Module 6: Linkages to Treatment, Care, and Support for Mothers and Families with HIV Infection

SECTION 1: Linkage with Local Treatment, Care, and Support Services for Mothers and Families

SECTION 2: Treatments, Care, and Support of the Mother with HIV Infection

SECTION 3: Treatment, Care, and Support of the Infant and Young Child Exposed to HIV

Objectives

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

- Explain the treatment, care, and support needs of mothers with HIV infection and their infants who are HIV–exposed.
- Identify local supportive resources for mothers, children, and their families.
- Develop and strengthen linkages with treatment, care, and support services for women and children infected with or exposed to HIV.

Introduction

The follow-up treatment, care, and support that women who are HIV-infected receive after delivery, and the care of their children and families, can be strengthened if linkages are made with comprehensive community health services that include HIV/AIDS treatment and care, social support, and patient advocacy. It is important that treatment and care extend beyond PMTCT prophylaxis for women, infants, and family members at risk for or infected with HIV.

Establishing linkages with appropriate health care services created synergy and helps ensures that the HIV positive mother and her infant access the range of promotive preventive and curative services that meet that diverse health needs and helps them to remain in optimal health. Establishing linkages with community-based health services, organizations and social support systems increases the range of resources available to the HIV-positive mother, promotes acceptance of PMTCT interventions at community level and helps reduce stigma and discrimination.

This module examines the range of linkages that can be established at health facility and community level and the services available from each of the links.

SECTION 1: Linkages with Local Treatment, Care, and Support Services for Mothers and Families

PMTCT interventions reduce, but do not eliminate, the risk of HIV transmission from mother to infant. Regular follow–up care is critical for an infant born to a mother with HIV/AIDS and for infants whose mothers' HIV status is unknown. This includes infants who have received ARV prophylaxis, because HIV exposure increases an infant's risk of illness and failure to thrive.

Linkages can be fostered in many ways

- Programme developers can establish linkages by integrating PMTCT services into existing maternal and child health (MCH) services.
- Clinicians and healthcare workers can expand their practices to include necessary referrals and then follow up to ensure families have easy access to linked services.
- Community workers, including lay counsellors, can assist women in obtaining treatment, care, and support services.

Linkages between MCH and HIV services

- MCH services are entry points for PMTCT and for the treatment, care, and support of women who are HIV–infected and their infants and other family members.
- PMTCT is integrated into MCH services through the development of human capacity and programme development.
- Caring for and treating families affected by HIV shared responsibility.
- All children born to women who are HIV–infected require follow up and appropriate care.
- Community MCH workers provide information on health promotion and disease prevention, as well as care and support services to these families.
- Specialists in HIV who care for women and children may provide consultation, antiretroviral treatment, and help with the ongoing management of HIV infection.

Linkages with other health programmes for special needs

- Some programmes target specific health needs, such as family planning, treatment of sexually transmitted infections (STIs), or assistance with substance abuse.
- Disease–specific programmes, such as those for people with tuberculosis (TB) may benefit women who are HIV–infected (see Appendix 6-A).
- Nutritional support programmes for mothers and children are especially important for people living with HIV/AIDS (PLWHA).

Linkages to community–based AIDS service organisations

Linkages to community–based organisations can provide the resources to help women who are HIV–infected and their families cope with the isolation, social stigma, economic and emotional pressures that often accompany a diagnosis of HIV infection. Such linkages may provide women infected with HIV, a way to become involved in voluntary or paid HIV–related work. These groups include:

- Non–governmental organisations (NGOs)
- Faith–based organisations (FBOs)
- Community–based organisations (CBOs)

- Traditional Healers

Building community teams for shared responsibility

- Formalise connections among MCH programmes, health systems, and community programmes, whenever possible.
- As people who work in community agencies and healthcare settings learn more about services available outside of their own setting, people living with HIV/AIDS can gain access to a wider range of services.

Exercise 6.1 Community linkages: small group discussion	
Purpose	Identify the range of services locally available to PLWHA. Encourage interagency networking and linkages. Facilitate client referral to community services.
Duration	45 minutes
Activities	▪ Participants will be divided into several small groups according to their geographic location or affiliation with a certain facility. ▪ Each group will assign someone to record information on paper and another person to act as spokesperson for the group when reporting information later on. ▪ Use copies of Appendix 6–B to help identify locally available community resources, then record them on paper. ▪ Under each resource category listed in the left–hand column, try to answer the following questions: ♦ Can you list a resource under each heading? ♦ Are you aware of the address, location and hours of operation of each service? ♦ For each resource listed, do you know of a contact person for networking and referral? ♦ Do you have resources missing from the list? ♦ Can you think of other resources that are not included? ♦ Are you in contact with key community members that you might partner with to expand your resource list? ▪ You will have 35 minutes to complete this exercise. When you are finished, each group will present their findings to be shared with all participants.

