this rate being confirmed for PLWH in St Petersburg as well. According to Russian regulations, ART is prescribed to patients with CD4 cell count below 350, yet in making this decision physicians take into account the patient's general state of health so ART can be prescribed even when CD4 cell count is above the cut-off point (Pokrovsky et al, 2011). However, the actual availability of ARV drugs across Russia is still subject to discussions, as reports of them being in short supply emerged during the hearings on HIV response held at the Chamber of Public

(<http://www.oprf.ru/ru/press/news/2012/newsitem/17200?PHPSESSID=falslsa7uh2m6ggmst4kdchi01>).

The 2011 UNAIDS/WHO Progress Report on the HIV/AIDS situation in Eastern Europe and Central Asia also points to problems with supply of ARV drugs in a number of the countries in the Baltic Sea region: "Interrupting antiretroviral therapy endangers the survival of people living with HIV and is a major concern in the east of the region especially. Weakness in supply-chain management systems, including poor planning and late procurement, have led to shortages of HIV medicines and other commodities, leading to stock-outs and interrupted treatment regimens. The Russian Federation has experienced significant interruptions to treatment regimens, and short-term interruptions have also been registered in Latvia, Romania and Ukraine." In other words, despite the official statistics indicating high ART coverage, the actual situation with availability of anti-retroviral drugs needs to be monitored across the region as shrinking health care budgets may result in interruptions of supply becoming more and more frequent.

### **3.3. NATIONAL RESPONSES TO THE HIV EPIDEMIC**

Responses to the HIV epidemics in the Baltic Sea regions tend to follow the UNAIDS-recommended "Three Ones" principles, with national coordinating authority established, action framework adopted and country-level M&E system being put in place. Structural characteristics of national responses to HIV are summarized in Table 2. The country-level Coordinating Authority for HIV with broad inter-sectoral representation was established everywhere in the region. In Estonia it is called the "*Multisectoral HIV and AIDS Committee*" and includes representatives of the Ministries of Social Affairs, Education and Research, Justice, Defence and Interior, as well as those from municipalities, PLWH and the youth organizations' union. In Norway, the Inter-ministerial Steering Group chaired by the Ministry of Health and Care Services and comprising representatives of six different ministries is charged with implementation of the *National HIV Strategy*. At the same time in Poland it is the National AIDS Centre which has been made responsible for coordinating activities linked to the implementation of the *National Programme for Combating AIDS and Preventing HIV Infections for 2012-2016*. In Sweden the National Coordination of HIV and STI Prevention Unit was established at the Swedish Institute for Communicable Disease Control (SMI), the agency entrusted with implementation of the *National Strategy to Combat HIV/AIDS and Certain Other Communicable Diseases* adopted by the Swedish Parliament. In Finland, Latvia and Lithuania there are legal provisions for representatives of non-government organizations (NGOs) being included in national coordination structures alongside their colleagues representing Ministries of Health, Justice, Education and Defence. In Lithuania they constitute one-third of the *National HIV/AIDS and STI Prevention and Control Programme Coordination Board* and are invited to participate in every HIV/AIDS related official event. Against this backdrop, it is the situation in Russia where the *Federal Commission on HIV Prevention, Diagnostic and Treatment* was disbanded on July 23, 2012 that does not fit the general pattern. However, even after this development the country still retains the *Coordination Council on HIV/AIDS* under the Ministry of Health.



**Table 2: Characteristics of National Responses to the HIV Epidemics**

COUNTRY	NATIONAL COORDINATION STRUCTURE ESTABLISHED	NATIONAL HIV RESPONSE STRATEGY ADOPTED	LOCAL SELF-GOVERNMENT INVOLVED IN HIV RESPONSE	GOVERNMENT FUNDING FOR NGOS PROVIDED
<b>1. Estonia</b>	Yes	Yes	Yes	Yes
<b>2. Finland</b>	Yes	Being developed	Yes	Yes
<b>3. Germany</b>	Yes	Yes	Yes	Yes
<b>4. Latvia</b>	Yes	Yes	Yes	Yes
<b>5. Lithuania</b>	Yes	Yes (expires in 2012)	Yes	
<b>6. Norway</b>	Yes	Yes	Yes	Yes
<b>7. Poland</b>	Yes	Yes	Yes	Yes
<b>8. Russia</b>	Yes	No	Yes	No
<b>9. Sweden</b>	Yes	Yes	Yes	Yes

\*under 29 yrs of age in 2010

\*\*Data as of Jan 1, 2011

Source: GARPRs (2012)

National HIV/AIDS response programs were adopted across the region, with Finland and Lithuania being in the process of updating their strategies. All of them involve contributions not only from the Ministry of Health but also from non-medical structures including NGOs. For example, in Poland the National Strategy was elaborated with the participation of all related Ministries, local authorities, experts representing various sectors as well as PLWH. Some programs require the agencies involved

to deliver HIV-related services in integrated fashion. For example, the National Strategy to Combat HIV/AIDS and Certain Other Communicable Diseases adopted in Sweden provides for close cooperation and coordination across sectors, both government organizations and NGOs. In Finland, Germany, Latvia, Norway, Poland, and Sweden inter-sectoral cooperation extends to government structures providing funding for NGOs who deliver HIV prevention, care and support services.

On the other hand, in Russia the respective programs have been developed at regional level while their national counterparts are missing. For example, in St Petersburg HIV-related activities are guided by the HIV/AIDS Response Program, 2009-2012. Yet, when discussing national action framework, the 2010 Country Progress Report submitted by Russia refers to policy documents such as “*The Strategy for National Security of Russia, 2009-2020*” where HIV is just mentioned among other communicable diseases as posing potential threat to public health. No specifications with respect to objectives, actions and implementing partners in the HIV/AIDS area are provided in this policy document. In fact, the absence of national strategy to respond to HIV/AIDS was one of the highlights of the discussion held at the Chamber of Public held in March 2012. There it was also revealed that the effective model of collaboration between government agencies and NGOs in the country is missing.

Local self-government is an integral part of HIV response in the Baltic Sea countries whose contribution varies from maintaining network of primary health care facilities and arranging social and medical care for PLWH at the advanced stages of the disease to cost-sharing of NGOs’ activities aimed at HIV prevention, testing (VCT) and support for PLWH in local communities. In Finland and Norway, for example, it is the municipalities who are required to ensure provision of health care services to their residents while regional health authorities arrange delivery of specialized medical help, both inside and outside of secondary care facilities. In these countries municipal health care services fulfill the basics of HIV work, but civil societies has a strong role in preventive HIV work with special groups like MSM and immigrants. In Latvia local authorities support operation of the NGO-managed 18 *HIV Counseling points* by providing premises and covering their staff costs. In addition to distributing information on HIV prevention, syringes and condoms, these units also run OST programs. However, relying on NGOs to deliver HIV-related services has a flipside: it is noted in the 2012 UNGASS Country Progress Report from Finland that “engaging civil society actors in HIV work may lead to a situation that municipal authorities no longer consider HIV work as part of their regular services.”

## 4. BEST PRACTICES OF INTEGRATED SOCIAL AND HEALTH CARE SERVICES

### 4.1. REVIEW OF SURVEY RESULTS ON INTEGRATED SERVICES IN THE NDPHS' COUNTRIES

We begin the discussion of integrated social and medical services for PLWH in the NDPHS' countries by reviewing the results of the survey conducted among members of the NDPHS' Expert Group on HIV/AIDS and associated infections. In June 2012 the respective instrument was distributed among them, with representatives of 9 countries of the region having the questionnaire completed. While the non-random design of this exercise means that one cannot treat the obtained results as representing the most accurate and complete summary reflecting the provision of integrated services in the Baltic Sea area, still they give one an idea of what most typical of them are and provide a context for discussing specific forms of their integration.

#### (a) Availability of Integrated Medical and Social Services

Starting with availability of integrated medical and social services for PLWH, one can state that sites providing these services in integrated fashion have been set up, practically, in every country of the region. When responding to the question as to whether integrated medical and social services are provided for PLWH in their country, representatives of Estonia, Finland, Latvia, Norway, Poland, Russia, and Sweden answered affirmatively. The only exception in this respect is Lithuania from where a negative response was received. Note that the above-mentioned survey question did not ask if these services were provided throughout the country or that they were available to all PLWH who needed them. It is not surprising then that both positive and negative responses came from different sites in Russia. At the same time getting these conflicting responses indicates that there is regional variation in the availability of integrated services in the countries included in the Northern Dimension Partnership.

