



*Continuing Care for Mothers, Children, and Families Following Prevention of Mother-to-Child Transmission of HIV (PMTCT) Programmes*

# **Trainer Manual**



July 2007





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The *Continuing Care for Mothers, Children, and Families Following Prevention of Mother-to-Child Transmission of HIV (PMTCT) Programmes* Module seeks to provide a Caribbean approach to linking HIV-infected women and their families with ongoing HIV care, treatment, and support needs after participation in a national PMTCT programme.

The components in this Module are:

- Trainer Manual
- Participant Manual
- PowerPoint Slides
- Field Visit Guide

# Table of Contents

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**Foreword**.....v

**Abbreviations/Acronyms**.....vi

**Introduction** .....viii

**Session 1: Introduction to Comprehensive Care for Mothers, Children, and Families**.....20

**Session 2: Linkages, Referrals, and Retention Strategies** .....41

**Appendices** .....61

**References/Resources**.....83

## Foreword

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The transmission of HIV from a pregnant woman to her infant during pregnancy, labour, delivery, or breastfeeding is the most significant source of HIV infection in infants and young children. The administration of antiretroviral prophylaxis, quality treatment, and care during the antenatal and intrapartum periods can dramatically reduce the rate of mother-to-child transmission of HIV (MTCT). Postpartum and follow-up care are essential components of a comprehensive care package for mothers and families affected by HIV.

This training module is targeted to healthcare workers in prevention of mother-to-child transmission of HIV (PMTCT) settings. PMTCT settings include both in-patient and community based antenatal (ANC), labour and delivery (L&D), and postpartum services where pregnant women or women who have recently given birth may present for healthcare services. This module is also targeted to healthcare workers who provide care to HIV-infected and HIV-affected clients in centres for HIV care, treatment and support; tuberculosis clinics; social and community welfare organisations; pharmacies; and private practice. This training is designed for a class room of approximately 25-30 participants.

The purpose of this module is to provide guidance on the ongoing HIV care, treatment, and support needs of HIV-infected women after they have participated in a PMTCT programme. This module assumes a family-centred approach, recognizing the care needs not only of the woman but also her infant(s), older children, partner, and other family members.

This module is *not* designed to prepare healthcare workers to *deliver* care and treatment to mothers or their families. Instead, this module is designed to familiarize healthcare workers with the comprehensive care needs of HIV-infected families. The purpose of this module is to bridge PMTCT with HIV care and treatment, so that the continuum of services for HIV-infected women and their families is seamless.

This is a generic module, developed for the Caribbean, but designed to be adapted through the incorporation of country guidelines and practices. The adaptation process should also ensure that the country-specific module complements existing national PMTCT and HIV prevention, care, treatment and support strategy, policy and programmes. For additional information on adapting this Module, please see the *Guide for Adapting the Continuing Care for Mothers, Children, and Families Following Prevention of Mother-to-Child Transmission of HIV (PMTCT) Programmes Module* or contact Rebecca S. Fry MSN, Advanced Practice Nurse/Global Programs at the FXB Center at [fryre@umdnj.edu](mailto:fryre@umdnj.edu).

## Abbreviations/Acronyms

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<b>AIDS</b>	Acquired immunodeficiency syndrome
<b>ANC</b>	Antenatal care
<b>ARV</b>	Antiretroviral
<b>CBC</b>	Complete blood count
<b>CDC</b>	Centers for Disease Control and Prevention
<b>CMV</b>	Cytomegalovirus
<b>DNA</b>	Deoxyribonucleic acid
<b>DPT</b>	Diphtheria, pertussis, and tetanus vaccine
<b>ELISA</b>	Enzyme-linked immunosorbent assay
<b>HAART</b>	Highly active antiretroviral therapy
<b>HBV</b>	Hepatitis B vaccine
<b>HCW</b>	Healthcare worker
<b>Hib</b>	Haemophilus influenzae Type b vaccine
<b>HIV</b>	Human immunodeficiency virus
<b>HTLV-1</b>	Human T-cell leukemia virus type 1
<b>IPV</b>	Inactivated poliovirus vaccine
<b>L&amp;D</b>	Labour and delivery
<b>LAM</b>	Lactational amenorrhea method
<b>LIP</b>	Lymphoid interstitial pneumonia
<b>MCH</b>	Maternal Child Health

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<b>MTCT</b>	Mother-to-child transmission of HIV
<b>NGO</b>	Non-governmental organisation
<b>OI</b>	Opportunistic infection
<b>OPV</b>	Oral polio vaccine
<b>PCP</b>	<i>Pneumocystis pneumonia</i>
<b>PCR</b>	Polymerase chain reaction
<b>PEP</b>	Post-exposure prophylaxis
<b>PLHIV</b>	People living with HIV
<b>PMTCT</b>	Prevention of mother-to-child transmission of HIV
<b>STI</b>	Sexually transmitted infection
<b>TB</b>	Tuberculosis
<b>TORCH</b>	Toxoplasmosis, other viruses, rubella, cytomegaloviruses, and herpes simplex viruses
<b>USAID</b>	U.S. Agency for International Development
<b>VCT</b>	Voluntary counselling and testing
<b>VDRL</b>	Venereal Disease Research Laboratory
<b>WHO</b>	World Health Organization

## Introduction

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The Trainer Manual is designed to support the implementation of the *Continuing Care for Mothers, Children, and Families Following Prevention of Mother-to-Child Transmission of HIV (PMTCT) Programmes* Module (the Module). The Trainer Manual contains the same material found in the Participant Manual, with additional instructions for the trainer. The Module is designed to be taught in two days. A field visit can be arranged for part or all of a third day. Please see the Field Visit Guide for more information on the objectives of a field visit and for guidance in how to set up an experience that complements the didactic portion of this training.

This Introduction includes the following sections to help the trainer use the materials provided, prepare for the training, and conduct the training session.

- Using the Trainer Manual
- Training Principles
- Training Methods

### Using the Trainer Manual

Keep the Trainer Manual with you for use as a reference, but avoid reading from it directly during sessions. The Trainer Manual contains the following materials:

- Information on how to prepare, plan, and organize each module.
- Training tips for lecturing, facilitating activities, and time management.

#### Icon key:

The Trainer Manual includes symbols (icons) to provide direction in conducting each session.



**Advance Preparation:** Describes trainer preparation for the session



**Clock:** Sets estimated time needed for session



**Trainer Instructions:** Notes specific trainer tasks



**For Inclusion in National Curriculum:** Notes area for suggested national adaptation



**Make These Points:** Draws attention to key concepts for emphasis

**In this Trainer Manual, text in dashed boxes appears in the Participant Manual. This allows the trainer to know what content is available to the participants.**

### **Before offering this module**

It is important to feel comfortable with the material you will be teaching. Your understanding of the Manual can help you plan an effective and engaging lesson.

- Read this Introduction from start to finish.
- Look at the icon key above; take note of the icons used throughout this manual.
- When reviewing the Manual, note the content that is included in the Participant Manual and the key points on the PowerPoint slides. Begin to consider interactive ways to present the material to the participants. “Trainer Instructions” and “Make These Points” offer helpful tips to guide the discussion and transition between ideas.
- Review the exercises you will facilitate. Take note of any advance preparation that might be necessary. Discuss case studies with colleagues to make sure you are comfortable with the suggested answers.
- Lectures and exercises may be conducted in the local language, if it will help participants.
- Take note of estimated times for your teaching sessions. Trainers have some flexibility in modifying the times to better meet participant learning needs. However, it will not be possible to finish the Module if trainers frequently run behind schedule.

### **Training Principles**

The Module is based on adult learning principles. This section describes these principles and gives guidance on using the key training methods used in this Module.

As a trainer, you are a facilitator of learning, not merely an instructor. Encourage participants to identify their aims and objectives for the Module, which you, as a trainer, will help them accomplish. Trainers play a unique role in helping their audiences confront the dynamics of the HIV/AIDS epidemic. Although you might be an expert in technical content and training, your role in this Module extends beyond lecturing or providing information. Trainers need to discuss comprehensive care issues within the social and cultural context and encourage participants to apply new knowledge to their daily practice.

#### **Principles of adult learning**

The key to successful adult training is active participation from the group through the sharing of ideas and experiences. Show respect for participants' experience by asking them to share ideas, opinions, and knowledge and by recognizing that they are a good resource. Principles to keep in mind when working with adult participants:

- **Adults are motivated by information or tasks that they find meaningful.**  
Talk to participants so that you are aware of what they want and need to learn, how much they already know. If possible talk with them in the weeks and days before the training in their work setting.
- **Adults need to relate to the examples and exercises provided in the training.**

Provide opportunities for participants to practise what they are learning and to address feelings and ideas that arise.

- **Visual aids should be used to enhance the learning experience.**  
See below for more information on using visual aids.
- **Adults feel anxious that participating in a group may make them appear weak either professionally or personally.**  
Create a supportive learning environment and establish safe training practices, e.g., be sure that participants feel confident their contributions will be received respectfully.
- **Build trust with participants.**  
Show that you are committed to the Module and are willing to share your own experiences.
- **Build teamwork and a sense of group belonging.**  
Encourage active participation.
- **The trainer has a role in adult learning.**  
The trainer's role is to facilitate the learning experience of the adult participant. To that end, you should create a climate in which participants can accomplish Module outcomes and explore their life experiences to help them to learn.

**Responsibilities of the trainer include the following:**

- Introduce each session and key concepts
- Lead group discussions and training exercises
- Answer questions
- Explain ideas and clarify issues
- Discuss how participants can apply the information to their own work
- Give constructive feedback

You are encouraged to go beyond formal lecturing. It is your job to answer questions, talk with participants about exercises, lead group discussions, and give participants any help they need.

Familiarity with the local environment is essential to effective group training. Training strategies could require modification to respect various cultural standards.

**Managing challenging participants**

Throughout the training, continually assess the interaction of the participants and the group dynamics. Occasionally, the learning environment might be disrupted by individual participants. A challenging participant might be overly talkative or dominating in discussions. He or she may be disrespectful, and as a result, other participants may

be hesitant to express their opinions. Depending on the situation, the trainer should address such behaviours either publicly or in private. It can be helpful to remind participants of the norms established at the beginning of the programme and to reinforce the ground rules throughout the day.

### Eliciting participation from all participants

HIV is a controversial subject in many communities that is likely to prompt debate among participants. The trainer should encourage all participants to contribute to the discussion. In some instances, the group may need additional time to agree on complex issues.

### Managing time

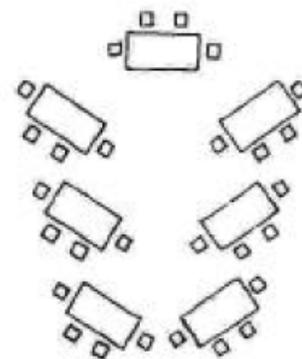
Times have been estimated for each lecture and activity. The estimated times are printed at the beginning of each session in both the Training Manual and Participant Manual. All of the training content is important; however, the trainer should acknowledge the particular needs, knowledge, and experience level of the group and make adjustments accordingly.

Each trainer may re-allocate time provided that the key concepts of each module are covered and the programme is presented as a comprehensive training within the overall time limit.

### Seating arrangement and room set up

To prepare for the day's activities, trainers will need to arrive early to organize the room.

- Set up the room so that participants can see each other and trainers have space to walk around. For didactic presentations, participants need to see the slides and flipcharts. At other times, participants will gather in groups for case studies and small discussions. Desks or small tables that can be rearranged easily work well for adult training.
- The seating arrangement can have a big influence on the learning environment, how well the trainer can engage the participants and create a participatory atmosphere. The traditional classroom seating in rows may not foster the needed participation to facilitate learning. Depending on the number of participants, furniture and the size of the room that will be used for training, the trainer should feel free to re-arrange seating in way that allows participants to interact and the trainer to walk around the room. For example, tables and chairs can be arranged in a circle, semi circle, or the fishbone/banquet style as illustrated.
- Ensure that the learning environment is comfortable and well lit. This will make participants feel respected and supported.



### Training equipment and supplies

- Ensure the following materials are available and working properly:
  - Overhead projector (LCD), screen and/or computer
  - Flip charts, markers, tape
  - Clock or watch to keep track of time
- Also ensure that all necessary supplies are available in sufficient supply: pens, pencil, and paper

### **Debriefing with trainers**

If there is more than one trainer facilitating the course, they should meet at the end of each day's training. Discussion about training technique can help trainers build a group dynamic. Feedback should be positive and constructive.

## **Training Methods**

### **Anonymous question bowl**

Anonymous Question Bowl (or envelope) where participants can submit questions they do not want to ask in front of the group.

#### **Anonymous question bowl or envelope**

Some questions are difficult to ask in a group. One method to encourage questions is to set up a question bowl or envelope along with paper and a pen or pencil that sits away from the centre of the room. When participants have a question that they do not want to ask in the group setting, they can write it down and place it in the bowl or envelope.

The bowl should be checked daily, perhaps before lunch or before finishing for the day. The questions should be read aloud to the group. Trainers can give the group some time to think about the questions, and review responses sometime in the afternoon or early the next day. However, it is important that all questions are addressed and that participants leave the session knowing the correct answer. If an incorrect or misinformed response is offered, provide the correct answer in a clear but tactful way.

### **Reviewing the previous day**

It is recommended that the second day's training begin with a recap of the key points covered the previous day. This can be done in approximately 10 minutes. Strategies to review the previous day's learning points might include:

- The trainer or a participant presents the previous day's key points using a lecture and question/answer format. If possible, write the key points on the board or flipchart in the morning before participants arrive.

- Large group discussion, which the trainer may open by asking the group, “What were the most important points from the previous day’s presentation?” The trainer should then add any additional key points that the group may have missed.
- Small group discussion—trainees break into small groups (or even pairs) and take five minutes to come up with the three most important points from the previous day’s presentations.

Once the key points have been summarized, ask trainees whether they have questions from the material covered during the previous day’s presentations.

### **Interactive exercises**

Interactive exercises are tools that facilitate participation, communication, integration, analysis, and reflection. They provoke discussion among the participants.

The interactive exercises that are used in the Module are explained below.

- **Ice-breakers**

At the beginning of the first session, an ice-breaker can be used to help participants learn each others names and share personal or professional information. It helps to create a friendly atmosphere by “breaking the ice” and putting the participants at ease.

- **Energizers**

Energizers are short, fun activities that break up periods of concentrated learning. They can involve physical activity, group songs and may also be related to the training topic. Energizers help participants maintain energy and attention and build rapport amongst participants.

- **Interactive lectures**

Lectures can be used to present scientific and technical content. This type of learning should progress from the simple to the complex. The trainer first reviews and outlines basic concepts. New material is integrated gradually and illustrated with practical examples when possible. Remember that participants can absorb and integrate only five or six new pieces of information at a time.

Lectures can be made interactive by tapping into the wealth of knowledge and experience that adult participants bring into the training. Ask the participants questions during the lecture and allow them to share their experiences. Avoid reading directly from the overheads or slides. Instead, supplement with examples, practical problems, and discussion questions. In teaching adults, strive for active participation from the group.

- **Role play**

A role play is a simulation or demonstration. A real-life situation is presented by two or more participants, or the trainer. The role play usually takes place within a small group; those not “acting” are participant-observers. Through the role play, the

“actors” show personal interactions, emotions, attitudes, procedures, behaviours (good, bad and controversial), processes or procedures. The small group then analyses and reflects upon what was acted out.

### Steps for conducting a role play

- Ensure that problem or situation is:
  - Related to the module or session objectives
  - Interesting to participants
  - Suitable for acting
- Collect all props and objects necessary to make the role play more realistic.
- Prepare debriefing questions to ask after the role play.
- Describe the characters and roles to the participants.
- Choose two or three participants to act in the role play. Encourage actors to feel and act like the characters they are representing.
- Ask participant-observers to compare their feelings and reactions with those of the persons in the role play. It is a good idea to ask participants to take notes that can be referenced later during the discussion.
- Watch carefully to ensure that actors are raising issues that are related to the main problem. Watch the participant-observers to see if they are still interested, or are becoming bored and restless.
- Stop the role play when you feel the actors have shown the feelings and addressed the ideas that are important in the problem situation, or when the other participants become restless.
- Thank the actors for their help and good work.
- De-brief by asking actors and other participants to discuss their feelings and observations. Ask participants how this role play may help them in their jobs and daily lives.

- **Group discussion**

A group discussion is an activity that allows participants to share their experiences and ideas, solve a problem, or apply content information to different situations. The participants do most of the talking rather than the trainer.

- Large group discussion — Participants from the large group discuss specific problems, topics, or issues. Large group discussions are usually facilitated by a trainer and should run for a limited length of time. All participants should be encouraged to contribute. The trainer should review the main points from the large group discussion.
- Small group discussion — Participants from the large group are divided into small groups (usually of 3-5 participants). Each small group is assigned a question or topic and given time for discussion. Upon completion of the discussion, small groups report back to the large group. Key points from each small group can be

written on flip chart paper and posted. Small groups are an excellent way to get more participants involved.