SECTION 2: Treatment, Care, and Support of the Mother with HIV Infection

Postpartum care of the mother with HIV infection

Healthcare workers should ensure that women who are infected with HIV and have given birth in a healthcare facility return for postpartum appointments or are visited at home.

Women who have given birth at home should be evaluated 1 week after the birth and again at 6 weeks.

During visits attention should be paid to the following:

Assessment of healing

- Check wound healing.
- Monitor uterine involution.
- Confirm cessation of postpartum bleeding.

Infant–feeding support

- Assess progress of infant feeding.
- Assist the mother to safely implement her chosen feeding option.
- Assess family support for the infant–feeding option.
- Work with the mother to develop a plan to address challenges.

Sexual and reproductive care

- Discuss family planning in the context of HIV
- Support the mother's choice of contraceptive method.
- Discuss condom use as dual protection (against STIs, including HIV, and for family planning).
- Discuss the importance of safer sex to prevent the spread of HIV and other STIs.
- Provide advice regarding early STI treatment, including recognition of symptoms and where to go for STI assessment and treatment.

Related services for HIV treatment, care, and support

The postpartum period is an ideal time to link the woman who is HIV–infected to comprehensive care that will support her health, prevent complications, and improve her ability positively HIV**.**

A range of related services should be provided directly or by referral, including those listed below:

- Prevention and treatment of opportunistic infections
- ARV treatment
- Treatment of symptoms and palliative care
- Nutritional support
- Social and psychosocial support
- Faith–based support
- Home–based care

Antiretroviral treatment

Support for antiretroviral treatment for women who are HIV–infected is becoming increasingly available. Women initially followed in PMTCT settings should be linked to treatment services for themselves and their families (PMTCT–Plus). International and national policies and guidelines provide support for this process including criteria for initiating treatment.

Combining ARV drugs to reduce the HIV viral load as much as possible–and for as long as possible–is the standard of care for HIV treatment. A combination of three or more ARV drugs, referred to as highly active antiretroviral therapy (HAART), slows replication of HIV.

The advantages of HAART are:

- Improved health status
- Decreased MTCT rates
- Reduced HIV–related hospitalisations
- Reduced number of deaths from AIDS

A high level of patient adherence to ARV treatment and care regimens may reduce drug resistance and ensure better efficacy. Creative strategies to help patients achieve optimal adherence are essential components of successful HIV/AIDS treatment programmes. Consider the following methods:

- Provide education and establish patient readiness prior to initiating treatment.
- Recognise that immediately postpartum, women will require additional support.
- Consider the use of practical adherence tools such as pill boxes, written and/or graphic instructions.
- Explore patient's daily meal patterns, work schedule, and sleep patterns to find the best time to take medications.
- Develop culturally appropriate strategies to overcome barriers and support adherence when possible.

Treatment of symptoms and palliative care

PLWHA are subject to HIV symptoms that can limit participation in family and community activities. Healthcare interventions that focus on managing symptoms and relieving discomfort can improve a woman's quality of life. Simple management of common HIV symptoms, such as nausea, vomiting, fatigue and skin problems can ease discomfort.

Assessment and management of more complex issues such as pain, weight loss and wasting resulting from disease progression can improve comfort, function and emotional well–being.

Palliative care

It is patient and family–centred care that:

- Provides access to information and honours a person's choices
- Optimises quality of life
- Anticipates, prevents, and treats suffering
- Addresses physical, emotional, social, and spiritual needs

Nutritional counselling, care, and support

Often, people with HIV infection or AIDS have symptoms that make food preparation and eating difficult. Appendix 6–C lists some of the symptoms of HIV/AIDS and ways in which people may reduce or overcome those symptoms while maintaining adequate nutrition.

Women receiving HIV–related medications require counselling on specific dietary practices and nutritional needs, in order to successfully manage side effects and avoid nutrition–related complications. Antenatal counselling for safer infant–feeding practices and postnatal support for the feeding option a woman selects may help ensure adequate nutrition and the proper growth and development of her child.

PLWHA are especially vulnerable to bacterial infections because their immune systems become weakened. Emphasise to PLWHA the importance of cleanliness during food preparation and storage.

Adequate nutrition, exercise, rest, good hygiene practices, and abstinence from harmful habits such as smoking, alcohol and drug abuse support overall health and improve immune function.

Social and psychosocial support

Because people with HIV face stigma in many communities (See *Module 8, Communication for PMTCT)*, women who are HIV–infected often are reluctant to disclose their sero–status to partners, family, or friends. Moreover, a woman who learnt of her HIV sero–status during antenatal HIV testing may still be adjusting to her diagnosis. Regular monitoring of mental health and psychosocial care and support are critical at all stages of HIV infection. The following services should be offered directly or by referral:

- Support to help the woman come to terms with her diagnosis
- Psychosocial support for the mother and her family when the infant's HIV status is uncertain, and when a positive diagnosis is made.
- Community support, including referrals to community–based and faith–based programmes
- Peer group counselling and support from health agencies or NGOs
- Support and counselling to assist women who are HIV–infected and their partners with disclosure issues

Faith–based support

Faith–based involvement provides mothers who are HIV–infected with spiritual and psychosocial support. It also may provide them with an important sense of belonging to a larger community that offers them compassionate care. In many programmes, faith–based organisations are providing comprehensive treatment, care, and support services.

