

# Integrating gender into HIV/AIDS programmes in the health sector

Tool to improve responsiveness to women's needs



World Health  
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<sup>1</sup> International Center for Research on Women (ICRW)

<sup>2</sup> Liverpool VCT and Care, Kenya (an NGO in Kenya providing HIV testing and counselling services)

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### For more information

Readers wishing to obtain more information on WHO's work in this area can access the web pages of GWH (<http://www.who.int/gender/en>).

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# Preface

The idea for this tool grew out of a global consultation on Integrating Gender into HIV/AIDS Programmes held on 3–5 June 2002 at WHO headquarters in Geneva. This meeting brought experts on gender and HIV/AIDS together with national AIDS programme managers to discuss how gender could be addressed more systematically within existing HIV health sector programmes. The participants recognized that for this goal to be achieved it was necessary to produce an operational tool for programme managers, and to address specific types of HIV/AIDS programmes.

The process of developing this tool has been iterative, with revisions being made continuously through interaction with numerous reviewers, people in the field and, in the final stages, through field testing in selected countries. The first version of the tool was developed with the International Center for Research on Women (ICRW) in 2003. This version was circulated extensively to both academics and experts on gender and HIV, as well as to people working on HIV programmes in developing countries. It became evident that translating commonly used terminology such as “gender-responsive programmes” into practical actions for programme managers with a limited understanding of gender equality was not a straightforward task. Comprehensive comments were received, which led to a total reorganization of the tool. A second draft was prepared in 2004, also with the support of ICRW. In this version, the tool was reorganized as a series of five modules focusing on HIV testing and counselling, prevention of mother-to-child transmission of HIV (PMTCT), HIV treatment and home-based care, plus a module on programme components that cut across these service-delivery areas. Parts of this version of the tool were presented at a workshop held at the Fifteenth International AIDS Conference in Bangkok in 2004. Valuable input was received from programme managers from a wide range of countries, which again led to modifications and simplification of the tool.

A third version of the tool was developed by WHO with inputs from consultants. In this revision, emphasis was placed on actions in the health sector. Each module was further divided into programme components (e.g. conducting an HIV test, supporting disclosure), and for each component key issues and actions were included. This version was once again peer reviewed by external reviewers as well as relevant technical staff in WHO. Comments were addressed by making the language more action-oriented, clarifying key gender concepts, and adding case studies and tools illustrating how gender inequalities have been addressed in field programmes. The entire version of the fourth draft was field-tested in the United Republic of Tanzania, and the HIV testing and counselling section was field-tested in El Salvador, Honduras, Nicaragua, and the Sudan.

In the United Republic of Tanzania, the field-testing was conducted in collaboration with the National AIDS Control Programme of the Ministry of Health and Social Welfare, and the German Technical Cooperation/Tanzanian German Programme to Support Health (GTZ/TGPSH). The field test was successful in raising awareness among the users of the tool regarding the links between gender inequalities and HIV/AIDS. The results of the field test were presented and discussed with several stakeholders, including the National AIDS Control Programme of the Ministry of Health and Social Welfare, donors, and civil society. One outcome of the discussion of the field test with these stakeholders was the identification of entry points for systematically integrating or mainstreaming gender into the implementation of the National AIDS Control Programme. This included, for example, the national HIV/AIDS health sector strategy that was being finalized at the time of the field test.

In the Sudan, field-testing was conducted in collaboration with the National AIDS Programme of the Federal Ministry of Health, and the Ahfad University for Women.

This process led to revisions in the national standard operating procedures for HIV testing and counselling of the Sudan, which incorporated the recommended actions from this tool. In Belize, Nicaragua and Honduras, the field-testing was conducted in collaboration with the Ministries of Health in each of these countries.

The tool was once again revised to reflect the issues that emerged during the field test. It was submitted once again to the WHO's Department of HIV/AIDS for another technical review and then finalized. At this stage, a description of how the tool can be used in the field, lessons learnt from the field test, and references to other WHO materials, were included to ensure that suggested actions were harmonized with other technical guidance on HIV. The structure was also reorganized once more to streamline the tool from a modular format to a single tool in which Section 1 is aimed at programme managers, and Sections 2 to 5 are aimed at service providers.

The process of finalizing this tool has highlighted several challenges. For example, it is necessary to specify why and how stakeholders in the health sector should and can respond to gender inequalities in practical ways, as addressing these inequalities is often perceived to require broader social change and hence, is seen as the responsibility of other social sectors. While recognizing the broad context of gender inequality and its role as a key driver of the HIV epidemic, especially among women, the document focuses on HIV/AIDS interventions delivered primarily through the health sector, e.g. HIV testing and counselling, PMTCT, HIV treatment and care, and home-based care and support.

For each type of programme or service delivery area, the tool identifies *key issues* related to gender inequalities, and suggests practical *actions* to address these in terms of the role and functions of the programme manager or service provider. The *key issues* and suggested practical *actions* in this tool are based on an extensive body of evidence linking gender inequalities to women's sexual and reproductive health and HIV. Evidence on interventions or best practices that address gender inequalities in HIV/AIDS programmes using the most rigorous study designs (e.g. randomized controlled trials) is limited. Therefore, the prescribed actions in this tool have been informed by available evidence from interventions that address gender inequalities, or interventions from the field of sexual and reproductive health, even when these

have less stringent evaluation designs. Many of the prescribed *actions* are also based on core UN mandates or values of promoting equality between women and men through gender mainstreaming, equitable access to programmes, and human rights. While recognizing the need for further research on and impact evaluations of gender-responsive HIV/AIDS interventions, this tool responds to an urgent need articulated by practitioners in the field of HIV/AIDS for practical guidance on how to respond to the gender-related needs and vulnerabilities of programme beneficiaries or clients.

Field-testing demonstrated the need to strike a balance between two basic goals. On the one hand, for people with a limited understanding of the basic concepts of gender mainstreaming, and the ways in which these are linked to health and HIV, there is the goal of increasing understanding of these concepts. On the other hand, for users of the tool who already have some basic understanding of gender and health there is a need to develop skills and practices that they can adopt within the context of their daily work. Another challenge faced was the difficulty of addressing in a single tool the gender-related needs of women and men, as well as those of specific groups such as injecting drug users (IDU), men having sex with men (MSM), adolescents, and sex workers. This tool, therefore, focuses on the gender-related needs of women. A separate tool will be required to address the specific gender-related vulnerabilities to HIV that affect men and communities such as IDU, MSM, adolescents, and sex workers.

The field of HIV/AIDS programming is rapidly evolving scientifically as well as in practice and policy developments. Thus, for example, male circumcision is now recognized as a key prevention approach and, as part of universal access to prevention, treatment and care services, there is increasing emphasis on expanding HIV testing and counselling through new approaches. This tool aims to reflect the latest developments in HIV/AIDS policy and programming, but as there will be new developments in the fields of gender mainstreaming and HIV/AIDS programming, this tool will need to be updated periodically. It should, therefore, be considered a work in progress, with scope for improvements, additions and revisions, as we learn from practice. It is anticipated that the suggested *actions* in this tool will remain valid for at least five years from the date of publication. The Department of Gender, Women and Health at WHO headquarters in Geneva will update this tool at that time. To facilitate such an update, the tool provides

users with the opportunity to provide feedback (Annex 3), which they can send to WHO to share their experiences in using and adapting this tool to their setting.

Globally, there is increasing recognition of and agreement on the need for gender to be addressed more systematically in all HIV/AIDS programmes. At the Twentieth Meeting of the Joint United Nations Programme on HIV/AIDS (UNAIDS) Programme Coordinating Board in 2007, the UNAIDS secretariat and its cosponsors were requested to address gender more substantially in HIV/AIDS programming. At the Replenishment Conference of the Global Fund for AIDS, TB and Malaria (GFATM) in Berlin and the

Sixteenth Global Fund Board Meeting in 2007, an explicit commitment was made to integrate gender into the Global Fund's own functioning, and to ensure that responses to HIV/AIDS, tuberculosis and malaria take gender into account. At the World Health Assembly in 2007, Member States mandated WHO to integrate gender into its various programmes, including HIV/AIDS. These developments provide an opportunity for this tool to be used in many ways. We hope that it will be useful to people who are at the forefront of HIV/AIDS programmes and are committed to equality for women and girls and to the health and well-being of all people, including those living with HIV.



# Introduction

## Purpose

The purpose of this operational tool is to:

- raise awareness of how gender inequalities affect women's access to and experience of HIV/AIDS programmes and services;
- offer practical actions on how to address or integrate gender into specific types of HIV/AIDS programmes and services.

## Target audience

The target audience for this tool comprises primarily programme managers and health-care providers involved in setting up, implementing or evaluating HIV/AIDS programmes. It includes programme managers and health-care providers in the public sector at the national, district and facility levels, as well as those running private sector programmes, e.g. nongovernmental organizations (NGOs).

## Rationale

The vulnerability of women, their risk of HIV infection and the impact of the epidemic on them are heightened by many factors. These include: the low status accorded to women in many societies, their lack of rights, their lack of access to and control

Deborah in Uganda lost her husband to AIDS and is herself very sick. Her brother-in-law tried from the very beginning to inherit her, but she categorically refused so as not to infect him and his wife. He repeatedly told her he did not care that she had AIDS and was willing to take the risk of becoming infected. He harassed her for almost a year; when she held firm and refused, he cut off all financial support to her and her four children. Once she refused him, she was ostracized by the entire family and cannot rely on them for anything, even moral support. Now he is trying to claim the land that his brother left jointly to them (1).

## BOX 1

### Women and HIV/AIDS: Facts at a glance (2, 3, 4)

- Globally, 50% of all people living with HIV are women.
- In sub-Saharan Africa, 61% of all people living with HIV are women. Young women (15–24 years) are three to six times more likely to be infected than men in the same age group.
- HIV prevalence is high among sex workers, a great majority of whom are young and female – ranging from 6% in Viet Nam to 73% in urban parts of Ethiopia.
- In some Asian countries, e.g. Cambodia and India, women are increasingly infected with HIV within the context of marriage.
- Fewer than 50% of young people have comprehensive knowledge of HIV/AIDS. In all but three countries recently surveyed, young women consistently had less knowledge than young men.
- Demographic and Health Surveys conducted in several countries show that the percentage of men having sex with non-regular partners in those countries was higher than that for women. In contrast, the percentage of women using condoms with non-regular partners was lower than that of men.
- In 2007, 18% of pregnant women in low- and middle-income countries received an HIV test, and 33% of pregnant women living with HIV received antiretrovirals (ARV) to prevent transmission to their children, a substantial increase compared with only 10% in 2004.
- Access to ARV therapy (ART) quadrupled from 7% in 2003 to 31% in 2007. In many countries, women have access to treatment in proportion to their expected need.
- Although in most parts of the world women live longer than men, AIDS has driven women's life expectancy below that of men in Kenya, Malawi, Zambia and Zimbabwe.

over economic resources, the violence perpetrated against them, the norms related to women's sexuality, and women's lack of access to information about HIV. Gender inequalities also affect women's experience of living with HIV, their ability to cope once infected, and their access to HIV/AIDS services. Despite this knowledge, many HIV/AIDS policy-makers, programme managers and health-care providers remain uncertain about how to address gender inequalities adequately in the design and delivery of programmes and services.

The mandate to integrate gender into HIV/AIDS programmes has been reinforced through various international agreements and declarations, including the Programme of Action of the 1994 International Conference on Population and Development (ICPD) and the Beijing Declaration and Platform for Action of the 1995 Fourth World Conference on Women (FWCW). Both of these conferences called for gender equality and gender mainstreaming, the empowerment of women, and the comprehensive fulfilment of women's sexual and reproductive health and rights. The 2001 and 2006 United Nations General Assembly Declarations of Commitment on HIV/AIDS expressly recognized the need for countries to address gender inequality as a key driver of the epidemic (5). With support from the global public health community, countries are attempting to meet the Millennium Development Goal (MDG) to halt and reverse the spread of HIV/AIDS by 2015 through universal access to HIV/AIDS prevention, treatment and care by 2010.

Gender equality and women's empowerment are necessary for the fulfilment of all MDGs, as well as being goals in their own right (6). Integrating gender into policies, programmes and services makes them more responsive to the social, economic, cultural and political realities of users and beneficiaries. This can help HIV/AIDS programmes and services better inform and empower clients, and improve access to and uptake of services. Thus, integrating gender not only contributes to improved health outcomes, but also to health equity and social justice (7).

## Scope

While recognizing that tackling HIV/AIDS and gender requires a multisectoral approach, this tool focuses on what can be achieved through the health sector in order to improve access and responsiveness to women's specific needs, and, hence, the quality of programmes and services delivered to them. Four specific HIV/AIDS programme areas that have a primary interface with the delivery of health-care services are covered in this tool: HIV testing and counselling; prevention of mother-to-child transmission of HIV (PMTCT); HIV treatment and care; and home-based care for people living with HIV. These areas have received insufficient attention with regard to the effective integration of gender into programme design and delivery. The information in the document is based on available research, and on experience derived from programmes addressing the gender dimensions of HIV/AIDS, as well as experience from other health programmes in various contexts.

HIV interventions such as the promotion of male and female condoms, behaviour change communication, programmes focusing on vulnerable groups, and programmes for diagnosing and treating sexually transmitted infections (STI) must remain central to HIV/AIDS programming. However, these are *not* covered in the present document, as there are already several published guidelines, training manuals and tools supporting the integration of gender into these programme areas and services (8–12). The present document complements some of these previous efforts on integrating gender into HIV/AIDS programmes.

## Outline

**FIGURE 1** (page xiv) provides a road map to the various sections of this tool. **SECTION 1** provides users with the core concepts related to integration of gender, and the basic steps in designing, delivering and monitoring gender-responsive programmes. It will be most useful to managers responsible for overall HIV/AIDS programmes. **SECTION 2** focuses on HIV testing and counselling, **SECTION 3** on PMTCT, **SECTION 4** on HIV treatment and care, and **SECTION 5** on home-based care. HIV testing and counselling (**SECTION 2**) is positioned as cross-cutting for **SECTIONS 3–5** because of its role as an entry point to PMTCT, HIV treatment and care and home-based care. **SECTIONS 2**

to 5 will be most useful to those specifically responsible for providing HIV testing and counselling, PMTCT, HIV treatment and care, or home-based care services. This includes supervisors, coordinators, counsellors, nurses, and community outreach workers providing these specific services.

In each section, components of programmes or service delivery that are most relevant for integrating gender are elaborated through a description of *key gender-related issues*, and *actions* to address these. Examples of integrating gender into HIV/AIDS and relevant health programmes or services are given, where available, and support tools and materials are presented in order to illustrate how a particular action can or has been operationalised in the field. **ANNEX 1** is a programme manager's checklist, accompanying section 1; and **ANNEX 2** is a service provider's checklist, accompanying **SECTIONS 2 TO 5**. The checklists are meant to support users to assess the extent to which they have integrated gender into their programmes and services. Space for feedback from users is provided in **ANNEX 3**.

## How to use this tool

This tool is intended to transform existing programmes or services by making them more gender-responsive, and to ensure that new programmes or services take gender inequalities into account at the outset through their design and implementation. It is intended to be used in conjunction with existing national and international tools or guidelines on HIV/AIDS programmes, and is *not* intended to replace them. Because programmes and services vary and have distinct needs, users should adapt the tool to meet the specific priorities, scope, resources and constraints of their own activities.

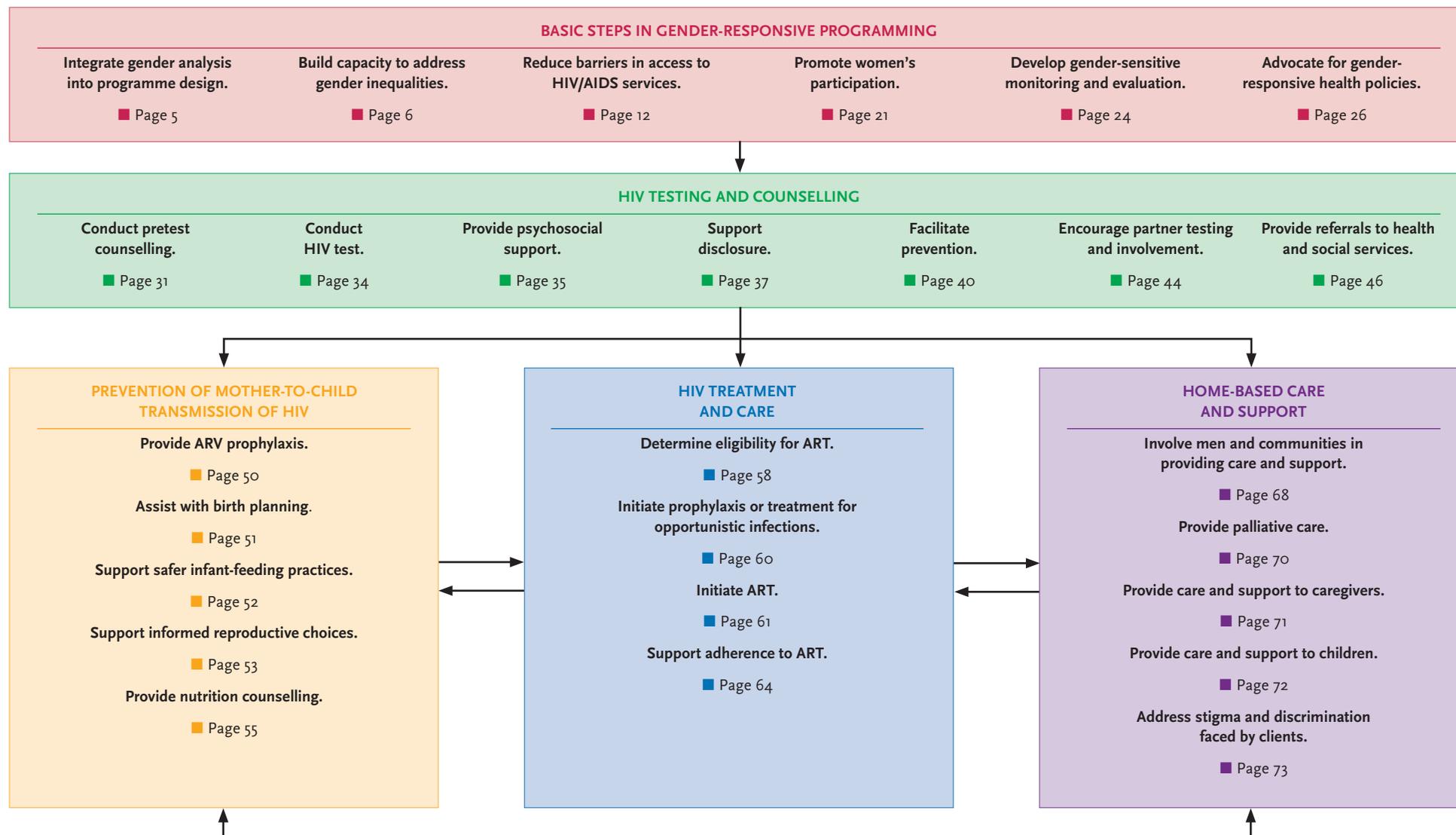
Users can incorporate the actions specified in the programme or service delivery components in the different sections individually, together, or in a phased manner over time, so as to achieve the most effective design and implementation. Potential

entry points for using this tool include: national, regional or district programmes and public sector facilities, private sector programmes (e.g. NGO or private hospital programmes), specific donor-supported programmes, and ongoing pilot initiatives that are to be scaled up.