#### (b) Integrated Services Provided to PLWH

As to the range of services provided in the integrated fashion, in the majority of countries surveyed it is *psychological and social support* that PLWH most often receive in combination with ART. Psychological counseling is available for PLWH in Estonia, Finland, Latvia, Norway, Poland, Russia and Sweden. Quite often, it is provided by social workers at the HIV treatment clinics and/or as a part of case management so that psychological counseling tends to be supplemented by provision of references to health insurance agency, employment office, education department and housing authority. For example, in Poland social workers at the Centers for HIV arrange medical insurance for those PLWH who do not have one, provide them with assistance in finding shelter, distribute food packages, condoms, and syringes among PLWH, as well as refer drug users among PLWH to rehabilitation services.

Social support is provided to PLWH in Estonia, Finland, Latvia, Norway, Poland, Russia and Sweden. Specific responsibilities of social workers attached to HIV treatment clinics vary from country to country: while in Scandinavia these employees, essentially, serve as intermediaries between systems of medical and social help with their function being to provide appropriate referrals, in countries like Latvia, Poland and Russia social workers play a more active role by

providing counseling to their patients and, if necessary, negotiating with government agencies on behalf of the latter.

Some clarification is necessary here as the term “social worker“ is quite broad covering both public servants based in medical facilities and welfare institutions as well as NGO staff or even priests who can provide psychological and other support, either as a part of community-based service or be attached to hospitals. For example, in Estonia social workers included in the personnel of the *Merimetsa Infectious Diseases Center* are public service employees. The same applies to staff of infectious diseases clinics in Norway and Sweden. In Latvia, on the other hand, a number of counselors and case managers are employed by NGOs such as DIA+LOGS and the Latvian Red Cross while there is also a position of social worker at the public institution - Center for Disease Prevention and Control (CDPC). Finland, too, has this combination when some social workers are employed by units of national or local government while others are affiliated with NGOs. Russia gravitates toward this end of the spectrum as social workers providing services to PLWH come from both government structures and NGOs. However, in Russia these organizational arrangements bear regional imprint so that experience of St Petersburg where city budget funds social workers providing services through Social Help Centers for Families and Children (HCFC) does not necessarily apply to other municipalities or provinces. Referring to the experience of neighboring province, one key informant in St Petersburg mentioned that there social services for PLWH are available only upon the patient getting disability status.

### **Center for IDUs in Helsinki**

*The centre offers all IDUs needle and syringe exchange, healthcare counselling, HIV testing and vaccinations. Additionally, the centre offers HIV positive IDUs food, washing facilities, short term accommodation, social work services, supportive housing, methadone maintenance, HIV antiretroviral therapy and other medication. Psychosocial support and rehabilitation are tailored to individual needs. There are weekly meetings, social activities and outings where both staff and service users take part. The centre also operates a mobile health unit, which complements its health counselling services. When needed, IDUs are referred to drug addiction treatment services, acute hospital or psychiatric care.*

*The centre creates a warm and inclusive environment where the service users feel safe. ....The programme is financed jointly by the Health Department and the Social Services Department of Helsinki and the neighbouring cities*

**(Respondent from Finland)**

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Needless to say that differences in institutional affiliation of social workers manifest themselves in their having different mandates and responsibilities: while social workers attached to government-run facilities provide assistance to specific categories of PLWH (patients, HIV-infected women with children), as defined by their institutions' regulations, responsibilities of the NGO-based social workers can be more extensive, covering several groups of PLWH or going as far as to include facilitating self-help groups among PLWH. For example, in St Petersburg the NGO-affiliated social workers specialize in providing assistance to drug-using PLWH, the latter are referred to NGOs by government-run HCFC. At the same time social workers affiliated with welfare institutions provide *care and support* services for PLWH.

The range of services provided in combination with ART tends to reflect specific requirements and needs of those groups whose members are likely to end up among PLWH. For example, in countries like Estonia, Latvia and Poland where contacts with infected blood during injecting drug use are among transmission routes for

HIV, there are sites providing *opioid substitution therapy* for PLWH. In Finland where MSM and migrants are among the groups driving the HIV epidemics, NGOs provide “culturally sensitive services to MSM, multicultural people”. Also of notice is the Helsinki Deaconess Institute maintaining service centre for HIV-positive IDUs where the latter can receive a range of services starting from syringe exchange and shelter to OST and referrals to health and social services in one place. This center operates under the contract with the Primary Health Services of the City of Helsinki. Health status of PLWH is also a factor in arranging integrated services as in every NDPHS’ country these patients also receive *treatment for opportunistic infections (OIs)* and other related medical services.

Again, the extent to which the available services such as OST cover the respective needs of PLWH is a different question. At this point it is important to note that there are cases when these needs have been taken into account when making decisions about the services to be offered in combination with ART. In Estonia, for example, the National Institute for Health Development coordinates regular need assessment among PLWH, with the respective results providing inputs for service planning.

### **(c) Coordination and Funding for Integrated Services**

Nomination of the agency to coordinate provision of integrated services, usually, depends on the source of their funding. In countries like Estonia, Finland, Latvia, Norway, Poland and Sweden where these services are funded through national/local budgets or national health insurance plans, the coordinating role tends to be assigned to government agencies such as the National AIDS Center in Poland or medical institutions. On the other hand, if the bulk of funding for integrated services is provided by international donor organizations, NGOs-recipients begin to play a role in their coordination, as is the case in Russia. It is important to note here that there are numerous examples of government agencies providing financial support to NGOs who deliver social services to PLWH. For example, in Latvia there are 18 *HIV counseling points* that provide medical and social services to MARPs and PLWH. These services are funded jointly by the Ministry of Health and municipal governments: while the Ministry of Health provides HIV counseling points with prevention materials, municipal governments provide premises and cover their staff costs. NGOs, on the other hand, bid for provision of these services on competitive basis. In Poland there are 30 VCT Centers run by NGOs where PLWH can receive referrals to medical and social services. To maintain these Centers, NGOs receive funding from national institutions such as the Ministry of Health, the National AIDS Centre and municipal administrations. Like in Latvia, national institutions supply HIV prevention materials such as condoms and syringes while municipal authorities provide premises and cover utility and staff costs. On the other hand, in Russia limited public funding is available to NGOs who are eligible to take part in tenders to supply services at the request of government agencies and receive compensation (“subsidies”) for their services from municipal and federal governments. The problem with government tenders is that they are open to all legal entities who are registered in the official database and the determining factor there is the bidder’s price. As result, there were cases when HIV-related tenders were won by organizations who have no experience in this field. Also, receiving compensation for services rendered from municipal government implies that the NGO has to invest its own resources first, the issue that is quite problematic, practically, for every non-government organization. Furthermore, the scale of these compensations, especially coming from municipal sources, is limited and entails restrictions as to what costs that are eligible for compensation. For example, purchasing office equipment is not going to be compensated through this mechanism.



To be sure, even in countries where public funding for provision of integrated services is secured, there are still issues to be addressed. Some examples can be found in the 2012 Country Progress Report from Finland:

*“Another challenge of outsourcing or NGO engagement is that over time the responsibilities laid down in the laws and regulations may become blurred. While the law on public health is clear on where the responsibility lies (i.e. within the municipal government), the perception among those who fund the services may be such that they have fulfilled their legal duty by such funding, even if it would be inadequate. On the other hand, the NGOs receive majority of their funding from external funders. The present funding principles of RAY (Slot Machine Association-BS) indicate that it does not wish to continue non-earmarked core funding to NGOs and especially not to fund activities that could be regarded as part of regular public service provision system – HIV testing being one these activities. This has put in jeopardy some of the well functioning NGO services and development of innovative programmes. Also, the global financial crisis has led to clear downturn on the funding amounts that RAY distributes, causing problems for NGOs to carry on their services in the future.”*

While accepting that the future of service provision even in countries like Finland cannot be taken for granted, it is important to highlight that the socio-economic context is qualitatively different in the countries where official policies promote reducing the role of government-sponsored health care services. In Russia where underfunding of health care system is a chronic problem, in 1996 the Federal Government issued a decree authorizing health care institutions to provide disease diagnostic and treatment on fee-for-service basis. As public funding for health care system has remained inadequate throughout the past 16 years, patients’ paying for health care services out of their own pocket, practically, becomes the norm. According to some studies, 40% of Moscow residents admitted paying for medical services they received in government-run institutions (<http://www.apcmed.ru/library/470.html>). In this environment maintaining referral networks for PLWH is quite challenging, as they are hardly able to pay for services they need, while government structures de-facto removed this responsibility from themselves.