Home–based care

In many resource–limited settings, home–based care provides services to PLWHA when hospital and outpatient services are expensive or not accessible. The advantages of home–based care for patients and families, and for communities and the healthcare system include:

- Provision of care in a familiar and supportive environment that allows for continued participation in family matters

- Reduction of medical expenses
- Involvement of the local community in caring for PLWHA may help counter myths and misconceptions
- Decreasing the burden on the healthcare system.

Exercise 6.2: Postpartum case study	
Purpose	To prepare participants to handle common problems that mothers may present during postpartum visits.
Duration	30 minutes
Activity	▪ In your group, read through the case study below. ▪ Select one member of the group as recorder to write down key issues that the group discusses. ▪ In your group, list each issue that the healthcare worker needs to address and discuss for 15 minutes strategies for resolving the issues on your lists. Ask the group recorder to write down the key issues. ▪ When you are finished, each group will present the key issues and strategies to the larger group.

Healthcare workers may offer direct psychosocial support and referrals to community resources. AIDS service organisations in the community may provide social support through peer group counselling, clubs, or referrals to other services.

Case study

Jummai is a 24–year–old woman who was diagnosed as HIV–infected during her recent pregnancy. She and her infant received the appropriate medication to prevent MTCT, as recommended by the National PMTCT guidelines. She has returned for her 6–week follow–up visit.

Jummai has chosen to exclusively breastfeed. She feels, however, that the baby is always hungry and is wondering if her breast milk is enough; she has also been giving him supplemental vitamins. Jummai and her husband, who is also HIV–infected, would like to resume sexual relations. She has been told that she will not need to use protection because breastfeeding eliminates her chances of getting pregnant.

Upon examination, Jummai appears to be doing well. She has a 0.3 cm fissure (crack) at the base of her right nipple. There is no observable redness, heat, or sign of infection. Jummai reports that she has been feeling more tired than usual and has about half her normal energy, but does not have any other physical complaints. She wants to know whether starting HIV medicine may help her feel better.

Jummai’s husband has been sitting in the waiting room. He is currently unemployed. While Jummai is getting dressed, he says, "I have always taken good care of my family, but now, without money coming in, I don't see how we are going to make it. I feel like God is punishing me, somehow, for infecting my wife with HIV."

What are the important issues for Jummai *and her husband?*

SECTION 3: Treatment, Care, and Support of the Infant and Young Child Exposed to HIV

Regular visits for health assessment and health promotion

To ensure that infants receive essential care, adequate nutrition, and support for feeding, the newborn should be seen in the healthcare facility or at home. The schedule for healthcare visits should be in accordance with national policy or as suggested below:

- If the infant was born at home, an assessment at the time of delivery followed by a visit in 7 days to monitor feeding progress is strongly advised. Special considerations apply when the infant is receiving ARV prophylaxis. (See Appendix 4–A.)
- It is recommended that subsequent visits be scheduled to coincide with the recommended schedule for immunisations. WHO recommends subsequent visits as follows:
  - At ages 6, 10, and 14 weeks
  - Once a month from 14 weeks to 1 year
  - Every 3 months from the ages of 1 to 2 years

Anytime the infant becomes ill or the mother suspects a problem, seeking early medical intervention is strongly encouraged.

Immunisation

Infants born to mothers who are HIV–infected should be immunised according to the national schedule of immunisation (See Appendix 6–D).

Nutrition and infant–feeding support

At each visit, workers should assess and support a mother's choice about infant feeding. Discussions about infant feeding are especially important in the early months of life and as new foods are introduced.

Infants who fail to grow require special attention. Health workers should assess feeding practices and diet for infants older than 6 months and provide appropriate counselling that considers locally available foods, family circumstances and feeding customs. Underlying infections should be treated immediately or ruled out as a cause of growth failure.

Subsequent Visits

Each visit with the healthcare worker should include the following:

- Assessment for common illnesses and appropriate management
- Identification of non–specific symptoms or conditions that could be related to HIV infection.
- Provision of HIV testing as indicated.
- Promote health and prevention of illness
  - Monitor growth and assess causes of growth failure, if observed
  - Provide PCP prophylaxis with cotrimoxazole from six weeks of age
  - Check immunisation status and immunise as indicated (Appendix 6–D)

- Treat for helminth infection if the parasite load in the environment is high or as recommended by Integrated Management of Childhood Illnesses (IMCI) guidelines
- Screen, provide prophylaxis for or treat TB if indicated

- Prevention and treatment of malaria, as indicated based on national policy or guidelines
- Treat anaemia, as indicated based on national policy or guidelines
- Counsel caregivers on infant feeding, nutrition, ARV treatment when indicated and other care as appropriate
- Ensure that the mother has access to quality reproductive health services.

