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A Handbook for Family Case Managers

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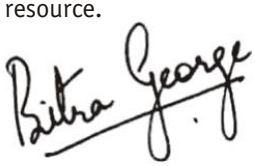
Foreword

In India, as per the recent estimates, new HIV infection has declined at the rate of 21% (UNAIDS Report 2011). It is estimated that children account for around 3.5% of all HIV infections (NACO press release December 2010). Though only a small proportion of children are actually infected, there are many more children have an HIV-positive parent or have been orphaned by AIDS. For years, attention has primarily been given on HIV care and treatment for adults while children who are infected by HIV lack access to care, support and treatment services. The lapse in early diagnosis of HIV has contributed greatly to the high mortality rate of children who are positive in India. Accessibility and adherence to pediatric ART is still a major area of concern. The situation gets exacerbated with the lack of information with families on the HIV care, treatment and support services that exist for children, which deters them from seeking these services. Among children who do access the services, dropout rates are high because of the absence of a continuum-of-care approach and follow-up.

Balasahyoga – meaning "active support to the child" is one of FHI 360's flagship programs in India. This five-year collaborative initiative (2007-2012) has successfully addressed the comprehensive care, support and treatment needs and vulnerabilities of children and their families affected by HIV. The program uses an innovative and effective outreach mechanism called "Family Case Management". This approach addresses the vulnerabilities faced by children while considering the family as a unit of intervention and not looking at the child in isolation.

This handbook is an endeavor to share our learnings on the Family Case Management approach with the wider health and development community. It details out the roles and responsibilities of Family Case Managers in addressing the wide array of health, psychosocial, nutrition, food security and education needs of the beneficiaries. The handbook establishes clarity about the processes involved in community mobilization to ensure the active support to the families. Further, it elucidates simple steps in prioritizing households and establishing a robust referral process to enable the HIV affected families to access various services and benefits as per their eligibility. Potential challenges that a Family Case Manager is confronted with have also been shared along with guidelines to overcome the same. The Frequently Asked Questions given under each section are helpful since they offer a quick reference for the user.

I hope this handbook is found useful by outreach workers involved in an HIV care and support program and helps to enrich their work and build their capacities. I extend my congratulations to the Balasahyoga team for their valuable inputs that contributed to the development of this useful resource.



Bitra George

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Contents

Acronyms

AAY	Anthodia Anna Yojana
ADMHO	Additional District Medical and Health Officer
AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ANM	Auxiliary Nurse Midwife
ART	Antiretroviral Therapy
AWW	Anganwadi Worker
BC	Backward Class
BSY	Balsahyoga
CAB	Community Advisory Board
CCC	Community Care Center
CD4	Cluster Of Differentiation
CHC	Community Health Center
CLHIV	Children Living with HIV
CoC	Continuum of Care
CSI	Child Status Index
CTX	Cotrimoxazole
CV	Community Volunteer
DAPCU	District AIDS Prevention and Control Unit
DBS	Dried Blood Spots
DC	District Coordinator
DNA PCR	Deoxyribonucleic Acid , Polymerase Chain Reaction
DOT	Directly Observed Treatment
DPM	District Program Manager
DRDA	District Rural Development Agency
DWACRA	Development of Women and Children in Rural Areas
EID	Early Infant Diagnosis

FBF	Fortified Blended Food
FC	Facility Coordinator
FCC	Family-centered Care
FCM	Family Case Manager
HIV	Human Immunodeficiency Virus
IAY	Indira Avas Yojana
ICDS	Integrated Child Development Scheme
ICTC	Integrated Counseling and Testing Center
IFA	Iron Folic Acid
IKP	Indira Kranti Patham
LIC	Life Insurance Corporation
LSE	Life Skills Education
LTFU	Lost to Follow-up
MAM	Moderate Acute Malnutrition
M & E	Monitoring and Evaluation
MIS	Management Information System
NCLP	National Child Labour Project
NFBS	National Family Benefit Scheme
NGO	Nongovernmental Organization
NHD	Nutrition and Health Day
NREGS	National Rural Employment Guarantee Scheme
NVP	Nevirapine
OI	Opportunistic Infection
PHC	Primary Health Center
PID	Patient Identification Digit
PLHIV	People Living with HIV
PNC	Postnatal Care
PPTCT	Prevention of Parent to Child Transmission of HIV
RNTCP	Revised National Tuberculosis Control Programme

SAM	Severe Acute Malnutrition
SC	Scheduled Caste
SFI	Severely Food Insecure
SHG	Self-Help Group
STI	Sexually Transmitted Infection
TB	Tuberculosis
UIP	Universal Immunisation Programme
VCTC	Voluntary Counseling and Treatment Center

1 Introduction

In India, children who are affected by HIV lack easy access to care and support. The barriers are historic and systemic. For years, India has focused its attention on building an apparatus of HIV care to protect and treat adults. Pediatric antiretroviral therapy (ART) was not introduced until late 2006; early infant diagnosis was not introduced until 2010. Health care facilities such as ART centers treat individuals, not family units, so they do not as a matter of course determine whether the children of adult clients have the virus, as well. This lapse in HIV testing procedure has contributed greatly to the high mortality rate of Indian children who are HIV-positive. To make matters worse, Indian families are generally uninformed about the HIV care, treatment and support services that exist, and as a result are deterred from seeking these services out. Among clients who do access the services, dropout rates are high, because a continuum-of-care approach is absent and follow-up is poor.

Family case management is an approach to HIV care, treatment and support that ensures comprehensive services for children affected by the virus. It is an effective way to address the vulnerabilities of families who must deal with HIV.

The largest and broadest program in India to adopt the family case management strategy was launched in April 2007 by FHI 360 in partnership with CARE International and the William J. Clinton Foundation. Called Balasahyoga (a Telugu word meaning “active support to the child”), this five-year initiative focused on children and their families holistically rather than as individual clients in isolation. It set out to reach 68,000 children in 11 of the 23 districts of Andhra Pradesh and has resulted in significant improvements in access to services and retention in care.

Central to Balasahyoga's family-focused care is the family case manager (FCM). The program enlisted and trained 600 FCMs and assigned to each one between 100 and 125 households for regular home visits. The role of the FCM was to use the home visits to

- educate parents who are HIV-positive about the urgency of testing their children for HIV and initiating treatment of children who test positive without delay
- offer child-friendly messages to support disclosure, HIV testing and treatment adherence
- equip children with a minimum package of services across five domains
    - health
    - education
    - psychosocial needs
    - nutrition and
    - food safety and security

This handbook explains family case management and the roles and responsibilities of an FCM. It discusses how an FCM should gather and use information from facility or community sources to identify HIV-affected households in need of services. Because assigning priority to clients is essential to the success of any community-based program, this handbook details the steps an FCM should take in order to set priorities for home visits, using tools appropriate for the task. It also describes how an FCM should address the health, nutritional, food safety and security, psychosocial and educational needs of clients. The handbook covers the process of mobilizing a community to ensure its active support of families affected by HIV. Finally, the handbook presents the steps involved in establishing a referral process, so that HIV-affected families can access services for which they are eligible.

Although the handbook is a training tool for FCMs, it will be useful to any outreach worker whose duties include support for HIV-affected families.

For quick reference, the handbook is divided into 13 topical sections with key points highlighted. Each section discusses the challenges related to the topic that an FCM might face and offers guidance to overcome them. A set of frequently asked questions also appears in each section.

2 Family Case Management

2.1 What is family-centered care?

Family-centered care (FCC) is a set of systems and services that enable coordinated HIV care for children and their families who are HIV-positive or affected by HIV.

- It addresses the needs (physical, mental, emotional, social and spiritual) of the entire family – adults and children alike – over time.
- To the extent possible, it attends to parents or other caregivers and children living with or affected by HIV as a group rather than individually (that is, in separate facilities by different providers or at different times).
- It uses a case management approach.

The key elements of FCC are

- co-location of services

  HIV care is provided in one place for adults and children rather than in separate locations. It is rendered by one case manager rather than many. The result is increased access to services.
- case management

  This is an ongoing process or cycle of assessing needs, preparing a plan to address those needs, coordinating support to meet the needs, and re-assessing to uncover new needs.
- continuum of care (CoC)

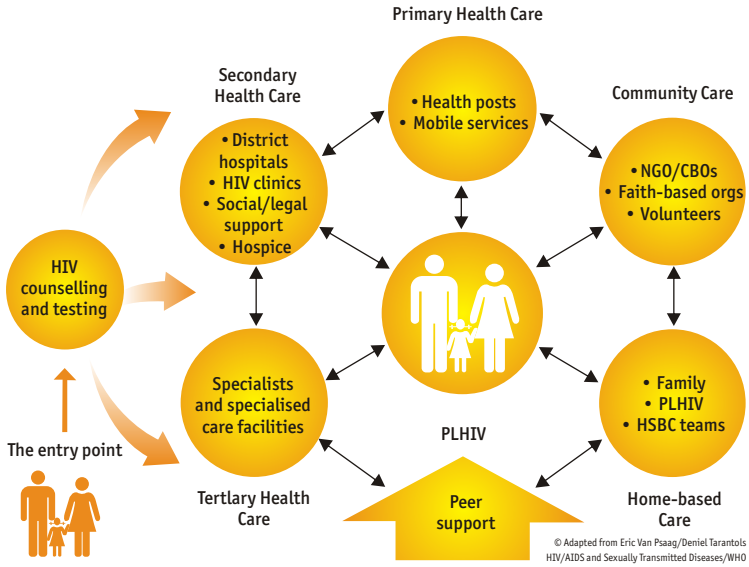
  Children and their families affected by HIV may need to go to many different service sites for care over time. This can lead to less coordinated, more complicated, costly and fragmented care for families. A continuum of care establishes strong links and referral systems connecting the health facility and the community and home-based care and support services in order to minimize gaps and confusion.

2.2 Why is family-centered care important for children?

Families are the center of love and support for most people.

Children are more likely to develop into healthy adults if they are cared for at home and have at least one primary caregiver who is responsible for them.

Figure 2.1 The Continuum of Care



2.3 What is case management?

Case management is a long-term relationship with people who are dealing with chronic issues such as cancer, HIV, mental health disorders, addiction and abuse. The needs of these clients are complex and change over time. Children, whose needs change quickly as they develop, pose an even greater challenge for FCMs.

For a beneficiary family, getting the support and services that are needed can be difficult and expensive. Parents may worry about the following questions:

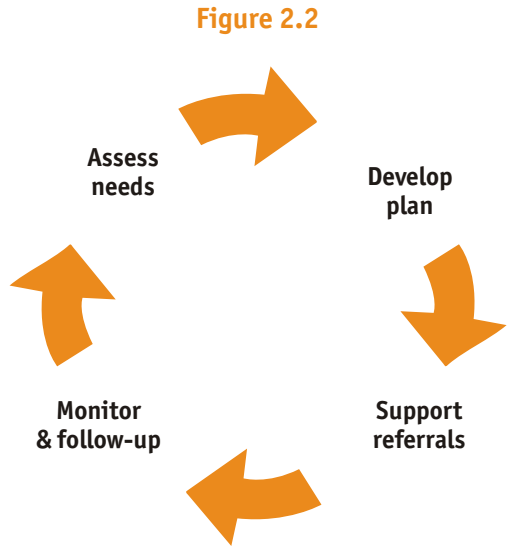
- What can I do to live better?
- How can I plan for my children?
- Where can I go for services to help my family?
- How do I get to the service site?
- Can I afford the services?

Family case management is a family-centered process to help children and their families access care and coordinated health and social services. Family case management constructs a bridge between families and the care and support they need. It helps families to identify their problems and pursue solutions by building on their own strengths, which in turn increases their confidence in their ability to handle their problems. The ongoing relationship between a family and an FCM is founded on mutual understanding. It is a partnership of the child, the child's family and the FCM. For children in particular, the FCM is a guide or mentor who walks with them through their childhood, helping them to grow and develop in the best possible way.

Family case management begins with the enrollment of a family affected by HIV and an initial assessment to identify in order of priority the family's needs for services in the five core domains: health, nutrition, food security, education and psychosocial support.

The FCM uses the needs assessment to develop a care plan and then arranges for the families to receive support to implement it. The FCM reviews the family's progress in following the care plan, reassesses needs, and updates the care plan during routine follow- up visits. Each visit continues the cycle. In time, some children and families will reach a point at which they no longer need support and can be discharged from the program.

Care management is a process with four main steps:



1. Enroll an eligible child and the child's family in the program.
2. Draw up a baseline assessment and care plan for the child and the family. These involve:
    - assessing the child's and the family's needs
    - helping the child and family to prioritize their most important needs
    - preparing a child and family care plan
    - supporting the family to implement the care plan, by providing services directly or by making referrals to other services
3. Conduct routine monitoring and follow-up visits. These involve:
    - reviewing the current care plan
    - assessing new or upcoming needs of the family
    - revising the care plan to meet the family's new needs
    - providing necessary support to ensure implementation of the care plan
4. Determine when the family has developed the strength and resources necessary to function without being monitored, close the care management relationship, and make room in the program for a new vulnerable child and family to participate.

Although the same cyclic process of care management is used for each child and family, the needs identified and services provided will vary. The duration of support will vary, as well, depending on the extent of the household's needs.

3 Roles and Responsibilities of Family Case Managers

Family case managers are outreach workers who provide comprehensive HIV care to children and to family and other household members. They position a family to be able to handle adversity by drawing on the family members' own strengths and network of resources – a crucial skill that the Balasahyoga program refers to as resilience. Family case managers achieve this goal by providing continuous counseling and other social support services within their geographic reach.

3.1 What is the role of a family case manager?

An FCM conducts out reach sessions with people living with HIV (PLHIV), children living with HIV (CLHIV), and their caregivers in order to assess the family's needs and support the family to meet those needs. The FCM maintains consistent and long-term partnerships with a defined caseload of clients.

3.2 What are the general functions that a family case manager performs?

The family case manager

- identifies children and caregivers who need support and conduct outreach to them
- assesses the needs of each child and his or her caregivers comprehensively
- develops a service plan with the child and caregivers
- provides health education, counseling and care to the child and caregivers as needed
- implements the service plan, by linking the child and caregivers to the service delivery system
- monitors service delivery
- serves as an advocate for PLHIV and CLHIV, protecting their rights and entitlements
- conducts periodic evaluations of the needs of the children and caregivers

(Refer Annexure 1: The Job and Qualities of a Good Family Case Manager)

3.3. What are a family case manager's responsibilities?

- Register the household
- Make the first contact with a household where HIV is present and provide the household with a unique registration number
- Assess needs
- Conduct an annual health and income assessment of each HIV-affected household

- Set priorities

  Having identified the needs of the children, parents and other caregivers in a household, the FCM determines their relative urgency and prepares to address them using the tools of health education, counseling and care. One component of this responsibility is to partner with community workers to evaluate the household's food security and means of livelihood. Another is to conduct a nutritional assessment of the household twice a year.

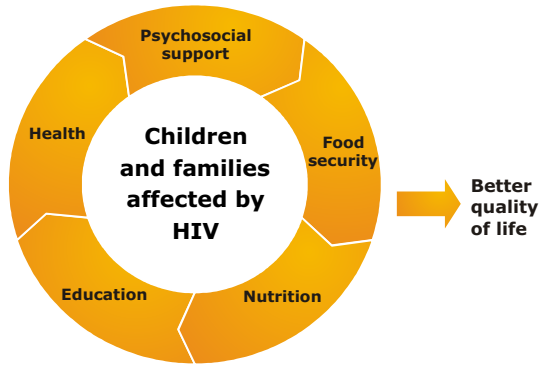
- Offer psychosocial support

Many strategies exist to help an FCM discharge this responsibility. The FCM can provide counseling on HIV testing and treatment, education, emotional and social challenges and interventions to improve food security. The FCM can also provide palliative care ranging from treatment of minor pain to end-of-life care. An FCM mobilizes the community to reduce stigma and discrimination. Finally, an FCM seeks lasting solutions by working with a community to establish local entities such as community advisory boards (CABs) and support groups for children and adults living with HIV.

- Support HIV testing and treatment of household members

  The FCM should accompany children and caregivers to a facility such as a community care center (CCC) or a voluntary counseling and testing center (VCTC) for such services as counseling, testing, prevention of parent to child transmission of HIV (PPTCT), Pre ART screening and preparation for and maintenance on ART. When children and adults under the FCM's care are registered for services at these centers, the FCM should make sure that they are networked to community-based services, as well.

Figure 3.1



- Set up referrals and other linkages

  The FCM's job is to ensure that children and adults in households under their care have access to government facilities that offer services appropriate to their needs. In particular, the FCM should link these households to rural livelihood and other social security programs.

- Monitor

  Periodically throughout the FCM's relationship with a registered household, the FCM should monitor the quality of the comprehensive care, support and treatment services the household receives.

- Support community volunteers

  The FCM is responsible for providing supportive supervision, mentoring and training to community volunteers (CVs). Each CV should submit regular reports to the FCM, who in turn analyzes them and keeps them on file.

- Intervene to protect household food security

  The FCM should build the capacity of registered households to support themselves, by developing home-based kitchen gardens in peri-urban and urban areas and by improving farmyard production in rural areas. These initiatives can supplement a household's sources of nutrition and generate income. On a larger scale, the FCM can help a community establish a grain bank and also a garden to demonstrate the viability of potentially valuable plants not commonly grown in the area.

How the family case manager serves HIV-affected children

For a child younger than 18 months old who has been exposed to HIV:

- Refer parents for PPTCT counseling and refer the child for HIV testing using the deoxyribonucleic acid polymerase chain reaction (DNA PCR) method – the diagnostic test recommended for infants.
- Provide cotrimoxazole prophylaxis for mother and child.
- Assess the child for signs and symptoms of exposure to tuberculosis (TB) and other opportunistic infections (OIs) and refer as necessary for treatment.

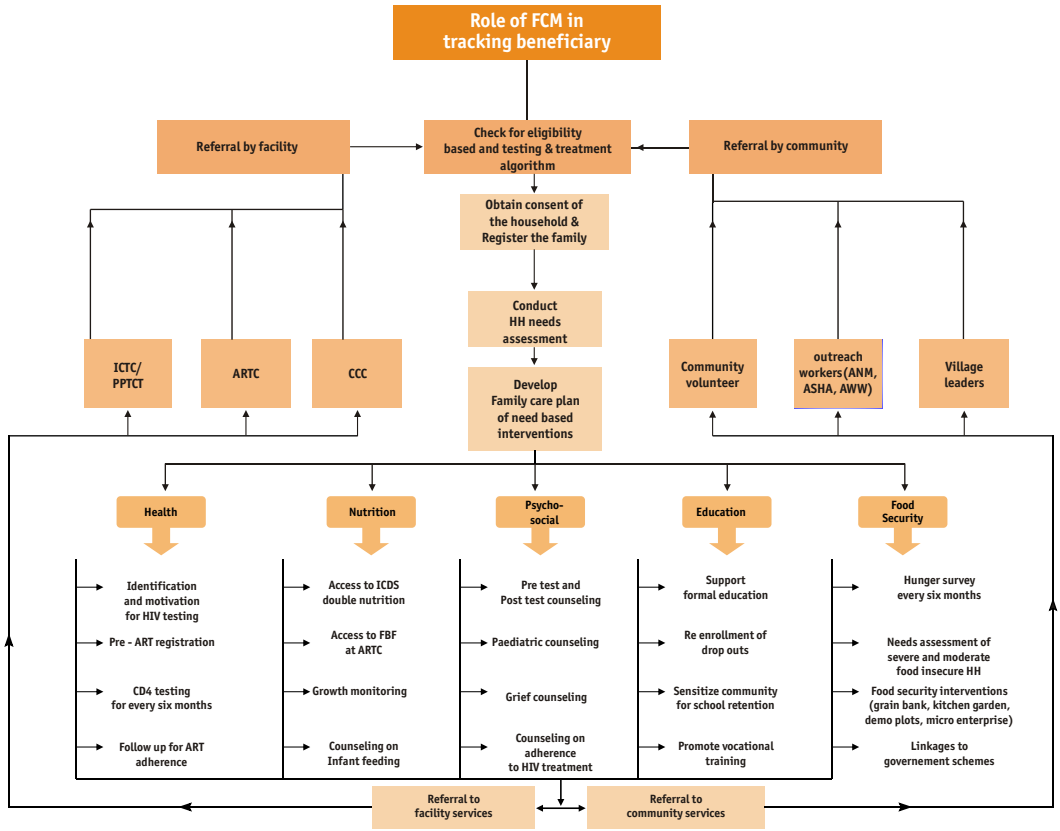
If a child below 18 years of age is diagnosed as HIV positive, provide the child with the following specialized care:

- regular CD4 count
- cotrimoxazole prophylaxis for prevention of OIs
- early management of OIs
- pediatric ART, including adherence counseling
- nutritional assessments
- fortified food

In an HIV-affected household, if a child is diagnosed as HIV-negative (younger than 18 months using the DNA PCR method or older than 18 months using the HIV antibody test), provide the child with the following care:

- general health services
- supportive services
- if the child is an orphan, a needs assessment and appropriate support
- assistance to bolster the child's resilience, through pediatric counseling using age-appropriate, interactive communication strategies such as role-playing, puppetry and drama.
- connection to nearby social services such as a Life Skills Education (LSE) program and a child support group
- enrollment of a child who has dropped out of school in informal schooling or other educational programs
- advocacy to protect the rights of the HIV-affected child

Figure 3.2 The role of the family case manager in tracking beneficiary households



[1] An orphan is defined as a child under the age of 18 who has lost one or both parents.

4 Registration of the Household

Registration was a crucial and basic step in the process of identifying a person or household eligible in any program offering HIV-related care and social services.

4.1 What registration means

In the parlance of Balasahyoga, "registration" is the enrollment in the program of a child or a pregnant woman with HIV. With the child's or pregnant woman's registration, the family becomes part of the program, as well, and is entitled to a wide range of services. During registration, details about all children younger than 18 in the household and their immediate family members or caregivers are recorded. Each child receives a unique identification number, which is entered in the family's case file.

4.2 Why conduct registration

Registration begins the process of identifying and meeting a household's needs. For participants in Balasahyoga, it opened the door to the package of services across the program's five domains of care: health, education, nutrition, psychosocial support and food security.

4.3 Whom to register

The criteria for registration should be clearly stated. Initially, Balasahyoga restricted eligibility to children younger than 18 living in households with at least one HIV-positive member, living or dead. Later, the program expanded to admit pregnant women with HIV, whether their households included a child or not.

4.4 Where to conduct registration

Registration can take place in a facility or in the community.

- **Provider-initiated registration:** When community-based services are networked with CCCs, ART clinics and integrated counseling and testing centers (ICTCs), providers who see eligible clients have an opportunity to describe the community-based service and steer clients to it. In Balasahyoga, providers obtained the consent of these clients to share information about them with an FCM.[2] At least once every two weeks, FCMs collected this

[2] In addition to obtaining a potential client's consent for testing and treatment, the facility provider invites the client to sign another form consenting to be registered in the community-based HIV program and receive the program's package of care and support services.

information from facilities in their catchment areas and followed up with the clients. A mechanism like this makes it easier for the community-based service to identify eligible households, and also places community- and facility-based services in partnership to support those households.

- **Community-initiated registration:** For many reasons, households affected by HIV are not invariably connected to support facilities that could help them. For example,
  - sometimes a person who tests positive for HIV does not return to a facility for follow-up.
  - A person who receives the diagnosis from a private health facility may not be aware that publicly funded support is available.
  - A family who moves may not know how to find a facility near their new home.
  - A person may have HIV without knowing it, or may unwittingly engage in activities that increase the risk of exposure to the virus without realizing that facilities offer counseling to minimize risk behavior.
  - A sexually abused child is unlikely to be seen at a facility so long as the abuse continues unrecognized, especially if the abuser is a parent or other caregiver.

  It is identified that community sources can play a key role in identifying eligible beneficiaries, they can provide active support to the beneficiaries by linking them to the community-based HIV support program like Balasahyoga. Community-based services are positioned to identify HIV-affected individuals and households that elude the reach of facilities.

  An FCM can identify a community's key stakeholders – village leaders, Panchayat members, Anganwadi workers (AWWs), auxiliary nurse midwives (ANMs) and self-help group (SHG) members – and organize a sensitization meeting to seek their cooperation in identifying and supporting HIV-affected families.
- **Client-initiated registration:** The registration of a client who voluntarily joins the program is termed "client-initiated." This form of registration often occurs in communities of PLHIV as peers share information and motivate one another to seek help.

4.5 How to conduct registration

Step 1: Identify a household

An essential document in the process of identifying candidates for community-based HIV services is the HIV test report, which shows that a person has tested positive for the virus. Alternatively, a cluster of differentiation (CD4) test or ART records may be used to confirm HIV status. Documentation of HIV status is the evidence needed to admit a household into the program.

Step 2: Obtain consent

For a client and members of the client's household to participate, the FCM seeks consent in writing from the head of the household. If the client is a minor child and an orphan, community members known to consider the child's best interests can provide consent, with the child's active involvement in making that decision.

Take the following precautions during registration:

- Assure the individual and the household that their confidentiality will be protected.
- Explain the program's benefits to the household and answer questions.
- Check an HIV test report or ART card to confirm eligibility.
- Obtain informed consent before proceeding.
- Do not promise any kind of material or financial support to the household.
- Assure the household that the FCM will schedule visits at the household's convenience.

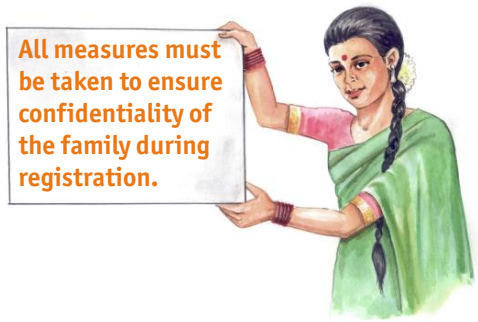
Step 3: Fill out the program's registration form

The registration form captures basic details about the household and its members. The FCM should interview the head of the household and record these details on the form.

Step 4: Assign identification numbers

To facilitate the unambiguous identification of a household and its members, the FCM should assign to each a unique identification code number.

Step 5: Create a family case file



The information on the registration form should be entered in a household case file. The file includes the consent form, the registration form, an adult profile, an adult data sheet, a child profile, a child data sheet, a household visit form, a service form, an antenatal care (ANC) form (if appropriate), a household care plan, a household food security assessment form, a nutrition assessment form, a growth monitoring chart and counseling forms. All of these forms should be updated on a regular basis.

4.6 How to deregister a client

The program extends services to eligible beneficiaries who are willing to accept them. If at any stage a beneficiary does not want to be part of the program, the household can be deregistered. Once a household ceases to be part of the program, household members may not receive the program's support.

The conditions under which a household would be deregistered are

- services are no longer needed and the household graduates from the program and is phased out
- permanent migration
- voluntary withdrawal

Challenges in the registration process and strategies to overcome them

Challenges	Strategic responses
An expectation on the part of community members for remuneration for cases they refer	Inform community members that the program needs their help to identify HIV-affected households and that they have a social responsibility to support these families.
Mobilizing community involvement	Community mobilization is essential to link households to entitlements and also to create a stigma-free environment. Local communication media can aid this effort.
Getting the buy-in of community members	Use participatory approaches to identify and mobilize the audience. Involve local leaders in conducting the mobilization meetings.
Unwillingness of households to participate	Emphasize the benefits of registering in the program. Seek the support of PLHIV support groups for peer support in this effort. Reassure the household that its confidentiality will be secure. Do not register unwilling households.
Procuring a duplicate ICTC test report to confirm a household's eligibility in the absence of the original report	Trace the patient identification digit (PID) assigned by the ICTC. With the PID a duplicate test report may be procured. To obtain it, seek support from ICTC staff.

How to register a child

Customarily, parents or legal guardians give consent on behalf of their children for registration in the program. Verbal communication is normally adequate for the purpose. Concerns related to developmental stage, emotional maturity and legal requirements make it unusual for an FCM to seek separate informed consent directly from a child younger than 10.

Parents or guardians may not be available to give consent on behalf of orphans, child survivors of rape, abandoned infants and street children. In such cases an FCM can make the decision to register the child.

In all cases it is important to involve the child in the registration process. A child has a right to information about his or her health status, commensurate with the child's developmental age and level of maturity.

According to the United Nations Convention on the Rights of the Child, a child has the right to "participate in decisions affecting his or her life." The convention also holds that a child's desires should be "given due weight" in accordance with the child's "maturity."

Frequently asked questions: Registration

1. **What if the HIV-positive adult is dead? Is a child in that person's household eligible to be registered? What if the household has no proof of a positive HIV test?**

   Even if the HIV-positive person is dead, the household can be registered if a child in the household is younger than 18, regardless of the child's own HIV status. If the household cannot produce documentation of a positive HIV test, the FCM can seek a duplicate test report.

2. **What can a family case manager do if a client has given the facility an incorrect address?**

   The FCM may cross-check the address with the local center for ART and TB and other sources of services for PLHIV. The FCM may also establish rapport with community members to trace the correct address.

3. **How can a family case manager avoid double registration?**

   Many double registrations occur when a pregnant woman who registers after her baby is delivered does so at the place of the birth and also at home. To make sure the woman has not registered twice, the FCM should directly ask a new mother if she has already registered before beginning a new registration process.

   Migration is another common source of double registrations. An FCM who visits a household that has migrated from elsewhere should get in touch with the FCM for that region to find out if the household has an existing file.

5 Prioritizing and Conducting House Visits

5.1 Why are home visits important?

Home is the contact point for the FCM to provide services. An eligible household must give formal consent to visits by the FCM to their home (or to some other place more convenient for household members, if necessary). Some of the reasons why an FCM visits a household are to collect information about the household and its members in order to create a household case file; to assess the household's needs (for Balasahyoga, within the program's five domains of care); to develop a care plan responsive to the needs of the child and the household as a whole; and to offer counseling support, growth monitoring, accompanied referrals, and linkages to additional providers of health and non-health services.