#### **(d) Disseminating Information and Assessing Quality of Integrated Services**

The coordinating agencies are among the primary sources where clients get information about integrated services. In Estonia, Norway, Poland and Sweden PLWH are informed about medical and social services available to them through VCT Centers, treatment facilities and/or government agencies. In Russia both government agencies and NGO staff including outreach and social workers disseminate this information. To be sure, this is not an “either-or” situation as NGOs are involved in distributing information among patients even in those countries where the provision of services is coordinated by government agencies or medical institutions and vice versa. Also, the respective public services or NGOs maintain websites (e.g., [www.ltkb.ee](http://www.ltkb.ee) and [www.biv.ee](http://www.biv.ee) in Estonia; [www.bivplus.lv](http://www.bivplus.lv) in Latvia) where both government- and NGO-sponsored services are advertised.

In every NDPHS country the integrated services to PLWH are offered in confidential manner. However, if their provision involves funding through government sources or national insurance plans anonymity of clients cannot be maintained. Funders and coordinators also determine how the quality of the services delivered is assessed. In Estonia the National Health Insurance Fund and the National Institute for Health Development conduct these assessments using a combination of methods including survey of patients. Patients’ reports on the quality of the services they had received were also used to assess partners’ performance by the National AIDS Centre in Poland. In Finland municipal governments in Helsinki and Vantaa put together Steering Groups to supervise delivery of services to PLWH including assessment of their quality. In Latvia the service-related

indicators to be reported on and the frequency of reporting is determined by the national CDCP who coordinates their provision. In St Petersburg monitoring of quality of services provided at the Help Centers for Families and Children is conducted on quarterly basis by the Municipal Committee on Social Affairs. A special form that includes data reflecting clients' adherence to ART and/or other medical protocols as well as trends in his/her social well-being has been developed for this purpose.

While talking about quality of medical and social services to PLWH, it is important to note that prejudicial attitude toward them still remains a problem, even in countries like Finland. The 2008 assessment of the effectiveness of "low-threshold" service centers for injecting drug users - who tend to end up among PLWH as well - in this country contains a revealing dialogue between medical professional working in this Center and his former colleague who also belongs to health care system. The fact that a considerable number of PLWH come from socially disadvantaged segments of the population only reinforces discriminatory attitudes towards them, especially in cash-strapped settings. Furthermore, these attitudes can be reinforced by existing legal provisions. For example, in Russia HIV registration makes a migrant subject to deportation from the country, so that migrant workers living in cities like St Petersburg tend to avoid medical services even when it comes to pregnancies (Roman Jorick at the Hearings at the Chamber of Public, March 31 2012).

**Q: What do your colleagues working in the medical system think of you?**

A: My neighbor had a comment once. She had heard from somebody that I was involved in providing these services and when we met she said: "Stay away from us, we don't want to get infected through you!" I could only express my surprise in response.

**Q: Perhaps, it was just a joke?**

A: No, she wasn't joking. She asked: "Aren't you afraid?" And I just don't know what I should be afraid of. No, I'm not afraid of them. My former colleague was shocked: "You are just looking for trouble!"

**(Arponen et al, 2008, p. 57)**

### **(e) Sustainability of Integrated Services**

Given that most of our respondents referred to large-scale operations covering over 100 clients on a monthly basis, the positive news is that integrated services for PLWH provided in the NDPHS' countries demonstrate high level of sustainability. In Estonia, Finland, Latvia, Norway, Poland, Russia and Sweden the respective services were provided for, at least, 5 years. Furthermore, representatives of these countries are confident that these services will be sustainable in the future as well. Partly, this optimism stems from funding for these services being integrated in national and/or local budgets as well as national health insurance plans. Yet even in Russia where funding comes, mostly, from international donors, respondents are confident in their ability to deliver integrated services in the future. At the same time they do see the need for putting these activities including their funding on a more solid legislative footing.

## **4.2. BEST PRACTICES OF INTEGRATED SERVICES**

During site visits to the three countries, interviews were held with health care professionals, NGO activists and government officials on specific examples of provision of social and medical services to PLWH in their municipalities and/or countries. Below is the summary of these interviews highlighting organizational arrangements and the range of services in social and medical fields available to PLWH in the respective countries.

### **(a) Social and Psychological Support**

Starting in 2007, personnel of the Infection Clinic at the Riga Eastern Clinical University Hospital, a structural unit of the Latvian Center for Disease Control and Prevention (CDCP) includes social worker who is responsible for ensuring that patients adhere to treatment protocol. The latter acts in cooperation with psychiatrist and a chaplain who provide psychological counseling and support. Their services extend to all patients of the Center including PLWH and are premised on individual contracts with them. One of the propositions of this document is confidential manner in which social worker assists his or her client in solving problems that prevent one from getting medical help. The range of issues addressed by social worker in this respect goes from finding accommodation for homeless PLWH, assisting them in preparing paperwork for welfare payments or insurance programs to monitoring their adherence to treatment protocols. In cases when treatment protocol is violated, social worker contacts patients (in case of children, their parents) to find out about their circumstances and, if necessary, provides them with referrals to the respective medical and social services. These actions are coordinated with the physician responsible for ART with respect to specific patient. Social worker also maintains ties to the NGO “*Agikhas*” where PLWH can receive peer-to-peer counseling. In case of psychological stress, drug use or alcohol abuse and mental illness, social worker refer his/her clients to chaplain, drug treatment specialists or psychiatrist affiliated with the Center. Psychiatrist also provides counseling to social workers themselves to prevent them from “burning-out”. In 2011 social worker at the HIV/AIDS Outpatient Department of the Latvian Center for Disease Prevention and Control provided 188 referrals to doctors and medical personnel, contacted and ensured continuation of ART for 43 patients who originally had stopped their participation in the treatment program and assisted 38 children with medical references. Chaplain working at HIV/AIDS Outpatient Department provided psychological assistance to 96 patients while the number of patients seeking counseling from the psychiatrist was also high. The demand for services provided by these three specialists outstips their capacities by far as the respective government funding remains limited. Beyond that, data on the effects of social assistance provided to PLWH are not available as no formal procedures to assess their quality are in place.

Similar arrangements exist in Poland where ART is provided at 20 Reference Centers for HIV Therapy. Their staff includes the position of social worker whose task is to arrange medical insurance for those PLWH who do not have one and provide patients with assistance with finding shelter, distribute food packages and HIV prevention materials (condoms, syringes), as well as references for rehabilitation services for drug users.

Sweden features the National Federation of Noah’s Ark Associations (Noaks Ark) is an HIV/AIDS Service Organization that has since the mid-1980’s worked towards limiting the spread of the HIV epidemic and its consequences for individuals and society. Noaks Ark organizations have been



developed at six different places in Sweden. Through information and public awareness campaigns Noaks Ark work towards raising awareness of HIV and reducing the social vulnerability of PLWH. The activities rely on a cognitive perspective that is the foundation for both HIV prevention and support efforts. The organization is specialized in HIV-oriented cognitive psychotherapy for PLWH and those with high vulnerability to HIV infection, and collaborate with the infectious disease clinics in their efforts to reach out with support to PLWH.

### **(b) Community-Based Care and Support Services for PLWH**

Through Social Services established in each of the 110 districts of Latvia PLWH can receive care and support services. The specialists providing these services are also called “social workers”, however, as opposed to their counterparts working at the medical institutions, the former is responsible for improving the patient’s living environment and delivering household and other basic services (house cleaning, getting client to medical facility) that PLWH may find difficult to perform. In some districts of Latvia food distribution among those in need is available so that PLWH can be referred there as well. The so-called “Hot Soup Kitchens” are maintained by NGOs through donations and municipal support and operate in shelters and centers for homeless, mostly in winter months. Where necessary, social workers visit their clients together with nurse who administers medical procedures for PLWH required by treatment protocol. Social workers also act on behalf of their clients before other government services operating in their communities and, if necessary, ensure that PLWH gets subsidized housing or is placed in nursery home, receives welfare payments and is aware of the range of medical services available. On the other hand, his/her duties also include facilitating contacts of health care facilities with their clients. For example, social worker assist medical professionals in locating their patients in the community. The extent to which community-based services meet the needs of PLWH is difficult to establish as no formal assessment has been conducted to date. At the same time funding for these services is limited so that some of them such as food distribution are provided sporadically.

