Module 8: Communication Issues in Stigma and Discrimination

SECTION 1: Stigma and Discrimination

SECTION 2: Key Issues in Communication for PMTCT

SECTION 3: Communication Interventions

Objectives

At the end of this module, participants should be able to:

- Identify HIV/AIDS–related stigma and discrimination
- Address stigma and discrimination in the context of providing PMTCT services
- Identify communication gaps in PMTCT of HIV
- Outline human rights issues in PMTCT
- Explain personal values and attitudes with regard to HIV/AIDS prevention and care.
- State the importance of enlisting the support of all stakeholders for PMTCT

Introduction

Nigeria continues to face many challenges in terms of the HIV/AIDS epidemic. Poverty, lack of knowledge on prevention, lack of empowerment of women and girls, vulnerability of youth with 60% of the population under 24, and strong stigma and discrimination against people living with and affected by HIV/AIDS (source: UNAIDS, www.unaids.org/Unaids/EN/Geographical+area/By+country/nigeria.asp).These challenges have clear repercussions for MTCT of HIV.

Many of the core challenges of PMTCT involve a lack of understanding and communication among key stakeholders. These gaps in communication and information influence behaviours, services and support that are needed to empower HIV-infected women to seek and receive the treatment, care and support needed to prevent HIV transmission to their infants, and to reduce stigma and discrimination. In order to reduce the spread and impact of HIV transmission among women of reproductive age, their infants and families, there must be integration of strategic communication interventions, as well as strategies to combat stigma and discrimination.

Three phases of the HIV/AIDS epidemic have been identified: the epidemic of HIV; the epidemic of AIDS; and the epidemic of stigma, discrimination, and denial. The third phase is as central to the global AIDS challenge as the disease itself. All these phases of the epidemic can only be effectively controlled if we can ensure effective communication that promotes positive behavioural changes and creates an enabling

supportive environment for HIV/AIDS interventions, including PMTCT. The communication interventions should include:

- Advocacy for resource mobilisation and creation of favourable policy environment
- Social mobilisation of NGO, FBO and CBO so as to expand coverage with interventions
- Behavioural change communication for the promotion of individual behavioural changes.

The communication messages should target all stakeholders.The key stakeholders are:

- Mothers
- Partners
- Family
- Healthcare workers
- Media
- Community and opinion leaders
- Religious leaders
- Government (local, state & federal)
- Development partners (international and local)
- NGOs, FBOs & CBOs
- PLWHAs

The core challenge of PMTCT is reaching more pregnant women and women of child-bearing age with information, services and support, to empower them as catalysts in the interruption transmission of HIV to their babies. A strong and sustainable PMTCT communication component is central to faclilitating both supply-provision, demand-creation and for reversing the downward spiral of child survival occasioned by MTCT.

Often, it is failure or gaps in communication that fuel stigma and discrimination. Stigma and discrimination promote the spread of the epidemic as it drives it underground and acts as barrier to uptake of services by PLWHA.

Definitions

Communication is the process of exchange of information, ideas and thoughts between individuals or groups for the purpose of establishing understanding.

Stigma refers to unfavourable attitudes and beliefs directed toward someone or something.

Discrimination is the treatment of an individual or group with partiality or prejudice.

Stigma and discrimination are often defined in terms of human rights and entitlements in various spheres, including healthcare, employment, the legal system, social welfare, and reproductive and family life.

This module examines issues in communication particularly as they concern stigma and discrimination in the context of PMTCT.

Exercise 8.1: Communication	
Purpose	Discuss issues that make communication less effective.
Duration	60 minutes
Activities	The participants will divide into two groups. Each group will take one of the assignments below. Within each group, choose someone to record the plan on a flip chart, and someone to present the final plan. You will have 40 minutes to develop your plans. When the groups come back together, you will share and discuss both plans. Listen for additional ideas that can be contributed to the plans. **<u>Group 1</u>** should develop the contents of an advocacy visit to the council of elders in this village, highlighting the crucial points that the elders should know with the view of developing a plan for PMTCT. **<u>Group 2</u>** should develop a strategy that will be used to generate a demand for PMTCT services in this village and surroundings, paying careful attention to 1) the message 2) media 3) target audience.

SECTION 1: Stigma and Discrimination

Exercise 8.2:	Labels interactive game
Purpose	To help recognise the role of stereotypes in stigma.
Duration	20 minutes
Activities	▪ A "label" will be attached to your back using tape as you enter the room. Please do not look at the label that has been attached to you. ▪ Move around the room and engage in conversation with other participants. With each participant, react as a member of society might react to a person with the label the participant is wearing. It is important to talk with other participants clearly, conveying societal attitudes toward the label they are wearing without telling them what their labels are. ▪ After 5–7 minutes, return to your seats and comment on your feelings as you circulated in the room talking to each other. ▪ Try to guess the label you were wearing based on the reactions of the other participants to you. ▪ Take the label off your back and look at it. ▪ In the large group discussion, share your thoughts about the following questions: Did you guess what your label was? How did it feel to be treated in a stereotyped way? What was the experience like for you? Were you puzzled or surprised by how you were treated? Identify some specific ways to combat stereotypes and help decrease stigma in your clinical setting.