Because the health of mother and child is so closely related, assessment of maternal health and nutrition should be concurrent with assessment of the infant and appropriate referrals for maternal care should be given during infant checkups.

Integrated Management of Childhood Illnesses (IMCI)

HIV testing and counselling

ARV prophylaxis reduces, but does not eliminate, MTCT. Therefore, services must be identified or developed to provide follow–up care, HIV testing and appropriate treatment to HIV-exposed infants (see Appendix 6-E).

Counselling parents about their child's HIV test is important. The suspicion or confirmation of HIV diagnosis in an infant or child is difficult for the parents. Workers should discuss the diagnosis compassionately and confidentially, and they should offer the parents information about services available for the child (see Appendix 6-F).

All infants born to HIV-infected mothers will test HIV-positive with antibody tests if tested at birth. Antibody tests are not reliable until 18 months of age, unless tests results are negative in children over 9 months of age. For those that are breastfed, test 6 weeks after cessation of breastfeeding. DNA and RNA PCR tests, where available, are reliable and diagnostic in early infancy.

Clinical presentation and assessment of an infant born to a mother who is HIV–infected

An infant born to a mother who is HIV–infected and presents with symptoms of illness should be assessed using the IMCI guidelines as adapted for areas with a high prevalence of HIV infection.

The signs and symptoms most commonly associated with HIV infection in infants are low weight and/or growth failure; pneumonia, oral candidiasis (thrush); lymphadenopathy; parotid gland swelling; recurrent ear infections; persistent diarrhoea, and TB (Table 6.1). Healthcare workers should teach mothers and other caregivers to recognise early signs of those conditions and to seek early care for the child.

Interventions to relieve symptoms, such as oral rehydration for acute diarrhoea, nutritional interventions to promote weight gain, and screening for TB, are important strategies for improving the health of infants who are HIV–infected.

Integrating the care of infants who are HIV–infected into ongoing care using IMCI

Several countries have adapted guidelines, including those outlined in IMCI, to include recognition of the special needs of children with HIV infection and to help healthcare workers assess and provide better management when HIV is suspected or confirmed. Adhering to guidelines may help integrate the care of children with symptomatic HIV infection into MCH services.

Antiretroviral treatment

Where ARV treatment is available, healthcare workers must monitor infants and children (considering laboratory findings, when available) for symptoms of HIV infection that would make them candidates for ARV treatment, and refer them for appropriate HIV treatment and care.

Before treatment begins, healthcare workers need to assess a family's beliefs about drugs and treatment, the family's readiness to begin treatment, and their ability to follow a dosing schedule. Treatment decisions follow international and national policies and guidelines.

When CD4 cell assays are available the use of the CD4 cell percentage is recommended for decision–making on ARV treatment rather than the absolute CD4 cell count, because the former varies less with age.

Table 6.1: Clinical conditions or signs of HIV infection in a child who is HIV–exposed

Specificity for HIV infection	Signs and conditions
Common in children who are HIV–infected; also seen in ill, uninfected children	▪ Chronic, recurrent otitis media with discharge ▪ Persistent or recurrent diarrhoea ▪ Failure to thrive ▪ Tuberculosis
Common in children who are HIV–infected; uncommon in uninfected children	▪ Severe bacterial infections, particularly if recurrent ▪ Persistent or recurrent oral thrush ▪ Chronic parotitis (often painless) ▪ Generalised persistent noninguinal lymphadenopathy in two or more sites ▪ Hepatosplenomegaly ▪ Persistent or recurrent fever ▪ Neurologic dysfunction ▪ Herpes zoster (shingles), single dermatome ▪ Persistent generalised dermatitis unresponsive to treatment

Specific to HIV infection	▪ *Pneumocystis carinii* pneumonia ▪ Oesophageal candidiasis ▪ Lymphoid interstitial pneumonitis ▪ Herpes zoster (shingles) with multidermatomal involvement ▪ Kaposi's sarcoma

For infants who are sero–positive and aged less than 18 months, WHO recommends the initiation of ARV therapy in the following:

WHO Paediatric Stage I (i.e. asymptomatic) and CD4% <20%. (asymptomatic circumstances):

The infant has virologically proven infection (using HIV DNA PCR, HIV RNA assay, or immune–complex dissociated p24 antigen) and has:

- WHO Paediatric Stage III HIV disease (i.e. clinical AIDS) irrespective of CD4%; or
- WHO Paediatric Stage II HIV disease, with consideration of using CD4 <20% to assist in decision–making; or children, i.e. WHO Stage I, should only be treated when there is access to CD4 assays).

If virological tests to confirm HIV infection status are not available but CD4 cell assays are available, WHO recommends that ARV treatment can be initiated in infants who are HIV–sero–positive and have WHO Stage II or III disease and a CD4 percentage below 20%. In such cases, HIV antibody testing must be repeated at age 18 months in order to definitively confirm that the children are HIV–infected; ARV therapy should only be continued in infants with confirmed infection.