### **(c) Drug Treatment and OST Services for PLWH**

As considerable number of PLWH in Latvia are active drug users, getting timely drug treatment and OST is one of the conditions for their adhering to ART. As a general rule, drug treatment is delivered by the Riga Centre of Psychiatry and Addiction Disorders, together with hospitals operating under the supervision of the Ministry of Health and funded by the state budget of the Health Payment Centre. Drug treatment services are also available in outpatient and inpatient clinics, and in addiction units at general medical treatment institutions which are either publicly or privately funded. Since 1996, the Riga Centre of Psychiatry and Addiction Disorders has been providing methadone maintenance treatment, and since 2005, maintenance treatment has been offered using buprenorphine. By 2012, OST was available in ten districts of Latvia and this year it is expanded into prison system. At OST sites patients can also receive consultations from medical specialists, psychologists and social workers as well as to undergo tests for infectious diseases. In 2012, 49 PLWH were among OST patients who tend to rate these services highly. As it is the case with other medical and social services for this category of patients, the funding is limited so that their supply falls behind demand. In addition, the attitudes towards OST programs among police officers and

prison staff are mixed, so that holding information seminars and discussions with law-enforcement agencies is vital for these programs to be continued.

In Poland OST was introduced in 1993. Until 2005, this treatment was carried out only by public health care units granted permission by the governor of the region in collaboration with the Ministry of Health. According to the Drug Law of 2005, NGOs can also establish and carry out an opioid substitution programme, and the first programmes provided by non-public health centres and private facilities were established in 2007. Currently, OST is provided in all but two provinces of the country and its provision extends to detention centers and some prisons. To receive OST one has to be enrolled into drug treatment programs which means the OST is always provided in combination with psychosocial support services, detoxification and drug rehabilitation and social integration programs. About 100 PLWH undergoing ART also receive substitution therapy in Poland.

### **Acting on Behalf of Families with Children**

*X is an HIV-infected woman with two children eligible for child support from municipal sources. However, at the welfare office her request was refused as she could not provide her husband's income declaration as he was working at the monastery in exchange for accommodation and food. The respective statement from the monastery representative of the welfare office found to be insufficient. X was concerned that her pursuing this issue further would lead to her admitting that her husband is a drug user before the welfare office. At this stage social worker contacted the director of the welfare office and agreed the statement's content that would make her client eligible for child support. Upon this statement being signed by the head of the monastery and accepted at the welfare office, X started to receive child support.*

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### **(d) Social Help Centers for Families and Children**

St Petersburg features Social Help Centers for Families and Children (HCFC). Funded through municipal budget these Centers are established in 18 districts of the city and include HIV Units whose responsibilities are focused mainly on providing assistance to families where either mothers or children are HIV-infected. PLWH-males, especially those with drug using experience, are referred to similar services maintained by the NGO "Humanitarian Action". The Unit's staff includes social worker, psychologist, nurse and a lawyer who provide respective services to their clients. Close cooperation is maintained with specialist for infectious diseases and pediatric service. In addition, the Centers also maintain shelters where families in crisis situations can be accommodated for up to twelve months.

Patients are recommended to register with HCFC when HIV is diagnosed. Even though the client's information is kept confidential, registering with HCFC means revealing one's own or her child's status to its staff, so that only about 50% of families where mothers and/or children are PLWH agree to that. Another principal factor in determining whether referrals to HCFC are provided is long-term or complex nature of issues that PLWH have to deal with to ensure adherence to ART or stability of their family life. Typically, single issues are addressed on the spot during voluntary counseling and testing (VCT), without HCFC being involved.

Upon arrival at HCFC the client is offered a questionnaire whose objective is to determine what his/her needs and problems are. Starting with this information, social worker conducts personal

interview with the client and then develops the patient's plan where actions to address specific problems of PLWH are specified. Clients are actively involved in formulating the objectives, priorities and specific actions to be included in this Plan. Cooperation between social worker and the patient is premised on the Agreement for Social Support concluded for the 12-month period. Typically, this cooperation goes from the "intensive" phase when social worker is actively involved in addressing the patient's problems to the "supporting" and then to the "monitoring" phase when social worker just responds to the issues raised by the patient. HCFC works in close cooperation with medical facilities including the City AIDS Center so that social workers receive regular feedback on their clients' adherence to treatment. If necessary, they can contact their clients and ensure that nothing interferes with the latter's access to ART. In total, 970 families in St Petersburg received support from HCFC's social workers, 53% of these families report that their "social situation" improved. However, this end-of-service interview with patients from which the above-mentioned statistics is derived is the only quality assessment instrument used by the HCFC. Instruments and mechanisms for on-going monitoring of HCFC's services are yet to be established.

### **(e) Case Management among PLWH-IDUs**

As it was mentioned earlier, government-sponsored services in St Petersburg are not in position to provide social assistance to IDUs: while drug treatment dispensaries can be relied on for medical help, they do not have capacities to provide social one. On the other hand, Social Help Centers are oriented to support PLWH-women and their children and not drug-using males whose issues and lifestyle may differ from that of families with children. The latter are referred to the Case Management Program for PLWH-IDUs maintained by the NGO "Humanitarian Action". Being a part of the Municipal Coordination Council on HIV/AIDS and of the similar body for TB, this NGO is well-integrated into the system of HIV-related services in St. Petersburg. The decision to be enrolled in this program is voluntary and the prospective client has to request assistance explicitly to receive support from the NGO's social workers. Upon getting the request, social worker invites prospective client to sign Social Assistance Agreement (SAA), where rights and responsibilities of both sides are defined. Based on this document and depending on specific circumstances of the client, social worker can provide him/her with referrals to medical institutions and ensure that they receive services there. Quite often, this involves assisting clients with obtaining identification documents, health insurance or residence registration. Social worker also facilitates contacts between client and his/her family members and assists in integrating him or her into supporting environment through enrolment in self-help groups, provision of psychological counseling or "peer-to-peer" consultations. In addition to addressing most pressing issues that their clients go through, social assistance provided by case managers is also aimed at building client's skills to deal with problems and act independently.

In this context the contribution of the NGO "Positive Wave" can be highlighted. In 2010 its specialists conducted training seminars for PLWH to prepare them for ART. As the respective account goes: "Seminars were held in resort areas outside of St Petersburg, accommodation for participants were paid by organizers. During seminars PLWH received medical information and developed practical skills to begin ART. For some of them it was the first opportunity to discuss their problems with their peers. Now some of them has new friends, while two of them even decided to marry".

<http://nen.pozvolna.ru/>

An integral part of SAA is Social Assistance Plan that specifies problems to be addressed, responsible parties, strategies for solving specific problems, performance indicators and deadlines.

According to this Plan, case manager and client bear mutual responsibilities that may extend to case manager visiting health professionals or social welfare services together with client to ensure that the latter is not denied service because of his/her drug use. As a result, case manager may become the “reference source” from which representatives of various medical and social institutions receive information on the client’s progress along other relevant dimensions as direct links between the respective institutions are weak or missing. For example, this role of case manager may become especially important when it comes to client undergoing treatment of both drug use and TB or TB and HIV. Special guidelines outlining provision of case management services for this category of patients were developed at the NGO “Humanitarian Action”.

Assessment of quality of social assistance services, certainly, has some room for improvement in this case as well. In the publication summarizing the experience of HIV prevention programs among MARPs, managers and providers of these services admit that “there are difficulties with defining assessment criteria”, as in their view, social assistance is aimed at “introducing positive changes, as perceived by client” (Tsekhanovich et al, 2011). As this definition of objective is difficult to operationalise, they suggest using output-level indicators such as receiving medical services or obtaining specific documents to monitor the quality of social assistance. However, no format for that is suggested.

Being one of the few organizations providing services to PLWH-IDUs in St Petersburg, the NGO “Humanitarian Action” is strained financially as most of its IDU-related services had been funded by USAID whose activities in Russia were stopped as of October 1, 2012. The NGO managed to receive two small-size allotments (~EUR 2,300 each) from the municipal budget to support its programs among commercial sex workers. Lack of funds manifesting itself in low salaries for staff members results in high turnover rates among NGO’s social workers, the fact that puts sustainability of service provision under question.