Introduction to the Concepts of Stigma and Discrimination

Concepts of stigma and discrimination

HIV/AIDS is not only the greatest health challenge of our time, but it is also the greatest human rights challenge. People who are aware that they are HIV–infected shoulder the twin burdens of stigma and discrimination. Fear of becoming infected underlies stigma and discrimination, which remain major impediments to preventing HIV transmission and providing treatment, care, and support to people who are HIV–infected and their families.

The most effective responses to the HIV/AIDS epidemic are those that work to prevent the stigma and discrimination associated with HIV, and to protect the human rights of people living with HIV and those at risk of infection.

HIV/AIDS–related stigma

HIV/AIDS–related stigma refers to all unfavourable attitudes and beliefs directed toward people living with HIV/AIDS (PLWHA) or those perceived to be infected and also toward their loved ones, close associates, social groups and communities.

Stigmatising attitudes are often directed not only toward the person with HIV, but also toward behaviours believed to have caused the infection. Stigma is particularly pronounced when the behavior linked to the origin of a particular disease is perceived to be under the individual's control, such as prostitution or injection drug use.

Stigmatisation and discrimination

Stigmatisation reflects an attitude, but *discrimination* is an act or behaviour. Discrimination is a way of expressing, either on purpose or inadvertently, stigmatising thoughts.

Stigma and discrimination are linked. Stigmatised individuals may suffer discrimination and human rights violations. Stigmatising thoughts can lead a person to act or behave in a way that denies services or entitlements to another person.

Stigma and discrimination have been documented in association with other disfiguring or incurable infectious diseases, including tuberculosis, syphilis, and leprosy. However, HIV/AIDS–related stigma appears to be more severe than the stigma associated with other life–threatening infectious diseases.

Examples of discrimination are**:**

- A person with HIV is denied services by a healthcare worker.
- The wife and children of a man who recently died of AIDS are ostracised from the husband's familial home or village after his death.
- An individual loses her/his job because it becomes known that s/he is HIV–infected.
- A person finds it difficult to get a job once it is revealed that s/he is HIV–infected.
- A woman who decides not to breastfeed is assumed to be HIV–infected and is ostracised by her community.

Values Clarification (Individual Perspective)

The face of stigma

HIV/AIDS–related stigma is complex, dynamic, and deeply ingrained. The points below may provide PMTCT programmes with a framework for developing and implementing interventions to address HIV/AIDS–related stigma and discrimination.

Attitudes and actions are stigmatising

People are often unaware that their attitudes and actions are stigmatising. A word, action or belief may be unintentionally stigmatising or discriminatory toward an individual who is HIV–infected. People often exhibit contradictory beliefs and behaviours. For example, consider the following:

A person who is opposed to stigmatisation or discrimination may simultaneously believe that PLWHA indulge in immoral behaviours, deserve what they get, or are being punished by God for their sins.

A person who claims to know that HIV cannot be transmitted through casual contact may still refuse to buy food from a vendor who is HIV–infected or allow his family to use utensils once used by a PLWHA.

Choice of language may express stigma

Language is central to how stigma is expressed. People may not realise that they are stigmatising with their choice of words in referring to HIV disease or PLWHA. One way that language can be stigmatising is in the use of derogatory references to those with HIV/AIDS. In some countries people refer to HIV, not by name, but rather indirectly as, for example, "that disease we learned about" and refer to PLWHAs as “walking corpse” and “expected to die”.

Lack of knowledge and fear foster stigma

Knowledge and fear interact in unexpected ways that allow stigma to continue. Although most people have some understanding of HIV transmission and prevention, many lack in–depth or accurate knowledge about HIV. For example, many do not understand the difference between HIV and AIDS, how the disease progresses, the life expectancy of PLWHA, or that HIV/AIDS–related opportunistic infections (such as tuberculosis) are treatable and curable. Others equate an HIV–positive test result with imminent death. The fear of death is so powerful that many people will avoid individuals suspected to have HIV–even though they know that HIV is not transmitted through casual contact.

Shame and blame are associated with HIV/AIDS

Sexual immorality, shame, and blame are associated with HIV/AIDS. Stigmatisation often centres on the sexual transmission of HIV. Many people assume that individuals who are HIV–infected must have been infected through sexual activities deemed socially or religiously unacceptable. People who are HIV–infected are often presumed to be promiscuous, careless, or unable to control themselves, and therefore responsible for their infection.

