PMTCT

HIV Care & Treatment

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

Adaptation Guide

October 2007

CHART

CARIBBEAN HIV/AIDS REGIONAL TRAINING NETWORK

Acknowledgments
The development of the *Continuing Care for Mothers, Children, and Families Following Prevention of Mother-to-Child Transmission of HIV (PMTCT) Programmes* Module is the result of a collaborative effort among many individuals whose dedication and hard work is gratefully acknowledged. The Module was developed for the Caribbean HIV/AIDS Regional Training Network (CHART) by the François-Xavier Bagnoud (FXB) Center at the University of Medicine and Dentistry of New Jersey (UMDNJ) in collaboration with a Caribbean Curriculum Review Committee and the University of Washington's International Training and Education Center on HIV (I-TECH). The Module was developed with funding from the U.S. Agency for International Development (USAID) through cooperative agreement (532-G-00-05-00004-00) and the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA). Its contents are solely the responsibility of the authors and do not necessarily represent the views of USAID or HRSA.

The Caribbean Curriculum Review Committee provided overall direction for the project as well an invaluable Caribbean perspective. Members included Nicholas Adomokah, Chris Behrens, Celia Christie-Samuels, Shirley Curtis, Kevin Harvey, Sheena Jacob, Marva Jervis, and Julianne Steel-Duncan. Our thanks to those who opened their doors for site visits during the development of the original Module: Alison Levarity of the Coconut Grove Clinic, Pervical McNeil of the Princess Margaret Hospital, and Celia Christie-Samuels of the Victoria Jubilee Hospital in Kingston. Our gratitude also goes to all the trainers and participants who took part in the pilot test of the training materials, coordinated by Bernadette Saunders and the staff of CHART-Bahamas in March 2007. The FXB Center team included Rebecca S. Fry, Virginia Allread, Gisele Pemberton, Magaly Garcia, Karen Forgash, and Deborah Hunte.

All inquires or questions on adapting the Module should be emailed to Rebecca S. Fry MSN, Advanced Practice Nurse/Global Programs at the FXB Center, fryre@umdnj.edu.

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

This Adaptation Guide was developed for the group or individual tasked with adapting the generic Caribbean materials for implementation in a specific setting or country.

Adaptation Guide

This Adaptation Guide provides guidance to the group or individual tasked with adapting the *Continuing Care for Mothers, Children, and Families Following Prevention of Mother-to-Child Transmission of HIV Programmes* Module (the Module). The Module is designed as a stand-alone training with two days of didactic training followed by one day devoted to a field visit (for more information on the field visit, see the Field Visit Guide).

The Module was written as a generic document — developed for use in any of the countries of the Caribbean. This Guide provides guidance on how to adapt each of the components of the Module (i.e., Trainer and Participant Manuals, PowerPoint Slides and Field Visit Guide) for a specific setting or country. It is organized into 3 sections.

- The Adaptation Process
- Suggested Timeline for Adapting and Piloting the Module
- Adaptation Table

The Adaptation Process

Introduction to the Adaptation Process

"Adaptation" as used in this Guide refers to the process of amending the content of a document so that it is consistent with national or local policies and guidelines; supports national goals; reflects the structure of the national health system; reflects local epidemiology, culture, practices, language; and meets the learning needs of the reader or training participant. The *Continuing Care for Mothers, Children, and Families Following Prevention of Mother-to-Child Transmission of HIV Programmes* is a generic training module designed for the Caribbean, but to be adapted by the Caribbean countries in which it will be used.

Adapting Content in the Module

Review the entire Module to identify all potential areas for adaptation. There are symbols or icons (see below) to guide the adaptation process by indicating where country-specific content should be added.

For Inclusion in National Curriculum

- Insert national schedule of postpartum visits.

The Adaptation Table at the end of this guide outlines additional areas for adaptation.