#### **(f) An integrated national support for children living with HIV**

For the past ten years, Karolinska University Hospital Huddinge in Sweden has been running a national operation known as the “HIV school”. It is funded by governmental grants via Stockholm County Council. The aim is to gather all children over the age of ten and teenagers living with HIV in Sweden at least once a year. During these get-togethers, the children are educated in groups about HIV, medicines, protection against transmitting HIV, puberty, feelings, sexuality and relationships. The education is adapted to age and the children are given the opportunity to discuss and share their own thoughts and questions. The goal is to show the children that it is possible to live a good life with HIV without any risk of exposing others for the infection. Participation in the HIV school is incorporated into the care programme for children with HIV infection at Karolinska University Hospital Huddinge. Like children with other chronic diseases, children with HIV infection have a lot to gain from meeting other children in the same situation. When the child participates in group activities, he/she establishes a contact network that reduces the feeling of being alone, and make it easier for the child to accept the disease.

#### **(g) Providing Assistance for Patients with HIV/TB**

One of the serious problems in the Baltic Sea region is HIV-related tuberculosis (TB). Four of the region’s countries were singled out in the 2011 UNAIDS Progress Report on HIV/AIDS in Europe

and Central Asia in this respect: “Nine countries have an estimated HIV prevalence of 8% or greater among people newly diagnosed with TB, including Estonia, Latvia, Lithuania, the Russian Federation and Ukraine, where people with TB and HIV had a greater risk of having multidrug-resistant TB than people with TB but without HIV infection.” This conclusion is supported by the results of the 2010 WHO study: “TB patients co-infected with HIV in three Eastern European countries (Estonia, Latvia, and the Republic of Moldova) were at a higher risk of having MDR-TB compared to TB patients without HIV infection.” (WHO, 2010). According to some reviews, in Leningrad oblast 43% of patients co-infected with HIV and TB have its MDR forms, while 16% have XDR. There, it is also pointed out that TB patients with drug addiction “do not function well in society and are prone to psychological disorders” (Zagdyn, 2012).

It is widely recognized that responding to both epidemics and preventing the emergence of drug-resistant strains of TB requires integrating HIV and TB treatment services as well as social ones (WHO 2010). While the international recommendations on this issue tend to emphasize the need to move away from vertical structures when separate institutions are responsible for treating specific infectious diseases, the arrangement that result in attrition of patients going between services or providing them in untimely manner (Alban 2006), local stakeholders are less enthusiastic about that, considering these administrative reforms “next to impossible” (Zagdyn 2012). Instead, they propose to introduce facility-level integration of services by adding positions of infectious diseases or drug treatment specialists to the staff of TB Dispensaries or by promoting various forms of social support provided to TB patients through NGOs.

The experience of the St. Petersburg NGO “Positive Wave” deserves attention in this respect. In 2008-2010 the NGO implemented several projects aimed at promoting social services among PLWH and PLWH/TB. Among them are “Developing non-medical service system for people living with HIV in the Leningrad Region” through which social workers provided counseling and arranged examination for TB for sex workers and IDUs mostly in the city of Vyborg. If cases of active TB were detected, NGO staff assisted in placing their clients for treatment at the TB Dispensary. Currently, through the EU-funded cross-border cooperation project “Reducing social consequences of HIV in Estonia and Leningrad oblast of Russia,” these activities are extended to cities of Kingisepp (Russia) and Narva (Estonia).

### **(h) Providing Assistance to Migrants or MSM**

Development of the HIV epidemic, especially in Scandinavian countries, is influenced by significant influx of migrants in Finland, Sweden and Norway. Their impact was recognized at the EU level and in 2009 the European Center for Disease Prevention and Control (ECDC) was commissioned to conduct a study “Migrant health: Access to HIV prevention, treatment and care for migrant populations in EU/EEA countries“. The study singled out a number of factors that serve as barriers in migrants assessing HIV prevention and treatment services. Among them are

*“policies to disperse migrants within countries were reported to limit access to prevention and treatment services. Legal status — lack of residence status and health insurance — was mentioned most often as a barrier to HIV treatment, in particular by respondents in new EU Member States. Lack of culturally sensitive information in relevant languages, suitably trained professionals and services tailored to the specific needs of migrants were barriers in all three areas of services. Within migrant communities, culture, religion, fear of discrimination and limited knowledge of services prevent access to services. Within the wider society,*



*stigma and discrimination towards migrants prevent access to prevention and care services in particular...*"  
(ECDC, 2009)

While dealing with some items in this list can be addressed at the political level only, others can be alleviated through complementing or integrating social services with medical ones. Scandinavian countries feature examples of successful experience in this respect. The NGO *Aksept* in **Norway** uses peers to provide psychosocial support for migrants living with HIV. The African women's network AKN in **Sweden** unites several organisations and aims to improve the sexual health of African women and girls. The network carries out advocacy initiatives and organises meetings for network members. As to government organizations, in **Latvia**, the Office of Citizenship and Migration Affairs ran the EU-funded project 'Improvement of rendered services for asylum seekers, refugees and persons with subsidiary protection'.

As to MSM living with HIV, recent studies suggest that substance abuse leading to risky sexual behavior is quite widespread among them (Beyrer et al, 2012). Responding to this threat, a number of civil society organisations in **Poland**, such as NGO "Pozytywni w Tęczy" ([www.pozytywniwteczy.pl](http://www.pozytywniwteczy.pl)) have developed websites or printed information booklets that explain the effects of drugs commonly used by MSM, and describe ways in which any associated harms might be mitigated. They often also include information about the legal status of each drug, and provide referral information for direct contact services if readers consider their use problematic. Through its website, the NGO "Pozytywni w Tęczy" currently promotes building up a network of volunteers to assist people suffering from substance abuse.

## 5. FOLLOW-UP AND EVALUATION OF PRACTICES

Given relatively recent introduction of integrated social and medical services for PLWH and the fact that their effectiveness *vis-a-vis* stand-alone services is still being debated, it is appropriate to begin the evaluation of the respective experience in the Baltic Sea area with the question of whether outcome of ART is affected by providing social and other medical services to PLWH. If so, then the next question is whether PLWH themselves are interested in receiving these services, i.e. whether the type of social and/or medical assistance they receive reflects their needs. The positive answer to this question brings another one: To what extent their needs are covered? Finally, the quality of services they receive also needs to be examined as low quality reduces coverage by making PLWH less willing to seek help. Admittedly, while the available evidence does not allow to answer these four questions in comprehensive manner, highlighting them may stimulate development of practical recommendations as well as the agenda for further research.

### 1. Does providing integrated social and medical services affect outcome of ART?

In the opening sections of this review we listed concerns over the added value of providing integrated services for PLWH expressed by some students of this subject. Apparently, the experience accumulated across the region suggests otherwise as the *2011 UNAIDS/WHO Progress Report on HIV/AIDS in Europe and Central Asia* links adherence to ART to PLWH receiving social services and argues for their expansion:

*Another crucial factor in the survival of people living with HIV is adherence to treatment protocols. To ensure adherence, particularly for key populations at higher risk, health services, including those*

*in prisons, need to be closely linked with the NGOs offering social and psychological support, especially initiatives that involve peer support from people living with HIV. Integrated services should be scaled up, including opioid substitution therapy and care for drug dependence, TB and hepatitis and their links with prison health services. (p.120)*

Although regional experience does not include studies on the impact of getting combined medical and social services among PLWH, of interest is the 2008 assessment of the effectiveness of “low-threshold” services including social assistance and psychological support in preventing infectious diseases among IDUs in Finland. These researchers draw a link between counseling and support received by IDUs and the reduced incidence of infectious diseases within their networks that took place over the same time period (Arponen et al, 2008). Reports about 53% of HCFC clients in St. Petersburg improving their “social situation” also point in the same direction as the client’s “Social Passport,” the document used to track his or her progress at HCFC, includes such parameters as “registration as PLWH at AIDS Center”, and “adherence to ART”. To make this argument more convincing, explicit links need to be established between the number of PLWH receiving social services through HCFC and their adherence to ART. This indicator can then be traced back to 2007 when the service was established as well as compared to ART adherence rates among those who do not receive social support.