5.2 Whose houses does a family case manager visit?

All households who meet the program's criteria for registration and who have given consent for household contact by an FCM should be visited regularly.

5.3 What does "prioritizing households" mean?

Prioritizing households entails assessing the status of the households and grading them in order of the urgency of their need. FCMs assign priorities to the households under their care in order to plan household visits according to a schedule that ideally brings them to the households when their presence is most required. Obviously, households with high priority should receive more frequent visits.

5.4 How do family case managers set priorities for their caseloads?

The FCM should calculate how many households can be reasonably reached on average in a day, week or month. If a family can be visited only a few times a year, the impact will be limited. More frequent visits contribute to better outcomes.

The FCM should take care to determine whether a household needs intensive follow-up. For example, a child whose parent is very ill or has recently died may need more frequent visits – perhaps as often as a few times a week – than would a child in need of economic support who is living in a stable household and doing relatively well in most respects.

5.4.1 Tools for setting priorities

Baseline assessment: A baseline needs assessment is conducted to identify the most pressing needs of vulnerable children and their families. It offers the FCM an opportunity to identify households requiring longer and more frequent house visits. (Refer Annexure 2: the Family Assessment Form)

Guidelines: The Balasahyoga program established a clear set of guidelines to help an FCM set priorities for field visits, so that households requiring immediate support would get it. The guidelines call for the FCM to visit each household at least once a month for the first six months following enrollment in the program. They also spell out circumstances warranting more frequent visits. (Refer Annexure 3: Algorithm to Set Priorities for Family Case Manager Visits to Households)

5.5. What are the steps involved in conducting a home visit?

The FCM should plan the first visit in accord with the following guidelines:

5.5.1 Before the first home visit

- Secure the family's approval of a convenient time and date for the visit. The first visit usually runs long, so be generous in setting aside time for it.
- Prepare documents that will be needed during the visit, including the shell of a family care plan and forms for the management information system (MIS).
- Prepare mentally for the visit, making sure you have allowed enough time for it and that you are feeling calm.
- Plan your transportation to the meeting place.
- If parents or other caregivers are HIV-positive, find out before the visit if they have disclosed their status to everyone in the household. If they have not done so, ask how they would like you to explain the reason for your visit.
- If a child in the household is HIV-positive, find out what the child knows about his or her HIV status.

Some clients ask to have the first visit with an FCM somewhere other than at home. When this happens, be sure to make a repeat visit within three months of the first contact.

5.5.2 During the visit

The first visit should proceed as follows: 1) introductions; 2) taking the history of the child and the child's parents or other caregivers; 3) scheduling the next visit. In the first visit you need to build rapport with the household before you start to take the family history and assess the members' needs. Building rapport may take two or three visits followed by needs assessment. you can stop the needs assessment whenever a client seems to lose interest and continue when you return for the

next visit. When you finish assessing needs, creat a care plan and decide on the action steps that the household will take before you visit again.

5.5.3 Introductions

- Greet the clients and introduce yourself.
- Initiate friendly conversation with the clients to establish rapport.
- Describe your roles and responsibilities and explain what you can do to help.
- Be clear about the types of support you can and cannot provide.
- Ask the clients if they have an urgent need requiring your immediate attention or if you can take time to ask some questions about their situation.

5.5.4 Taking histories

- Explain that a history of the household will help you assess the household's needs.
- Ask who would be the best person in the household to answer questions related to the household's history. The prompts for your questions should be the information you will need to fill out the household registration form, an assessment form for each child and an assessment form for each adult.

(Refer Annexure 4: Adult Assessment Form and Annexure 5: Child Assessment Form)

When you take the household history, sit at eye level with the client who has agreed to provide information. Assure the client that all information they give will be confidential. As you elicit the household's history, communicate respectfully and patiently. After the conversation, thank all the clients in the household for allowing the information to be shared with you.

5.5.5 Assessing the family's needs

You should assess the family's health, emotional, social, mental and spiritual needs, using the following procedures:

Physical needs

- In households where an adult has HIV, assess that person's health first and then move on to the children. If the adults in the household do not have HIV, start by checking the physical condition of the children those who are HIV-positive and those who are HIV-negative, because all of them may suffer from physical problems.
- Record the client's medical history and current issues, such as pain, diarrhea, rash and difficulty breathing. Ask about sleeping and eating habits and medicines the client is taking. If the client is taking antiretroviral drugs, ask to see the ART logbook. If the client is a child, check to see if he or she seems to be growing normally. Stunted growth is a danger sign. Refer children who are severely malnourished to a hospital.

- Explain to the client and others in the household that for your service to be effective, you must examine the client from head to toe, and do so with the client's consent. (Refer Annexure 6: "Conducting a Basic Physical Assessment.")
- Based on what you learn from taking the client's history and examining the client, treat the client's symptoms.
- Demonstrate caregiving skills to other members of the household in particular those who look after the client.
- If you encounter in the household an infant born to a mother with HIV, ask the mother how she feeds the infant and if the child is receiving cotrimoxazole prophylaxis. Also ask if the child's HIV status has been determined through the early infant diagnosis (EID) method. As you examine the infant, be alert for signs that the child needs immediate medical attention, such as recurrent fever, Vomiting, diarrhea and convulsions.
- Review medicines that the client is taking, inquiring about the dose and frequency prescribed by the client's doctor. Discuss drug adherence, and if the client is having difficulty with that, help household members to prepare a calendar noting when and how to take the medicines.
- If the client needs to be referred for outpatient or inpatient care, help with transportation to the clinic or hospital as necessary.
- Ask adult clients if they plan to have children in the near future.
- Wrap up the physical examination by asking the client and the client's family or caregivers if they have any specific questions, or if they want general advice about providing good care.

If you believe that a child or adult in the household has symptoms of a critical condition, quickly determine whether that person can be transported to a hospital. If the family agrees, call the hospital to make the emergency referral. You may accompany the client to the hospital to ensure that appropriate emergency care is provided.

If the client is nearing the end of life, the client and family will need to make the very difficult decision whether or not to shift the client to the hospital. A client who is conscious and aware of his or her situation must be allowed to lead the decision-making process. Your role is to help the client and the client's caregivers make this decision, not decide for them.

Psychosocial needs

- **Emotional well-being:** Ask how the caregiver and children in the family are feeling. Are they happy or sad? Are they able to sleep well? Observe the children: Are they quiet, shy, withdrawn, crying, clinging or angry? If you identify signs of unusual stress, plan to return to the home within the next few days for further assessment and to begin counseling. With the children use interactive communication strategies.
- **Stigma and discrimination:** Ask about incidents of stigma and discrimination – for example, have the children been teased or rejected by other children or adults at school or in the community?
- **Spiritual support:** Observe the client if spiritual counseling by a religious leader would be helpful, or if the client would like to make funeral plans with a temple, church or mosque.
- **Financial situation:** Ask if the household has a plan to improve its financial situation. Probe to see if help in developing a vocational skill, getting a loan or finding a job would be useful.
- **Peer support:** Ask household members if they have joined a PLHIV support group. If not, tell them about groups they could consider joining and provide the telephone numbers and addresses of the group leaders.

Food security needs

- Ask about the family's access to food.
- Find out if they ever go to work without meals because they cannot afford food.
- Ask if they are taking advantage of government schemes related to food security.
- If they are, ask if they have experienced any problems of access.

Educational needs of children

- Determine whether any school-aged children are in the household.
- Ask if the children are enrolled in school.
- Ask if the children's attendance is irregular.
- Ask if the children have the school materials they need.

Child protection needs

- Are there any children in the house who are younger than 14 and working? If so, find out what work they do, how much time they spend at work and how much time they spend playing and going to school.
- Inquire about and watch for signs of abuse, especially among foster children who might be disregarded in the household.
- Ask about and watch for other signs of abuse in the household: Do the parents or other caregivers engage in substance abuse?

- Ask about and watch for signs of domestic violence in the household. For example, do any household members have an unusual number of bruises?

Referral needs

- Ask what public services the household is using.
- Tell the household about services that are available in the community, such as Anganwadi centers, Life Skills Education classes, PLHIV support groups, and government schemes or grants for which household members might be eligible.
- Ask household members if they would like access to any of these services. If they would, make participation in these services part of the family care plan.

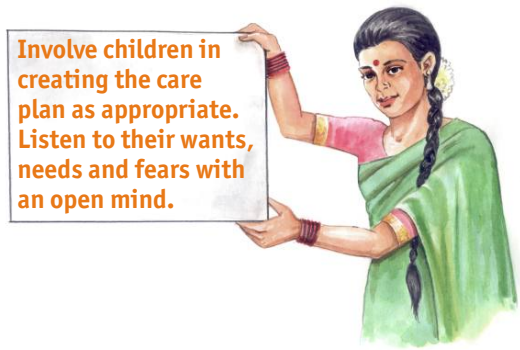
Needs Assessment and Plan for Family-Centered Care					
Family code: ..... Family name:					
Date of visit: ..... Prepared by (name):					
	Main concerns or needs	**Actions to address needs (Direct care or referral)**	**Person(s) responsible**	**When action to be taken/completed**	**Outcome/ follow-up**
1.					
2.					
3.					
4.					
5.					

5.5.6 Creating a family care plan

Once you have taken histories and assessed needs, creating a family care plan can help a household to prioritize its most pressing needs and identify steps to meet them. Such a plan makes the FCM and the children and adults in a household formally accountable to one another. They allow the program to track the changing needs of clients over time and know what has been done to address those needs.

You can create a care plan for an individual as well as an entire household.

Review your assessment of the household's needs, emphasizing the most important ones. If household members are literate, write these primary needs on a piece of paper and ask if the list is correct. Then ask the household members to say which needs they would like to tackle first.



- Show the care plan form to the household and explain how it is used.
- Review all needs that household members have said are priorities and ask what actions the household could take to address each one. Provide information about services that could support the effort. Determine who will be responsible for each action and what the target date for completion will be. Work with the family to distribute tasks in accord with the capacity of household members to handle them.
- You may help by lining up the services and other resources the household needs and by providing health education, counseling and care. Your responsibilities should be listed in the care plan, as well.
- Work with the household to decide key aspects of the plan that may require quick follow-up or referrals.

5.5.7 Ending the visit

- Ask the client and caregiver if they have any more questions or requests.
- Summarize what was accomplished and next steps.
- Thank the household members
- Make sure you have given the household some tools to deal with problems identified during the visit for example, condoms and a directory of services.
- Repeat that you will arrange referrals and help with follow-up, if necessary.
- Schedule your next visit.

5.5.8 After the visit

- Review your main findings and identify follow-up mechanisms for the household.
- Check the household case file to make sure it is correct and that medicines or supplies that have been given to the family are recorded in the logbook.
- The file should then be stored in a safe place.
- Follow up on the referrals you made.
- Debrief your supervisor about what went well during the visit and what needs improvement the next time.

- If issues arose during your visit that you were not sure how to handle, ask your supervisor for advice.

5.5.9 Follow-up

- During each monthly visit, review the care plan with household members and update it to reflect the progress the household has made in meeting its needs.
- Find out if any new needs have come up and revise the plan to meet them.
- Schedule the next visit.

How does a family case manager determine the priority of a child's need for service

Case managers use the Child Status Index (CSI) to track the well-being of each child in their care. The CSI reveals a child's baseline level of need and is a tool for follow-up assessments of need periodically throughout a child's participation in the project. The CSI captures the needs of a child in the context of the household setting. An FCM can also use the CSI for a community assessment, to identify the neediest children and assign priorities for home visits accordingly. (Refer Annexure 7: Child Status Index and Annexure 8: Child Community Home-Based Care form)

Challenges in assigning priority to households and strategies to overcome them

Challenges	Strategic responses
Aversion to meeting the FCM at home	Work with the beneficiaries to determine alternative meeting places that are suitable and convenient.
Unacceptability of a male FCM in a woman-headed household or in a household with adolescent girls	A female FCM can visit the household.

Frequently asked questions: Home Visits

1. What are the criteria for a house visit to have high priority?

Here are some examples:

- A member of the household is on ART.
- A household member has recently started ART.
- A household member has recently been diagnosed HIV-positive.
- A child who is HIV-positive is on ART.
- A household is coping with OIs.
- A child or adult with HIV is sick or at the end of life.
- Household members are bereaved.

2. What challenges does a family case manager face during the first house visit?

Here are some common challenges:

- A person who signed a consent form at an ICTC is no longer willing to participate.
- The beneficiary expects financial support.
- Household members are unwilling to provide information to the FCM.
- The date, time and place of a visit that is convenient for the beneficiary is inconvenient for the FCM.

6 Health

6.1 What does "restoring health" mean?

Although people living with HIV can be healthy and strong and lead perfectly normal lives, they can also experience HIV-related symptoms that affect their daily lives and place them in need of assistance. People living with HIV require complete information on the potentially debilitating effects of HIV, the infection's progression and measures to reduce morbidity and mortality. They require easy access to health services and support to avoid transmitting the virus. "Restoring health" means strengthening the quality of care to reduce mortality and morbidity in children and adults with HIV.

6.2 Whose health should be protected?

An effective package of HIV services should protect the health of all members of HIV-affected households.

6.3 What essential services are provided in the health domain of Balasahyoga's HIV care and support package?

6.3.1 Testing, care and treatment for adults in registered households

This service covers counseling and referral for HIV testing; pre-ART registration; CD4 testing; ART treatment and support for adherence; TB tests; OI treatment and support for adherence; and palliative care for pain and other symptoms, routinely and at the end of life.

6.3.2 Testing, care and treatment for pregnant women in registered households

This service covers counseling and referral for registration for antenatal care (ANC) and clinical examination; HIV testing; registration at an ART center; ART prophylaxis, treatment and support for adherence; ANC follow-up and check-ups; registration in India's Integrated Child Development Scheme (ICDS) and in Anganwadi centers for nutrition and immunization services for mothers and children, as well as for iron folic acid (IFA) supplementation; registration for PPTCT services; institutional delivery and administration of nevirapine; and services to support breastfeeding, weaning and complementary feeding.

6.3.3. Testing, care and treatment for children and adolescents

This service covers counseling and referral for institutional delivery and administration of nevirapine (NVP); cotrimoxazole (CTX) prophylaxis; registration in the Universal Immunization Program (UIP); EID using the DNA PCR test; registration for double nutrition in ICDS; growth monitoring; for children, management of OIs, supplements of fortified blended food (FBF), deworming and treatment of severe acute malnourishment; CD4 testing; ART treatment, prophylaxis and support for adherence; testing and treatment of TB and other OIs and support for adherence; and palliative care for pain and other symptoms, routinely and at the end of life.

6.3.4 Services for discordant couples

Discordant couples are those in which only one partner is HIV-positive. Among the services such couples require are counseling and referrals for support for family planning and safe sex practices.

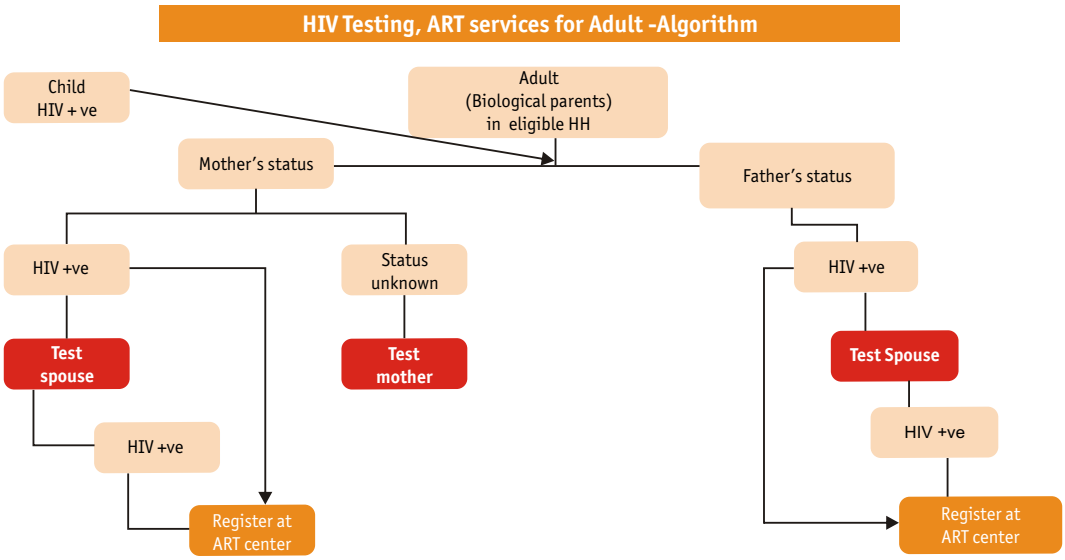
6.4. HIV testing (adult and child)

This section explains what HIV testing is, where it can be done, who should be assigned priority for the test, the importance of EID and the role of the FCM in ensuring that all eligible individuals are tested for HIV.

6.4.1 Steps to ensure access to HIV testing

- Identify adults and children eligible for testing, using the algorithm depicted below in Figure 6.1.
- Assign priorities to the households to be visited, using the eligibility criteria given in Balasahyoga's household prioritization tool. (Refer Annexure 3)
- Counsel and motivate family members and caregivers on the importance of HIV testing.
- Offer home-based pre-test counseling.
- Refer clients to an ICTC for testing.
- Set the day of the visit to the ICTC for HIV testing.
- Accompany the client and other household members as appropriate on the first visit to an HIV testing site, which could be an ICTC, a CCC or a clinic for PPTCT, ART or the directly observed treatment strategy (DOTS) for TB.
- Provide post-test counseling and follow-up.

Figure 6.1



6.4.2 Steps in pretest counseling

Pretest counseling is an opportunity for an FCM to motivate a client who is HIV-positive to take the family to be tested. To achieve this, the FCM

- explains that early detection of HIV is important, because it opens the door to early care and support and prevention of mother to child transmission,
- probes a client's barriers to HIV testing (Research has shown that simply providing information on the importance of testing does not bring about behavior change),
- lists these barriers, and
- helps the client see and surmount the barriers, by asking open-ended and hypothetical questions such as, "What would happen if your wife is also found to be HIV-positive?"

Pretest counseling allows the FCM to provide moral support for clients who want to be tested and prepare clients for additional support when test results are reported.

6.4.3. Steps in post-test counseling following a diagnosis of HIV-positive status

The FCM should help the client to accept and cope with HIV. Make effective use of silence to give the client space to overcome his or her emotions.

- Explore the client's feelings, asking open-ended questions such as, "What are your major concerns about being HIV-positive?"

In response to the concerns the client expresses, the FCM may continue counseling on topics such as planning for the future (family planning, financial planning, care for children); emotional support (family support, social and spiritual support, peer support, access to organizational support); medical care (treatment and prevention of infection and disease); preventing transmission of the virus to a child; preventing transmission of the virus to a sexual partner, using risk-reduction strategies such as abstinence, being faithful, using condoms, having fewer partners and disclosure of status; and preserving health (positive living), through good nutrition, cleanliness, rest, drinking water and exercise.

6.4.4 Where can clients be referred for testing?

The FCM needs to know the location of HIV testing sites within reach of clients. The list of centers in a district can be obtained from the medical officer at a primary health center (PHC), and also from the district medical officer.

Referrals for testing are generally made as follows:

- Children born to HIV-positive mothers who are between six weeks and 18 months of age can receive the DNA/PCR test at the district ICTC.
- All eligible children older than 18 months and all eligible adults can be tested at ICTCs.
- Pregnant women can be tested at an ICTC or at a center for PPTCT.
- HIV-positive children and adults can receive CD4 testing at ART centers
- HIV-positive children and adults should go to a PHC or a community health center (CHC) every six months to be tested for TB.

The FCM can help women and men in the village with information about integrated counseling and testing centers nearby.

6.4.5. Who should receive priority for HIV testing?

- Children of HIV-positive women, if they have not already been tested
- Orphans who have not been tested
- Adolescents who are sexually active
- Any child reporting sexual abuse
- Pregnant women whose HIV status is unknown and whose spouse or partner is HIV-positive
- Anyone whose sexual partner is HIV-positive or HIV-reactive (that is, who has a preliminary but inconclusive diagnosis of HIV)
- Parents of children who are HIV-positive
- Anyone with symptoms or a diagnosis of TB

HIV and TB are common co-infections. An FCM should encourage anyone with active TB to be tested for HIV.

- Individuals with symptoms of HIV
- Anyone who has a sexually transmitted infection (STI)

6.4.6 How should a family case manager handle the testing of children at risk for HIV?

Counsel the caregivers and the child on the importance of testing

Testing a child will benefit the child and the caregiver in the following ways:

- If the child receives an HIV-negative diagnosis, worry about the child's status will end.
- A child who is HIV-positive is entitled to free care and treatment at government ART centers.
- A child who is HIV-positive can begin to take advantage of government-provided treatment to prevent HIV-related OIs (CTX prophylaxis, for example), which can help the child to avoid illness and hospital stays.
- The caregiver will know why the child sometimes gets sick and what to do when that happens.
- The caregiver can explain why the child gets sick and involve the child in his or her own care.
- The child and caregiver can plan appropriately for the future.
- The child and caregiver can take early advantage of social and emotional support services.

Arrange for a child to be tested for HIV at the appropriate time

Infants and children should be tested under the following circumstances:

- to determine an infant's status for the purpose of appropriate follow-up, which includes provision of CTX prophylaxis, ART prophylaxis and/or treatment for HIV
- for early diagnosis (at around four to six weeks of age or as soon thereafter as possible) of an infant who may have been exposed to the virus through mother-to-child transmission
- to confirm the HIV infection status of a child born to an HIV-positive mother six weeks after the child's exposure to HIV through breast feeding has ceased or at 18 months, whichever is sooner
- to determine whether a child who is presenting with an HIV-associated illness, such as tuberculosis or malnutrition or a recurrent, common childhood illness such as pneumonia or diarrhea, has acquired the virus
- to determine the status of a child whose sibling or parent has been diagnosed with HIV or whose parent has died of AIDS or of a debilitating but undiagnosed illness
- to determine the status of a child who has been exposed or may have been exposed to HIV through sexual abuse, sticks with a contaminated needle, receipt of potentially infectious blood or blood products or through some other route, such as wet nursing

Procure the child's informed consent

Parents or legal guardians usually give consent for medical procedures, including HIV testing, on behalf of children younger than 10. It is unusual to seek informed consent directly from a child in that age group. A child who is older than 10 is usually involved in the process of discussing HIV testing and obtaining consent from the parent or guardian. According to the United Nations Convention on the Rights of the Child, a child has the right to "participate in decisions affecting his or her life." The convention also states that children's desires should be "given due weight in accordance with their maturity." Verbal communication is normally adequate for the purpose of obtaining informed consent from the parent or guardian. Consent from one parent (maternal or paternal) should be considered sufficient.

Orphans, child survivors of rape, abandoned infants and street children may not have a parent or guardian who can give consent on their behalf. In such situations, the FCM should determine the best interests of the child and make the decision.

Use age-appropriate communication techniques to counsel children about the HIV test

Appropriate counseling is inseparably linked to HIV testing. Uncertainty about how to properly counsel children about HIV is one reason why caregivers are reluctant to have children tested. The skills required to counseling children about HIV are not the same as those required to counsel adults and adolescents. The counselor must be able to accurately assess maturity when informing children of their HIV status. Interactive tools such as drawing, storytelling and skits can help children to express themselves, explore sensitive issues and identify solutions. Because these are forms of play, they help children to feel safe in the counseling setting. It is important for the FCM to be equipped to use many such tools in a single session, because most children's attention spans are short.

Protect the child's confidentiality when reporting the results of the test

All children have a right for their HIV status to be kept confidential. The United Nations Convention on the Rights of the Child obliges member states that ratified it (among them, India) to respect children's privacy. The term "disclosure" is often used to refer to the process of informing a child that he or she is HIV-positive. Disclosure is best undertaken in a planned and supportive way, gauged to a child's age and readiness. The FCM may inform the child, a parent may do so, or the FCM and the parent may conduct the conversation together. A caregiver may participate if a parent is not available. Disclosure can occur over time, as the child receives care and treatment.

Disclosure carries risks of stigma, discrimination and violence but its benefits are improved adherence to treatment and better understanding of HIV infection control.

6.4.7 What is early infant diagnosis?

The HIV tests now available in India make it possible to know if a child is HIV-positive even before she or he is 18 months old, at which point immunoassay tests for antibodies to the virus deliver reliable results. Until that age some children still have their mother's HIV antibodies in their blood, which can produce a false-positive test result. The DNA PCR, which tests directly for the DNA of the virus, not the antibodies, can provide reliable results for infants as young as six weeks. Originally, this valuable tool for EID required a liquid blood sample, and the refrigerated transport needed to deliver the sample to a testing facility put the DNA PCR test out of bounds for many people. The advent of a dried blood spots (DBS) sampling option removes that obstacle and has brought EID within reach of poor and rural households.

The FCM's responsibilities for child testing are as follows:

- Ensure that all children older than six weeks whose mothers are HIV-positive are referred to an ICTC for a DNA PCR test – most likely the DBS test.
- Ensure that children who are tested, whether the result is positive or negative, return to the clinic to be informed about the result. Those with a positive result need to undergo a test for confirmation.
- Retain infants who are breastfeeding in care until they are weaned, at which point the final test to determine their status should be administered.
- Link infants and children who are identified as HIV-positive to pediatric HIV care and treatment services.

Refer to the algorithm (Figure 6.2, below) to determine a child's eligibility for HIV testing. Children from 6 weeks to 18 months of age who are known to have been exposed to HIV need to be referred to an ICTC for a DNA PCR test. Children between 18 months and 14 years of age should be referred to an ICTC for an HIV immunoassay test (the standard diagnostic tool for adults, as well).

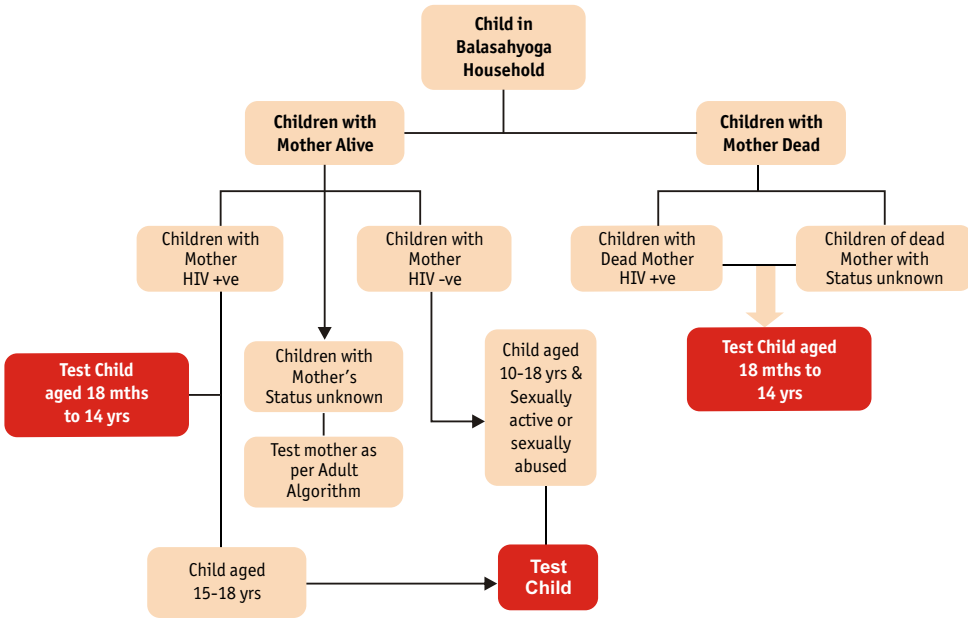
Children of all ages need to be assessed for their vulnerability to sexual abuse, which is a risk factor for exposure to HIV. Older children should also be assessed for sexual behavior that could expose them to the virus. Children determined to be at risk for HIV should be referred to an ICTC to be tested. The FCM should support the referral in the following ways:

- Make a home visit a priority and use the time to motivate the family to have a vulnerable child tested, by describing the benefits of early testing.
- Explain the testing procedure for children and assure the family that confidentiality at all levels will be maintained.
- Obtain consent from parents or caregivers for the child to be tested.
- Schedule the test and let the child and family know where and when it will be.
- Go to the household before the child's appointment and accompany the child (and possibly the child's family, as well) to the ICTC.

An FCM can educate family members about the high quality and reliability of HIV testing at government facilities.

Figure 6.2

Algorithm for Testing Children



Challenges in the child testing process and strategies to overcome them

Challenges	Strategic responses
Refusal to consent to testing of children, perhaps for fear that results will be positive	Counsel family members on the benefits of testing a child early.
Refusal to test adolescents (especially girls) for fear of harming their prospects for marriage	Counsel by sharing case studies, without compromising confidentiality. Seek the support of PLHIV support groups to motivate the family for testing.
Refusal of adolescents to be tested, because they believe they have no chance of acquiring HIV	Educate the adolescents about risk behaviors and the process of HIV transmission.

6.5 HIV treatment

This section describes the care and support services available to people who are HIV-positive and the role of the FCM in supporting access to those services.

The following services are essential for HIV care and treatment:

- pre-ART registration
- CD4 testing
- ART treatment and adherence to treatment
- testing, treatment and adherence to treatment of OIs, including TB

6.5.1 Pre-ART registration and CD4 screening

The CD4 test is a blood test whose result indicates the body's immune status – that is, the body's capacity to fight infections. The higher the CD4 count, the stronger the body's immune system is. The CD4 test is available at no charge at all ART centers and district hospitals in India. A CD4 count lower than 250 indicates the need for more tests and possible initiation of ART.

An FCM can help clients prepare for ART in the following ways:

- Encourage clients to visit the health facility for regular check- ups so a doctor can determine when ART is needed.
- Help clients understand all of the benefits and drawbacks of ART before therapy begins.
- Motivate PLHIV to undergo CD4 tests every six months.

An FCM may encourage all those diagnosed as HIV-positive to register at ART centers and have a CD4 test done right away. These steps position PLHIV to begin free ART as soon as the therapy is needed.