- **Case study**

A case study is a vignette drawn from real situations and presented to participants for discussion and analysis. The case study should relate as much as possible to situations that participants may encounter in their life and work. The case study is usually first discussed in small groups. Each group then shares their ideas and conclusions with the large group. The exercise is facilitated like a small and then large group discussion.

### Visual aids

- Visual aids present the information in short, clear phrases. PowerPoint Slides or flipcharts offer the chance to summarize the main points on each topic.
- In order to use visual aids efficiently:
- Make sure visual aids are visible to the entire audience. The writing should be large enough for participants to read easily.
- When writing on flipcharts, move to one side so that the chart can be seen. Use dark markers.

*Visual aids are an aid to communication, not a substitute for it.*

Use visual aids sparingly to highlight and support key points. Talk to the audience, not the visual aid. Trainers should look at the audience at least 80% of the time.

### Guidelines for leading exercises

#### 1. Prepare for the exercise

The trainer should be thoroughly familiar with Module content. Preparation is the key to conducting a successful exercise. Complete the following before starting an exercise:

- Read introduction and purpose of exercise.
- Complete advanced preparation for each exercise.
- Obtain and organize the materials, if needed.
- Ensure you understand the instructions for participants.
- Read and understand the debriefing questions and learning points from each exercise.

#### 2. Introduce the exercise and give instructions

The trainer must give clear instructions to all participants. An exercise should be introduced by explaining the purpose and method to complete the exercise.

The Trainer Manual contains instructions; however, when explaining the exercise to participants, keep the following in mind:

- What are the participants going to do?
- Who are they going to do it with?

- Where are they going to do it?
- How are they going to do it?
- For how long will the exercise last?

### 3. Conduct the exercises

See the exercise definitions above for guidelines on conducting the different exercises.

### 4. Summarize key points in the exercise and debrief

#### Debriefing an exercise

Debriefing occurs when the trainer stimulates discussion and analysis of the activity by asking carefully formulated questions. This process allows participants to reflect on the topic, rationalizing the experience and adapting it for future use.

After an exercise has been conducted, it is important to debrief. Debriefing involves a discussion that will allow participants to recall and reflect on the activity that took place and its application to the larger framework. Trainers should be prepared to ask key questions that will encourage the participants to come to conclusions on the material that has been discussed and then summarize for the group in one or two sentences the key learning points.

#### Tips for leading the sessions and exercises

- Emphasize the immediate usefulness and applicability of material presented.
- Elicit personal experiences.
- Make an effort to learn participants' names early on and to use their names whenever possible.
- Encourage group interaction and participation early in each session. During the first day, interact at least once with each participant, and encourage them to interact with you.
- During breaks, remain in the classroom and talk with participants.
- Be available after each session to answer questions and discuss concerns.
- Use repetition to encourage remembering.
- Use the PowerPoint slides to enhance the learning experience. Avoid relying too heavily on the content in the PowerPoint slides. Adults will learn better if they see, hear and participate in interactive activities to help apply the new material.
- Pay attention to the order and flow of activities to ensure that new information is covered at an appropriate pace. Make sure that participants complete the Module with a clear action plan for applying their knowledge.
- Assess participants' throughout the day to gauge their comprehension and attentiveness. Generally, the more conversation and noise in a room, the less the participants are focused on the material. Pay attention to nonverbal cues to assess the participants' attentiveness.

- Praise or thank participants when they perform an exercise well, participate in a group discussion, ask a question, or help other participants.

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## Continuing Care for Mothers, Children, and Families Following Prevention of Mother-to-Child Transmission of HIV (PMTCT) Programmes

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**Total Module Time: 9 hours and 30 minutes**

**After completing the module, the participant will be able to:**

- Describe comprehensive HIV care for women, children, and their families.
- Understand the basic principles and purpose of family-centred care.
- Identify and strategically address gaps in the provision of comprehensive HIV care for women, children, and their families.
- Recognize common signs and symptoms of HIV in infants and young children.
- Understand the importance of male involvement in PMTCT and HIV programmes and be able to suggest creative strategies to encourage their participation.
- Describe the difference between linkages and referrals.
- Improve referral practices between PMTCT and HIV care and treatment programmes.
- Discuss retention strategies for keeping women and their families in care.
- Practise problem-solving skills to address social issues affecting a client's capacity to follow-up with care and treatment.

## Session 1 Introduction to Comprehensive Care for Mothers, Children, and Families

Activity/Method	Time
History of PMTCT and HIV Care and Treatment Programmes, lecture, and discussion	90 minutes
Exercise 1 — Facilitating Referrals between PMTCT and HIV Care and Treatment (large group discussion)	45 minutes
Lecture and discussion	60 minutes
Exercise 2 — Clinical Presentation of HIV in Infants and Children (large group discussion and case studies)	60 minutes
Lecture and discussion	25 minutes
Question and answers	10 minutes
<b>TOTAL SESSION TIME</b>	4 hours and 50 minutes

## Session 2 Linkages, Referrals, and Retention Strategies

Activity/Method	Time
Lecture and discussion	90 minutes
Exercise 3 — Community Resources (small group discussion)	60 minutes
Lecture and discussion	30 minutes
Exercise 4 — Retention Strategies (role play)	60 minutes
Lecture and discussion	15 minutes
Question and answers	10 minutes
<b>TOTAL SESSION TIME</b>	4 hours and 40 minutes



### Advance Preparation

- Session 1 requires advance preparation. Please review the suggestions of how to introduce the session with an invited speaker.
- Exercise 2, 3, and 4 all require advance preparation. Please see the individual exercises.
- In preparation for both sessions, review the following documents if available:
  - National policies and/or guidelines that describe the structure of MCH, PMTCT, and HIV care and treatment programmes

## Session 1 Introduction to Comprehensive Care for Mothers, Children, and Families



### Advance Preparation

**One or two week(s) in advance:** Invite a representative from the national or local health service in your country to present a brief history of PMTCT and HIV care and treatment programmes. This representative should discuss the continuity of care between prevention, care, and treatment as well as the role of healthcare workers in each setting in providing or supporting comprehensive HIV care of families. The representative may use the questions below as a guide. If a national representative is not available, the trainer can present an overview of PMTCT and HIV care and treatment services.



**Total Session Time:** 4 hours and 50 minutes

### After completing the session, the participant will be able to:

- Describe comprehensive HIV care for women, children, and their families.
- Understand the basic principles and purpose of family-centred care.
- Identify and strategically address gaps in the provision of comprehensive HIV care for women, children, and their families.
- Recognize common signs and symptoms of HIV in infants and young children.
- Understand the importance of male involvement in PMTCT and HIV programmes and be able to suggest creative strategies to encourage their participation.



### Trainer Instructions

Slides 1-8

After introducing the module objectives as well as the objectives for Session 1, have the representative from the national or local health service summarize the history of both PMTCT and HIV care and treatment programmes in your country using the following questions as a guide. If such a representative is not available, the trainer should provide this introduction.

**Discussion questions**

- When did the PMTCT programme start?
- How has it changed/adapted over the last year, last 5 years (e.g., staffing, space, politics, changing research, laboratory capacity)? What have been the major challenges and successes?
- When did the HIV care and treatment programme start?
- How has it changed/adapted over the last year, last 5 years (e.g., staffing, space, politics, changing research, laboratory capacity)? What have been the major challenges and successes?
- At present, how does staff at the PMTCT programme ensure that their HIV-infected clients get the care and treatment they need?
- Describe how the two programmes are integrated at present. Describe future integration plans or initiatives.
- Give examples of how the PMTCT programme is expected to adapt in the future to ensure that women and families have access to comprehensive care and treatment for HIV.

**Trainer Instructions**

Slides 9-10

- Ask participants the questions in the “Discussion questions” box below. Summarize their responses on a flipchart. Note that in Exercise 1 they will discuss strategies to address the gaps identified.
- Answers should orient the trainer to participants’ level of understanding and their experiences with providing HIV-infected women with comprehensive care.
- Review the role of the healthcare worker in the comprehensive care needs of mothers and families as described below. Remind participants that it is likely that they first learned this information in their PMTCT training.
- End the discussion by asking participants what they think their role is in delivering comprehensive HIV care and treatment. Compare and contrast with the content below.

**Discussion questions**

- What are the barriers to accessing HIV-related care, treatment, and support for HIV-infected women?
- Are these barriers the same for infants and children?
- Are the needs of male partners addressed within the PMTCT programme? How about within the healthcare system? Please give examples.
- What is the role of a PMTCT healthcare worker in ensuring their HIV-infected clients (and their families) receive comprehensive care and treatment? Relate answers to the list below.



## Make These Points

- PMTCT programmes must be integrated into adult and paediatric HIV care and treatment programmes to ensure that mothers and families receive the full range of services they need.
- Knowing when and how to make effective referrals for HIV care and treatment is a critical part of comprehensive care of HIV-infected mothers.
- In general, PMTCT healthcare workers are responsible for ensuring that women, children, and their families are referred to the range of comprehensive care services they need.



## For Inclusion in National Curriculum

- Adapt the list of PMTCT healthcare workers roles, below.

### Role of PMTCT Healthcare Workers in Delivering Comprehensive HIV Care and Treatment

The specific role of PMTCT healthcare workers in HIV care and treatment will vary according to country, region, and even by facility. In general, healthcare workers in PMTCT should:

- Know how to assess client needs for care, treatment, and support services.
- Be able to recognize common HIV-related infections in adults and children.
- Establish effective linkages and referral systems between PMTCT programmes and centres for HIV care, treatment, support, and prevention in both the public and private sector.
- Have a clear understanding of when and how to refer pregnant (or recently delivered) women for ARV therapy.
- Participate in ongoing client case management as a part of a team whose goal is to deliver comprehensive care to clients.
- Advocate for change to ensure the ongoing health-related needs of women with HIV and their families are met.



## Trainer Instructions

Slides 11-21

When reviewing Table 1 on page 7 of the Trainer Manual, which lists the components of comprehensive care for clients living with HIV, it is *not* necessary to read the full listing of services. Instead, the trainer can ask participants if there is a service or a referral that they are unfamiliar with as a method of introducing the aspects of comprehensive care.



## Make These Points

- The components of comprehensive care for HIV-infected clients will differ per resources available and approaches to linking and integrating HIV services.
- Comprehensive family-based HIV care recognizes all members of the family unit, whether they are relatives, partners, or friends.
- One of the advantages of family-based care is it can help identify all members who are affected and who may be infected with HIV.

### **Comprehensive Management of a Person with HIV**

The responsibility for providing care to an HIV-infected client is usually shared by a multi-disciplinary professional team, the community, the client, and their family. The balance of responsibility changes with time and the needs of the client. Best practices in comprehensive care are achieved using a team approach that is carefully planned, executed, and documented. Many needs of people living with HIV (PLHIV) are similar to those living with other chronic illnesses, however because of the stigma that surrounds HIV, the client and family may have additional pressing needs and challenges that keep them from obtaining and staying in care.

**Table 1: Components of comprehensive care, treatment, and support**

Mother and partner	<ul style="list-style-type: none"> <li>• HIV testing for partner</li> <li>• ARV therapy assessment and referral according to national guidelines</li> <li>• Screening, prevention, and treatment of opportunistic and HIV-related conditions</li> <li>• Adherence counselling and support</li> <li>• Nutritional counselling</li> <li>• Psychosocial and spiritual support</li> <li>• Safer infant-feeding counselling and support</li> <li>• Safer sex and long term family planning counselling</li> <li>• Links and relationships with community service organizations and agencies to promote continuity of care</li> <li>• Referrals and links to domestic violence organizations</li> <li>• Disclosure counselling</li> <li>• Palliative care when indicated and available</li> <li>• Drug and alcohol misuse/abuse counselling and treatment as appropriate</li> </ul>
Child	<ul style="list-style-type: none"> <li>• ARV therapy assessment and referral according to national guidelines</li> <li>• Screening, prevention, and treatment of opportunistic and HIV-related infections</li> <li>• Growth and development monitoring</li> <li>• Immunizations</li> <li>• HIV diagnosis by laboratory test or presumptive diagnosis</li> <li>• HIV education, as appropriate</li> <li>• Psychosocial support</li> <li>• Disclosure counselling, as appropriate</li> <li>• Links and relationships with community service organizations and agencies to promote continuity of care</li> </ul>
Family	<ul style="list-style-type: none"> <li>• HIV testing for older children</li> <li>• Adherence counselling</li> <li>• Links and relationships with community service organizations and agencies to promote continuity of care</li> <li>• HIV education</li> <li>• Psychosocial and spiritual support</li> <li>• Referrals and links to domestic violence organizations</li> <li>• Bereavement counselling</li> <li>• Social support services               <ul style="list-style-type: none"> <li>○ Legal advice and services</li> <li>○ Employment, income-generation activities</li> </ul> </li> </ul>

## Goals of Family-based Comprehensive Care

The primary goals of family-centred comprehensive care services are to:

- Decrease morbidity and mortality through access to HIV care, treatment, and support.
- Improve the quality-of-life for HIV-infected women, children, and their families.
- Reduce transmission of HIV through secondary prevention counselling and education, also known as “prevention for positives.”

## General Principles of Family-based Care

There are multiple opportunities within PMTCT programmes to broaden services to families:

- Provide counselling and testing for all sexual partners.
- Assist with disclosure of HIV status to partners and other family members.
- Teach all family members about the importance of adherence to ARV prophylaxis or treatment.
- Use appointments for a pregnant mother as an opportunity to encourage other family members to seek care.
- Use postpartum appointments to ensure that HIV-exposed infants are linked to the HIV-related and routine well child care that they will need.
- Use MCH appointments to discuss with mothers the HIV status of, and possible HIV-related symptoms in, sexual partners and older children.
- Screen for other potential domestic or psychosocial issues and refer as appropriate.

Family-centred care recognizes all persons who function as family members, as identified by the person living with HIV infection. Family members may be relatives, in-laws, partners, or friends. A principle of family-based care is to include these family members in decisions about care, treatment, and support of HIV-infected clients and affected members of the family unit. Family-based care implies that a woman should be treated and respected as a part of a whole; a part of her family and community. The barriers to delivering family-based care will be discussed in Session 2.



### Trainer Instructions

Slides 22-23

The *immediate* postpartum care for HIV-infected mothers has historically been the responsibility of PMTCT programmes. However, the purpose of this module is to look at ways to broaden our thinking about the needs of HIV-infected women in the Caribbean. It is likely that PMTCT healthcare workers will have to expand their understanding of their role to ensure that women with HIV and their families receive comprehensive care.

Ask participants for examples of how their responsibilities have expanded. Encourage participants to discuss how they felt about this expanded role.

Review Appendix A, Checklist for Postpartum Visit for HIV-infected Women and HIV-exposed Newborns.



### Make These Points

- Mothers who miss ANC or postpartum appointments should be identified and either visited at home or encouraged to come in for care.
- Planning for a mother and her family's ongoing HIV care should be done during her pregnancy; the postpartum period is the time to implement the plan.

### Care of the Mother with HIV Infection in the Postpartum Period

Healthcare workers should ensure that mothers who are HIV-infected return for all postpartum appointments or are visited at home. Medical and psychosocial information from the mother's antenatal care and labour and delivery should be provided to the healthcare staff responsible for postpartum visits. Additionally, healthcare workers should routinely ask clients about HIV-related care for themselves and their family members. For more information about what should be included in the immediate post-delivery setting as well as postpartum care, see Appendix A.



### For Inclusion in National Curriculum

- Insert national schedule of postpartum visits.

In the postpartum period, a mother with HIV infection should receive care that supports her health, prevents complications, and improves the family's ability to live positively with HIV infection.

It may be especially difficult to coordinate postpartum needs for mothers who do not follow-up with appointments. Women who miss appointments during ANC should be targeted for additional support in the postpartum period. Healthcare workers may need community-based support to facilitate this important follow-up care. Relationships and connections in rural areas may require creative efforts that include governmental,

community-based, and faith-based organizations. For example, a church that distributes food to those in need can also give out flyers to women with infants, advertising the importance of following up after delivery.



### Trainer Instructions

Slide 24

Introduce the next exercise using the information below.