Stigma makes disclosure more difficult

Disclosure (the sharing of HIV status with others) is advocated but often difficult – and uncommon – in practice. Most people believe that disclosure of HIV status should be encouraged. Yet many people infected with HIV avoid disclosing their HIV status for fear that doing so will subject them to unfair treatment and stigma. Some of the benefits of disclosure are the following:

- Disclosure can encourage partner(s) to be tested for HIV.
- Disclosure can help prevent the spread of HIV to partner(s).
- Disclosure allows individuals to receive support from partner(s), family, and/or friend(s).

Stigma can exist even in caring environments

Care and support can coexist with stigma. Caregivers who offer love and support to family members living with HIV/AIDS may also exhibit stigmatising and discriminatory behaviour (such as blaming and scolding). In many cases, the caregivers don't recognise this behaviour as stigmatising. Stigmatising attitudes exist even among those

individuals, communities and healthcare workers who are opposed to HIV/AIDS–related stigma. The following scenarios may generate stigmatising attitudes:

- People can have both correct and incorrect information about HIV at the same time. For example, an individual's understanding of the routes of HIV transmission may be accurate in some respects but inaccurate in others.
- People express both sympathetic and stigmatising attitudes toward PLWHA.
- Families that provide genuine and compassionate care may sometimes stigmatise and discriminate against a family member with HIV/AIDS.

Effects of stigma

Stigma is disruptive and harmful at every stage of the HIV/AIDS continuum, from prevention and testing to treatment and support. For example, people who fear discrimination and stigmatisation are less likely to seek HIV testing while persons who have been diagnosed may be afraid to seek necessary care. PLWHA also may receive suboptimal care from workers who stigmatise them.

Stigma may reduce an individual's choices in healthcare and family/social life.

Stigma may limit access to measures that can be taken to maintain health and quality of life.

HIV/AIDS–related stigma fuels new HIV infections

- Stigma may deter people from getting tested for the disease.
- Stigma may make people less likely to acknowledge their risk of infection.
- Stigma may discourage those who are HIV–infected from discussing their HIV status with their sex partners and/or those with whom they share needles.
- Stigma may deter PLWHA from adopting risk–reduction practices that may label them as HIV–infected.

Stigma and discrimination can lead to social isolation

Studies in Nigeria have found that both men and women who are HIV–infected face social isolation. The isolation may manifest as

- Rumours and gossip
- Divorce by spouse
- Physical violence
- Ejection from the home
- Rejection by the community
- Verbal abuse
- Isolation in house
- Segregation of feeding utensils, etc.

One person in the study stated, "There are those who will tell you face–to–face that you are no longer needed in their friendship, those who will just isolate you." Another said, "People make jokes about HIV–infected people and point fingers at them."

Stigma and discrimination can limit access to services.

HIV/AIDS–related stigma and discrimination may discourage individuals from contacting health and social services, thereby increasing the risk of transmission to partners or children. In many cases, those people most in need of information, education and counselling will not benefit from these services–even when they are available.

Secondary stigma (stigma by association)

The effects of stigma often extend beyond the infected individual to stigma by association also known as secondary stigma*.* **Secondary stigma** is evidenced in statements like "If I sit near someone with AIDS, others will think that I have AIDS too." HIV/AIDS programme social workers and peer educators in South Africa reported that they were sometimes stigmatised because of their work with PLWHA. Thus secondary stigma could be extended to:

- People that contnue to associate and interact with PLWA
- Healthcare providers and those involved in the community care of them
- Children and other relations of PLWA

International human rights and HIV–related stigma and discrimination

Freedom from discrimination is a fundamental human right founded on principles of natural justice that should be universally applied to people everywhere. According to recent United Nations Commission on Human Rights resolutions, "***discrimination on the basis of HIV/AIDS status, actual or presumed, is prohibited by existing human rights standards***." In other words, discrimination against PLWHA or people thought to be infected is a clear violation of human rights.

The forms of stigma and discrimination faced by people with HIV/AIDS are varied and complex. Individuals are stigmatised and discriminated against not only because of their HIV–positive status but also because of what that status implies. UNAIDS–sponsored research in India and Uganda showed that women with HIV/AIDS may be doubly or triply stigmatised:

- As women
- As PLWHA
- As the spouse of a person who is HIV–infected, or the widow of a person who died of AIDS

A woman may face additional stigmatisation as a "woman who is HIV–infected and is pregnant and/or has children." For example, she may be treated poorly or denied medical and psychosocial support services.

Protect, respect, and fulfill human rights in relation to HIV

- All women and men, irrespective of their HIV status, have a right to determine the course of their sexual and reproductive lives and to have access to information and services that allow them to protect their own and their family's health.
- Children have a right to survival, development, and health.
- Women and girls have a right to information about HIV/AIDS and access to the means of protecting themselves against HIV infection.
- Women have the right to access to HIV testing and counselling and to know their HIV status.
- Women have a right to choose not to be tested or to choose not to be told the result of an HIV test.
- Women have a right to make decisions about infant feeding, on the basis of full information, and to receive support for the course of action they choose.

