



Stigma in women living with HIV

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Introduction and definitions



Definition of stigma

Goffman defined stigma as . . .

“an attribute that is deeply discrediting” and that reduces the bearer “from a whole and usual person to a tainted, discounted one”¹

- Using the Goffman definition, stigmatisation is thought to exist when society labels an individual or group as different or deviant¹
- Stigma is also viewed as *“a process of devaluation of people either living with, or associated with, HIV and AIDS”²*



Definition of discrimination

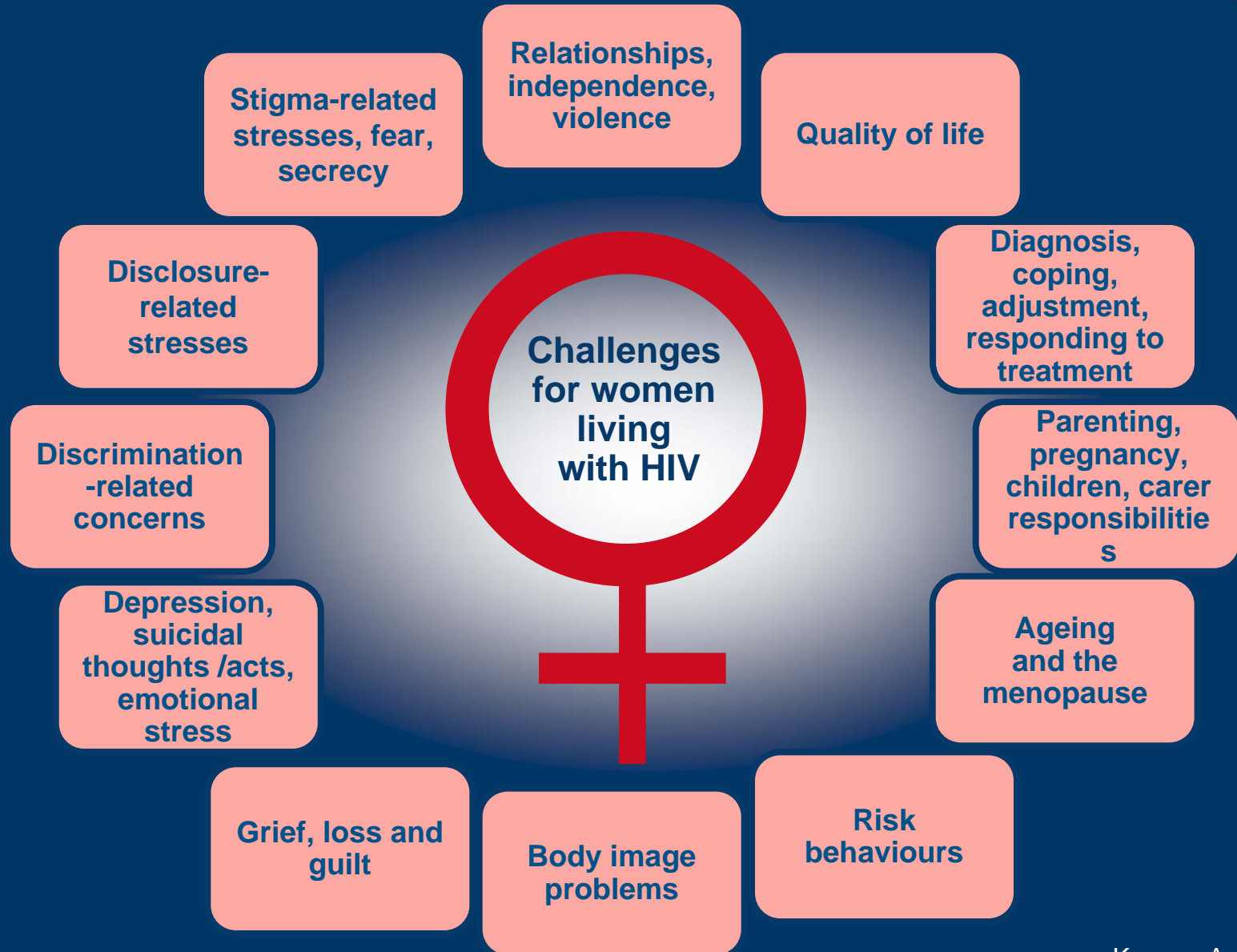
- Discrimination is a consequence of stigma and is defined as . . . *“when, in the absence of objective justification, a distinction is made against a person that results in that person being treated unfairly on the basis of belonging or being perceived to belong to a particular group”*¹