An FCM should approach registering children in an ART center with special care, as follows:

- Counsel caregivers about the children's potential need for ART. (Refer to Figure 6.3, below: the ART treatment cascade.)
- Counsel children and their caregivers on the importance of registering in an ART center before the therapy is needed and also on the value of the TB screening that these centers provide. Educate them about the registration process.
- Write formal referral slips for HIV-positive children to visit an ART center.
- Be aware that orphans may not have adequate support from the adults in their lives to manage registering at an ART center for a CD4 test. If necessary, accompany the child to the center for pre-ART screening.

6.5.2 ART treatment and adherence

To date, HIV has no cure. Antiretroviral therapy is a combination of drugs that is effective in suppressing the virus – keeping the virus cells from multiplying – for a long time. The therapy reduces morbidity and mortality and improves quality of life. Not all children with HIV need ART. Eligibility for the therapy is determined at government-operated ART centers after clinical, laboratory and psychological evaluation.

Antiretroviral drugs are usually administered in tablet form. For smaller children who cannot swallow tablets, syrups are prescribed.

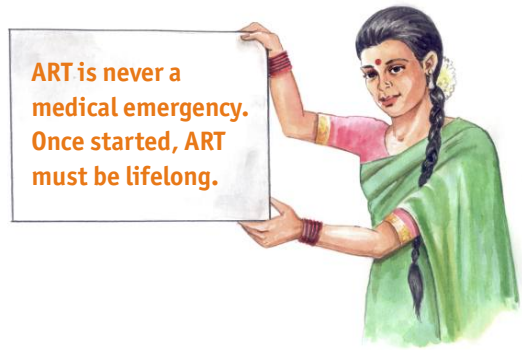
To support clients newly introduced to ART, the FCM should make their households a priority and visit once every 15 days for three months. The FCM's tasks during this period are to educate the clients about the therapy and prepare them for lifelong treatment.

Successful adherence requires understanding the dosage regimen (dose, duration and frequency); integrating the regimen in daily life, which makes remembering to take the medicines easier; understanding potential side effects and how to manage them; and recognizing signs of a toxic reaction to the drugs. The more clients know about the progression of HIV and OIs, about the operation of the body's immune system and about their own condition, the less trouble they will have managing the regimen. The FCM can help with all of this.

The FCM should begin by assessing their clients' willingness and readiness for ART, reviewing systems already in place to support their clients' adherence, and sizing up potential barriers to adherence such as lack of transportation.

The FCM's plan for regular follow-up should include the following checklist:

- client's adherence to counseling, based on pills counts and self-reports
- asking about side effects and encouraging the client to report them early
- review of diet, nutrition and positive living
- review of the impact of treatment on other areas of life and vice versa
- asking about the client's sources of social support
- assessing barriers to adherence and developing plans to overcome them.



Clients newly initiated on ART will need frequent visits. The FCM should keep the ART center constantly in view, referring clients to the center for help managing side effects and reminding them about their next scheduled visit.

The 5 Rs of good adherence:

- Right drug: Take the drug that is prescribed.
- Right dose: Take the drug as prescribed.
- Right time: Take the drug at the time it is prescribed.
- Right way: If the drug is in syrup form measure the dose with a spoon or a measuring cup or cap.
- Right frequency: ART is lifelong and the drugs must be taken every day.

6.5.3 Signals of a client's capacity for ART adherence

Predictors of good adherence are

- clients' willingness to disclose their own status
- availability of emotional and practical support
- ability to fit medication into the daily routine
- feeling comfortable taking medication in front of others
- belief and confidence in the providers and in the efficacy of the medicines
- personal determination to adhere to treatment
- improvement of symptoms in response to ART
- availability of adequate food and regular meals
- keeping appointments with the center

Predictors of poor adherence are

- poor relationship with treatment center
- active mental illness or depression
- drug abuse or alcoholism
- lack of education
- poor nutritional status
- lack of reliable access to primary health care and education
- side effects of medication or fear of side effects
- domestic violence
- belief systems and cultural practices that interfere with positive living

6.5.4 Adherence counseling

Before ART begins, the FCM should schedule at least two sessions with a client and use them to develop a rapport built on trust. During this period the FCM should conduct a behavioral and psychosocial assessment of the client; educate the client about ART, emphasizing the importance of adherence; encourage the client to invite peers to participate in the process; and help the client identify people who will support the therapy.

The FCM should also take advantage of this period to encourage (but not force) disclosure, assess the client's readiness for and commitment to ART, develop an individual treatment plan, explain side effects and provide information sheets.

When ART begins, the FCM should reassess the client's readiness to initiate antiretrovirals and counsel the client on all aspects of the therapy. The main points to cover are that ART is lifelong; why adherence is important; what the medicine does; what the side effects might be; and that side effects usually resolve within the first three months of treatment. The FCM will also advise the client on storing the medication; anticipate and resolve any practical problems in the treatment plan; and assess financial difficulties and help access secondary sources of support. This is also a good time to confirm the client's contact details.

Two weeks after ART initiation, the FCM should assess adherence on the basis of pill counts and the client's self-report. If the client is not taking the correct doses, the FCM needs to find out why and work out strategies for adherence. For example, if the client is experiencing side effects, the FCM can offer an explanation of them and reassurance that they are probably short-term. The FCM should check for use of alcohol and non-ART drugs (prescribed and unprescribed), because they can hinder adherence and create or exacerbate side effects. The client's plan for positive living, including adequate diet, nutrition and exercise, should be reviewed. The conversation should also touch on ART's impact on other areas of the client's life; the FCM can suggest ways to minimize some of the negative effects. Going over the follow-up plan, the FCM should confirm that family and community support anticipated in the plan has in fact been consistently available to the client.

To support adherence to pediatric ART, an FCM should apply the same standard for adequate adherence to children as to adults: 100 percent. The same approach to support for adherence can also be adopted, with ageappropriate modifications. For example, caregivers will need education on adjusting dose to a child's weight, because as the child's weight increases, doses must change. Explanations of ART and the importance of adherence need to be pitched to the child's level of understanding, using such interactive communication strategies as role-playing, storytelling and games. For adherence to be successful, the family must support the child's other essential needs; the FCM can help with this through counseling and arranging for services. Peer education or involvement in PLHIV family groups can be helpful, as well.

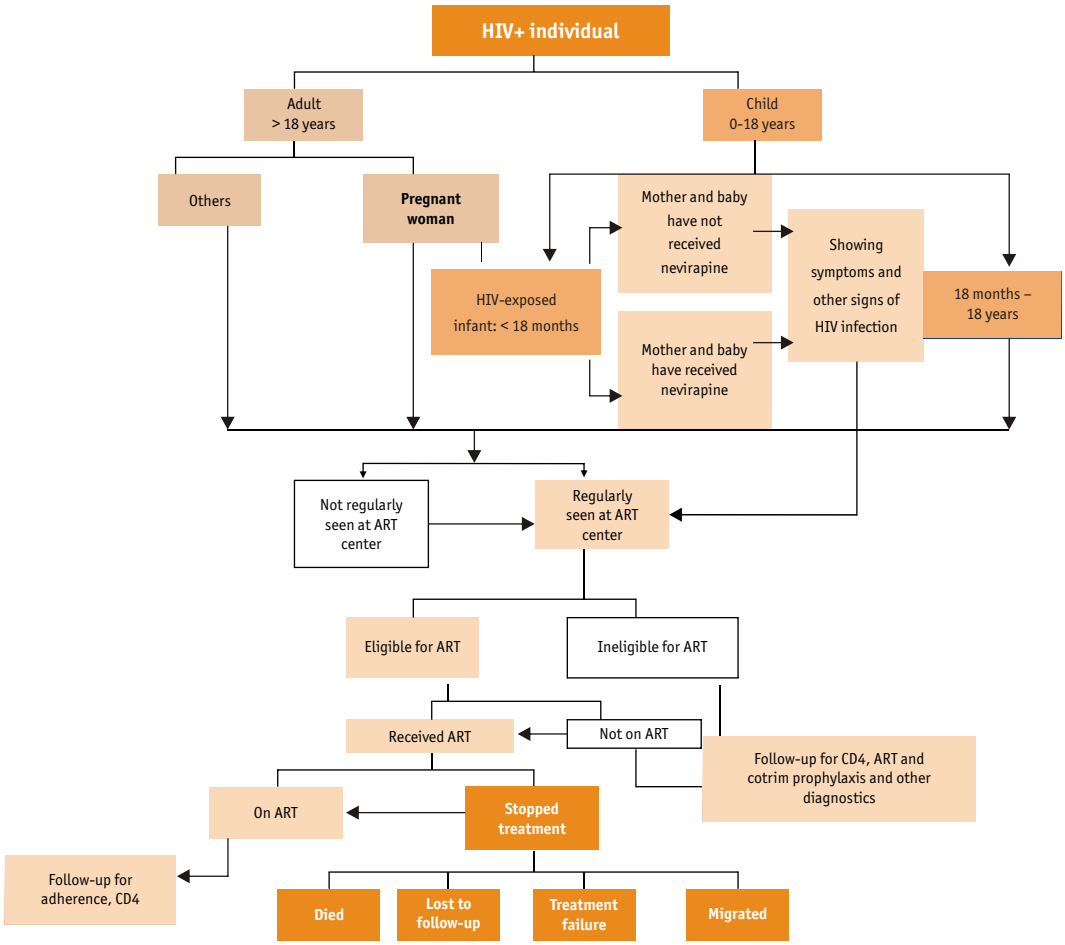
Tips for parents and other caregivers to troubleshoot adherence to pediatric ART

- If the child vomits within two hours of taking antiretroviral medicine, repeat the dose.
- If the child misses a dose, give it as soon as you realize it – up to six hours late for a twice-per-day medicine and then continue on the regular schedule. However, do not give two doses at the same time.
- If the child refuses the medicine, say that you understand that taking medicine is not fun. Threatening, punishing or yelling at the child makes the situation worse. Instead, mix the medicine with a small amount of food or liquid: porridge, clean water or juice. Keep trying until you find a combination the child will accept, and don't give up.
- Help children achieve selfconfidence and maintain a positive attitude towards ART.

An important task for the FCM is to tell clients that side effects are common with ART and they usually go away in two to three weeks.

Figure 6.3

Treatment cascade



6.5.5 Clients who are lost to follow-up

Clients who are three months late for ART and still have not returned to the ART center for treatment are considered lost to follow-up (LTFU). Some common reasons for this lapse are

- migration
- death
- unwillingness to continue ART
- wrong address

- lack of a means of affordable transportation to the ART center
- limited or no mobility because of the client's physical condition
- financial constraints
- high client load at the center
- client's fear of disclosure
- loss of the client's file or errors in the file
- malfunction of the CD4 machines
- inadequate number or capacity of the CD4 machines
- client dislikes the center's staff or feels disregarded by them
- client has chosen to relay on traditional medication

Part of the FCM's job is to find clients who are LTFU and get them back on schedule for ART. Follow-up visits with the households of these clients should be a priority. Once contact is made, the FCM should attempt to find out why the client has not returned to the ART center for treatment and repeat the counseling on adherence, enlisting the support of family members if necessary.

Strategies to prevent loss of clients to follow-up

- Attempt to connect clients whose conditions are critical with a trained counselor for counseling.
- Analyze and troubleshoot client flow and waiting time in coordination with ART center staff.
- Link the client to a support group of PLHIV for peer counseling.
- Report clients who are unwilling to continue ART to the field supervisor, who will consult with the facility coordinator.
- Educate the client's family members on the benefits of ART, by sharing success stories.
- Conduct community sensitization meetings in areas with clusters of clients who are LTFU.
- Inform clients about incentives for PLHIV to adhere to the ART regimen (pension; free bus passes).

6.6 HIV prevention strategies for discordant couples

The FCM can help discordant couples in the following ways:

- Ask if the HIV-positive partner has disclosed his or her status to the HIV-negative partner.
- If not, discuss the reasons for nondisclosure.
- Educate the client on the benefits of disclosure to the HIV-negative partner and other family members.
- Educate the client about strategies for disclosure: complete disclosure and partial disclosure. (Refer to Training in basic counseling methods for family case managers: Trainer's guide. FHI 360/India).
- Discuss the possible consequences and challenges of disclosure and ways to address them.
- After the client has disclosed his or her status, counsel the HIV-negative partner about HIV prevention, infection and treatment.
- Enroll the client in a PLHIV support group.
- If the female partner is of childbearing age, discuss family planning. Explain the options for contraception and their availability. Discuss the importance of using condoms along with another family planning method to prevent pregnancy and HIV transmission.

6.7 Services for pregnant women who are HIV-positive

The FCM can make a big difference in PPTCT, by teaching mothers about HIV and supporting them over time. In the absence of intervention, about one in three babies born to women who are HIV-positive will acquire the virus. HIV can be passed from mother to baby during pregnancy, during labor and birth or during breastfeeding. The risk of transmission is especially high when breastfeeding is mixed with bottle-feeding. Transmission of the virus is not inevitable, however. The FCM has several tools during pregnancy, delivery and the postnatal period to prevent HIV transmission from mother to child.

6.7.1 The family case manager's role in preventing mother-to-child transmission

The broad scope of an FCM's responsibilities in this arena extend from helping to keep women safe from HIV before they become pregnant to helping pregnant women who are HIV-positive avoid transmitting the virus to their babies.

Supporting primary prevention of HIV infection among women of reproductive age

The optimum way to protect infants from HIV is to teach women how to protect themselves from acquiring the virus. The FCM can educate women in a community about HIV prevention strategies and motivate them to adopt the strategies.

The FCM can disseminate prevention messages community-wide and to women, in particular. The case manager can also promote the services available through ICTC and ART centers. The case manager is well-positioned to teach HIV-positive women who are pregnant how they can prevent transmitting the virus to their baby.

Helping women who are HIV-positive prevent unintended pregnancies

The FCM should take care to affirm the right of women who are HIV-positive to bear children, if they wish. The case manager can then present the variety of contraceptive methods in the context of their availability and provide a referral to a nearby health facility for the woman's method of choice. The client should be informed about emergency contraceptive pills and where she can obtain them if she has unprotected sex. The case manager should also let the client know that medical termination of pregnancy is available and help her think about that option in terms of her personal needs and wishes.

An important message for households affected by HIV is that all women, regardless of their HIV status, have the right to choose whether or not to have children.

Helping HIV-positive mothers prevent transmitting the virus to their children

This service should begin before the child is born. The FCM should make sure that all pregnant women in households affected by HIV are tested early, so that those whose status is positive can obtain the diagnosis and be treated.

Pregnant women who are HIV-positive should be registered at an ART center. When antiretroviral drugs are given during pregnancy, delivery and postnatally, they reduce the concentration of the virus in maternal fluid, tissues and breast milk. The therapy reduces the risk that the virus will be transmitted to the infant and also improves the health of the mother.

The FCM should refer all pregnant women in households affected by HIV to an ICTC for HIV counseling and testing, in order to combat transmission of the virus from parent to child.

Networking HIV-positive pregnant women to AWWs and ANMs is a good way to ensure that they receive regular ANC check-ups. The FCM should refer these clients for diagnosis and treatment of STIs such as pelvic inflammatory disease and bacterial vaginosis, because these conditions increase the risk of mother-to-child transmission. The expectant mother should be encouraged to choose an institutional setting for delivery, and she and her family should be counseled about proper nutrition during pregnancy.

At women's group meetings, the FCM should talk about the services available to women who are HIV-positive, explaining how those who are pregnant or planning a pregnancy can avoid passing the infection to their children.

Supporting access to intrapartum and postpartum services

The FCM should make sure that the drug nevirapine (NVP) is administered. A single dose of given in labor to the mother and to the baby immediately after birth helps prevent transmission of HIV from

mother to child. This drug is given free of charge at hospitals that have centers for PPTCT services.

The FCM must ensure that all HIV-exposed infants have HIV virological testing at four to six weeks of age or as soon as possible thereafter. Refer all children younger than two whose test result is positive for initiation of ART, regardless of their CD4 count and stage according to the World Health Organization's criteria.

The FCM must ensure that all infants with an initial HIV-positive virological test result are referred to an ART center for immediate initiation of the therapy. Parents and caregivers must be informed that they should not withhold ART while they wait for the result of a test to confirm the preliminary diagnosis.

Counsel HIV-positive mothers on breastfeeding options: either exclusive breastfeeding or exclusive formula feeding. (Refer to the section below on infant feeding.)

The FCM should watch for symptoms of HIV or progression to AIDS in the baby.

It is also the FCM's duty to make sure the baby goes to a health facility for immunization, growth monitoring, medicines and CTX prophylaxis. (Refer to the section below on CTX.)

6.8 The role of the family case manager in cotrimoxazole prophylaxis for children

Cotrimoxazole is an antibiotic. Used as a prophylaxis, the drug helps infants exposed to HIV stay healthy, and should therefore be given once a day until the virus can be reliably ruled out. Babies and older children who are HIV-positive should continue taking the drug, because it prevents OIs and reduces mortality by half.

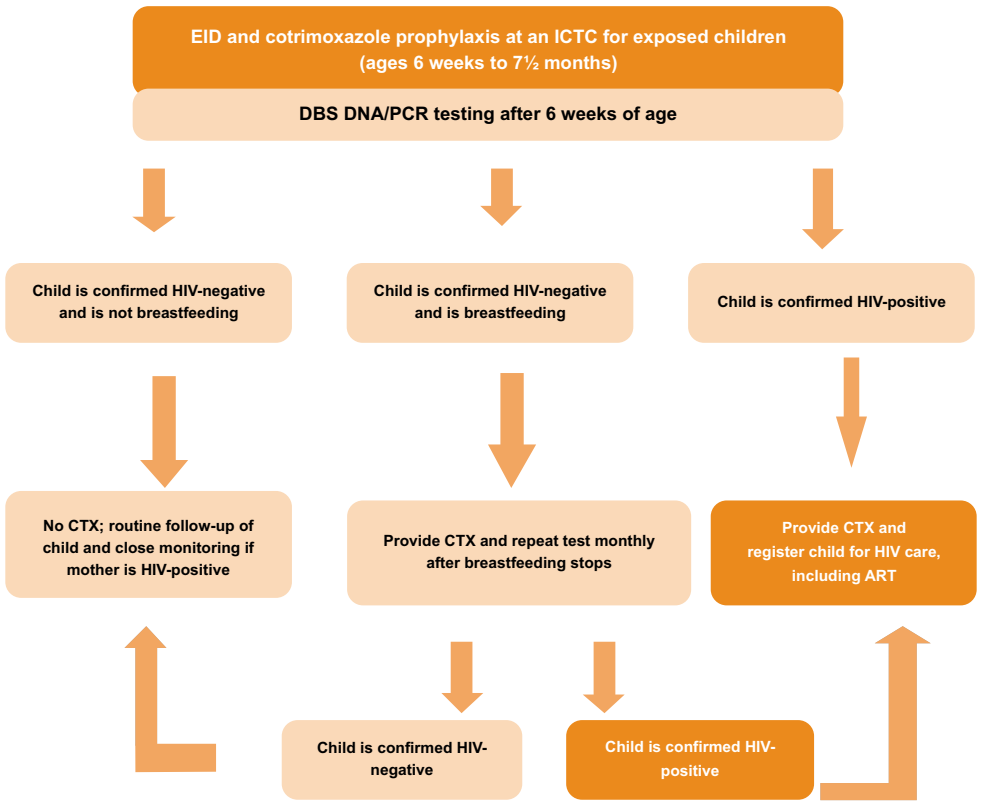
Cotrimoxazole prophylaxis is safe and inexpensive. The FCM can play a key role in ensuring children's access to it. Its scope is as follows:

- Explain to mothers why HIV-exposed infants need CTX prophylaxis.
- Ensure that the drug is given from six weeks of life onward, in doses appropriate to the weight of the infant and in accord with the doctor's advice.
- Provide instructions on administering CTX. If the child is breastfeeding, the tablet can be dissolved in expressed breastmilk and given on a clean tablespoon. If the child is not being breastfed, dissolve the tablet in one to two tablespoons of boiled water.

- Make sure a caregiver collects CTX supplies from the CCC or ART center each month until the child is confirmed to be free of the virus. Even children who test negative for HIV should continue on CTX for as long as they are breastfeeding. All infants and children who are confirmed to be HIV-positive should remain on CTX until they reach the age of five, are on ART, and show good clinical and immunological response to the therapy. (Refer to Figure 6.4.)
- Monitor the child's response to CTX prophylaxis and ensure adherence to the regimen prescribed as appropriate to the child's age and weight, providing counseling on adherence when necessary.

The FCM should ensure that every child born to a mother who is HIV-positive receives cotrimoxazole prophylactic therapy.

Figure 6.4



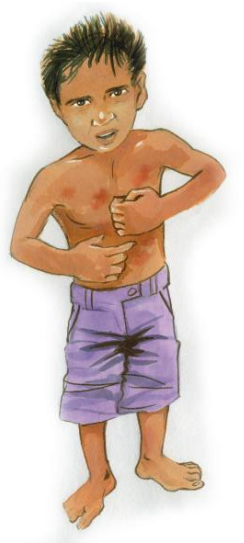
6.9 Managing opportunistic infections

Opportunistic infections are those likely to occur in people whose immunity is weak. The appearance of many OIs correlates with the CD4 count – the clinical indicator of poor immune status.

In the early phase of HIV, people can develop tuberculosis, malaria, bacterial pneumonia, herpes zoster, staphylococcal skin infections and septicemia. People with normal immune systems can get these diseases, as well, but they occur at a much higher rate among people with HIV. A person with HIV also needs more time to recover from OIs than someone with a healthy immune system does.

When HIV advances to a late stage, further weakening the immune system, many OIs can be fatal.

6.9.1 Prevention and treatment of skin problems



The FCM should be familiar with HIV-related skin problems and advise clients and their caregivers on ways to avoid and manage them, as follows:

- Keep the skin clean and dry.
- Wash with mild soap and water.
- Wear shoes.
- Drink plenty of water.
- Keep nails short and clean to avoid breaking the skin when scratching.
- Cool the skin with water or a fan when itching is severe.
- Use the flat part of the hand to scratch, not the fingernails.
- If a child or adult cannot resist scratching to the point of damaging the skin, put soft gloves or socks on their hands.
- Use any local herbal remedies that are effective.
- Apply petroleum jelly (Vaseline) to dry skin.
- Rub pressure areas during bathing and during massage to improve blood circulation and prevent sores.
- Do not use powder on skin with open sores.

Some skin problems, such as abscesses and worsening skin infections, must be treated at health facility. The FCM can help these clients by referring them for medical attention.

6.9.2 Prevention and treatment of sore mouth and throat

The FCM should be familiar with HIV-related sores on the mouth and throat and advise clients and their caregivers on ways to avoid and manage them, as follows:

- Rinse the mouth with warm water with a pinch of salt.
- Suck on a lemon to ease the pain of white, patchy sores on the lips and in the mouth.
- Use any local remedies that are soothing and safe.
- Eat soft foods.
- Use a straw for soups and other liquids.
- Take cold food and drinks or ice to numb the mouth and relieve the pain.

Refer for medical attention a client who has thrush on the esophagus and can't swallow without burning or deep pain in the chest.

6.9.3 Prevention and treatment of pain

People with HIV often suffer from headaches, muscle pain, joint pain and generalized pain. Infants and children may not be able to communicate that they are in pain with words but rather with a change in their behavior, such as crying, restlessness or withdrawing from activities they usually enjoy. The FCM should teach families what to do when a household member with HIV is in pain, as follows:

- Use any local remedies that ease pain.
- If the person is lying in bed, help him or her to change position frequently and elevate the legs or swollen body parts on pillows or folded blankets.
- If the person is experiencing pain in the chest, have the person sit in an upright position as much as possible.
- Rub and massage sore muscles, using oils or lotion.
- Talk with the person. Distract the person from their pain with conversation, music or telling a story.
- Keep the environment as calm as possible.
- Rely on the health facility for the right dose of basic pain medicines such as paracetamol. taken with lots of water.
- For headaches, encourage the person to avoid strong tea or coffee and to rest in a quiet, dark room with a cold cloth over the eyes and forehead.

Refer for medical attention a client whose pain is new, different and strong; whose pain does not respond to basic pain medicines; or whose pain is causing breathlessness.

6.9.4 Prevention and treatment of fever

The FCM should advise clients and their caregivers on the following ways to avoid and manage fever:

- Bathe with cool water or wipe the skin with cool, wet cloths.
- Drink more fluids (water, tea, broth or juice) than usual. Offer drinks every one or two hours for the client to sip if he or she cannot drink quickly.
- Use any safe local remedies that reduce fever.
- Wear light clothing.
- Help the person stay clean and dry.

Refer for medical attention a client who has had a high fever for a long time that does not drop with fluids and the application of cool compresses. Also refer a client whose fever is accompanied by severe weight loss and coughing.

6.9.5 Prevention and treatment of diarrhea

The FCM should advise clients and their caregivers on ways to avoid and manage diarrhea, as follows:

- Prevent infection from food or people by washing hands regularly, properly cooking and storing food and making sure that water is clean or boiled before drinking.
- Consume more liquids than usual: boiled water, lemon water, weak tea, broth or juice.
- Continue eating solid foods: porridge and fruit (especially bananas) are recommended. Eat more frequently and make sure the food is clean and not spoiled.
- Wash and dry the skin around the anus and buttocks after every bowel movement.
- Protect dry skin with petroleum jelly (Vaseline).
- Look out for other problems, such as skin irritation that may require medicine.
- Be sure water is clean and has been boiled before drinking.
- Give oral rehydration solution as well as lots of water, soup and juice.
- Watch for signs of dehydration, such as sunken eyes, dry lips or loose skin. (Test for loose skin by pinching the skin on the back of the hand gently between finger and thumb and releasing it. With dehydration the skin will not snap back into position quickly.)
- Eat small meals several times a day.
- Avoid greasy, spicy and fatty foods and favor bland foods such as rice, soup, bananas and biscuits.

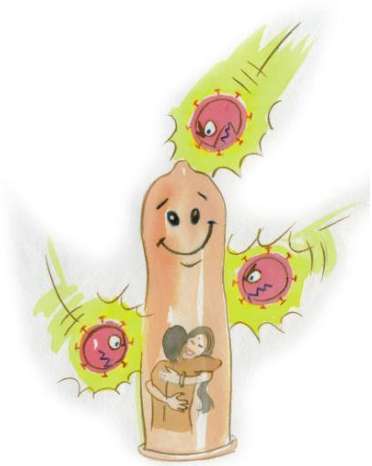
Refer a client for medical attention when dehydration does not improve despite increased fluid intake; when the client is very thirsty but cannot eat or drink properly; when the client has many watery stools; when there is blood in the stool; when diarrhea does not stop; and when diarrhea is accompanied by fever, convulsions and vomiting.

People with HIV can avoid nausea and vomiting by eating small meals frequently; avoiding greasy, spicy and fatty foods; and drinking clean water (boiled, if necessary), weak tea, lemon water or a tea made with fresh ginger. When nausea occurs, the following precautions should be observed:

- Take small, frequent sips of oral rehydration solution, boiled water or weak tea.
- Take medicine with food if the treatment plan allows.
- Watch for the signs of dehydration, such as sunken eyes, dry lips or loose skin.

Refer for medical attention when vomiting is frequent and/or continues for more than 24 hours; when vomiting is accompanied by fever and dehydration; when blood appears in the vomit; when vomiting is accompanied by a swollen belly.

6.9.7 Prevention and treatment of genital problems



The FCM should be familiar with HIV-related genital problems and advise clients and their caregivers on ways to avoid and manage them, as follows:

- Encourage people with HIV to use condoms to protect themselves from STIs (for example, syphilis, gonorrhea, chlamydia, herpes and warts) and also to protect their partners.
- Make women aware of the differences between normal vaginal discharge and discharge that signals an infection. Normal discharge is usually white and thin. If discharge is yellow or green, if there are white clumps that look like curds, or if the discharge smells like rotten fish, there may be an infection.
- Also teach women to prevent genital problems by always using condoms when having sex and by keeping the vulva and the anal area clean.

Refer for medical attention a client who has any of the following symptoms:

- **pain when urinating**
- **genital ulcers and sores**
- **unusual, colored discharge from the vagina or penis**

- **pain in a woman's lower belly, especially urgent when accompanied by fever**
- **irregular period or no period**
- **swelling or pain in the scrotum**

6.10 Managing the side effects of antiretroviral therapy

Side effects are problems created by the medicines given to treat disease or infections. Most of the side effects are mild and temporary, but some of them are serious. Most of the side effects are felt in the first few weeks of ART as the body gets used to the drugs and begins to fight infections. Side effects from ART are not the same for everyone. (Refer Annexure 9: Side Effects of Antiretroviral Therapy.)

6.11 The family case manager's role in palliative care

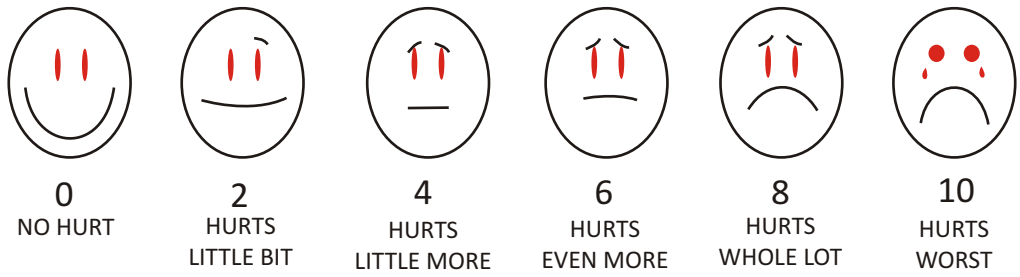
Medical issues related to HIV and to HIV treatment can hinder physical and psychological well-being and compromise adherence to ART. Symptoms can occur early in the progression of the disease and are common among PLHIV taking ART. Palliative care seeks to alleviate pain and other symptoms. The role of the FCM is to understand the spiritual, psychological and social problems of their clients and help as needed.

6.11.1 The family case manager's role in home-based palliative care and support

The FCM can provide palliative care directly for such symptoms as moderate to severe pain, headache, fever, nausea, diarrhea, cough, OIs and fatigue. The FCM can also teach the client self-care practices and can teach the client's household members to provide care, as well, so that symptoms can be managed when the FCM is not present.