Based on the field-testing results, some of the suggested uses of this tool are to:

- Conduct stand-alone training on gender and HIV/AIDS for programme managers and service providers. For example, in the United Republic of Tanzania a week-long training of trainers and service providers was conducted in two regions with 19 programme managers and 40 service providers.
- Incorporate the actions recommended in the tool as part of pre-service and/or in-service basic training curricula for HIV testing and counselling, PMTCT, HIV/AIDS treatment, and home-based care and support. This was suggested by several stakeholders at the dissemination meeting for the field test in the United Republic of Tanzania.
- Revise existing relevant national HIV/AIDS and other programmatic guidelines or strategic plans. For example, in the Sudan, through a national stakeholder consensus workshop, the national HIV testing and counselling standard operating procedures were revised to reflect the actions suggested in the tool. In the United Republic of Tanzania, at the dissemination meeting for the field test, stakeholders recommended that the tool be used to integrate gender into the upcoming HIV health sector strategy, and to revise national home-based care guidelines and health management information systems.
- Incorporate gender into regional or district health and HIV/AIDS management plans and teams. This was suggested in the United Republic of Tanzania.

FIGURE 1 ROAD MAP OF THE TOOL FOR INTEGRATING GENDER INTO HIV/AIDS PROGRAMMES



## BOX 2

### Summary of key actions for integrating gender into HIV programmes and services

SECTION 1 Basic steps in gender-responsive programming	SECTION 2 HIV testing and counselling	SECTION 3 Prevention of mother-to-child transmission of HIV	SECTION 4 HIV/AIDS treatment and care	SECTION 5 Home-based care for people living with HIV
Conduct a needs assessment by gathering information on how gender norms and practices, and the power dynamics between men and women, affect uptake of services.	Provide pretest information or counselling that gives clients the option to choose the sex of their counsellors; avoid reinforcing harmful gender stereotypes; assess client risk in the context of sexual power dynamics with partners.	Provide ARV prophylaxis while addressing women's concerns about side-effects and fears about inadvertent disclosure; take account of women's limited autonomy in making reproductive decisions.	Promote equitable access to HIV treatment by ensuring that the eligibility criteria for ART do not exclude certain groups of women, such as single women or migrant women, or those who cannot pay or co-pay.	Support women in their caregiving roles by involving men and communities in home-based care; highlight the value of providing home-based care; and avoid reinforcing the notion that only women can or should look after the sick.
Analyse existing programme objectives in light of the gender-related differences including norms, roles and identities of the beneficiaries; develop specific objectives to address gender-related barriers.	Conduct the HIV test, emphasizing the voluntary nature of the test and confidentiality. This is particularly important for women, who may not feel empowered to say no to health-care providers, and may at the same time fear violence from their partners.	Assist women with birth planning by educating family members and communities about the necessity of supporting women to access skilled care during childbirth; help women and their partners to develop a birth plan for delivery before the onset of labour.	Provide treatment for opportunistic infections by educating women living with HIV about the benefits of, and need for seeking, timely care, as many women may be reluctant to seek treatment due to shame and embarrassment associated with reproductive tract symptoms.	Provide palliative care by supporting caregivers to give pain medication, taking into account cultural differences between men's and women's experiences and expressions of pain.
Build staff capacity to: examine their values, beliefs and practices related to gender roles, and towards most-at-risk people and people living with HIV; address issues of sexuality in interactions with clients; respect patient and human rights as they apply to health and HIV.	Explain test results using simple language, ensuring that the results are understood by clients, especially women, who typically have lower levels of literacy than men.	Support women and their partners to adopt safer infant-feeding practices by providing complete information; help women to make a choice between exclusive breastfeeding and replacement feeding, based on a realistic appraisal of their family situations.	Initiate ART by assessing women's readiness to start it and their support systems; help women to safely disclose their status; and consider women's daily routines in prescribing treatment regimens.	Provide support to caregivers by referring families facing acute food insecurity to food support and micronutrient programmes; provide caregivers with counselling on coping with burnout.

## BOX 2

*Summary of key actions for integrating gender into HIV programmes and services (continued)*

<b>SECTION 1</b> Basic steps in gender-responsive programming	<b>SECTION 2</b> HIV testing and counselling	<b>SECTION 3</b> Prevention of mother-to-child transmission of HIV	<b>SECTION 4</b> HIV/AIDS treatment and care	<b>SECTION 5</b> Home-based care for people living with HIV
Address violence against women by raising awareness of the links between violence and HIV; train staff to respond to violence in the context of HIV testing and safer sex counselling; develop and implement protocols for the management of rape and sexual abuse.	Provide ongoing psychosocial support, taking into account the emotional consequences of women finding out that not only they but also their children may be HIV-positive.	Assist women living with HIV to make informed reproductive choices, taking into account the contradictory social pressures they face to have children, on one hand, and, on the other, to not have children if they are diagnosed with HIV; promote and protect women's reproductive rights; and support women to involve their partners in their reproductive decisions.	Support adherence to ART by identifying and addressing barriers related to gender roles and norms; recognize and address the pressures to share their ARVs with their partners that some women may face; provide counselling to manage side-effects, including those that affect women's body image.	Provide care and support to children by providing information, skills and referrals to community-based resources to assist girls and boys involved in caregiving.
Train staff to: take into account issues of provider-client power dynamics in interpersonal communications; translate medical/technical terms into lay language; protect client confidentiality.	Assist women to safely disclose their HIV status by discussing the benefits and potential disadvantages of disclosure; help those who are at risk of violence with safety planning or mediated disclosure.	Provide nutrition counselling and support to women living with HIV by identifying sociocultural norms and practices that could contribute to weight loss experienced by some women; refer women to food assistance programmes; address women's roles in food preparation by providing counselling on safe food preparation and storage.		Address stigma and discrimination in families and communities by sensitizing community leaders, religious leaders, family members and caregivers regarding gender stereotypes or norms that fuel such stigma.
Create awareness through communication strategies that are accessible to women with different levels of literacy; promote the notion of shared responsibility for sexual and reproductive decisions and health-seeking behaviours; and counter harmful gender norms and practices.	Facilitate the prevention of sexual transmission of HIV by taking into account women's difficulties in negotiating safer sex; provide skills in negotiating use of male and female condoms; assist women to develop a plan for risk reduction; and encourage women to bring their partners for safer sex counselling.			

<b>SECTION 1</b> <b>Basic steps in gender-responsive programming</b>	<b>SECTION 2</b> <b>HIV testing and counselling</b>	<b>SECTION 3</b> <b>Prevention of mother-to-child transmission of HIV</b>	<b>SECTION 4</b> <b>HIV/AIDS treatment and care</b>	<b>SECTION 5</b> <b>Home-based care for people living with HIV</b>
<p>Improve physical access to services by taking into account women's limited autonomy and mobility, and bringing services close to the community; identify appropriate opening hours; and minimize the number of clinic visits that women need to make.</p>	<p>Encourage partner testing and involvement by providing information about HIV and services offered for partners; offer the option of couple testing; and counsel couples to manage feelings of blame, anger and anxiety.</p>			
<p>Eliminate stigma and discrimination in health services by training staff to: recognize stigmatizing beliefs such as "Women are to blame for bringing HIV into the family," or "Women are immoral"; use non-stigmatizing language; and provide clients with information about their rights.</p>	<p>Provide referrals to HIV treatment, care and support and other social services by identifying the range of needs of women living with HIV; compile a directory of all available community resources and services, and follow up on referrals.</p>			
<p>Provide comprehensive services by identifying the range of services needed by women; plan appropriate linkages to medical and psychosocial services.</p>				
<p>Mobilize community participation by meaningfully involving women living with HIV in all aspects of programme design, implementation, and monitoring and evaluation, enabling their needs to be taken into account.</p>				

**BOX 2***Summary of key actions for integrating gender into HIV programmes and services (continued)***SECTION 1**

**Basic steps in gender-responsive programming**

**SECTION 2**

**HIV testing and counselling**

**SECTION 3**

**Prevention of mother-to-child transmission of HIV**

**SECTION 4**

**HIV/AIDS treatment and care**

**SECTION 5**

**Home-based care for people living with HIV**

Engage men as partners, fathers and beneficiaries in order to take into account the ways that power relations with men affect women's access to services; make services more male-friendly; and engage male community leaders to challenge harmful gender norms.

Develop gender-sensitive monitoring and evaluation for measuring the impact gender-responsive HIV programmes and services have on women by ensuring appropriate sex and age disaggregation and gender analysis of routine data.

Address gender inequalities in human resources in order to deliver services that women and their partners are comfortable using; explore ways to recruit, train and retain a mix of male and female health-care providers at appropriate levels.

Promote gender-responsive health financing by addressing the financial and social vulnerabilities of women in user fee policies.

**SECTION 1**  
Basic steps in gender-responsive programming

**SECTION 2**  
HIV testing and counselling

**SECTION 3**  
Prevention of mother-to-child transmission of HIV

**SECTION 4**  
HIV/AIDS treatment and care

**SECTION 5**  
Home-based care for people living with HIV

Advocate for gender equality in laws and policies by promoting those that protect women's rights, such as those that prohibit early marriage, end violence against women, and protect women's rights to property and inheritance.



## SECTION 1

# Basic steps in gender-responsive programming

### Objectives 1

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## Objectives

This section explains the core concepts used in integrating gender into health programmes, and the principles for gender-responsive programming. It describes gender inequalities affecting women's vulnerability to HIV that are encountered across all types of HIV/AIDS programmes, and elaborates related actions to address these. Hence, this section contributes to the creation of a policy and health systems environment that enables gender-responsive HIV/AIDS programmes. It will be most useful to managers responsible for overseeing all types of HIV/AIDS programmes in the health sector, e.g. hospital, facility or overall programme managers, district or regional health managers, and national AIDS control programme managers.

### 1.1 Core concepts for gender-responsive programming

Several core concepts and principles central to the tool are referred to throughout the document. They are described in **BOXES 1.1 to 1.7** (pages 1 to 4). Specifically, in order to integrate or mainstream gender into HIV/AIDS programmes and reduce vulnerability to HIV, programmes must take into account the specific needs of men, women, girls and boys with respect to both biological/sex differences and sociocultural gender differences. Programmes should also promote both gender equality and health equity and should be grounded in a rights-based approach. This requires challenging harmful sociocultural norms and stereotypes related to masculinity and femininity. Another concept critical to gender-responsive HIV/AIDS programming is that of sexuality. Taboos related to sexuality exacerbate the spread of HIV/AIDS, and gender influences sexuality and HIV risk in several ways discussed throughout this document.

#### BOX 1.1

##### Sex and gender (13, 14)

**SEX** refers to the different biological and physiological characteristics of males and females (e.g. reproductive organs, hormones, chromosomes).

**GENDER** refers to what a society believes about the appropriate roles, duties, rights, responsibilities, accepted behaviours, opportunities and status of women and men in relation to one another, i.e. to what is considered “masculine” and “feminine” in a given time and place. In simple words, people are born female or male but learn to be girls and boys who grow into women and men. This learnt behaviour makes up gender identity and determines gender roles.

Gender-related beliefs, customs and practices vary in the lives of women and men, and within and between cultures. Gender roles are often unequal and hierarchical. Women generally do not have equal access to resources such as money, power and influence, relative to men. In most societies, what is defined as “masculine” is more highly valued than what is defined as “feminine”. This gives rise to gender inequalities.

The following examples show how gender inequalities affect HIV/AIDS programmes.

- Women may not have the power to negotiate condom use with their partners. Risk-reduction counselling that does not empower women may be less effective than HIV/AIDS programmes that provide skills to negotiate safer sex.
- Women are often fearful that abandonment or violence would occur if they disclosed their HIV status to their partners, and this is a barrier to HIV testing.
- In many societies, women need permission from partners and families to seek health care, which reduces their access to health services, including those for HIV.

## SECTION 1: BASIC STEPS IN GENDER-RESPONSIVE PROGRAMMING

## BOX 1.2

**Gender equality and equity in health (14, 15)**

**GENDER EQUALITY** refers to the equal treatment of women and men in laws and policies, and equal access to resources and services within families, communities and society at large. In other words, women and men should have the same opportunities to access and control socially valued goods, tools and resources, including, but not limited to, legal entitlements, education, health-care services, employment opportunities and civic participation. In order to achieve gender equality it is sometimes necessary to support groups of people with limited access to such goods, tools and resources. Usually these groups consist of women, as they have often been disadvantaged through the years. Gender inequality is generated by society's written and unwritten norms, rules, laws and shared understandings. It is pervasive across societies and is the most prevalent form of social inequality. It cuts across other forms of inequality such as class, caste, race and ethnicity.

**EQUITY** differs from equality: while equality carries a notion of sameness, equity carries a notion of fairness. A focus on gender equality would argue that men and women should be treated in the same way. A focus on equity in health refers to the absence of unfair and avoidable or preventable differences in health between populations or groups that are defined socially, economically, demographically or geographically. In order to promote equity in health, therefore, the different and unequal needs of, and barriers affecting, women and men in accessing and benefiting from health-care programmes must be considered when resources are being allocated to programmes, as well as when programmes are being designed, implemented and monitored.

Both equality and equity should be promoted in HIV/AIDS programmes. Gender equality is a prerequisite for health equity because, in order to have fairness, all people must have the same chances and opportunities to benefit from the fair policies and programmes that health equity requires.

## BOX 1.3

**Gender mainstreaming (16)**

The Beijing Platform for Action defines gender mainstreaming as the process of assessing the implications for women and men of any planned action, including legislation, policies or programmes, in all areas and at all levels. It is a strategy for making women's as well as men's concerns and experiences an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes in all political, economic and societal spheres, so that women and men benefit equally from these, and inequality is not perpetuated. The ultimate goal is to achieve gender equality.

## BOX 1.4

**Gender-sensitive and gender-responsive programming (17)**

**GENDER-SENSITIVE** programming refers to programmes where gender norms, roles and inequalities have been considered and awareness of these issues has been raised, although appropriate actions may not necessarily have been taken. For example, in a gender-sensitive PMTCT programme there is explicit acknowledgement that women may not have the status, rights and decision-making power to practice safer sex and adopt safer infant-feeding practices.

**GENDER-RESPONSIVE** programming refers to programmes where gender norms, roles and inequalities have been considered, and measures have been taken to actively address them. Such programmes go beyond raising sensitivity and awareness and actually do something about gender inequalities. For example, a gender-responsive PMTCT programme is one where women's lack of decision-making is addressed by reaching out to men and the male partners of women (with the women's permission), to promote joint decision-making regarding safer sex and infant feeding.

### BOX 1.5

#### Sexuality (18, 19)

A working definition is that sexuality is a central aspect of being human throughout life, and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. It is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors. Gender influences sexuality, sexual behaviour and the risk of HIV in several ways. This includes ideas that women have to remain pure and virginal until marriage, preventing them from accessing HIV information, and that men have to engage in heterosexual sex only, or dominate women in sexual interactions, in order to prove their masculinity. Such notions contribute to prejudice against men having sex with men, and compromise women's ability to negotiate safer sex with their partners.

### BOX 1.6

#### Practical versus strategic needs (20)

To plan programmes and services from a gender perspective an important distinction is made between practical and strategic needs.

The **PRACTICAL NEEDS** of women are those that correspond to their immediate, perceived necessities. For example, practical needs arise out of women's responsibility for the health and well-being of their families. Providing good quality, easily accessible health-care services, and ensuring easy access to clean water would be considered as meeting women's practical needs. Likewise, HIV/AIDS services that are easily accessible, confidential, clean, and have well trained staff would be considered as meeting women's practical needs.

The **STRATEGIC NEEDS** of women are those that are related to their position as subordinate to men in society. These needs relate to the gender division of labour, power and control, and include issues such as legal rights, violence, equal wages and women's control over their bodies. Therefore, programmes, policies or services that meet women's strategic interests go a step further than those that only respond to women's practical needs. In addition to meeting women's basic necessities, such programmes and services also seek to challenge and transform existing harmful gender roles and stereotypes and women's subordination to men. For example, beyond providing male and female condoms to women, HIV/AIDS programmes and services considered as meeting women's strategic needs would also teach skills to negotiate safe sex, make women aware of their rights and risks related to HIV, and would involve and support men to take responsibility for safer sex.

While it is important that women's practical needs be met, this alone will not transform their situation. Therefore, actions to also address their strategic needs are equally important if they are to have lasting benefits. Throughout this document, actions that are suggested to address gender inequalities respond to both women's practical needs for quality HIV/AIDS services as well as strategic needs for transforming their roles and relationships with partners and in the larger community.

## 1.2 Principles for gender-responsive programming

**BOX 1.7** summarizes the core principles of HIV/AIDS programming. Although these principles are not articulated explicitly in gendered terms, they are the basis for client-centred HIV/AIDS programming, and, hence, meet the practical needs of women for good quality services.