A summary of the International Guidelines on HIV/AIDS and Human Rights, as adopted by the Second International Consultation (July 2002), can be found in Appendix 8–A.

Exercise 8.3 Examples of stigma and discrimination: large group discussion	
Purpose	To encourage participants to consider examples of stigma and discrimination in their own settings.
Duration	10 minutes
Activities	Share examples of stigmatising and discriminatory messages or attitudes that you have seen in each of the following places: ▪ Media (newspapers, television, or radio programmes) ▪ Health services ▪ Workplace ▪ Religion ▪ Family ▪ Community

Examples of stigmatisation and discrimination

In the media

Suggesting in the media that there are specific groups of people with HIV who are guilty (such as sex workers or injection drug users) whereas others (such as infants) are innocent

Depicting HIV/AIDS as a death sentence, which perpetuates fear and anxiety, and labels HIV as a disease that cannot be managed like any other chronic disease

Using stereotypical gender roles, which may perpetuate women's vulnerability to sexual coercion and HIV infection

In health services

Refusing to provide care, treatment, and support to PLWHA

Providing poor quality of care for PLWHA

Violating confidentiality

Providing care in stand–alone settings (such as clinics for sexually transmitted infections) that further stigmatise and segregate PLWHA

Using infection–control procedures (such as gloves) only with patients thought to be HIV–positive, rather than with all patients

Advising or pressuring PLWHA to undergo procedures, such as abortion or sterilisation, that would not be routinely suggested for others

In the workplace

Requiring testing before employment

Refusing to hire people who are HIV–infected and HIV–affected

Mandating periodic HIV testing

Being dismissed because of HIV status

Violating confidentiality

Refusing to work with colleagues who are HIV–infected because of fear of contagion

In the context of religion

Denying participation in religious/spiritual traditions and rituals (such as funerals) for PLWHA

Restricting participation of PLWHA in religious activities

In the family and local community

Isolating people who are HIV–infected

Restricting participation of PLWHA in local events

Refusing to allow children who are HIV–infected or HIV–affected in local schools

Ostracising of partners and children of PLWHA

Using violence against a spouse or partner who has tested HIV–positive

Denying support for bereaved family members, including orphans

SECTION 2: Key Issues in Communication for PMTCT

What does communication entail?

The communication pathway involves the following:

Sender	One who sends the message
Message	Information in a form that the sender expects to be received
Medium	Channel through which the message is transmitted, e.g., radio, TV, newspaper, etc.
Receiver	Person who receives the information
Feedback	Information from the receiver to the sender to ascertain level of comprehension of the message

Barriers to effective communication

In communication, information sent may not be the same message perceived by the receiver. This is because of distortions that may occur at different stages.

- The **sender** may not give the information in a way that it is readily understood. His/her non–verbals may communicate the opposite of what he actually intends to say.
- The **message** may itself not be in a clear form that the receiver can understand without difficulty.
- **Media** used may not be appropriate. For example, if one intends to send a word to all Fulani nomads to come and access PMTCT services, the television will not be the right medium. A radio would be more relevant because this group moves around very well and carry radios rather than television sets. .
- Where the sender and **receiver** are not of the same background, the correct information may not be received as intended.

Consequently, when developing communication materials on PMTCT a lot of care is required to ensure that the correct messages are transmitted to target audiences. The messages should be derived from an assessment of information and knowledge gaps of the target audience. The messages should be carefully developed with the target audience in mind. These messages should be pre–tested to assess what perception and understanding and necessary changes made before production and widespread dissemination to the target audience. HIV/AIDS is still a very sensitive issue and so, requires very effective communication of all information. Advocacy and community mobilisation rely completely on effective communication to succeed.

Common issues in PMTCT in Nigeria requiring communication interventions

A national formative research on PMTCT conducted in 2001 indicated the following gaps in PMTCT settings:

- Lack/inadequate knowledge of issues related to PMTCT (Basic information about HIV/AIDS, benefits of VCT and the risks associated with mixed infant feeding)
- Cultural and/or religious barriers to the promotion and support for modern family planning including condom
- Lack of proper understanding among stakeholders of their roles and responsibility in support of PMTCT
- Stigma and discrimination against PLWHA
- Lack/inadequate community dialogue and participation
- Male dominance in decision making and health seeking behaviour at house hold level
- Lack of male partner involvement in certain PMTCT interventions
- Negative attitudes and behaviour of service providers to clients

SECTION 3: Communication Interventions

Stigma and PMTCT services

Stigma and discrimination pose distinct challenges to the delivery of PMTCT services. Notably, in many areas women may avoid replacement feeding because they know that they will be labelled as HIV–infected if they are not breastfeeding. The children of mothers who participate in PMTCT programmes may experience secondary stigmatisation because people assume that they are HIV–infected.