General adaptation tips

Wording throughout the Module should:

- Be easily understood and reflect general levels of HIV and PMTCT knowledge.
- Reflect local guidelines and processes, e.g., if DNA-PCR (viral) testing is not widely available, language should focus on the role of HIV antibody testing in detecting HIV in children.
- Reflect local terminology e.g., if the term maternal child health (MCH) is not used, replace it with the term used nationally to describe the system of healthcare for women and children.
- Support national priorities for PMTCT and HIV care and treatment programmes e.g., if the goal of the national PMTCT programme is to have fewer women returning to PMTCT programmes in a subsequent pregnancy, the content on family planning in the appendix can be used to expand this material.

Even though the Module is based on the *Caribbean Guidelines for Care and Treatment of Persons Living with HIV/AI*DS 2006, the Module is designed to be adapted so that it reflects each country's own guidelines and policies. Where available, the following national policies should be used to support the adaptation process:

- National PMTCT and HIV care and treatment guidelines
- Guidelines on postpartum care (for both HIV-infected and uninfected women)
- HIV testing algorithms and policies for HIV-exposed children
- Guidelines on care and treatment of HIV-infected adults and children
- National and/or local referral processes and forms
- Relevant national policies, strategies, and curricula

One of the most important areas to emphasize in a country adaptation is the interconnection and relationship among all of the programmes that care for HIV-infected clients. An understanding of how these programmes overlap, communicate, and refer to one another will support best practices in comprehensive care delivery. Specifically, the Module should be adapted to reflect the linkages or integration among the following national and/or local programmes:

- PMTCT
- Postpartum care
- HIV care and treatment for adults
- HIV care and treatment for HIV-infected infants and children
- Maternal and child health clinics or programmes that follow HIV-exposed infants and children

- Social welfare agencies and community-based organizations working with PLHIV
- General primary care and community health systems
- Tuberculosis treatment
- Mental health services and treatment

Using Content from the Module

Exercises and content can be pulled from this Module and added to an existing national PMTCT or HIV care and treatment curriculum or refresher course. For example, if the current PMTCT curriculum is being updated, consider incorporating an exercise or specific content from the Module into the updated PMTCT curriculum.

Using the Module as a Refresher Course

Refresher courses are important for keeping healthcare staff knowledge current and for addressing skills development in PMTCT. Refresher courses are offered within weeks, months, or a year after the original PMTCT training. As an example, the Bahamas has adapted the Module and will use it as a refresher course for participants about one month after participation in the national PMTCT course.

Responsibility for the Adaptation Process

As this Module is not lengthy, its adaptation would typically require a sub-group of individuals from an existing national TWG, or a group appointed by the entity responsible for overseeing training nationally or locally (Ministry of Health, an educational institution, or another body). Recommended membership for this sub-group includes representation from a broad spectrum of comprehensive care services, including HIV care and treatment, paediatrics, maternal child health, social welfare agencies, mental health, and PMTCT.

Four Phases of the Adaptation Process

A suggested approach to adapting the Module is described here as a 4-step process that typically takes 4 to 5 months, but can take less time if the process is prioritized. During the **first phase** of the adaptation, work focuses solely on the Trainer Manual of the Module. Adaptation of the Participant Manual, PowerPoint Slides and Field Visit Guide follow approval of the Trainer Manual

The first phase of the adaptation is generally the most work-intensive; it is the phase during which the following tasks are undertaken:

- Comparing existing curricula and guidelines with the content in the Trainer Manual of the Module

- Incorporating national guidelines on comprehensive care of HIV-infected women and their families into the relevant sessions and exercises in the Trainer Manual
- Updating the “Make these points” and the “Trainer instructions” to reflect changes in content

During the first phase of the adaptation, the following questions may help the TWG to identify which text will need adapting:

- Does the text support national policy?
- Does the text reflect the national challenges around delivering comprehensive care to HIV-infected women and families?
- Are the language and wording appropriate?
- Is the text appropriate for the knowledge level/training of healthcare workers in our country?
- Is the text culturally sensitive/appropriate?
- Does the text reflect expected practices with respect to linkages and referrals?
- What additional documents or reference materials need to be included in the Module as appendices?
- What content in the appendices should be moved to the text of the Trainer Manual?