The principles for gender-responsive programming are based on a quality-of-care framework, which places the client at the centre of programming and service delivery.<sup>1</sup> This framework emphasizes the importance of technical standards, positive attitudes on the part of health-care providers, and increasing client access to information about services. It is applicable to public and private sector programmes in clinical as well as community-based settings. (21–23) The framework specifies that provision of good quality care needs to take into account the specific needs of women and men, and promote and respect the human rights of clients. For example, it is important to consider how gender norms affect women's lives and health, and how providers' own attitudes towards gender equality can affect their interactions with their female clients. Likewise, health programmes must enable staff to promote and protect their clients' rights to informed consent, informed choice, respectful and non-discriminatory treatment, and confidentiality, as well as to sexual and reproductive health.

<sup>1</sup> The quality-of-care framework was initially developed for improving family planning services and can be applied to improve HIV/AIDS programmes and services.

### BOX 1.7

#### Core principles for HIV/AIDS programming (21, 22, 24, 25)

HIV/AIDS programmes and services must be governed by the following core principles:

**NON-DISCRIMINATION:** Treat all clients fairly, regardless of age, sex, sexual orientation, gender identity, ethnicity, religion, class, occupation and mode of transmission.

**INFORMED CHOICE:** Enable clients to make well-considered, voluntary decisions by providing a full range of information and options related to their health care.

**INFORMED CONSENT:** Provide sufficient information about medical procedures and tests to ensure that these are understood, and respect the individual's autonomy in making fully informed decisions.

**CONFIDENTIALITY:** Ensure that all medical records and information are kept confidential. Only health-care professionals with a direct role in the management of clients' or patients' cases should have access to such records, on a need-to-know basis.

**RESPECT FOR ALL:** Each programme stakeholder and beneficiary must be treated with respect and dignity.

**ACCESS FOR ALL:** Make services accessible to as many people as possible with regard to availability, affordability and acceptability.

**WORKING IN PARTNERSHIP:** Build partnerships between government and civil society, and among all social sectors, both public and private.

**LINKING PREVENTION, TREATMENT AND CARE:** Build comprehensive programmes by linking HIV prevention, treatment and care services, as well as other related health services needed by clients.

**MEANINGFUL PARTICIPATION AND INCLUSION OF PEOPLE LIVING WITH HIV AND OTHER AFFECTED GROUPS:** Actively involve people living with HIV in all aspects of the design, planning and delivery of programmes. This includes their involvement as decision-makers, experts and implementers. The participation of people living with HIV must be based on voluntary disclosure of HIV status, and supported through skill and capacity-building.

**PROMOTING THE RIGHTS OF INDIVIDUALS AND GROUPS:** Promote, respect and enforce the human rights of clients or patients, including the right to adequate health information, and reproductive rights.

**FOSTERING ACCOUNTABILITY:** Foster the accountability of all staff, including programme managers and decision-makers, for the achievement of gender-related goals and objectives.

**EMPOWERING COMMUNITIES:** Contribute to the creation of an enabling environment for clients by empowering individuals and communities through outreach and community education about HIV/AIDS and related gender inequalities.

### 1.3 Addressing gender inequalities in overall programme design and service delivery

The following broad programme components, and the specific actions suggested within each of these components, will assist in creating a supportive environment for the integration of gender across all types of HIV/AIDS programmes. They apply to programmes for HIV testing and counselling, HIV treatment and care, and home-based care.

- 1.3.1 Integrate gender analysis and gender-responsive actions into programme design.
- 1.3.2 Build the capacity of programme staff to respond to gender inequalities.
- 1.3.3 Reduce barriers to access to HIV/AIDS services.
- 1.3.4 Promote women's participation.
- 1.3.5 Develop gender-sensitive monitoring and evaluation.
- 1.3.6 Advocate for gender-responsive health policies.

#### 1.3.1 Integrate gender analysis and gender-responsive actions into programme design

##### CONDUCT NEEDS ASSESSMENTS THAT INCLUDE GENDER ANALYSIS

##### KEY ISSUES

■ Many needs assessment efforts are “gender-blind”, that is, they do not explore or take into account the differential risks, vulnerabilities and barriers in access to services faced by women and men, nor do they situate these in the sociocultural and economic realities of programme beneficiaries, such as unequal power relations, gender roles, and harmful norms and practices.

##### ACTIONS

- Conduct a needs assessment that includes a gender analysis of issues affecting programme uptake and implementation. A gender analysis involves understanding how inequalities between women and men contribute to who gets sick, and where, how, when, why, and with what consequences. For example, explore the following:
  - Which groups are more likely than others to contract HIV, and why?
  - Where services are provided, are they physically accessible to women?
  - Is information about HIV and services available for women and tailored to their needs?
  - Are there concerns about privacy, the attitudes of health staff or language barriers?
  - What are the costs of the services for clients, and are they affordable to women?
- Collect and analyse disaggregated data (e.g. by sex, age and rural or urban area) related to illness patterns, underlying factors, and the use of health services.
- Gather supplementary information on sociocultural and economic factors with regard to gender norms, practices and power relations between men and women, in order to understand the context in which health outcomes and access to services may be compromised for women.
  - For example, carry out a rapid assessment in order to understand how household decision-making or control of resources may affect women's access to HIV treatment and care services.
- Involve community members and other stakeholders (e.g. people living with HIV, community leaders, NGOs) in this process so as to have a better understanding of their perspectives and to engage them in programme design.
- Take into account any biases that may result from unequal power relations among different community groups or members due to age, ethnicity or other differences.
  - For example, involving only older, more vocal women in a needs assessment may not adequately reflect the needs of young women and new mothers, who may be disempowered because of their age or status as daughters-in-law.

## SECTION 1: BASIC STEPS IN GENDER-RESPONSIVE PROGRAMMING

## DEVELOP GOALS AND OBJECTIVES TO ADDRESS GENDER INEQUALITIES

## ACTIONS

- Examine how inequalities experienced by women, harmful sociocultural norms, and women's roles could affect programme goals.
  - For example, if one of the primary goals is to increase women's participation in PMTCT programmes, identify barriers faced by women in attending antenatal services, or explore why women do not return for HIV test results.
- Develop objectives to address barriers that women face as a result of the inequalities they experience.
  - For example, if lack of permission from male partners is identified as a barrier to women's participation in programmes, develop an objective to increase male involvement by providing male partners with information about and services for HIV testing. Identify specific objectives to reach and target men, including making services more male-friendly.

## 1.3.2 Build the capacity of programme staff to address gender inequalities

## BUILD STAFF CAPACITY TO ADDRESS GENDER, SEXUALITY AND HUMAN RIGHTS AS THEY RELATE TO HIV/AIDS

## KEY ISSUES

- Programme staff may not be aware of how the different roles, responsibilities and degrees of power of women and men in society contribute to their unequal access to, and control over, resources. They may not understand how these inequalities create barriers to women's access to health services and affect women's health outcomes (26).
- For various reasons, programme staff may not be willing or able to address harmful gender norms in their communities, unequal power relations between female clients and their partners, gender-based violence, or the sexual behaviours of their clients. Programme staff may consider certain harmful gender norms to be normal, or may themselves experience the inequalities that their clients face and may, therefore, accept them as legitimate (e.g. they may accept men coercing their wives to have sex as normal). They may believe that addressing gender is not part of their mandate or scope as health workers. They may face high workloads or believe that a woman's lack of power to persuade her partner to practice safer sex is a family matter in which they should not interfere. They may also not know how to explore inequalities experienced by their clients, or what to do about them. They may face institutional constraints whereby these issues are not considered to be a health priority or an important area for intervention.
- Programme staff may hold beliefs and values related to gender, sexuality and gender-based violence that reflect the societies in which they live. For example, they may believe that relations between unmarried girls and boys or older men, or exchanging sex for money, or same-sex relations between women or between men, are deviant behaviours. Such beliefs and values may translate into judgemental attitudes, blame, prejudice or discriminatory practices towards some clients, including those living with HIV. This may deter clients from seeking HIV/AIDS services.
- Programme staff may not be aware of the rights of patients (including the rights of people living with HIV), human rights charters that their countries have signed, or the sexual and reproductive rights of their clients. They may not be aware of laws and policies in their countries that promote and protect such rights, or they may believe that upholding or promoting these rights is not part of their job.
- Many programme staff providing HIV/AIDS services are not comfortable discussing issues related to sexuality and sexual behaviour, and may even be reluctant to discuss or demonstrate condom use.

**ACTIONS**

- Through in-service and pre-service training of programme staff, provide information on, and generate awareness of, how gender inequalities increase vulnerability to HIV/AIDS.
- Identify both institutional and personal barriers that programme staff face in addressing gender inequalities, sexuality and rights with their clients. Through training, assist them to develop solutions to address these.
- Highlight the relevance of addressing gender inequalities, sexuality and human rights for improving quality of care.
- Highlight what the health sector can and cannot do to address gender inequalities and sexuality, and to protect and promote the rights of clients.
  - In many instances, for example, if health-care providers ask, they may be the first persons with whom women discuss their problems and concerns about sexual relationships. This opportunity may enable programme staff to provide appropriate advice that takes into account the realities of women's situations.
- Help programme staff to examine their values and beliefs about women's and men's roles in society and the family, harmful social norms and practices, and sexual behaviours. This may help programme staff understand their own prejudices and behaviours towards their clients, including those belonging to most-at-risk groups such as sex workers, young girls and people living with HIV.
- Address the comfort levels of programme staff in discussing issues of sexuality and sexual behaviour, orientation and practices, and in demonstrating condom use to clients, as these matters are vital for providing HIV/AIDS services. Facilitate discussions on taboo sexual activities such as premarital and extramarital sex and same-sex relationships.
- Facilitate a discussion of patient rights and human rights as they apply to health and HIV, including the rights of people living with HIV and the reproductive rights of all clients. A charter of patients' rights and reproductive rights could be made available to programme staff (see **BOX 1.8** on page 8 for an example of reproductive rights) (27).
- Provide clients with information on relevant laws, policies and operational procedures that exist to protect and enforce these rights, and of programme staff's own entitlement to the same rights and to freedom from discrimination.
- Emphasize that the responsibilities of programme staff in addressing gender inequalities and sexuality lie primarily in listening, validating clients' feelings, being empathetic and non-judgemental, providing accurate information, providing options, assisting clients in appraising their situations and making plans, and providing appropriate referrals to other resources or care when necessary.
- Through training, provide opportunities for programme staff to reflect on unequal power relations, sexuality and related vulnerabilities to HIV in their own lives.
- Develop support mechanisms so that when difficult questions or issues arise in the lives of clients, programme staff can seek help if they don't know what to do.
  - This may include developing a community resources list and inviting community-based organizations, the legal and judicial sectors (e.g. police, legal services) and NGOs to explain the services they provide, or to inform programme staff about laws protecting the rights of women.
- Integrate training on gender, sexuality and human rights into a broader capacity-building strategy for HIV/AIDS programmes.
  - For example, integrate such training into basic training on HIV testing and counselling or on HIV treatment and care. This will enable the participants to more concretely link gender, sexuality and human rights concepts to skills learnt in implementing programmes and providing services, e.g. providing gender-responsive prevention counselling or adherence support.
- Follow up training on gender with regular support, supervision and performance appraisals of programme staff. Trained programme staff who expect some sort of follow-up activity and whose supervisors promote gender equality are more likely to apply what they have learnt to their work than would otherwise be the case.

**BOX 1.8****Examples of reproductive rights (27)**

The following examples of reproductive rights are adapted from the WHO manual on gender and reproductive rights in reproductive health. They can be used to protect and promote gender equality in sexual and reproductive health, including in matters related to HIV.

**RIGHT TO LIFE:** This right is traditionally understood as freedom from arbitrary deprivation of life. However, according to recent interpretations given by human rights courts, it also includes the positive obligation of the state to prevent, for example, mortality related to HIV/AIDS. The right to life can be invoked to provide treatment to the millions of people living with HIV.

**RIGHTS TO BODILY INTEGRITY AND SECURITY OF THE PERSON:** Traditionally related to actions concerning individuals in the custody of the state. Recently, however this right has been also interpreted in the context of security from sexual violence and assault by one's partner or others. This right also encompasses the right of women living with HIV to make free, non-coercive choices with respect to their fertility (e.g. without being compelled to be sterilized or to undergo abortion without their consent).

**RIGHT TO PRIVACY:** This right traditionally refers to privacy in relation to a person's home or correspondence. However, it is also applicable to protect the sexual freedom of persons. In the context of HIV testing and counselling, it can also apply to the right of a person to have his or her HIV status be kept confidential, and to receive family planning services according to his or her choice.

**RIGHT TO THE BENEFITS OF SCIENTIFIC PROGRESS:** This right encompasses, for instance, women's right to protect themselves from HIV through access to microbicides or female-controlled prevention methods, such as female condoms.

**THE RIGHT TO SEEK, RECEIVE AND IMPART INFORMATION:** This right refers to the right of men and women, including those living with HIV, to have complete information about HIV and sexual and reproductive health, in order to enable them to make fully informed choices about prevention, testing, treatment and care.

**THE RIGHT TO EDUCATION:** Protecting and promoting the right to education includes women and girls' right to free and accessible education. This has particular importance in the context of HIV/AIDS, as there is clear evidence that girls' education helps them practise safer sex and protect themselves from HIV.

**THE RIGHT TO HEALTH:** The right of individuals to attain the highest attainable standard of physical and mental health implies the responsibility of governments to their citizens to create conditions for all to enjoy the highest attainable standard of health. This responsibility includes the provision of facilities to treat illness, including HIV/AIDS, and facilities for the rehabilitation of health, with special attention to those who are in a vulnerable situation, including young women and women living with HIV, children, sex workers, and injecting drug users. Governments have a responsibility to provide comprehensive HIV prevention, treatment and care services to these populations, including, for example, cervical cancer screening services for women living with HIV.

**THE RIGHT TO EQUALITY IN MARRIAGE AND DIVORCE:** This right is vital for enabling women to control and make decisions about their lives. In relation to HIV, it is applicable to young girls' right to not be coerced into early marriage, which makes them vulnerable not only to HIV, but also to many other reproductive health problems. This right is violated when women whose husbands die of HIV/AIDS are forced to marry other male family members, a customary practice in some countries. The right to equality in marriage should be especially protected in situations where women are abandoned by their husbands because of their HIV status.

## BUILD CAPACITY TO RESPOND TO VIOLENCE AGAINST WOMEN

Violence against women is one of the most pervasive forms of gender inequality. It increases vulnerability to HIV and can also be a consequence of being diagnosed with HIV. It is important to recognize the links between violence against women and HIV, and to address such violence as an integral part of an HIV/AIDS response.

### KEY ISSUES

- Violence prevents many women from negotiating safe sex, including the use of condoms, with their partners, and is therefore likely to arise as an issue in risk-reduction counselling (28, 29).
- Research shows that, for some women, fear of violence is a barrier to disclosure of HIV status, and that, for a small proportion of women, violence is an outcome of disclosure (28, 29).
- Women may accept violence against women as normal and in some situations may even justify it (e.g. in cases where a married woman refuses to have sex with her husband).
- Women may be reluctant to disclose their experience of violence to health workers because of the fear and stigma associated with it.
- Programme staff themselves may experience violence. They may accept different forms of abuse as normal or feel helpless to do anything about them.
  - For example, an intervention involving training on gender-based violence for nurses providing voluntary counselling and testing (VCT) services in South Africa indicated that the nurses themselves needed the opportunity to discuss and reflect on issues of violence and gender inequality in their own relationships (30).
- A lack of availability of referral services for addressing violence makes it difficult for HIV programme staff to address violence against women.

### ACTIONS

- Raise awareness among programme staff, clients and communities regarding the links between violence against women and HIV/AIDS by developing and disseminating information and advocacy materials about how HIV and violence are interlinked.
- Include training on violence against women as a part of overall gender, sexuality and human rights training, or incorporate it as a part of core training on HIV testing and counselling or safer sex/risk-reduction counselling.
- Where referral services are available, prepare a list of them and work with existing groups such as NGOs, women's groups, peer support groups and shelters for women experiencing domestic violence.
  - For example, develop a two-way referral process to help women who experience violence to access both health and social services.
- Develop and implement protocols for the management of rape and sexual abuse, including the provision of post-exposure prophylaxis (PEP) where appropriate, as well as emergency contraception. This should be done in line with WHO<sup>1</sup> and national guidelines on PEP (where available).
- Develop mechanisms for providers to address violence in their own lives, including through referrals to counselling services if these are available.
- **BOX 1.9** on page 10 outlines a resource for building the capacity of programme staff to identify and respond to women who may be at risk of violence from partners or other family members.

<sup>1</sup> See WHO guidelines on medico-legal care of victims of sexual violence (31) and the joint WHO/ILO guidelines on post-exposure prophylaxis (PEP) to prevent HIV infection (32).

**BOX 1.9****Capacity-building for addressing gender-based violence through VCT (33)**

Vezimfihlo! (*To break the silence*) is a training programme developed in South Africa that aims to equip counsellors who work in VCT settings to address gender-based violence. The programme explores why gender-based violence is a public health concern and how health workers can help abused patients; it also builds identification, consultation, communication and response skills. The target audience includes lay counsellors and other service providers who give VCT. Key topics in the manual include:

- the social construction of gender
- gender-based violence – a public health priority
- how the health sector can respond to gender-based violence
- attitudes to gender-based violence
- gender-based violence – causes and consequences
- experiences of gender-based violence
- identification of gender-based violence
- barriers to the identification and disclosure of violence
- the role of the health sector in ensuring safety
- asking about abuse and performing safety assessments
- consultation skills – how to improve communication
- options for abused women
- gender-based violence in VCT
- building support systems, including community resources.

**Key messages for addressing violence against women in the health sector**

- Gender-based violence is a health problem, so the question is not whether to engage with it but how to do so.
- Health workers in a VCT setting, and those supporting abused women, need to engage with factors that place women at risk and interfere with the ability of HIV-positive women to live healthy lives.
- The role of health workers in addressing gender-based violence is to:
  - ask about it
  - be empathetic and non-judgemental
  - discuss how it can increase HIV risk
  - discuss its effect on disclosure and living positively with HIV
  - talk about safety and give information about options.