<b>Exercise 1 — Facilitating Referrals between PMTCT and HIV Care and Treatment (large group discussion)</b>	
<b>Purpose</b>	To discuss client and facility-level barriers to accessing care, focusing on HIV-related services to which a recently diagnosed client has been referred.
<b>Duration</b>	45 minutes
<b>Introduction</b>	One of the major challenges to PMTCT programmes is how to retain a women and her family in care. Even with referral systems in place, sometimes women can be “lost to care,” sometimes until her next pregnancy. The first step to ensuring continuity of care is to provide clients with referrals that meet their care needs. Emphasize that the responsibility of providing comprehensive care is shared by the entire healthcare team.
<b>Activities</b>	<ul style="list-style-type: none"> <li>• Begin by asking participants to describe a scenario when an HIV-infected pregnant woman was lost to follow-up care.</li> <li>• Use the following questions to guide the participant examples: <ol style="list-style-type: none"> <li>1. How or why did the client “slip through the cracks?”</li> <li>2. What systems are in place within the PMTCT programme that did not function as planned?</li> <li>3. What systems are in place within care and treatment facilities that did not function as planned?</li> <li>4. What happened to the client’s child? Did they receive appropriate follow-up care?</li> <li>5. What happened to her partner?</li> </ol> </li> <li>• Add participants’ suggestions to the flipchart listing started at the beginning of this session.</li> <li>• Ask for examples with both negative and positive outcomes—sometimes our most important learning experiences are from mistakes.</li> <li>• Using the list of suggestions, ask participants the following question for each of the answers offered: <ol style="list-style-type: none"> <li>1. What systems need to be in place at the clinic?</li> <li>2. What systems need to be in place in the community?</li> <li>3. What policies would facilitate referrals between PMTCT programmes and care and treatment programs?</li> <li>4. What procedures need to be in place to facilitate communication between the public and private sector?</li> <li>5. Why do clients sometimes not follow-up with referrals? What can we do to make it more likely that a client will follow-up?</li> <li>6. Ask participants what changes (within their clinics, communities or at the country-level) they would advocate for to facilitate referrals? How would they start this process?</li> </ol> </li> </ul>
<b>Debriefing</b>	Summarize possible next steps. Remind participants that as

### Exercise 1 — Facilitating Referrals between PMTCT and HIV Care and Treatment (large group discussion)

healthcare workers, they understand the healthcare system and can see gaps in care: the identification of a problem is the first step toward finding a solution. Thank participants for their suggestions and encourage them to continue to consider potential solutions during this training.



#### Trainer Instructions

Slide 25

Tell participants that we will now discuss the follow-up care needs of infants who are HIV-exposed.

### Follow-up Care of the HIV-exposed Infant

Recommendations about the follow-up care for the infant exposed to HIV are set forth in national guidelines and typically follow best practices for all infants. Typically, HIV-exposed and infected infants and children are followed by a team of healthcare workers who specialize in paediatric HIV care. HIV-exposed infants are put on cotrimoxazole prophylaxis at 4 to 6 weeks of age or at the first encounter with the healthcare system. Cotrimoxazole prophylaxis is continued until HIV-infection is ruled out and the mother has stopped breastfeeding completely.

All follow-up visits contain a full physical exam with a focus on early identification of HIV-related infections. In addition, growth, nutrition, and development are carefully assessed and vaccination status reviewed. For a complete list of what should be included in each infant/child follow-up visit according to the Caribbean Guidelines for Care and Treatment of Persons with HIV, see Appendix B. Additional information about the importance of growth, nutritional, and developmental assessment can be found in Appendix C.



#### For Inclusion in National Curriculum

- National schedule of follow-up visits for infants and children
- Adapt schedule of infant and child follow visits listed in Appendix B



#### Trainer Instructions

Slides 26-27



## Make These Points

- National guidelines will indicate which tests to use, and when to diagnose HIV infection in infants and young children.
- The Caribbean guidelines recommend that an HIV DNA PCR test, viral test, should be performed at 6-8 weeks of age or older. If positive, a repeat test on a second specimen is recommended to confirm diagnosis of HIV.
- HIV antibody testing can play a role in ruling out HIV infection in children beginning as early as 9 months.
- Children breastfed within six weeks before an HIV test should be re-tested at least 6 weeks after complete cessation of breastfeeding.
- The months before testing are a difficult time for parents and they will require ongoing support.

### Diagnosis of HIV Infection in Infants

The identification and follow-up of infants born to HIV-infected mothers are critical first steps toward diagnosing HIV infection in children. *All* infants who are known or suspected to be exposed to HIV should be monitored closely. HIV-exposed infants should be given cotrimoxazole prophylaxis starting at 4-6 weeks of age or at first encounter with the health system. If diagnosed with HIV, cotrimoxazole prophylaxis should be continued according to national guidelines.

The immune system of an infant and young child is immature and HIV progression can occur rapidly in HIV-infected infants. Some HIV-infected children will be critically ill when they present for care in a MCH setting. By 1 year of age, more than one-third of HIV-infected infants will have died; by age 2, half will have died. It is very important that these high risk children are diagnosed by clinical assessment or HIV testing and put on ARV therapy according to national guidelines.

### Diagnostic Testing of HIV-exposed Infants and Young Children

The type of HIV test performed will depend on the age of the child and the tests available. If a child exposed to HIV develops signs and symptoms of HIV infection, early diagnosis and intervention are critical. National HIV testing policies should provide specific guidance on how to obtain informed consent for testing of children. As with HIV testing of adults, all initial positive results should be confirmed with a second test.

The timely diagnosis of HIV infection in infants is challenging in many countries in the Caribbean. The Caribbean guidelines recommend that an HIV DNA PCR test, viral test, should be performed at 6-8 weeks of age or older. HIV viral tests are the standard for diagnosing HIV infection in infants and children under the age of 18 months. However, viral tests such as DNR PCR can be expensive and require trained laboratory staff. Where the technology is not available in-country,

sometimes DNR PCR testing is undertaken outside of the country. For countries that do not have access to PCR testing, an HIV antibody test can be used to diagnose children age 18 months and older.

Antibody tests, such as rapid tests or ELISA, when used to test children less than 18 months of age may be positive due to the presence of maternal antibodies to HIV circulating in the child's body. A child who is not infected with HIV will lose their mother's antibodies some time before 18 months of age. Some countries may use antibody tests to *rule out* HIV infection in infants starting when a child is 9 months of age. However, a positive antibody test below the age of 18 months should never be used alone to diagnose HIV infection. Refer to national policy for guidance on timing of antibody testing in children when viral tests are not available.

If a child presents with symptoms of HIV and their mother's status is unknown, the child should be referred to a healthcare team specializing in HIV care. The mother should be offered HIV counselling and testing and referred for HIV care, treatment, and support if HIV-infected. The draft WHO recommendations on testing infants and children are in Appendix D. The criteria for making a presumptive diagnosis are in Appendix E.

It is critical that healthcare workers responsible for infants and children are familiar with the common signs and symptoms of HIV infection and able to refer for diagnosis as well as care, treatment, and support. Without care, treatment, and support, most of these children will die before their 2<sup>nd</sup> birthday.



### **For Inclusion in National Curriculum**

- National guidelines and algorithms for HIV testing in infants and children
- Replace Appendix D with national diagnostic algorithms



### **Trainer Instructions**

Slides 28-36

Ask participants about the symptoms they have seen in infants who were exposed to HIV who later tested HIV-positive. Reassure participants that there will be an opportunity to discuss the clinical presentation of HIV infection in children in Exercise 2.



## Make These Points

- All infants and children born to mothers whose HIV status is unknown should be considered at risk for having been exposed to HIV. Continue to offer HIV counselling and testing to the mother. If she declines testing, invite her to discuss her reasons for refusing to test. Correct any misconceptions, offer couple or family counselling where available, and reiterate the importance of HIV testing for both herself and her infant.
- If the infant or child has symptoms of HIV infection, refer to a healthcare team specializing in paediatric HIV care.
- Educating mothers and other caregivers about early signs and symptoms of HIV-related conditions in their children may encourage early access to care and help avoid serious outcomes.
- Growth failure is one of the key presentations of HIV infection in children.
- If one child in a family shows signs and symptoms of HIV infection, all siblings need to be tested and, if infected, evaluated by a healthcare team specializing in paediatric HIV care.

### **Infants of Mothers whose HIV-status is Unknown**

All infants born to mothers whose HIV status is unknown should be considered at risk of exposure to HIV. Risk factors in a mother's medical history include signs and symptoms of HIV or the presence of an STI. All mothers with unknown status should be encouraged and supported to test as soon as possible. Continue to offer HIV counselling and testing to the mother. If she declines testing, invite her to discuss her reasons for refusing to test. Correct any misconceptions, offer couple or family counselling where available, and reiterate the importance of HIV testing for both herself and her infant. If she tests HIV-positive she should be referred for HIV care and treatment. If the mother is diagnosed with HIV infection, all of her children need to be tested and, if infected, followed by a healthcare team specializing in HIV care. The infant/child of a mother of unknown HIV status who has signs of symptoms of HIV infection should be referred to a healthcare team specializing in HIV care.

### **Recognizing HIV Infection in Infants and Young Children**

#### **Common signs and symptoms of HIV infection**

The signs and symptoms most commonly associated with HIV infection in infants are:

- Low weight and/or growth failure — measured against standard growth charts (See Appendix C)
- Lymphoid interstitial pneumonia (LIP) — characterized by gradual onset shortness of breath, cough, and fever
- Hepatosplenomegaly — enlarged spleen and liver
- Pneumonias, including PCP

- Oral candidiasis (thrush) — white adherent plaques on mucous membranes of the mouth
- Lymphadenopathy — swollen lymph glands
- Parotid gland swelling
- Recurrent ear infections
- Persistent diarrhoea — for more than one week
- Tuberculosis

**Table 2: Clinical conditions or signs of HIV infection in a child who is HIV-exposed**

Specificity for HIV infection	Signs and symptoms
Common in children who are HIV-infected; also seen in ill children without HIV infection	<ul style="list-style-type: none"> <li>• Chronic, recurrent otitis media with discharge</li> <li>• Persistent or recurrent diarrhoea</li> <li>• Failure to thrive</li> <li>• Tuberculosis</li> </ul>
Common in children who are HIV-infected; uncommon in children with out HIV	<ul style="list-style-type: none"> <li>• Severe bacterial infections, particularly if recurrent</li> <li>• Persistent or recurrent oral thrush</li> <li>• Chronic parotiditis (often painless)</li> <li>• Generalized persistent non-inguinal lymphadenopathy in two or more sites</li> <li>• Hepatosplenomegaly</li> <li>• Persistent or recurrent fever</li> <li>• Loss of developmental milestones (see Appendix C)</li> <li>• Herpes zoster (shingles) (single dermatome)</li> <li>• Persistent generalized dermatitis unresponsive to treatment</li> </ul>
Specific to HIV infection	<ul style="list-style-type: none"> <li>• Lymphoid interstitial pneumonitis (LIP)</li> <li>• Pneumocystis pneumonia (PCP)</li> <li>• Oesophageal candidiasis</li> <li>• Disseminated herpes zoster</li> <li>• Kaposi's sarcoma</li> </ul>

### **Growth failure**

Poor growth is reported in as many as 50% of HIV-infected children. Growth failure is a persistent and unexplained decline or levelling-off in weight and the speed of growth despite adequate nutrition. Nutritional status also has a direct effect on the survival of the HIV-infected child. Growth failure and malnutrition observed in children who are HIV-infected is due to several factors:

- Decreased intake due to oral thrush or painful swallowing, or to nausea associated with ARV medications
- Increased metabolic activity in a child fighting HIV infection and other common illnesses of childhood

**Growth Monitoring**

Close clinical follow-up is critical for HIV-exposed and HIV-infected infants. Poor growth may be one of the first indicators of infection. Growth and nutritional assessments should be conducted at each follow-up visit. For more information on monitoring growth of infants and children, see Appendix C.

As growth and development are assessed and monitored in well child settings, linkages between these sites and PMTCT, Voluntary Counselling and Testing (VCT), and HIV care and treatment sites are critical to the health of children.

**Trainer Instructions**

Slide 37

Exercise 2 will provide participants with an opportunity to discuss the common HIV-related signs and symptoms in infants and children who are HIV-infected.

<b>Exercise 2 — Clinical Presentation of HIV in Infants and Children (large group discussion and case studies)</b>	
<b>Advance Preparation</b>	<p>Trainers should familiarize themselves the common signs and symptoms of HIV infection in children; the following may be helpful:</p> <ul style="list-style-type: none"> <li>• Appendix E: WHO Clinical Staging for HIV-infected Infants and Children and diagnostic criteria for presumptive diagnosis of HIV infection in infants and children</li> <li>• Table 2 above</li> </ul> <p><i>If possible</i>, have participants review these documents prior to the session.</p> <p>Note that the case studies may be more useful for participants who do not have access to DNA PCR for diagnosing HIV infection in children. In areas with access to viral testing, the trainer may prefer to revise the cases.</p>
<b>Purpose</b>	To familiarize participants with the common HIV-related signs and symptoms in infants and children and to become familiar with the criteria for making a presumptive diagnosis of HIV infection in infants and children.
<b>Duration</b>	60 minutes
<b>Introduction</b>	This exercise will focus on the role of the healthcare worker in recognizing signs and symptoms of HIV. Sometimes a diagnosis of HIV may be delayed due to the unavailability of HIV viral tests.

<b>Exercise 2 — Clinical Presentation of HIV in Infants and Children (large group discussion and case studies)</b>	
	It is therefore critical that healthcare workers can recognize HIV infection in infants and children and know the criteria for making a presumptive diagnosis of HIV infection.
<b>Activities</b>	<ul style="list-style-type: none"> <li>• Before starting, tell participants that this exercise has two parts: a large group discussion followed by case studies.</li> </ul> <p><b>Part 1 – <u>Large group discussion</u></b></p> <ul style="list-style-type: none"> <li>• Ask participants if they understand all terms used in Table 2 that describe the clinical signs and symptoms of HIV-infection in children.</li> <li>• Clarify terms or turn to a participant with paediatric clinical experience for assistance.</li> <li>• Write on flipchart: “Signs and symptoms of HIV infection in infants and children.”</li> <li>• Ask participants to identify the presenting sign and symptoms of HIV infection in an infant or child that they have seen in clinic. (Prompt: “What are some of the symptoms and signs of HIV infection that relate to the child’s general appearance?”)</li> <li>• Record participants’ responses on the flipchart. Possible answers: <ul style="list-style-type: none"> <li>○ Being underweight</li> <li>○ Being small for age</li> <li>○ Failure to thrive</li> </ul> </li> <li>• Ask participants to refer to the list on the flipchart and to answer the questions below for each of the symptoms of HIV infection that was given as an example. (If there are too many symptoms listed, ask which ones are most common and focus on these symptoms.)</li> <li>• What else could the symptom indicate?</li> <li>• Using the simplest language possible, how would you explain to a mother how to recognize this symptom?</li> <li>• What would you tell a mother to do if she recognized this symptom in her child?</li> <li>• Does this symptom help you to formulate a presumptive diagnosis of HIV infection? (Please note this question may not apply to all symptoms, refer to Appendix E for more information)</li> <li>• Encourage participants to refer to Appendix E and Table 2 as needed.</li> </ul> <p><b>Part 2 – <u>Case studies</u></b></p> <ul style="list-style-type: none"> <li>• Divide participants into 3 groups; assign one case study to each group.</li> <li>• Instruct participants that in the case study they should assume that there is no or limited access to HIV viral tests.</li> <li>• Encourage participants to refer to Appendix E – WHO Clinical</li> </ul>

<b>Exercise 2 — Clinical Presentation of HIV in Infants and Children (large group discussion and case studies)</b>	
	<p>Staging and Criteria for Presumptive Diagnosis of HIV Infection in Infants and Children.</p> <ul style="list-style-type: none"> <li>• Allow 10 minutes for the groups to discuss their answers to each of the case studies.</li> <li>• Ask a volunteer from each group to read the case study, the questions, and the group's answer.</li> <li>• After each small group reports, invite members of the larger group to contribute to the discussion.</li> </ul>
<b>Debriefing</b>	<ul style="list-style-type: none"> <li>• Stress to participants that educating mothers to recognize early symptoms of HIV infection and seek medical care immediately may prevent complications and even death.</li> <li>• Reinforce that many symptoms of HIV infection are also commonly seen in other illnesses and evaluation by an HIV specialist is necessary.</li> <li>• The healthcare worker who recognizes the signs and symptoms of HIV can play an important role in getting undiagnosed infants and children into life-saving HIV-related care, treatment, and support.</li> </ul>

### **Exercise 2 – Clinical Presentation of HIV in Infants and Children (case studies)**

#### **Case study 1**

Your patient has come to the MCH clinic with her nephew who is 4 months old. The boy's mother abandoned him shortly after birth and neither her HIV status nor her whereabouts is known. The aunt tells you that the child has been formula fed. Today the child has a fever and a cough which is causing respiratory distress. On physical exam you note that the child is in the lowest percentile for both weight and head circumference. You also observe a white adherent film in the baby's pharynx.

1. What factors lead you to believe that this baby is infected with HIV?
2. Which symptoms specifically would contribute to a presumptive diagnosis of HIV-infection?
3. What is your first step in making a presumptive diagnosis of HIV-infection? Refer to Appendix E for more information.
4. What should your next steps be in order of priority?
5. What are you going to say to the boy's aunt?

#### **Case study 2**

Sarah, a small but healthy-appearing 2 year old, is in your office with her mother and new baby sister. Sarah presents with discharge from her ear, a low grade fever, and asymmetrical tender lymphadenopathy. Even before your physical exam, you suspect otitis. This is the third time Sarah will have been diagnosed with otitis media in less than one year. You also care for Sarah's mother, who is infected with HIV, and the youngest child.