For children who are HIV–sero–positive aged 18 months or older, WHO recommends initiation of ARV therapy in the following circumstances:

- WHO Paediatric Stage III HIV disease (clinical AIDS), irrespective of CD4%; or
- WHO Paediatric Stage II disease, with consideration of using CD4 <15% to assist in decision–making; or
- WHO Paediatric Stage I (asymptomatic) and CD4 <15%.

Breastfed infants are at risk of HIV infection during the entire period of breastfeeding. A negative virological or antibody test at one age does not exclude the possibility of infection occurring subsequently if breastfeeding continues.

Exercise 6.3: Clinical presentation of HIV in infants	
Purpose	To familiarise participants with the signs and common conditions in infants who are HIV-infected.
Duration	20 minutes

Activity	▪ Comment on the most common presenting sign of HIV infection in an infant or child; the facilitator will list responses on the flipchart.
	▪ Identify which body systems or organs may be involved in early presentation of HIV infection; the facilitator will list responses on the flipchart.
	▪ The large group will be divided into three smaller groups. Each small group will receive a card labelled:
	  ▪ GI system
	  ▪ Pulmonary system
	  ▪ Immune function
	▪ List on the card any symptoms indicating HIV infection that are related to the card heading. Determine if the symptom is HIV–specific and give your recommendations for care, including prophylaxis.
	▪ Select a representative to present the group's work to the larger group.

Module 6: Key Points

- A continuum of care is provided through linkages between PMTCT, MCH and available HIV treatment, care, and support services, including those offered by NGO, CBO and FBO groups in the community.
- Linkages to NGOs and FBOs may help families living with HIV/AIDS gain access to social support and assistance with specific needs such as housing, transportation, food, and income–generating activities.
- Postpartum care includes clinical assessment, infant–feeding support, family planning, cervical screening, and referral for HIV–related treatment and care.
- Infants who are HIV–exposed require follow–up care to monitor growth and development, immunisations, and prophylaxis for infections. They also require testing to determine HIV status.
- IMCI guidelines may help healthcare workers integrate care for children who are HIV–exposed or HIV–infected into ongoing MCH services.
- PMTCT–Plus programmes provide linkages to treatment, care and support services for mothers who are HIV–infected, their children, and other family members.
- Timing of testing and diagnosis of HIV infection in infants and young children varies according to feeding practices and available tests.

APPENDIX 6–A: Tuberculosis (TB)

Background

HIV infection leads to increased susceptibility to TB, promotes progression of recent and latent *Mycobacterium tuberculosis* infection to active TB disease, increases the risk of recurrence, and complicates the clinical course of TB disease. TB is cited as the leading cause of death among persons who are HIV–infected; an estimated 40% of PLWHA acquire TB during their lifetime.

In sub–Saharan Africa, up to 70% of patients with pulmonary TB are HIV–infected. TB prevention, screening, care, and treatment are becoming priority concerns in patients who are HIV–infected; prevention, screening, care, and treatment of HIV/AIDS are priority concerns in patients with TB.

Case Detection

Cough is the most common symptom of pulmonary TB. All patients referred to a health facility, irrespective of their HIV status, with a cough lasting 2–3 weeks should be screened for TB. Other TB symptoms include:

- Fever
- Haemoptysis
- Weight loss
- Chest pain
- Fatigue

BCG Vaccine

Bacille Calmette–Guerin (BCG) is a live attenuated vaccine given intradermally to protect young children against severe TB. The usual dose is 0.05 ml in neonates and infants under 3 months of age, and 0.1 ml in older children.

WHO's policy regarding this vaccine states that BCG should not be given to children with symptomatic HIV infection (i.e. AIDS). In asymptomatic children, the decision to give BCG should be based on the local risk of tuberculosis:

- Where the risk of tuberculosis is high, BCG is recommended at birth or as soon as possible thereafter, in accordance with standard policies for immunisation of children who are not HIV–infected;
- *In areas where the risk of tuberculosis is low but BCG is recommended as a routine immunisation, BCG should be withheld from individuals known or suspected to be infected with HIV.*

Treatment

Treatment protocols for both active and latent TB are standardised. In each country, guidance is provided on screening, treatment, and monitoring of the patient with TB. Prophylaxis against TB should be part of a package of care for people living with HIV/AIDS. This prophylaxis is recommended for individuals who are HIV–infected and test positive for TB infection, and those in whom active TB has been excluded.

APPENDIX 6–A: Tuberculosis (TB) (continued)

Prophylaxis may also be considered for individuals who are HIV–infected and living in a community with a high prevalence of TB infection, where skin testing is unavailable. Six to nine months of isoniazid (INH) is the regimen recommended for preventive treatment of latent TB infection.

Patients who are HIV–infected and who have active TB should also receive cotrimoxazole therapy to prevent secondary bacterial and parasitic infections.