## BUILD CAPACITY FOR GENDER-RESPONSIVE INTERPERSONAL COMMUNICATION

Interpersonal communication between health workers and clients, including through counselling, comprises a key element of HIV/AIDS programmes and services, and gender inequalities in this area can impede the uptake of and delivery of services.

### KEY ISSUES

■ Unequal power dynamics between programme staff and clients can inhibit interpersonal communication. This circumstance may be exacerbated not only by differences in the educational levels of providers and clients but also by ethnic, class, age, caste and gender differences (34).

■ For example, in many societies, women are socialized not to question, assert their own opinions, or challenge the opinions of men. They may therefore, hesitate to ask questions of, or express their concerns to, male providers (35).

■ The use of technical and medical terms may be intimidating, especially for people who are not literate. In many settings, women are more likely than men to be illiterate, or may be less literate than men (36).

■ For example, a multi-country study to improve provider-client relations in delivering gender-sensitive services to women showed that providers sometimes reinforced unequal power relations with clients by using complicated words (37).

■ A lack of confidentiality where family members are present, or where there is no private space, may prevent women from discussing sensitive issues (e.g. sexual relationships, coercion, violence) with health workers (38).

■ As a result of patient overload and a lack of supervision and training, health workers may not be able to adequately provide information, answer questions, or spend time listening to women's concerns (39).

### ACTIONS

■ As part of basic training in HIV/AIDS services, such as HIV testing and counselling or HIV treatment and care, build skills in gender-responsive interpersonal communication among programme staff, especially those who are most likely to spend a lot of time directly interacting with clients (e.g. counsellors). This includes skills in listening, validating the client's feelings, and showing empathy and respect to clients in both verbal and non-verbal ways.

■ Sensitize providers to be aware of power differences between themselves and clients that arise from gender, class and ethnic differences, and of conveying judgemental attitudes and personal biases to clients.

■ Build providers' skills in explaining medical and technical terms in lay language so that they are understood by clients.

■ Also address providers' non-verbal communication to their clients (e.g. facial expressions, gestures), which can convey as much as verbal communication.

■ Support confidentiality in interpersonal communication (e.g. by using a separate space, or by waiting until only provider and client are in a room before sensitive issues are raised).

■ Recruit and train peer or lay counsellors from within the community to provide additional information and counselling related to HIV/AIDS.

■ **BOX 1.10** on page 12 describes a gender-responsive counselling intervention for women.

## SECTION 1: BASIC STEPS IN GENDER-RESPONSIVE PROGRAMMING

## BOX 1.10

**Women-centred gynaecological counselling (40)**

The women-centred health project in India was a collaborative intervention involving the Municipal Corporation of Greater Mumbai, SAHAJ (a local NGO) and the Royal Tropical Institute (KIT), of Amsterdam. The project aimed to provide gender-sensitive reproductive health care to women through clinical as well as counselling interventions. Communication with health-care providers was observed to be an important aspect of the quality of care from the perspective of poor, marginalized women seeking health-care services. The project therefore developed a counselling centre that was based on the concept of women-centred counselling.

Women-centred counselling was defined as an integrated and empowering approach enabling women to regain control over their lives, helping them to make choices and set goals, and encouraging them to believe in and nurture themselves. Training was developed for nurses, community health workers and medical officers. The topics included: women-centred counselling; counselling skills and principles; communication skills and principles; communication about issues of sexuality; counselling for adolescent girls; gender-based violence and gynaecological health; and documentation and recording. The training also included skill-building exercises using role-playing, a focus on the qualities of a good counsellor, and concepts of gender and sexuality. It was supported by:

- regular feedback on communication style through structured observations of provider-client communication;
- development of checklists for self-evaluation;
- fact sheets for recording counselling cases;
- checklists to monitor the quality of counselling.

Evaluation focused on whether counsellors established a good rapport with clients, ensured confidentiality, gave accurate and complete information, ensured gender sensitivity in their messages, used visual aids, used sensitive and appropriate language, spent adequate time with clients, documented information, and scheduled follow-up counselling.

**1.3.3 Reduce barriers in access to HIV/AIDS services**

The barriers in access to HIV/AIDS services that women face are usually related to service delivery and community and household factors. Programmes that address such barriers to access are responding to women's practical needs for quality services that are easily accessible.

**CREATE AWARENESS ABOUT PROGRAMMES AND SERVICES**

The creation of awareness in communities and among individuals about the importance and availability of HIV testing and counselling, HIV treatment and care, and home-based care is a first step towards increasing women's access to and uptake of these services.

**KEY ISSUES**

- Many women do not consider themselves at risk if they have had only one partner or are faithful to their partners. Monogamous women may feel that HIV prevention messages emphasizing being faithful are not relevant to them and hence, may not take appropriate actions to protect themselves from HIV (41).
- Stigma and discrimination associated with being at risk for, infected with, or affected by, HIV/AIDS may particularly deter women from seeking HIV/AIDS information.
  - For example, because societal norms dictate that young unmarried women should not be sexually active or have knowledge about sexual and reproductive health and HIV/AIDS issues, and because of the fear of being labelled "immoral" or "promiscuous", young unmarried women may be hesitant to obtain reliable information on HIV/AIDS (42).
- Women tend to have lower educational and literacy levels than men, and this limits the effectiveness of print media and written communications directed at them (36).
- In many societies, sociocultural norms require women to consult their partners and extended families on key decisions affecting their health, especially their reproductive health, such as those related to the place of delivery (e.g. at home or in a health facility), infant-feeding practices and postpartum care. This has implications for the uptake of HIV/AIDS programmes.
  - For example, research in Botswana and Zambia shows that women trying to decide whether to participate in HIV/AIDS programmes are strongly influenced by the opinions of spouses, partners, and family and community members (43).

## CREATE AWARENESS ABOUT PROGRAMMES AND SERVICES

■ In many settings, pregnant women do not access basic antenatal care, and only come into contact with maternal and child health services if either they need emergency obstetric care or their children need health care after delivery. Thus a lack of awareness of services may be linked to a basic lack of information and to poor access to, and a lack of use of, maternal and child health services (36, 44).

■ Home-based care for people living with HIV is provided mostly within families by females, especially older women and girls, and is often invisible, unremunerated and unsupported by the health sector or communities (36). Often women have to struggle to balance providing care with their other roles, including financially supporting families, or girls have to forgo attending school in order to care for sick family members.

### ACTIONS

■ Develop communication strategies and messages that generate knowledge of the different risks that young women, pregnant women and older women might face with regard to HIV, and that indicate the importance of seeking HIV testing, treatment and care services.

■ For example, married women may need specific messages highlighting the importance of their seeking HIV/AIDS services despite being monogamous. Likewise, specific information and strategies for generating awareness may be required for sex workers, female IDUs, adolescent girls or young unmarried women.

■ Develop messages that acknowledge and value the contribution of women and girls in HIV prevention, treatment and care, as caregivers in families, communities and health services, and as community leaders, mothers and peers, in order to counter some of the stigma and burden of care that women face.

■ Avoid HIV prevention, treatment and care messages that reinforce harmful stereotypes about women, men or any marginalized groups.

■ For example, avoid messages such as one on HIV testing and counselling that recently appeared in an industrialized country: “What kind of mother could have given her baby HIV? An untested one.” This stigmatizes women by implying that it is the mother who is to blame if her child is HIV-positive (45).

■ Develop messages that are positive and show the shared responsibility of women and men for sexual, reproductive and health decisions (such as those concerning HIV testing, condom use, ARV prophylaxis) and for the provision of care to persons living with HIV in families.

■ For example, develop messages showing a husband and wife attending an HIV testing clinic together (see **FIGURE 1.1** on page 14).

■ Deliver messages using media that are accessible to women with different levels of literacy and that appear in a range of different places where women and girls gather (e.g. women’s group meetings, work places, schools).

■ For example, apart from written materials, use visual aids, such as videos in waiting rooms, and radio and television, or community-based approaches such as local theatre, to reach women and girls who cannot read or write (46).

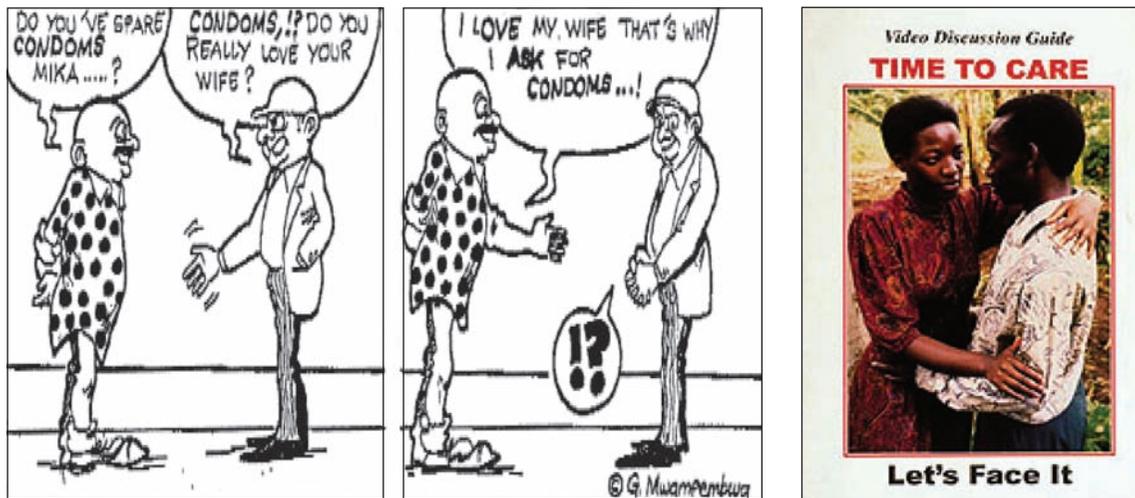
■ Develop communication strategies, materials and messages for men and the male partners of women clients seeking HIV/AIDS services, as well as messages targeted to influential community members and opinion leaders.

■ Involve women living with HIV and community-based groups in designing communication strategies and materials for generating awareness about HIV/AIDS issues and available services.

■ Develop messages and information on harmful sociocultural norms and practices, such as violence against women and restrictions on women’s mobility and autonomy, including those that affect sexual decision-making.

■ Provide information to clients and communities about services that are particularly required by women (e.g. legal services, microcredit schemes, nutrition programmes and childcare).

## SECTION 1: BASIC STEPS IN GENDER-RESPONSIVE PROGRAMMING



Examples of gender-sensitive messages (1, 47)

These materials (left) illustrate the notion of shared responsibility for sexual decision-making and HIV prevention.



Example of a gender-stereotypical message (48)

This image reaffirms the idea that men are active in sexual relationships and women are passive.

FIGURE 1.1 GENDER-SENSITIVE AND GENDER-STEREOTYPICAL MESSAGES

## IMPROVE PHYSICAL ACCESS TO SERVICES

### KEY ISSUES

- Requiring clients to travel long distances to obtain services may especially disadvantage women, as they are often less mobile or have less access to money than men (36).
  - For example, women who need HIV treatment and care may face challenges in adhering to ART due to their limited mobility and other time commitments, which may hinder their ability to return for additional ARVs and follow-up care (49).
- Many pregnant women, including those living with HIV, continue to give birth at home because of transport problems, unaffordable costs, or cultural preferences. Consequently, their access to HIV/AIDS services is constrained (50).
- Women may need permission from their partners or other family members to travel. Moreover, they often have to try to balance seeking health care with domestic tasks, income-generating activities and increasingly, caring for household members with AIDS-related illnesses (36, 44).

### ACTIONS

- Develop strategies to bring services as close to the community as possible, including the provision of services through primary health-care facilities.
  - For example, for an HIV treatment and care programme, deliver ART in neighbourhoods so as to bring drug delivery as close as possible to those being served. This could be done by strengthening the capacity of peripheral facilities and developing community-based mechanisms for re-supplying ARVs, and for follow-up care.
- Work with communities to challenge harmful norms that restrict women's mobility, autonomy and status in the household.
- Consult local communities to identify the most appropriate opening hours for the provision of services.
  - For example, take into account the times when childcare is available in keeping clinic hours that are convenient to women.
- Minimize the number of visits that clients need to make to health facilities.
  - In many settings, for example, rapid HIV testing with same-day results is being introduced, and this has increased the number of women receiving their test results as they do not have to return for them (51).

## IMPROVE HEALTH INFRASTRUCTURE FOR CLIENTS

Poor quality health infrastructure particularly affects women, who often rely on public sector services because they lack the resources that would enable them to use private sector services. Therefore, improving the quality of the health infrastructure addresses the practical needs of women for good quality, accessible health services that are sensitive to their specific situations.

## KEY ISSUES

- In resource-constrained settings, especially in the public sector, the physical structure and layout of health facilities may contribute to inefficient patient flow, overcrowding in waiting rooms, and long queues and waiting times (38–39).
  - For example, the absence of a clean water supply, the lack of clean and separate toilets for women, and a general lack of cleanliness may deter many from seeking services, or make the experience of the service an unpleasant one.
- Interruptions in drug supplies in the public sector force clients to purchase drugs from the private sector. This may jeopardize access to medicines, especially for women who have limited access to cash (39).
- A lack of privacy in consulting rooms may inhibit women from discussing intimate topics in relation to their needs for HIV/AIDS prevention, treatment and care. It may also make women uncomfortable to be physically examined (especially for gynaecological exams) (38).

## ACTIONS

- Develop and implement a quality assurance programme to address health infrastructure issues such as patient flow, waiting space, privacy concerns, cleanliness and separate toilets for women and men.
  - For example, make existing waiting areas friendlier for women with children (e.g. by providing a small children’s play area).
- Improve procurement, supply and inventory, to provide a regular and reliable supply of essential drugs, commodities and medical equipment, so that women do not have to make multiple trips to health facilities, or resort to obtaining their requirements in the private sector.
  - For example, an intervention called “Health Workers for Change” was developed to deliver gender-responsive, quality services to women. The intervention helped providers improve their interactions with clients, and addressed constraints such as the lack of availability of drugs. An evaluation of this intervention, which was implemented in South Africa, Nigeria, Ghana, the United Republic of Tanzania, Kenya and Argentina, showed improvements in the availability of drugs, among other factors, which contributed to better client satisfaction with services (52).
- **BOX 1.11** (below) provides a facility checklist for assessing health infrastructure from a gender perspective.

## BOX 1.11

## Quality-of-care facility checklist (25)

- Does the facility have a specific area for consultation?
- Can clients be heard or seen from outside the consultation area?
- Is there a specific separate and private area for counselling?
- Is there a specific area where clients can obtain general information about the clinic and other educational materials?
- Does the facility have a childcare area?
- Are there separate toilets for women and men?
- Are the bathrooms on the premises satisfactory (clean, stocked, properly functioning)?

## REDUCE STIGMA AND DISCRIMINATION IN HEALTH SERVICES

### KEY ISSUES

- Women's experiences of health services are shaped by their interactions with programme staff. Moralistic views about sex, and corresponding negative or judgemental attitudes towards people living with HIV affect relations between health workers and clients.
  - For example, in one setting, women living with HIV reported being sent home early after a caesarean section and being told that their babies would die as a result of HIV (53).
- Women living with HIV face stigma and discrimination from programme staff.
  - A study in four countries in Asia and the Pacific found that up to 49% of people living with HIV experienced AIDS-related discrimination from health workers. Pregnant women living with HIV were more likely to report coercive HIV testing, or to experience a delay in treatment, or a violation of their reproductive rights (e.g. being coerced into abortion or advised not to have children) than other respondents not living with HIV (54).
- Stigma and discrimination in health-care settings arise in part because programme staff – many of whom at the front lines are women – also fear being stigmatized if they acquire HIV through occupational exposure (55). In part, the fear of occupational exposure may be related to programme staff not being able to practice universal precautions with respect to medical procedures (e.g. they may not have access to gloves, clean needles or syringes while treating clients).<sup>1</sup>

<sup>1</sup> See WHO planning tool on health-care worker protection, which outlines key elements of universal precautions (59).

### ACTIONS

- Develop and implement policies that do not discriminate against people living with HIV, including staff who may be living with HIV (57–58).
- Develop and enforce recourse measures for people who have experienced discrimination in health-care services.
- Help programme staff to clarify their values about sexual and gender norms and talk about their fears related to HIV, and sensitize them to use language that does not stigmatize anyone who seeks HIV services.
- Train health workers to: maintain confidentiality; seek informed consent for procedures; and respect patient rights, including the reproductive rights of women.
  - For example, sensitize providers to respect the rights of people living with HIV to be sexually active, to decide freely and responsibly the number, spacing and timing of their children, and to have the information and the means to do so.
  - Make materials available in clinics, e.g. a charter of rights for people living with HIV. See the WHO and CDC generic training package for prevention of mother-to-child transmission for an example of a charter of client rights (60).
- Provide information to clients about their rights, including those of people living with HIV, so that they are aware of their rights and their entitlement to care without discrimination.
- **FIGURE 1.2** on page 18 describes types of stigma experienced in health-care settings and strategies to combat it.

## SECTION 1: BASIC STEPS IN GENDER-RESPONSIVE PROGRAMMING



General stigma picture 20

**FIGURE 1.2** EXAMPLES OF STIGMA IN HEALTH SERVICES (56)

### Stigmatizing behaviours in health facilities

**FORMS OF STIGMA:** Isolation and neglect of chronically ill patients. Limited physical contact from health workers because of the fear of getting HIV. Lack of contact demoralizes patients and makes them feel unwanted. Health workers gossiping about patient's sexual history (as "promiscuous") and breaking patient's confidentiality. Some health workers give up on patients, assuming they are going to die quickly, so "Why waste our time?" Providers are too scared to get tested themselves, fearing stigma from colleagues.

**STRATEGIES TO COMBAT STIGMA:** Update health workers on HIV, ARVs and stigma through in-service training. Help health workers talk about their own feelings and fears about HIV. Teach skills in how to interact with patients sensitively. Get feedback from clients (e.g. have the community walk through the clinic to identify stigma points).