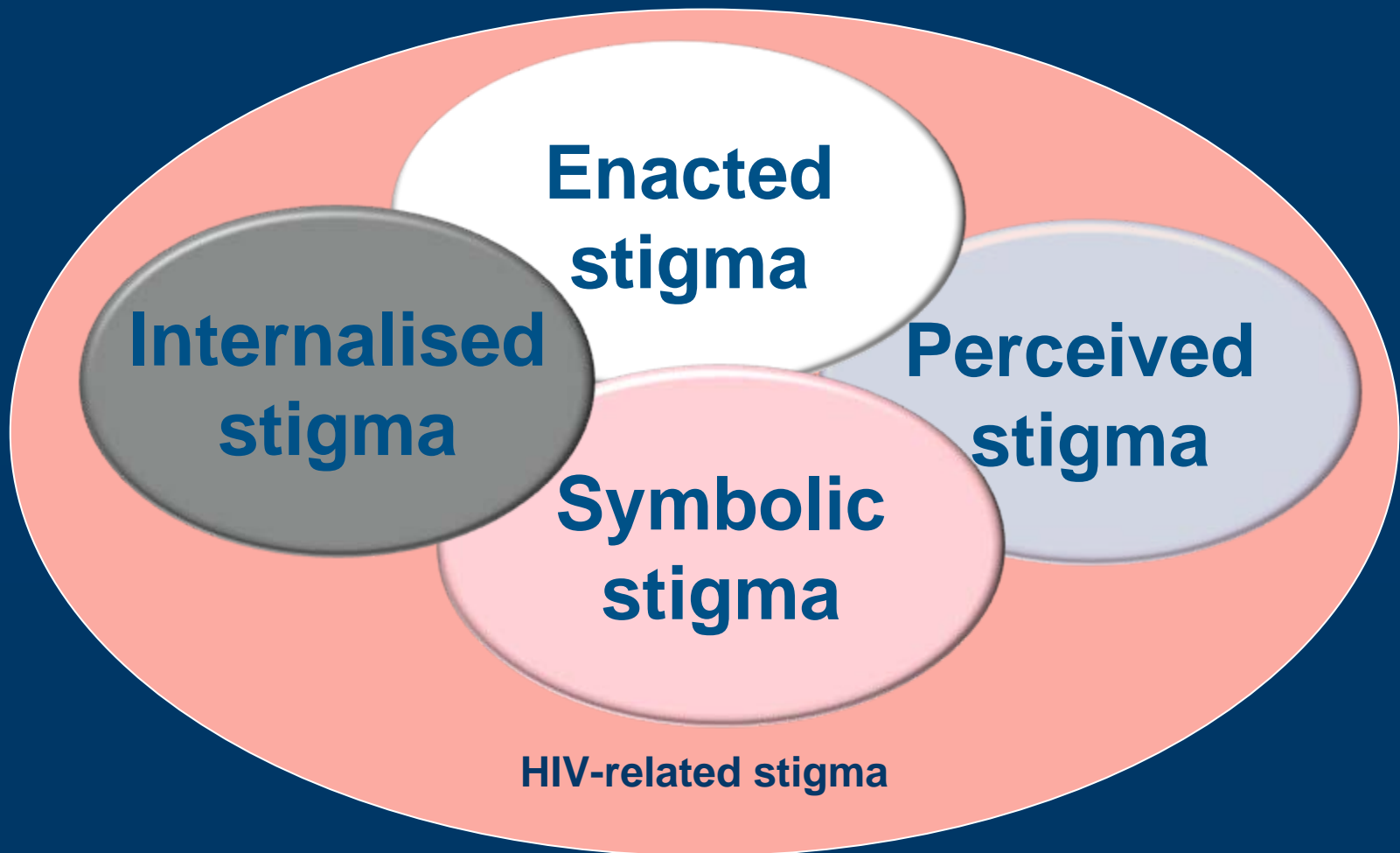
Definition of HIV-related disclosure

- Disclosure is defined as *“the act of informing another person or persons of the HIV-positive status of an individual”*
- An act of disclosure may be done by the woman living with HIV herself, or by another person, with or without the consent of the individual

Disclosure, stigma and discrimination are among the many challenges facing women with HIV