Consequences of stigma in PMTCT programmes

Discourages women from accessing antenatal care services

Prevents people from receiving HIV testing and, as a result, PMTCT services

Discourages women from discussing their HIV tests and disclosing results to their partner(s)

Discourages women from accepting PMTCT interventions e.g., ARV teatment and prophylaxis

Discourages the use of recommended PMTCT safer infant–feeding practices (replacement feeding or early cessation of breastfeeding)

Addressing stigma in PMTCT programmes

To increase participation in PMTCT services, programmes should implement interventions that address HIV/AIDS–related stigma. These efforts should occur at all levels:

- National
- Community, social, and cultural
- PMTCT site
- Individual

Stigmatisation is a social process that must be addressed on the community level. Because PMTCT healthcare workers and patients are influenced by the community and culture in which they live, it is essential that PMTCT programmes collaborate with the community to address HIV/AIDS–related stigma and discrimination. This section presents various interventions that may be implemented by PMTCT programmes and the communities they serve. These interventions cover a wide range of activities; each programme should set priorities for initial interventions and phase in additional efforts over time.

National level

High–level political support for national HIV/AIDS initiatives and policies that address the human rights of PLWHA is important. High–ranking politicians and other high–profile

individuals, such as television stars and musicians, may serve as leaders and role models in these efforts. It is essential to secure both formal and informal support at the national level, without which local initiatives will struggle to succeed.

National level activities that affect HIV/AIDS and PMTCT–related legislation and healthcare practice may include the following:

- Support and advocate legislation that protects the rights of PLWHA as human beings and patients.
- Support legislation that protects the legal rights of women in healthcare, education, and employment.
- Advocate for laws supporting anti–discrimination policies at the administrative, budgetary, and judicial levels.
- Support national efforts to scale–up of PMTCT services and treatment of HIV with antiretroviral (ARV) drugs for those in need.
- Involve PLWHA and women in national advocacy and elicit their help in designing, developing and evaluating programmes and policies.
- Advocate for sufficient funding for PMTCT services and staff training.
- Publicise programme successes by inviting national and local politicians to clinics to see how PMTCT programmes work.
- Ensure that the problems and solutions are communicated to those who have the power and authority to address them when issues require national level solutions (such as national shortages in ARV prophylaxis and shortages in the supply of breast milk substitutes).
- Educate national leaders about the importance of PMTCT programmes.
- Encourage national leaders to serve as role models in their professional and personal lives.
- Encourage leaders to hire staffs that are HIV–infected.
- Encourage leaders to praise the good work of PMTCT clinics to the public and to the press.
- Encourage leaders to visit an AIDS service organisation.
- Encourage leaders to speak out against emotional, verbal and physical abuse directed at women infected with HIV.
- Remind leaders to promote funding of HIV/AIDS care programmes.
- Suggest that leaders be tested for HIV.

Community level

1. HIV/AIDS education and training

Provide HIV/AIDS education and training to members of the community, especially key opinion leaders, NGO, FBO, CBO, traditional birth attendants, traditional healers, healthcare staff in referring organisations, community and religious leaders, and managers in private industry. Educational and informational initiatives can accomplish the following:

- Increase knowledge about HIV
- Increase awareness of issues faced by PLWHA
- Increase awareness of domestic violence faced by newly diagnosed women

- Communicate, through community leaders, that violence against women is inappropriate, immoral, and/or illegal
- Encourage leaders to make their workplaces HIV–friendly
- Promote PMTCT activities as an integral part of healthcare and HIV/AIDS prevention and treatment
- Educate the community about PMTCT interventions (including ARV prophylaxis and safer infant–feeding practices), stressing the importance of community and family support in PMTCT initiatives
- Increase referrals to and from PMTCT services
- Secure the involvement of community members and PLWHA in organising, developing, and delivering HIV education, prevention, and support programmes.

2. Community awareness of PMTCT interventions

Increase community awareness of PMTCT interventions to help men and women recognise their roles and responsibilities in protecting themselves and their families against HIV infection.

Greater community awareness should also strengthen social support for the partner, extended family and community. The people who cope the best with their HIV infection tend to be those who have social and family support.

For example, families and close friends can help remind those with HIV infection to take their medicines on time. If the person with HIV is pregnant, family members often help ensure that she gives birth at the health centre and that she takes her ARV prophylaxis. They can also help ensure that the baby receives ARV prophylaxis and support infant–feeding methods that reduce the risk of HIV transmission.