The pain assessment tool below can help the FCM, the client, and the client's caregivers recognize when the client's condition warrants medical attention.

Figure 6.5
Pain assessment scale



6.11.2 The family case manager's role in support for social problems

A person with HIV can experience the loss of a job, changes in personal relationships, and an inability to fulfill social and familial obligations and responsibilities. The FCM can help the client cope with social distress. If the client is at the end of life, the FCM can help the dying person and family members make adequate preparation for care of the client's children and inheritance rights.

6.11.3 The family case manager's role in support for emotional problems

A person with HIV can experience isolation, fear, hopelessness, gloom, guilt and fear of death. The FCM needs to make sure the client has emotional and spiritual support and guidance (where appropriate) and be available for the ill person and the family and caregivers.

Bereavement counseling

The FCM must provide support and counseling to a person who is dying and help the person prepare adequately for death. The FCM is also responsible for counseling the family before the client dies (to help them prepare) and after death. Bereavement counseling should continue as long as necessary. In particular, the bereavement issues of children — especially those who are orphaned — must be attended to. The FCM may use the basic elements of effective interpersonal communication to address issues related to death and dying for individual and group bereavement counseling.

Mustering community support

The FCM should encourage community volunteers — for example, members of a PLHIV support group — to provide emotional and spiritual support within the home. In addition, the FCM can work with the community to form peer groups — especially groups of children — to provide mutual support in dealing with bereavement.

6.12 The family case manager's role in managing tuberculosis

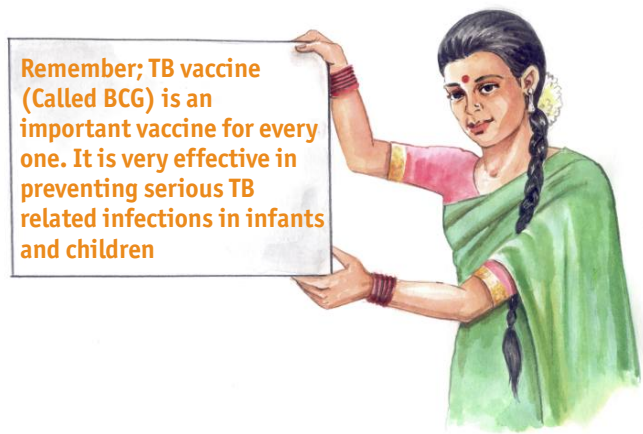
Respiratory problems, particularly lung infections such as TB and pneumonia, are common among PLHIV: about half of all people with HIV develop active TB. Although curable, TB is quite serious. Not only are PLHIV at high risk of acquiring TB; the infection worsens more quickly among those with HIV than among those who are HIV-negative. A person living with both HIV and TB is at risk of developing other serious health problems. Tuberculosis is the leading cause of death among PLHIV.

Tuberculosis and pneumonia and the problems associated with them are often avoidable. The FCM can help, by referring such clients to a health facility. The antibiotics a facility can provide are highly effective in treating TB and pneumonia.

6.12.1 Preventing tuberculosis

An FCM should convey the following information to clients and their families:

- People with signs of TB or who are in their first two months of treatment for TB should sneeze, cough and spit into a tissue, cloth, piece of paper or a leaf, and then dispose of it safely.
- Clients who have signs of TB or who are in their first two months of treatment should spend time outside where there is fresh, moving air to minimize the risk of transmission to others.
- People living with and/or caring for people with signs of TB or who are in their first two months of treatment should keep windows open and allow lots of fresh air to come into the home.
- Remember; TB vaccine (Called BCG) is an important vaccine for every one. It is very effective in preventing serious TB related infections in infants and children
- It is best for a baby not to stay in the same room as a person who has signs of TB or who is in the first two months of treatment, even if that person is the baby's mother.



6.12.2 Treating tuberculosis

An FCM should keep the following information in mind:

- Everyone with a cough lasting for two weeks should be tested for TB at a health facility, because treatment is available. Treatment will help cure the person with TB and also reduce the spread of the disease.

- On their own, many people do not take their medicines on time, because of side effects or because they forget. This can lead to drug resistance. Directly observed treatment (DOT) is as effective a guarantor of adherence to a TB treatment regimen as it is for adherence to ART. FCMs and caregivers alike can practice DOT.

- TB treatment has common minor side effects: nausea, vomiting, diarrhea, sudden heat flashes, reddish urine and muscle aches. There are also some major side effects that

require referral to health facility. These include a yellow tinge in the eyes or on the skin, vision problems and shortness of breath.

6.12.3 When clients need referral for a tuberculosis test

The following symptoms are indicators for referral:

- a cough lasting more than two weeks
- severe pain and discomfort and difficulty in breathing
- fast and noisy breathing
- sputum or spit that contains blood
- sputum or spit that is grayish-yellow or green
- among children, faster than normal breathing, fever and unwillingness to eat or drink

6.12.4 What to teach the client and the caregiver

The FCM can share the following tips:

- Drink lots of fluids, especially if there is fever.
- Raise the head and upper body on pillows or raise the head of the bed on blocks to assist breathing.
- Use any safe local remedies that are soothing to the throat.
- Breathing difficulties can be frightening. If the FCM isn't present, the caregiver should sit with the person and encourage a sense of calm.

The FCM should inform people about the existence and quality of free diagnostic and treatment facilities for tuberculosis. India's Revised National Tuberculosis Control Programme has made these facilities locally available nationwide in India.

Frequently asked questions: Health

1. Why should HIV testing be part of antenatal care?

Testing women early in their pregnancy allows early diagnosis, which in turn makes it possible to protect infants in utero by administering NVP and other maternal ARVs.

2. Can antiretroviral medicines cure HIV?

No. HIV, like diabetes and hypertension, is a chronic disease that requires constant attention and care. Antiretroviral medicines prevent OIs and bolster the immune system, thereby increasing lifespan. They do not cure HIV.

3. What is DOT and what purpose does it serve?

DOT stands for directly observed therapy; it is part of a short course of treatment for TB. DOT means that a health care worker meets with a person who has TB to help him or her remember to take the medicines and monitor the intake of the medicine. The health care provider watches the patient take each drug dose. Everyone who has HIV needs to be tested for TB and, if the test is positive, seek DOT.

4. What are the symptoms of a sexually transmitted infection?

Some common signs are abdominal pain; patches, wounds or sores on the genitals, heavy white discharge, burning in the genital area and frequent urination. Many STIs, however, have no symptoms.

5. How long can a person who is HIV-positive live?

People who are HIV-positive live for an average of 20 to 25 years from the point of diagnosis. An individual's prognosis depends on their health status apart from HIV, their adherence to ART, their nutrition and their psychological management.

6. What is a missed case and what is lost-to-follow-up case?

If a person on ART does not attend the ART center for one month the case is considered missed from that point up to 89 days. At the 90-day mark the person's case is considered lost to follow-up.

7. What basic documents are required for screening at an antiretroviral therapy center?

A person referred to an ART center to be screened for eligibility for ART should present the test report from the ICTC, passport-size photographs, a certificate or other document providing proof of residence in India and a referral form.

8. What is the importance of adherence to the antiretroviral therapy regimen?

Adherence to any prescribed medicine is important, because the body needs to have the medicine as prescribed in order for it to work best. If medicines are not taken on schedule, the disease may become resistant to the drug so that it no longer works as well or at all.

ART, when taken correctly, greatly reduces the ability of HIV to replicate. This allows the immune system to slowly rebuild and become healthy again. Partial or poor adherence can lead to rapid spread of the virus, making the person sick again. It can also lead to the emergence of a strain of HIV that is resistant to antiretroviral drugs, making the drugs much less effective .

That is why better than 95-percent adherence (missing no more than three doses in a month) is essential for PLHIV.

9. How can a family case manager help a person who is on antiretroviral therapy?

The FCM can discuss the schedule of medication, measures to be taken during medication, and the importance of adherence. The FCM can enlist family members to support a client's effort to take medicine as prescribed. Calendars with checkboxes for the client to note when medicine were taken each day, pillboxes with the day's complement of medicines meted out and mobile phone text-message reminders are also very helpful, if the FCM can arrange for the client to have access to these. Alternatively, the FCM can help the client to create a monthly calendar with reminders.

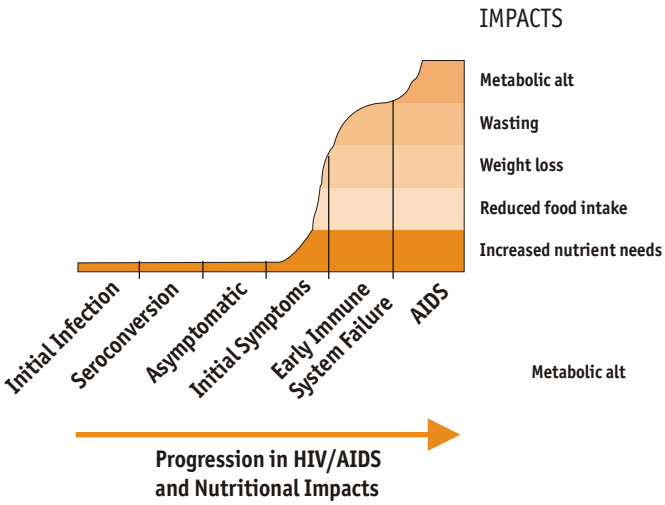
The FCM should emphasize the benefits of adherence to ART and show appreciation for a client who is adherent. If the client is having problems with adherence, the FCM should make a referral to obtain support from the ART clinic. If the person is illiterate, the FCM can suggest paying attention to regularly scheduled prayers broadcast from a mosque or church bells or factory sirens as indicators of times when ART medicines should be taken.

7 Nutrition

HIV and nutrition are closely linked. HIV infection can lead to malnutrition, while poor diet can in turn speed the disease progress. When the body fights any infection, it uses more energy; hence good nutrition is essential. Good nutrition can be a problem for many people with HIV. Often PLHIVs feel sick and eat less than normal. A good diet and nutrition helps many PLHIVs feel healthier.

Figure 7.1

Nutritional complications at different stages of HIV



7.1 Nutrition's contribution to an HIV care and support program

Nutritional care and support is an evidence-based intervention to alleviate the overall burden of malnutrition and to reduce the severity and complexity of the impact that HIV and malnutrition have on each other. Nutritional intervention involves helping manage symptoms, promote a positive response to medical treatment, reduce the progression of the disease and increase the quality of life of families affected by HIV. Nutritional interventions are critical to the success of a family case management approach to care and support for PLHIV.

7.1.2 The golden rules of good nutrition

Eating a wholesome, balanced diet means eating a variety of foods, because no single food contains all the nutrients that we need. The fundamental tenets of such a diet are as follows:

- Eat whole (unrefined) foods.
- Eat natural (unprocessed) foods.
- Eat foods that are in season and grown locally.
- Eat a variety of foods chosen from each food group.
- Drink clean water; boil for 10 minutes if needed.
- Eat small amounts of food often (five times a day)

7.2 Whose nutritional status should an HIV care and support program safeguard?

The FCM is responsible for monitoring the nutritional needs of everyone children and adults – who live with a client who is HIV-positive.

The FCM needs to inform clients about the strong relationship between nutrition and HIV, advising them to be careful about what, how much and how often they eat.

7.3 When can a family case manager start counseling families about nutrition?

As soon as families are registered in an HIV care and support program, an FCM can assess their nutritional requirements and counseling can begin.

7.4 Who can provide nutritional counseling?

Normally, the FCM handles this counseling, but a family with special needs may be referred from time to time to a nutrition care center and a counselor trained in nutrition.

Life-stage-specific issues a family case manager may address in nutritional counseling

Life stage	Nutrition
ANC	**Counseling topics for an expectant mother** • adequate nutrition prior to and during pregnancy (In order for the fetus to develop normally into a baby that is healthy at birth, the mother-to-be needs to eat as healthily as possible.) • increasing energy intake by adding one meal to the daily diet • improving the variety of food consumed (cereal; starchy roots, animal foods; legumes; nuts plus fruits; vegetables)

Life stage	Nutrition
	• eating plenty of fresh fruits and vegetables, whole grains, brown rice, and seeds and nuts • reduced workload (or at least adding regular rest periods) • daily use by all family members of iodized salt • monitoring weight gain in pregnancy (A woman should gain 10 to 12 kilograms over the course of a pregnancy.) • obtaining IFA and take-home rations at an ICDS center • accessing nutritional counseling during Nutrition and Health Days organized at Anganwadi Centres of ICDS in Andhra Pradesh.
PNC	**Counseling topics for mother and newborn** • initiation of breastfeeding within 60 minutes from birth. • nutritional value to an infant of colostrum, or "first milk" • exclusive breastfeeding; no water or other liquids or foods for the infant's first six months of life • positioning the baby for breastfeeding • good nutrition for the mother postpartum • continued access to take-home rations at an ICDS center if mother insists on formula feeding, review with her the AFASS criteria for doing so successfully (acceptable, feasible, affordable, sustainable and safe)
0 to 2 years	**Counseling topics for mother and child** • importance initiating breastfeeding early, so that baby receives the mother's colostrum • exclusive breastfeeding • timely initiation of weaning foods • growth monitoring • supplementation with pediatric IFA (after six months, infants have consumed all of the iron stored in their bodies at birth and need to be given iron from locally available sources of food in addition to breastmilk.) • management of acute malnutrition • management of diarrhea (at home, with oral rehydration solution)

Life stage	Nutrition
3 to 5 years	• growth monitoring • adequate micronutrient supplementation (using locally available foods and other fortified foods suggested by the nutritionist or other health professional) • access to supplementary nutrition • access to double ration • fortified blended food (for children with HIV)
6 years to adulthood	• nutritious food that is low cost , locally available and seasonal
Severe acute malnourished and moderate acute malnourished children	• regular growth monitoring • practices for feeding children • encouragement for frequent feeding in small amounts • planning a balanced and high-calorie diet for a child with HIV • kitchen gardening • cooking methods and low-cost recipes • simple home-based techniques to double calorie intake, such as adding ghee, oil or jaggery to food • sanitation and hygiene • access to fortified blended food at ART centers • access to double rations and supplementary nutrition programs • referrals to pediatricians • deworming
Adults and children with OIs who are on ART	• common OIs such as oral thrush • ART (Interactions among drugs, food and nutrients can affect nutritional status negatively, by reducing food intake or nutrient utilization. This may lead to weight loss and undernourishment. Side effects of medications can affect food intake and nutrient absorption and can also deter adherence to medications. **Counseling to encourage PLHIVs to** • maintain a healthy weight • eat a variety of foods • reduce their intake of refined sugar and excessive carbohydrates • increase their intake of fiber

Life stage	Nutrition
	• avoid alcohol • exercise daily **Counseling on the following illnesses** • anorexia (appetite loss) • diarrhea • nausea, vomiting • fever; thrush • constipation

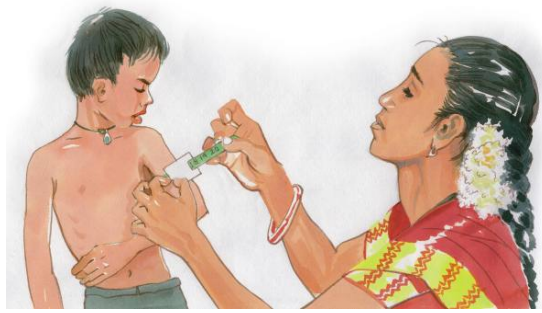
Steps an FCM should take to ensure proper nutritional care for children with HIV

1. Nutrition screening and assessment
   Ensure that age-appropriate growth monitoring is done for the child regularly.
2. Prompt management and treatment of danger signs
   Take a child who has danger signs of illness to the nearest health facility for treatment.
3. Improved diet to meet growth and development needs
   The child's diet should contain carbohydrates, fat, protein, vitamins and minerals.
4. Promotion of good hygiene and food and water safety
   Food should be prepared, served and consumed in a hygienic manner. The utensils should be clean and hands should be washed before preparing food and again before serving it.

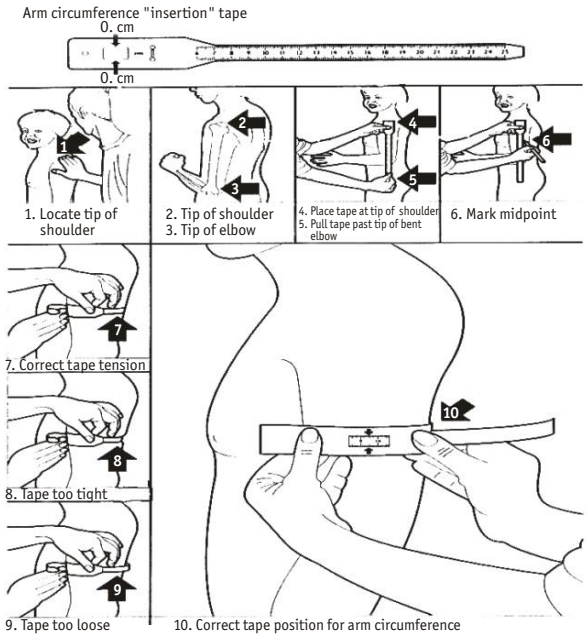
7.5 Nutritional assessment

7.5.1 Mid-upper arm circumference (MUAC)

This is a simple, quick way to determine acute malnutrition. The circumference of the left upper arm (MUAC) is measured at the midpoint between the tip of the shoulder and the tip of the elbow. This measurement is only recommended for use with children between the ages of one and five. To reduce the risk of error, the FCM should be trained to take this measurement, using the following guidelines:

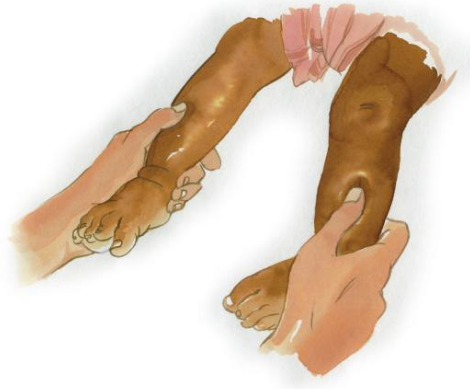


- To find the midpoint, ask the child to stand, or if the child is not yet walking, have the caregiver hold the child. The left arm should be bent at a 90-degree angle.
- Place the zero point of the MUAC tape measure – a colored strip that should be part of every FCM's equipment – on the bone that forms the tip of the shoulder. (The zero point will usually be in the middle of the tape measure's window.)
- Extend the MUAC tape to the tip of the elbow.
- Read the distance between shoulder and elbow in millimeters; then divide the result by two to find the midpoint. (Alternatively, fold the tape in half between the zero point and the tip of the elbow.)
- Use a pen to mark the midpoint on the child's arm.
- Now have the child stand or sit with the left arm hanging loosely by the side of the body. Muscles should not be flexed at all.
- Place the MUAC tape around the left arm at the midpoint just marked. The tape should be snug around the arm without constricting it. Read the number in the window of the tape to the nearest millimeter.



A number that is red indicates severe acute malnutrition (SAM). A number that is yellow indicates moderate acute malnutrition (MAM). A number that is green indicates only mild malnutrition or normal nutritional status.

7.6 Assessment of edema



Bilateral pitting edema of any grade is a sign of severe acute malnutrition. It is assessed by pressing the thumbs into a child's feet, legs, arms or head. If the pits that form remain, the child has pitting edema. If pitting occurs when both sides of the body are tested, the child has bilateral pitting edema. Edema often begins on the feet and moves to the legs, the hands, the face and ultimately the entire body.

Bilateral pitting edema can be assessed as follows:

- While the child is sitting, grasp both feet in your hands.
- Apply firm thumb pressure to the tops of both feet for three full seconds. Remove the thumbs.
- If the depression from your thumbs remains on both feet, the child has bilateral pitting edema. (It may be easier to feel the depression in the flesh than to see it.)
- If tops of the feet are edematous, repeat the process on the shins.
- If the shins are edematous, repeat the process by pressing the thumb into the child's forehead.

Figure 7.2 Grading of bilateral pitting edema

Bilateral Pitting Oedema	
Grade of Oedema	**Definition**
Absent	Absent
Grade +	Mild: Both feet/ankles
Grade ++	Moderate: Both feet, plus lower legs, hands, or lower arms
Grade +++	Severe: Generalized oedema including both feet, legs, hands, arms, and face/head

7.7 Identification of clinical signs of malnutrition

Malnutrition can take different forms, depending on the severity of the caloric deficit and the specific nutrients that are missing in the diet. Each form has its own set of clinical signs.

7.7.1 Marasmus

Marasmus, or wasting, is the most common form of acute. It occurs when the body breaks down fat or muscle as sources of energy in the absence of food. Among children, marasmus has the following characteristics:

- Thin face that looks like that of an elderly person
- Apathy (The child is quiet and does not cry.)
- Ribs and other bones are easily seen from the front and the back
- Loose skin under the upper arms
- In extreme cases, the skin on the buttocks has the look of baggy pants
- No bilateral pitting edema is present
- Weight is less than that of well-nourished children of similar height

7.7.2 Kwashiorkor

Kwashiorkor is a severe protein deficiency common among children whose diets consist almost entirely of starch. This form of malnutrition is characterized by bilateral pitting edema. Among children, kwashiorkor can have these characteristics:

- Moon face
- Dermatosis (flaky skin or patches of abnormally light or dark skin in severe cases)
- Apathy; little energy
- Loss of appetite
- Changes in the color or texture of the hair
- Irritableness; cries easily

7.7.3 Marasmic kwashiorkor

In this mixed form of marasmus and kwashiorkor, a child has the characteristics of both forms of malnutrition: severe wasting combined with bilateral pitting edema.

7.7.4 Identifying a severe acute malnourished child

The presence of edema in either foot and/or severe wasting (weight less than 70 percent of what is normal for the child's height or length or weight that is less than -3 standard deviation of the World Health Organization's growth standards) are signs that a child has severe acute malnutrition (SAM). If weight-for-height or weight-for-length cannot be measured, the FCM should look for other visible signs of severe wasting. A child with visible severe wasting appears very thin and has no fat. There is severe wasting of the shoulders, arms, buttocks and thighs and the outline of the ribs is visible.

Key diagnostic features of severe acute malnutrition (SAM) in children (6-60 months old) are:
Weight for height < -3SD and/or MUAC < 115 mm and/or Bilateral pitting edema

If the anthropometric parameters do not reflect SAM but the child's feet have bilateral pitting edema, the child should be referred to a health facility. A child who has medical complications such as infection, diarrhea or liver problems should be admitted to a hospital for treatment.

Children whose weight is less than 60 percent of what is normal for their age may be stunted but not severely wasted. Stunted children do not require hospital admission unless they have an additional, serious illness.

7.7.5 Moderate acute malnutrition (MAM)

MAM is characterized by moderate wasting (Weight for length/ height <-2SD WHO Growth standards or mid upper arm circumference (MUAC 125 -115mm). Management of MAM is crucial to prevent mortality by reducing deterioration into Severe Acute Malnutrition (SAM).

Key diagnostic features of moderate acute malnutrition (MAM) in children (6-60 months old) are:
Weight for height < -2SD and/or MUAC 115- 125 mm*

7.8 Management of malnourished children who are living with HIV

Children identified for home-based management should be treated with calorie-dense and nutrient-dense foods. In some settings, a diet of locally available nutrient-dense foods along with added micronutrient supplements may be appropriate, but the quantity of food must be sufficient to yield adequate nourishment.

Children who are known to be HIV-positive and who develop SAM should have access to therapeutic feeding to improve their nutritional status. If diagnosed as HIV-positive, they should also qualify for cotrimoxazole prophylaxis to prevent the risk of contracting *Pneumocystis* pneumonia and other infections, and for antiretroviral therapy when indicated.

Managing HIV-positive children with SAM is similar to managing HIV-negative children with SAM.

7.8.1 Dietary recommendations for HIV-positive children with moderate acute malnutrition

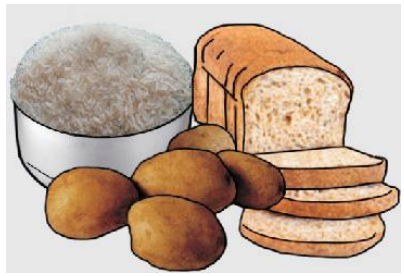
A child with moderate acute malnutrition (MAM) should be monitored closely for signs of improving rather than deteriorating nutritional status. An FCM can connect the household with an ICDS center and, if appropriate, an ART center for food supplements. An FCM can also give the child's caregivers the following advice:

- Give energy-dense foods.
- Include some animal food sources in a plant-based diet.
- Malting, fermentation and soaking of foods is beneficial.
- Prefer washed pulses (legumes) to whole pulses.
- Use vegetable oils.

7.8.2 Nutritional management of symptoms of people living with HIV

The FCM can advise people with HIV and their caregivers to use dietary strategies to cope with the symptoms of many conditions.

Severe weight loss



- Eat small, frequent meals and supplement with snacks of nuts, fruit, yogurt or bread.
- Eat more staple foods such as rice, maize, ragi or bread.
- Eat more beans, soy products, lentils and peas.
- Eat meat (beef, pork, lamb, chicken and other poultry), fish and eggs as much as possible.
- Use more fats and oils and, unless diarrhea is present, eat foods with high vegetable fat content, such as avocados and nuts.
- Eat more dairy products such as cheese and full-fat milk unless they cause stomach cramps, diarrhea or rashes. Add whole milk or dry milk powder to foods such as porridge, cereals and sauces.
- Add sugar, honey, syrup or jam to food.
- Rinse the mouth before eating so food will taste better.
- Eat with family or friends.
- Do light exercise to increase appetite.

Anemia

- Eat more meat, legumes, fish, green leafy vegetables, dried fruit and whole grains such as ragi
- Do not drink coffee, tea, milk or cocoa during a meal because these drinks reduce iron absorption.

- Make fruits and vegetables high in vitamin C (for example, oranges, lemons and green, leafy vegetables) part of most meals to increase iron absorption.
- Take a multiple vitamin tablet that has iron or add iron tablets to the regimen.

Diarrhea

- Do not stop eating.
- Drink lot of fluids – at least eight glasses each day – to prevent dehydration. Good choices are oral rehydration solution, water, tea, juice diluted with clean water, thin soups and coconut juice.
- Eat soft mashed foods that are easy to chew and swallow such as rice , porridge, banana and papaya.
- Avoid spicy foods, acidic fruits, and foods that are deep fried or very oily, because these may make diarrhea worse.
- Avoid unrefined grains and cereals (for example, whole wheat) and foods that cause gas, such as beans, broccoli, cabbage, onions and capsicum.
- Coffee, tea and alcohol can worsen dehydration. Replace these drinks with water, herbal tea and soups.

Nausea

- Sit up when eating and do not lie down immediately after eating.
- Eat small amounts of food throughout the day to avoid an empty stomach. An empty stomach makes nausea worse.
- Take small sips of fluids.
- Eat dry bread or biscuits.
- Eat soups, unsweetened porridge and fruits such as bananas.
- Eat sour or salty rather than sweet foods.
- Avoid greasy, spicy foods and foods with a strong smell.
- Avoid coffee, tea and alcohol.

Sore mouth

- Eat soft, mashed or moist foods.
- Add liquid to dry foods to make them softer.
- Chew small bits of green mango or green papaya; these may soothe mouth pain.
- Avoid salty or spicy foods especially foods with chili pepper.
- Avoid foods that require a lot of chewing.
- Avoid very hot food. Cold foods may numb the mouth.
- Avoid acidic or very sour foods.

Oral thrush

- Follow the advice above for sore mouth.
- Drink lemon water or suck on a lemon.
- Avoid sugary foods, which worsen not only oral thrush but also yeast infections.
- Avoid alcohol.
- Eat plain, unsweetened yogurt, sour milk or sour porridge.
- Eat garlic.

Dry mouth

- Take small sips of water at a time to keep the mouth moist.
- Suck on small pieces of crushed ice.
- Suck on or eat citrus fruits (oranges, lemons and limes). They may help create saliva and make chewing easier.

Taste changes

- Change the sweetness, saltiness or sourness of food by adding sugar, salt, jam or lemon to improve flavor.
- Try different herbs and spices.
- Eat more fish or chicken; meat can often have a metallic taste.
- Eat lentils, beans or split peas.
- Brush the teeth after eating to remove any aftertaste.

7.9 Improving diet to meet the growth and development needs of people with HIV

Recommendations for nutritional care vary depending on a person's nutritional status and the extent to which HIV has progressed. Nutritional recommendations should take into account the stage of the disease and the person's physical condition. Management of symptoms is essential during the middle and end stages of HIV. An FCM has the following responsibilities:

- Visit the household, conduct a nutritional assessment and prepare a family care plan. Households assessed to be severely food insecure (SFI) and with children who have SAM or MAM should have priority for frequent subsequent visits.
- The FCM should elicit reasons for the poor nutritional status of clients who have unintentionally lost more than 5 percent of their body weight in the previous three months. Some of the possible reasons are infections or inadequate dietary intake because of symptoms, poor access to food or psychosocial factors.
- The FCM must be aware that children who are HIV-positive need more calorie-dense foods than those who don't have the virus. Those who are asymptomatic need 10 percent more

energy than healthy children do. Children who are symptomatic but have not experienced weight loss need 20 to 30 percent more energy. Symptomatic children who have lost weight need 50 to 100 percent more energy. The FCM should meet these increased energy requirements by making sure the children have an extra meal or snack or by adding food, such as an egg or a banana, to one or more of the children's meals.

- Children with SAM need to be referred to pediatricians.
- There is no need to feed children with MAM highly fortified therapeutic foods designed to replace the family diet.
- Counsel the family about low cost, locally available sources of nutrition.
- Enable caregivers to manage nutritional deficiencies in order of their priority.
- Counsel caregivers in accord with the availability of food, factors limiting access, the client's preferred food choices and opportunities at hand to improve the client's nutrition.
- The FCM should counsel the family on the importance of breastfeeding. If the mother insists on formula feeding, review that option with her from the perspective of the AFASS criteria.
- Ensure that all children in the household younger than five receive double ration through an ICDS center.
- Provide counseling on the importance of deworming.
- Ensure vitamin A supplementation to all eligible children through Anganwadi centers.
- Support the families by linking them with food security interventions and schemes offered by the Indian government and by nongovernmental organizations.
- Ensure that all beneficiaries of the HIV family case management program access the pension schemes.
- Introduce adolescent girls and mothers to ICDS Nutrition and Health Day (NHD) sessions.