Discrimination can be driven by each different type of stigma





Stigma can occur on several levels

MICRO LEVEL

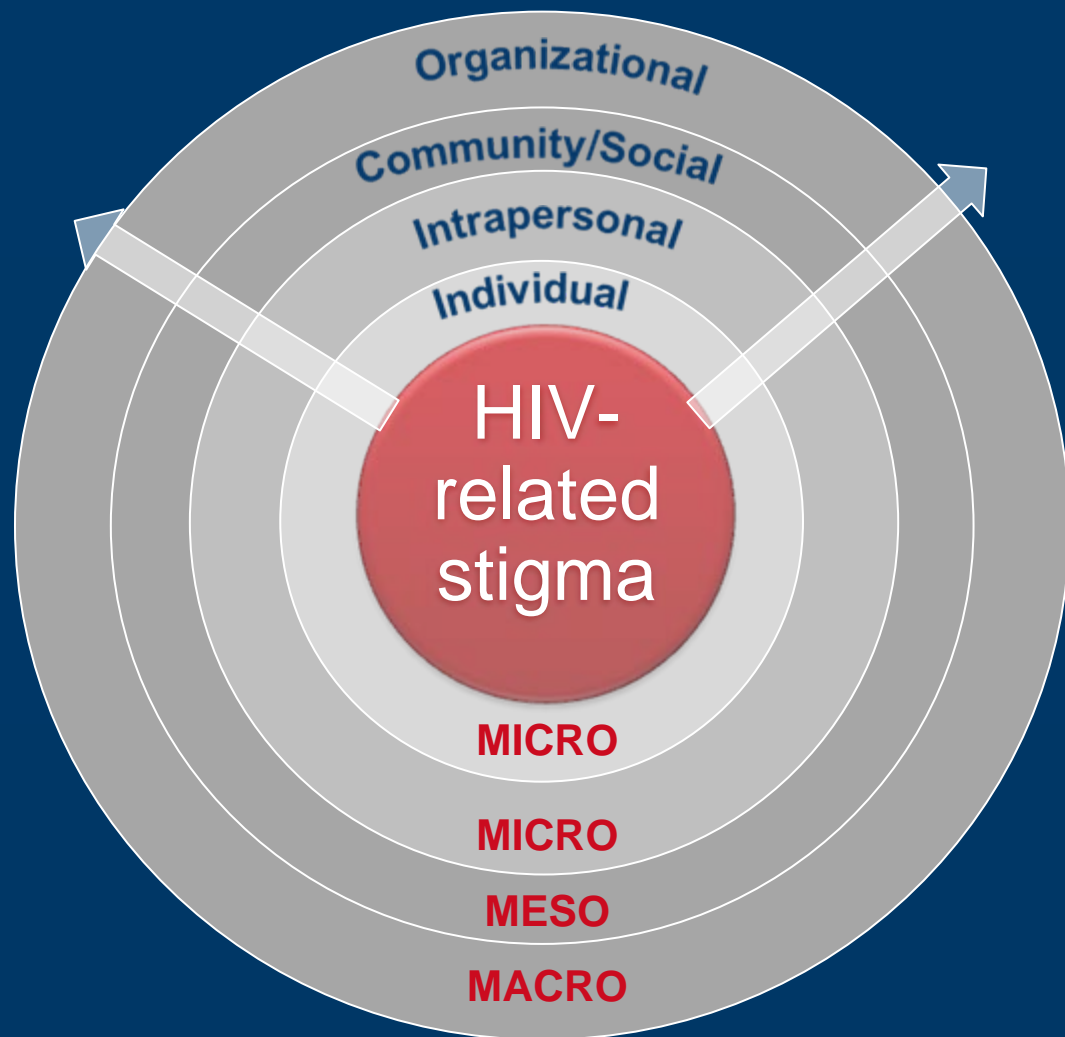
- Related to individual beliefs and interpersonal aspects e.g. relationships with family, friends and partners and social support

MESO LEVEL

- Stigma from community or religious groups

MACRO LEVEL

- Involves organisations and political powers, laws and policies, and health and social service systems





Impact of HIV-related stigma and discrimination



Women living with HIV experience greater stigma than men



- HIV-related stigma experienced by 1,065 people living with HIV in Ontario, Canada

	Female (n=186)	Male (n=879)	P-value
Enacted stigma subscale score	11.5	9.0	<0.001
Disclosure subscale score	16.0	15.0	<0.001
Internalised stigma subscale score	13.0	10.0	<0.001
Perceived stigma subscale score	15.0	12.0	<0.001
Total HIV-related stigma score	55.0	48.0	<0.001

HIV-related stigma and discrimination: Impact on wellbeing and health



- Poor care / access to care
- Negative experiences with doctors and medical institutions
- Poor medication adherence
- Avoidance of HIV testing
- Continuation of breastfeeding / increased rates of vertical transmission
- Risk of late diagnosis
- Exclusion from drug clinical trials / research
- Reluctance to plan for a family

HIV-related stigma and discrimination: Personal and psychological effects



- Loss of hope and feelings of worthlessness

- Fear of disclosure

- Depression and other psychological effects

- Double stigma – burden of HIV and emotional wellbeing

- Intensification of stigma experiences – anticipation of stigma

- Increased internalisation of negative cultural views of HIV infection

- Increased chance of engaging in risky sexual behaviour

HIV-related stigma and discrimination: Social and community effects



- Loss of income and job/career options

- Exclusion from religious/cultural communities

- In some communities women with HIV are treated differently to men

- Difficulties with education and housing

- Avoidance of social interaction or reluctance to develop sexual relationships

HIV-related stigma and discrimination: Partnership and family life effects



- Reduced chance of marriage, partnership or sexual relationship

- Loss of sexual health and child-bearing options

- Rejection by partner, family and friends

- Withdrawal of caregiving in the home

- Increased efforts to conceal HIV status

- Reluctance to disclose / delayed disclosure to children / family



HIV-related stigma impacts on access to care and treatment adherence



- HIV-related stigma may be associated with suboptimal ART adherence
 - ~ 42.5% reported suboptimal ART adherence
 - ~ this relationship may be partially mediated by lower mental health status
- People living with HIV and AIDS experiencing high levels of stigma had over four times the odds of reporting poor access to care
 - ~ 77% reported poor access to care and 10.5% reported no regular source of HIV care