3. Community partnerships

Build partnerships with churches, schools, and social or civic organisations when developing PMTCT services. Promoting PMTCT services in community organisations will enhance sustainability and will help develop a broad base of support for the PMTCT initiative.

4. Other community level interventions

Additional community level interventions may include the following:

- Facilitating the exchange of information and ideas among healthcare professionals and other caregivers of PLWHA through roundtable case discussions and social activities
- Providing input into curricula for students in healthcare professions (primary healthcare workers, nurses, midwives, physicians)

5. PLWHA involvement

Invite PLWHA to become involved in national and local initiatives. Doing so will empower them. It will also help the community realise that PLWHA are not the cause of the HIV/AIDS problem but are part of the solution. Involving PLWHA in initiatives will:

- Help PLWHA gain and practise life skills in communication, negotiation, conflict resolution, and decision–making, which empowers them to challenge HIV/AIDS–related stigma and discrimination
- Encourage PLWHA to join together to challenge stigma and discrimination.
- Promote the active involvement of PLWHA in national and local activities to foster positive perceptions of people living with HIV
- Support the establishment of PLWHA organisations and networks, including those that enable people to demand recognition and defend their rights

6. Training programmes for PLWHA

Develop and implement training programmes for PLWHA to help them advocate for their rights and take an active role in their own healthcare. By participating in interventions (such as PMTCT services or HIV prevention and care education) as volunteers, advisors, board members, or paid employees, PLWHA will demonstrate their ability to remain productive members of the community. This normalises the experience of living with HIV infection.

PMTCT programme level

PMTCT services should be integrated into and supported by the local community. Although PMTCT programmes often reflect the communities in which they are based, they can take the lead in challenging long–held community perceptions and practices, including stigmatisation of and discrimination against PLWHA and PMTCT patients.

1. Integration of PMTCT interventions into antenatal care (ANC) services

Integrate all PMTCT interventions into mainstream antenatal care (ANC) services for all women. Offer voluntary HIV testing and counselling to all clinic attendees, regardless of their perceived HIV risk. Mainstreaming HIV services with routine ANC services helps normalise HIV/AIDS.

2. Participation of partners

Develop ways to increase the participation of partners in all aspects of PMTCT services. Educate partners about PMTCT interventions (including ARV treatment and prophylaxis and modified infant–feeding practices) and stress the importance of partner testing, partner and family support in PMTCT, particularly with respect to ARV prophylaxis and infant feeding.

As an example, two sites in Kenya invited men to visit the PMTCT clinic for counselling and testing and PMTCT education designed specifically for a male audience. As a result of these interventions, the programme:

- Improved spousal communication about PMTCT
- Increased HIV testing among male partners of PMTCT patients
- Increased HIV test disclosure rates for both partners

3. Educational sessions

Offer group or individual education sessions (onsite and offsite), which can help draw attention to the role that partners play in HIV transmission and reduce stigmatisation of women.

- Couples counselling offers another opportunity to reduce the blame that can be directed at women and emphasise the couple's shared responsibility in PMTCT.
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When male partners do not normally attend ANC clinics, PMTCT programmes should reach out to them in male–friendly settings (e.g., workplaces, mosques and churches, barber shops, bars, clubs, motor parks, cafeterias).

4. Healthcare worker training

Educate and train healthcare workers. The success or failure of a PMTCT programme depends upon the attitudes, skills, and experience of its employees. Training healthcare workers at all levels (manager, nurse, midwife, physician, social worker, counsellor and outreach worker) is critical to the success of PMTCT initiatives. Employee training should include:

- Complete and accurate information about the transmission of HIV and the risks factors for infection
- Activities that address HIV/AIDS–related stigma

5. Understanding the perspectives and rights of PLWHA and their families

In addition to presenting information, it is important for educational initiatives to address employee attitudes, correct misinformation, and assess skills.

Educate healthcare workers to better understand the perspectives and rights of PLWHA and their families. Without adequate HIV–related education, staff may have irrational fears, practise inappropriate care, and use stigmatising language and behaviour. Accordingly, training healthcare workers to reduce stigmatising behaviour will address assumptions about the educational, social, economic, and class status of PLWHA and encourage participants to examine their prejudices.

During training activities, strive to increase awareness of the language used to describe HIV/AIDS and PLWHA. The training should include:

- Exercises designed to encourage participants to explore personal attitudes and prejudices that might lead them to use stigmatising language
- Summaries of institutional confidentiality, anti–discrimination, and infection control policies as well as the consequences of policy breaches and grievance procedures

6. Infection control

Ensure infection control by providing all healthcare workers with the necessary equipment and supplies (including high–quality, well–fitting gloves) needed to adhere to infection control policies and prevent transmission of HIV in the workplace (See *Module 7: Safety and Supportive Care in the Work Environment*). Apply universal precautions to all patients regardless of assumed or established HIV status.