*(Adapted from the CHANGE tool kit.)*

## PROVIDE COMPREHENSIVE CARE

### KEY ISSUES

- Providing comprehensive health-care services that take into account the needs of women throughout their lives, as well as their multiple roles and responsibilities, is specified as a key gender-responsive approach to women's health in the Beijing Platform for Action (61). A comprehensive approach thus, takes into account the multiple and changing needs and roles of women vulnerable to, living with, and affected by HIV.
- Focusing on the reproductive role of women, e.g. on the prevention of HIV transmission to infants, without addressing the needs of women themselves, fails to provide them with comprehensive, holistic care, which is essential for a gender-responsive approach to the provision of services. Such a narrow focus also misses the opportunity to reach sexually active, non-pregnant women who may be at risk of, or living with, HIV.
- In most settings, HIV/AIDS, reproductive health, maternal health and tuberculosis are addressed in vertical programmes that are not integrated or linked through referral mechanisms. Integration and linkages within HIV/AIDS programmes, and to other services and programmes, improve access to services and provide women with gender-responsive, comprehensive holistic care (62).

### ACTIONS

- Identify the range of services that women need. This includes information about and services related to: prevention of HIV; ongoing HIV counselling; family planning; pregnancy-related care; and treatment for reproductive and sexually transmitted infections, and for opportunistic infections such as tuberculosis.
- Develop or strengthen linkages among HIV testing and counselling, PMTCT and HIV treatment and care programmes and services, and with sexual and reproductive health services (e.g. family planning, STI, screening for cervical cancer) (63–64).
  - For example, train family planning providers to see women living with HIV as part of their regular clientele, offer them a full range of contraceptive options, and refer them appropriately for other health needs.
- Develop a formal or informal referral network among various services.
  - For example, Family Health International has developed three models of referral networks: one for staff in HIV/AIDS programmes or units; another for community-based organizations; and a third in which HIV/AIDS programmes assign a case manager to identify client needs and coordinate different programmes and services (65).

## ADDRESS THE PSYCHOSOCIAL NEEDS OF CLIENTS

## KEY ISSUES

- Many women living with HIV find themselves abandoned, ejected from their homes, without assets (land or other property), and without any means of earning an income or supporting themselves when their husbands die (66).
  - For example, available evidence from Latin America, Africa and South Asia suggests that a fraction (less than 30%) of the land is owned by women as compared to men (36).
- Facing such poverty, many women are forced to exchange sex for money, food or other survival needs, thus putting their health at further risk.
  - For example, a cross-sectional, population-based study in Botswana and Swaziland found that among women not having enough food to eat during the previous 12 months was associated with inconsistent condom use, the exchange of sex for money, and other manifestations of risky sexual behaviour (67).
- Women living with HIV may find themselves without a job and unable to make arrangements for their families and children to be looked after.
- Women living with HIV and their families have to cope with grief, anger, fatigue and fear. They may also face blame and rejection from family members, neighbours, work colleagues and friends.
- Young women and girls may be withdrawn from school to provide care and support for family members living with HIV. This further puts many of them at risk of HIV by denying them an education, the ability to earn an income in the future, and opportunities to gain knowledge, information and skills that would help them to prevent HIV infection (68).

## ACTIONS

- Develop and strengthen linkages to programmes that provide ongoing psychosocial support and counselling, nutrition support (e.g. micronutrient supplementation for HIV-positive mothers and their infants) and home-based care for people living with HIV (69–71).
- Develop and strengthen linkages with social services, including HIV-positive mothers' support groups, legal services, income generation schemes, food security initiatives, home-based and community-based care programmes, orphan care, and services for women living with violence, where available.
  - In Zimbabwe, for example, support groups provided women living with HIV and their families with health education, help with childcare and housework, palliative nursing, and money for medical and funeral expenses. Members of the support groups reported lower levels of depression, anxiety and insomnia than non-members (53).

### 1.3.4 Promote women's participation

The principle of promoting women's participation is based on the understanding that as beneficiaries and community members women often possess the expertise, skills, knowledge, capacity and will to bring about changes in structures, norms and values, and to make informed choices and decisions related to HIV/AIDS (36). Women living with HIV understand from personal experience both the challenges and rewards of using HIV services. Some women living with HIV may be willing to disclose their status publicly and, hence, can openly assist in programme planning, implementation and evaluation. The principle of promoting women's participation is embodied in the Greater Involvement of People Living with AIDS (GIPA) Declaration (73–73). This principle responds to women's strategic needs to transform the underlying conditions that make them vulnerable to ill health and constrain their access to services.

#### MEANINGFULLY INVOLVE WOMEN LIVING WITH HIV

##### KEY ISSUES

- The involvement in programmes of women living with HIV can be undermined by the stigma and discrimination they may experience in publicly disclosing their status, and by the attitudes of programme colleagues and co-workers.
- Sometimes the involvement in programmes of women living with HIV is tokenistic, i.e. they may be invited to give testimonies but their concerns may not be taken seriously, or they may not be involved in making decisions (74).
- The involvement of women living with HIV often relies on their volunteering spirit, which may not be sustainable, as they have to support themselves and their families financially.
- The participation of marginalized women living with HIV may be undermined by the criminalization of their status.
  - For example, sex workers who are living with HIV may be afraid of being reported to the authorities.

##### ACTIONS

- While the involvement of women living with HIV should be encouraged, the HIV status of staff and volunteers working in treatment, care and support programmes is not always known. Disclosure must always be voluntary.
- Facilitate active participation of networks of women living with HIV – including those representing young women and marginalized communities – in designing and delivering programmes at all levels.
- Recognize the value of input by women living with HIV by remunerating them, rather than relying on their volunteering spirit. This may be especially beneficial to women, who often lack alternative sources of livelihood.
- Develop and implement workplace practices, policies and procedures that do not discriminate against employees who are living with HIV.

## SECTION 1: BASIC STEPS IN GENDER-RESPONSIVE PROGRAMMING

## ENGAGE MEN AS PARTNERS, FATHERS AND BENEFICIARIES

In a gender-responsive approach, involving men in HIV/AIDS programmes responds to the strategic needs of women, as the goal of involving men in such programmes is to transform the sociocultural norms, gender roles, stereotypes and unequal power relationships that constrain women's access to and uptake of programmes.

## KEY ISSUES

- Many health programmes, particularly reproductive health services (e.g. family planning, antenatal clinics) do not reach out to men.
  - For example, research conducted in Nepal on barriers to promoting male involvement in maternal health services suggested that hospital policy, problems with facility space, and a lack of enough staff, among other factors, posed barriers in encouraging male involvement in maternal health (75).
- Social norms in many places dictate that women bear the burden of responsibility and the brunt of blame when things go wrong. In many settings, women need permission from men and extended families to make health decisions.
  - For example, Demographic and Health Survey data on women's autonomy show that in some countries up to 75% of women say that their husbands alone are making health decisions (36).
- The lack of male involvement particularly affects the uptake of interventions for PMTCT because some women do not get permission to undergo HIV testing, are afraid to disclose their HIV status to their partners, or are prevented from adopting safer infant-feeding practices (76).
- Norms related to masculinity sanction men to dominate sexual and reproductive decisions, have multiple partners, or perpetrate violence against women. Such norms also prevent men from seeking health-care services, including HIV testing and counselling, until they are very sick, and consequently make both men and women vulnerable to HIV (24).
- Women and girls provide the majority of HIV/AIDS-related care, as this is seen as a continuation of their role as care providers within families.
  - For example, duties that are related to home-based care are seen as domestic and are therefore considered to be women's work (36). This places an enormous burden of care on women, who are not recognized, valued or remunerated for the care work that they perform.
- Men are traditionally associated with earning income for their families and seldom carry out work that is unpaid (36).
- Men may not have the skills necessary to provide care and support – such as cooking, washing clothes, childcare, and treating and washing insecticide-treated nets for malaria prevention – as these tasks are usually learnt and performed by women.
- Men may prefer to listen to, accept, discuss and share issues related to HIV/AIDS, including care and support, with other men rather than with women.

**ACTIONS**

- Target harmful norms related to masculinity that encourage men and boys to dominate sexual decisions, or not to seek health services and information until they are very sick.
- Portray men as positive role models.
  - For example, reach out to young men in communities to teach values about responsible sexual behaviours or greater involvement in fatherhood. Work with men's groups and male community leaders to address issues of men's responsibility in PMTCT and their role as fathers. This will help to mitigate negative outcomes that women may experience as a result of being the first to take home an HIV-positive result, and will make it less likely that men will restrict their female partners' use of services.
- Reach men where they are most likely to gather, e.g. at work, places of worship, bars and sports events. Men can also be reached through workplace programmes and private sector services for STIs and tuberculosis.
- Make sexual and reproductive health services more male-friendly.
  - This can be done, for example, by: making the physical spaces of facilities more male-friendly; making services available at times that are convenient for men; developing information materials targeted to men; training health-care providers, including male staff, to reach out to men; and offering men information on where to access HIV testing and counselling services (77).
- Work with male community leaders to take responsibility for challenging socio-cultural norms that condone violence against women, restrict women's knowledge of sexual and reproductive health, and limit their autonomy.
- Work with male health workers and volunteers to engage other men in providing home-based care.
  - This could involve establishing men's discussion forums or support groups that provide information about caregiving and discuss barriers, challenges and experiences.
- **BOX 1.12** describes a gender-responsive intervention to involve male partners in PMTCT.

**BOX 1.12**

**Involving male partners in PMTCT (78)**

A recent study conducted in Nairobi, Kenya showed that partner participation in HIV testing and counselling of pregnant women receiving antenatal care was associated with an increased uptake of PMTCT. Women attending an antenatal clinic were recruited to the study during their first visit. They were informed about sexual and mother-to-child transmission of HIV, and were encouraged to tell their partners about the availability of HIV testing and counselling. They were asked to return a week later for routine antenatal tests and optional HIV testing and counselling, and were given the choice of attending alone or with their partners.

On the basis of their initial preferences, women and their partners received post-test counselling either individually or together. Women diagnosed with HIV and their partners were asked to return two weeks later, when they were counselled about PMTCT. This included advice on the use of nevirapine and on infant feeding. All women living with HIV were offered both maternal and infant doses of nevirapine. A week after delivery they were asked if their babies had received nevirapine and to describe the method of infant feeding they were using. They were asked to return with their babies after three and six months for additional counselling and optional HIV testing of babies.

Women whose partners came for HIV testing and counselling were three times more likely to receive nevirapine ( $p = 0.02$ ), and more than three times more likely to report using the maternal or infant dose of nevirapine ( $p = 0.009$ ). Women who received HIV testing and counselling with their partners were eight times more likely to attend the follow-up appointment after three months ( $p = 0.03$ ), and were significantly less likely to breastfeed ( $p = 0.03$ ). At three months after delivery, partner notification was associated with a trend for lower HIV infection rates in infants ( $p = 0.07$ ). HIV testing and counselling with a partner was associated with a trend towards more condom use after HIV diagnosis ( $p = 0.07$ ).

Involvement of male partners in HIV testing and counselling was associated with an increased uptake of interventions to prevent mother-to-child and sexual transmission of HIV. The researchers recommended couple counselling as a strategy to reduce perinatal HIV transmission, and emphasized the need for feasible and affordable approaches to encourage men to participate in PMTCT interventions.

### 1.3.5 Address gender in monitoring and evaluation of programmes

#### KEY ISSUES

- Many programmes may not collect the baseline data needed for monitoring and evaluation from a gender perspective.
- Programmes may not have an explicit policy, plan or capacity to develop, gather, analyse and use data disaggregated by sex and other variables, such as age, in order to be able to track gender inequalities in outcomes.
- In the absence of electronic health information systems, many programmes are using paper-based systems. They are burdened with collecting, compiling and reporting many programme indicators. Consequently, the compilation of disaggregated data may not be easy.
- Programme managers may not see the value or utility of disaggregated data for programme monitoring, and may prefer to focus on indicators related to clinical outcomes without disaggregating them.
- Routinely collected data are not necessarily disaggregated appropriately (e.g. by sex and age) for analysing how a programme is affecting women and men of different ages (36).
- Routinely collected data are usually not adequate to monitor or explain underlying sociocultural attitudes, behaviours, and unequal power relationships between women and men (e.g. the negotiation of safe sex within couples, provider attitudes towards women whose tests are positive, women's fear of disclosure).
- Equity in reaching women and men may not be a consideration, either in setting targets for providing HIV/AIDS services or in programme monitoring.

### 1.3.5 Address gender in monitoring and evaluation of programmes

#### ACTIONS

- WHO and UNAIDS monitoring and evaluation guidelines on HIV/AIDS recommend the disaggregation of data by sex and age.<sup>1</sup> In following this recommendation, programmes may need to have a policy and plan for gathering and analysing disaggregated data and using them for making appropriate modifications to programme design and implementation.
- Revise or develop health information systems so as to enable appropriate disaggregation of routine programme indicators (e.g. by sex and age).
- Where specific programme modifications are made in order to address gender inequalities, develop process indicators that measure progress towards programming that reduces these inequalities. Such monitoring may require special or periodic studies or assessments.
- Use qualitative approaches to increase understanding of why certain differences or patterns might be observed in programme outputs and outcomes.
  - For example, if data disaggregated by sex reveal that more women than men are attending services for HIV treatment, a qualitative assessment may yield an understanding of the reasons for this.
- Sensitize programme staff to the importance of collecting, compiling and using disaggregated data.
  - For example, the process of field testing this tool revealed that some programme staff did not understand the relevance of disaggregated data and hence, compiled disaggregated data only sporadically (80).
- Train staff responsible for monitoring programmes to collect, compile, interpret and analyse data for indicators that measure progress towards, and outcomes of, gender-responsive programme strategies.
- Involve women from communities (e.g. networks of women living with HIV, women's groups, youth groups, other civil society organizations, community leaders) in the monitoring and evaluation process so that their needs, priorities and experiences are taken into account in the ongoing improvement and development of programmes (81).
- Consider equity (i.e. in proportion to HIV prevalence and hence, need) in the setting of targets for reaching women and men with services and in programme monitoring.
  - For example, an HIV treatment programme may need to set targets for reaching women to be started on ART in accordance with the local epidemiology (82).

<sup>1</sup> See UNAIDS guidelines on the construction of core indicators for UNGASS reporting (79).

### 1.3.6 Advocate for gender-responsive health policies

To sustain and institutionalize efforts to address gender in HIV/AIDS programmes, it is important that overall health policies, as well as policies indirectly affecting health, promote the goals of gender equality and health equity. HIV/AIDS programme managers may or may not be involved in policy-making, depending on the level at which they operate. However, many of them can play an important role in advocating for gender equality in health and other policies. Advocacy to create enabling health policies addresses both the practical and strategic needs of women, as some are related to improving service delivery and others are related to improving women's sociocultural conditions.

#### ADDRESS GENDER IN HUMAN RESOURCES FOR HEALTH

Providing and retaining an appropriate mix of trained staff for delivering health care, including HIV/AIDS-related services, is a challenge. This is especially the case in many developing countries, which currently face a severe crisis in recruiting and retaining a trained and skilled health workforce. A lack of adequate human resources in the formal health sector also affects women in households and communities, as they have to assume a greater burden of caring for the sick.

#### KEY ISSUES

- In many settings, much of the front-line health care is provided by nurses, midwives and community health workers, the majority of whom are women (83). The preponderance of women in these roles is seen as an extension of their stereotypical roles as caregivers and nurturers. This has implications for the ability of HIV/AIDS programmes and services to attract certain clients and meet their needs.
  - For example, during the field testing of this tool in the United Republic of Tanzania, a shortage of male counsellors or male community health outreach workers was cited as a reason for difficulties in attracting men or encouraging male partners to attend services (80).
- Programmes may rely on women as volunteers for unremunerated health care provision, or programmes may not provide adequate remuneration and social benefits to front-line workers.
- In many settings, female health staff tend to be at the lower levels of decision-making, whereas male providers tend to occupy higher levels of decision-making (e.g. as programme managers, clinicians or medical officers) (84–86).
- It has been reported that in some settings the lack of female clinicians is a deterrent to women seeking care, especially if intimate physical examination is required (e.g. gynaecological examination) (87–88).
- Female staff may be reluctant to work where health facilities are remotely located, housing is inadequate, and there are safety concerns, especially if they have to be separated from their families (89).
- Gender inequalities in the lives of clients may be mirrored in the lives of programme staff.
  - For example, female health staff may experience sexual exploitation in their workplaces and homes, thereby increasing their vulnerability to HIV (86).
- Studies have shown that the issues described above have resulted in the perspectives of female health staff not being reflected or addressed in the design and delivery of programmes and services. These studies highlight the poor working conditions resulting from poor salaries, unsatisfactory supervision, lack of training, a high work load, harassment, and an unsafe work environment, which leave many female health staff feeling isolated, disempowered and dissatisfied. This in turn may affect the quality of care provided to clients (84–89).

## ADDRESS GENDER IN HUMAN RESOURCES FOR HEALTH

### ACTIONS

- Involve all programme staff, especially women at the lower levels of decision-making, in relevant programme decisions.
- Implement and enforce workplace policies that address the safety of programme staff in remote postings, taking into account that female staff may be vulnerable to violence.
- Explore ways in which unpaid health care provided by community health workers can be remunerated, including remuneration in kind.
- Explore ways to recruit, train and retain a mix of male and female health-care providers at appropriate levels, so that male and female clients can receive services from providers with whom they are comfortable.
  - For example, consider recruiting, retaining and training male health workers to provide some front-line services, including counselling, nursing and community outreach.
- Provide training to programme staff so that they are comfortable discussing taboo topics, such as sexual behaviours, with clients of the opposite sex.
  - Female counsellors, for example, may have to be trained to talk to men, especially if no male counsellors are available.
- Provide equal opportunities for female and male health staff for training, continuing education and development of professional skills.
- Advocate for and enforce policies related to non-discrimination in recruitment, remuneration and benefits, with respect to sex, ethnicity, caste, sexual orientation and HIV status.
- Establish and enforce directives to protect staff from sexual harassment, coercion and exploitation in the workplace.