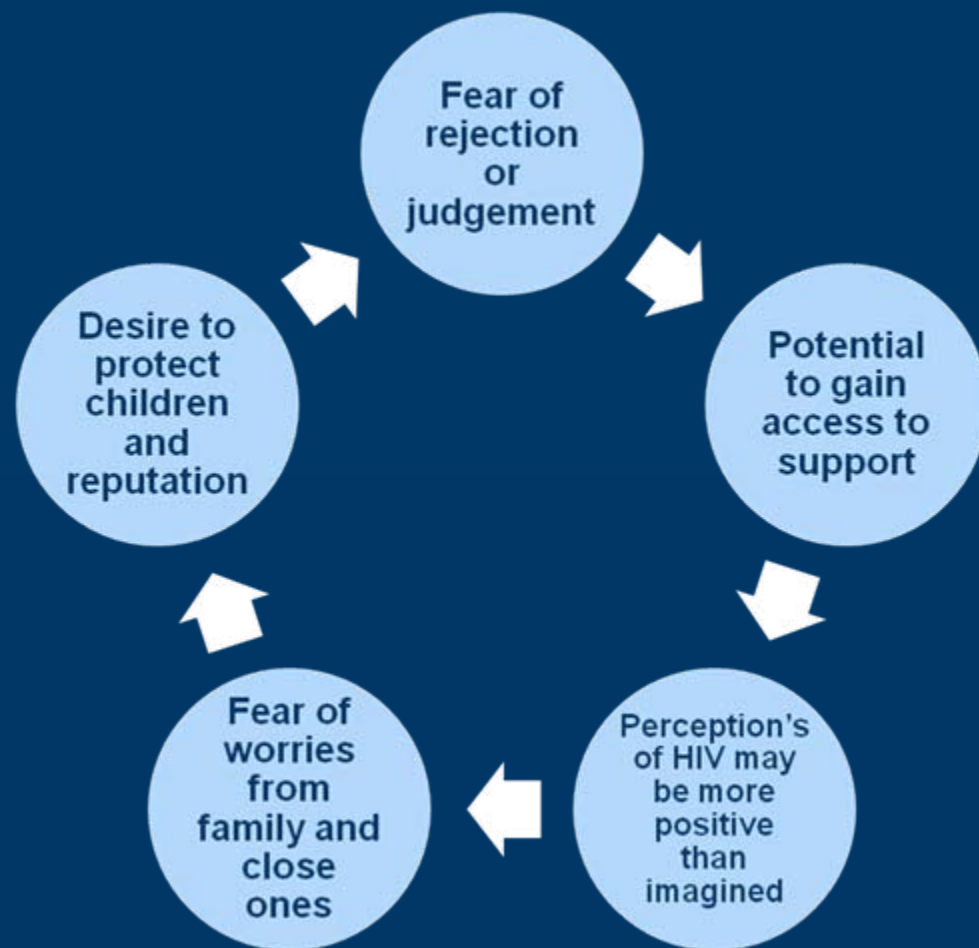
Empowering women to make a choice about disclosure



Disclosure in women living with HIV

Factors considered by women when thinking about disclosure¹

- **Disclosure** is a major factor in all aspects of life and **recurs over the course of a lifetime**¹
- HIV-related stigma negatively affects a woman's willingness to disclose²