When selecting drugs to treat TB, women taking oral contraceptives, pregnant women, and patients who are HIV–infected and receiving ART require special consideration. With careful clinical management, however, patients with HIV–related TB can receive simultaneous TB and HIV treatment. The revised (2003) WHO guidelines, *Scaling up antiretroviral therapy in resource–limited settings: treatment guidelines for a public health approach*, provide up–to–date information on ARV therapy for the special category of patients who are receiving concomitant TB treatment.

In primary care settings and PMTCT programmes healthcare workers can play an active role in TB screening, as well as in treatment or referral for treatment and monitoring of patients with TB and HIV.

Adapted from WHO. 2004. *Scaling up antiretroviral therapy in resource–limited settings: Treatment guidelines for a public health approach*. WHO: Geneva. Retrieved 30 July 2004, from http://www.who.int/hiv/pub/mtct/en/arvdrugsguidelines.pdf

APPENDIX 6–B: Community resource information worksheet

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

COMMUNITY RESOURCES THAT SUPPORT THE PMTCT PROGRAMME		
Resource Category	**We Have**	**We Need**
Voluntary testing and counselling for partners		
Health care (STIs, reproductive health, TB treatment, etc.)		
HIV/AIDS care and ARV treatment		
Nutritional support		
Support group or club		
Community–based AIDS service and faith–based organisations		

APPENDIX 6–C: Suggestions to maximise food intake for PLWHA

Symptom	Suggested Strategy
Fever and loss of appetite	▪ Drink high–energy, high–protein liquids, fruit juices. ▪ Throughout the day, eat small portions of preferred soft foods with a pleasant aroma and texture. ▪ Eat nutritious snacks whenever possible. ▪ Drink liquids often.
Sore mouth and throat	▪ Avoid citrus fruits, spicy foods. ▪ Avoid very sweet foods. ▪ Drink high–energy, high–protein liquids with a straw, if available. ▪ Eat foods at room temperature or cooler. ▪ Eat thick, smooth foods such as pudding, porridge, mashed potato, mashed carrot or other non–acidic vegetables and fruits.
Nausea and vomiting	▪ Eat small snacks throughout the day and avoid large meals. ▪ Eat toast and other plain, dry foods. ▪ Avoid foods that have a strong aroma. ▪ Drink diluted fruit juices, other liquids, soup. ▪ Eat simple boiled foods, such as porridge, potato, beans.
Loose bowels	▪ Eat bananas, mashed fruits, soft rice, and porridge. ▪ Eat smaller meals, more often. ▪ Eliminate dairy products to see if they are the cause. ▪ Decrease high–fat foods. ▪ Avoid foods with insoluble fibre ("roughage"). ▪ Drink liquids often.
Fat malabsorption	▪ Eliminate oils, butter, margarine and foods that contain or are prepared with them ▪ Eat only lean meats. ▪ Eat fruit, vegetables, and other low–fat foods.
Severe diarrhoea	▪ Drink liquids frequently. ▪ Drink oral dehydration solution. ▪ Drink diluted juices. ▪ Eat bananas, mashed fruits, soft rice, and porridge.
Fatigue and lethargy	▪ Have someone precook foods to save energy and time spent in preparation. ▪ Eat fresh fruits that don't require preparation. ▪ Eat snack foods often throughout the day. ▪ Drink high–energy, high–protein liquids. ▪ Set aside time each day for eating.

Woods, MN: 1999. Dietary recommendations for the HIV/AIDS patient. In: *Nutritional Aspects of HIV Infection*, ed. T. Miller and SL. Gorbach, Arnold Press, London. pp 191–203.

APPENDIX 6–D: National Immunization Schedule

Age of Infant	Vaccine
Birth	BCG*, OPV–0 HBV
6 weeks	DPT–1, OPV–1 HBV
10 weeks	DPT–2, OPV–2
14 weeks	DPT–3, OPV–3 HBV
9 months[1]	Measles[1] YF

Key:
BCG = Bacille Calmette Guerin HBV = Hepatitis B Vaccine
OPV = oral polio vaccine
DPT = diphtheria, pertussis, tetanus

[1] WHO recommends that an additional, early dose of measles vaccine should be given at age 6 months if the following conditions are met:

- Measles morbidity and mortality before age 9 months represents more than 15% of cases and deaths.
- There is a measles outbreak.
- The infant has a high risk of measles death. This includes infants:
  - with documented HIV infection
  - living in refugee camps
  - admitted to the hospital or
  - affected by disasters

* BCG–do not give to infants with symptoms of HIV/AIDS.

All children who have been exposed to HIV should be fully immunised according to their age. Because most children who are HIV–infected do not have severe immune suppression during the first year of life, immunisation should occur as early as possible after the recommended age to optimise the immune response.

BCG and yellow fever. Children with known symptomatic HIV infection should not receive BCG and yellow fever vaccines. However, because most infants who are HIV–infected are asymptomatic at birth, when BCG immunisation occurs, and thus will have unknown HIV status, the birth BCG immunisation should be given.

Oral polio vaccine. If the child has diarrhoea and is scheduled to receive OPV, the dose should be given as scheduled. However, the dose should not be counted in the schedule, and an additional dose of OPV should be given after the diarrhoea has resolved.