## PROMOTE GENDER-RESPONSIVE HEALTH FINANCING MECHANISMS

## KEY ISSUES

- For poor households, both the direct costs of health care (e.g. user fees, drugs) and the indirect costs (e.g. transport, food, water, lost wages) are among the most significant barriers to accessing HIV/AIDS services (90).
- Women face additional challenges because of a lack of control over family resources, the relative poverty of households headed by females, and the prioritization of certain family members (usually children and men) for obtaining health care (91–92).
  - For example, HIV-positive mothers may use scarce household resources to obtain care for their HIV-exposed infants, while neglecting their own needs for care.
- Men, who often control household expenditures, may value care for infants more than postpartum care for women. As a result, women living with HIV may not have the resources to access services for themselves.
  - For example, in a recent UNICEF report, in some countries one third to two thirds of women stated that their husbands alone make decisions on household expenditures (36).
- Indirect costs associated with HIV/AIDS services affect women disproportionately.
  - For example, taking antiretroviral (ARV) medicines requires persons under treatment to drink a lot of water and eat three balanced and nutritious meals a day. This not only involves the costs of obtaining water, food and fuel, but also social costs, especially with regard to women's time, as women bear the main responsibility for fetching water, gathering fuel and preparing meals (93).
  - Time-use surveys show that globally women work longer hours than men, and in developing countries a substantial proportion of that is time spent in unpaid domestic chores, including caring for children, the sick and the elderly (36).
- The allocation of financial resources to HIV/AIDS programmes may fail to respond to the different needs of women and men, and to the different roles they play in the household and in communities.
  - For example, as the funding of health services and programmes declines, the responsibility for providing care to people living with HIV is being transferred from the formal health sector to households and communities. It is primarily women who are affected by such changes as they are responsible for caring for the sick, reflecting an assumption that they are willing and able to commit extra unpaid time to care activities (93).

## ACTIONS

- Consider and advocate for free provision of HIV/AIDS treatment and care services at the point of delivery in order to increase access, particularly for the poor and for women.
- Ensure that there are no hidden de facto charges levied on patients who qualify to receive free services (90).
- Take into account the financial and social vulnerabilities of women when determining selection criteria for groups to be exempted from user fees, receive services at subsidized cost, or pay the full user fees (91).
- Provide information about exemptions from user fees to communities and clients where relevant.
- Provide information about and referrals to community-based programmes, such as those concerned with income generation and food supplementation.
- Analyse the allocation of resources to HIV/AIDS programmes and services with reference to the benefits for, and costs to, women or men. This may require budget analysis to identify which groups are being underserved or unequally affected by existing resource allocation priorities (94).
- Advocate for allocation of financial, technical and human resources to develop and implement gender-responsive interventions.
  - This may include, for example, financial and human resource allocations to give community support for volunteers who provide home-based care, the majority of whom are women.

## PROMOTE GENDER EQUALITY IN NATIONAL HIV/AIDS POLICIES

### KEY ISSUES

- In most countries, HIV/AIDS programmes are implemented within a framework of national HIV/AIDS strategic plans and policies. Many HIV/AIDS policies and strategic plans do not take gender into account, in part because stakeholders may not have the capacity to analyse the links between gender inequality and HIV/AIDS (95).
- Programme managers may be called upon as stakeholders in the policy formulation process, providing an opportunity for them to advocate for addressing gender in overall national policies and thus establish a mandate to address gender at the programmatic level.

### ACTIONS

- Sensitize stakeholders, including policy-makers involved in developing national HIV/AIDS plans and policies, to recognize the links between gender inequality and HIV/AIDS, in order to create an enabling environment for addressing gender at the programmatic level (24).
- Advocate to align operational policies related to HIV with principles of gender equality and human rights. For example, this may include advocacy to change:
  - policies that prevent women and minors from giving consent for medical procedures and tests without approval from partners, parents or guardians;
  - policies on mandatory partner or parental notification of HIV test results for persons considered to be legal minors (e.g. young people, women in some countries) or groups such as sex workers and injecting drug users.

## SECTION 1: BASIC STEPS IN GENDER-RESPONSIVE PROGRAMMING

## ADVOCATE FOR GENDER EQUALITY IN MULTISECTORAL POLICIES THAT HAVE A BEARING ON HIV/AIDS

## KEY ISSUES

- Laws and policies favour men over women in many countries.
  - For example, laws concerned with property rights and inheritance often favor men. As a result, women living with HIV often find themselves abandoned, ejected from their homes and without any shelter, assets or resources when their spouses die and property is transferred to relatives (66).
- An increasing number of countries have laws to prevent violence against women. However, these are often either inadequate to protect women from all forms of violence or are inadequately enforced.
  - For example, marital rape is not a recognized offence in many countries, making it difficult for married women to refuse unwanted, unsafe sex with their partners.<sup>1</sup>
- In AIDS-affected households, young girls are often withdrawn from school to take care of family members. This not only deprives the girls of education but also makes them more vulnerable to HIV.
  - For example, a global review of evidence shows that educating girls plays both a direct and indirect role in decreasing their risk of HIV (68).

## ACTIONS

- Use policy forums to highlight laws and policies that exacerbate gender inequalities; advocate for laws that promote gender equality, such as those that give women and men equal rights to property and inheritance.
- Call for the enforcement of existing protective laws, such as those prohibiting early marriage and violence against women.
- Advocate for gender-responsive, multisectoral strategies developed to combat HIV/AIDS, including those developed for the educational, labour and agricultural sectors.
  - For example, advocate for educational policies that support young girls remaining in school.

<sup>1</sup> Some countries have revised their criminal laws to recognize rape within marriage as a legal offence. For example, in 1983 Canada revised its criminal law to define rape not just as coercive penetrative sex, but more broadly, as sexual aggression in which any form of intentional force, used directly or indirectly against another person against their consent – including threats, sexual assaults, and infliction of bodily lesions – is considered a criminal act with a maximum of 10 years imprisonment (articles 265 and 271 of the Canadian Criminal Code.) The enforcement of this law, however, has been weak.

## SECTION 2

# HIV testing and counselling

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## Objectives

This section explains how gender inequalities affect women's access to and experiences of HIV testing and counselling services. It describes actions to improve the gender-responsiveness, and thus the quality of HIV testing and counselling for all women, including pregnant women receiving antenatal care. It may be most useful to health-care providers and supervisors of HIV testing and counselling services.

### 2.1 Background

HIV testing and counselling is a key entry point for a range of HIV/AIDS services, such as the prevention of HIV, the management of HIV-related illnesses, PMTCT, ART, and psychosocial and legal support (96).

WHO and UNAIDS recommend two main types of HIV testing and counselling for individuals (97–98). *Client-initiated* testing and counselling, also called voluntary counselling and testing (VCT), involves individuals actively seeking HIV testing and counselling at facilities that offer these services. Until recently the provision of VCT services has been the primary model for HIV testing in many countries. However, in many countries only a fraction of people know their HIV status. In order to expand access to HIV testing and counselling, health-care providers now routinely recommend such testing and counselling to persons attending health-care facilities, including antenatal care clinics, where pregnant women who are diagnosed with HIV can benefit from receiving a package of HIV/AIDS services (97). This is called *provider-initiated* testing and counselling. Regardless of the model, all HIV testing and counselling programmes are guided by the principles of the “3 Cs”: confidentiality, counselling and informed consent (98).

Gender inequalities play a critical role in shaping access to and uptake of HIV testing and counselling, including disclosure of HIV status. For example, a review of evidence on the utilization of HIV testing and counselling showed that fear of negative consequences is a major barrier to the uptake of HIV testing. Consequences feared include a breakdown in social relationships, loss of employment or housing, and other forms of discrimination and violence (99). Fear of possible negative consequences of

testing and disclosure have been more frequently documented in women, especially pregnant women (29, 99). Research in four Asian countries has indicated that while men are tested if they have HIV-related symptoms, women are more likely to be tested if their partners have positive test results. This reflects the more vulnerable position of women (54, 99). Studies also indicate that, outside of prenatal care programmes, women are tested less frequently than men (99). Therefore, in order to expand services to women who are not pregnant, other entry points, such as family planning services and workplaces, may be needed. These can help to reach women who are not pregnant, young people, and men, and to avoid reinforcing the view that women bring HIV into families.

### 2.2 Addressing gender inequalities in some components of HIV testing and counselling services

The following components of HIV testing and counselling services are identified as being most relevant for addressing gender inequalities. The key issues and actions specified for each component respond to both women's practical needs for high quality services, and their strategic needs for transforming their unequal life conditions.

- 2.2.1 Provide pretest information or counselling.
- 2.2.2 Conduct an HIV test.
- 2.2.3 Provide psychosocial support.
- 2.2.4 Support disclosure.
- 2.2.5 Facilitate prevention (with a focus on sexual transmission).
- 2.2.6 Encourage partner testing and involvement.
- 2.2.7 Provide referrals to HIV treatment, care and support and other social services.

#### 2.2.1 Provide pretest information or counselling

Pretest information, and/or pretest counselling, provides clients, especially women, with an important opportunity to obtain basic information about HIV, assess their risk, think about risk reduction, and prepare themselves for the test results.

### 2.2.1 Provide pretest information or counselling

#### KEY ISSUES

- Women may not be comfortable discussing their sexual behaviour and risks with counsellors of the opposite sex, or doing so may not be culturally appropriate.
- In providing HIV information, health-care providers may consciously or unconsciously reinforce harmful norms and negative stereotypes or convey judgemental attitudes (e.g. the use of blaming or stigmatizing language when talking to adolescent girls or sex workers) (55, 100).
- In many resource-limited settings health-care providers are overloaded and therefore, while assessing women's risk and counselling them, providers may not explore women's unequal power relationships with their partners (e.g. risk of violence, inability to negotiate safe sex, inability to seek services without partners' permission) (101–102).
- While some women who initiate HIV testing may have discussed it with their partners beforehand, many others, especially those who are offered a test when they come in for some other service (e.g. antenatal care), may not have considered testing and its potential benefits or consequences beforehand (29).
- An HIV test and diagnosis may contribute to additional disadvantage (perceived or real) in women's relationships with their partners, family members and other community members.
  - For example, some studies have shown that fear of negative consequences, e.g. abandonment, is one of the main barriers to the uptake of testing among women (29, 99).
- Many women find out about their HIV status when they are tested in the context of pregnancy or delivery, and are often the first in their families to be tested and diagnosed with HIV. As a result, women are often blamed for bringing HIV into their families and passing it on to their children (54, 66, 103).

#### ACTIONS

- Where possible, offer the option of choosing the sex of the counsellor, so that women of all ages are comfortable about discussing sensitive issues related to sexual behaviour.
- For antenatal care settings, WHO currently recommends routinely offering an HIV test to all pregnant women as part of the essential package of antenatal care (104).
  - Evidence from a few settings where HIV testing is routinely offered to all pregnant women suggests that testing as part of antenatal care may be acceptable to women, and may cause them less anxiety. A possible reason for this is that such testing may avoid assumptions about women's sexual behaviour and, hence, about their moral worth (99, 105).
- Where simplified pretest information is offered, e.g. in antenatal care settings, advise women about the benefits and potential risks of testing, such as discrimination, abandonment or violence by partners or other family members.<sup>1</sup>
- Address the potential stigma experienced by pregnant women for undergoing an HIV test through health education and community sensitization, conveying the message that HIV testing is part of a basic package of care.
- Recognize and avoid communication that reinforces negative stereotypes or prejudices towards clients undergoing testing, including unmarried women and sex workers.
- Where possible, assess not only women's own risk behaviours but also their unequal power relations with their partners (e.g. coercion, fear, and lack of communication and trust).
  - The matrix presented in **BOX 2.1** on page 33 may help health-care providers to conduct gender-responsive counselling. It has been adapted from a tool prepared by EngenderHealth and the International Community of Women Living with HIV/AIDS (ICW) for assessing the sexual and reproductive health needs of women living with HIV (106).

<sup>1</sup> See WHO guidance on provider-initiated HIV testing and counselling (97).

**BOX 2.1**

**Tool to help gender-responsive counselling (106)**

REDI <sup>a</sup> Stages	Already doing	Need training	Challenges anticipated
<b>Rapport Building</b>			
• Welcome client.			
• Make introductions.			
• Introduce subject of HIV.			
• Assure confidentiality.			
<b>Exploration</b>			
• Assess risk			
• Explore client's sexuality and sexual behaviour.			
• Explore context and circumstances of risk, including power relationships.			
• Assess knowledge of HIV and provide prevention information and options.			
• Provide information about HIV testing and related services.			
<b>Decision-making:</b> Helping to make an informed decision about HIV testing.			
• Provide information about benefits and potential consequences of testing.			
• Explore potential barriers, constraints and consequences that client might face by deciding to undergo testing.			
• Discuss options to address the constraints to testing.			
• Encourage client to make her or his own decision.			
<b>Implementing the decision</b>			
• Help client identify decisions she or he needs to make related to the HIV test (e.g. to discuss prevention or disclosure with partner).			
• Help identify what skills are needed by client.			
• Practice skills needed by client (e.g. role plays, condom use).			
• Plan follow-up.			
• Provide information/referrals about/to additional resources/services.			

<sup>a</sup> REDI stands for Rapport building, Exploration, Decision-making, and Implementing the decision.

### 2.2.2 Conduct an HIV test

#### KEY ISSUES

- Unequal power dynamics between provider and client could undermine the process of informed consent if the right to refuse testing is not clearly explained, as could attempts to persuade the client to undergo testing (105).
- The process of informed consent may be undermined in situations where women are afraid of being denied other health-care services that they are seeking if they do not agree to testing.
  - For example, research on informed consent to HIV testing in several settings has suggested that clients may agree to be tested for one or more of the following reasons: they are used to agreeing to health professionals' requests; they think that they will receive improved care; they do not think that they can decline; or they perceive that refusing the test could have adverse consequences (99, 107–109).
- In many settings women do not have the information or power to disagree with the requests of health professionals, especially if the latter are senior male health professionals.
- In some countries, health providers may either by law or informally require women to obtain the consent of their partners or male family members before conducting medical procedures. This compromises women's autonomy, confidentiality and ability to give voluntary consent (110–111). The issue of the legal age of consent for testing applies to adolescent girls, as many countries require the consent of parents or guardians for medical procedures for minors.
- Many pregnant women do not seek antenatal care, only attending health-care facilities during labour or the postpartum period in order to seek services for their babies. Women who are offered an HIV test during labour may not have adequate time to consider the implications in order to provide well-informed consent.

#### ACTIONS

- Emphasize the voluntary nature of the test, the client's right to decline the test, and that declining to have the test will not affect the client's access to services, which do not depend on the knowledge of HIV status.
- Ensure privacy and protect confidentiality during the consultation and regarding disclosure of the results. This is particularly important for women who fear violence or other negative outcomes, or who may not have informed their partners about undergoing an HIV test.
  - This requires that informed consent, post-test counselling, and other communication related to HIV status be conducted in a place away from other clients and health-care providers not involved with the client's care.
  - Women, particularly those who are not literate, may need advice on safekeeping of their records where their HIV status is recorded (97).
- In determining how best to obtain informed consent for women and adolescent girls, take account of national and local laws and policies related to the age and legal ability of the person to provide independent consent to an HIV test.<sup>1</sup>
- Where consent is required from parents or legal guardians (possibly including husbands in some countries), consideration should also be given to potentially negative outcomes of testing on women or adolescent girls (97).
- Take into account women's emotional state and ability to provide informed consent when they are offered an HIV test during labour or shortly after delivery.

<sup>1</sup> The right to make free and informed decisions about health care, including decisions about one's own fertility and sexuality, is enshrined in article 12 of the Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW). Where providers ask for consent from male relatives within the context of national laws, or as informal practice, consideration should be given to violations of international norms, practices and standards, as well as to obligations to fulfil commitments to international treaties on human rights (112).

### 2.2.3 Provide psychosocial support

#### KEY ISSUES

- The use of technical terms or inaccessible language in explaining test results may be intimidating for women, especially those who are less literate.
- Women who learn of their HIV-positive status have to cope emotionally with the implications of their results for themselves, their partners, their children and other family members.
  - For example, pregnancy is a vulnerable time for many women, when they often face social and cultural expectations related to motherhood.
- An HIV diagnosis could contribute to feelings of hopelessness, a fear of death, worries about the future of unborn children, and guilt for potentially passing on the infection to one's baby.
- Depression, which is more common among women than men, may also be exacerbated or triggered by an HIV diagnosis (113).
  - Research has shown that women diagnosed with HIV face considerable psychosocial stress related to their parenting and caregiving roles, as well as a sense of shame, loss and grief associated with their diagnosis (114).

#### ACTIONS

- Explain the technical and scientific issues related to the test results in simple terms, using visual aids for women who are less literate. Ensure that women understand the information. Provide sufficient time to consider the implications of the results.
- Counselling plays a key role in emotionally preparing women to cope with their diagnosis. For pregnant women, this includes offering hope that there are options to prevent HIV transmission to their unborn children.
- While counselling women about positive living,<sup>1</sup> take into account their roles in preparing food, taking care of the sick and ensuring cleanliness and hygiene, as part of providing information on nutrition, exercising and preventing opportunistic infections, including those that are specific to women (e.g. vaginal infections) (115).
- Arrange for follow-up counselling, especially through peer counsellors or community-based lay counsellors who may be able to give more time to women than clinic-based counsellors.
  - For example, women living with HIV who have themselves gone through PMTCT can act as peer counsellors and support to other women, especially in providing reassurance that PMTCT can help to reduce the risk to unborn children. They can also be powerful role models for others, informing individual women, couples and communities through their own example that a programme is safe and effective. (See **BOX 2.2** on page 36 for an example of a peer counselling intervention.)
- Recognize the potential for and assess any signs of depression (e.g. suicidal thoughts) and provide appropriate referral to mental health services, support groups and crisis counselling services, where available.
- Help women identify sources of social support within their households, families and communities to help cope with depression.

<sup>1</sup> Positive living is a lifestyle adopted by a person with HIV in order to live as fully as possible while slowing the progression of the disease. It includes making positive choices to care for one's mental and physical health, having a positive outlook on life, and avoiding risky behaviours.