7.10 Feeding options for children who have or are affected by HIV

Approximately 40 percent of all transmissions of HIV from mother to child occur through breastfeeding. However, not breastfeeding may place the child at a greater health risk. Where formula feeding is available, mothers must be counseled carefully about:

- feeding options
- vertical transmission risks
- benefits of breastfeeding
- advantages and disadvantages of formula feeding
- strategies for feeding safely

7.10.1 Exclusive breastfeeding

Mothers are advised to make breastfeeding the infant's only sustenance. This means:

- no food, fluid or water other than breastmilk
- no bottles, teats or pacifiers

Oral polio vaccine and cotrimoxazole are allowed. Oral rehydration solution is also allowed for treatment of diarrhea.

Exclusive breastfeeding for the entire first six months of an infant's life is recommended for all mothers, including those who are HIV-positive. Breastfeeding should be continued even when infants younger than six months are ill. Breastfeeding needs to begin on the first day of a child's life; the first milk (colostrum) is especially nutritious. No other liquids (for example, water or honey) should be provided until the child reaches seven months.

Advantages of exclusive breastfeeding

- Exclusive breastfeeding lowers the risk of transmission of HIV, because breast milk keeps the baby's stomach protected from the virus.
- Breast milk is free.
- Exclusive breastfeeding combats breast problems such as swelling and infection.
- Exclusive breastfeeding helps the mother heal from childbirth and can prevent pregnancy.
- Because exclusive breastfeeding is a common cultural practice in India, it will not be questioned by family and community members.

Disadvantages of exclusive breastfeeding

- Any form of breastfeeding, including exclusive breastfeeding, is associated with risk of HIV transmission (but breastfeeding exclusively diminishes the risk).
- If the mother is working, she may not be able to take her infant with her, so exclusive breastfeeding may not be feasible.
- Exclusive breastfeeding may be difficult if the mother becomes severely ill.

Medical reasons not to breastfeed

- mastitis (the nipple is inflamed and can bleed)
  (Stop until swelling is reduced and express milk instead.)
- sputum positive for tuberculosis
  (The mother should not be in direct contact with the infant until sputum is negative.

(tubercular mother can safely express breast milk for bottle-feeding by someone else)

- mother is being treated for tuberculosis
- breast cancer
- syphilis
- malaria
- mother is being treated with an antithyroid drug
- infant fails to thrive as the result of inability to digest breast milk
- infant has oral thrush

7.10.2 Heat-treating breast milk

Expressing and heat-treating breast milk

Expressing breast milk means squeezing the breast to extract milk. Breast milk can then be boiled heat-treated to kill HIV. Once the breast milk cools it can be fed to the child by cup or bottle (but cup is better A cup has less chances of contamination as cleaning a cup is much easier than cleaning a bottle and cleaning a nipple. In addition, it takes much less time to thoroughly clean a cup. Feeding from a cup or bowl with a spoon also familiarizes the infant with textures, flavors and smells, whereas feeding them by bottle, deprives the infant of these sensory experiences. Feeding from a cup is also thought to enhance the development of chewing and swallowing mechanisms, including coordination of the two).

Advantages of expressing and heat-treating breast milk

- Heat-treating kills HIV.
- The technique is cost-effective, because breast milk is free.
- Untreated milk can be stored in a clean, covered container for up to eight hours at room temperature and up to 24 hours in a refrigerator.

Disadvantages of expressing and heat-treating breast milk

- Heat-treated milk may not have all the nutritional components of normal breast milk.
- Expressing and heat-treating milk needs to be done frequently and requires time and money. However, it is still cost-effective in comparison with formula feeding.
- Heat-treated milk should be stored in a cool place and needs to be consumed within one hour.
- Expenses associated with expressing and heat-

treating breast milk are fuel for boiling the milk and clean water and soap to sanitize containers and utensils.

- The infant should be fed with a cup, which requires practice.
- Family and community members may criticize the mother for expressing and heat-treating breast milk and speculate about the mother's HIV status.

7.10.3 Replacement feeding

Replacement feeding is the practice of not feeding an infant any breast milk. Replacement foods may be either commercial or home prepared formula , animal milk or other breast milk substitutes, which may not have all the nutrients the infant requires.

Advantages of replacement feeding

Withholding breast milk from an infant avoids exposing the infant to HIV. Where good- quality formula can be provided in a consistent, clean and correct way, it is an acceptable substitute for breast milk. Moreover, home-modified animal milk can be used for short periods when the mother is too ill to breastfeed.

Disadvantages of replacement feeding

A number of disadvantages are associated with replacement feeding:

- increased incidence of diarrhea and pneumonia as the result of unhygienic preparation of replacement foods
- high financial cost, not only in terms of the cost of commercial infant formula but also of fuel, clean water and soap required to sanitize the container and utensils When the cost of replacement feeding is calculated for 6 months, it is revealed to be even higher.
- time-consuming preparation of replacement foods
- lack of all the nutrients necessary for infants younger than six months in home-modified animal milk

Questions to ask mothers who are thinking about replacement feeding

- Is a public source of treated, clean and safe drinking water readily available at your house or nearby?
- Do you have money to spare for formula? Will you be able to buy formula every month until the child is six months old?
- Can you boil water easily?
- Can you sterilize all feeding equipment (cups, bottle and utensils) prior to every feeding? (Explain to the mother that this means boiling utensils for at least ten minutes before each use.)

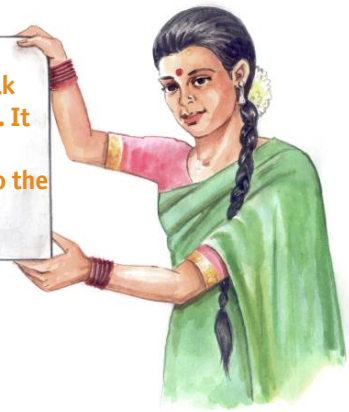
- If you are formula feeding during the day, will your partner or family members find it acceptable to provide formula feeding at night? (Inform mothers that mixed feeding practices appear to increase the risk of transmission.)
- Does your family know your status, and do they support formula feeding?
- If you are working, will the person caring for the baby be able to make the formula and provide it to the baby in sterilized containers?

Formula feeding instructions

The correct technique to prepare commercial formula is important, because if the preparation is too thick or too thin it may be harmful to the infant. The FCM should instruct the mother as follows:

- Wash your hands with soap (or ash) and water; also wash the containers and utensils you will be using with soap (or ash) and water EVERY TIME before preparation.
- Measure the correct amount of formula and water according to the instructions on the box or tin of the formula you are using.

Mixed feeding means giving both breast milk and formula to a baby. It increases the risk of transmission of HIV to the baby and should be avoided.



- Boil some water until the surface moves vigorously for one to two seconds.
- Add the boiling water to the formula.
- Prepare only enough formula for one feeding.
- Use a clean cup or bottle to feed the child. Cups are better, because they are easier to clean. Protect the cup or bottle used for feeing from flies, dust and dirt.
- Discard leftover milk one hour after its preparation.

7.10.4 Mixed feeding

Mixed feeding – giving both breast milk and formula or home-modified animal milk to a baby is not an acceptable option. The risk of HIV transmission when mixed feeding is practiced is 11 times greater than when infants are breastfed exclusively. Introducing fluids and solids other than breast milk damages the baby's stomach; that is why the risk of HIV transmission is so much greater.

7.10.5 Complementary feeding

Complementary feeding is the practice of giving an infant solid and liquid foods other than breast milk, formula or animal milk when the infant reaches seven months of age. Breast milk alone is not sufficient for the growth and development of infants older than six months, so additional foods have to be introduced. Because HIV-positive mothers are encouraged at that point to rapidly wean their infants and stop breastfeeding soon after, complementary foods are an important component of this new phase of feeding. Complementary foods should be introduced gradually and in small quantities. They should come from the following groups.

- energy foods: rice, potatoes and breads
- animal foods: liver, red meat, chicken, fish and eggs
- milk products: milk, yogurt and cheese
- vegetables: spinach, carrot, pumpkin and sweet potato
- pulses: chickpeas, lentils and kidney beans
- oils and fats in limited quantities
- pastes made by grinding groundnuts and the seeds of pumpkin, sunflower and melon
- water

7.11 Follow-up and review of nutritional support

Holistic care and treatment of a person who is HIV-positive requires continuous, integrated follow-up both at the health facility and at home. The FCM has the following responsibilities:

- Keep accurate client records.
- Monitor nutritional and dietary indicators.
- Ask about side effects from the use of ARVs and other drugs.
- Treat or refer and manage opportunistic and other infections.
- Counsel to address barriers to good nutrition.
- Offer support and encouragement.
- Review and record changes in meal plans, exercise and drug regimens and in the client's nutritional and health status.

Certain ART medications have direct interaction with nutrients. For this reason, the FCM should ask caregivers to share their dietary practices with ART medical officers.

7.12 Infection transmission and prevention

The FCM must know how infection is transmitted and share this knowledge with clients, caregivers and other household member. The pathways are

- from person to person
- from unclean surfaces to people
- through the air to people
- through water and food to people
- from chickens, cats, dogs and farm animals to people
- from soil to people
- from mosquitoes and flies to people

7.12.1 Personal strategies to prevent infection

- Wash hands to make sure germs are not carried to and from a person who is HIV-positive
- Keep nails short and clean to avoid scratches that can become infected.
- Keep the body clean and free of harmful germs
- Keep clothes clean
- Wash cuts and scrapes well with soap and water
- Drink clean water (boiled or treated). Many infections come from water. To clean water by boiling it, the water should boil for at least 10 minutes
- Avoid eating street food
- Wash fruits and vegetables carefully before eating

7.12.2 Preventing infection in the house

- Store food carefully
- Wash and dry dishes well
- Keep animals and insects away from dishes and food
- Clean towels, bedding and floors often
- Clean the latrine or toilet area

7.12.3 Preventing infection in the compound

- Remove animal droppings
- Burn or bury waste
- Cover the water supply
- Fill pools of standing water with dirt

Challenges in managing good nutrition and strategies to overcome them

Challenges	Strategic responses
Accessibility and use of double ration by HIV-affected families	Counsel the mother to explain the severity of the child's nutritional status and the risks associated with delay in initiating the double ration. Inform her about the confidentiality standards of Anganwadi centers.
Migration of children to the households of grandparents and other relatives disrupts regular nutritional assessment	Educate relatives about the importance of routine assessment of the child's nutritional status. Link the child to the FCM or Anganwadi center closest to the child's new home.
Myths and misconceptions about feeding methods and foods	Explain the benefits of infant feeding options, providing correct information. Involve family members in decision making. Share local success stories.
Absence of a district-level facility to address SAM and MAM	Make use of pediatric wards in government hospitals and CCCs.

The FCM may make the following referrals for nutritional support:

- **refer to ANM for health information**
- **refer to Anganwadi worker for ICDS services of double ration and other supplementary nutrition**
- **refer to line departments to support access to entitlements**
- **refer to other stakeholders for example, nongovernmental organizations offering nutritional support for the families**

Frequently asked questions: Nutrition

1. What are the goals of nutritional care and support?

- Improve nutritional status by maintaining weight, preventing weight loss and preventing loss of muscle mass.
- Ensure adequate nutrient intake by improving eating habits and building stores of essential nutrients, including carbohydrates, protein, important antioxidant nutrients and other vitamins and minerals necessary for the functioning of the immune system.
- Prevent food-borne illnesses by promoting hygiene and food and water safety.
- Enhance quality of life by promptly treating infections and managing symptoms that hinder food intake, to minimize the nutritional impact of secondary infections when they occur.

2. How soon should the mother stop breastfeeding after initiating complementary feeding?

Weaning could take from two to three days to two to three weeks. Weaning should be gradual, because stopping breastfeeding suddenly can be hard for the infant and hard for the mother, leading to breast problems such as mastitis.

3. What foods and food habits should people who are HIV-positive strictly avoid?

The following foods and habits should be avoided:

- Raw eggs, unpasteurized milk and dairy products from unpasteurized milk may contain bacteria (particularly salmonella) that are harmful to the already weakened immune system of a person with HIV.
- Undercooked meats and chicken may contain bacteria that are harmful to a person with HIV, whose immune system is already compromised.
- Junk food such as chips, biscuits and sweets have little nutritional value. The sugar in sweets promotes the growth of fungi (thrush).
- Alcohol and coffee decrease appetite and interfere with metabolism. Alcohol may interact with some medications, decreasing their efficacy.
- Smoking increases the number of free radicals in the body, which are associated with aging and illness.
- Expired foods, acidic foods, foods with preservatives and oily foods aggravate symptoms related to diarrhea, nausea or vomiting, loss of appetite and sores in the mouth and throat.

4. What type of food is beneficial to pregnant and lactating women?

Pregnant women and those who have recently given birth are at risk of anemia (iron deficiency). Pregnant women should eat foods rich in iron, such as liver, meat, fish and legumes – especially cow peas and round nuts. Vitamin C is needed to absorb the iron, so fruit and dark green vegetables should also be eaten. Health facilities give iron supplements to pregnant women during antenatal care.

5. Why is exclusive breastfeeding recommended for the first six months?

International guidelines recommend exclusive breastfeeding for the first six months based on scientific evidence of the benefits for infant survival, growth and development. Breastmilk provides all the energy and nutrients that an infant needs during the first six months. Exclusive breastfeeding reduces infant deaths caused by common childhood illnesses such as diarrhea and pneumonia, hastens recovery during illness and helps women space births.

6. What are the reasons for malnutrition in HIV-positive children and adults?

The following are the major contributors to malnutrition in people with HIV:

- reduced food intake
- impaired nutrient absorption
- changes in the digestive system
- chronic infections and illnesses
- diarrhea and fever
- abdominal pain
- nausea and frequent vomiting
- thrush (whitish spots on the tongue and inside the mouth)
- anemia (inadequate number or quality of red blood cells)

7. What is the impact of HIV on the nutrition of HIV-affected families?

People with HIV and others in the family – particularly young children and orphans – may experience the following nutritional impacts:

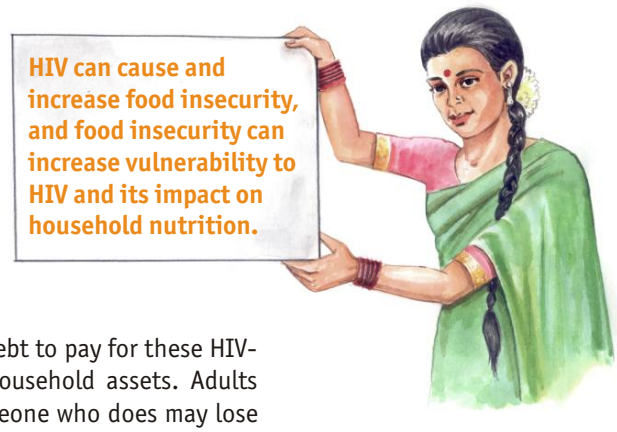
- too sick to work and cannot continue
- reduced income
- fewer resources (labor and money) to obtain food
- overwork, either to produce income or to provide care for the person with HIV
- deterioration of everyone's nutritional status
- household poverty and food insecurity

8 Food Security and Safety Net

The family case management approach promotes resilience in coping with the economic hardship that is often the visible manifestation of the presence of HIV in a household. Loss of good health leads to frequent hospitalization and forces adults with the virus to miss days at work. The result is a drastic decrease in household income.

The Balasahyoga project engaged multiple institutions at a variety of levels to support the households within the project's ambit. Community- based institutions such as nongovernmental organizations and support groups of PLHIV, governmental nodal agencies and governmental departments have been working with the most vulnerable sectors of the project's participants. They are creating an enabling environment in which PLHIV gain some resilience and position themselves to take advantage of the government's schemes and policies.

8.1 What is food security in the context of HIV care and support?



Food security refers to the availability of food in sufficient quantity at all times and access to it. A household is considered food-secure when its occupants do not live in hunger or fear of starvation. HIV imposes a series of dynamic shocks on livelihoods. It decreases a household's productivity; imposes the financial burden of medical costs and later, funeral costs; and increases a household's burden of debt to pay for these HIV-related costs, compelling the sale of household assets. Adults who have the virus or who live with someone who does may lose employment as a consequence of illness or because of time away from work to care for the sick, leading to depletion of financial capital and, sometimes, to destitution. As the prevalence of HIV in India rises, social networks within communities also fragment. All of these impacts have tremendous consequences for the food security of households affected by HIV.

8.2 Whose food security do we ensure?

The food security and nutritional needs of all children and adults who are enrolled and registered in a family case management program of HIV care and support should be addressed by means of a network of initiatives and support mechanisms.

The food insecurity commonly faced by HIV-affected households can make it difficult for people living with HIV to receive appropriate nutritional care and support. A thorough assessment of a household's food security status and the constraints on care for HIV-positive household members caused by lack of food and poor access to food is a start toward identifying feasible and effective interventions.

8.3 Assessing the food security and needs of beneficiary households

The FCM can support a household's effort to improve its food security by means of a number of strategies.

8.3.1 Food security assessment

The FCM should assess a household's food security status mild, moderate or severe in order to begin appropriate interventions.

The information an FCM gathers from a household to complete the hunger survey form (Refer Annexure 10) indicates the severity of a household's food insecurity. Knowing the household's status, the FCM can determine the household's priority for service. Among families whose status is moderate or severe, households headed by children, women and grandparents merit highest priority.

Challenges in assessing food security and strategies to overcome them

Challenges	Strategic responses
Uneasiness in answering certain questions (Families may be embarrassed to reveal that they do not eat enough.)	Explain the benefits of frank sharing of correct information.
Unwillingness to spend the time required to answer the questions on the hunger survey form	Make the assessment more interactive by using the questions as prompts for conversation.
Information provided is false, to qualify an economically sound household for nutritional support	Augment the survey with other proxy indicators (for example, observation of the household's visible socioeconomic status

The FCM should conduct a food security assessment of child- and grandparent-headed households every six months. Assessments of households headed by a woman or a man may be conducted annually.

8.3.2 Needs assessment

Once a household's food insecurity status is clear (severe, moderate or borderline), the FCM should conduct a needs assessment that will point to solutions.

8.4 Safety net interventions

Interventions are essential to build the resilience of project participants. The Balasahyoga project developed five interventions to help participants build assets and access entitlements in order to overcome their vulnerabilities. These interventions improve the quality of life of PLHIV and their households.

8.4.1 Micro enterprises and other income-generating activities

Often the household member who has acquired HIV or succumbed to it is the primary or sole breadwinner. The loss of income has severe consequences for most of these families.

An essential component of the Balasahyoga project is to help HIV-affected households acquire the means to earn a gainful living. (Refer to Annexure 11: Process Guidelines on Micro Enterprise.) This is done either by helping household members put skills they already possess to use or by teaching them new skills.

Developing micro enterprise

The FCM can help households build micro enterprises in a variety of ways.

- Identify moderately and severely food-insecure households and also child-headed and grandparent-headed households.
- Build on the existing experience and skills in the household.
- Start with small-scale initiatives that a household can support and sustain.
- The FCM can be the one to initiate the enterprise on the household's behalf.
- Work with the household to open a bank account.
- Teach household members how to track investments versus returns. Continuously motivate the family to save a part of their earnings, however small.
- Address gaps in the household's skill base through linkages with institutions that have resources for training: for example, the Khadi and Village Industries Commission, the Employment Generation and Marketing Mission (EGMM), the Mission for Elimination of Poverty in Municipal Areas (MEPMA), the Scheduled Castes Development Corporation, the National Backward Classes Finance and Development Corporation, the Coir Board, Mahila Pranganam district resource centers, the National Academy of Construction and technical resource agencies in the districts.

- Support linkages with financial and nonfinancial institutions such as the development corporations for scheduled castes and for backward classes and District Rural Development Agencies.

Challenges in promoting micro enterprise and strategies to overcome them

Challenges	Strategic responses
Inadequate planning, experience and entrepreneurial skills and lack of resources for guidance	Arrange with the field coordinator for support from local organizations offering technical resources.
Unanticipated fluctuations in the market that affect the enterprise	Build the beneficiary's skills to anticipate market fluctuations.
Burdensome storage requirements and short shelf life of products	Arrange technical support for storage issues and help procure infrastructure for storage. Work with families to select products that have longer shelf life or to organize better market linkages so that goods move faster.
Limited market for food products because of social stigma	Ensure that beneficiaries keep confidential the source of the products marketed and counsel to address self-stigma.
Low profits deter saving	Constantly motivate households to save, however small the amount may be.

8.4.2 Kitchen garden

Kitchen gardens for the cultivation of vegetables and fruits used to be common at homesteads in the rural areas of the Indian subcontinent. They have all but disappeared as a result of urbanization, limited access to seed and saplings and above all loss of interest in the tradition. With the decline in kitchen gardens even rural folk have become dependent on markets for food they used to grow themselves.

Another intervention of Balasahyoga has been the revival of the kitchen garden as an efficient and economical way to meet the nutritional requirements of households affected by HIV – especially children– in rural areas.

Advantages of a kitchen garden

The kitchen garden is an effective use of available land and water to meet the nutritional

requirement of households (especially PLHIV). It makes a greater diversity of fruits and greens, tubers and other vegetables available to a household, which improves the nutrition and ultimately the health of all household members. (Refer Annexure 12: Process Guidelines for a Kitchen Garden.) Consuming a nutritionally adequate diet is essential for a healthy and active life.

A kitchen garden strengthens household economy. The financial pressure of repaying the loan needed to establish the garden will be more than compensated by the drop in expenses for food bought at market, by the drop in medical expenses as nutrition and health improve and by the income generated by selling any surplus harvest.

Kitchen gardens promote healthy environmental conditions. They convert wasteland into clean and green spaces. The use of kitchen and bathroom waste water for fertilizer and irrigation improves sanitation.

A kitchen garden changes a family's food habits for the better and requires daily exercise, which is good for emotional as well as physical well-being. When neighbors see these positive effects, they are motivated to establish gardens of their own.

Characteristics of a successful kitchen garden

Having convinced a household to adopt a kitchen garden by explaining these benefits, the FCM can coach household members to organize the garden for year-round maximum nutritional value.

The case manager can begin with training on the design of the kitchen garden and the selection and location of plants according to the size and shape of the plot.

- Plant different species so that fruit and vegetables mature for harvest in each season.
- Make full use of the garden space at ground level and above, by planting tubers, leafy vegetables, creepers, bushes and trees.
- Choose local varieties rather than hybrids, because they are usually hardier and their seeds can be saved for the next cycle of production.
- Make the majority of plants leafy vegetables, because these mature quickly (from one month to fifty days after they go in the ground).
- Choose tree and fruit species with small canopies to allow sunlight to reach lower-growing plants.

The case manager should provide information about probable crop diseases and their remedies. The FCM should also train the household to adopt traditional practices of cultivation. First discuss the counterproductive effects of chemical fertilizers and promote the use of organic sources (compost and manure) instead. Then explain how the garden's water requirements can be met by collecting rainwater and by diverting waste water from kitchens and bathrooms.

Challenges in promoting kitchen gardens and strategies to overcome them

Challenges	Strategic responses
Expectation of other forms of financial support	The FCM must inform the household that no other forms of financial support from the family case management program will be provided.
Time constraints on the mobilization of families for kitchen gardens	The FCM can make consultation about the garden part of the agenda of routine visits and allow time for closer support when issues arise – for example, problems procuring the initial complement of seed.

8.4.3 Demonstration plots

The Balasahyoga program conducted situational assessments of the districts in its operational area. These suggested that HIV has affected many agrarian households. These households must restart their agricultural practices, using the skills many still possess to gain some livelihood. Demonstration plots showing multi-cropping and other current agricultural techniques available on a small scale can benefit not only households affected by HIV but also other food-insecure households, as well. (Refer Annexure 13: Types of Demonstration Plots)

Developing a demonstration plot

An FCM can support the establishment of a demonstration plot in a variety of ways, as follows:

- Identify a household with past experience in cultivation and an interest in local food and crops.
- Work with the household to secure a plot that is at least a half-acre with access to a supply of the minimum quantity of water needed to farm it.
- Support the family in choosing crops that require minimal investment, reach maturity quickly, are resistant to pests and disease and have a high yield.
- Support the creation of a bank account in the beneficiary's name.

- Educate the beneficiary in organic farming, pesticides, intercropping, regular monitoring and seed regeneration.
- Support the household's links to agricultural extension services, the district Horticulture Directorate and appropriate marketing venues.
- Promote savings in order to reduce dependence on the moneylender.

Challenges in promoting demonstration plots and strategies to overcome them

Challenges	Strategic responses
Inability of child-headed families to manage demonstration plots	Identify interventions that are feasible for the family.
Health constraints	Refer for appropriate medical attention.
Natural calamities	Conduct advocacy with the agricultural department to provide crop insurance. Seek the support of the agriculture and horticulture departments to procure from existing government programs subsidies for seeds, micro irrigation systems, farm implements and crop insurance.
Fluctuations in market prices	Educate families to understand seasonal variations in market price and anticipate demand and inflation.
Lack of information on savings or the use of profits for other than food needs	Educate families to understand seasonal variations in market price and anticipate demand and inflation.

8.4.4 Grain banks

Many HIV-affected families live at a bare level of subsistence and own very few assets. Any adverse situation – for example, lost income as the result of illness and the related expenses of medical services and travel to obtain them – can have devastating consequences for these families' nutritional status.

Grain banks organized by PLHIV and their families and run on the principle of self-help can be a food-security safety net providing relief to vulnerable communities, especially in emergencies.

Advantages of a grain bank

Grain banks have both direct and indirect benefits for the communities they serve. These banks

- safeguard children and households affected by HIV against food shortages
- reduce morbidity and mortality associated with chronic malnutrition and starvation
- endow HIV-affected households with a habit of selfhelp, instilling confidence in their capacity to take care of their basic needs
- make society as a whole more secure, by reducing the incidence of mortgaging and/or disposing of assets to buy food (Refer to Annexure 14: Formation and Management of a Grain Bank)

The family case manager's role in a grain bank intervention

The FCM can be useful to a community both in organizing and managing a grain bank, in the following ways:

- assessing the need for a grain bank and the community's level of interest in establishing one
- selecting beneficiaries of the grain bank: for example, a mix of borderline food-insecure, moderately food-insecure and severely food-insecure households and households headed by children, women and grandparents
- forming groups of seven to ten beneficiary households
- explaining the concept of a grain bank intervention to these groups in detail
- identifying a responsible person in each group to be its leader
- enabling these leaders to open a joint bank account and deposit the capital in it
- facilitating the formation of purchase committees
- ensuring community ownership by motivating community members to participate actively and to contribute their share of grains to the grain bank
- linking the grain bank to Indira Kranti Patham (IKP), to the District Rural Development Agency (DRDA) and to local millers

- ensuring proper and regular updating of the account books, minutes, stock register, repayment register and issues register
- supporting storage and pest control measures
- ensuring repayment of grain to the members

8.4.5 Linkages to government social security schemes

The Indian government has multiple schemes in place to ensure that the sectors of society most in need are supported equitably. Beneficiary families needing more support than a family case management program such as Balasahyoga provides can be linked to these government-funded schemes as well as those offered by nongovernmental agencies, to better access their entitlements to basic services and to services designed specifically to enhance the livelihoods of PLHIV. The main objective is to help people who are eligible gain access to their basic entitlements as well as to services offering economic opportunities such as employment, market opportunities and production technology to improve their physical and financial assets.

Some schemes that can be leveraged from government agencies are:

- Social Security pensions
- public distribution schemes
- income generating activities
- housing
- subsidies for horticultural and agricultural activities
- assistance for animal husbandry

Some of the skill development programs that can be leveraged from government agencies and corporate bodies are:

- MEPMA
- Employment Generation and Marketing Mission (EGMM)
- District Rural Development Agencies
- IKP
- Khadi and Village Industries Commission (KVIC) a rural employment and economic development program of the Indian government
- Khadi Gramodyog Maha Vidyalaya (KGMV)a training program of KVIC
- Coir Board
- National Scheduled Castes Finance and Development Corporation

The family case manager's role in linking eligible individuals and households to government schemes

The FCM can streamline the process of qualifying and networking households to entitlement programs, in the following ways:

- Map the existing government programs.
- Create a list of beneficiaries in the FCM's assigned area who meet the eligibility criteria set forth by government order.
- Finalize the list in discussion with the FCM's supervisor.
- Submit applications in priority order.
- Make sure that the applications go to the appropriate officials.
- Track the applications and follow up progress towards approval regularly.

The FCM may link parents and other caregivers who are unable to pay children's school fees to vocational training institutes such as Mahila Pranganams (district resource centers catering to women) and self-help groups. The short training programs offered there are an opportunity for parents and caregivers to upgrade their skills in order to run a micro enterprise or find a job.

Challenges in linking to government schemes and strategies to overcome them

Challenges	Strategic responses
Delays resulting from government procedures in approving eligibility for entitlements	Organize advocacy meetings at various levels. Address the issue at community advisory board meetings
Fear of stigma and discrimination if status as a program beneficiary is revealed	Seek the support of PLHIV networks.
Lack of documents to establish eligibility – for example, a death certificate, ration cards, voter identification card or proof of residency	Meet with district officials and conduct advocacy meetings to address specific issues involving barriers to access.

Frequently asked questions: Food Security

1. What are the benefits of a kitchen garden?

In a kitchen garden, the household can use its backyard to grow different foods, such as green leafy vegetables, fruits, tubers, legumes and creepers. By following certain practices of organic farming, the family can have good nutritious food and sell surplus crops for a profit to help meet daily expenses.

2. How are micro enterprises useful?

Micro enterprises boost income, ensure a consistent amount of basic income, promote commitment to saving, and bring about changes in attitude and behavior. They involve little risk and are relatively easy to maintain. When households are financially secure, the health status of those with HIV and other household members improves.