1. What factors may or may *not* lead you to believe that Sarah is infected with HIV?
2. What symptoms concern you and how would you assess them further? (Refer specifically to Appendix E)

3. What is your plan today?
4. What are you going to say to Sarah's mother?

### Case study 3

You recently started working at a rural MCH clinic and are asked by one of the community healthcare workers for your opinion on a 2-year old girl who is very ill and staying with her grandmother in a nearby village. This is the first you are hearing about the child and the doctor is not in the clinic this week. The other nurses, who are familiar with this family, suspect that the child has TB of the lymph nodes.

1. If the child is confirmed to have non-pulmonary TB, would this meet the criteria for a presumptive diagnosis of HIV infection? Why or why not?
2. Excluding treatment of non-pulmonary TB, what are some of the other steps in caring for this child?
3. How would you include the family in the care of the children?
4. What are you going to say to the grandmother?
5. How would you involve your TB care and treatment services in this case? How would you refer this case to a TB clinic?

### Suggested answers to guide discussion for Exercise 2- Clinical Presentation of HIV in Infants and Children

**Please note, the answers to case studies are not exhaustive and should be used to guide the discussion.**

#### Case study 1

1. *What factors lead you to believe that this baby is infected with HIV?*

The baby's symptoms of pneumonia e.g., fever and respiratory distress, are of immediate concern. The presence of a severe pneumonia is one clue that the child may be infected with HIV. The baby needs to be stabilized so that he can breathe. After this immediate need is addressed, you can think about other factors that may lead you to believe the baby is infected, e.g., a fall off of the growth curve. In addition, the mother's HIV status is unknown.

2. *Which symptoms specifically would contribute to a presumptive diagnosis of HIV-infection?*

The presence of oral candidiasis can be a contributing factor in making a presumptive diagnosis of HIV infection as would the presence of severe pneumonia.

3. *What is your first step in making a presumptive diagnosis of HIV-infection?*

The first step in making a presumptive diagnosis (if viral tests are not available) is to do a HIV antibody test according to national guidelines to establish exposure to HIV.

4. *What should your next steps be in order of priority?*

Answers may differ but the first priority should be stabilization and treatment of the baby's pneumonia. A presumptive diagnosis of HIV infection with referral for HIV care and treatment, if found to be HIV-positive. If they can be found, the mother, older siblings, and the father need to be tested and referred for care if found to be infected.

5. *What are you going to say to the boy's aunt?*

Again, answers will vary. The aunt obviously needs to be comforted and assured that she did the right thing by bringing her nephew in for care. You need to establish a partnership with the aunt in order to develop a plan to find and then test the other members of the family, who may be infected with HIV. You will need to strategize with her about how to convince her sister to test.

**Case study 2***1. What factors may or may not lead you to think that Sarah is infected with HIV?*

The fact that Sarah's mother is infected with HIV puts her at risk for acquiring HIV infection. As Sarah is 2 years old, she can be tested for HIV immediately using an antibody test, if this hasn't occurred already. If an HIV test was performed, you will want to make sure that it was at least 6 weeks after Sarah's mother stopped breastfeeding her. There are several factors that require more assessment and investigation, specifically Sarah's growth and development. The frequency and severity of her otitis media also requires attention. However, otitis media is a common childhood infection. Children below the age of 7 are more prone to otitis media due to the shape of their Eustachian tubes. Lymphadenopathy, which occurs as a result of an active infection, is different from persistent generalized lymphadenopathy which is common in HIV-infected children and adults.

*2. What symptoms concern you and how would you assess them further? (Refer specifically to Appendix E)*

You are concerned about the frequency of otitis and her growth. Confirm your diagnosis of otitis by physical exam and assess Sarah's growth, nutritional patterns, and development using national standards and tools regardless of whether she is infected with HIV or not.

*3. What is your plan today?*

Participants will discuss. HIV antibody testing should be performed at this appointment if not already done. Her otitis should be treated with an antibiotic. A plan needs to be made for follow-up of both the otitis, as it is reoccurring, and her growth, if found to be inadequate.

*4. What are you going to say to Sarah's mother?*

You are going to try and find out whether the mother is in care. Also, if Sarah has not been tested, you should also explore why in a non-judgmental and constructive manner.

**Case study 3***1. If the child is confirmed to have non-pulmonary TB, would this meet the criteria for a presumptive diagnosis of HIV infection? Why or why not?*

Yes, the child would meet the criteria for a presumptive diagnosis of HIV infection, provided the child tested positive for HIV with antibody testing. Extrapulmonary TB is considered an AIDS-indicator condition. The child already falls into WHO clinical stage 4.

*2. Excluding treatment of non-pulmonary TB, what are some of the other steps in caring for this child?*

Some possible answers:

- A partnership must be formed between the TB treating physician and an HIV care and treatment clinic. The management of these co-infections must be well coordinated.
- Other members of the family need to be evaluated for active tuberculosis, especially the grandmother.
- The family will need extensive education on the side effects of both TB and ARV medications in addition to support for adhering to the treatment regimen.

*3. How would you include the family in the care of the children?*

Participants will discuss their answers. If TB is even suspected, the entire family and all close contacts need to be evaluated as soon as possible.

*4. What are you going to say to the grandmother?*

Participants will discuss. It will be important to evaluate the grandmother for active TB as soon as possible so you will need to develop a plan with her to be evaluated.

*5. How would you involve your TB care and treatment services in this case? How would you refer this case to a TB clinic?*

Participants will discuss their answers according to the structure of TB care in their countries.



## Trainer Instructions

Slides 38-41

Tell participants that they will now turn their attention from the needs of HIV-exposed children to the healthcare needs of male partners. Begin by reviewing participant responses to Exercise 1 on the gaps in services for male partners of women who were diagnosed with HIV in PMTCT programmes.



## Make These Points

- Typically, men control how a couple has sex and whether to use a condom or not. As such, it is men who have an important role in protecting themselves and their partners from HIV.
- There are many culturally defined male risk-taking behaviours that are barriers to adopting safer sex.

## Male Partner Involvement in HIV Prevention, Care, Treatment, and Support

### Rationale for male involvement

The Caribbean hosts the second highest adult incidence of HIV, second only to Africa, with 250,000 people currently living with HIV. By far, the primary mode of transmission amongst adults is heterosexual intercourse. Men are in a unique position of power to alter the course of the HIV epidemic in the Caribbean: both in preventing HIV infection to their partners and children and in supporting HIV-related prevention, care, and treatment efforts for themselves and their families.

### Men and HIV risk

Risk-taking behaviours, many of which are culturally defined, increase men's chances of contracting and transmitting HIV:

- It is culturally acceptable for men to father multiple children with multiple female partners.
- Women are exposed to an increased risk because men are more likely to have more sex partners; consecutive and concurrent.
- Men who migrate for work and live apart from their families may adopt risky behaviours to cope with the stress and loneliness of living far from home e.g., paying for sex and using alcohol or drugs that may contribute to risk taking.
- Risky situations involving sex and drug-use are supported by cultural beliefs and expectations about "manhood."
- Virility may be defined by frequent and unprotected sex.
- Men are culturally expected to determine when, where, and how couples have sex.

### **Barriers to safer sex for couples**

The following are examples of cultural norms and beliefs that can act as barriers to HIV prevention:

- Cultural norms that encourage women to bear multiple children at a young age.
- Belief that men are invincible and not able to become infected.
- Misinformed concerns that condoms break easily, are clumsy, or can reduce sexual pleasure.
- Beliefs that contraception is a woman's responsibility.
- The mistaken belief that marriage necessarily equates with mutual faithfulness.
- The perception that women or girls who ask their partners to use condoms are promiscuous or unfaithful.
- The fear of reprisal, including physical violence, if a woman asks to use a condom. The fear of violence makes it more difficult for women to refuse unsafe sex or negotiate for condom use. Domestic violence, rape, and sexual abuse are not only violations of human rights but also opportunities for HIV transmission.
- Stigma surrounding homosexuality, which is not discussed or considered culturally-acceptable behaviour. Non-disclosure of high risk sexual behaviour puts female partners at risk.



### **Trainer Instructions**

Slides 42-45

Discuss the importance of involving men in the ongoing care and treatment of their partners and children. Use the discussion questions below to encourage participants to discuss specific examples of how men can be involved in ANC, PMTCT, postpartum, and comprehensive care.

Then review the strategies to include men in these programmes.

#### **Discussion questions:**

- Do men normally attend ANC clinics visits with their partners? How about labour and delivery or postpartum care? How about HIV-related care and treatment? Do they attend well child visits?
- How can we encourage men to be more involved in the health of their families?
- What societal norms have to change for this involvement to occur?
- As healthcare workers, what can we do to encourage the involvement of men?
- How can we also encourage men to access healthcare services for their own health?

**The evolving role of men**

Studies have shown that when male partners are involved in ANC services, rates of HIV testing are higher and women are more likely to agree to PMTCT interventions. Partner support is likely to be important in women's decision about: taking the HIV test, adhering to ARV medications, attending postpartum and comprehensive care for themselves and their infants. Involving men in the care of their families involves challenging beliefs about traditional roles.

**Strategies to include male partners in HIV prevention, care, treatment, and support**

- Offer HIV counselling and testing for male partners.
- Arrange flexible counselling and testing times to accommodate work schedules.
- Promote HIV prevention, care and treatment and other health-related messages in places where men congregate:
  - Sporting events
  - Places of work
  - Barber shops
- Support and help develop male-oriented public health campaigns supporting the responsibility of men in HIV prevention, care, treatment, and support that focus on a man's role in keeping their partner and children HIV-free.
- Hold all-male pre-test counselling sessions that emphasize the role of the father as "protector of his family."
- Invite male role models from the community to learn more about men's role in HIV prevention, care, treatment, and support. When men understand the importance of PMTCT interventions and HIV care to their family's health, they are better prepared to encourage their female partners to be involved, this promotes shared responsibility for family health.
- Support or sponsor HIV prevention outreach efforts that challenge traditional norms of masculinity, stigma, and acceptability of domestic violence.
- Take measures to normalize male partners attending ANC and postpartum visits with their partners.
  - Hold general primary care visits for men during ANC or postpartum clinic times or well child visits.
- Target male partners of clients who do not attend ANC, postpartum, or follow-up care and encourage them to support their partners to attend clinic.
- Make partner referral a standard part of PMTCT, postpartum, and HIV care and treatment programmes.
- Offer family planning counselling to couples. For guidance on how to conduct a family planning counselling session please see Appendix F.

## Session 2 Linkages, Referrals, and Retention Strategies



### Advance Preparation

#### The day before: Exercise 3

Review Exercise 3 and assign completion of the Community Resource Information Worksheet the day before this session will be taught. Instruct participants to complete as much of the Worksheet as possible, they should feel free to work with colleagues or other participants.

#### The week before: Exercise 4

Adapt the role play scenarios to ensure they reflect the local context. Ask colleagues working in the field of social work or clinical nurses for suggestions. Prepare a co-trainer or participants to demonstrate the role play exercise.



**Total Session Time:** 4 hours and 40 minutes

#### After completing the session, the participant will be able to:

- Describe the difference between linkages and referrals.
- Discuss retention strategies for keeping women and their families in care.
- Improve referral practices between PMTCT and HIV care and treatment programmes.
- Practise problem-solving skills to address social issues affecting a client's capacity to follow-up with care and treatment.



### Trainer Instructions

Slides 46-52

Introduce linkages by defining the term and differentiating it from referrals. Stress the importance of linkages with community as well as governmental organizations and why linkages should be family-centred.

Once you have defined what a linkage is, ask participants for examples of linkages that they have relied on in their healthcare settings.



## Make These Points

- Linkages are between agencies whereas referrals are between a healthcare provider and the client.
- Linkages and referrals should focus on the needs of the woman, her children, and family.
- Linkages between PMTCT and HIV care and treatment programmes will become even more important as the standard of care for PMTCT evolves to triple combination ARV prophylaxis and HAART regimens.
- PMTCT healthcare workers play an important role in ensuring that women and their families have access to a referral network.

### Introduction to Linkages and Referrals

Because HIV can be a debilitating and life-threatening illness and the diagnosis of HIV infection a life-altering event, HIV-infected women will need access to comprehensive care and support services. In addition, women who test HIV-negative and those whose HIV status is unknown may also need referrals to local services. Although many of these services are available within PMTCT programmes, many other necessary interventions and services are provided outside of the programme. In order to offer truly comprehensive care, health facilities must often partner or link with governmental, community-based organizations, faith-based organizations, and similar agencies that provide care, treatment, and support services for mothers who are HIV-infected and their family members.

In some smaller Caribbean countries, coordination between agencies and healthcare facilities may take place informally while in other countries the process is more complex and systemized.



### For Inclusion in National Curriculum

- Description of how maternal child health (MCH), family planning, PMTCT, and HIV care and treatment are interrelated
- Add an algorithm that describes the responsibilities of each service and the links that inter-connect them as an appendix.

### What are Linkages?

Linkages are formal networks between organizations or an agency and the community. Linkages facilitate the referral of the client and her family for needed services. Linkages can also facilitate the referral of pregnant women from the community into PMTCT services. The goal of linkages is to provide a “seamless” continuum of care delivered efficiently and conveniently as if there were a single entity delivering care.

PMTCT programmes, which strive to provide a continuous flow of clients between ANC, labour and delivery, and postpartum care should also be linked with:

- Tertiary referral hospitals, district hospitals, peripheral health facilities
- Other government organizations e.g., schools, social welfare agencies, and local government
- The communities they serve
- Non-governmental and faith-based community organizations
- Private doctors and healthcare providers

Linkages can also result from informal relationships of healthcare workers who know one another professionally or personally. These informal relationships can smooth the passage of women from one agency or healthcare facility to another.

The advantages of linkages include:

- Better access of PLHIV to key HIV, family planning and care and treatment services tailored to their needs
- Better understanding of how to manage the more complex ARV prophylaxis or treatment regimens
- Promotion of PMTCT activities and PMTCT messages amongst all healthcare workers
- Reduced HIV-related stigma and discrimination
- Improved coverage of underserved and marginalized populations
- Improved quality of care
- Enhanced programme effectiveness and efficiency

Not only do linkages provide clients with comprehensive care, but linkages also enable the development of a sense of joint purpose and joint achievement. They enable healthcare workers to feel part of the broader strategy to improve the health of the community and, as such, increase staff motivation and satisfaction.

It is essential that PMTCT services foster a wide range of linkages, those between PMTCT and care and treatment services are essential:

- Caring for and treating families affected by HIV is a shared responsibility.
- Children born to women who are HIV-infected require close follow-up and appropriate care.
- Specialists in HIV who care for women and children may provide consultation, antiretroviral therapy, and help with the ongoing management of HIV infection.
- As the standard of care for PMTCT evolves to triple combination ARV prophylaxis and highly active antiretroviral therapy (HAART) regimens, the collaborative relationship between PMTCT and care and treatment programmes become vital to the management of the client.



### **Trainer Instructions**

Slides 53-55

Discuss the importance of linkages and relationships with community-based services.

#### **Discussion questions:**

- What community services do you refer patients to?

- What services have you learned about from your patients (e.g. church groups, support groups)?



### Make These Points

- Non-traditional partners are important resources to ensure clients have access to the continuum of care, particularly non-medical services.

### Community Linkages

It is important that linkages are expanded to include a range of community-based services as well as paediatric and adult care and treatment programmes. Community linkages can provide the resources, such as support groups and social activities, to help women who are HIV-infected and their families cope with the isolation, social stigma, and emotional pressures that often accompany a diagnosis of HIV. National HIV programme budgets are always stretched and looking to the community and other non-traditional partners can help to meet the needs of PLHIV. Working with the community can also help to decrease stigma and discrimination around HIV.

Community-based organizations may also provide women infected with HIV a way to become involved in voluntary or paid HIV-related work. Faith-based organizations and churches can be powerful allies for counselling and supporting HIV-affected families. Local business organizations can offer public education about HIV and HIV prevention.

PMTCT healthcare workers can facilitate a connection with community-based initiatives by networking with supportive community agencies, identifying key partners, and formalizing methods of contact and communication. PMTCT healthcare workers can provide HIV training to non-traditional partners in the not-for profit and for-profit industries.



### Trainer Instructions

Slides 56-62

Ask participants if they would add to the table of suggested linkages or referrals below.

Review the benefits of strong linkages and comparison them to the potential consequences of poor linkages in Table 5 on page 29 of the Trainer Manual.



## Make These Points

- PMTCT healthcare workers need to be familiar and have relationships with locally available services within their communities.
- Linkages and referrals also benefit uninfected mothers and families.