Diphtheria, pertussis, tetanus. Children who have either recurrent convulsions or active central nervous system disease or who have had shock or convulsions within 3

days of receiving a DPT vaccination should not receive subsequent DPT vaccination. For those children, substitute DT (diphtheria–tetanus) formulation; all other immunisations may be given.

APPENDIX 6E: Diagnostic testing of infants and young children exposed to HIV

HIV antibody testing of infants and young children less than 18 months

Early diagnosis of infection in these infants is difficult, especially in resource–constrained settings, and is further complicated by breastfeeding. Since maternal antibodies cross the placenta, all infants born to mothers infected with HIV will test antibody positive, irrespective of their own infection status. Because maternal antibodies persist, antibody testing prior to 18 months cannot provide a reliable diagnosis of infant infection status, especially when the child is breastfeeding. In resource–constrained settings where breastfeeding is common, initial antibody testing is recommended at 18 months as shown in figure 3.2. In countries with increased capacity for multiple testing and where replacement feeding or early weaning is common, testing can be done at 9–18 months. However, healthcare workers should consider repeating the test at 18 months to confirm the status of the child.

For children who are *not breastfeeding* or where breastfeeding cessation occurred at least 6 weeks previously:

- A negative HIV antibody test result for a child 18 months or older indicates that the child is not HIV–positive.
- A positive HIV antibody test at 18 months or older indicates the child is infected with HIV.

OR

- A negative HIV antibody test result for a child age 9–18 months indicates that the child is not infected with HIV.
- A positive HIV antibody test at 9–18 months of age indicates that the child may have antibodies from the mother and the test should be repeated at 18 months.

For children who *are breastfeeding*:

If the test is negative at 18 months of age or older and the infant was breastfeeding in the last 6 weeks, the antibody test should be repeated 6 weeks after complete cessation of breastfeeding.

A positive HIV antibody test result at 18 months indicates that the child is HIV–infected.

HIV viral assays in infants

Viral assays that detect HIV in the infant's blood, such as the DNA or RNA PCR test, may be used to diagnose HIV infection in infants at a younger age than antibody testing. Early diagnosis of HIV allows the provider to promptly initiate counselling about methods of infant feeding and facilitates early clinical care for the infant who is HIV–infected.

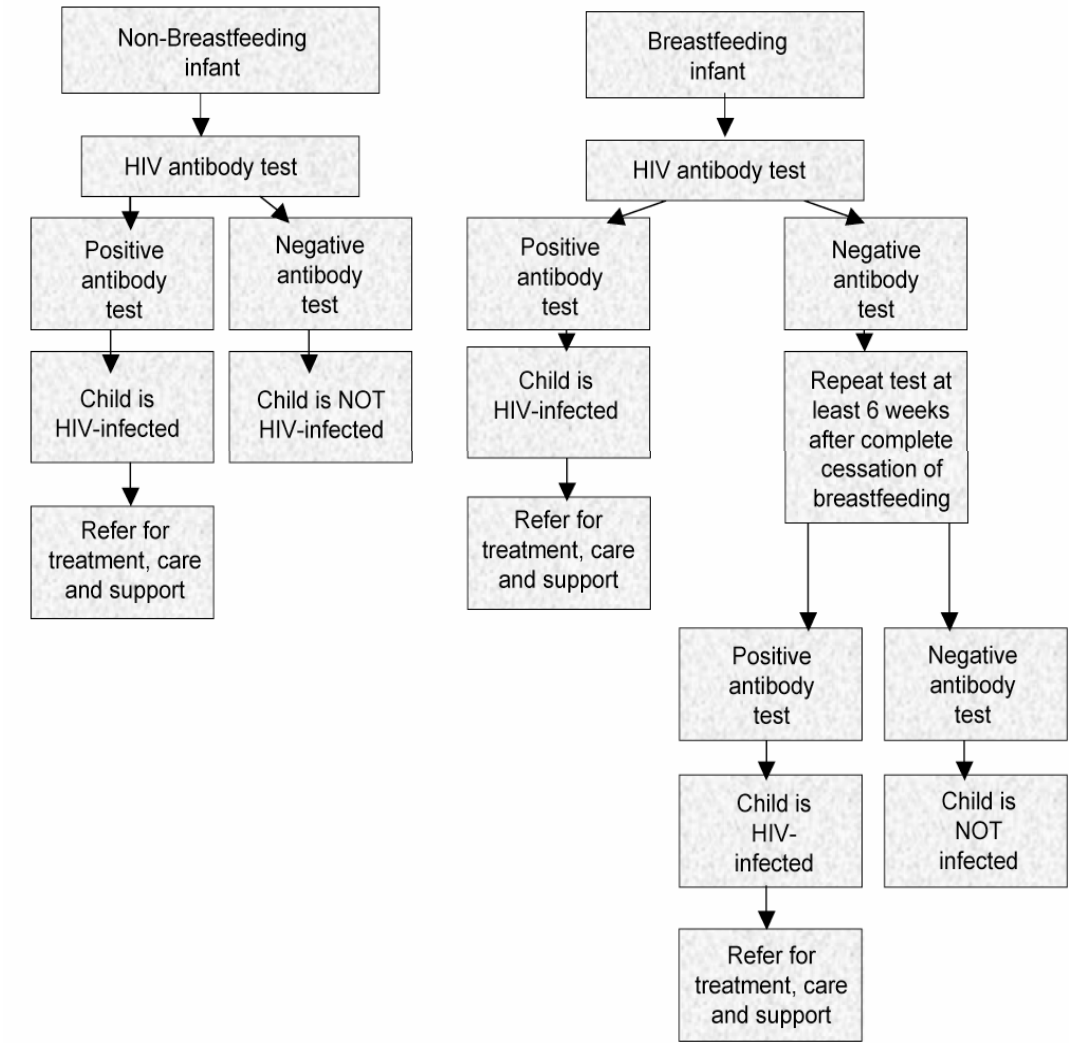
Programs need to develop practical and appropriate guidelines based on locally available diagnostic technologies and additional evidence as it becomes more readily available for early diagnosis. A viral assay can be performed from age 6 weeks to allow decisions related to ARV treatment and care. Where virological testing is available, the sample algorithm in Figure 3.3 may be used. When virological tests are rarely available