7. Patient confidentiality

Safeguard patient confidentiality by developing policies and procedures and establishing discrete plans for implementing them. Confidentiality in healthcare facilities is also discussed in *Module 3, HIV Testing and Counselling for PMTCT*. Confidentiality policies should include:

- Directions on how to record and securely store patient information
- Assurances that neither PLWHA nor their medical files (whether paper or electronic) will be labelled to reveal HIV status
- Assurances that all patient consultations, from the initial contact with the receptionist to the consultation with the physician, will respect personal information

The confidentiality policy should emphasise that all personal conversations and consultations should take place in private settings. It should also establish:

- Policies for disclosure of medical information to a patient's family (which should only occur with the patient's informed consent)
- Policies for addressing and disciplining breaches of confidentiality
- Steps patients can take to address breaches of confidentiality
- Requirements for staff confidentiality training
- The critical importance of confidentiality and the effects that breaches may have on individual patients and the PMTCT service as a whole

8. Role models

Encourage PMTCT staff to serve as role models by treating PLWHA just as they would treat patients assumed to be HIV–negative. Healthcare workers are role models, and their attitudes toward PLWHA are often imitated in the community. Staff should aim to normalise all casual contacts with PLWHA.

9. Knowing the local community

Get to know the local community, which will help to identify local HIV–related stereotypes and rumours. Ensure that these misconceptions are addressed at appropriate times during PMTCT services. In many cultures, for example, women who bottle–feed or cup–feed their infants may be labelled as HIV–infected. In such cultures, PMTCT workers should address this stereotype during counselling and educational sessions and emphasise the importance of safer infant–feeding practices for reducing MTCT.

Individual

1. Women's rights

Advocate for women's rights. Ensure that women diagnosed with HIV are educated about their rights and know where to turn for help, including legal advice, to challenge discrimination and stigmatisation.

2. Peer and community support

Facilitate peer and community support. Recognise that support groups in the ANC setting provide an opportunity for pregnant women who are HIV–infected to share experiences

and be linked to other support services. PMTCT programmes can facilitate such support groups by:

- Supporting mentoring programmes. South Africa's Mothers–to–Mothers–to–Be is a mentorship programme for pregnant women who are HIV–infected. Mothers who are HIV–infected and have recently given birth return to the ANC facility as mentors to educate, counsel, and support pregnant women who are HIV–infected. The mother–mentors share personal experiences to encourage adherence to treatment, help with making infant–feeding decisions, and assist with negotiating care and support services. The mentoring has resulted in better understanding and greater acceptance of interventions to reduce MTCT.
- Encouraging peer support. Encourage PLWHA to pair up with another person–HIV–positive or negative–which can provide friendship, companionship, advice, or mentoring.

Involving PLWHAs in PMTCT programmes can help address stigma and discrimination issues and promote better understanding of and support for those with HIV infection.

3. Counselling and education for PLWHA

Counselling and education for PLWHA, provided either within the PMTCT service or through linkages to other services, can address HIV–related stigma in a number of ways:

- Counsellors can encourage, empower, and support PLWHA to disclose their HIV status to family and eventually to friends. As more people disclose their HIV status, PLWHA become more visible, which encourages community acceptance of PLWHA?
- Counsellors should be trained to ask all their patients, particularly women, about domestic violence. Women found to be at risk of physical, verbal, or emotional abuse should receive support and referrals.

Role of PMTCT programme managers

It is vital for PMTCT programme managers to ensure that policies and procedures are in place to protect individuals from discrimination and stigmatisation. PMTCT programme managers also play an important role in the development, implementation, and enforcement of confidentiality policies. Some of the actions managers can take to reduce stigma and discrimination include the following:

- Maintain policies against discriminatory recruitment and employment practices.
- Support workers who are HIV–infected so they continue to perform optimally in their positions.
- Offer flexible hours and access to healthcare services.
- Establish policies that guarantee all patients equal treatment regardless of HIV status.
- Ensure procedures for reporting discrimination and protocols for disciplining staff who breach the non–discrimination policy.
- Promote the programme's policies to staff and patients, and remind patients that they can file a complaint if they feel they have been the target of discrimination.

In addition, programme managers can also help ensure that all staff follow universal precautions, which may reduce the stigma associated with fear of infection. The manager can:

- Update the facility's infection control policy as necessary.
- Ensure ongoing access to infection control supplies and equipment.
- Make sure that staff members apply universal precautions at all times.
- Discipline employees who breach the universal precautions policy.
- Make post–exposure prophylaxis (PEP) accessible to staff in cases of accidental exposure to blood and body fluids as per national/local policy where it exists.