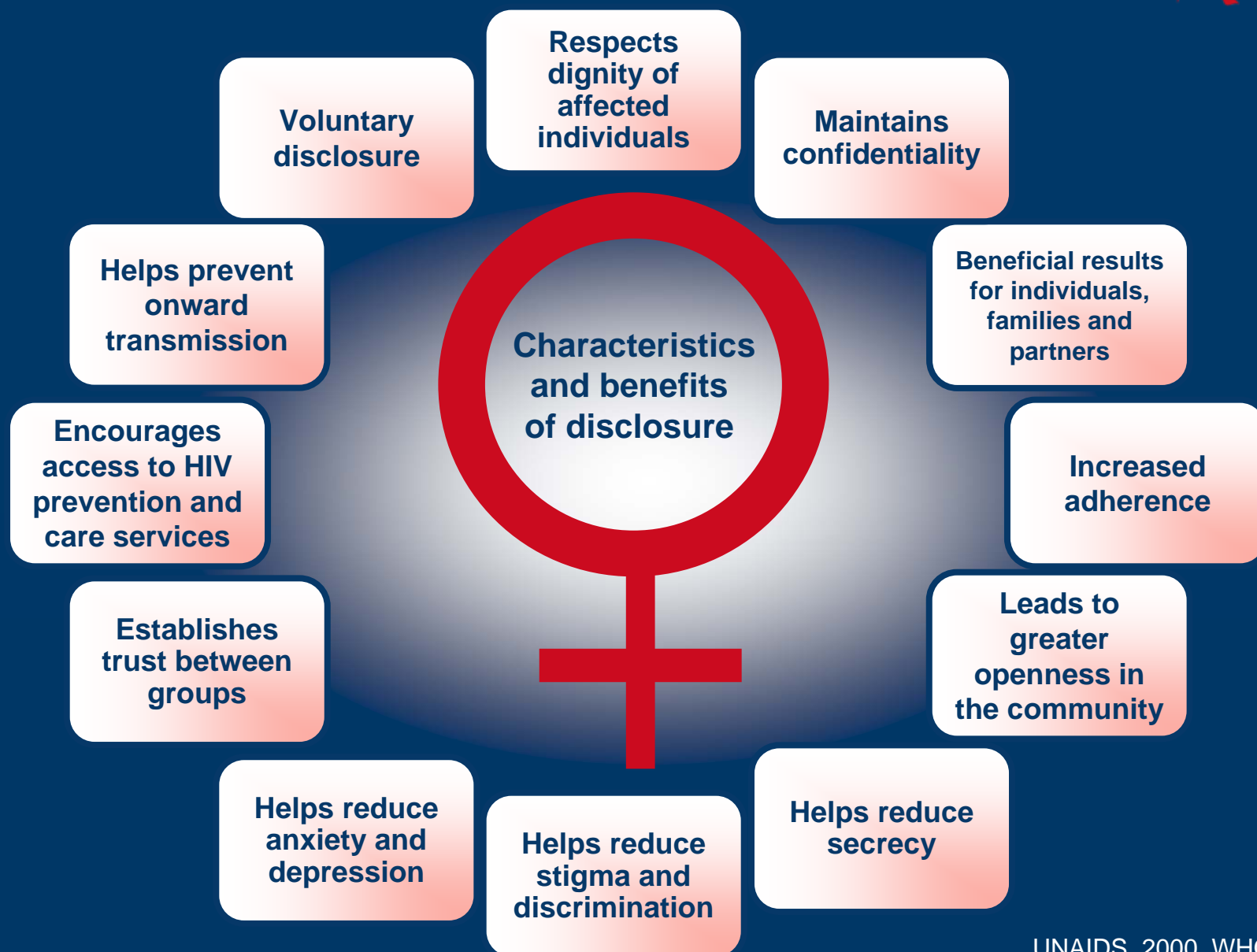
Disclosure should be a personal choice

Disclosure should feel like a safe event, where the benefits clearly outweigh any potential risks

- Important to promote openness about HIV *BUT* equally important to protect human rights
- Each individual should be assured that the result of an HIV test is confidential and that decisions about disclosure will be decisions that *they* themselves must make
- Disclosure is a lifetime process, tailored to the individual woman
 - ~ There are many levels and stages of disclosure, and no one path is suitable for everyone



Positive impact of disclosure





Factors that motivate women to disclose their HIV status



Initiatives to help support women who decide to disclose their HIV status



Policy and programme approaches

- Train healthcare workers in HIV management
- Establish more VCT services, including in rural areas and for marginalised groups
- Reform laws on discrimination and confidentiality

Counselling approaches

- Ongoing counselling and HIV support groups
- Role play
- Mediated disclosure
- Involving women in HIV testing and counselling

Community-based initiatives

- Public information campaigns and community forums aimed at promoting tolerance, compassion and understanding, and reducing fear, stigma and discrimination



Disclosure to children

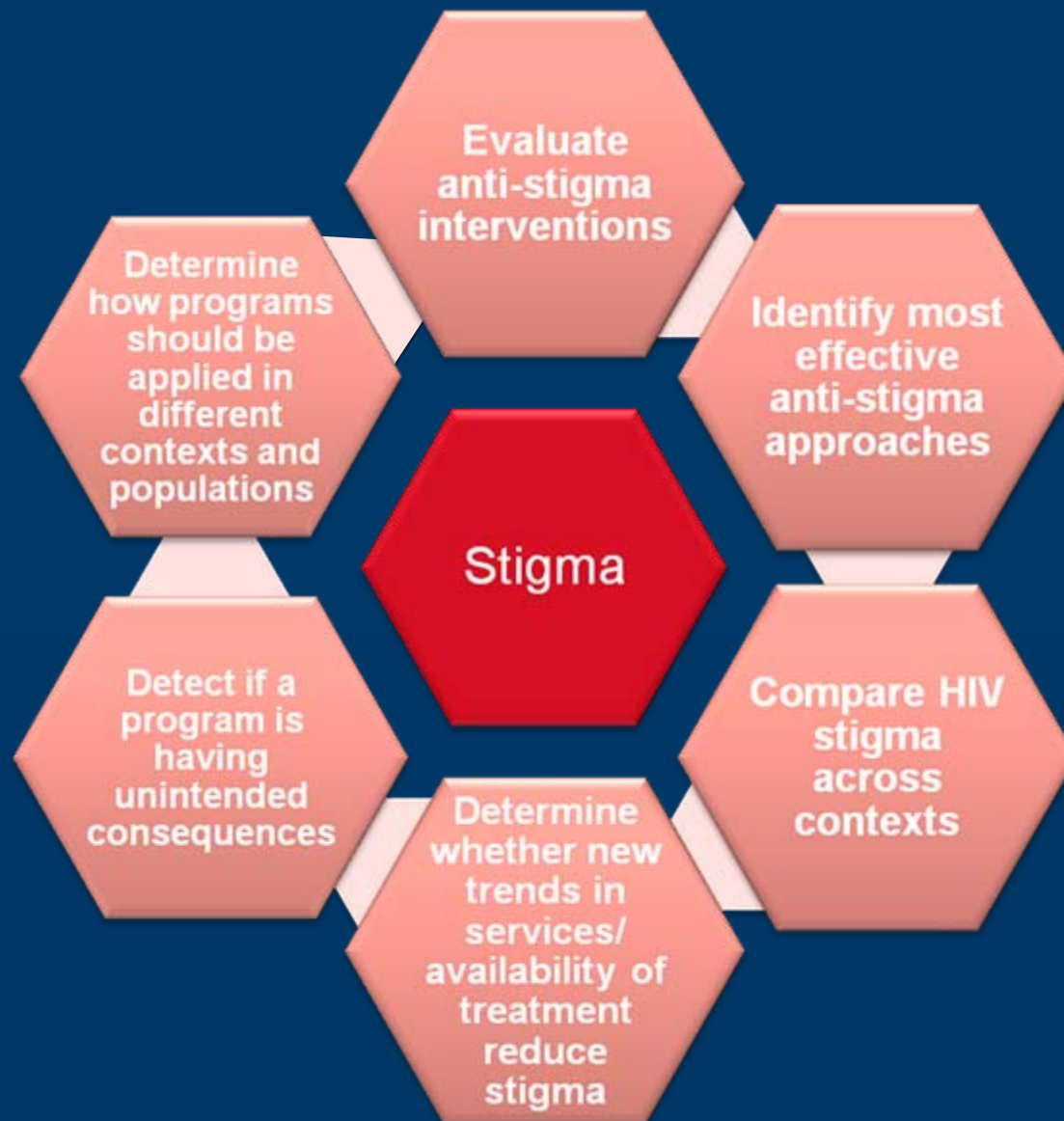
- Disclosure to children is complex
- Concerns about scaring the child, and preserving a care-free childhood
- Disclosure can address the child's concerns / misconceptions, and allow the mother to gain comfort from child
- Disclosure may lead to short term behavioural problems and adjustment challenges
- A child with HIV is significantly more likely to adhere to their own treatment if the mother discloses
- Recent WHO guidance developed to support disclosure to children