**Table 3: Suggested Linkages and Referrals**

**For HIV-negative women (and women of unknown HIV status) and their families:**

- |   |   |
|---|---|
| • Counselling and testing (partner and family testing)          | • Nutritional education and support for new mothers and infants |
| • Routine well baby or well child care, including immunizations | • Treatment and support for drug and/or alcohol abuse           |
| • Family planning and safer sex counselling                     | • Mental health services  |
|   | • Domestic violence services                                    |

**For HIV-infected women and their families:**

- |  |  |
|--|--|
| • Counselling and testing (partner and family testing)                                       | • Tuberculosis clinics and treatment programmes  |
| • HIV care, treatment, support, and prevention of HIV-related conditions and ARV therapy     | • Sexually transmitted infection (STIs) treatment programmes   |
| • Routine well baby or well child care, including immunizations                              | • Laboratory services  |
| • Healthcare providers in private specialized practice                                       | • Organizations providing supportive counselling including support groups and positive mothers' clubs  |
| • Family planning and safer sex counselling  | • Community-based HIV groups   |
| • Nutritional education and support programmes for mother, child and infected family members | • Faith-based and community organizations that offer services such as psychosocial care, housing, transportation, food assistance, legal assistance, and income-generation |
| • Safer infant feeding counselling and support   | • Treatment and support for drug and/or alcohol abuse  |
| • Community/home-based care services   | • Mental health services   |
|  | • Domestic violence services   |

#### Table 4: Linkage Enablers

A number of factors facilitate the building of strong linkages.

- Informal personal relationships e.g., having studied together in nursing or medical school
- Good communication systems from phones and E-mail to comprehensive referral forms
- Transport systems, good roads, and public transportation
- Shared continuing education or training courses
- Integration of management and support functions such as planning, education and training, supplies and maintenance including ordering ARV drugs

#### Table 5: Consequences of Poor Linkages

When linkages are ineffective, a number of problems may occur:

- Gaps in service
  - HIV-exposed children are not diagnosed and do not receive ARV therapy
  - Potentially infected siblings are not tested for HIV
  - Male partners are not tested for HIV
  - Women present back to PMTCT programmes only after another pregnancy
- Service duplication, e.g., local NGO provides HIV counselling and testing near an ANC clinic which houses a PMTCT programme
- Inappropriate division of tasks. PMTCT sites may take on tasks they are not sufficiently equipped to do or which could have been handled more efficiently at another level.
- Clients who could have been treated locally for HIV may be treated at the referral hospital at higher expense than necessary.



#### Trainer Instructions

Slides 63-71

Define “referral”; describe the criteria for referral and the process, if one exists.

As an introduction to Exercise 3: Community Resources, discuss how participants can develop a referral network to support clients attending PMTCT services using the discussion questions below.

#### Discussion questions

- Describe a situation where you referred a client for a service but the client did not attend. Why did they not attend? How did you handle the situation?
- What mechanisms have been successful in your own communities and facilities to develop formal referral networks?



## Make These Points

- Best practices in making a referral requires much more than handing a client a referral form.

### What are Referrals?

Referrals are the guided or orchestrated movement of clients to obtain services based on the specific needs of the client.

### Criteria for Referral

The client should be referred to another service under the following circumstances:

- Client or family member has unmet needs
- Unavailability or inaccessibility of services at the facility
- Client or family request

### Steps in the Referral Process

The steps in the referral process should include:

- Assess the client's care needs: clients will have individual care, treatment, and support needs based on the status of their HIV infection and their individual circumstances.
- Outline the health and social services available to the client. Help the client determine the most suitable referral site in terms of distance, cost, and appropriateness.
- Conduct an assessment of the possible barriers to the client attending a referral e.g. lack of child care or transportation, work schedule, prohibitive cost, and fear of stigma. Ensure the mother understands why it is recommended that she go to the referral agency. A client that understands why she is going for an appointment is more likely to keep that appointment.

If a client does not want to go to the referral agency, ask her why. Reasons may include cost, transportation, child care, lack of support at home, fear of the unknown, or not understanding the benefits of the referral. Work with her to address these barriers to care and encourage her to seek the services she needs.

- Document the referral, including date, medical criteria such as laboratory and physical exam characteristics pertinent for the referral service, and any additional information needed by the referral agency.

- Discuss issues of confidentiality and privacy with all individuals involved with the referral.
- Give the client a list of other available services with addresses, telephone numbers, and hours of operation.
- Ask the client for feedback on the quality of services they attended. Document and evaluate the experience to inform future referrals.

- Establish a mechanism with referral agencies to facilitate feedback from medical referrals (feedback from non-medical services is optional depending on the wishes of the client).
- Reassess barriers.

The medical criteria for a referral are based on national guidelines. For a sample client referral form, see Appendix G.



### **For Inclusion in National Curriculum**

- Add forms used by PMTCT programmes to refer clients to care and treatment clinics and/or other comprehensive care services as an appendix.

## **Monitoring Referrals**

Feedback from referrals is important as a quality assurance mechanism:

- Referring facilities can assess the success and appropriateness of their referrals
- The organization receiving the referred client can review the records for patterns suggesting that a healthcare worker (in the referring agency) needs additional technical support or training

Create mechanisms to communicate with referral agencies to facilitate monitoring and process improvement. A sample form for tracking referrals is in Appendix H.

## **Developing a Referral Network**

Functioning referral networks require that PMTCT healthcare workers be fully versed in the range of clinics, departments, units, and organizations that provide services to clients with HIV, their partners, and families.

Referral networks take time and commitment to create and maintain. The first step in creating a network is to map all possible referral resources and to create a directory of these services. A referral network can include the following components:

- A lead organization to coordinate the referral system
- Regular meetings of network providers or another way to communicate (e.g., E-mail, telephone, newsletter)
- A designated referral person at each of the organizations, who will be the first contact for people referred. This person will handle any paperwork involved in processing referrals and attend network meetings
- A standard referral form that all network members can give to clients and use for managing referrals
- A system that tracks referrals and lets network members know when a referral has been successfully completed

If the PMTCT programme has a community coordinator, this person could play a key role in meeting community partners and participating in the referral network.



## Trainer Instructions

Slide 72

Ask participants to complete the Community Resource Information Worksheet the day before this session is taught, using the instructions numbered 1 through 4 under “Activities.”

Lead the small group discussion in Exercise 3 on mapping a network of community resources.

<b>Exercise 3 — Community Resources (small group discussion)</b>	
<b>Advance Preparation</b>	<p>Ask participants to complete the Community Resource Information Worksheet the day before this session is taught, using the instructions numbered 1-3 under “Activities.”</p> <p>Write each of the 9 resource categories (e.g. “HIV care and treatment for adults,” “HIV care and treatment for infants and children,” “Counselling and testing for partners”) at the top of a sheet of flipchart paper (use 9 sheets of flipchart: one for each resource category). Post all 9 sheets of flipchart around the training room.</p>
<b>Purpose</b>	<ul style="list-style-type: none"> <li>• Identify the range of services available to PLHIV</li> <li>• Encourage interagency linkages and facilitate client referral to community and healthcare services</li> <li>• Create or update a list of referral agencies</li> </ul>
<b>Duration</b>	60 minutes
<b>Introduction</b>	<p>Once a healthcare worker recognizes <i>when</i> to refer a client, the next step is to find out <i>where</i> to refer the client.</p> <p>This exercise will give participants a chance to share information on the HIV-related services offered in their communities. By the end of this exercise, participants will have compiled a partial list of HIV-related resources and identified areas where services are needed.</p>
<b>Activities</b>	<p><b>Setting up groups the day before</b></p> <ul style="list-style-type: none"> <li>• Divide participants by geographic location or association with a particular facility (not more than 4–5 groups if possible).</li> <li>• Ask participants to refer to the Community Resource Information Worksheet in their manuals.</li> <li>• Using this worksheet as a guide, ask each small group to identify available community resources and record them on their worksheets.</li> <li>• Ask them to address each category of community resources in the left-hand column and answer the following questions:             <ol style="list-style-type: none"> <li>1. Can you list the organization name, contact person, address, location, fees, and hours of operation?</li> <li>2. What resources are missing on your list?</li> </ol> </li> </ul>

<b>Exercise 3 — Community Resources (small group discussion)</b>	
	<p>3. Who in the community can help fill in the missing agencies?</p> <p><b>Presenting Resources</b></p> <ul style="list-style-type: none"> <li>• Ask for volunteers to write on the flipchart sheet the name and contact information for the referrals that they identified in their small group.</li> <li>• Ask that the volunteers record all the agencies they identified in an effort to complete all 9 of the categories of referral. Tell participants to avoid repeating the same resources.</li> <li>• Save flipchart paper for assembly into an updated list of resources for future distribution.</li> <li>• Suggest that participants take the opportunity during this training to secure missing information such as addresses, phone numbers, contact persons, and hours of operation, and report back to the group.</li> </ul>
<b>Debriefing</b>	Remind participants that establishing linkages requires interagency teamwork. One person within each PMTCT programme should be responsible for researching and regularly maintaining a directory of resources.

## Community Resource Information Worksheet

Use this form to list the contact information for agencies that provide services to women and families living with HIV.

COMMUNITY RESOURCES THAT SUPPORT THE PMTCT PROGRAMME		
Resource Category	We Have...	We Need...
HIV care and treatment for adults	Name of agency: Contact person: Address: Telephone number: Fees: Hours:	
HIV care and treatment for infants and children	Name of agency: Contact person: Address: Telephone number: Fees: Hours:	
Counselling and testing for partners	Name of agency: Contact person: Address: Telephone number: Fees: Hours:	
Family planning services	Name of agency: Contact person: Address: Telephone number: Fees: Hours:	

<b>COMMUNITY RESOURCES THAT SUPPORT THE PMTCT PROGRAMME</b>		
<b>Resource Category</b>	<b>We Have...</b>	<b>We Need...</b>
Substance abuse treatment services	Name of agency: Contact person: Address: Telephone number: Fees: Hours:	
Nutritional support	Name of agency: Contact person: Address: Telephone number: Fees: Hours:	
Support group(s) or club(s)	Name of agency: Contact person: Address: Telephone number: Fees: Hours:	
Community- and faith-based organizations	Name of agency: Contact person: Address: Telephone number: Fees: Hours:	
Other		



## Trainer Instructions

Slides 73-77

Start a discussion about the most common reasons clients do not stay in care or follow-up with treatment plans. Ask participants to be specific about the social problems that affect their clients and how this influences access to comprehensive care. Strategies to address these problems will be discussed in the next exercise.



## Make These Points

- It is important that clinical healthcare workers learn and use counselling and education strategies to help their clients cope with social problems.
- There are many strategies and incentives that can be used to keep clients in care.
- Healthcare workers should look to their social work colleagues for support and ideas of how to retain clients.

## Barriers to Comprehensive HIV Care

Sometimes, despite an extensive referral system, clients still do not follow-up with referrals. The many circumstances that surround a woman's life can affect her ability to receive truly comprehensive care for herself and family.

### Stigma

The profound stigma experienced by many clients with HIV can keep them from acknowledging that they need ongoing care for their HIV. There is fear and shame associated with this disease that can outweigh a mother's good intention to care for herself and her family. Clients may also fear that their status may be revealed when they attend clinic. This can occur when HIV care and treatment sites are not integrated into mainstream medical care. For example, HIV care and treatment sites are referred to as the "HIV clinic" or specific healthcare workers become known as "the HIV doctor." Clients may have second thoughts about HIV testing or care at a site where a friend or relative is employed.

### Financial

Some women will drop out of care or not follow-up with a referral for financial reasons. Even if services are free or low cost, e.g. ARV therapy or infant formula, the fear of a hidden cost or lack of money for e.g., transportation or child care, may keep clients from accessing care.

### Time commitment

Attending truly comprehensive care can involve many appointments. While some countries have polyclinics where clients and their children receive both routine and specialized HIV treatment, care, and support, due to distance these clinics are not available to all HIV-infected clients. For those without access to a polyclinic, the logistics of getting oneself and one's children to numerous

appointments in numerous places can be daunting for anyone, especially a new mother.

### **Healthcare worker lack of knowledge about referral systems**

Busy healthcare workers may not have the time to ensure that a proper referral is made for a client. It is also possible that healthcare workers are not familiar with the availability of services provided by a community for their HIV-infected clients. Links and interrelationships between programmes need to be built and maintained even as programmes develop and change.



## **Trainer Instructions**

Slides 78-81

Now continue a discussion with participants about what can be done about the barriers to care outlined and identified above as well as those previously identified by participants. Ask participants if any of the strategies or incentives list below are practical in their healthcare settings.



## **Make These Points**

- Efforts in the region to combat stigma have broken down some of the most significant barriers to PLHIV receiving comprehensive care.
- Healthcare workers can improve their counselling skills to help their clients disclose their HIV status.
- Incentives can attract patients to stay in care.

## **Strategies to Overcome Barriers to Comprehensive HIV Care**

Strategies to attract and retain clients in care must be tailored to the individual client. Often, something such as a snack can keep a client coming to care. While for others, it is the welcoming environment created by motivated staff that keeps clients returning. Usually, it is a combination of many factors that retain clients. It is also important to work within a multi-disciplinary team (which includes a range of staff working in the clinic, such as: nurses, social workers, counsellors, outreach workers, and physicians) on difficult cases. Sharing expertise and strategies to retain clients is a collective responsibility.

### **Disclosure counselling**

Fear of stigma and discrimination prevents many from disclosing their status. Disclosure of one's HIV status can be extremely difficult, particularly disclosure to partner(s). Studies have shown that most HIV-infected women who disclose their status to their partners do not experience physical violence or abandonment. However, for women whose partners do react negatively, the consequences can be severe. Disclosure is an important first step in asking for care, treatment, and support from professional caregivers. It is also an important step towards getting partners and children tested and referred for the care and treatment that they need.

Healthcare workers can play a critical role in supporting a woman's decisions about disclosure. The subject of disclosure should begin during pre-test and continue during post-test counselling sessions. As disclosure is a process and not a one-time event, healthcare workers can continue the discussion with their clients as a part of ongoing comprehensive care. Healthcare workers bear the responsibility of keeping their clients results confidential. For more information about how to conduct a discussion about disclosure, see Appendix I, which also includes questions to assess for domestic violence.

### **Incentives to Overcome Barriers to Care**

Possible incentives to attract and retain clients include the following:

- Letter to the client's employer to notify them of the client's upcoming appointments and requesting that the client be excused for necessary medical evaluation. It is very important that the text of the letter is agreed upon with the client in advance.
- Assistance with child care arrangements.
- Transportation to appointments, either directly or by cash vouchers.
- Food at the clinic, either prepared or groceries to take home.
- Clothing
- Offer to accompany clients to first appointment with the healthcare team specializing in HIV care for a recently diagnosed infant/child.
- Assistance with obtaining social welfare benefits, signing up for programs or receiving government assistance.
- Prizes or small gifts for clients who follow-up consistently with appointments and referrals. These can be particularly effective around holidays.
- Tickets for a clinic raffle for clients who attend scheduled appointments. Award a small prize every month.

A warm, welcoming non-stigmatizing clinic environment where clients are not singled out as HIV-infected will promote client retention.



### **Trainer Instructions**

Slide 82

Introduce the next exercise which will be conducted as a role play.

<b>Exercise 4 — Retention Strategies (role play)</b>	
<b>Purpose</b>	<ul style="list-style-type: none"> <li>Practise supportive counselling and problem solving skills to help clients cope with social problems that may interfere with continuity of care.</li> </ul>
<b>Duration</b>	60 minutes
<b>Introduction</b>	<p>As healthcare workers working with HIV-infected clients, we are all familiar with the many social and economic problems that our clients experience. Perhaps, we are even overwhelmed by them. It is important to develop strategies not only to help our clients receive the services they need but to care for ourselves in the process.</p> <p>By the end of this exercise, participants will have practised and shared strategies that will help them support clients to more effectively manage the personal issues affecting their healthcare.</p>
<b>Activities</b>	<p><b>Part 1 – Trainer demonstration</b></p> <p>Working with a co-trainer, identified and prepared in advance, choose one of the role play scenarios below and demonstrate in front of participants how to counsel a client to stay in care and treatment. Counsellors should use the questions below the role play as a guide.</p> <p>Ask participants for their observations and opinions of what they observed.</p> <p><b>Part 2 – Small group role plays</b></p> <ol style="list-style-type: none"> <li>1. Arrange groups of 3 people and assign each one of the role play scenarios below.</li> <li>2. Ask one person from each group to play the role of “counsellor”, another participant should be the “client” and the third the “observer.”</li> <li>3. Remind participants that the goal is not to “fix” the client’s problem but to think about how they would forge a relationship with the client and develop a preliminary plan to address the important issues.</li> <li>4. Remind participants to address the family planning issues raised in the role play, consulting Appendix F as needed.</li> <li>5. When the role play is finished, the group should spend a few minutes reviewing the experience. The questions below can act as a guide: <ul style="list-style-type: none"> <li>o Was there anything important left out of the role play?</li> <li>o What was the most challenging part of this exercise?</li> </ul> </li> <li>6. Have the “observer” from each group present one strategy that was used to try and keep a client in care.</li> </ol>

<b>Exercise 4 — Retention Strategies (role play)</b>	
	<p>7. Depending upon the amount of time, ask a group(s) to enact one of the other role plays, ensuring that the group members change roles so that someone else gets to play “counsellor”, “client”, and “observer.”</p> <p><b>Part 3 - Large Group Discussion</b></p> <ul style="list-style-type: none"> <li>▪ Ask volunteers to present a personal strategy they used to keep calm and professional throughout the role play and at work when dealing with difficult clients. Write suggestions on a flipchart.</li> </ul>
<b>Debriefing</b>	Remind participants that a client’s personal and social issues can be overwhelming, a multi-disciplinary approach ensures the client has the best care available and that the burden of work is shared within a team of professionals. Once the social issues are managed, the client can then focus on her physical health.