## **2. Are PLWH willing to receive these services ?**

While examples of comprehensive needs assessments conducted among PLWH in the Baltic Sea region turned out to be challenging to find, the respective methodology is widely available and has been applied to PLWH communities elsewhere (Norfolk TGA Comprehensive PLWH/A Needs Assessment, 2008; Luerksen et al, 2008; Context Research 2011). Admittedly, findings from these assessments conducted overseas cannot be applied to the context of the Baltic Sea countries directly, yet it is important to note that the available pieces of evidence coming from this region are in line with the conclusions established through these systematic exercises. For example, one of their findings is that PLWH are particularly concerned about *the lack of availability of quality medical services* including their costs as well as *high degree of stigma and discrimination* surrounding HIV and the difficult experiences faced by PLWH as a result. Issues related to *covering basic needs* also figure prominently among PLWH who rank obtaining housing, food and clothing as their priority. Finally, respondents frequently refer to *issues related to their emotional well-being* indicating that they suffer from disorders such as depression, anxiety, fear, loneliness, and shame and pointing to their need for support, compassion, and acceptance.

Against this backdrop, the results of the 2011 study among IDU in St. Petersburg and Leningrad oblast conducted by the NGO “Stellit” deserve to be mentioned here. Data analysis for this study included breaking down respondents into the PLWH and non-PLWH groups. PLWH among respondents indicated receiving HIV prevention services at the level almost twice below that of their non-PLWH counterparts. The number of unemployed among IDU-PLWH was twice as high compared to IDUs who were not HIV-infected. In other words, there are reasons to believe that, at least, in some countries PLWH experience problems with access to medical services and suffer from economic hardships to the extent that obtaining food, clothing or housing becomes problematic.

With respect to stigma and discrimination of PLWH exhibited even by medical professionals, in addition to the report from Finland by Anne Arponen and her colleagues, one can also refer to the results of Polish study among doctors and nurses conducted by Maria Gańczak (Gańczak, 2007). Having reviewed responses from medical professionals on the need for universal HIV testing among patients, she concludes: “The most notable feature of this study lies in the divergence between official policy as stated by WHO and Polish regulations (Recommendation for Medical Staff, 1997; WHO, 2000) and the views (although maybe not the practices) of surgeons and surgical nurses. In our survey, the vast majority of respondents favoured pre-operative HIV antibody testing and a large majority also supported universal HIV testing for all admissions.” These results indicate that even medical professionals who have information on HIV transmission routes and preventive measures available, display discriminatory attitudes towards PLWH and this may affect the way they provide treatment for their patients.

The latter, on the other hand, already have a slew of emotional problems to deal with. As revealed by the so-called PROQOL-HIV (Patient Report Outcomes Quality of Life – HIV) study, with the participation of 152 HIV-positive patients in nine countries, including Latvia, there are eleven areas of concern for PLWH. Among them are *social relationships* covering issues like “receiving support from a main partner, feeling socially acceptable despite illness or side-effects, actual and perceived stigma, the fear of transmission of HIV to others, worries over rejection, loneliness and difficulties with disclosure”. *Emotions* or feelings of shame, guilt, inferiority, inadequacy or embarrassment. Also common were sadness, anxiety, irritability and stress. *Sleep* as many patients described difficulties falling asleep and reduced sleep time. Frequently it was related to pain or worries related to thinking about the consequences of infection with HIV. Also reported by large numbers of patients were *fears* about the future because of HIV. For example, some patients believed that even minor infections such as flu would be fatal (Carter, 2012).

Summarizing this discussion, let us note that while a systematic assessment of PLWH needs in the NDPHS’ countries is yet to be conducted, there is a number of indications that the affected individuals can be interested in receiving psychological support, social assistance and employment services as well as better access to medical ones. They can also benefit from these services being provided in non-judgemental way.

### **3. To what extent is their needs covered?**

While the available evidence does not allow to answer this question exhaustively, we do not have grounds to believe that PLWH needs in social and medical assistance are fully covered. To begin with, there are financial constraints that prevent health care systems from providing certain types of treatment that PLWH may need. For example, the annual cost of hepatitis C treatment is about \$30,000 which is prohibitively expensive even for international donors such as the Global Fund to Fight AIDS, TB and Malaria (GFATM). Needless to say that very few among PLWH co-infected with Hepatitis C can come up with personal funds to cover these costs. The cost of MDR-TB treatment is also significant, with XDR-TB treatment being even more expensive (WHO 2010).

Yet even putting aside these expensive types of medical treatment, there is a shortage of public funds to support much more modest kinds of social assistance. The number of PLWH receiving social assistance or case management services in Latvia or St Petersburg is below 1% of the total



number of PLWH registered in these places. Key informants there pointed to financial constraints as the main reason behind their not being able to expand the respective programs. Lack of funds also figures prominently behind regional variations in availability of social and medical services for PLWH as capital cities tend to have bigger and more stable tax base. However, even in capitals and major cities financial resources available for provision of social support are limited. In Latvia limited and unstable funding was singled out as the primary reason behind interruptions of food provision and the CDCP's social workers and psychiatrists being overloaded with cases. In Poland key informants from NGOs providing services for MARPs and PLWH indicated that they had to cut their operating hours and even some services as government funding shrank in recent years. In St Petersburg the NGO director providing the bulk of social services for MARPs indicated that there had to be, at least 15 social workers per each district in the city, while currently there are only 3-4 of them. In other words, the impact of economic problems on the capacities of medical and social welfare systems to provide services to PLWH in mid-income level countries of the Baltic Sea region is significant.

In addition, arranging integrated social and medical services for PLWH requires cooperation from local authorities as these services by definition are premised on community-level structures. A number of the Baltic Sea countries including Scandinavian ones, Latvia, and Poland feature well-developed links between national HIV/AIDS coordinating structures, NGOs and local authorities, with the latter assuming costs of service delivery of not only municipal and district-level institutions but also of NGOs. In St Petersburg cooperation among municipal government, district administrations and NGOs has also improved in recent years, with the NGO "Humanitarian Action" being included in the Coordination Councils on HIV/AIDS and TB established in the city. However, it is not always the case in Russia as indicated by the response from Kaliningrad, another Baltic Sea province of Russia, stating that no integrated services for PLWH are available there.

#### **4. What is the quality of integrated services that they receive?**

As was mentioned above, the procedures for assessing the quality of services provided to PLWH are determined by their funders and coordinators. As a result, their outcomes across the region are difficult to compare. More importantly, though, is that they differ in the extent to which they are formal or involve getting feedback from clients themselves. Among survey respondents, it is only colleagues from Estonia who indicated that their agencies conduct these assessments using a combination of methods including survey of patients. There the National Institute for Health Development coordinates regular need assessment among PLWH, with the respective results providing inputs for service planning. In other countries the impact of prospective clients' needs on these decisions was less visible. To be sure, patients' reports on the quality of the services they had received were also a factor in assessing NGO-partners' performance by the National AIDS Centre in Poland. However, in other countries these assessments seem to be premised on reports by service providers but not direct feedback from clients. While provider's reports along with statistical data is a valuable source of information, relying on them entirely may lead to biases in quality assessment as in this case the provider is called to assess one's own activities.

## 6. RECOMMENDATIONS

In light of wide variety of socio-economic conditions and organizational arrangements related to the provision of integrated social and medical services to PLWH in the NDPHS' countries, coming up with the list of recommendations applicable to all of them is challenging. Still, some general themes and issues have emerged from the review of the materials collected during this study, making it possible to formulate several recommendations to promote delivery of these services in the Baltic Sea region:

1. To ensure optimal use of limited resources, provision of integrated social and medical services has to be premised on empirical assessment of the PLWH's needs and priorities. To minimize costs, needs assessment among PLWH can be conducted on the basis of existing institutions providing these services. Where possible, external agencies can be invited to direct these studies in an attempt to ensure unbiased answers from respondents.
2. Once PLWHs' needs for integrated social and medical services are identified, the respective planning exercise involving national stakeholders can be conducted. Its agenda will include identification of financial resources required to reach the effective coverage with integrated services as well as their ranking in terms of their impact on the HIV epidemic and socioeconomic well-being of PLWH. Given that the amount of support provided by international donors for HIV-related programs is shrinking, a similar exercise can be conducted at the regional level to identify alternative funding sources for countries like Latvia or Russia where the exit of international agencies is unlikely to be compensated by the increase of funding from federal, regional or municipal budgets.
3. To promote provision of integrated services and to contribute to the reduction of stigmatization of PLWH, a review of policies regulating their provision and access to them in the Baltic Sea region can be conducted. The review has to address issues like limits on the number of medical services a patient can receive per day set by the National Insurance Funds in some countries. Also, it has to involve analysis of regulatory barriers for social groups like migrants to access medical and social services and to contain recommendations on how to remove or modify them in order to minimize stigmatization.
4. In light of substantial scale of the HIV/TB co-infection in the region and the emergence of MDR/XDR-resistant strains of TB, links among treatment services for HIV and TB have to be promoted. Depending on local conditions, this cooperation can be premised on either of the four models suggested by the WHO (2012), starting from entry via TB service and referral for HIV testing to TB and HIV services provided at a single facility ("one-stop service"). Introducing drug treatment and case management services in TB dispensaries is also a priority.
5. Given higher rates of TB observed in prisons, current and former inmates released into the community deserve special focus. To ensure continuity in treatment, links between medical

services inside and outside of prison system have to be promoted, especially when it comes to sharing medical records on the to-be-released inmates. As considerable number of them end up getting settled in the area around prisons, NGOs/GOs offering social assistance to former inmates there should be supported.