How can stigma be assessed?



Why measure HIV-related stigma?





The challenge of assessing stigma

- Defining and assessing stigma is challenging
- Progress has been made in developing programs to reduce stigma and discrimination
 - ~ However lack of standardised indicators for measuring effectiveness has inhibited application and scale-up of proven strategies
- Measurement tools are designed to assess stigma from one of two perspectives
 - ~ the 'stigmatisers' e.g. general public or specific groups like healthcare workers
 - ~ the 'stigmatised' e.g. women living with HIV



The People Living with HIV Stigma Index



Tool to assess trends in the stigma and discrimination experienced by those living with HIV

Comprised of a survey to collect information about the experiences of people living with HIV, in relation to stigma, discrimination and their rights





The People Living with HIV Stigma Index



Aims

To empower people living with HIV, their networks and communities to create and encourage change

To enhance the understanding of stigma and discrimination-related experiences in a locality

To detect changes and trends in experiences over time



Stigma Index: 10 key areas of measurement

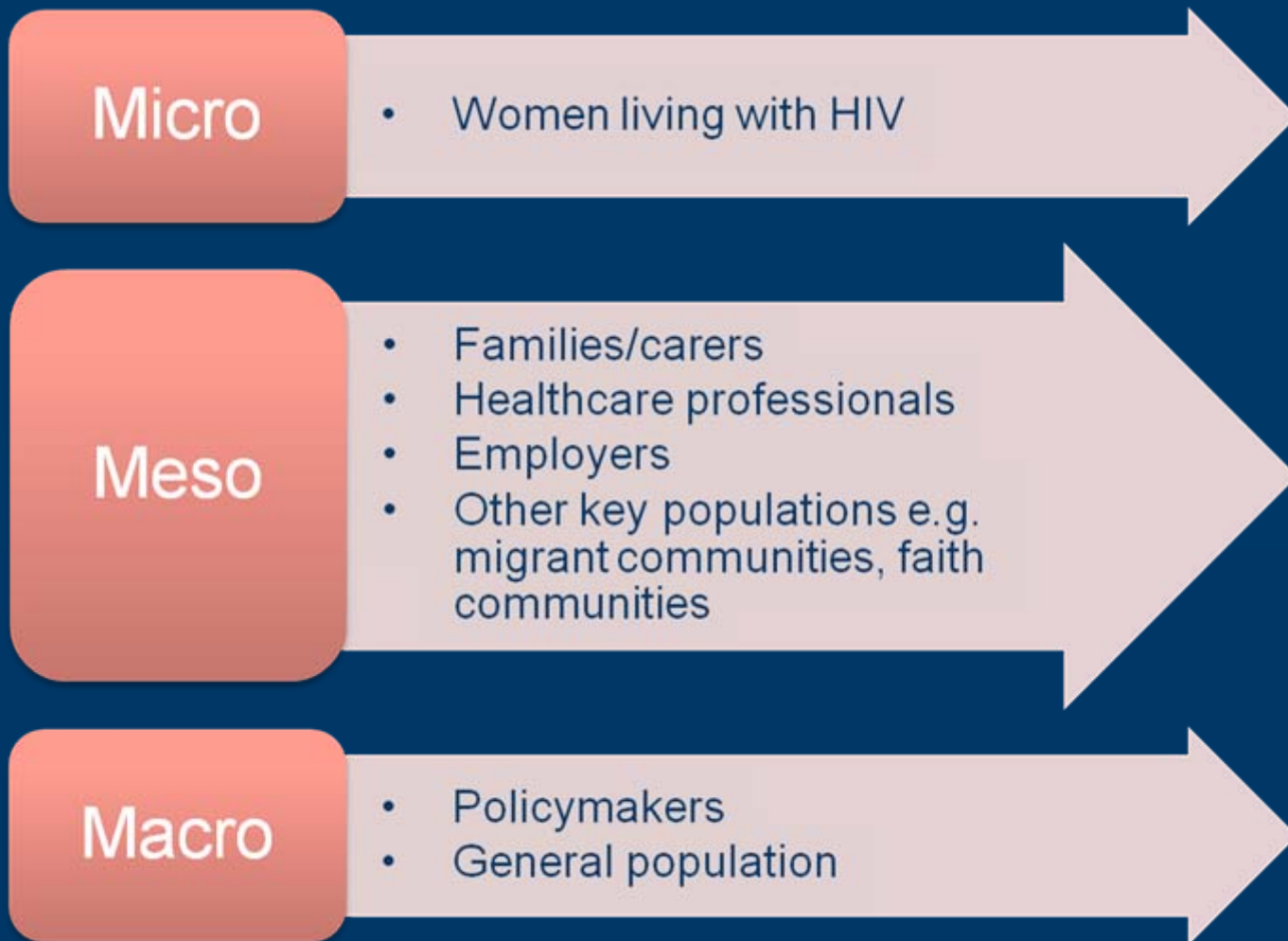




How can we overcome stigma and discrimination?



Key target audiences for stigma prevention initiatives





The GIPA Principle

- GIPA, Greater involvement of people living with HIV
- Universal right to self-determination and participation in decision-making processes
- Based on fact that direct experience and commitment have no substitute
 - ~ no one can respect the interest of people living with HIV better those people themselves
- Widely recognised and accepted
- Should be implemented at all opportunities when working with organisations and individuals



Benefits of GIPA

Increased self-determination and personal development
for women living with HIV

- Strong HIV organisations
- Women with HIV engaged in and leading programmes
- Those with HIV are recognised as experts
- Increased self-esteem
- Decreased depression and social isolation
- Improved treatment adherence
- Increased employability
- Promoted overall health and well-being

Benefits of GIPA

Better local responses to HIV and stronger community systems

- Stigma is reduced
- Key populations are engaged
- Communities meet their needs
- Discrimination is challenged
- Strong, supportive accessible health services
- Inequality is addressed
- Strong community systems and better local responses
- Rights are realised



Peer support and peer education

- Allows sharing of feelings and information
- Provides mutual support
 - Helps women to realise they are not alone
 - Acceptance of HIV
 - Disclosure to family or loved ones