Ask stakeholders to review the adapted Trainer Manual to ensure accuracy, concordance with policy, and readability. This consultation also helps to ensure stakeholder support for future training efforts.

Consider involving a specialist to review specific sections. For example, a paediatric care and treatment specialist may focus on adapting the appendices that apply to HIV-exposed children, whereas stakeholders working in social welfare settings may be interested in ensuring that the exercise on community resources is appropriate.

Once stakeholders have approved the Module’s Trainer Manual, **the second phase** can begin, which includes adaptation of the other components of the Module:

- PowerPoint Slides
- Participant Manual
- Field Visit Guide (specifically the Field Visit Interview Guide)

The second phase is mostly administrative and does not typically involve the TWG and can be led by a responsible individual within the overseeing body. The adapted Trainer Manual contains all of the content of the Participant Manual. Participant Manual exercise instructions will need to be adapted if any of the exercises were changed. The PowerPoint Slides and Field Visit Guide (Field Visit Interview Guide) also need to be adapted to reflect the changes made to the Trainer Manual.

All of the Module materials then need to be pilot tested before being launched nationally. The pilot test is the **third phase** of the adaptation process. Review of the evaluation information from the pilot will suggest additional changes in both the written materials and training methods. Regardless of how carefully the materials were adapted, pilot testing helps to ensure the content is appropriate for the target population. The **fourth phase** is the national launch and roll out of the entire Module.

Technical Assistance for Adapting the Module

Questions on adapting the Module may be addressed to Rebecca S. Fry, Advanced Practice Nurse/Global Programs (*fryre@umdnj.edu)* at the François-Xavier Bagnoud (FXB) Center, University of Medicine and Dentistry of New Jersey (UMDNJ). As the Module was developed for the Caribbean HIV/AIDS Regional Training Network (CHART), requests to fund technical assistance to adapt the Module should be made to Virginia Gonzales, Senior Program Advisor (*gonza@u.washington.edu*) at I-TECH, the US-based technical assistance partner of the CHART Network.

Suggested Timeline for Adapting and Piloting the Module

Phase 1: Develop the first draft of an adapted Trainer Manual.

Step	Estimated Timeframe
Establish a Technical Working Group (TWG) consisting of experts in PMTCT and HIV care, treatment, and support	2 weeks (or less if TWG already established)
Assemble and review existing PMTCT and HIV care and treatment guidelines and documents	1 week
Develop the **first draft of the adapted Trainer Manual**	3 weeks
Review of the first draft of the adapted Trainer Manual by stakeholders	2 weeks
Total	8 weeks

Phase 2: Develop the second draft (pilot version) of the adapted Module

Step	Proposed Timeframe
Develop the **second draft (the pilot version) of the Trainer Manual**	2 weeks
Develop the Participant Manual, PowerPoint Slides, and Field Visit Guide (Field Visit Interview Guide)	1 week
Photocopy and assemble the Trainer Manual, Participant Manual, PowerPoint Slides, and Field Visit Interview Guide.	1 week
Total	4 weeks

Phase 3: Pilot test all of the components of the adapted Module

Step	Proposed Timeframe
Develop agenda and participant list for pilot	*
Perform all logistics related to pilot	*
Prepare tools to evaluate the Module during the pilot tests	*
Conduct trainer orientation to the Module	1 day
Coordinate and facilitate the 3-day pilot test, including the collection of feedback from observers, trainers, and participants	3 days
Total	1 week
* Activities can occur concurrent with those in Phase 2.	