and severe cost constraints exist, a viral test may be done, *regardless of breastfeeding*, if the child presents with symptoms of HIV at less than 18 months of age.

For children who are *not breastfeeding*, consider testing the infant from age 6 weeks.

- If a DNA PCR or RNA PCR test is positive, the child is HIV–infected.
- If a DNA PCR or RNA PCR test is negative, the child is not HIV–infected.

Figure 6.2 HIV diagnosis in children 18 months and older with antibody tests in resource-constrained settings



For children who *are breastfeeding*, consider testing the child from 6 weeks–6 months.

- If a DNA PCR or RNA PCR test is positive, the child is considered HIV–infected.

- If a DNA PCR or RNA PCR test is negative, repeat viral assay 6 weeks after complete cessation of breastfeeding.
- If a DNA PCR or RNA PCR test is negative 6 weeks after complete cessation of breastfeeding, the child is not HIV–infected.
- If a DNA PCR or RNA PCR test is positive 6 weeks after complete cessation of breastfeeding, the child is HIV–infected.

APPENDIX 6–F: Talking with parents about their child's HIV test results

Prepare for the talk with parent or guardian.

- Make sure you have the child's test result and inform the parent that you have the result.
- Schedule an appointment.

Greet the parent and establish rapport.

- Ask if the parent or guardian has had any questions since the child's blood test. Answer the questions and let the patient know that counselling will continue to be available to help with important decisions.

Inform the parent of the test result.

- Ask, "Are you ready to receive your child's HIV test result?"
- State, in a neutral tone, "The baby's test result is positive. That means that the baby has HIV infection."
- Pause and wait for the parent to respond before continuing. Give the parent time to express any emotions.
- If the parent would like to see proof of the result, provide it.
- Check the parent's understanding of the result's meaning. Discuss and support the parent's feelings and emotions.
- Explain that the blood test revealed evidence of HIV, the virus that causes AIDS, in the baby's body. Review the testing procedure with the parent and check to be sure he or she understands the test results. Explain the accuracy of the test. Allow time for silence.
- Reassure the family that, although there is no cure, there are treatments for infections that the child can receive. Emphasise that children can live many years before they become sick with AIDS–related illnesses. Talk about available ARV treatments for HIV.
- Recognise that many people may interpret this diagnosis as a death sentence. Anticipate reactions of grief, shock, disbelief, denial, and anger. Offer appropriate support.

Discuss ways to keep the child healthy.

- Emphasise the need for immunisations.
- Talk about good nutrition.
- Stress that the child should be allowed to live an active life and play like other children whenever possible.
- Review the importance of prompt medical attention as well as preventive care
- Refer the child for HIV treatment and care if not provided in your facility.

APPENDIX 6–F: Talking with parents about their child's HIV test results *(continued)*

Review Universal Precautions.

- Reassure the family that close contact with family members and normal baby care do not transmit HIV.
- Review measures for diaper/nappy changing (no gloves are necessary), blood spills (use a barrier), and open sores (they should be covered).

Identify other family members who may be at risk of HIV infection.

- Identify, counsel, and test siblings who may be at risk. Families must be given the time and support to do this.

Identify a support system.

- Identify a personal support system for the family.
- Assess the psychological status of mother and other family members.
- Refer family to a support group, if they are interested.
- Provide the family with written material that they can take home, if they are interested.

Review issues of confidentiality.

- Introduce disclosure issues.
- Explain how confidentiality is handled in the clinical setting.

Assess the family's understanding of the diagnosis, treatment, and care at each visit.

- Review and offer additional information as appropriate.