Exercise 8.4: PLWHA Panel	
Purpose	To give PLWHA an opportunity to share their experiences in the healthcare system and to help educate healthcare workers.
Duration	60 minutes
Instructions	▪ Observe the interaction between the moderator and the panellists. Pay special attention to the remarks of the PLWHA about their experiences with stigma and discrimination in the healthcare setting, family, and/or community. ▪ When the moderator indicates, please ask questions of the panellists. Be especially aware that questions should be non–judgemental.

Module 8: Key Points

- Stigma reflects an attitude, while discrimination is an act or behaviour.
- Discrimination is often defined in terms of human rights and entitlements in health care, employment, the legal system, social welfare, and reproductive and family life.
- Stigma and discrimination are interlinked. Stigmatising thoughts can lead to discrimination and human rights violations.
- In communication, the intended information may not be understood by the receiver if the message is not adequately passed or the wrong medium is used.
- Community mobilisation is necessary for the development and group ownership of PMTCT. This ensures sustainability.
- Advocacy, the process of gathering, organising and formulating information into arguments, is a very important tool in community mobilisation for PMTCT.
- International and national human rights declarations affirm that all people have the right to be free from discrimination on the basis of HIV/AIDS status.
- PMTCT programme staff have a responsibility to respect the rights of all women and men, irrespective of their HIV status.
- HIV/AIDS–related stigmatisation and discrimination may discourage PLWHA from accessing key HIV services. It may also:
- Discourage disclosure of HIV status
- Reduce acceptance of safer infant–feeding practices
- Limit access to education, counselling, and treatment even when services are available and affordable
- PMTCT programme staff can help reduce stigma and discrimination in the healthcare setting, in the community, and on the national level.
- Encourage PMTCT staff to serve as role models by treating PLWHA just as they would treat patients assumed to be HIV–negative.
- Involve PLWHAs in every aspect of the PMTCT programme.
- Promote partner participation and community support.

GUIDELINE 1:

States should establish an effective national framework for their response to HIV/AIDS, which ensures a coordinated, participatory, transparent and accountable approach, integrating HIV/AIDS policy and programme responsibilities across all branches of government.

GUIDELINE 2:

States should ensure, through political and financial support, that community consultation occurs in all phases of HIV/AIDS policy design, programme implementation and evaluation and that community organisations are enabled to carry out their activities, including in the field of ethics, law and human rights, effectively.

GUIDELINE 3:

States should review and reform public health laws to ensure that they adequately address public health issues raised by HIV/AIDS, that their provisions applicable to casually transmitted diseases are not inappropriately applied to HIV/AIDS and that they are consistent with international human rights obligations.

GUIDELINE 4:

States should review and reform criminal laws and correctional systems to ensure that they are consistent with international human rights obligations and are not misused in the context of HIV/AIDS or targeted against vulnerable groups.

GUIDELINE 5:

States should enact or strengthen anti–discrimination and other protective laws that protect vulnerable groups, people living with HIV/AIDS and people with disabilities from discrimination in both the public and private sectors, ensure privacy and confidentiality and ethics in research involving human subjects, emphasise education and conciliation and provide for speedy and effective administrative and civil remedies.

GUIDELINE 6:

States should enact legislation to provide for the regulation of HIV–related goods, services and information, so as to ensure widespread availability of qualitative prevention measures and services, adequate HIV prevention and care information, and safe and effective medication at an affordable price.

GUIDELINE 7:

States should implement and support legal support services that will educate people affected by HIV/AIDS about their rights, provide free legal services to enforce those rights, develop expertise on HIV–related legal issues and utilise means of protection in addition to the courts, such as offices of ministries of justice, ombudspersons, health complaint units and human rights commissions.

GUIDELINE 8:

States, in collaboration with and through the community, should promote a supportive and enabling environment for women, children and other vulnerable groups by addressing underlying prejudices and inequalities through community dialogue, specially designed social and health services and support to community groups.

GUIDELINE 9:

States should promote the wide and ongoing distribution of creative education, training and media programmes explicitly designed to change attitudes of discrimination and stigmatisation associated with HIV/AIDS to understanding and acceptance.

GUIDELINE 10:

States should ensure that government and the private sector develop codes of conduct regarding HIV/AIDS issues that translate human rights principles into codes of professional responsibility and practice, with accompanying mechanisms to implement and enforce these codes.

GUIDELINE 11:

States should ensure monitoring and enforcement mechanisms to guarantee the protection of HIV–related human rights, including those of people living with HIV/AIDS, their families and communities.

GUIDELINE 12:

States should cooperate through all relevant programmes and agencies of the United Nations system, including UNAIDS, to share knowledge and experience concerning HIV–related human rights issues and should ensure effective mechanisms to protect human rights in the context of HIV/AIDS at international level.

Source: OHCHR, UNAIDS. 2002. *HIV/AIDS and Human Rights International Guidelines, Revised Guideline 6: Access to prevention, treatment, care and support*. Geneva, August 2002, pp 10–12.