- Many opportunities for women with HIV to provide support and encouragement to others
 - Active participant in a support group
 - Giving presentations
 - Communicating personal experiences
 - Becoming a peer worker
- Can support women with HIV to understand instances when people may be uninformed about HIV e.g. a healthcare professional without HIV specialist knowledge

Existing peer support initiatives for women living with HIV



The collage features the following logos and banners:

- The Global Coalition on Women and AIDS**: Logo with a red ribbon and two figures.
- BRIDGE development - gender**: Logo with the word BRIDGE in purple and development - gender in blue.
- anRS**: Logo with the letters anRS in blue and red.
- NAPWA**: Logo with stylized blue figures and the letters NAPWA.
- VIH & SIDA en Latinoamérica**: Banner with a woman's face and a map of Latin America.
- LACCASO**: Red banner with navigation links: PAGINA PRINCIPAL, ACERCA DE LACCASO, DIRECTORIO, CENTRO DE INFORMACION, EVENTOS, ENLACES.
- Organización Panamericana de la Salud**: Logo with a globe and the text "Organización Panamericana de la Salud".
- COPRESIDA**: Logo with a red ribbon and the text COPRESIDA.
- AIDES**: Logo with a red ribbon and the word AIDES.
- TAC**: Stylized black logo with the letters TAC.
- Network Persone Sieropositive**: Logo with a red ribbon and the text Network Persone Sieropositive.
- Femmes et SIDA**: Logo with a red ribbon and the text Femmes et SIDA.
- ONUSIDA**: Logo with a red ribbon and the text ONUSIDA. Below it: PROGRAMA CONJUNTO DE LAS NACIONES UNIDAS SOBRE EL VIH/SIDA.
- FUNDACION HUESPED**: Logo with a red ribbon and the text FUNDACION HUESPED en acción contra el sida.
- ICW**: Logo with a globe and the text ICW.
- STOP AIDS in Children**: Logo with a blue circle and the text STOP AIDS in Children.
- pozfem-uk**: Logo with the text pozfem-uk in green.
- POSITIVELY WOMEN**: Purple banner with the text POSITIVELY WOMEN.
- Positivo**: Logo with the text Positivo and Viver com o VIH.
- COALICIÓN DE PRIMERAS DAMAS Y MUJERES LÍDERES DE AMÉRICA LATINA**: Logo with a red ribbon and the text COALICIÓN DE PRIMERAS DAMAS Y MUJERES LÍDERES DE AMÉRICA LATINA.
- Red de Mujeres para el Desarrollo / Women's Development Network**: Logo with a map of Latin America and the text Red de Mujeres para el Desarrollo / Women's Development Network.
- Despacho de la Primera Dama Xiomara Castro de Zelaya**: Logo with a red heart and the text Despacho de la Primera Dama Xiomara Castro de Zelaya.
- ABRACOS**: Logo with the text ABRACOS and PORQUE A SIDA EXISTE !
- The Teresa Group**: Logo with a teal circle and the text The Teresa Group.
- Women WON'T wait**: Logo with the text Women WON'T wait.
- Las mujeres NO esperamos**: Logo with the text Las mujeres NO esperamos.