**BOX 2.2****Peer counselling for HIV-positive pregnant women:  
Mothers-to-Mothers (M2M) programme (116–117)**

The **MOTHERS-TO-MOTHERS (M2M)** programme in South Africa recruits HIV-positive mothers who have recently given birth with a view to their educating, counselling and supporting HIV-positive pregnant women who attend antenatal clinics for PMTCT. At every such visit, mentors engage pregnant women in conversation, share personal experiences, encourage adherence to ARV prophylaxis, and help them during their hospital stay. The mentors also receive continued education and support, including a small stipend. The first M2M programme was started in a tertiary care hospital, and others are scheduled to open in several primary care maternity centres. The peer support mentorship programme fits seamlessly into routine antenatal care. The programme helps to educate pregnant women and mothers and thus empowers them in their families and communities. Empowerment contributes to the destigmatization of HIV infection and to improved community health.

Postpartum women who had two or more contacts with the programme were significantly more likely than non-participants to have disclosed their HIV status to someone (97% versus 85%;  $p < 0.01$ ). Participants were significantly more likely to have received ARV prophylaxis (95% versus 86%;  $p < 0.05$ ) and to report an exclusive method of infant feeding (i.e. either exclusive breastfeeding or exclusive replacement feeding). Moreover, they reported a significantly greater sense of well-being than their counterparts, feeling that they could do things to help themselves, cope with caring for infants and live positively.

## 2.2.4 Support disclosure

Serostatus disclosure to partners and families is important for enabling women to access care, support and HIV prevention and treatment interventions.

### KEY ISSUES

- Women worry about people finding out that they have been tested and what the results are, about being stigmatized by partners, families, friends and communities, and about losing their jobs and livelihoods.
- In many communities, sociocultural norms perpetuate the belief that sexually transmitted infections, including HIV, are spread from women to men.
- Because of their economic dependence on men, women may be especially anxious about losing their children, suffering violence or being abandoned by their partners (66).
  - A review of studies in high-income and low-income countries found that fears of abandonment, rejection by family members, discrimination and violence prevented many women from disclosing their HIV status. The lowest rates of disclosure were reported in studies conducted among women who tested positive for HIV in the context of antenatal care in sub-Saharan Africa (29).
- Young women, especially those under the legal age of consent, may be particularly worried about disclosure in settings where policies require that programme staff disclose the results of HIV tests to parents or guardians (118).
- Women engaged in sex work, transactional sex or injecting drugs may be worried, not only about the stigma of being HIV-positive, but also about the stigma of engaging in illegal or illicit behaviours.
- Some countries may have policies related to third-party disclosure or partner notification that can especially affect women who fear negative outcomes and violence from their partners.
- For women in polygamous marriages, the disclosure of HIV status may also affect their status and relationships with the co-wives in the household.

### ACTIONS

- Reassure clients that you will keep their results confidential and that disclosure is voluntary.<sup>1</sup> This is particularly important for women who fear partner violence.
- Discuss the benefits of disclosure, such as obtaining social and emotional support, being able to access prevention, treatment and care services, including for unborn children, and being able to lead a more healthy and productive life.
- Explore the disadvantages of disclosure, including the potential for negative outcomes, e.g. abandonment, loss of economic support, and violence perpetrated by partners or family members.
  - The protocols described in **BOX 2.3** on page 38 may help counsellors assess the potential for violence while discussing disclosure (118).
- Help women plan to whom, when, where and how they will disclose their status. In supporting disclosure, the client's safety should be paramount. Use role-play and other behavioural rehearsal techniques to address fears of negative outcomes. Give clients the opportunity to rehearse how they will disclose their status.
- Assist women who are at risk of violence with safety planning.
  - For example, help women to identify whom they can turn to for support if they face negative consequences of disclosure. **BOX 2.4** on page 39 provides tips to assist women with safety planning.
- If necessary, ask clients if they want counsellors to be present when they disclose their status, or offer assistance with disclosure (i.e. mediated disclosure).

<sup>1</sup> See UNAIDS and WHO guidance on encouraging beneficial disclosure and ethical partner counselling, and WHO guidance on disclosure in Integrated Management of Adolescent and Adult Illness (IMAI) guidelines on chronic HIV care with ART and prevention (119–120).

**BOX 2.3****Protocols to address violence in counselling on HIV status disclosure (118)****Example 1. Counselling protocol from Dar es Salaam, the United Republic of Tanzania**

In a voluntary HIV counselling and testing clinic in Dar es Salaam, researchers piloted the following protocol to raise the issue of violence during counselling on HIV disclosure. Counsellors asked women the following questions:

1. Is your partner aware that you will be tested for HIV?
2. If you told your partner you tested positive for HIV, do you think he would react supportively?
3. Are you afraid of how your partner will react if you share your HIV test results with him?
4. Has your partner ever physically hurt you?
5. Do you think that your partner may physically hurt you if you tell him that you have tested for HIV and your HIV test results are positive?

Counsellors supported women's decision to disclose if they answered positively or negatively to question 1, positively to question 2 and negatively to questions 3–5. If women answered negatively to question 2, and positively to any of questions 3–5, then counsellors proceeded with caution and explored in more depth each woman's risk of disclosure-related violence. If the counsellors determined that the risk was high, they explored alternative options, including: opting not to disclose; deferring disclosure to a time when a woman's safety was ensured; or developing a plan for mediated disclosure in which women either brought the partner to the clinic to disclose, or identified a trusted family member or friend to be present when they shared their HIV test results with their partner. If women answered negatively to question 2 and positively to questions 3–5, regardless of how they answered question 1, then counsellors explored these alternative options for disclosure.

**Example 2. Family Health International (FHI): Asia-Pacific region**

In the region that FHI designates as the Asia-Pacific region, FHI staff have developed the following protocol for counsellors to use when counselling clients regarding disclosure.

1. Counsellor asks: "There are some routine questions that I ask all of my clients because some are in relationships where they are afraid that their partner may hurt them. What response would you anticipate from your partner if your results came back positive?"
2. If the client indicates that she or he is fearful or concerned, then the counsellor asks, "Have you ever felt afraid of your partner? Has your partner ever pushed, grabbed, slapped, choked or kicked you? Threatened to hurt you, your children or someone close to you? Stalked, followed or monitored your movements?"
3. If the client responds affirmatively to any of these points, the counsellor then adds, "Based on what you have told me, do you think telling your partner will result in a risk to you or your partner?"

The client is then encouraged to make a decision to disclose based on a realistic appraisal of the threat.

## BOX 2.4

### Safety planning with women at risk for violence (33, 121)

- Ask about violent and controlling behaviours.
- Show a sympathetic attitude; do not blame or judge women.
- Inform women of their rights and the services available to them.
- Help women to make their own choices about their relationships, and discuss the implications of violence against women with regard to the risk of HIV and to living with HIV.
- In the event that a woman decides to stay with a violent partner, assist her in planning what to do if the violence increases.
- In the latter circumstance, in the event that a woman decides to leave her partner, assist her in planning what to do. This involves answering the following questions:
  - Where could she go?
  - How would she get there?
  - Is money needed? Does she need her identification documents?
  - Would she need emergency clothes, etc.?
  - Can she always keep a bag packed?
  - Would it help to agree on a signal to neighbours in order to get their help?
- Provide formal options for support, including police, social workers, community-based organizations, women's NGOs, etc., if available.
- Discuss informal options for support, including neighbours, friends and relatives.
- Key messages about disclosure to give women affected by violence:
  - Decide on the best time and place to have a conversation.
  - Choose a time when you expect that you will both be comfortable, rested and as relaxed as possible.
  - Think about how your partner may react to stressful situations.
  - If there is a history of violence in your relationship, consider your safety first and plan the situation with a case manager or counsellor.
  - Imagine several ways in which your partner might react to the news that you are HIV-positive. Write down what he might say, then think about what you might say in response.

### 2.2.5 Facilitate prevention (with a focus on sexual transmission)

The key to preventing sexual transmission of HIV lies in promoting safer sexual behaviour. The ABC approach involves programmes and services discussing abstinence (refraining from sexual intercourse), faithfulness (to one partner not infected with HIV), reducing the number of partners, and condom use (providing condoms and supporting their correct and consistent use). This approach may suit some people but may not work for others, especially women, because unequal power in their sexual relationships undermines their ability to practise safer sex (122).

#### BOX 2.5

##### Key messages on women and safer sex (71)

###### Providers can:

- help women to learn how to negotiate safer sex with their partner;
- try to make the issue one of safety and not of trust;
- discuss safer sex in the context of pleasure;
- talk to male partners of women clients about safer sex and condoms;
- conduct community sensitization and outreach with men and community leaders, highlighting the need for men to practice safer sex and use condoms;
- highlight the fact that being married does not give a man the right to have sex with his wife without her consent.



#### KEY ISSUES

- In many settings, sexual norms dictate that women be kept ignorant about sex, that they should not discuss or initiate sex, and that they should remain faithful to one partner and passive in sexual relationships. These norms prevent women from obtaining information on how to protect themselves (24).
- Many married women are not able to refuse sex with their husbands even if they know they could be at risk for HIV infection, particularly if they are economically disadvantaged (24).
- Many women, including those living with HIV, may either fear or experience negative reactions from their partners if they ask them to use male condoms.
  - For example, such a request may generate suspicions and accusations of infidelity, because condom use is often associated with promiscuity and having sex outside a primary partnership (24).
- Certain practices, such as dry sex to increase male pleasure, vaginal douching, and anal sex may increase the risk of HIV transmission (123).
- People living with HIV may be subjected to moralistic attitudes about being sexually active. Women living with HIV may be expected to refrain from being sexually active, despite not having control in their sexual relationships (124).
- Providers may not be comfortable in discussing sexuality with clients, or may believe that people living with HIV should abstain from sex (125).
- Pregnant and postpartum women may be more vulnerable to infection, especially if there are periods of sexual abstinence during which their partners have had other partners. Becoming infected with HIV during pregnancy may increase the likelihood of transmission to the baby because of the increase in the maternal viral load caused by a new infection (126).

## 2.2.5 Facilitate prevention (with a focus on sexual transmission)

### ACTIONS

- Explore women's risk of HIV without making a judgement about their sexual behaviour.
  - For example, avoid moralistic judgements about people living with HIV being sexually active.
- Recognizing that women may be constrained in their ability to practise safer sex, provide information on how to have a healthy and safer sex life. This includes information on non-penetrative sexual activities that pose no risk of infection (e.g. mutual masturbation and massage).
- Assist women to develop a plan for risk reduction by helping them to problem solve and to identify barriers to practising safer sex.
  - For example, use role-play to assist women in rehearsing how they will approach their partners about condom use or negotiate with them if they refuse (see **BOX 2.6** on page 42).
- Where women are unable to negotiate the use of male condoms with their partners, offer female condoms (if available), or provide information on these, or refer women to sources of these. Train women to use female condoms as a dual protection method.<sup>1</sup>
- Providing condoms free of charge or at subsidized prices may increase access for women who may not have the financial resources to pay for condoms.
- Promote and protect the rights of all to have sex free of coercion and violence, including women, people living with HIV, young people and marginalized groups.
- Promote messages on shared responsibility between men and women for sexual decision-making. This could include messages encouraging women and men to discuss and make joint decisions on condom use with their partners. (See **BOX 2.5** on page 40 for examples of messages on safer sex.)
- Provide information about the potential risks associated with practices such as dry sex, douching and anal sex.
- Discuss the implications for sexuality of an HIV-positive diagnosis (e.g. feelings of shame associated with wanting to have sex, or worries about decreased sexual desire or satisfaction).
- Encourage women to bring their partners for counselling, and offer safer sex counselling to them either individually or as a couple.
- Address sexual practices that could place women at increased risk of becoming infected during pregnancy. Provide information on the implications for a pregnant woman or new mother of transmitting an STI or HIV to an unborn or breastfeeding child.

<sup>1</sup> See WHO guidelines on the use of male and female condoms for dual protection (127).

**BOX 2.6****Role play to negotiate safer sex (128)**

If your clients are sexually active and wish to remain so, emphasize that condoms provide dual protection against STI and HIV transmission, as well as unintended pregnancy. Women, especially young girls, may need strong negotiation skills for practising safer sex. You can help your clients practice what to say if their partners are pressuring them to not use a condom. Role-play talking about condoms.

**If her partner says:**

“I don’t like using condoms. It does not feel good.”

“We have never used a condom before.”

“Using condoms is no fun.”

“Don’t you trust me?”

“Why should we use a condom? Do you think I have AIDS?”

“I will pull out in time.”

“I thought you said condoms were for casual partners.”

“I guess you really don’t love me.”

“We’re not using condoms and that’s it.”

“Just this once without.”

**Additional scenarios to address the risk of violence:**

“If you don’t have sex with me without a condom, I will force you.”

“I have a right to have sex with you without a condom.”

“Stop asking me to use a condom. It makes me angry.”

**Your client can say:**

“I feel more relaxed, and if I am more relaxed. I can make it feel better for you.”

“I don’t want to take any more risks.”

“Unplanned pregnancy or getting an STI is much less fun.”

“I trust you are telling the truth. But with some sexually transmitted infections there are no symptoms. Let’s be safe and use condoms.”

“No, but I could have an STI. We need to protect both of us.”

“I can still get pregnant or get an STI.”

“I decided to face facts. I want us to stay healthy and happy.”

“I do, but I don’t want to risk my health to prove it.”

“Okay, let’s do something else, then.”

“It only takes once to get pregnant, or get an STI, or get HIV.”

“Forcing me to have sex is not the answer. Let’s talk about this calmly.”

“You do not own me or have a right to my body. If you love and respect me, you will understand that.”

“I am sorry that you are getting angry. Maybe we should wait to have sex until you feel less angry.”

## BOX 2.7

### Example of messages targeted to men (71)

Community outreach could encourage men to:

- practice safer sex;
- support their partners to go for antenatal care visits and accompany them at least once (if the women agree);
- go for HIV testing and counselling;
- help mothers to stay healthy, support them to care for their babies, and encourage them to attend health facilities when necessary;
- talk to other men in the community about PMTCT, why it is important to obtain HIV testing and counselling and use condoms, and why women should get good care during and after pregnancy;
- form men's support groups.

### 2.2.6 Encourage partner testing and involvement

#### KEY ISSUES

- Partner or couple testing can have several benefits (129). It can:
  - help couples to plan how to protect themselves, particularly where women find it difficult to negotiate safe sex practices with their partners;
  - reduce the burden of blame on women for bringing HIV into the family, and provide the opportunity to change unequal power relations by emphasizing the importance of the shared responsibility of women and men for health decisions;
  - enable HIV-positive mothers to be supported in their decisions and choices related to ARV prophylaxis and infant feeding, and thus improve the uptake of interventions;
  - improve women's access to HIV treatment and care and encourage adherence; enable a more rapid identification of large numbers of women and men living with HIV than might occur through the use of other approaches to service delivery;
  - provide an entry point for men to learn about their own status, and, if necessary, to access treatment and care services.
- Despite the recognized importance of male involvement, the proportion of individuals tested as part of a couple remains low.
  - For example, in sub-Saharan Africa a majority of HIV services are targeting individuals rather than couples (130).
- Women may not be aware of the HIV testing and counselling and other services that are available for partners.
- Women may not be able to approach their partners about the need for testing for fear of negative outcomes, e.g. accusations of infidelity, abandonment, and violence.
- Women who have already undertaken the HIV test without having discussed it with their partners may be particularly anxious about disclosure.
- Men may not feel comfortable using maternal health services as these are woman-oriented. Traditionally, most maternal health services do not reach out to male partners of pregnant women.
- Male partners who want HIV testing and counselling may not be able to access services at the regularly scheduled times or locations because of work commitments.
- Where couples are tested and a positive result is obtained by one or both partners, emotions of anger, blame and mistrust are frequently experienced and may be directed at the female partner.

## 2.2.6 Encourage partner testing and involvement

### ACTIONS

- See **BOX 2.7** on page 43 for an example of key messages to encourage men to go for partner testing and become involved.
- Support and, if necessary, facilitate male partner involvement only with the female partner's permission or if she so chooses.
- Promote HIV testing for partners as part of an effort to improve the health of the entire family.
  - For example, discuss how involving men could increase acceptance of condom use and facilitate safer sex and appropriate reproductive choices. This may help to decrease the risk of suspicion faced by women and increase their access to services (129).
- Provide women with specific information about HIV and services offered for male partners and family members.
  - For example, provide information on where men can obtain HIV testing and counselling in the community, including mobile testing and counselling vans and workplace programmes.
- Sensitize communities on testing, treatment and care services available for men, including male partners of clients.
- Where feasible, offer women the option of returning with their partners for couple testing and counselling, thus possibly reducing the burden of blame on the partner who tests first.
- Ensure that each person in the couple separately and voluntarily consents to HIV testing. The consent or presence of partners should not be a prerequisite for HIV testing, as not all women are part of a couple and violence may be a possibility in some relationships.
- Emphasize that test results and counselling for each member of a couple will be kept confidential, and that results for either partner will be disclosed to the other only with his or her consent or involvement.
- In post-test counselling, depending on the outcome of the test for one or both members of a couple, assist with managing feelings of blame, anger and anxiety, and prevent escalation to physical or verbal abuse (118).
- Especially in antenatal care services, make the area used for HIV testing and counselling more male-friendly by providing HIV-related information materials targeted to men or, if possible, by providing separate waiting areas for men (77).

### 2.2.7 Provide referrals to HIV treatment, care and support and other social services

#### KEY ISSUES

- Women living with HIV are vulnerable to a range of conditions, including TB infection and cervical cancer, and have numerous follow-up medical and health needs, including during pregnancy and the postpartum period (124, 131).
- In many settings, inheritance laws favour men and deprive women of their rights to property and other assets. This can leave many women living with HIV without any source of income, shelter or means of taking care of themselves or their children (132).
- Women living with HIV are confronted with difficult choices related to childbearing, which in many parts of the world plays a central role in defining women's status and identity in their communities (124).
- Women living with HIV may also bear the responsibility for taking care of other sick members of their families. Consequently, they need support in their caregiving roles.