3. Why are we linking households to government programs?

Any HIV care, support and treatment program is limited to the scope of its mission. Linkages with governmental and nongovernmental programs make additional support available, expanding the scope of service. Also, the government is mandated to provide certain entitlements that households affected by HIV may miss, despite their eligibility for them.

4. To which services and institutions can an FCM refer beneficiary households?

The FCM may refer beneficiary households to the multiple wings of the Department of Rural Development and the Department of Women and Child Welfare, in accord with the eligibility requirements attached to their programs. The FCM may refer individuals and households to the various government pension, welfare and economic enhancement schemes: for example, pensions for widows and people with disabilities; poverty elimination programs such as IKP; employment programs such as those of KVIC and the national finance and development corporations for scheduled castes and backward classes; and employment programs attached to the National Rural Employment Guarantee Act. Educational support, bridge schools, vocational training programs and double ration are available from India's Integrated Child Development Services. ICDS also presides over the Kishori Balika scheme, which helps families to support girls. Children with SAM and MAM may be referred to the pediatric department of the nearest government hospital. They may also be referred to Anganwadi centers for participation in the Supplementary Nutrition Program (SNP) and to receive pediatric IFA, deworming and vitamin A supplementation.

9 Education

The right to education of children in households affected by HIV is threatened, because often, the primary caregivers (parents or others) who have the virus are too sick to provide for the children's needs. Many die before their children reach the age of 18. Under these circumstances, access even to education that is free is jeopardized. Instead of going to school, many children are forced to work for wages to support themselves and their households.

A family case management-focused program of HIV care and support must pay attention to education. Surviving parents or caregivers should receive vocational training or other forms of education so that they can support the formal education of these children. Where this is not possible, the adolescent children who cannot access formal education should be offered opportunities for vocational training.

9.1 What do educational interventions involve?

An educational intervention in the context of an HIV care and support program can make the following contributions:

- identifying children who are out of school as program beneficiaries and re-enrolling them
- keeping children in school by addressing the challenges that hinder retention
- encouraging enrollment of preschool children in Anganwadi center educational programs
- motivating children who have dropped out of school and are unwilling to return to pursue vocational education

9.2 How does an FCM promote education?

The FCM should counsel children, parents and other caregivers in households registered in the program on the importance of education. Moreover, the FCM can help with the enrollment and retention of children in school and with the re-enrollment of children who have dropped out.

9.3 How can a family case manager determine who needs educational support?

The FCM can elicit this information when conducting the household assessment. The FCM is also likely to identify these children in Life Skills Education (LSE) groups.

9.4 Steps to support education

The FCM can support education in HIV-affected households from several vantage points.

9.4.1 Home-based support

- Motivate eligible children who are not in school to seek formal schooling.
- Re-enroll children who have dropped out of school in either formal or informal schools and monitor their attendance regularly during home visits. Motivate caregivers to enroll these children in formal schools when they are ready.
- Motivate caregivers of children who are between 15 and 18 years old in vocational training programs and monitor their performance.
- The FCM should continue to counsel family members and children on the value of education to support retention.

9.4.2 School and institutional support

- Visit the schools of beneficiary children periodically and monitor their progress.
- Conduct sensitization meetings with the staff of schools where beneficiary children are enrolled.
- Ensure the linkage of children to governmental scholarship schemes.
- Enroll children who are unable to go back to school and who are older than 15 in government-certified vocational training institutes organized by nongovernmental organizations or faith-based organizations to learn employable skills.
- Coordinate with training schools and link children to opportunities to acquire skills.
- Conduct regular school visits and interact with teachers to monitor the children.
- Conduct regular counseling with the school staff to ensure confidentiality

9.4.3 Community-based support

- FCM may address the educational issues of beneficiary children as a group by enlisting the support of the program's community advisory boards.
- Children in food-insecure households are especially likely to become child laborers. The FCM should link the households to the program's community-based food security interventions, and in that way relieve a source of pressure on children to leave school.
- The FCM can mobilize local resources to equip children with books and other school materials and to reinforce the habit of attending school.

Direct ways to motivate children

- The FCM may screen children to find out why they are unwilling or unable to stay in school.
- The FCM should counsel or refer for counseling children between the ages of six and 17 who are experiencing self-stigma (shame).
- The FCM can use LSE sessions as an ideal platform to motivate school dropouts to re-enroll.

- The FCM should provide one-to-one counseling or group counseling, incorporating peer support or success stories.
- The FCM may seek the support of PLHIV network support groups to render peer counseling to the beneficiary children

Challenges in ensuring education for beneficiary children and strategies to overcome them

Challenges	Strategic responses
Direct support for education is not available under the program	Indirect support can be rendered through linkages at different levels: with the National Child Labour Project (NCLP), for example. Incentives for uniforms and books and linkages to special midday meal schemes and travel concession can be mobilized.
The caregiver is too sick to take the child to school for re-enrollment or lacks the money to support the child's education	Indirect support can be rendered through linkages at different levels: with the National Child Labour Project (NCLP), for example. Incentives for uniforms and books and linkages to special midday meal schemes and travel concession can be mobilized.
The child has dropped out long ago and is unwilling to re-enroll	Counsel the child to enroll in a vocational training program.

Frequently asked questions: Education

1. How can the FCM help children who drop out of school?

The FCM needs to find out the specific reasons why a child has left school and motivate the child's return by explaining to the child and the family the importance of education and then addressing the deterrents. The FCM can offer support for the child's education either from the project directly or by mobilizing funds from local resources. The FCM can introduce the child to a peer group of children who are in school. The FCM can motivate the child to join an LSE group.

2. What is meant by re-enrollment?

A child who returns to school after dropping out is re-enrolling.

3. What kind of material support for education do children need?

Children need books, bags, stationery and play material. The FCM should mobilize it from other governmental and nongovernmental agencies.

4. What is the difference between formal and informal education?

Formal education is classroom-based and conducted by trained teachers. Informal education happens outside the classroom – in after-school programs, museums and libraries; at community-based organizations; and at home. Both formal and informal education are valuable. They contribute different strengths to an educational outreach project.

10 Community Mobilization

10.1 What is community mobilization?

A community is a group of people who share common interests and/or who live in the same locality. Mobilization is the act of marshaling forces, organizing and taking action. Community mobilization in the context of this manual is the effort of enlisting a community to support people in households affected by HIV and help them adopt strategies to support themselves.

To improve the quality of life of beneficiary families, several types of communities should be mobilized. The FCM may mobilize influential leaders and people's representatives in programs and community-based institutions to help the registered households access their entitlements and resources to meet immediate needs. Potentially supportive sources of support are networks of PLHIV, self-help groups and faith-based organizations.

Communities are the key stakeholders in fighting the consequences of HIV.

10.2 How is community mobilization conducted?

Tools for community mobilization are community advisory boards, support groups, community sensitization meetings and special events.

10.2.1 Forming a Community Advisory Board (CAB)

A community advisory board (CAB) consists of the key representatives of the community at the village or block level. The CAB meets to address issues of concern to PLHIV.

Steps in forming a CAB

- Family case managers should begin by identifying the mandals or taluks (administrative divisions) within their jurisdiction for formation of CABs. Ideally each mandal will have at least 25 children.
- An FCM should prepare to recruit CAB members by conducting formal and informal gatherings to sensitize community members about the health, economic, psychosocial, educational and nutritional problems of people affected by HIV.
- Each FCM must then identify the key people in the mandals. These people usually represent some sector of the community. Examples of candidates are Panchayat (block council) members, municipal ward members, Anganwadi workers, people who work or volunteer for

the relief organization, ASHA , Auxiliary nurse midwives (ANMs), Medical officers in Primary health centers (PHC), school representatives and self-help group members.

- The FCM should make sure the CAB members understand why the board is needed and what its objectives are.
- With the consent of the CAB members the FCM may plan the day, date and time of the first CAB meeting.
- The FCM must have a planned agenda for the meeting with clear expected outcomes.
- The agenda should be informed by information the FCM has gathered from the community about their concerns related to HIV. For example, a community seriously affected by HIV may be worried about the growing number of orphans and vulnerable children.
- Board members, not the FCM, should facilitate the CAB meeting, and begin by sharing information, identifying challenges for PLHIV and their families and working out action plans to address them. Examples of these challenges are access to good-quality health services and to government schemes, stigma and discrimination, motivating the families to be tested for HIV, keeping children in school, care for orphans and vulnerable children and organizing child support groups.
- The FCM's chief role at this point is to facilitate the meeting's proceedings.
- The FCM should encourage the CAB to put the list of its concerns in priority order. Board members can then identify internal community resources and knowledge as well as the skills and talents of individuals that can be tapped to solve the problems on the list: "Who can do what; who is already doing what; what resources do we have; what else can we do?"
- With this information, the CAB can create an action plan with a clear timeline and assign board members to take responsibility for specific tasks. The action plan must be part of the minutes.
- The board members should set the date and time of their next meeting; this, too, should be recorded in the minutes.
- Acting as an adviser, the FCM will gradually orient the CAB members to carry out the action plan, modifying it when necessary, drawing on external resources when internal resources have been exhausted, and pursuing their mission in a way that can be sustained over time.

Challenges in ensuring education for beneficiary children and strategies to overcome them

Challenges	Strategic responses
CAB members are losing their motivation to address HIV	The FCM needs to attend CAB meetings at regular intervals to assess the members' commitment and remind them of the need for their service.

Challenges	Strategic responses
The focus on HIV gives way to more general community challenges	The FCM can conduct awareness camps and meetings to sensitize board members to HIV-related issues. The FCM can also involve members in activities of the family case management program.
Attendance is irregular because of time constraints and conflicts with personal priorities	Formalize the meetings. Engage CAB leaders by meeting at their convenience. Tighten meeting agendas.
Members are scattered and have trouble getting to meetings	Provide travel support.
Board members expect to be compensated for their participation	Remind CAB members of their voluntary role.

10.2.2 Forming support groups

The main objective of a PLHIV support group is to serve as a network to increase access to HIV and wrap-around services. It is also to give PLHIV an opportunity to take a leadership role, by facilitating a support group meeting. Support groups help PLHIV with self-care, family care, home based care, self-empowerment, ART adherence, personal hygiene and mitigating stigma and discrimination.

Encourage PLHIV to talk with others who are HIV-positive. People who are HIV-positive have similar worries and questions and can help one another.

Formation of PLHIV network support groups

- Share the purpose and benefits of support groups with the PLHIV; motivate them to form groups.
- Mobilize PLHIV to join existing support groups
- Estimate the number of PLHIV likely to be in a support group, based on geographic distribution.
- Set the day, date, time and venue for the support group meetings.
- Facilitate introduction of the members of the support groups to one another.
- Sensitize group members on the need for confidentiality.
- Work with the support group to identify their needs and the needs of their families, to identify needs that require immediate attention and to decide how they can address those needs.
- Encourage members to discuss effective health-seeking behavior of adults and children.

- Build the capacities of the groups to encourage positive living by sharing success stories
- Strengthen the groups so that they can sustain themselves as the FCM gradually withdraws support.

Challenges in ensuring education for beneficiary children and strategies to overcome them

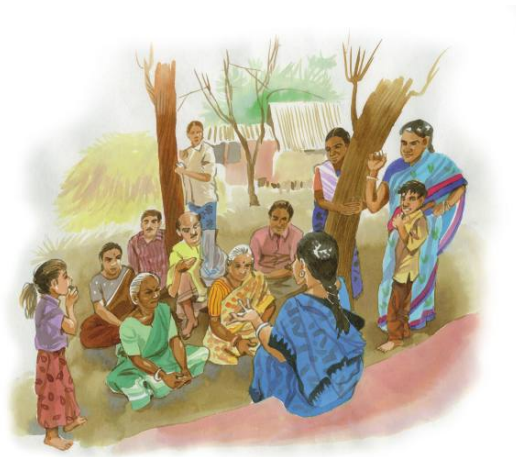
Challenges	Strategic responses
Hesitation to join a group for fear of a breach of confidentiality	Educate the support group members on the importance of keeping information about their support group members confidential.

10.2.3 Organizing community sensitization meetings

The purpose of a community sensitization meeting is to seek the psychosocial support of a community for the PLHIV and their families in their midst and to assure access to services without stigma and discrimination. The FCM needs to identify areas where case loads are high, areas where stigma and discrimination are strong, and areas with relatively large numbers of incorrect addresses that could be corrected by making connections with community members. These areas are most in need of community sensitization meetings.

Steps in conducting a community sensitization meeting

- Identify the areas that need community sensitization meetings.
- Secure permission of the sarpanch (the village council head) in advance.
- Identify a suitable venue to conduct the sensitization meeting.
- Publicize in locally appropriate ways the day, date, time, venue and purpose of the meeting.
- Invite local community representatives to speak at the meeting.
- Start the discussion with general issues and gradually proceed to specifics: the importance of early testing, the negative consequences of stigma and discrimination, the need for unobstructed access to HIV-related service centers and so forth.



- Inform participants about the goal, objectives and activities of the family case management program for PLHIV.
- Explain the role of the FCM and provide contact information.

10.2.4 Conducting other activities to mobilize a community

The FCM has several tools in addition to those already discussed, as follows:

- special events such as World AIDS Day, Candle Light Memorial Day, Women's Day and Children's Day
- formation of children's clubs

  Child clubs support children both emotionally and socially. They allow children to form bonds with peers and provide a safe environment in the neighborhood in which children can enjoy their childhood.
- formation of caregiver clubs

  Caregivers need to understand issues related to HIV and the effects of HIV on children. These clubs help them learn from other caregivers.

Challenges in mobilizing a community and strategies to overcome them

Challenges	Strategic responses
Stigmatization of the FCM following a community sensitization meeting and unwillingness of beneficiary families to meet with the FCM to access their benefits, for fear of revealing their status to neighbors	Have an FCM assigned to a different mandal or taluk conduct the community sensitization meeting.
Scattered populations of children and caregivers who are potential club members	Form clubs in areas where HIV-affected children and caregivers are clustered.
Reluctance of community members to attend a meeting about HIV and participate in discussions of issues associated with the virus	Put other diseases prevalent in the community on the agenda, as well, and discuss those first. Then turn the discussion to concerns and issues related HIV and the special care that PLHIV require.

Ensuring active community participation

- **Know your community well and understand their problems and specific needs.**
- **Be aware of beliefs and practices prevalent in the community.**
- **Always listen to community members closely.**
- **Do not introduce interventions that contradict existing practices and beliefs.**
- **Analyze community dynamics and adjust to them.**
- **Involve a community in the HIV program from the beginning.**
- **Demonstrate respect for a community's negative experiences with public service projects, if any, and try to minimize adverse factors.**
- **Be prepared to share complete information about government schemes.**
- **Map the organizations already working in the area and form alliances with them.**

11 Psychosocial Support

HIV is a chronic life-threatening illness that forces people and their families to cope with the trauma of uncertain progression, a complicated medication regime, and the grief that comes with the loss of health and possibly the loss of family members. Unlike other chronic, terminal illnesses, HIV is further complicated by the stigma related to two of the ways in which it is transmitted: sexual activity and intravenous drug use. Fear of this stigma leads many families to isolate themselves from their relatives and communities in order to shield themselves and their children from mistreatment. Isolation in turn puts them at risk for mental health disorders (for example, depression, post-traumatic stress disorder and anxiety), developmental deficits, and behavioral problems (for example, drug or alcohol use, failure in school, the inability to hold down a job, and crime).

11.1 What is psychosocial support?

The term "psychosocial" refers to the close relationship between an individual and the collective aspects of any social entity. They mutually influence each other. The psychological effects are caused by a range of experiences that affect a person's emotions, behavior, thoughts, memory and learning capacity, while the social effects are the shared experiences that affect the relationships among people.

According to the Balasahyoga program, psychosocial refers to emotional and social development. Psychosocial support is one of the ways in which the program builds resilient families.

11.2 What are the key psychosocial dimensions of a family case manager's responsibilities?

Build family resilience to HIV infection

- Assess psychosocial needs of the family periodically.
- Render need-based psychosocial counseling.
- Refer people with critical problems to counselors connected to the project, the ART center or the CCC.

Render age and stage appropriate intervention using a participatory approach

- Engage children between the ages of eight and 18 in an LSE program.

Build structural support systems for children and families to enhance their resilience

- Establish Community Advisory Board

- Establish support groups for PLHIV
- Establish support groups for children affected by HIV
- Take advantage of the network of support services by making referrals to them

Build an enabling environment

- Convene community sensitization meetings.
- Encourage PLHIV and their families to overcome fear of stigma and discrimination.

11.3 Strengthening a family's resilience to deal with HIV

11.3.1. Psychological needs assessment

Assessment of emotional well-being

Ask how the caregiver and children in the family are feeling. Are they happy or sad? Are they able to sleep well? Is there anything that they would like to talk about? Is there anything the FCM can help with?

- Observe the behavior of the children. Are they quiet, shy, withdrawn, crying, clinging or angry?
- Observe the adult caregivers: Do they seem sad, withdrawn or worried?
- If the family does not seem to be coping well, return to the home within the next few days for further assessment and to begin counseling.

Recognizing the signs of depression

Depression is a state or condition that differs from normal sadness in its intensity, duration and crippling effect on daily activities. Depression can interfere with clients' ability to manage and cope with their HIV and to live positively. Depression comes in many forms. It can manifest as sadness that persists over a long period or as sharp, sudden feelings of hopelessness and thoughts of suicide.

Many people with HIV (and their family members) experience depression. Depression makes PLHIV less able to adhere to HIV treatment and care and less likely to eat nutritious food.

How to assess depression

Two signs of depression are

- feeling sad most days, for two weeks or more during the previous month
- having difficulty most days finding pleasure in activities that used to be enjoyable, for two weeks or more during the previous month

If a client says "yes" to either or both descriptions, consider using the depression assessment tool to determine whether the depression is mild, moderate or severe.

For a client who has mild or moderate depression

- Attempt to lessen the depression through problem-solving.
- Increase the client's self-esteem through counseling
- Enable the client to think positively by mirroring a positive attitude.
- Help the client understand the relationship between feelings, thoughts and behaviors.

Assessing a client's risk of suicide

- When people are feeling severely depressed or overwhelmed by problems, they might have thoughts of wanting to harm themselves or take their own lives.
- An FCM should always ask about suicidal thoughts if a client is moderately or severely depressed or seems overwhelmed by life, whether or not the client raises the subject.
- Asking a client about thoughts of suicide will not cause the client to think about suicide.
- Asking a client about thoughts of suicide will not cause the client to act on suicidal impulses.

If the client is at immediate risk:

- Provide immediate referral to a psychiatrist.
- If a psychiatrist is not available, consider psychiatric hospitalization.
- If neither of these options is possible, have a relative or friend stay with the client to assure the client's safety until a referral can be made.

11.3.2 Alcohol and substance use

Family case managers are likely to see a lot of alcohol and drug use among their clients. When case managers suspect that clients are using alcohol or drugs, they should convey the following information:

- Drugs and alcohol can worsen the symptoms of HIV.
- They keep some medications from being fully effective.
- They can lead clients to miss medications, which can lead to drug resistance.

If a client refuses all suggested interventions and the FCM believes there is an imminent risk of suicide, the FCM may break confidentiality to discuss the client's suicide risk with doctors and or family as a safety measure. The FCM should provide minimal information to as few people as possible.

[3]Follow-up counseling tool kit, International Training and Education Center on HIV.

The family case manager's role in substance abuse

Counseling for substance abuse should include

- behavior modification
- working with clients to reduce their drug and alcohol intake gradually
- helping clients set goals with deadlines
- supportive therapy, working with clients on self-esteem and helping them to observe their emotional reactions (denial, shock and anger)

The FCM can also refer clients to motivational programs, detoxification facilities and rehabilitation centers.

11.4 Ensuring psychosocial support

11.4.1 Mobilizing psychosocial support

An FCM may mobilize parents, members of the community, PLHIV support groups, peer groups, other FCM, counselors at HIV medical facilities and CABs to provide social support. At times some of the externally trained counselors to whom clients in critical condition are referred also provide psychosocial support. For children, the most important sources of support are usually parents or other relatives.

11.4.2 Prioritizing households

A household's priority for support must be based on the psychosocial needs of the members. Situations with a high priority for psychological counseling are early HIV testing, status disclosure and issues of stigma and discrimination. In addition, an FCM may also identify and address the psychological needs of children who are in a vulnerable position: for example, children who are sad, withdrawn, demonstrate low self-confidence and do not have many friends; who have just enrolled in the program; whose parent, guardian or sibling is very sick; who have recently lost a close relative; and who have been moved to a new household.

Another indicator of priority for an FCM's attention and counseling is maternal depression, because that has been shown to have a significant impact on a child's cognitive, psychosocial and physical development. (Refer Annexure 3: House Visit Prioritization Tool)

11.4.3 Psychosocial counseling

Psychosocial counseling is defined as a process of helping others to identify and solve their own problems. Besides the regular counseling provided by an FCM, psychosocial counseling is needed to address emotional and social suffering. An FCM must utilize the basic counseling skills to address specific issues.

11.5 Making referrals for psychosocial support

An FCM needs to develop referral relationships with services that offer psychiatric and psychosocial care. Follow-up linkages need to be established with counselors working at health facilities who are trained in HIV counseling. Certain social problems can be referred to positive networks, support groups and CABs.

11.6 Addressing stigma and discrimination

HIV-related stigma has a profound effect on the HIV epidemic's course. Stigma and discrimination are the main reasons why people are reluctant to be tested, to disclose HIV status or to take antiretroviral drugs. The FCM needs to assist families in addressing specific instances of stigma and discrimination. This support may involve helping children with problems at school or helping family members and neighbors to understand HIV better. The FCM should be aware that self-imposed stigma often precedes stigma imposed by others. Both require attention. To provide it, the FCM may seek the help of community support groups and PLHIV support groups.

11.7 Creating an enabling environment by establishing structural support systems for children and families

11.7.1 Support groups for people living with HIV

Support groups for PLHIV help families registered in an HIV program, by reducing stigma within families, in neighborhoods and at facilities. They support families, specifically by addressing their needs and generally by creating a sense of care and belonging. Where support groups have not been formed, an FCM can bring families together to create them.

11.7.2 Community Advisory Boards

Community advisory boards can be formed at the village level to address the major issues of families affected by HIV: stigma and discrimination, child protection, referral to relevant health and non-health services, sharing information and coordinating frontline staff of organizations and agencies that serve PLHIV.

Challenges in ensuring psychosocial support for beneficiary children and strategies to overcome them

Challenges	Strategic responses
Insensitivity of CAB members to HIV	Orient CAB members on the program, the purpose of the CAB meetings and expected outcomes.
Difficulty recruiting adolescent girls for LSE sessions	Conduct classes at the most convenient places for adolescents. Classes may or may not be conducted in the presence of parents, as appropriate to local culture. Announce the topics of upcoming sessions to sustain interest.
Assembling children for LSE by age group	Conduct sessions on holidays and Sundays at an hour that suits children. Nurture peer comradeship and cohesiveness.
Ensuring the frequency of support group meetings	Organize the meetings at a time convenient to the majority of participants. Prepare a clear agenda and list of expected outcomes so that the time will be used efficiently. Ensure follow-through on the group's action plan.
Referral of clients in critical condition to trained counselors	With the support of the field supervisors and the project counselor, list the facilities that can be contacted to render psychosocial support. Establish referral linkages with them.

11.8 Providing age- and stage-appropriate psychosocial support for children

11.8.1 Life Skills Education

Life Skills Education gives children between the ages of eight and 18 a chance to spend time with others at their stage of development. In the process, most of children share their experiences in the skills they acquire in the LSE sessions to their own situations. An FCW can motivate LSE children to act as peer educators, influencing other children their age. The program consists of 20 sessions conducted over several months. In facilitating the sessions, the FCM uses age-appropriate communication skills.

Steps in conducting an LSE session

- Determine the number of beneficiary households in a village. Surrounding villages may be tapped, as well, if they are close by.
- A group should consist of 15 to 20 children and be a mix of program beneficiaries, orphans and other vulnerable children (for example, child laborers, school dropouts and children who lack close attention at home)
- Inform caregivers about the importance of LSE and obtain their consent.
- Divide the children into age groups.
- Set a day, date, time and venue for the LSE sessions that will be convenient for the majority of children. Conduct the sessions for an hour per week, following the LSE module. (Refer to Life skills education tool kit for orphans and vulnerable children in India, FHI 360/India).
- Track attendance and follow up with children who drop out.
- Allow time for recreation during the sessions.
- Strengthen the capacities of children to become peer educators and form child support groups.
- Invite active LSE children to co-facilitate LSE sessions.

Challenges in involving beneficiary children in Life Skills Education

Challenges	Strategic responses
Unwillingness of parents to send their children to LSE	Offer LSE in areas where beneficiary households are clustered.
Expense of travel for children to attend the sessions	Hold the sessions in or near the neighborhoods where the children live.
Dividing the groups by age results in groups with too few children from beneficiary households	Offer LSE in areas where beneficiary households are clustered.

11.8.2 Pediatric counseling

Very young children cannot use words to express their emotions or thoughts. Thus, an FCM needs less abstract ways to communicate and help these children express their feelings.

Steps in conducting pediatric counseling

The goals of pediatric counseling are to enable children to become capable of solving problems on their own. To accomplish this, the FCM must make the child's needs paramount in the counseling process.

- Tailor the counseling to a child's physical and psychological development.
- Promote the child's potential and abilities.
- Use appropriate interactive tools such as drawing, storytelling and skits, which can help children explore sensitive issues and identify solutions.

11.8.3 Creating a memory book for children

A memory book is a way for parents who are living with HIV to document the family's history and traditions and other important personal information for their children. A memory book has many advantages for a child. The book

- opens channels of communication between parents and children, improving the relationship.
- helps children understand their families' traditions and beliefs
- encourages parents to plan for their children's future
- encourages a parent to set up a will, making the child's inheritance more secure if the parent dies
- increases the child's knowledge of family assets and how to manage them
- helps a parent realize the importance of naming a guardian for the child and establishes a link between the child and the guardian
- puts a child in touch with a “lost” parent and perhaps also that parent's family
- improves the self-image and self-esteem of parents who are HIV-positive
- encourages parents to disclose their HIV status to their children, and possibly to the wider community, as well
- increases the child's knowledge of HIV and how to avoid acquiring it

Steps for FCM in creating a memory book

An FCM should encourage parents to create memory books (or memory boxes) for their children. Examples of things to include are

- personal history and important life experiences
- family background
- family traditions
- guidance about how to face up to life, on whom to rely and how to contact relatives
- photographs and other types of pictures

Frequently asked questions: Psychosocial Support

1. What comes after Life Skills Education?

Children who have received LSE can act as peer educators or form child support groups so that they can continue to support one another's emotional needs.

2. How many children should be in a support group?

The ideal number ranges from 15 to 20.

3. What issues do CABs address at their meetings?

The issues generally addressed during CAB meetings are

- follow-up of PLHIV needing support
- planning joint visits with auxiliary nurse midwives and ASHA workers to PLHIV household
- death certificates and pension schemes
- stigma and discrimination
- quality of services
- access to double ration

12 Referrals

12.1 The referral process

People with HIV who are identified at a health facility are referred to an FCM for support. In turn an FCM can refer clients to government agencies, institutions for counseling, welfare schemes, treatment centers, clinics for health examinations and other service providers. Meeting the needs of the growing number of PLHIV, their caregivers and their family members requires the collective effort of facilities and organizations, both clinic- and community-based. Strengthening access to HIV-related services for those in need and promoting communication among service providers requires a formalized referral network.

Family case managers are the focal point for referrals, because they help individuals and families define and meet their needs. Beneficiary households are often referred at the community level to AWWs, ANMs, ASHA workers or any other community worker. They are also referred to health facilities (ICTCs, CCCs, ART centers) for testing and treatment. They are referred to several government departments for entitlements in the areas of food security, education (schools and vocational training centers), income generation, thrift and funds created for children and adults with HIV (pensions, scholarships).

The referral system entails coordinating service delivery to ensure that

- access to needed services is expedited
- confidentiality is maintained
- referrals among organizations in a network can be tracked
- referrals and their outcomes are documented
- a feedback loop is in place to inform all concerned that the requested service has been delivered and has met the needs of the client

12.2 Starting and strengthening a health-facility-based referral network

Starting a new referral network or strengthening an existing one is a multistep process involving many players and stakeholders. The main steps are described below.

12.2.1 Convene a workshop for stakeholders

- Identify and bring together the stakeholders to initiate a community dialogue, seek input on creating a formal referral network and generate buy-in for the workshop.
- Convene the workshop.
- Conduct a participatory mapping exercise.
- Identify gaps and discuss how a referral network can fill them.

The plan of action to follow the workshop should include putting systems in place to develop and support the referral network and mobilizing the community to use and support the referral network.

Examples of stakeholders are district (government) health staff, key staff of health facilities at all levels (from tertiary to community level), PLHIV support group representatives, social welfare office representatives, local nongovernmental and community-based organizations and faith-based organizations.

Participatory mapping exercise

The point of a mapping exercise is to generate a list of all organizations and facilities providing HIV-related services within the geographic area that might be included in the referral network.

The mapping should identify key entry points: that is, how a client gets into the referral network, potential barriers to access and how the network will be linked to existing comprehensive care and support services in health facilities and community-based organizations. Support groups PLHIV can be an excellent resource in this activity and should play an active role.

As part of the process, a directory of services can be created showing all clinical and social service agencies and nongovernmental organizations that might assist HIV-positive clients and their families in the catchment area.

12.2.3 Putting systems in place to develop and support the referral network

Begin by determining the roles and responsibilities of each organization within the referral system. Then hold sensitization meetings with stakeholders and staff of participating organizations to achieve consensus on operating principles, such as ensuring that all referrals are honored.

Supervisors in the network organizations should make sure that staff understand the referral network and how it works and train staff at all levels (clinic or community-based) to provide referrals as necessary.