Faith-based organisations (FBOs)

- Faith and religion can have a positive impact on wellbeing and emotional health¹⁻³
- FBOs, such as tearfund, have the ability to influence the attitudes and behaviours of their community members, who are in close and regular contact with all age groups in society
- Some faith groups provide an important source of comfort, friendship and practical support to those with HIV
- There are a growing number of initiatives aimed at equipping faith leaders with the information and tools to challenge HIV-related stigma and discrimination in their communities



Empowering healthcare professionals to recognise stigma



- Healthcare professionals should recognise the impact of stigma on healthcare outcomes
- Overall outcomes can be improved by providing appropriate and individualised support
- Healthcare professionals should aim to develop a greater understanding of challenges faced by women and effective coping strategies
 - Coping within the context of HIV can be used as a positive mechanism for stigma reduction
- Pharmacological and behavioural interventions can help women to cope and to plan for the future



Discriminatory health care experiences can affect ART adherence



- Thrasher et al (2008) investigated the impact of discriminatory healthcare experiences and healthcare provider distrust on ART adherence



- Over 33% of participants reported a discriminatory health care experience

- 24% did not trust their health care providers

- More discrimination was predictive of greater distrust, weaker treatment benefit effects and poor adherence

- Distrust affected adherence by increasing treatment-related psychological distress and weakening beliefs around the benefits of treatment

Supporting women to cope with HIV-related stigma



- There are a number of strategies which a healthcare professional can use or suggest to help support women experiencing stigma

Emotional coping strategies

- Rationalisation
- Seeing self as OK
- Letting it pass
- Turning to God
- Having hope
- Humour
- Keeping active/busy

Problem solving strategies

- Joining formal or informal support groups
- Disclosing
- Speaking to others
- Getting counselling
- Peer support and education to gain knowledge
- Modifying behaviour
- Learning from others/following positive role models



Overcoming the challenges of stigma and discrimination: case studies



Case study: Belarus



- **Positive Movement:** An initiative focussed on changing stigmatising attitudes towards people living with HIV

Objectives

- Prevent further spread of HIV in Belarus
- Provide psychosocial support and anti-stigma activities

Actions

- Weekly self-help groups
- Group and individual therapy
- Telephone hotline
- Legal advice
- Involvement of people living with HIV

Outcomes

- Access to information, support groups
- Nationwide seminars
- Stories covering people with HIV provided by the media



Case study: Thailand



- Sangha Metta project: An initiative designed to mobilise religious leaders to foster respect and compassion for people living with HIV and AIDS, and participate in prevention activities

Objectives

- To train religious leaders to play a role in the community response to HIV

Actions

- Religious leaders:**
- Run seminars with local religious groups
 - Make home visits to those with HIV
 - Provide support and assistance for orphans affected by HIV
 - Run local support groups

Outcomes

- Religious leaders are offering support to those with HIV who have not yet disclosed
- Those with HIV are taking a more active role in the community
- Women with HIV have been accepted into women's groups in villages in northern Thailand



Case study: South Africa



- Soul City: An 'edu-tainment' initiative aiming to enhance quality of life for people with HIV

Objectives

- To change peoples perceptions and quality of life of people living with HIV
- Topics include:
- Stigma and discrimination
- Living positively with HIV
- Importance of education

Actions

- Five TV series of *Soul City* and another TV series named *Soul Buddyz 1* were aired
- Radio broadcasts
- A series of booklets, including those on *AIDS in our community and Living Positively with HIV/AIDS*

Outcomes

- Opinions and attitudes to people living with HIV improved, particularly amongst younger age groups
- Acknowledgement that people living with HIV can live a normal, healthy life
- Reported increase in openness around youth sexuality

Case study: Deciding when to disclose



- HIV-positive woman diagnosed several years ago
- Disclosed to her husband, hoping that he would support her, but he accused her of infidelity and left her
- She suffered alone for the next 5 years without telling anyone
 - ~ She didn't disclose to her family as she thought they were very negative about HIV and feared experiencing stigma
 - ~ She lost a lot of weight as she didn't know how to care for herself
- After 5 years she attended a counselling session, which turned her life around
 - ~ Learnt that she was not alone
 - ~ Stopped mourning for herself and became confident in her ability to live a full life
 - ~ Improved her diet and gained weight

Case study: Deciding when to disclose



- She began talking about HIV issues to her friends and family, without referring to herself
- She realised that they were now understanding, and so she felt that the time was right to disclose
 - ~ Her family were not shocked, but said they had always felt that she was keeping something from them
 - ~ Her family are very supportive - emotionally and practically
- She now talks openly about her status at work, at home and at support groups for other women with HIV

Disclosure is a process, not a single event

Counselling can help women to recognise and develop their own coping capacity, so they can deal more effectively with problems

Along with peer support, counselling can support women in the process of disclosure



Summary

Summary

- HIV-related stigma and discrimination can affect women living with HIV at multiple levels
- HIV-related stigma may result in:
 - ~ Lower uptake of HIV preventive services, and testing and counselling
 - ~ Reduced and delayed disclosure
 - ~ Poor treatment adherence
- Stigma and discrimination disproportionately affect women and girls
- There are initiatives available to help support with disclosure and to combat against stigma and discrimination