6. Economically-disadvantaged status of many PLWH also suggests promoting professional training, career counseling and employment services among them. This is in addition to traditional forms of social assistance such as subsidized housing, transportation and child care provided to PLWHA.
7. Prevalence of emotional disorders requires expanding mental health, prevention of substance abuse and psychological support programs among PLWH in general and MSM in particular.
8. Discriminatory attitudes among service providers toward PLWH, as revealed by studies conducted in several countries of the region, makes it necessary to promote educational programs aimed at increasing familiarity with HIV transmission routes, HIV-related legislation among medical staff.
9. Assessment of quality of social and medical services provided to PLWH has to rely on formal instruments and be conducted on regular basis. It is also recommended to involve clients in assessing the quality of social and medical services they receive. This can be done through conducting surveys among them on regular basis or by soliciting feedback upon them getting the respective service.
10. In some countries, there are high turnover rates among policy-makers at the ministerial level resulting in inconsistencies in health and social welfare policies. This requires implementing regular advocacy campaigns aimed at promoting their support for provision of integrated services.

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## ANNEX B: LIST OF RESPONDENTS INTERVIEWED

Name	Position
<i>Smate, Inga</i>	Director, Latvian Center for Disease Control and Prevention (CDCP), Latvia
<i>Sniedze, Ingrida</i>	Head of HIV/AIDS, STI and TB Risk Analysis and Prevention Unit, CDCP, Latvia
<i>Upmace, Inga</i>	Baltic HIV Association, Latvia
<i>Molokovskis, Aleksander</i>	Chair, NGO "Association HIV.LV", Latvia
<i>Seya, Agita</i>	NGO "DIA+LOGS", Latvia
<i>Cirule, Iveta</i>	Department for International Cooperation, CDCP, Latvia
<i>Dišlere, Liene</i>	Department for International Cooperation, CDCP, Latvia
<i>Gąsior, Iwona</i>	National AIDS Centre, Poland
<i>Zawada, Beata</i>	National AIDS Centre, Poland
<i>Jankowska, Joanna</i>	National AIDS Centre, Poland
<i>Kaczmarek, Anna</i>	National AIDS Centre, Poland
<i>Kubicka, Joanna</i>	Doctor, Hospital for Infectious Diseases, Poland
<i>Bąkowska, Elżbieta</i>	Doctor, Hospital for Infectious Diseases, Poland
<i>Marczyńska, Magdalena</i>	Doctor, Hospital for Infectious Diseases, Poland
<i>Ołdakowska, Agnieszka</i>	Doctor, Hospital for Infectious Diseases, Poland
<i>Zawadka, Konrad</i>	Doctor, Hospital for Infectious Diseases, Poland
<i>Jabłoński, Piotr</i>	Director, National Bureau for Drug Prevention, Poland
<i>Bukowska, Bogusława</i>	Co-Component Leader, National Bureau for Drug Prevention, Poland
<i>Lutarewicz, Artur</i>	NGO Społeczny Komitet ds AIDS, Poland
<i>Łukasik, Robert Piotr</i>	President, NGO "Pozytywni w Tęczy", Poland
<i>Waluszko, Agnieszka</i>	NGO "Fundacja Edukacji Społecznej", Poland



<i>Latoszyński, Roman</i>	NGO “Res Humanae”, Poland
<i>Dugin, Sergei</i>	NGO “Humanitarian Action”, Russia
<i>Tarita, Lyubov’</i>	Deputy Director, Municipal AIDS Center, St. Petersburg, Russia
<i>Zbukova, Marina</i>	Chair, Municipal Committee on Social Policies, St Petersburg, Russia
<i>Smol’skaya, Tat’yana</i>	North-West District AIDS Center, St. Petersburg , Russia
<i>Levina, Olga</i>	NGO “Stellit”, St. Petersburg, Russia

## ANNEX C : SUMMARY OF DISCUSSIONS DURING SITE VISTS

### 1. Center for Disease Prevention and Control (CDPC)

(Latvia, Riga, July 23, 2012)

At the government level provision of medical services is separated from social ones. The former falls within the purview of the Ministry of Health while the Ministry of Welfare is in charge of the latter. However, both ministries along with other medical services and NGOs cooperate within the *Coordination Commission on Restricting HIV infection, TB and STI expanding*, established by the Ministry of Health and involving local networks – NGOs, CBOs, specialists for infectious diseases including TB - as well. Furthermore, at the level of municipalities these services tend to be offered in the integrated fashion. Throughout Latvia there are 18 *HIV counseling points* that provide medical and social services to MARPs and PLWH. The range of services provided there includes distribution of HIV prevention materials such as sterile syringes and condoms, VCT, and referrals to medical specialists and social workers. At two of these sites opioid substitution therapy is also provided to clients. In 2011 the number of clients served at these 18 *HIV counseling points* reached **14,886**. The latter made **55,545** visits there.

These services are funded jointly by the Ministry of Health and municipal governments: while the Ministry of Health provides HIV counseling points with prevention materials, municipal governments provide premises and cover staff costs. On competitive basis, NGOs are allowed to bid for provision of these services. The challenge is that from Sept 1, 2012 patients will be required to have a referral from their family doctor to be examined by medical specialists or undergo treatment. Otherwise, they will be required to pay for these services. As social workers employed at the HIV counseling points are not medical specialists, their referring clients to services such as VCT has to be confirmed by the family doctor responsible for the respective client.

HIV treatment also tends to be integrated with provision of other medical and social services as personnel of the Infection Clinic at the Riga Eastern Clinical University Hospital including the “Infectology Center of Latvia” providing HIV treatment also includes social workers who are responsible for ensuring that patients adhere to treatment protocol. In cases when treatment protocol is violated, social worker contacts patients to find out about their circumstances and, if necessary, provides them with referrals to the respective medical and social services thereby assisting them with sticking to their treatment protocol. Specifically, in 2011 social worker at the HIV/AIDS Outpatient Department of the „Infectology Center of Latvia” provided 188 referrals to doctors and medical personnel, contacted and ensured continuation of ART for 43 patients who originally had stopped their participation in the treatment program and assisted 38 children of the respective patients with medical references. Chaplain working at HIV/AIDS Outpatient Department provided psychological assistance to 96 patients.

Social workers and medical specialists also tend to provide *care and support services*. Specifically, **local municipality’s social workers** and **health care specialists** cooperating with nurses or GPs ensure provision of services to PLWH in integrated fashion. For these patients social workers can arrange medical appointments, if necessary.

- Medical specialists and social workers provide PLWH with referrals to self-support groups and the Internet-based forum ([www. hivplus.lv](http://www.hivplus.lv))
- Provision of treatment to PLWH with TB or TB patients with HIV also tends to be highly integrated. According to the Cabinet of Ministers' Regulations, PLWH are required to be tested for TB while TB patients are tested for HIV. To maintain IDUs' adherence to treatment, substitution therapy and needle exchange are provided at the at the Riga Eastern Clinical University Hospital Tuberculosis and lung disease centre's ambulance HIV prevention services or counseling point.

Social workers and nurses received several training courses on various aspects of integration of medical and social services. Among them were

- Training course on "Human resources and employment" by the European Social Fund Programme „Raising competence and skills of personnel involved in Health care and health promotion institution work”;
- Training courses arranged by the project „Sustainable development of further education of personnel involved in Health care and health promotion institution work” sponsored by the European Commission;
- Training courses for social workers of the 18 HIV counseling points provided by the CDPC as well as those arranged by NGOs on “Voluntary testing: information on HIV, HCV, HBsAg, syphilis”, „Express tests, practical trainings of testing”; “Ensuring patients’ adherence to ART.”