#### ACTIONS

- Identify the range of needs of women living with HIV, related to both their health and social well-being.
- Compile and maintain an updated directory of all available resources and services in the community to which women living with HIV can be referred (see **BOX 2.8** on page 47).
- Make referrals as necessary to HIV treatment, care, support and PMTCT programmes, and to other health programmes and medical services, e.g. screening for and treatment of TB infection and cervical cancer, and the prevention and treatment of malaria.
- Make referrals to social services provided through community or faith-based organizations, including legal support, post-test clubs, religious and spiritual support, income generation opportunities, and services for women who experience violence, if available.
  - In particular, HIV-positive mothers may need support through community-based organizations in order to access postpartum care and services for themselves and their children.
- Support women living with HIV in their reproductive decisions and choices. Offer or provide referrals to family planning services so that women living with HIV can obtain counselling about their options for having children, delaying childbearing or not having any more children. Women who want to have children need information about services, and those who want to delay or prevent a pregnancy need information about and access to appropriate contraceptive methods (133–134).
- Provide referrals to home-based care programmes so that women living with HIV can access psychosocial support and be supported as carers of other sick members of their households.

## BOX 2.8

### Types of referral network services (65)

#### MEDICAL AND HEALTH-CARE SERVICES

- ART, including treatment support and literacy, and adherence counselling
- Clinical care for opportunistic infections
- Obstetrics and gynaecology, including cervical cancer screening
- Sexual and reproductive health (SRH) services, e.g. family planning, antenatal and maternal care, reproductive and sexually transmitted infection services, adolescent SRH services, sexuality counselling
- HIV testing and counselling
- PMTCT services
- Mental health services
- Needle exchange
- Post-exposure prophylaxis (PEP)
- Pharmacy
- Prevention (condoms, social marketing)
- Services for marginalized groups (e.g. sex workers, injecting drug users (IDU) and men having sex with men (MSM))
- Management of alcohol, drug and substance abuse
- Malaria prophylaxis
- Tuberculosis services
- Palliative care

#### PSYCHOSOCIAL SERVICES

- Childcare, including care for orphans and vulnerable children
- Financial and material support
- Home-based care
- Legal support (property, employment, making a will)
- Microfinance and microcredit for income generation
- Nutritional interventions and counselling
- Peer counselling, psychosocial support, bereavement counselling
- Post-test clubs and mutual support groups, youth groups
- Spiritual support (e.g. faith-based groups)
- Domestic violence, women's and self-help groups



## SECTION 3

# Prevention of mother-to-child transmission of HIV

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## Objectives

This section explains how gender inequalities affect women's access to and experience of PMTCT services, and describes actions for improving the gender-responsiveness and quality of these services. It may be most useful to health-care providers and supervisors of PMTCT services.

### 3.1 Background

Globally, more than 90% of the 2.1 million children under the age of 15 years living with HIV have acquired the infection through their mothers. Children accounted for nearly 17% of all new infections in 2007. Nearly 90% of HIV-positive children live in sub-Saharan Africa (4). One area of HIV prevention where there are feasible interventions in resource-limited settings is the prevention of HIV transmission from women with HIV to their children during pregnancy and delivery, and through breastfeeding.

Unfortunately, the coverage of such interventions is low. By 2007 an estimated 18% of pregnant women had received an HIV test, and 33% of pregnant women living with HIV received ARVs for preventing transmission to their infants (4). Research from various settings (e.g. China, India, Kenya, and Zambia) has shown that gender inequalities, including stigma and discrimination experienced by women, are factors undermining the uptake and impact of interventions. In Zambia, for example, the proportion of women seeking antenatal care was higher than the proportion receiving an HIV test, and the proportion of pregnant women living with HIV in need of ARV prophylaxis was higher than the proportion who actually received ARV prophylaxis and counselling on infant feeding. This was partly attributed to men's resistance to their female partners' use of these services, fear of stigma, and factors related to service delivery, e.g. staff shortages (135–136).

Early interventions focused primarily on preventing vertical transmission from pregnant women or lactating mothers living with HIV to their infants. With the growing efforts to increase access to ART in resource-constrained settings, existing services provide unique opportunities and entry points for the provision of expanded treatment, care and support for women living with HIV, their children and other family members

(137). Experience has shown that the timely and appropriate use of services can be increased by interventions to: reduce barriers in access to services, improve the quality and acceptability of services, and promote prevention as the shared responsibility of pregnant women and their partners. For example, an evaluation of pilot interventions sponsored by the United Nations indicated that, among other factors, increasing male involvement led to an improvement in women's uptake of services in Kenya and Zambia (135).

### 3.2 Addressing gender inequalities in some components of PMTCT programmes

The WHO and other UN agencies endorse a comprehensive approach to PMTCT that includes: primary prevention of HIV infection among women; prevention of unintended pregnancies in women living with HIV; prevention of HIV transmission from women living with HIV to their babies; and providing treatment, care and support to women living with HIV and their families (137). This section addresses gender-responsiveness in select components of PMTCT programmes that are delivered through health services. These include:

- 3.2.1 Provide ARV prophylaxis to prevent HIV infection in infants.
- 3.2.2 Assist women with birth planning.
- 3.2.3 Support safer infant-feeding practices.
- 3.2.4 Support women living with HIV to make informed reproductive choices.
- 3.2.5 Provide nutrition counselling and support for women living with HIV.

The key issues and actions specified for each component respond to both women's practical needs for quality services and their strategic needs for transforming their unequal life conditions. Gender-responsive actions related to HIV testing and counselling for pregnant women and lactating mothers are covered in **SECTION 2** (pages 31 to 48). Gender-responsive actions related to HIV treatment and care for pregnant women and lactating mothers, which are the same for all women living with HIV, are covered in **SECTION 4** (pages 57 to 66). Health-care providers and supervisors of PMTCT services should therefore read the present section in conjunction with **SECTIONS 2 AND 4**.

### 3.2.1 Provide ARV prophylaxis to prevent HIV infection in infants

WHO recommends screening all women diagnosed with HIV for ART eligibility, based either on the CD4 cell count or defined clinical stages of AIDS-related symptoms. Women who are eligible for HIV treatment are offered ART. Pregnant women who are not yet eligible for HIV treatment are offered ARV prophylaxis to prevent transmission of HIV to their children.<sup>1</sup>

#### KEY ISSUES

- Many women who are tested and found to be eligible to receive ARV prophylaxis medications do not use them because of concerns about the effects of ARVs on their babies, and doubts about the ability of drugs to prevent HIV transmission from mother to child (43).
- Some women are fatalistic about their own situations and may not accept ARV prophylaxis even when medication is available (43).
- Women may not be able to make decisions about taking ARV prophylaxis without the consent of partners and family members, or may not have the time, money or ability to return for further treatment.
- Women may experience difficulty in adhering to ARV prophylaxis because of concerns related to maintaining confidentiality and avoiding inadvertent disclosure of HIV-positive status if they have not disclosed their status to their families (138).
- Women have reported discrimination and stigmatizing attitudes on the part of providers as barriers to returning for further treatment and care (139–140).

#### ACTIONS

- With women's consent, provide women and their partners clear information (verbal, written or pictorial) and counselling on dosage and the expected side-effects of ARVs, in order to reduce misconceptions about them.
- Recognize and address women's concerns about side-effects, their desire to be good mothers, and their limited autonomy to make decisions related to pregnancy. Address these issues in health education and community sensitization of women, men, families and community leaders, in order to find ways of reducing barriers for women and increasing the uptake of ARV prophylaxis.
- Address fears about inadvertent disclosure while providing adherence counselling.
  - For example, provide advice on and the means to take ARV prophylaxis discreetly (e.g. small pill boxes that can be easily hidden).

<sup>1</sup> See WHO guidance on antiretroviral drugs for treating pregnant women (104).

### 3.2.2 Assist women with birth planning

WHO recommends that pregnant women, especially those living with HIV, deliver at a health facility because the risk of transmission of HIV is highest during labour and delivery, especially in relation to prolonged labour, tearing and bleeding.<sup>1</sup> Barriers that prevent women from delivering at health facilities need to be addressed as part of assisting women to make a birth plan.

#### KEY ISSUES

- In many settings, women do not seek antenatal care or give birth in health-care facilities because of various economic, social and cultural factors.
  - For example, women living in rural and remote areas may not have transport or other resources necessary for reaching health facilities. Others may not have the autonomy in their households to decide where to give birth (141).
- Many women have a cultural preference for giving birth at home with the help of traditional birth attendants, who often belong to their own communities and are trusted (141).

#### ACTIONS

- Educate communities and the partners of women living with HIV about the necessity of supporting women to access skilled care during childbirth.
- Before the onset of labour help women and their partners to develop a plan for delivery. The plan should include where delivery will take place, who will be present, financial and logistical arrangements for transportation, and guidance on referrals in case of complications.

<sup>1</sup> See WHO guidelines on the sexual and reproductive health of women living with HIV/AIDS and their children (133).

### 3.2.3 Support safer infant-feeding practices

In order to reduce the risk of mother-to-child HIV transmission through breastfeeding while not increasing the risks of exposure to other causes of morbidity and mortality, the WHO currently recommends that when replacement feeding is acceptable, feasible, affordable, sustainable and safe, all breastfeeding by mothers living with HIV be avoided. Otherwise, exclusive breastfeeding is recommended during the first six months of life, after which it should be discontinued as soon as feasible.<sup>1</sup>

#### KEY ISSUES

- In many settings, women are strongly influenced in their practices related to infant feeding by their desire to be good mothers and by social pressures (142).
- Many women face a dilemma with respect to breastfeeding. While mothers living with HIV are advised not to breastfeed because of the risk of transmission through the breast milk, the avoidance of breastfeeding carries other important health risks for their babies. It may also result in de facto disclosure of their serostatus to their families and communities, making them vulnerable to stigma and discrimination.
  - For example, in many societies, social norms about infant feeding stigmatize women who do not breastfeed and, in some settings of high HIV prevalence, not breastfeeding a baby is considered to be a sign that the woman concerned is HIV-positive (142–143).
- Formula feeding imposes demands on women as regards costs, time and the availability of clean water for preparing the formula safely.
  - For example, women may not be in a position to meet such demands because they do not have access to or control over financial resources (i.e. to buy formula), lack the necessary time (because of other household responsibilities, including caring for sick family members), or have to bear the additional burden of fetching and preparing clean water (144–145).

#### ACTIONS

- Discuss the risks of transmission through breastfeeding. Explain the benefits and discuss the feasibility and challenges of both feeding options with women and their partners (with the woman's permission).
- Support each woman in making a choice based on a realistic appraisal of her situation.
- Educate communities about the risk of transmission via breastfeeding and about safer infant-feeding practices, in order to create an enabling environment in which women can choose the appropriate infant-feeding option.
- Support women in adhering to their choice regarding infant feeding with ongoing counselling and clear information (verbal, written or pictorial) on how to breastfeed or hygienically prepare replacement feeding.
- Refer women to community-based programmes and support groups that could assist with income generation, childcare or other household responsibilities, in order to support their choice regarding infant feeding.
- **BOX 3.1** below describes an intervention to support couples in safer infant feeding choices.

#### BOX 3.1

##### Supporting couples in safer infant feeding choices (146)

In Zimbabwe a project involving HIV-positive mothers demonstrated that the establishment of support groups for couples facilitated communication on sensitive issues. One of the issues that arose most frequently concerned explaining alternative methods of infant feeding to members of extended families. Support groups made it easier for couples to discuss such issues, and allowed them to examine various effective strategies and take joint decisions. As a result, they were better able to withstand pressure from extended families to adopt traditional feeding practices that might be inappropriate for people living with HIV.

<sup>1</sup> See WHO guidance on HIV and infant feeding (142–143).

### 3.2.4 Support women living with HIV to make informed reproductive choices

Supporting women living with HIV to prevent unintended pregnancies is a key PMTCT approach. Family planning is seen as important for enabling women living with HIV to plan for their own health and that of their families. Women who are tested for HIV before becoming pregnant can make timely decisions and choices about becoming pregnant, or delaying or preventing pregnancy. Therefore, offering HIV testing through family planning services, and providing contraception to women living with HIV and their partners, are considered to be important services for helping women make informed reproductive choices.<sup>1</sup>

#### KEY ISSUES

- Whether to have or not to have children is a dilemma for women living with HIV. For many women, motherhood fulfils both a biological and a social need.
  - In many cultures, for example, women face tremendous pressures to bear children as a way of achieving social status. Therefore, they may feel pressured to become pregnant, regardless of their HIV risk or HIV status. Men may justify having unprotected sex with their wives on the grounds that they are entitled to have children (147).
- Some women living with HIV may not wish to have children because of concerns about: their children's health (e.g. not wanting to have children with HIV); their children's well-being (e.g. not being present to take care of them); or their own health. Women may face stigma for not having or not wanting to have children because of the value associated in some cultures with women's childbearing (e.g. higher status assigned to women who have children, or who have many children or male children) (147).
- Unequal power relations between women and their families or health-care providers may undermine the ability of women to exercise their reproductive choices.
  - For example, research has shown that women living with HIV experience coercion related to their reproductive choices, whether in accepting one family planning method over others (e.g. sterilization), or as pressures to refrain from having children (54).
- Some family planning methods appropriate for women or couples living with HIV may not be consistent with the individual's or couple's method of choice.
  - For example, men may not be willing to use condoms because they may believe that it is their right to have unprotected sex with their partners, especially if they are married, or because they feel that using condoms reduces sexual pleasure or undermines their masculinity.
- **BOX 3.2** on page 54 describes the dilemmas faced by women living with HIV in making reproductive choices.

#### ACTIONS

- Assist women living with HIV to make informed reproductive choices and decisions by providing the full range of information about: potential pregnancy outcomes associated with HIV infection (e.g. low birth-weight, premature or stillborn babies); all appropriate contraceptive methods for those who wish to delay or prevent pregnancies; and PMTCT interventions for those who wish to have children (i.e. ARV prophylaxis, safer infant-feeding choices and birth planning).<sup>2</sup>
- Promote and protect the reproductive rights of women living with HIV, including the right to safe abortion in contexts where it is not against the law.
- Discuss family planning in a way that does not coerce women living with HIV into accepting any particular method, e.g. sterilization.
- Support women living with HIV who want to avoid pregnancy in consulting their partners about their reproductive decisions, and provide them with the necessary information. This should be done only if women choose to involve their partners.
- Sensitize communities about the importance of preventing unwanted pregnancies where one partner is, or both are, living with HIV, in order to create an enabling environment in which women living with HIV can make reproductive choices.

<sup>1</sup> See WHO guidelines on sexual and reproductive health for women living with HIV/AIDS and their children (133).

<sup>2</sup> See WHO guidance on reproductive choices and family planning for people living with HIV (134).

**BOX 3.2****Examples of the conflicting stigmas faced by women living with HIV with respect to reproductive choices (56)****STIGMA OF NOT HAVING CHILDREN**

- Society does not see me as a woman.
- There is no one to look after me when I am ill or old.
- People keep asking me, “Why don’t you have kids?” or they say I am useless because I have no children.
- If you have no children, your partner leaves you.
- Pressure from relatives to have children.
- My name is not used to name a relative’s child for fear that my situation (childlessness) will be passed on.
- Fear of behaving differently (i.e. not having children).

**STIGMA OF WANTING TO HAVE OR HAVING CHILDREN**

- If a woman is HIV-positive, she cannot bear children.
- If a woman is HIV-positive, she will miscarry or the baby will be stillborn.
- If a woman is HIV-positive and gets pregnant, it is a big strain on the immune system and she will die much more quickly.
- People living with HIV who have children are being selfish.
- It’s not fair to the children.
- Children will be orphans when the parents die.

### 3.2.5 Provide nutrition counselling and support for women living with HIV

HIV-positive pregnant women and lactating mothers need additional and specific nutritional support and counselling compared to HIV-negative women. This arises because of the higher nutritional requirements associated with pregnancy and the postpartum period, especially in contexts where malnutrition and food insecurity are endemic, combined with the wasting and higher energy expenditure associated with HIV infection (148).

#### KEY ISSUES

- In many settings, while women are primarily responsible for producing, gathering, purchasing and preparing food for their families and themselves, including sick members of their households, they do not have decision-making power related to food production, purchase or preparation (149).
- In settings of high HIV prevalence, where male members of households are sick or have died because of AIDS, women face poverty and food insecurity. This places an additional burden on them, as they are responsible for finding and preparing nutritionally adequate foods for their families and themselves (13).
- In some settings, cultural norms and women's status dictate that women are the last in the household to eat after feeding the men, children and other household members. This means that women may not get enough food to eat, or may get food that is not nutritionally adequate (150–151).
- In many settings, women work as subsistence farmers or field workers with long and demanding working hours. Poor food intake during pregnancy or lactation, coupled with heavy physical labour, puts women in a negative energy balance that can be exacerbated by HIV infection (13, 149).
- Anaemia is common among women, especially during pregnancy, and is often more severe in those living with HIV than in others. In many settings, social norms and cultural practices related to food intake during pregnancy and the postpartum period can affect the nutritional status of women, including those living with HIV (152). For example, pregnant women may be proscribed from eating certain nutritionally rich foods because of beliefs that these can harm the foetus (152–153).
- Women living with HIV also have to be especially concerned about maintaining good hygiene for themselves, their families and their children in food preparation (e.g. with reference to bottle-feeding and hand-washing) in order to avoid contracting food-related infections.

#### ACTIONS

- Work with women and men in households, communities, and agricultural programmes to identify and address causes of household food insecurity, including sociocultural norms and practices related to food production, purchasing, and preparation.
  - For example, an intervention to improve food security in HIV-affected households in Uganda changed norms related to the sharing of food and increased women's access to nutritionally rich foods, which were previously kept only for men (151).
- Address the sociocultural norms and practices that influence food intake for women during pregnancy, as part of providing information about appropriate foods for achieving weight gain during pregnancy, preventing anaemia and supporting lactation.<sup>1</sup>
- Refer pregnant women who are unable to gain weight, are losing weight, or are experiencing acute food insecurity, to programmes that provide food assistance, either as part of a home-based care programme or through another programme (e.g. kitchen gardens, micronutrient supplementation).
- Provide counselling on food safety, preparation and storage in order to minimize the risks for women living with HIV, and their families, of becoming sick from food-related infections. This may be especially important for HIV-positive mothers who are considering alternative feeding for their infants.
- For women who are taking ARVs, provide counselling on the management of side-effects that have nutritional implications, such as nausea, diarrhoea and vomiting, and on the food and water requirements of the relevant drug regimens.

<sup>1</sup> See WHO guidelines on nutrition counselling, care and support for HIV-infected women (148).