Phase 4: Finalize all of the components of the adapted Module

Step	Proposed Timeframe
Develop the **third and final draft** of Trainer Manual as indicated by pilot test data and submit to the TWG for approval	3 weeks
Make any revisions to the Trainer Manual as requested by the TWG during the final review. Submit **fourth draft** to the TWG for final approval.	2 weeks
Once final approval has been given by the TWG, develop **final** Participant Manual, PowerPoint slides, and Field Visit Guide	1 week
Total	6 weeks

Adaptation Table

The middle column ("Add") is a list of the content suggested for inclusion. The column entitled "Adapt/Revise" lists the sections that typically need to be edited to ensure the content supports national guidelines and policies. All page citations refer to the Trainer Manual; it is assumed that the Trainer Manual will be adapted and approved first and then the Participant Manual will be developed by cutting the trainer-specific content from the Trainer Manual. The PowerPoint slides and Field Visit Guide should be based on the approved Trainer Manual.

SESSION 1 — INTRODUCTION TO COMPREHENSIVE CARE FOR MOTHERS, CHILDREN, AND FAMILIES		
LOCATION	**ADD**	**ADAPT/REVISE**
Page 22		Adapt the list of PMTCT healthcare workers' roles
Page 24 (Table 1)		Adapt list of components of comprehensive care, treatment, and support so that it mirrors services available locally and/or nationally
Page 25		Revise and, if possible, expand examples of opportunities to broaden PMTCT services to families
Page 26	Insert national schedule of postpartum visits	Revise content on follow-up mechanisms to locate women who miss postpartum appointments
Page 28	Insert national schedule of follow-up visits for HIV-exposed infants	Adapt language around recommendations for follow-up for HIV-exposed infants, including when to start cotrimoxazole prophylaxis
Pages 29-30	Insert national guidelines on HIV testing in infants and children	Adapt language around HIV testing of infants and children to correspond to national guidelines, specifically: • Role and timing of both HIV antibody and DNA/PCR testing • HIV testing of infants and children when mother's status is unknown
Page 31		Adapt language around how to promote HIV testing for mothers of unknown status
Pages 31-32		Ensure that the list of common signs and symptoms of HIV infection in infants and children reflects what is seen nationally
Page 33		Adapt language around growth monitoring to reflect national guidelines, policies, or initiatives
Page 38	Insert national HIV incidence rates to introduce the rationale for male involvement	"Men and HIV risk," adapt language to best reflect cultural practices and norms
Page 39		"Barriers to Safer Sex for Couples," adapt language to best reflect cultural practices and norms
Page 40		"Strategies to Include Male Partners," adapt and/or revise to best reflect cultural practices and norms

SESSION 2 — LINKAGES, REFERRALS, AND RETENTION STRATEGIES		
LOCATION	**ADD**	**ADAPT/REVISE**
Page 42	Description of how maternal child health (MCH), family planning, PMTCT, and HIV care and treatment and other comprehensive care services are interrelated	"Introduction to linkages and referrals" adapt and/or add to list of organizations that cooperate with healthcare agencies to deliver comprehensive care
Page 42-43		Adapt and/or add to list of why linkages between PMTCT and HIV care and treatment are important Add another example of a linkage with PMTCT that is a national priority e.g., the Bahamas adaptation included a section on linkages between PMTCT and mental health services
Page 44		"Community Linkages," adapt/revise language to feature national and/or local community-based programmes or agencies
Page 45 (Table 3)		"Table 3: Suggested Linkages and Referrals," adapt/revise according to national and/or local programmes and services e.g., drug treatment services may not be available in all countries
Page 46 (Table 4)		"Table 4: Linkage Enablers," add best practice example(s) that have worked nationally
Page 46 (Table 5)		"Table 5: Consequences of Poor Linkages," add example(s) of a consequence of a poor linkage(s) that occurred nationally
Pages 47-48		"Steps in the Referral Process," revise according to national best practices Include information on how referrals are monitored/tracked at a national and/or local level, when available Discuss any national indicators used to track PMTCT referrals, when available
Pages 53-54		"Barriers to Comprehensive HIV Care," adapt/revise to reflect challenges that women and their families face on a national and/or local level
Pages 54-55		"Strategies to Overcome Barriers to Comprehensive Care," incorporate national best practice(s) Utilize examples of incentives that have been used nationally
Pages 59-60		"Successful PMTCT Programmes," add an example(s) of a best practice from your country in comprehensive care delivery