#### **Exercise 4 — Retention Strategies (role play)**

##### **Role play scenario 1**

Joan and her 3 children are well known to the local MCH clinic staff. Joan was diagnosed with HIV during her first pregnancy at the age of 17. She was born and raised in the surrounding community and lately she has developed a reputation as a “trouble-maker.” Joan is infamous for loud dramatic fights, which have occasionally turned physical, with the father of her most recent child. Community members have occasionally intervened by calling the police but this has had little effect. While two of Joan’s children have tested negative for HIV infection, the status of the third child who is 18 months old is not known. In the past the clinic staff has even fought with Joan as she accused them of disclosing her HIV status to the father of one of her babies.

1. How are you going to keep Joan coming back to the clinic? What are the short term and long term strategies that you can use?
2. What is your plan for the rest of Joan’s family, especially her youngest child?
3. Who else can you turn to for help with Joan’s case? What organizations or programmes listed in the exercise on community resources could assist?
4. How do you assess for the potential for domestic violence in this case?
5. Assess the appropriateness of male involvement. Should Joan’s partner be involved? If so, what can you do to encourage his involvement?
6. What are the family planning issues raised in this role play? How will you advise her?
7. What other services does Joan require in order for her care to be truly comprehensive?

**Role play scenario 2**

You notice Matilde sitting in the corner of the MCH clinic quietly holding a young listless child. You saw Matilde once for an ANC visit where she tested HIV positive. She never returned for any routine ANC care and you assume she must have delivered at home. You think that there may have been a misunderstanding at the first visit due to a language barrier. You know that she has recently arrived from Haiti and works as a housecleaner in another part of town. She tells you that today she is here because her child is "sick."

1. What is your plan to support Matilde to stay in care?
2. What services does she need and what strategies will you use to ensure she receives them?
3. What incentives could you and others use to encourage Matilde and her child to return for continuing care?
4. How will you and others be able to manage the language barrier now and in the future?
5. What are your concerns for the child? Using what you learned about the signs and symptoms of HIV-infection in infants, what would you assess for at this visit?
6. Assess the appropriateness of male involvement. Should Matilde's partner be involved? If so, what can you do to encourage his involvement?
7. What are the family planning issues raised in this role play? How will you advise her?

**Role play scenario 3**

Sharon is a 25 year old HIV-infected client of yours whom you've known for 10 years. While endearing, she seems never to have grown-up. Sharon is the mother of 5 little girls who are all cared for by their grandmother. During her ANC and subsequent postpartum appointments, she complains constantly about having to come into the clinic, stating, "Why can't you visit me at home?" She has never held a job and describes herself as "having no focus." You have tried many times to get her to follow-up at the care and treatment clinic in the next town to no avail. Sharon often proclaims, "But you are my doctor why do I need to go anywhere else?" Her last postpartum CD4 count from one month ago was just above 200. Today Sharon says she is very upset about an incident with her boyfriend last night when he refused to wear a condom during sex. However, she refuses to be examined at this visit saying that she is in a hurry and has to meet a friend. Sharon's cell phone is going off constantly during your discussions with her.

1. What is your plan of care for Sharon today and in the short-term future?
2. How are you going to support Sharon to better adhere to her care plan?
3. Should other family members be involved? If so, how?
4. Does Sharon need other types of support and referrals?
5. Assess the appropriateness of male involvement. Should Sharon's partner be involved? If so, what can you do to encourage his involvement?
6. What are the family planning issues raised in this role play? How will you advise her?
7. How do you keep yourself from being frustrated with Sharon?
8. What strategies have you used to cope with frustrating clients?



## Trainer Instructions

Slides 83-84

Use the “Discussion questions” below as a guide to lead a discussion on the strategies used to ensure the success of a PMTCT programme.

### Discussion questions:

- Think of a successful healthcare program, why was it successful and how did it become successful?
- How could these strategies be applied to other clinics and programmes?
- What resources would be needed to accomplish the goal?



### For Inclusion in National Curriculum

- Insert a comprehensive care best practice example(s) from your country.

### Successful PMTCT Programmes

There are many examples of PMTCT programmes that are able to provide comprehensive care to their clients either directly or through linkages and retain clients in care. Below are two examples:

#### The Paediatric Case Management Meeting

A multidisciplinary case conference meeting is held every week following the paediatric HIV clinic day at the Princess Margaret Hospital in Nassau. Each case presentation begins with a brief medical update followed by a discussion of the strengths and weaknesses of each case with respect to attaining the goal of viral suppression. Barriers to care are then discussed among the team of social workers, psychiatric nurses, HIV nurses, HIV paediatricians, health educators, and laboratory staff. The care plan is action-oriented with a focus on problem-solving. Assignments and tasks are distributed among the team, e.g., if a lab result was not available, a member of the team from the laboratory will investigate the results. If a mother did not come for an appointment, a phone call is made the same day.

To follow, a member of the team may schedule additional calls or a home visit to explore the mother’s individual challenges. If a teenager’s compliance with her ARV medication comes into question, a member of the team whom the client trusts conducts an assessment and a plan is made for follow-up. Team members are also matched with clients based on rapport. Each member of the team has a manageable amount of follow-up work and is expected to report to the group as soon as possible with outcomes and decisions. An oral report is given and followed by a note to the medical file. A paediatric case coordinator ensures that follow-up plans are performed, delegated, or referred to the appropriate person on the team. The case conference is also a time for the group to share their

perspective on the client, which contributes to a whole picture of the child within the context of their family.

### **PLHIV Trained as Adherence Counsellors**

In Kingston Jamaica, the comprehensive HIV clinic provides adherence counselling training for select clients; the training includes information on ARV therapy, adherence counselling, and mentorship. These clients, who attend the comprehensive HIV clinic for their own health, play an active role as peer educators and counsellors. The peer adherence counsellors assist other clients to address barriers to care by helping with decision-making about how to take medications and sharing experiences.



### **Trainer Instructions**

Slides 85-92

Conclude this module by summarizing the key points listed below.

#### **Module Key Points**

- PMTCT healthcare workers play a vital role in ensuring that their clients with HIV receive the care, treatment, and support they need. When possible, care of an HIV-infected client should extend to all family members.
- Healthcare workers should ensure that mothers who are HIV-infected return for all postpartum appointments or are visited at home.
- It is important that healthcare workers recognize the signs and symptoms of HIV-related infections in infants and children so that they can make timely referrals for care and treatment.
- When male partners are involved in the care of their family, women are more likely to agree to PMTCT interventions. Partner support is also likely to be important in helping women adhere to ARV medications and attend continuing care. Involving men in the care of their families involves challenging beliefs about traditional roles.
- Linkages are formal networks between organizations or an agency and the community, facilitating the referral of the client and her family for services.
- Referrals are the guided movement of clients to obtain services based on the specific identified needs for continuity of care. The referral process involves the ongoing assessment of a client's needs, coupled with coordinated service delivery by a group of linked organizations.
- Referral networks take time and commitment to create and maintain. The first step in creating a network is to list all possible referral resources.

## **APPENDIX A Checklist for Postpartum Visit for HIV-infected Women and HIV-exposed Newborns**

When providing postpartum care to women infected with HIV, healthcare workers should follow their national guidelines. The following areas require special attention in the immediate post-delivery setting and ongoing postpartum visits:

### **Checklist of immediate post-delivery care**

#### **General care**

- Assess the amount of vaginal bleeding (use Standard Precautions).
- Dispose of blood-stained or blood-soaked linens or pads safely.

#### **Infant feeding before discharge from hospital or clinic**

If mother has not yet chosen a feeding option:

- Explain the risk of MTCT.
- Explain the advantages and disadvantages of the feeding options.
- Explore with the mother her home and family situation.
- Help the mother choose an appropriate option.
- Demonstrate how to practise the chosen feeding method.

For all mothers:

- Observe feeding technique before discharge and provide support (demonstration if needed) and assistance.

#### **Signs and symptoms of postpartum infection**

- Review the signs and symptoms of postpartum infection before she leaves the hospital or clinic, and provide information on where to seek treatment if necessary.
  - Burning with urination
  - Fever
  - Foul smelling lochia
  - Cough, sputum and shortness of breath
  - Redness, pain, pus or drainage from incision or episiotomy
  - Severe lower abdominal pain

#### **ARV drugs**

- Teach mother how to administer ARV prophylaxis to the infant.
- Ask mother to demonstrate to you how to administer ARV drug to infant.
- Review mother's medication list. Ensure that mother understands her own need for ARV prophylaxis, ARV therapy, and any other possible prophylactic medications e.g., cotrimoxazole.

### **Checklist for postpartum visits**

#### **Infant feeding assessment, support, and education**

If she is replacement feeding, check that she:

- Is using a suitable type of replacement milk.
- Is able to get new supplies of milk before she runs out.
- Is measuring the milk and other ingredients correctly.
- Is giving an appropriate volume and number of feeds. If not, recommend that she adjust the amount according to the baby's age.

## **APPENDIX A Checklist for Postpartum Visit for HIV-infected Women and HIV-exposed Newborns (Continued)**

- Is preparing the milk cleanly and safely.
- Is cup-feeding
- Is not breastfeeding.

If mother is breastfeeding:

- Check if she breastfeeds exclusively and gives no other milks or water to the baby.
- Check if she breastfeeds as often as the baby wants and for as long as the baby wants.
- Observe a breastfeed and check the mother's breasts.
- If the baby is approaching 6 months, discuss the possibility of stopping early.

### **ARV drugs**

- Ensure proper administration of and adherence to infant ARV prophylaxis schedule.
- Support and assess mother's adherence to ARV therapy, a continuing ARV prophylaxis regimen, or any prophylactic medications e.g., cotrimoxazole.
- Provide prescriptions of medications if necessary.

### **Health Education**

- Teach the mother about perineal and breast care.
- Ensure that the mother knows how and where to dispose of potentially infectious materials such as lochia-and blood-stained sanitary pads.
- Teach and refer for well-women and well child care.

### **Continuing care and treatment**

- Continue teaching about the importance of continuing care for an HIV-infected mother and her HIV-exposed infant.
- Ensure mother has and understands the schedule of postpartum visit(s) and any ongoing HIV care and treatment appointments. Involve other members of the family if possible.
- Briefly assess for any possible recent HIV-related infections and refer for treatment.
- Conduct or refer for nutritional counselling for mother and members of family.

### **Family planning counselling**

- Discuss family planning with the mother and her partner if available. For more information about how to conduct a family planning counselling session see Appendix F. The main family planning goals for the woman who is HIV-infected are:
  - Preventing unintended pregnancy
  - Spacing children appropriately, which can help reduce maternal and infant morbidity and mortality
  - Educating women and families about contraceptive choices for HIV-infected couples

## **APPENDIX B Infant/Young Child Follow-up Visits**

The following schedule is based on the Caribbean Guidelines for Care and Treatment of Persons with HIV. National guidelines may differ.

### **Prior to discharge from hospital**

- Infants should be seen by a paediatrician or the most senior available clinician prior to discharge
- Schedule follow-up appointment for infants
- Teach mothers to administer ARV prophylaxis
- Investigate and address issues that may prevent adherence to ARVs
- Infant feeding counselling and support, see “Infant feeding assessment, support, and education”, above. If mother is replacement feeding — provide supply of formula; make an appointment date with a nutritionist if needed

### **Follow-up in 1-2 weeks**

- Provide routine physical exam (the components of the physical exam are listed in the box entitled “Baseline and follow-up physical exams include:” at the end of this appendix)
- Assess and document growth and development, using anthropomorphic measurements; height, weight, and head circumference
- Check adherence to ARV prophylaxis
- Monitor side effects of ARV prophylaxis
- Infant feeding counselling and support, see “Infant feeding assessment, support, and education”, above. If mother is replacement feeding — provide supply of formula; make an appointment date with a nutritionist if needed
- Address concerns of parents
- Perform PCR testing according to national guidelines

### **Follow-up at 6 weeks of age**

- Provide routine physical exam
- Assess and document growth and development (For more information see Appendix C)
- Discontinue ARV prophylaxis according to national protocol
- Start cotrimoxazole prophylaxis, dose according to weight, and continue until the HIV status is confirmed negative
- Start iron and vitamin supplementation
- Draw blood samples for HIV DNA PCR
- Draw blood samples for other tests e.g. CBC with differential, TORCH screen, VDRL, and Hepatitis BsAg and HTLV-1 serology as appropriate
- Start vaccinations for pentavalent (DPT, Hib, and Hepatitis B (HBV)) and polio should. IPV is preferred but if not available OPV can be administered to asymptomatic infants
- Infant feeding counselling and support, see “Infant feeding assessment, support, and education”, above. If mother is replacement feeding — provide supply of formula; make an appointment date with a nutritionist if needed
- Treat any medical problems

## **APPENDIX B Infant/Young Child Follow-up Visits (continued)**

- Address concerns of parents
- Conduct any confirmatory PCR testing according to national guidelines

### **Follow-up beyond 2 months**

- Provide routine physical exam
- Assess and document growth and development
- Give second dose of vaccinations
- Continue cotrimoxazole prophylaxis
- Continue iron and vitamin supplements
- Infant feeding counselling and support, see “Infant feeding assessment, support, and education”, above. If mother is replacement feeding — provide supply of formula; make an appointment date with a nutritionist if needed
- Treat any medical problems
- Address concerns of parents

### **Follow-up beyond 4 months**

Ideally, HIV-exposed children should be followed by a multi-disciplinary team that includes a paediatrician, nurse, social worker, and nutritionist. The routine follow-up schedule is similar to that of children who are not exposed to HIV.

Subsequent to the 4 month visit, clients should be seen again at age 6 months, then at 3-month intervals or more frequently if indicated.

### **At each subsequent visit (6 months, and then every 3 months or more frequently if indicated)**

- Perform routine physical exam
- Assess and document growth and development
- Infant feeding counselling and support, see “Infant feeding assessment, support, and education”, above. If mother is replacement feeding — provide supply of formula; make an appointment date with a nutritionist if needed
- Teach about complementary feeding
- Ensure adequate vaccination coverage
- Continue cotrimoxazole prophylaxis
- Continue iron and vitamin supplementation
- Assess for evidence of HIV-related or opportunistic infections (OIs)
- Treat medical problems
- Address concerns of parent

#### **Baseline and follow-up physical exams include:**

- Weight, height, and head circumference (plotted on standardized growth chart)
- Assessment for thrush, adenopathy, and skin eruptions
- Examination of ear, nose, throat, chest, and abdomen for abnormalities
- Perform neurological exam
- Assess developmental milestones

More information about monitoring growth, nutrition, and development in HIV-exposed and infected infants and children can be found in Appendix C.

## **Appendix C – Monitoring Growth, Nutrition, and Development of HIV-exposed Infants and Children**

### **Role of the healthcare worker in growth, nutritional, and developmental monitoring**

- Weigh and measure child and plot results on a national growth curve and/or WHO Growth Curves.
- Measure head circumference for children 2 years and under.
- Provide health education on the importance of growth monitoring and good nutrition.
- Ask about the mother's resources and constraints.
  - "How does your family support itself?"
  - "Do you have enough money to buy food for your family?"
- Ask mother about her child's eating habits.
  - What did your child eat/drink today?
  - How about yesterday?
- Counsel and educate mother about the child's nutritional needs.
- If child is stunted or wasted, explore with the mother possible causes of growth failure. Discuss management or refer appropriately.
- Educate mother on hygienic food preparation.
- Discuss the child's developmental needs: enquire about age-appropriate play and specific development milestones
- If you suspect a problem, refer for developmental testing according to national policy and availability.

### **1. Growth monitoring**

Growth monitoring is regular growth surveillance. Growth surveillance is monitored by regular anthropometric monitoring. Anthropometric measures for children include the measurement of weight and height. Children under two years of age should also have their head circumference measured and monitored. Anthropometrics are interpreted by using age and gender specific growth standards. Growth monitoring standards include growth curves that have been developed nationally or globally. WHO has created comprehensive growth standards that are available at <http://www.who.int/childgrowth/en/>. It is important to train all HCWs working with children, particularly those who may be infected or exposed to HIV, about the proper use and interpretation of tools to measure growth.