*Issues to be addressed:*

- PLWH tend to be concentrated around prisons as many of them are former inmates. However, some of these municipalities have limited range of HIV-related services (uneven geographic distribution of HIV-related services)
- Official policies and funding tend to be focused on HIV treatment while HIV prevention is given only limited attention.
- High turnover rates among policy-makers at the ministerial level result in health policies being inconsistent, with policy objectives and priorities being changed with the appointment of new minister
- NGOs providing HIV-related lack stable sources of funding inside the country and, thus, need external support.

**2. The National AIDS Center, Hospital for Infectious Diseases, National Bureau for Drug Prevention, NGO Społeczny Komitet ds. AIDS; NGO “Pozytywni w Tęczy”, Res Humanae; Fundacja Edukacji Społecznej**  
(Poland, Warsaw, July 25-26, 2012)

As of June 30, 2012, there were **15,724** registered PLWH in Poland, with about 13,000 of them maintaining contacts with medical institutions. About 60% of them have been infected via sexual route while 40% (5, 913 cases) through injecting drugs. The popularity of injecting drugs is decreasing, especially among Polish youth, so that sexual transmission of HIV is getting prominence. In 2011 about 90% of new HIV registrations are linked to unsafe sex and only 10% to drug injections. In Poland, 28% of PLWHA are people who are not even 39 years old and 46% 29 years old, nearly 7% were not even 20 when they were infected.

As of June, 2012 the number of PLWH receiving ART was **5,900**.

Integration in providing HIV-related medical and social services is being promoted at the level of national government and local (regional, municipal) administrations. At the national level provision of services is coordinated by the National AIDS Centre and also by the National Bureau for Drug Prevention. Under their auspices the respective National Programs to respond to HIV/AIDS and drug abuse were adopted for the period of 2012-2016. Various government institutions as the Ministry of Health, Ministry of Interior, Ministry of Justice, Ministry of National Education and the Ministry of National Defense are involved in these coordinating structures and programs. The bulk of activities and funding provided through these program goes to treatment (96%) while only a small fraction of these allocations is dedicated to prevention (4%).

As to provision of services, HIV testing is being offered through 30 VCT Centers who tend to be run by NGOs across the country. NGOs receive funding to provide VCT services through competitive bidding arranged by national institutions such as the National AIDS Centre and municipal administrations. As a rule, national institutions supply HIV prevention materials such as condoms and syringes while municipal authorities provide premises and cover utility and staff costs. VCT Centers are linked with the respective medical institutions where they refer their patients for confirmatory HIV tests. Between 2007 and 2011 government funding for implementing HIV prevention programs including VCT shrunk from 2,119 mln zlotyh (~518,780 EUR) to 1,336 mln zlotyh (~327,092 EUR)

Services provided at the Residential Treatment Facilities and outpatient clinics.

- ART is available for free for all PLWH who have clinical indications to receive this treatment. In addition to ART, these patients can also receive aid from other medical specialists such as the ones for STIs and infectious diseases, dermatologist, psychiatrist, obstetrician, gynecologist as well as psychological support. Stationary care is provided by 4 Hospitals, University Hospital, and a Clinic for Children. All these services are covered by the National Insurance Fund whose coverage extends to the unemployed who are registered

at the Employment Office. Also, personnel of Centers for HIV includes position of social worker whose task is to arrange medical insurance for those PLWH who do not have one. In addition, social worker provides patients assistance with finding shelter, distribute food packages and HIV prevention material (condoms, syringes), and provides references for rehabilitation services for drug users. ART is also available for prison inmates.

- On behalf of the Ministry of Health, the National AIDS Centre provides funding for NGOs who arrange programs and events for PLWH, e.g. Annual meetings of PLWH rehabilitation camps for PLWH and the variety of other forms.
- Provision of ART is integrated with and TB as well as hepatitis treatment
- NGOs' activities among PLWH are also supported by private companies like pharmaceutical ones. Examples are such companies as *Roche*, *BMS*, *Gilead* who fund training seminars and PLWH conferences in Poland.
- About 100 PLWH undergoing ART are also enrolled in OST programs. OST is provided in all but two provinces of the country and its provision extends to detention centers and some prisons. To receive OST one has to be enrolled into drug treatment programs which means the OST is always provided in combination with psychosocial support services, detoxification and drug rehabilitation and social integration programs.

*Issues to be addressed:*

- ART is yet to be integrated with provision of STI treatment
- The demand for OST exceeds current possibilities to provide these services
- The number of places for palliative care is limited.

## **ANNEX D : KEY INFORMANTS' QUESTIONNAIRE**

### *Questionnaire on best practices on integration of social and health care for HIV-infected individuals (PLWH)*

This instrument is designed to access the experience and best practices of NDPHS countries with on integration of social and health care services for HIV-infected individuals.

By “*integration*” we mean medical and social services offered in combination to the same set of patients or clients among PLWH. These services can be provided in different premises yet in coordinated or complimentary fashion. Coordinating bodies may be government agencies, medical institutions as well as NGOs. Ultimately, their integration should be aimed at improving PLWH's access to treatment, care and support services.

Tentative list of services that can be provided in integrated fashion includes:

- Clinical services for PLWH: treatment of HIV/TB, HIV/HCV or HBV and HIV and STIs
- Services for PLWH-women
- Services for PLWH-children
- Substance abuse treatment
- Needle and syringes exchange
- Psychological therapy and support
- Mental health services
- Case management
- Community-based support and care services (housing, child care, transportation)
- Transportation, and housing assistance

Your participation in this survey is entirely voluntary and the respective data will be used in aggregated fashion. Providing your name is optional. Please respond by checking the appropriate box in response categories.

**Name:**

**Country:**

**Date:**



1. *Are there integrated medical and social services provided for PLWH in this region/country?*

YES

NO -----> INTERVIEW IS FINISHED. THANK YOU!

Don't know

2. *Which medical and social services this integration involves?*

\_\_\_\_\_  
(DESCRIBE, use as much space as needed. If there is a separate document describing the integrated services more detailed, please attach it to the questionnaire)

Please specify:

2a. *Name of the service:* \_\_\_\_\_

2b. *Provider of the service:* \_\_\_\_\_

2c. *Target group of the service:* \_\_\_\_\_

2d. *How was the service planned? Who participated in planning process (did clients participate)? Was there a needs assessment done before planning?*

\_\_\_\_\_  
(DESCRIBE, use as much space as needed)

2e. *Where do the clients get information about the service?*

\_\_\_\_\_  
(DESCRIBE, use as much space as needed)

2d. *Is the service a part of coordinated case management plan?*

YES

NO

Don't know

2e. Which professionals are involved in providing service?

- Only medical
- Medical and social aid, government employees
- Medical and social aid, NGOs
- NGOs only
- NGO and private companies
- Don't know

2f. How the quality of the service is assessed?

\_\_\_\_\_  
(DESCRIBE, use as much space as needed)

2g. Is the service anonymous and confidential? \_\_\_\_\_

3. If these integrated services are connected to some project, what is the official title of this project?

\_\_\_\_\_(LIST)

4. If possible, please provide contact details for coordinator for these services?

\_\_\_\_\_(LIST)

5. Who coordinates provision of these services?

- Government agency, National
- Government Agency, Local
- Medical Institution
- NGO, National
- NGO, Local
- Other, Specify: \_\_\_\_\_
- Don't Know

6. *Who provides funding for these services?*

- National budget
- Regional/Local budget
- International donor organization
- National (non-government) donor organization
- Private organization
- Other
- Don't Know

7. *How long these integrated services have been in operation?*

- Less than 12 months
- 12-24 months
- 2-5 years
- More than 5 years
- Don't Know

8. *How many clients are served by them on a monthly basis?*

- Less than 10
- 10-50
- 51-100
- More than 100
- Don't Know

9. *Do you think these services are sustainable?*

Yes

No

Don't Know

10. *What the main gaps or challenges that need to be addressed to make them sustainable?*

\_\_\_\_\_ (DESCRIBE)

11. *Has there been done any evaluation or research of the effectiveness of these integrated services?*

Yes - please enclose the report or the web address where to find it

No

12. *Does there exist a system of permanent monitoring of these integrated services?*

Yes

No

Describe: \_\_\_\_\_

13. *Do you want to add anything else that you think is essential to be taken into account when looking for best practices in integration of health and social services for HIV-infected individuals?*

\_\_\_\_\_

**THANK YOU FOR YOUR PARTICIPATION!**