EXERCISES
Exercise 2
• This exercise was written for an audience without consistent access to DNA-PCR viral testing of infants for HIV. In a country with reliable access to DNA-PCR testing, the case studies may require adaptation to better reflect the challenges to diagnosing children with HIV. • Consultation with a pediatric healthcare worker can add additional depth to the case studies.
Exercise 3
• Add to the list of resource categories depending upon which aspects of comprehensive care should be featured nationally • This exercise can be used to create a national resource list for comprehensive care services OR update a pre-existing one used nationally and/or locally.
Exercise 4
• Adapt the role play scenarios to best reflect the social challenges that healthcare workers face in the delivery of comprehensive care to women and families. • Consultation with healthcare workers in the field can add additional depth to the role play scenarios.
APPENDICES
APPENDIX A Checklist for Postpartum Visit for HIV-infected Women and HIV-exposed Newborns
• Revise based on: o National guidelines on immediate post-delivery care for HIV-exposed infants o National polices on postpartum infant feeding counselling and support o National guidelines on ARV prophylaxis and therapy for mother and infant o National guidelines on initiating cotrimoxazole in adults and HIV-exposed infants • Compare postpartum checklist against national guidelines • Specify where and how a women receives postpartum services, including family planning
APPENDIX B Infant/Young Child Follow-up Visits
• Add national immunization and follow-up schedule for HIV-exposed infants • Add package of care: physical exam for an HIV-exposed infant/child, laboratory tests, medications started or stopped, as well as specific education for HIV-infected mothers about how to care for their child • Revise based on: o National policy on HIV testing of infants/children o National policies on infant and young child feeding
APPENDIX C Monitoring Growth, Nutrition, and Development of HIV-exposed Infants and Children

- Adapt the role of the healthcare worker in growth, nutritional, and developmental monitoring
- Review and revise if local practice differs:
    - Growth charts
    - Growth and developmental monitoring (see suggestion below for a new appendix to include national growth charts or cards)
    - "Milestones and Assessment", ensure it corresponds to the schedule of follow-up visits for HIV-exposed infants and children e.g., if there is no visit scheduled at 15 months of age, eliminate the list of milestones

APPENDIX D Draft WHO Recommendations on Diagnosis of HIV infection in infants and children

- Replace with national algorithms

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

- Replace with CDC clinical staging system, if this is the preferred system
- Replace presumptive diagnosis criteria, if different criteria are used nationally

APPENDIX F Family Planning in the Context of HIV Infection

- Review and adapt:
    - List of healthcare worker responsibilities
    - Contraceptive options available nationally

APPENDIX G Sample Client Referral Form

- Replace with client referral form used nationally, when available
- Replace with best practice example of a client referral form used locally that includes elements of the sample form

APPENDIX H Sample Client Referral Tracking Form

- Replace with client referral tracking form used nationally, if available
- Replace with best practice example of a client referral tracking form used locally that includes elements of the sample form

APPENDIX I Sample Disclosure Counselling Script

- Adapt to ensure that the discussion is culturally relevant
- Include referral information for domestic violence services, when available
- Include national HIV counselling and testing policies on disclosure counselling

SUGGESTIONS FOR NEW APPENDICES

- Add an algorithm that describes the links between each service or national programme (MCH, PMTCT, HIV care and treatment).
- Insert forms used by PMTCT programmes to refer their clients to HIV care and treatment and other comprehensive care services.
- Add additional information on a comprehensive care service that has been prioritized

nationally e.g., the Bahamas adaptation includes an appendix on how to assess and refer for depression and an algorithm to help healthcare workers rule in or rule out suicidal behaviour.

ALL DOCUMENTS

- Revise the following:
  - Acknowledgments
  - Foreword
  - Table of Contents
  - "Abbreviations/Acronyms" to include any local/national abbreviations; delete any that were deleted from the text
  - Introduction
  - Resources/References