There should be a discussion of confidentiality, stigma and the potential for "shared confidentiality" and what that means to the community. Guidelines can then be adopted to address the issue of confidentiality within the referral network.

An appropriate mechanism for referral will include referral forms and registers to document the process for the referrals and follow-up. Once these forms are drafted and approved, they should be distributed along with published procedures for their use to all organizations in the network.

Providers at all levels should encourage one another to nurture personal contacts within the network to facilitate referrals and follow-up.

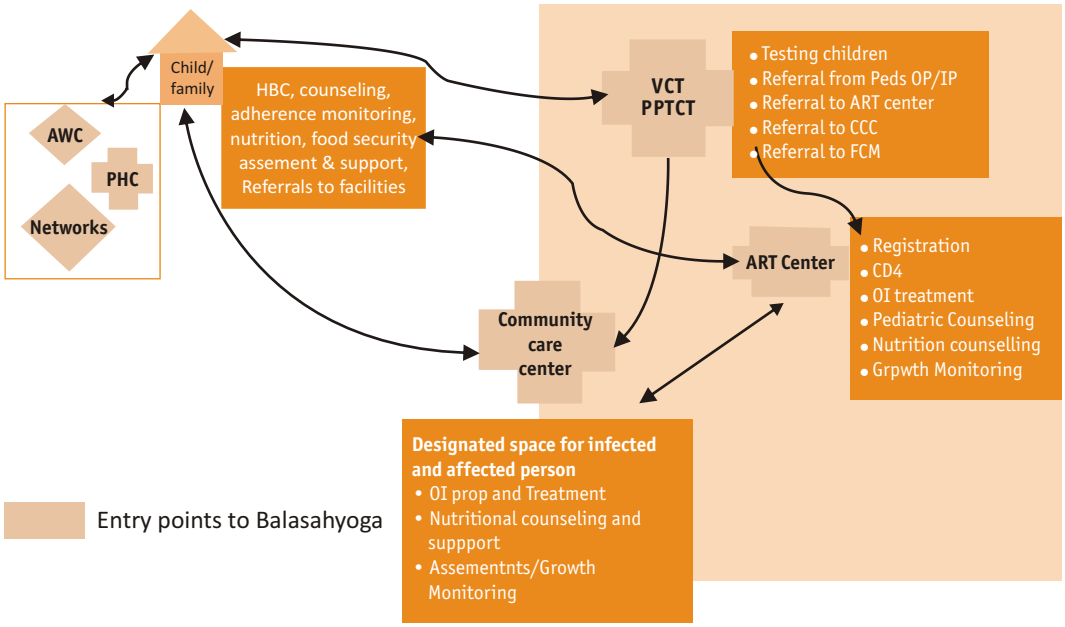
12.2.4 Mobilizing the community to use and support the referral network

- Undertake intensive community mobilization, holding public awareness activities to build demand for services.
- Seek the support of church and educational leaders, medical providers and policy makers to use their influence to increase community support for the network.

12.2.5 The family case manager's role in using and sustaining a health facility-based referral network

- In discussion with the patient and/or caregivers, and using the directory of services, the FCM determines the patient's needs and initiates referral to the appropriate service.
- The FCM must ensure that the patient receives a written referral form that includes information about the patient, the organization or individual making the referral, the service(s) needed and the organization or individual to whom the patient is being referred.
- A record of the referral goes into the program's family case file and the facility's referral register.
- The FCM obtains information on the outcome of the referral, including the client's satisfaction with the service(s). This can be accomplished at the client's next clinical visit or by communicating directly with the organization receiving the referral and the client.
- The network grows as the FCM establishes linkages with health facilities and other organizations providing services to PLHIV, their caregivers and their families within a defined geographical area.
- The FCM should schedule regular meetings of the network participants to discuss issues and challenges in operationalizing the referral process.
- The FCM also should conduct quality assurance to determine whether services are satisfactory to PLHIV, their caregivers and their family members and when gaps in services emerge, follow up to make sure they are addressed.

Figure 12.1 Routes of community and facility based refferals

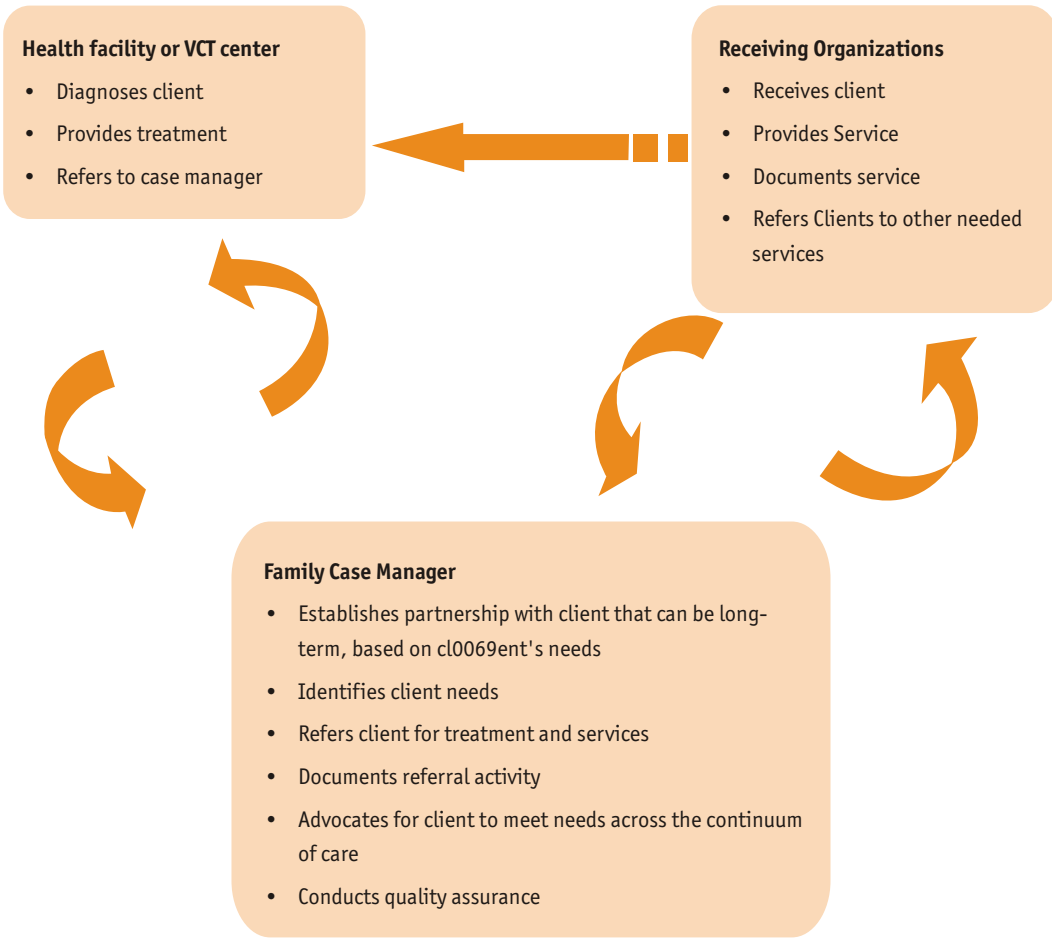


12.3 Establishing a community-based referral network

The FCM is well-positioned to coordinate a community-based referral system. The process often begins when a client is referred to the FCM for support and develops from there, as follows:

- An HIV-positive client at an ICTC or ART center is referred to an FCM.
- The FCM visits the client, assesses the needs of the client and the household, and develops with a care plan with the client and caregivers.
- The FCM implements the care plan by rendering HIV-related services such as prevention advice, advocacy, peer education, counseling, psychosocial support and information about home-based care.
- To support these efforts, the FCM consults with other community-based services such as food security interventions, government entitlements, PLHIV support groups, CABs, and child support groups.
- The FCM monitor service delivery by these entities and advocates for clients as needed.
- As the FCM continues to evaluate client needs, additional prospects for linkage and referral are identified and put in place.

Figure 12.2 FCM Referral Network

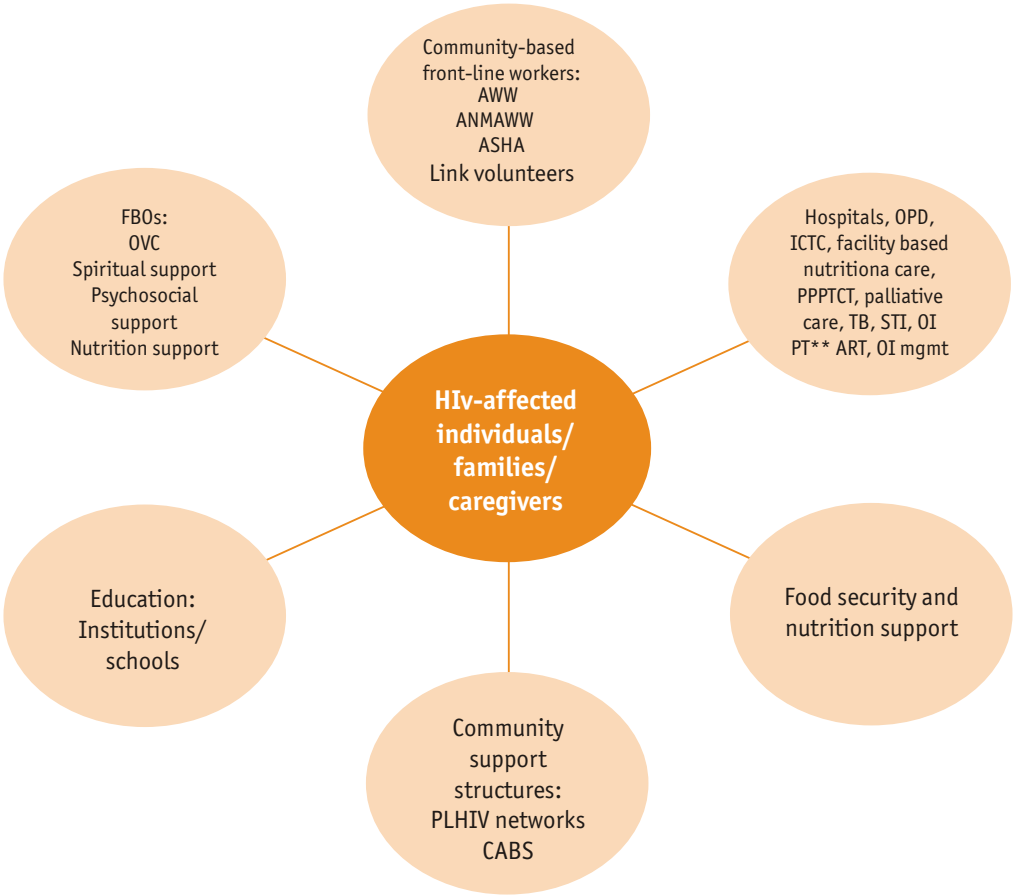


12.4 Characteristics of an effective referral network

The network should cover as broad a range of services as possible. Gaps in the services available in a community are common and should not stop an FCM from initiating a referral network. The gaps can be filled as the network matures.

Access is essential to the uptake of services. An FCM should seek to remove barriers to access so that the needs of clients can be met.

Figure 12.3 Referral network for prevention care and treatment



12.4.1 Periodic meetings of network providers

Regular meetings of organizations in the network are a venue for ongoing communication, exchange of information about the referral process, discussion of challenges and gaps in service and updates of the network services directory. The FCM may facilitate when the meetings are convened. Regular meetings promote collaboration and commitment to the referral process as an essential component of HIV service delivery.

12.4.2 Management of a directory of services/organizations within a defined catchment area

The FCM should prepare a directory of the services in the facility-based and community-based referral networks. A directory serves as an inventory of the services available within a geographical area and facilitates referrals by putting the inventory within easy reach.

A directory must be updated constantly to assure that information on service providers is current and accurate, that new providers are listed and that providers no longer offering a service are deleted.

Name of the organization	Type of services provided	Referral contact person	Location of service

12.4.3 Using a referral form

Adopting a standard referral form ensures that the same essential information is provided whenever a referral is initiated and that this information is received by the organization fulfilling the referral. (Refer Annexure 15: Referral Form)

FCM needs to fill in the minimum information required on the form:

- the date of the referral request
- the type of service needed
- the name of the client
- the name and contact information of the organization initiating the referral request (referring organization)
- the name and contact information of the organization to which the referral request is directed (receiving organization)
- the names of the designated contact people at both organizations

The FCM gives the completed form to the client, caregiver or family member to direct them to the service needed. The form introduces the client to the organization fulfilling the referral and identifies the organization and person initiating the request. It also indicates which services the client needs.

Ideally, after the services are completed and the referral is fulfilled, the FCM follows up with both the client and the receiving organization. If this is not feasible, then the client returns the form to the FCM. This feedback loop is important for documenting referrals and evaluating the system.

12.4.4 Referral feedback

It is important for the FCM to track a referral from the point of initiation to the point of delivery and, as a feedback loop, from the point of service delivery back to the point of initiation. This ensures that the client used the service(s) needed.

12.5 Types of referrals

In addition to facility-based and community-based referrals, the referrals an FCM makes can also be characterized by the circumstances under which they are made and by the way they are carried out.

12.5.1 Routine referrals

Some referrals an FCM makes will be for routine rather than one-time or short-term services. Most routine referrals are to facilities, and the FCM should support them by following up with the clients referred on a regular basis. Routine referrals are made for

- integrated counseling and testing, ART and the services of CCCs
- CD4 monitoring
- cotrimoxazole prophylaxis
- nutritional counseling and assessments

12.5.2 Emergency referrals

Emergency referrals include any health related emergency that needs immediate attention and medical care. These referrals include positive ANC delivery, TB diagnosis, danger signs in children born to positive mother, side effects of ART.

12.5.3 Accompanied referrals

The FCM generally accompanies clients referred to a facility – for example, an ART center – for the first time. In this way the FCM can provide moral support to the client and guide the client in accessing the services.

Frequently asked questions: Referrals

1. What services can be included in a referral network?

The referral network should ideally include organizations in a defined geographical area that are serving PLHIV, their caregivers and their families in the following domains:

- adherence counseling
- antiretroviral therapy
- child care
- clinical care
- education/schooling
- family planning
- financial support
- HIV counseling and testing
- home-based care
- legal support
- material support
- mental health services
- microfinance
- nutritional counseling
- OB/GYN services
- peer counseling
- post-exposure prophylaxis (PEP)
- pharmaceutical resources
- PLHIV support
- PMTCT services
- prevention services
- psychosocial support
- social services
- spiritual support
- STI services
- substance abuse management
- support for domestic violence victims
- treatment support

- TB services
- peer support for children, adolescents and adults

2. Is it essential to track or follow up on a referral?

To ensure that a referral is effective or fruitful, follow-up is crucial. An FCM has the following responsibilities:

- Revisit the client to find out if a client is satisfied with the service received and if his or her need was met.
- Maintain a written record that the referral process was completed and the service was delivered.

3. How is the referral documented?

At both ends of the referral – the referring FCM and the receiving organization – a written record of the referral is needed to document outcomes. Both are responsible for documenting their roles in the referral process.

A standardized referral register is one way for the FCM to document referrals.

13 Supervising and Reporting

13.1 What is monitoring?

The monitoring system of a family case management program of HIV care and support tracks the package of services accessed by each person (age and sero-status specific) and household registered in the program. For Balasahyoga, monitoring involved collecting data against key variables and logging it in family case files for all of the households and individuals registered in the program. The information in the files was updated using household visit forms and service forms filled in by staff visiting households and facilities to clear the way for clients to access services.

The information collected should also be entered in a computerized management information system (CMIS). The CMIS is used to analyze data against key performance indicators for purposes of planning and monitoring. For Balasahyoga nongovernmental partners were responsible for ensuring data quality and accuracy.

The information from the CMIS can be especially helpful when stakeholders meet to review the progress made toward a program's benchmarks and adjust the program's management accordingly.

13.2 What forms are helpful in registering a household?

Registration is the first step towards bringing a household and an individual into a program's fold. It involves assessing the eligibility of potential participants in accord with the program's criteria and obtaining consent for participation from the head of the household. Consent signifies permission for program staff to visit the household, to collect household and individual information and to use the information to organize services.

To register individuals and households, the Balasahyoga program adopted a standard form, which the FCM filled out (usually by interviewing the head of the household). The form collected the following basic details:

- address
- source of the referral
- proof of eligibility
- dates of birth, ages, educational status and relationships of household members
- deaths in the family and their causes

Data from the registration form was then entered in a family case file, on forms created to serve as profiles of the household as a whole and of each child and adult attached to the household.

13.3 Preparation of family case files

The Balasahyoga family case file contained household and individual information in areas of program intervention. For example, it has information on housing, access to such basic resources as drinking water and sanitation, the family's income and assets and the family's access to safety-net schemes and entitlement programs. The profiles of household members include the HIV status of the individual and the individual's biological parents and the individual's access to a basic package of services outlined in the program based on age and sero-status. This information has enabled the FCM team to assess a household's situation and create an action plan for the household and its members.

The Balasahyoga FCMs began preparing the family case file for a household soon after its registration and had four weeks to complete it. Each file contained the following documents:

- household profile
- child profile (for each child alive and living in the family)
- adult profile (for each adult alive and living in the family)
- ANC sheet (for each pregnant women identified at the time of registration)
- household food security assessment

Once completed, a field supervisor reviewed the file for completeness and forwarded it to the office of the project coordinator, where the data was entered into the CMIS. According to Balasahyoga protocol, the file was due back to the FCM within seven days of receipt and was to be stored in a place accessible to the FCM.

13.4 Family care plan

Information gathered for a family case file allows an FCM to prepare a family care plan, in consultation with the household. The plans created within Balasahyoga covered the domains of health, education, nutrition, psychosocial support and food security and safety. Each plan outlined specific actions for the following year that would enable the household to improve its condition.

13.5 Monitoring access to services

Balasahyoga adopted a household visit form and a service form to record access to a package of services for each household member in accord with age and sero-status. The household visit form, completed after each visit by a family care team consisting of the FCM, a counselor and a community volunteer, recorded access to any new service during the time since the previous visit. The service form, also completed by the family care team, recorded access to any new service at a facility. These forms were then used to update the family case file. Two new forms – a child data sheet and an adult data sheet –

were added to the family case file for a record of data collected continuously (for example, on ART adherence, growth monitoring and school attendance).

13.6 Reporting

The Balasahyoga project data were processed, checked and analyzed on a monthly basis and used to generate monthly quantitative progress reports. This allowed program managers to measure performance and respond to gaps.

Frequently asked questions: Supervising and Reporting

1. Can people who have not been tested for HIV be considered HIV-affected?

An FCM can describe people as affected by HIV who live in households where HIV is present, whether or not they have been tested and determined to have acquired the virus themselves.

2. How are the family case manager's family files reviewed?

A field supervisor reviewed the FCM's registration, service and household visit forms on a weekly basis for the Balasahyoga program and resolved any inconsistencies in consultation with the FCM. The field supervisor documented the review by signing and dating the forms.

3. What happens to the records maintained by a family case manager if the case manager leaves or is reassigned?

For Balasahyoga, these records were handed over to the new FCM by the previous FCM.

Annexes

Annex 1: The Job and Qualities of a Good Family Case Manager

A good FCM is...

- caring, loving and nurturing: knows how to provide care and love to children and understands what children need to thrive
- can communicate well with children and adults: uses respectful language and know how to communicate and play with children at different ages
- family centered: does not focus only on the child but instead assesses the child within the context of the family; assesses the family as a whole
- knowledgeable about child development: understands what children need at different ages in order to develop well and can recognize when a child is not developing well
- protective of confidentiality: keeps information about the family confidential and signs a statement pledging confidentiality
- alert to danger signs and knows when and where to refer: knows what the signs are when a child is sick, sad or abused and knows how to refer the child
- able to identify abuse and knows how to protect a child from further harm
- aware of the importance of empowering and supporting a family to make its own decisions
- empathetic, nonjudgmental and accepting of the family
- respectful of children, involving them in decision making
- reliable: provides follow-up care on a routine basis; lets the family know when the care team will visit; inspires trust

Annex 2: Family Assessment Form

Family code number:_____ Date: _____

Location and contact details-
House/Door number: Caste: OC/BC/SC/ST
Village/ward/division:
Mandal: Landmark:
District:

Section 1: Identification

Details of ALL household members (children and adults)	Individual identification number	Name	Age	Gender (M/F)	Relation to infected or affected child 1 = Parent 2 = Aunt / uncle 3 = Grandparent 4=Other: Specify	Education	HIV status +/ -/u

Section 2: Economic Support

2.1 Monthly household income: INR [__|__|__|__| **2.2 Main source of income:**_____
2.3 Main income earners:

Name	**Gender**	**Age**	**Job**
1. _____	F/M	[__|__]	_____
2. _____	F/M	[__|__]	_____
3. _____	F/M	[__|__]	_____

2.4 Do you feel you have enough money to meet basic needs? Y/N/Don't know

2.5 If no, what are your plans for income generation?_____
_____
_____

2.6 Receive external financial support? Y/N/Don't know	**2.7 If yes, what:_____**
2.8 Economic support needed by the family? Y/N Describe:	
Section 3: Food supply and nutrition	
3.1 How often do you have enough to eat: 1 = All the time 2 = More than 20 days in a month, but not always 3 = Half the month 4 = Less than a week in a month 5 = Never 6= Don't know	**3.2 Do you receive any food support from Govt. or nongovernmental sources? Y/N/Don't know** **3.3 Do you grow any vegetables or have any animals? Y/N/Don't know**
3.4 Food/nutritional support needed by family?* Y/N Describe:	
Section 4: Psychosocial and health status	
4.1 Overall wellbeing of caregiver 1 = Well/happy 2 = Fairly well/feel ok 3 = Unwell/unhappy	**4.1 If unwell/unhappy, what are the reasons?** 1 = Death in the household 2 = Chronic illness in the household 3 = Lack of finances in the household 4 = Not enough food to eat in the household 5= Discrimination by others 6 = Other: Specify
4.2 Overall, wellbeing among children living in household? 1 = Well/happy 2 = Fairly well/seem ok 3 = Unwell/unhappy	**4.2 If unwell/unhappy, what are the reasons?** 1 = Death in the household 2 = Chronic illness in the household 3 = Lack of finances in the household 4 = Not enough food to eat in the household 5= Discrimination by others 6 = Other: Specify
4.3 How often do you require medical help? 1 = More than 20 days in a month 2 = Half the month 3 = Less than a week in a month 4 = Never 5= Don't know	**4.3 If medical help required, where do you go?** 1= Primary health center 2= Private medical practitioner 3= Traditional healer 4=Other: Specify----------

4.4 What health care services needed by the family? Describe:	
4.4 Is emotional support or counseling needed? Y/N Describe:	
Section 5: Schooling	
5.1 Children have any problems accessing schooling? Y/N/Don't know	**5.2 If yes, describe:** 1 = School fees 2 = Buying books/uniform 3 = Stigma and discrimination 4= Other: Specify
5.3 Is schooling support needed? Y/N Describe:	
Section 6: Legal or other plans for the future	
6.1 Made plans for the future (talked about this with someone or wrote plans down in a will) about who will care for children/other dependents if something happens to you? Y/N	**6.2 Made a will (showing what is to happen to your property) should you die? Y/N**
6.3 Do the children have birth certificates? Y/N	
6.4 Is support for legal or other plans for the future needed? Y/N Describe:	
Section 7: Other needs	
7.1 Other issues/needs:	
Section 8: Overall needs	
8.1 Biggest needs of household? *(Ask clients to prioritize top needs.)* 1 = Psychosocial support 2 = Educational support	10.2 Biggest needs of children under your care? *(Ask clients to prioritize top needs of the children they care for.)* 1 = Psychosocial support 2 = Educational support

3 = Health care 4 = Economic support 5 = Food and nutrition 6 = Legal support 7 = Other_____ 8 = Don't know	3 = Health care 4 = Economic support 5 = Food and nutrition 6 = Legal support 7 = Other_____ 8 = Don't know
Signature of the family case manager:	
Name /Code of family case manager:	
⇨ **Next, assess each child using the child assessment form and each adult using the adult assessment form. If the child is HIV-positive, also use the child CHBC form. If the adult is HIV-positive, use the adult CHBC form.**	

Annex 3: Algorithm to Set Priorities for Family Case Manager Visits to Households

This tool is intended to help family case managers and community workers prioritize their field visits, so they can visit households with greater need more frequently. **FCMs should visit each household at least once a month.** Beyond this visit, more visits should be planned in accord with the directions in the table below.

The FCM along with community worker makes the initial visit to a household, and carries out the following tasks:

- Builds rapport with the household
- Prepares family file
- Prepares a family care plan
- Based on the family care plan, determines whether the household needs priority status or will require less frequent visits
- Color codes the family file: orange for priority family and green for standard family

The following households should be given priority for follow-up visits, by the FCM

Whom to visit	Frequency	What will be done during visit
Child-headed households	Once a fortnight	• Regular follow-up
Child who has tested HIV-positive within the past 3 months	Once a fortnight until registered at ART center	• Registration in ART center • Motivation of other family members to be tested
Child who has been on ART for less than 6 months	Once a fortnight for first 6 months; if possible FCM should visit the household just after ART prescription has been made to assess how well the caregiver and child understand adherence	• Adherence monitoring • Adherence counseling
Child who has been on ART for more than 6 months	Once a month	• Adherence monitoring • Adherence counseling
Danger signs in children: high fever, acute severe malnutrition, child not taking food, etc.	Once a week until child recovers	• Immediate accompanied referral to the nearest health provider: e.g. PHC/CCC/private practitioner

Whom to visit	Frequency	What will be done during visit
Adult who has tested HIV-positive within the past 3 months	Once a fortnight until registered a ART center	• Registration in ART center • Discordant couple counseling • Motivation of other family members to be tested • Explanation of positive prevention
Adult who has been on ART for less than 6 months	Once a fortnight for first 6 months; if possible FCM should visit the household just after ART prescription has been made to assess how well the caregiver and child understand adherence	• Adherence monitoring
Discordant couple	Once a week for 1st month after FCM becomes aware of discordant status; at least once a month thereafter	Promotion of: • awareness of risks of transmission • awareness of safe sex practices, including FP choices • awareness of positive living strategies • awareness of importance of early treatment, including ART and PPTCT • disclosure of status
HIV+ pregnant woman	Once a month until delivery	• Linkage to PPTCT services and an outreach worker • Infant feeding advice • IFA supplementation for mother • Encouragement of spousal testing
Lactating HIV+ woman witha child less than 6 months old	Once a month till child is 6 months old	• Linkage to PPTCT services plus outreach worker • Infant feeding advice • Encouragement of spousal testing
Recent death in the household	Once a week for 1 month immediately following the death	• Bereavement counseling

Whom to visit	Frequency	What will be done during visit
Child who is not attending school regularly	Once a month	• Follow up for the reasons for the school drop out • Counsel the child and the care givers about the drawbacks of not attending to school
Child who was never enrolled in school	Once in a month	• Counsel the child and the care givers about the importance of attending to school
Child with emotional problems (withdrawn, self-isolated, sad, anxious)	Once a week	• Use interactive communication strategies to counsel the child • Counsel the care givers to provide psycho social support to the child
Highly and moderately food-insecure households	Once a fortnight	
Adult/child in treatment for TB	Once a month for the duration of treatment	• Adherence monitoring

Note: A family's priority is not permanent. The priority assigned to some families will change over time.

Annex 4: Adult Assessment Form

Name: _____ Client code: _____ Sex: Male ☐ Female ☐

Date of birth: Day____ Month___ Year_____ Age___ (yrs.)

Part 1: HIV status and general information				
1a. HIV status ☐ Not tested ☐ HIV-positive ☐ HIV-negative	1 b. If not HIV tested, are you planning to be tested? ☐ Yes ☐ No	2a. Education – Last completed level of schooling:	2b. Literacy: Reading ☐ Yes ☐ No Writing ☐ Yes ☐ No	
3a. Working: ☐ Yes ☐ No 3b. Job:_____ 3c. Monthly income	4. Marital status: 1 = Never married 2 = Married 3 = Widowed 4 = Divorced 5= Deserted	5a. Have children? ☐ Yes ☐ No 5b. Number of children:____	6. Have you ever used a contraceptive method? ☐ Yes ☐ No	7. If yes, which of the following? a. Sterilization b. Condom c. Oral contraceptive pills d. Any other: Specify _____
8. If female: Are you pregnant? ☐ Yes ☐ No				
Part 2: If the adult is a pregnant woman				
8. Which month of pregnancy?	9. How many antenatal checkups have you had during current pregnancy? a. None b. One c. Two d. Three		10. How many doses of tetanus toxoid have you had? 1. One 2. Two 3. None	
11. Are you taking IFA (iron & folic acid) tablets? Yes No	12. Where are you planning your delivery? a. Home b. Government institution c. Private institution d. Other: Specify_____			

Part 3: Symptoms (men and women)	
12. In the last one month, did you have any of the following complaints? a. Genital discharge b. Lower abdominal pain c. Burning micturition d. Genital ulcer or sore e. Scrotal swellings	13. Do you have any of the following? a. Cough for > 3 weeks b. Weight loss c. Diarrhea > 14 days d. Unprotected sex with a nonmarital partner or commercial sex worker
Signature of family case manager:	
Name/code of family case manager:	

Annex 5: Child Assessment Form

Child's name:_____ **Child's age:** _____

Child's code number:_____ **Date:** _____

Section 1: Child health and nutrition (*Also use HBC form to assess child with HIV)

1.1a Immunizations provided on schedule? ☐ Yes ☐ No	1.2a Growth chart checked? ☐ Yes ☐ No	1.3a Child has an appetite and is eating normally? ☐ Yes ☐ No	1.3b Child feels s/he gets enough to eat ☐ Yes ☐ No	1.3c Child is generally healthy, does not get sick often ☐ Yes ☐ No	1.4 Child enrolled in Anganwadi center? ☐ Yes ☐ No
1.1b Immunizations completed? ☐ Yes ☐ No	1.2b Growth chart normal? ☐ Yes ☐ No				

1.5 Child's health seems to be: 1 = Poor 2 = Ok 3 = Good	1.6 Child is able to access health care services when ill ☐ Yes ☐ No	1.7a Child's HIV status has been checked ☐ Yes ☐ No	1.7b Child is: ☐ Yes ☐ No	1.7c If positive, child is registered at ART center ☐ Yes ☐ No

1.12 Child health/nutrition support needed? ☐ Yes ☐ No
Describe:

Section 2: Schooling and cognitive development

2.1 Child seems to be developing according to age ☐ Yes ☐ No	2.2 Child seems alert and engaged ☐ Yes ☐ No	2.3 Child has opportunities to play ☐ Yes ☐ No	2.4 School-age child is enrolled in school and attends regularly ☐ Yes ☐ No	2.5 Child has basic school materials ☐ Yes ☐ No	2.6 Child is treated normally in school ☐ Yes ☐ No

2.7 Child schooling and/or cognitive development support needed? ☐ Yes ☐ No
Describe:

Section 3: Psychosocial support and protection		
3.1 Child seems happy and hopeful ☐ Yes ☐ No	3.2 Child interacts with others and has friends ☐ Yes ☐ No	3.3 There are signs of abuse, neglect or exploitation ☐ Yes ☐ No
3.4 Child needs psychosocial support and/or protection? ☐ Yes ☐ No Describe:		
Section 4: Shelter and care		
4.1 Child has a stable and loving caregiver ☐ Yes ☐ No	4.2 Child lives in a safe home ☐ Yes ☐ No	4.3 Child lives in a safe environment ☐ Yes ☐ No
5.4 Shelter and care support needed by child? Yes No Describe:		
Other issues:		
Signature of family case manager:		
Name/code of family case manager:		
END		
⇨ **Next, complete family plan**		

Annex 6: Conducting a Basic Physical Assessment

After you have *observed*, *asked and listened*, you will need to *look and feel* to gain a better understanding of the symptoms your client is experiencing and to understand what is normal physically for your client.