### **Growth Indicators**

- Weight-for-age is a measure of weight according to age. This measure is mainly used during clinic visits, since it is a good way of assessing the nutritional evolution of a child over time.
- Weight-for-length/height is a measure of weight according to the length or height. This is a useful measure of acute malnutrition.
- Height-for-age is a measure of height according to age. This is useful for detecting chronic malnutrition and helps identify stunted children.
- Head circumference is the measured distance around the widest part of the skull. This is a useful measure of brain growth during the first 2 years.

## **Appendix C – Monitoring Growth, Nutrition, and Development of HIV-exposed Infants and Children (continued)**

### **Defining indicators of growth status**

#### **Underweight**

Weight-for-age is below the median minus 2 standard deviations or less than the 3rd percentile of the expected weight-for-age.

#### **Stunting**

Length/Height-for-age is below the median minus 2 standard deviations or less than the 3<sup>rd</sup> percentile of the expected length/height-for-age.

#### **Wasting**

Weight -for-length/height is below the median minus 2 standard deviations or less than the 3<sup>rd</sup> percentile of the expected weight for length/height.

#### **Severe wasting**

Weight-for-length/height is below the median minus 3 standard deviations

#### **Overweight**

Weight-for-length/height is above the median plus 2 standard deviations or greater than the 97th percentile of the expected weight-for-length/height.

### **2. Importance of nutritional assessment and support**

In infants and children with HIV infection, malnutrition further impairs immune function. Therefore, an early nutritional assessment should be a fundamental part of the care of infants and children who are HIV-exposed or HIV-infected. A nutritional assessment provides the opportunity to intervene and prevent growth failure and wasting, while maximizing infant and child growth and development.

- If the infant or child's HIV status is unknown, conducting a nutritional assessment is important as a diagnostic tool.
- HIV places increased metabolic demands upon a growing child. If a child is experiencing growth failure it is recommended that caloric intake be increased using locally available and affordable foods.
- ARV drugs may have side effects that affect food intake and nutrition.

### **3. Assessment of infant and child development**

Infants and children who are infected with HIV should have serial standardized assessments of their neurological and developmental status. The type of assessment performed will be determined by what scale or test is in use in country. Development can also be preliminarily assessed by healthcare workers using behavioural observation of the child and interaction with parents as well as asking about or observing developmental milestones. Developmental abnormalities are common and can appear as developmental delays as well as cognitive deficits, behavioural or psychiatric problems, or poor school performance in older children.

## Appendix C – Monitoring Growth, Nutrition, and Development of HIV-exposed Infants and Children (continued)

Selected developmental milestones by age

Age	Milestones and Assessments
Week 1	<ul style="list-style-type: none"> <li>• Baby responds to sound by blinking or crying</li> <li>• Fixates on human face</li> <li>• Follows with eyes</li> <li>• Responds to parents' voice</li> <li>• Moves all extremities</li> </ul>
1 month	<ul style="list-style-type: none"> <li>• Lifts head momentarily when prone</li> <li>• Can sleep 3-4 hours</li> <li>• When crying can be consoled by speak or being held</li> </ul>
2 months	<ul style="list-style-type: none"> <li>• Baby coos and vocalizes</li> <li>• Attentive to voice, visual stimuli</li> <li>• Smiles responsively</li> <li>• Lifts head, neck and upper chest with support on forearms</li> </ul>
4 months	<ul style="list-style-type: none"> <li>• Babbles, smiles, laughs, and squeals</li> <li>• Holds head upright</li> <li>• Rolls over</li> <li>• Opens hands</li> <li>• Grasps rattle</li> <li>• Self-comforts</li> </ul>
6 months	<ul style="list-style-type: none"> <li>• Says "dada" or "baba"</li> <li>• No head lag when pulling to sit</li> <li>• Bears weight when placed</li> <li>• Starts to self-feed</li> <li>• Interest in toys</li> </ul>
9 months	<ul style="list-style-type: none"> <li>• Responds to own name</li> <li>• Understands a few words</li> <li>• Creeps and crawls</li> <li>• Pokes with index finger</li> <li>• Plays peek-a-boo</li> <li>• May show anxiety with strangers</li> </ul>
1 year	<ul style="list-style-type: none"> <li>• Pulls to stand</li> <li>• May take steps alone</li> <li>• Pincer grasp</li> <li>• Says 1-3 words</li> <li>• Waves "bye-bye"</li> <li>• Imitates vocalization</li> </ul>
15 months	<ul style="list-style-type: none"> <li>• Says 3-10 words</li> <li>• Points to body parts</li> <li>• Understands simple commands</li> <li>• Feeds self with fingers</li> <li>• Listens to story</li> <li>• Communicates wants by pointing or grunting</li> </ul>
18 months	<ul style="list-style-type: none"> <li>• Walks quickly or runs stiffly</li> <li>• Throws ball</li> <li>• Says 15-20 words</li> <li>• Talks using 2-word phrases</li> <li>• Uses spoon and cup</li> <li>• Looks at pictures and names objects</li> <li>• Shows affection</li> <li>• Follows simple direction</li> </ul>

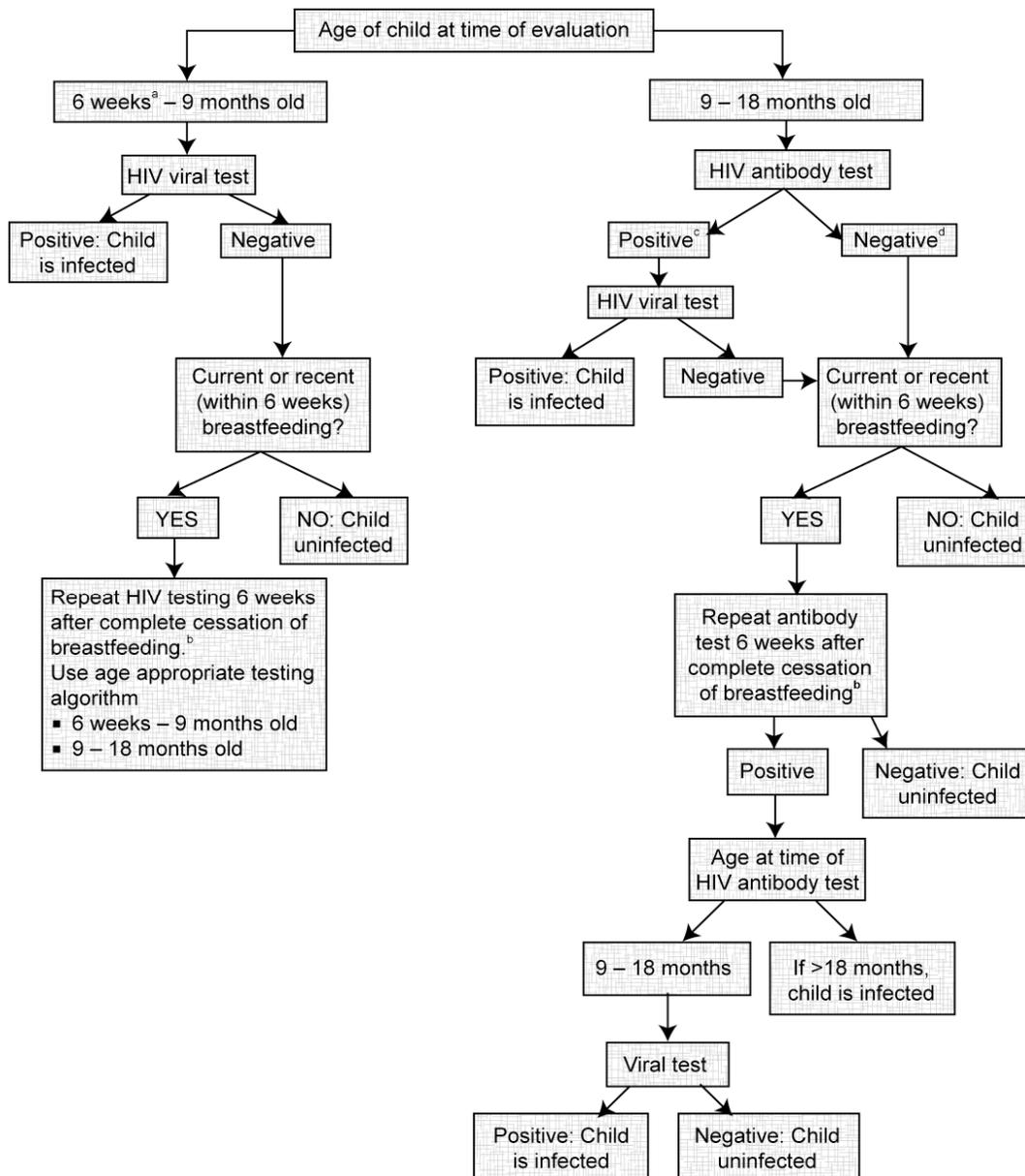
## Appendix C – Monitoring Growth, Nutrition, and Development of HIV-exposed Infants and Children (continued)

Age	Milestones and Assessments
2 years	<ul style="list-style-type: none"> <li>• Goes up and down stairs</li> <li>• Kicks ball</li> <li>• Says at least 20 words</li> <li>• Makes horizontal and circular strokes with crayon</li> <li>• Imitates adults</li> </ul>
3 years	<ul style="list-style-type: none"> <li>• Jumps in place</li> <li>• Knows name, age, gender</li> <li>• Has self-care skills</li> <li>• Shows early imaginative behaviour</li> </ul>
4 years	<ul style="list-style-type: none"> <li>• Sings songs</li> <li>• Draws person with 3 parts</li> <li>• Talks about daily activities and experiences</li> <li>• Hops and jumps on one foot</li> </ul>
5 years	<ul style="list-style-type: none"> <li>• Dresses self without help</li> <li>• Can count on fingers</li> <li>• Recognizes letters and can draw some</li> <li>• Plays make believe</li> </ul>
6 – 7 years	<p>Assess school performance</p> <ul style="list-style-type: none"> <li>• When he/she plays with other children, can they keep up?</li> <li>• Is he/she able to follow rules at school?</li> <li>• What does teacher say about progress?</li> <li>• Any trouble completing homework?</li> </ul>
8 years	<p>Assess school performance</p> <ul style="list-style-type: none"> <li>• Is he/she reading and doing maths at grade level?</li> <li>• Is he/she proud of achievements?</li> <li>• Does child talk about what happens in school?</li> </ul>
9-10 years	<p>Assess school performance and social development</p> <ul style="list-style-type: none"> <li>• Does child have interests or talents that they would like to develop?</li> <li>• Reading and doing maths at grade level?</li> <li>• Where and how is homework done?</li> <li>• Is child comfortable when healthcare worker speaks to them alone?</li> </ul>
Early adolescence	<p>Assess social and emotional development</p> <ul style="list-style-type: none"> <li>• What do you do for fun?</li> <li>• Who is your best friend?</li> <li>• What do you do when you are feeling down or depressed?</li> </ul> <p>Assess relationships and sexuality</p> <ul style="list-style-type: none"> <li>• Have you started dating anyone?</li> <li>• What questions do you have about sex?</li> <li>• Have you ever had sex?</li> </ul> <p>Assess family functioning</p> <ul style="list-style-type: none"> <li>• How do you get along with your family?</li> <li>• What would you change about your family if you could</li> </ul>

Adapted from: Adapted from: World Health Organization. Child Growth Standards 2006. Available at: <http://www.who.int/hiv/pub/guidelines/en/> and National Center for Education in Maternal and Child Health. (2002) *Bright Futures, Guidelines for Health Supervision of Infants, Children, and Adolescents (2<sup>nd</sup> ed. rev.) Pocket Guide*, available at: <http://www.brightfutures.org/pocket/index.html>

## APPENDIX D Draft WHO Recommendations on Diagnosis of HIV Infection in Infants and Young Children

Diagnosis of HIV infection in children from 6-8 weeks up to 18 months of age. Please note, recommendations below may differ from national guidelines or policies. HCWs should follow their national recommendations.



<sup>a</sup> A positive viral test at any age indicates infection: viral testing is recommended anytime after 6-8 weeks of age to maximize sensitivity.

<sup>b</sup> If a child has HIV-related symptoms, regardless of prior test results, repeat test even if child has not stopped breastfeeding.

<sup>c</sup> If a viral test is not available, repeat antibody testing at 18 months of age. If child has symptoms, evaluate for possible presumptive diagnosis.

<sup>d</sup> A negative antibody test for a child 9 to 18 months of age who is not breastfeeding, can be used to exclude HIV infection.

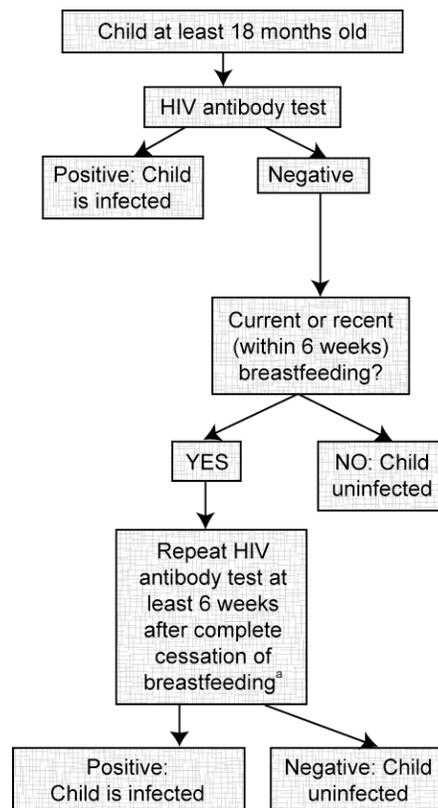
## APPENDIX D Draft WHO Recommendations on Diagnosis of HIV Infection in Infants and Young Children (continued)

### Key considerations for HIV testing in infants and young children

There are three key considerations for HIV testing in infants and young children:

- **Age of the child.** The presence of maternal antibodies in HIV-exposed children under the age of 9-18 months affects the utility of antibody testing for children under this age. Although, most children clear maternal antibodies by 12 months of age, an HIV-positive test in the child age 9-18 months may be due to the presence of maternal antibody rather than infection in the child. The test should be repeated at 18 months or at least 6 weeks after complete cessation of breastfeeding (whichever comes later).
- **Whether or not the child is breastfeeding.** Infants and children may become HIV infected through breastfeeding. A child should be tested for HIV at least 6 weeks after complete cessation of breastfeeding.
- **Availability of viral tests.** Because viral tests detect the actual HIV *virus* (rather than the antibody to the virus), they can be used from 6-8 weeks of age. Once a child is 9 months, the antibody test can be used to rule out HIV infection and determine who needs follow-up viral testing, as this can be more cost effective. The infant who tests HIV-negative by PCR, but is exposed to possible infection through breastfeeding, should be re-tested at least 6 weeks after complete cessation of breastfeeding.

### Diagnosis of HIV infection in children 18 months of age and older



<sup>a</sup> If a child has HIV-related symptoms, regardless of prior test results, repeat test even if child has not stopped breastfeeding.

## **APPENDIX E WHO Clinical Staging and Criteria for Presumptive Diagnosis of HIV Infection in Infants and Children**

*WHO clinical staging system of HIV infants and children less than 15 years of age with confirmed HIV infection*

### **Clinical Stage 1**

- Asymptomatic
- Persistent generalized lymphadenopathy

### **Clinical Stage 2**

- Unexplained persistent hepatosplenomegaly
- Papular pruritic eruptions
- Extensive wart virus infection
- Extensive molluscum contagiosum
- Recurrent oral ulcerations
- Unexplained persistent parotid enlargement
- Lineal gingival erythema
- Herpes zoster
- Recurrent or chronic upper respiratory tract infections (otitis media, otorrhoea, sinusitis, tonsillitis)
- Fungal nail infections

### **Clinical Stage 3**

- Unexplained moderate malnutrition not adequately responding to standard therapy
- Unexplained persistent diarrhoea (14 days or more)
- Unexplained persistent fever (above 37.5° intermittent or constant, for longer than one month)
- Persistent oral candidiasis (after first 6 weeks of life)
- Oral hairy leukoplakia
- Acute necrotizing ulcerative gingivitis or periodontitis
- Lymph node tuberculosis
- Pulmonary tuberculosis
- Severe recurrent bacterial pneumonia
- Symptomatic lymphoid interstitial pneumonitis
- Chronic HIV-associated lung disease including bronchiectasis
- Unexplained anaemia (<8 g/dl), neutropaenia (<0.5 x 10<sup>9</sup>/L<sup>3</sup>) or chronic thrombocytopaenia (<50 x 10<sup>9</sup>/L<sup>3</sup>)

## **APPENDIX E WHO Clinical Staging and Presumptive Diagnosis of HIV Infection in for Infants and Children (continued)**

*WHO clinical staging system of HIV infants and children < 15 years of age with confirmed HIV infection*

### **Clinical Stage 4<sup>1,2</sup>**

- Unexplained severe wasting, stunting or severe malnutrition not responding to standard therapy
- Pneumocystis pneumonia
- Recurrent severe bacterial infections (e.g., empyema, pyomyositis, bone or joint infection, meningitis but excluding pneumonia)
- Chronic herpes simplex infection (orolabial or cutaneous of more one month's duration or visceral at any site)
- Extrapulmonary tuberculosis
- Kaposi's sarcoma
- Oesophageal candidiasis (or candida of trachea, bronchi or lungs)
- Central nervous system toxoplasmosis (after the neonatal period)
- HIV encephalopathy
- Cytomegalovirus (CMV) infection: retinitis or CMV infection affecting another organ, with onset at age over 1 month
- Extrapulmonary cryptococcosis (including meningitis)
- Disseminated endemic mycosis (extrapulmonary histoplasmosis, coccidiomycosis)
- Chronic cryptosporidiosis (with diarrhoea)
- Chronic isosporiasis
- Disseminated non-tuberculous mycobacteria infection
- Cerebral or B non-Hodgkin lymphoma
- Progressive multifocal leukoencephalopathy
- HIV-associated nephropathy or cardiomyopathy

<sup>1</sup> Unexplained refers to where the condition is not explained by other causes.

<sup>2</sup> Some additional specific conditions can be included in regional classifications (e.g., Penicilliosis in Asia, HIV associated rectovaginal fistula in Africa)

## **APPENDIX E WHO Clinical Staging and Presumptive Diagnosis of HIV Infection in for Infants and Children (continued)**

### **Presumptive Diagnosis of HIV Infection in Infants and Children**

If an infant or child less than 18 months old, has symptoms that are suggestive of HIV infection and there is no virologic testing available, it is possible to make a *presumptive diagnosis*. WHO has developed criteria to help healthcare workers manage potentially HIV-infected children. A presumptive diagnosis should be followed by efforts to confirm the HIV diagnosis using the best available tests for age.

Presumptive diagnosis of a severe HIV infection should be made if the child has/is:

- Confirmed positive HIV antibody test<sup>a</sup>
- and**
- Diagnosis of any AIDS-indicator condition(s)<sup>b</sup>
- or**
- Symptomatic with two or more of the following:
  - Oral thrush<sup>c</sup>
  - Severe pneumonia<sup>c</sup>
  - Severe sepsis<sup>c</sup>

Other factors that support the diagnosis of HIV disease in an HIV-seropositive infant include:

- Recent HIV-related maternal death or advanced AIDS in the mother
- If available, a CD4% less than 20%

An HIV diagnosis in children older than 18 months should not be made on the basis of symptoms. In children older than 18 months, symptoms suggestive of HIV infection are an indicator of an urgent need to conduct antibody testing according to national guidelines.

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<sup>a</sup> While HIV antibody tests are difficult to interpret for children under the age of 18 months, when accompanied by these other symptoms, the antibody test can be used to form the presumptive diagnosis of HIV.

<sup>b</sup> AIDS indicator conditions include some but not all HIV paediatric clinical stage 4.

<sup>c</sup> As defined by the Integrated Management of Childhood Illness (IMCI)

Source: WHO. Antiretroviral treatment of HIV infection in infants and children: Toward universal access recommendations for a public health approach 2006 version, Available at: <http://www.who.int/hiv/pub/guidelines/en/>

## **APPENDIX F Family Planning in the Context of HIV Infection**

### **Guidance on the Family Planning Counselling Session for HIV-infected Clients**

#### **Healthcare workers counselling about family planning should:**

- Respect all patients' rights to privacy and confidentiality.
- Provide unbiased correct information.
- Ensure that all women, regardless of HIV status, are knowledgeable about and free to make informed choices about pregnancy and contraception.
- Be sensitive to a couple's unique family planning needs and circumstances and tailor their counselling accordingly.
- Support patients' family planning decisions, even if they do not agree.
- Seek additional sources for training and information about family planning.

#### **Undertake initial assessment<sup>1</sup>**

- Are you pregnant? Do you want to be pregnant?
- What family planning method are you using?
- Are you happy with this method?
- What, if any problems have you experienced?
- How is your general health? What problems are you experiencing? (Specifically ask about history of and assess for deep vein thrombosis and any other medical condition that could affect the choice of contraceptive method.)
- Are you familiar with condoms? What access do you have to condoms?
- What questions do you have about family planning?

Note to healthcare workers: Review advantages and disadvantages of the available contraceptive choices. Take time to note which methods protect against STIs and HIV and which do not.

#### **Discuss prevention for positives**

- Has your partner been tested for HIV? If no, what is your plan to discuss HIV testing with him? The only way to know if your partner(s) or children are infected with HIV is for them to test for HIV.
- How often do you use condoms with your partner(s)?
- Condoms are important as dual protection—to prevent pregnancy and reduce the risk of acquiring an STI.
- Condoms should always be used even if both partners are infected with HIV to avoid spreading resistant strains of HIV.
- How many other children do you have?
- Have all of your other children been tested for HIV?

<sup>1</sup> Although the assumption is that the client is female, this guidance can be adapted for use with male clients. Ideally all clients are accompanied by their partner.

## **APPENDIX F    Family Planning in the Context of HIV Infection (continued)**

### **Support the client to select a contraceptive method**

- What suits you best for both family planning and STI/HIV protection?
- Will your sex partner(s) agree to use this method?
- What if you can't stick to your first choice?
- What will you say to your partner(s) if they refuse?

### **Discuss HIV and pregnancy**

- Pregnancy does not accelerate HIV progression but, overall, HIV-infected pregnant women have poorer outcomes than uninfected women.
- A mother with HIV can pass the virus to her baby during pregnancy, labour and delivery and breastfeeding. If you are pregnant or become pregnant, it is important that you attend antenatal care, take advantage of available PMTCT interventions and get care and treatment for your HIV infection.
- Before deciding to have a (another) baby, a pregnant woman may want to consider the realities of caring for and raising a child, particularly if the child is unwell or even HIV-infected.

### **Support the client to select a contraceptive method**

- Most methods of contraception are safe for use by women with HIV.
- **Condoms** are important as dual protection—to prevent pregnancy, most STIs and further transmission of HIV. HIV infected women need continuing protection against STIs. Condoms also protect positive partners from spreading potentially-resistant strains of HIV.
- **Hormonal contraceptives** combined oral contraceptive pills and injectable methods (such as Depo-Provera/DMPA) are highly effective birth control methods, but:
  - Healthcare workers prescribing oral contraceptive pills for their HIV-infected patients on ARV therapy should counsel women about possible interactions between hormonal contraceptives and certain ARV drugs. Clients should understand that the clinical significance of these interactions is unclear but that using a back-up method like a condom is recommended to avoid unintended pregnancy.
  - Women taking rifampicin for tuberculosis usually need to use a back-up method of contraception like condoms while taking rifampicin, as rifampicin can lower the efficacy of some hormonal contraceptives (pills, monthly injectables or implants).
- **IUDs** can be used successfully in HIV-infected women on ARV therapy and in asymptomatic or mildly symptomatic women. IUDs are usually not recommended for women with advanced HIV who are not on ARV therapy.
- **Spermicides, or diaphragm with spermicides** should not be used by HIV-infected women due to enhanced risk of HIV transmission.
- **Fertility awareness-based methods** are difficult and unreliable in women with AIDS or on ARV therapy—due to changes in menstrual cycle and higher body temperatures.

## APPENDIX F Family Planning in the Context of HIV Infection (continued)

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- **Lactational amenorrhea method (LAM)** is a temporary contraceptive method that should only be used by women who (i) are less than 6 months postpartum, (ii) are exclusively breastfeeding, and (iii) have not resumed menstruating. Women who meet all three of these criteria have only a 1% to 2% chance of getting pregnant. As this method is temporary, every effort should be made to get women who desire family planning, on another method as soon as possible.
- **Sterilization** is a permanent method of birth control and an excellent method for women who do not desire any more children. There is no medical reason to deny sterilization to women with HIV infection.

### Discuss HIV and Fertility

- HIV may reduce fertility by as much as 40% but ARV therapy increases fertility. Women on ARV therapy should be made aware of the possibility of their fertility returning. Emphasize that family planning can reduce unintended pregnancy.
- HIV-infected men are more likely to have low sperm count and low sperm quality than HIV negative men.

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Adapted from:

WHO 2006. *Decision-Making Tool for Family Planning Patients and Providers*. Available at [http://www.who.int/reproductive-health/family\\_planning/counselling.html](http://www.who.int/reproductive-health/family_planning/counselling.html)

Family Health International 2006. *Contraception for Women and Couples with HIV*. Available at <http://www.fhi.org/en/RH/Training/trainmat/ARVmodule.htm>

## APPENDIX G Sample Client Referral Form

<b>SAMPLE CLIENT REFERRAL FORM</b>	
<ul style="list-style-type: none"> <li>Referring organizations: please fill out Part A and ask client to take it to the receiving organization.</li> <li>Please fill out one form per service needed.</li> <li>Receiving organization: please fill out Part B and either return it directly to the referring organization or ask the client to return it to the referring organization at next visit. Include relevant copies of any reports that would help deliver comprehensive care to this client</li> </ul>	
<b>Part A: Referral Slip: To be filled out by the organization making the referral (referring organization)</b>	
<b>Date:</b>	
<b>Client Name:</b>	<b>Date of Birth:</b>
<b>Referred from:</b>	
Person:	Organization:
Address/phone number:	
<b>Referred to:</b>	
Person:	Organization:
Address/phone number:	
<b>Services Needed/notes (please use codes below):</b>	

**APPENDIX G Sample Client Referral Form (continued)**

<b>Part B: Services Provided: To be filled out by the organization fulfilling the referral</b>				
<b>Date:</b>				
<b>Services Provided:</b>				
<input type="checkbox"/> Services provided (please use codes below): _____				
<input type="checkbox"/> Services completed as requested ____ Yes ____ No				
<input type="checkbox"/> Follow-up needed: services: _____ Date for follow-up: _____				
<b>Additional Comments:</b>				
For services use the following codes:				
1. Adherence counselling	8. Food support	15. Nutrition counselling	22. Post-test clubs	29. Support for domestic violence victims
2. ARV therapy	9. HIV counselling and testing	16. OB/GYN services	23. Prevention services	30. Treatment support
3. Child care	10. Home-based care	17. Peer counselling	24. Psychosocial support	31. TB services
4. Clinical care	11. Legal support	18. PEP services	25. Social services	32. Youth support groups
5. Education/schooling	12. Material support	19. Pharmacy	26. Spiritual support	33. Other_____
6. Family planning	13. Mental health services	20. PLHA support	27. STI services	
7. Financial support	14. Microfinance	21. PMTCT services	28. Substance abuse management	

Adapted from: Family Health International, (2005) Tools for Establishing Referral Networks for Comprehensive HIV Care in Low-Resource Settings

## APPENDIX H Sample Client Referral Tracking Form

*SAMPLE* Client Referral Tracking Form (to remain in client file)

Client name: \_\_\_\_\_ Registration Number: \_\_\_\_\_

Referral Information				Follow-up information			
Date:	Referred to (organization name):	Services needed: (use codes below)	Information entered into referral register: (check if yes)	Date services received (if services are continuing, please provide details)	Were client needs met? (yes/no)	Follow-up required: (yes/no: if yes, provide details)	Information entered into referral register: (check if yes)

For services use the following code numbers:

1. Adherence counselling	8. Food support	14. Microfinance	21. PMTCT services	28. Substance abuse management
2. Antiretroviral therapy	9. HIV counselling and testing	15. Nutrition counselling	22. Post-test clubs	29. Support for domestic violence victims
3. Child care	10. Home-based care	16. OB/GYN services	23. Prevention services	30. Treatment support
4. Clinical care	11. Legal support	17. Peer counselling	24. Psychosocial support	31. TB services
5. Education/schooling	12. Material support	18. PEP services	25. Social services	32. Youth support groups
6. Family planning	13. Mental health services	19. Pharmacy	26. Spiritual support	33. Other _____
7. Financial support		20. PLHIV support	27. STI services	

## APPENDIX I Sample Disclosure Counselling Script

Purpose of Question	Example of Question/statement
Explore client's feelings about telling partner(s)	<ul style="list-style-type: none"> <li>• <i>"Have you thought about telling your partner(s) about your HIV status?"</i></li> <li>• <i>"What are your feelings about talking to your partner(s) about your HIV status?"</i></li> <li>• <i>"What specific concerns to you have?"</i></li> <li>• <i>"Do you feel that you would be harmed, emotionally or physically, if you told your partner?"</i></li> </ul> <p>If there is a risk of domestic violence, ask questions below.*</p>
Remind client that their status does not indicate partner's HIV status	Remember your status is not an indicator of your partner's HIV status. Your partner must be tested in order to know their HIV status
Identify partner(s) who need to be informed	<ul style="list-style-type: none"> <li>• <i>"Whom do you believe may need to know your result?"</i></li> </ul> <p>This is your own personal decision. Right now only you and I know your HIV status, right now you have full control over who will find out and when.</p>
Discuss possible approaches to disclosing HIV status	<ul style="list-style-type: none"> <li>• <i>"When should you tell them?"</i></li> </ul> <p>It is important to tell when you are ready. In most situations, you can take your time to consider whom to tell and how to tell them.</p> <ul style="list-style-type: none"> <li>• <i>"Where is the best place to have this conversation?"</i></li> </ul> <p>Pick a private and safe place to tell the person, at a time when the person is relaxed.</p> <ul style="list-style-type: none"> <li>• <i>"What do you want to tell them about your HIV infection?"</i></li> </ul> <p>Learn about HIV so that you can answer their questions. Be prepared to discuss how HIV is NOT transmitted.</p> <ul style="list-style-type: none"> <li>• <i>"What do you want to tell them if they may be infected?"</i></li> <li>• <i>"What programmes and services are available to them?"</i></li> </ul> <p>Be ready to discuss why you think its important that they test</p>

## APPENDIX I Sample Disclosure Counselling Script (continued)

Purpose of Question	Example of Question/statement
Discuss expectations	<ul style="list-style-type: none"> <li>• <i>“What are you expecting from your partner or family?”</i></li> <li>• <i>“What is the worse consequence that you can imagine?”</i></li> </ul>
*Assess risk of domestic violence	<p>As healthcare workers we know that violence affects women’s health. Because of the widespread problem of family violence, we routinely ask everyone these questions:</p> <ul style="list-style-type: none"> <li>• <i>“Will you still be safe if you tell your partner your status?”</i></li> <li>• <i>“Since you’ve been pregnant, have you been hit, slapped, kicked or otherwise physically hurt by an intimate partner?”</i></li> <li>• <i>“Have you ever been afraid of a current or former partner?”</i></li> <li>• <i>“Prior to your pregnancy, was your partner hurting you or making you afraid?”</i></li> </ul> <p>Assess safety:</p> <ul style="list-style-type: none"> <li>• <i>“Are you afraid to go home?”</i></li> <li>• <i>“Can you stay with family or friends?”</i></li> <li>• <i>“Do you need access to a shelter?”</i></li> </ul> <p>Safety planning (if going home)</p> <ul style="list-style-type: none"> <li>• <i>Have someone she can call in an emergency</i></li> <li>• <i>Take the children with her</i></li> <li>• <i>Store the following in a safe place outside the home:</i> <ul style="list-style-type: none"> <li>○ <i>Identification for herself and children</i></li> <li>○ <i>Cash, clothes, set of keys</i></li> <li>○ <i>Copies of important documents</i></li> </ul> </li> </ul> <p>Make referrals</p> <ul style="list-style-type: none"> <li>• <i>Abuse of any form is unacceptable and is not tolerated under the laws of... If you fear abuse consider talking to_____ Shall I call this person for you right now?</i></li> </ul>
Discuss strategies to handle partner or family reaction	<p>Accept their reaction. You cannot control the fears or feelings or others.</p> <p>Stay calm, even if the person gets emotional. Try to address their concerns. If this is not effective, seek additional help from an HIV counsellor.</p> <p>Be patient, it may take time for those you tell to process the information.</p>

## APPENDIX I      Sample Disclosure Counselling Script (continued)

Purpose of Question	Example of Question/statement
Support client to refer partner(s) for testing	<ul style="list-style-type: none"> <li>• <i>“Are there particular partners you are worried about?”</i></li> <li>• <i>“Tell me your feelings about asking your partner to be tested.”</i></li> <li>• <i>“How would you and your partner handle it if he were HIV-negative?”</i></li> <li>• <i>“How would you handle it if he were HIV positive?”</i></li> </ul>
Practise	<ul style="list-style-type: none"> <li>• <i>“Let’s imagine that I am your partner. Tell me about your results and I will respond. It is good to practise this conversation.”</i></li> </ul>
Provide support	<ul style="list-style-type: none"> <li>• <i>“We have talked about a lot today. It is a challenge to deal with being HIV infected. With time and support, you will adjust and be able to live “positively.””</i></li> </ul>

Adapted from:

WHO/CDC 2006. Testing and Counselling for Prevention of Mother-to-Child Transmission of HIV (TC for PMTCT). Available at: <http://www.womenchildrenhiv.org/wchiv?page=vc-10-00>

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