Explain to your client that you would like to feel his/her body to get a better idea of how he/she is doing physically. Ask your client if it is okay if you touch him/her. If the client agrees, start the basic physical assessment. *Pay special attention to the areas of the body where your client reports having a problem.*

Conducting the physical assessment is important, because it helps you to know what is normal for your client. If you know what is normal, you will also be better able to recognize what is abnormal – that something is wrong with your client.

The steps below explain how to conduct the basic physical examination and what to do if you find certain physical problems. Not all home-care steps are listed below. Once you have identified which symptoms the client has, you can also use the self-care book for ideas about how to provide home-care for each symptom, if the client does not need to be referred immediately to a hospital.

Check vital signs

1. Temperature (either of the following two methods)

- Place the back (not the palm) of one hand on your own forehead and the other on the client's forehead. Leave your hands there long enough to be able to feel a difference in heat. This is not an exact method, but if you do not have a thermometer it can give you an idea if your client has a fever.
- Use a thermometer only if you know how to read it. If the client has a fever, take appropriate action, as follows:
  - ⇨ If the client's temperature is more than 37.2°C (99.0°F), provide home based fever care to reduce the temperature.
  - ⇨ If the temperature is > 38.5°C (101.4°F), in addition to the care above provide paracetamol (one or two 500mg tablets every four to six hours).
    - **Refer:** If the client's temperature does not come down, or if you find other problems in addition to fever (such as yellow eyes or chronic cough), refer the client to a hospital.

- **Refer:** If the client's temperature is between 40° and 42°C (104° to 107.6°F), the client needs immediate medical attention. Provide fever care including paracetamol and refer to a hospital.

2. Pulse

- The pulse is usually taken by pressing on the artery on the lower side of the neck, on the inner side of the elbow, or at the wrist. When taking a client's pulse:

  ⇨ Press the tips of your index and middle fingers firmly but gently on the artery until you feel the beat of a pulse.

  ⇨ Count the beats for 60 seconds.

  - **Refer:** The normal pulse range for a healthy adult is from 60 to 100 beats per minute. A pulse that is more than 10 beats faster or slower is a sign that the client is ill and needs to be referred to a hospital.

3. Respiration

- The respiration rate is the number of breaths a person takes per minute. To check your client's respiration rate, you will count the number of breaths the client takes in 60 seconds by counting the number of times the chest rises during that period. You may put your hand on the client's belly to feel the movement.

  ⇨ Respiration rates may increase with fever, illness and other medical conditions.

  ⇨ When checking respiration, you should also note whether the client has any difficulty breathing.

  - **Refer:** The normal respiration rate of healthy adults at rest ranges from 13 to 20 breaths per minute. A respiration rate that is over 25 breaths or below 12 breaths per minute when the client is at rest is a sign of serious illness and requires urgent referral of the client to a hospital.

Conduct a physical exam
(Note: If possible the client should go to the toilet before the exam begins.)

1. Head

- Observe the client's face. Does the skin color look normal?

  ⇨ Is the skin yellow?

  - **Refer:** Yellow skin signals a problem with the liver and requires referral to a hospital.

  ⇨ Is the skin very pale — almost blue?

- **Refer:** If the face (including the lips and tongue) has a blue tinge, the client's respiration is in danger. *Arrange immediate transfer to a hospital.*

- Now, look into the client's eyes.
  - ⇨ Are they yellow?
    . . . very red?
    . . . sunken?
  - ⇨ Do you see unusual spots on the eyeballs?
    . . . sores near or around the eyes?
    . . . a pink rash near or around the eyes?
    - **Refer:** Any of these problems is a sign of illness. Refer the client to a hospital.
  - ⇨ Gently pull down each lower eyelid to see the color of the tissue. If it is very light (pale) rather than pink or red, the client could have anemia.
    - **Refer:** Anemia is especially dangerous for people on ART. If you suspect anemia, refer the client to a hospital.
  - ⇨ Ask the client these questions:
    Are your eyes itchy?
    Do you have trouble seeing?
    Do you feel pain in your eyes?
    - **Refer:** If the answer to any of these questions is yes, the client may be ill and should be referred to a hospital.

- Now, look in the client's nostrils.
  - ⇨ Is there a lot a mucous? Are they irritated?
    - **Refer:** These are signs of illness. If you see them, you should refer the client to a hospital.
- Now, using a torch, look in the client's ears.
  - ⇨ Are they clean? Do you see discharge? Are they irritated?
  - ⇨ Ask the client these questions:
    Do your ears hurt?
    Has your hearing changed?
    - **Refer:** If the answer to any of these questions is yes, the client may be ill and should be referred to a hospital.
- Now, look at the client's mouth.
  - ⇨ Are the lips dry or cracked?
    - Apply petroleum jelly to the lips and teach the client and family how to keep the lips moist.

- ⇨ If you see any blisters or ulcers on the lips . . .
  . . . ask if they are painful.
  - **Refer:** If the answer is yes, refer the client for treatment for pain.
    . . . ask if there are blisters elsewhere on the body and if they are painful.
  - **Refer:** If the answer is yes, refer the client to a hospital.

- Now, ask the client to open his or her mouth.
  - ⇨ Do you see patchy white spots on the tongue?
    - **Refer:** If spots are present, refer the client to a doctor. Also, teach the client and the client'
  - ⇨ Can the client swallow easily? If not, is the client able to eat? Drink? Take medicines?
    - **Refer:** Pain in swallowing, eating, drinking and/or taking medicines is a danger sign. Refer the client to a hospital.
  - ⇨ Look at the gums and teeth.
    Are the gums red and bleeding?
    Is the client experiencing any tooth pain — a sign of tooth decay?
    Does the client have bad breath?
    - If any of these problems are present, show the client and the family how to keep the mouth and teeth clean by brushing regularly and gargling with salt.
    - **Refer:** You should refer a client who has tooth pain/decay or bleeding gums to a hospital.

2. Neck

- Press the lymph nodes along the side of the neck, feeling for a hard lump under the ear and the jaw.
  - ⇨ If the client's condition is normal, you should feel nothing.
  - ⇨ If you feel small hard lumps . . .
    . . . ask the client if it is painful for you to touch them.
    . . . note if the hard lumps are on only one side or on both sides of the neck
    - **Refer:** Small hard lumps could be normal, but in combination with other symptoms —fever, difficulty swallowing, cough — they are a sign of infection. In that case you should refer the client to a hospital.
  - ⇨ If you feel and perhaps even see large hard lumps . . .
    . . . ask the client if it is painful for you to touch them.
    . . . note if the hard lumps are on only one side or on both sides of the neck.
    . . . ask if it is also difficult for the client to swallow.
    - **Refer:** These are signs that the client is ill and should be referred to a hospital.

3. Underarms

- Feel for a hard lump in your client's underarms.
  - ⇨ If you find any. . .
    . . . ask the client if it is painful for you to touch them.
    . . . note if the hard lumps are under only one arm or under both arms.
    - **Refer:** Lumps under the arms could be normal, but in combination with other symptoms — fever, skin infection near the underarm, cough, in females sore breasts/nipples — they are a sign of infection. In that case you should refer the client to a hospital.

4. Groin

- Only with your client's permission, feel for a hard lump in the client's groin.
  - ⇨ If you find any . . .
    . . . ask the client if it is painful for you to touch them.
    . . . note the number of lumps — one or two or more.
    - **Refer:** Lumps in the groin could be normal, but in combination with other symptoms —fever, pain in the groin, soreness in the genital area or genital discharge— they are a sign of infection. In that case you should refer the client to a hospital.

5. Abdomen

(Note: If the client has a full bladder, pressing the abdomen may be painful. This is why it is best for the client to use the toilet before the exam begins.)

- Gently press the abdomen in a slow, circular motion. The stomach should feel soft.
  - ⇨ Note any unusually hard areas.
  - ⇨ Ask if the client feels any pain when you press, and if so, where and how strongly?
    - **Refer:** Unusual hardness and/or strong pain to the touch are a sign that something is wrong and that you should refer the client to the hospital.

- ***Skin***
  - Check the skin of the trunk, front and back.
    - ⇨ Does the skin look dry and scaly?
      - Moisten the skin with a little water and apply petroleum jelly. Teach the client and family this procedure to keep the skin moist. See the self-care book for additional instructions to provide appropriate care for minor skin problems.

- ⇨ Do you see a rash? Lumps? Does the client feel itchy?
- ⇨ Do you see any wounds or abscesses? Are they infected? (Signs of infection are pus, redness, and swelling.)
- ⇨ Do you see blisters clustered on the back or stomach? Are these blisters painful?
    - **Refer:** A rash on the trunk could be the sign of a serious problem and requires referral to a hospital as soon as possible. A wound that is infected is also dangerous, especially if the client has a fever. An infected wound also requires referral to a hospital.

- Observe and feel the client's hands, arms and legs.
    - ⇨ How do the nails look? Are they an abnormal color (blue, red, black?)
    - ⇨ Does the skin look dry and scaly?
        - If the skin is dry, moisten it with a little water and apply petroleum jelly. Teach the client and family this procedure to keep the skin moist.

          If the nails are in abnormal colour, it may be side effect of ART medication. Ask them to inform doctor about it.
    - ⇨ When you do the dehydration skin test (pinching the skin on the back of the hand for a few seconds and releasing),check if the skin return to normal quickly, as it would if the client's hydration is adequate. If does not return quickly it indicates dehydration
        - **Refer:** If the dehydration skin test shows that the client is dehydrated, encourage the client to drink oral rehydration salts and refer to the hospital as soon as possible.
    - ⇨ Do you see a rash? Lumps? Does the client feel itchy?
    - ⇨ Do you see any wounds or abscesses? Are they infected? (Signs of infection are pus, redness, and swelling.)
    - ⇨ Do you see blisters clustered on the back or stomach? Are these blisters painful?
        - **Refer:** A rash on the arms and/or legs could be the sign of a serious problem and requires referral to a hospital as soon as possible. A wound that is infected is also dangerous, especially if the client has a fever. An infected wound also requires referral to a hospital.

- ***Discuss***

  Once you have completed the basic physical examination, explain to the client and family using clear, commonplace language what you have found. Discuss with them what you think needs to be done.

- ***Decide/do***

  Take action as mutually agreed upon by the client, family and you.

- ***Follow up and repeat***

  When you visit your client again, refer to the findings you reported and the actions that were decided during your previous visit. Ask the client what actions were taken and how he or she is feeling now. Conduct another basic physical assessment to determine any changes in the client's well-being between the two visits.

Annex 7: Child Status Index (CSI)

DOLMIN	Food and Nutrition		SHELTER AND CARE		PROTECTION	
	1. Food Security	2. Nutrition & Growth*	3. Shelter	4. Care	5. Abuse and Exploitation	6. Legal Protection*
Goal	Child has sufficient food to eat at all times of the year.	Child is growing well compared to others of his/her age.	Child has stable shelter that is adequate dry, safe, and lives like others in household.	Child has at least one adult (age 18 or over) who provides consistent love and support	Child is safe from abuse, neglect, or exploitation.	Child is protected legally and has access to legal support when needed.
Good =0	**0** Child is well fed, eats regularly.	**0** Child is well grown with good height, weight, and energy level for his/her age.	**0** Child lives in a place that is safe, adequate, dry, and lives like others in household.	**0** Child has a primary adult care giver who is involved in has/her life, and who protects and nurtures him.	**0** Child does not seem to be abused, neglected, do inappropriate work or be exploited in other ways.	**0** Child is fully protected legally (e.g., has necessary documents and access to legal support).
Fair=1	**1** Child has enough to eat some of the time, depending on season or food supply.	**1** Child looks slightly thin and less energetic compared to others of the same age.	**1** Child lives in a place that needs some repairs but is fairly adequate, and child lives like others in household	**1** Child has an adult who provides care but who is limited by illness, work, other children, or seems indifferent to child.	**1** Child is sometimes neglected, overworked, or not treated well or there is suspicion of maltreatment.	**1** Child has civil registration but is not fully protected legally in other ways, although there is no current need.
Bad=2	**2** Child frequently has less food to eat than needed, complains of hunger.	**2** Child is smaller in weight or height compared to others of the same age.	**2** Where child lives is not adequate, needs major repairs, is overcrowded, does not protect from weather; and/or lives in a way inferior to others in the household.	**2** There is no consistent adult who provides love and support.	**2** Child may be frequently neglected or given inappropriate work for his or her age.	**2** Child does not have civil registration, is not fully protected legally, and is at risk of being exploited and/or abused in a way that could be alleviated through legal protection.
Very Bad = 3	**3** Child rarely has enough to eat and goes to bed hungry most nights.	**3** Child is malnourished, significantly shorter (stunted) or thinner (wasted) than others of the same age.	**3** Child has no stable place to live.	**3** Child is completely without the care of an adult and must fend for him-or herself.	**3** Child is abused, sexually or physically, and/or is being subjected to child labor or otherwise exploited.	**3** Child is being exploited in a way that demands an urgent legal response.

DOLMIN	HEALTH		PSYCHOSOCIAL		EDUCATION AND WORK	
	7. Wellness	8. Health Care Services	9. Emotional Health	10. Social Behavior	11. Performance	12. Education/Work
Goal	Child is health.	Child receives health care services, including medical treatment care (e.g., health education, immunizations).	Child is happy and content with a generally positive mood and hopeful outlook.	Child is cooperative and enjoys participating in activates with adults and other children.	Child is progressing well in acquiring knowledge and skills at home school, job training, or an age ap-propriate productive activity.	Child is enrolled and attends school or skills training, or is engaged in an age appropriate activity or job. Infant or preschooler is stimulated by play
Good =0	**0** In past month, child has been healthy and active, with no fever, diarrhea, or other illnesses.	**0** Child has received all or almost all necessary health car treatment and preventative services.	**0** Child seems happy, hopeful, and content.	**0** Child likes to play with peers and participates in group or family activities. Infant enjoys playing with adults.	**0** Child is learning well, gaining life skills, and progressing as expected by caregivers, teachers, or other leaders.	**0** Child enrolled in and attending school regularly infants or preschoolers play with caregiver. Older child has age-appropriate activities or job.
Fair=1	**1** In past month, child was ill and less active for a few days (1to3 days) but she/he participated in some activities.	**1** Child received medical treatment when ill, but some health care services (e.g. preventative care) are not received.	**1** Child is sometimes happy and sometimes unhappy. Infant may be crying, irritable, or not sleeping well some of the time.	**1** Child has minor problems getting along with others and argues, or gets into fights sometimes.	**1** Child is learning well and gaining life skills moderately well, but caregivers, teachers, or other leaders have a few concerns about progress.	**1** Child enrolled in school but attends irregularly or shows up inconsistently for productive activity job, Younger child played with sometimes but not daily.
Bad=2	**2** In past month, child was often (more than 3 days) too ill for school, work, or play.	**2** Child sometimes or in consistently receives needed healthy care services (treatment or preventative).	**2** Child is often unhappy or sad. Infant may cry frequently or often be inactive.	**2** Child is more disobedient to adults than others of same age and frequently does not interact well with peers, guardian, or others at home or school.	**2** Child is learning and gaining poorly or is falling behind. Infant or preschool child is gaining skills more slowly than their peers are.	**2** Child enrolled in school or productive activity (work) but rarely attends. Infant or preschool child is rarely stimulated by play.
Very Bad = 3	**3** In past month, child has been ill most of the time (chronically ill).	**3** Child rarely or never receives the necessary health care services.	**3** Child seems hopeless, sad withdrawn, or wants to be left alone. Infant may refuse to eat, sleep poorly, or cry a lot.	**3** Child has behavioral problems, including stealing, early sexual activity and/or other risky or disruptive behavior.	**3** Child has serious problems with learning and gaining skills.	**3** Child not enrolled or not attending school and not involved age-appropriate productive activity or job. Infant or preschooler is not being stimulated by play.

1. CSI SCORES:	Date:	
Domains	Scores (Circle One)	
FOOD & NUTRITION		
1. FOOD Security	0 1 2 3	
2. Nutrition & Growth*	0 1 2 3	
SHELTER & CARE		
3. Shelter	0 1 2 3	
4. Care	0 1 2 3	
PROTECTION		
5. Abuse & Exploitation	0 1 2 3	
6. Legal Protection*	0 1 2 3	
HEALTH		
7. Wellness	0 1 2 3	
8. Health Care Services	0 1 2 3	
PSYCHOSOCIAL		
9. Emotional Health	0 1 2 3	
10. Social Behavior	0 1 2 3	
EDUCATION AND SKILS		
11. Performance	0 1 2 3	
12. Education/Work	0 1 2 3	

Source(s) of information: *(Circle all that apply.)*	Child, Parent/Caregiver, Relative, Neighbor, Teacher, Family Friend, Community Worker, Other (Specify)_____	
II. Important Events: *(Check any events that have happened since the last CSI assessment)*	__Child left program __Child pregnant __Child died __Parent ill __Parent/guardian died __Family member died __Change in caregiver __Change in living location __Community violence __Other (Spcify)_____	**Comments(s)** *if necessary:*

III. TYPES OF SUPPORT / SERVICES PROVIDED *(since last CSI):*	What was provided?	Name of Provider *(Organization)*
a. Food & nutrition support (such as food rations, supplemental foods)		
b. Shelter & other material support (such as house repair, clothes, bedding)		
c. Care (caregiver received training or support, child placed with family)		
d. Protection from abuse (education on abuse provided to child or caregiver)		
e. Legal support (birth certificate, legal services, succession plans prepared		
f. Health care services (such as vaccinations, medicine, ARV, fees waived, HV		
g. Psychosocial support (clubs, group support, individual counseling)		
h. Educational support (fees waived; provision of uniforms, school supplies, tutorials. other)		
i. Livelihood support (vocational training, micro-finance opportunities for family. etc.)		
j. Other		
Suggestions for other resources or services needed.		

Annex 8: Child Community Home-Based Care: First Visit Form

Name: _____ Client code: _____ Sex: Male ☐ Female ☐

Date of birth: Day____ Month___ Year_____ Age___ (yrs.) If <1yr old ___ (months)

Registered with ART center? Yes ☐ No ☐ Name of ART center: _____

Name/code # of family caregiver: _____

Child was referred by: _____ (PLHIV group, ART clinic, VCT, PPTCT, OVC, family, etc

Part 1: HIV-status, feeding and immunizations

1a. Child's HIV status? ☐ HIV-exposed, status unknown ☐ HIV-infected	1b. If not yet tested, is family planning to test child? ☐ Yes ☐ No	2. Child's birth weight: _____kg	3. Mother received ARV(s) ante-, intra-, and/or postpartum? ☐ Yes ☐ No ☐ Unknown	4. Child received ARV(s) during the newborn period as perinatal prophylaxis? ☐ Yes ☐ No ☐ Unknown

5a.Currently being breastfed? ☐ Yes ☐ No	5b. Child receiving any foods or liquids other than breast milk (including water)? ☐ Yes ☐ No	5c. If the child is being bottle-fed, is formula being prepared correctly and hygienically? ☐ Yes ☐ No

6. Has the child received any immunizations ☐ Yes ☐ No /If yes, fill out table below.

Vaccine	Yes	# doses	Completed? Y/N	Vaccine	Yes	# doses	Completed? Y/N
BCG				MMR			
DPT				Tetanus toxoid			
Polio				Vitamin A			
Measles				Other 1**			

(** Specify)

Part 2: History, symptoms and care

7a. Within the last month, has the child experienced any symptoms?
☐ Yes ☐ No If yes, specify below:

	Symptom	Yes	Now has		Symptom	Yes	Now has
Major danger signs	**Not able to drink or breastfeed**			GI tract	**Vomiting everything**		
	Convulsions				**Acute diarrhea > 5 loose stools in 24 hrs**		
	Lethargic or unconscious				**Chronic diarrhea >14 days**		
	Signs of dehydration (dry tongue; sunken eyes; less elastic skin; less urine)				Mild diarrhea: 3 loose stools; no blood		
General	**Not gaining weight/low weight according to growth chart**				Oral thrush		
	In severe pain				Poor appetite		
	In mild to moderate pain			Skin	**Any rash while on ARVs or cotrimoxazole**		
	Fever > 38 C for more than 24 hours				**Painful rash (e.g., herpes zoster)**		
					Painful sores in corner of mouth		
					Itchy skin		
Respiration	**Difficulty breathing/rapid breathing /bluish color**						
	Persistent cough >2 weeks			Neuro	**Persistent headache**		
	Recurrent or chronic ear infections or discharge				**Changes in vision, speech, ability to walk**		
					Sad; anxious; withdrawn		

7b. Other symptoms:

8. Last CD4 count:
_____/mm3_____%

Test Date: _____/___/_____

9. Child meets appropriate development milestones?
☐ Yes ☐ No

10. What medications is the child currently taking or has the child previously taken? ☐ Yes None [or]

- TB treatment ☐ Previously ☐ Currently
- Cotrimoxazole prophylaxis ☐ Previously ☐ Currently
- ART (specify)_____ ☐ Previously ☐ Currently
- Vitamins ☐ Previously ☐ Currently
- Other (herbal, traditional agents, complementary, nonprescription, etc.)

_____ ☐ Previously ☐ Currently

_____ ☐ Previously ☐ Currently

Vital signs/physical examination/care provided				
11. Temp: _____0C	Pulse: _____/minute	Breaths: _____/minute	Length/Height: ___cm* If possible to measure	Weight: _____ kg* If possible to measure
Vital signs/physical examination/care provided				
13. Care provided:			14. Self-care education provided:	

Part 3: Adherence and referral

15a. ART adherence assessment ☐ Child/caregiver are very clear on how to take medicines and demonstrate >95-percent adherence ☐ Child/caregiver need education on adherence ☐ Child caregiver need to be referred to doctor/ ART center for adherence support	15c. Action taken if needed:
15b. Cotrimoxazole and TB medicines ☐ Child/caregiver are very clear on how to take medicines and demonstrate adherence ☐ Child/caregiver need education on adherence ☐ Child caregiver need to be referred to doctor/ ART center for adherence support	
16a. Referral needed for: ☐ HIV testing ☐ Urgent medical care ☐ Routine medical care ☐ Nutrition ☐ Immunizations ☐ Adherence support ☐ Other:_____	16b. Site referred to/contact:
16c. Referral follow-up actions required:	
17. When is the child's next appointment? Date: _____/_____/_____ **Completed by:** Signature and name: _____ Date: ___/___/_____ • **Be sure also to complete the Child Assessment Form for the child on first visit.**	

Annex 9: Side Effects of Antiretroviral Therapy

ART drugs/ combinations	Side effects	What to do
Zidovudine, stavudine, lamivudine, nevirapine, abacavir	Nausea and/or vomiting	• Common; presents within first few weeks of starting ART and stops on its own • Give the drug with food • Give oral fluids, continue breastfeeding/feeding and give rest to the child • If the nausea/vomiting continues consult a pediatrician/ ART center medical officer
Stavudine, nevirapine, lamivudine, efavirenz, abacavir, tenofovir	Diarrhea	• Presents within first few weeks of starting ART • Reassure the child and family that if the diarrhea is due to ART, the child will improve in a few weeks • Ensure adequate hydration; give oral rehydration salts; if breastfeeding, continue • Use clean and safe water; keep utensils clean; dispose of waste by burning • If after 2 weeks the child is not getting better, take the child to a hospital or inform FCM for medical help
Nevirapine	Yellow eyes	• Symptom of jaundice • Stop the drugs and immediately take the child to a hospital or inform FCM for medical help
Zidovudine, efavirenz, tenofovir	Headache	• Common and stops on its own; provide a painkiller such as paracetamol • Advise putting a cold towel or cloth on child's head and having the child lie down • If headache continues for more than 2 weeks, take the child to ART center/pediatrician
Nevirapine, abacavir	Skin rash	• Presents within 6-8 weeks of starting ART; usually resolves on its own

ART drugs/ combinations	Side effects	What to do
		• If generalized or skin is peeling or accompanied by fever, stop the drugs and take the child to a hospital immediately • If rash develops while taking abacavir, immediately take child to ART center
Zidovudine	Anemia/fatigue	• Fatigue due to anemia usually lasts for 4-6 weeks, especially if child has started on zidovudine • If fatigue becomes severe or persists beyond 6 weeks, refer to ART center/medical facility
Zidovudine	Blue/black nails	• Reassure: common with zidovudine
Stavudine	Tingling, numbness or pain in feet/legs/hands	• Immediately take the child to a hospital or ask FCM to secure medical help
Stavudine	Lipodystrophy (arms, legs, cheeks and buttocks become thin while stomach and back of neck become fat)	• Immediately take the child to a hospital or ask FCM to secure medical help
Tenofovir	Severe abdominal pain	• Immediately take the child to ART center

Annex 10: Food Security Questionnaire

General food sufficiency question/screener: Questions 1, 1a, 1b (OPTIONAL: These questions are NOT used in calculating the food-security/hunger scale.) Question 1 may be used as a screener: (a) in conjunction with income as a *preliminary* screen to reduce respondent *burden for higher income households only*: and/or (b) in conjunction with the 1st stage internal screen to make that screen " more open"—i.e., to provide another route through it.

1. [IF ONE PERSON IN HOUSEHOLD, USE "I"; OTHERWISE, USE "WE."]

- Which of these statements best describes the food eaten in your household in the past 12 months:
- enough of the kinds of food (I/we) want to eat
- enough, but not always the kinds of food (I/we) want
- sometimes not enough to eat
- often not enough to eat?

[1] Enough of the kinds of food we want to eat [SKIP 1 a and 1b]

[2] Enough but not always the kinds of food we want [SKIP 1 a; ask 1 b]

[3] Sometimes not enough to eat [Ask 1 a; SKIP 1 b]

[4] Often not enough [Ask 1 a; SKIP 1b]

[ ] Doesn't know (hereafter, DK) or refused to answer (SKIP 1 a and 1 b)

1.a [IF OPTION 3 OR 4 SELECTED, ASK] Here are some reasons why people don't always have enough to eat. For each one, please tell me if that is a reason why YOU don't always have enough to eat. [READ LIST. MARK ALL THAT APPLY.]

YES	NO	DK	
[]	[]	[]	Not enough money for food
[]	[]	[]	Not enough time for shopping or cooking
[]	[]	[]	Too hard to get to the store
[]	[]	[]	On a diet
[]	[]	[]	No working stove available
[]	[]	[]	Not able to cook or eat because of health problems

1.b [IF OPTION 2 SELECTED, ASK] Here are some reasons why people don't always have the quality or variety of food they want. For each one, please tell me if that is a reason why you don't always have the kinds of food you want to eat. [READ LIST. MARK ALL THAT APPLY.]

YES	NO	DK	
[]	[]	[]	Not enough money for food
[]	[]	[]	Kinds of food (I/we) want not available
[]	[]	[]	Not enough time for shopping or cooking
[]	[]	[]	Too hard to get to the store
[]	[]	[]	On a special diet

BEGIN FOOD-SECURITY CORE MODULE (i.e. SCALE ITEMS)

Stage 1: Ask all households Questions 2 through 6

1 [IF ONE PERSON IN HOUSEHOLD, USE "I," "MY," AND "YOU"; OTHERWISE, USE "WE," "OUR," AND "YOUR HOUSEHOLD." IF UNKNOWN OR AMBIGUOUS, USE PLURAL FORMS.]

2 Now I'm going to read you several statements that people have made about their food situation. For each one, please tell me if the statement was often true, sometimes true or never true for (you/your household) in the past 12 months — that is, since last (name of current month.)]

The first statement is "(I/We) worried whether (my/our) food would run out before (I/we) got money to buy more." Was that often true, sometimes true or never true for (you/your household) in the past 12 months?

[] Often true
[] Sometimes true
[] Never true
[] DK or refused to answer

3 "The food that (I/we) bought just didn't last, and (I/we) didn't have money to get more." Was that often, sometimes or never true for (you/your household) in the past 12 months?

[] Often true
[] Sometimes true
[] Never true
[] DK or refused

4. "(I/we) couldn't afford to eat balanced meals." Was that often, sometimes or never true for (you/your household) in the past 12 months?

[] Often true
[] Sometimes true
[] Never true
[] DK or refused

[IF CHILDREN UNDER 18 IN HOUSEHOLD, ASK Questions 5 through 6;
OTHERWISE SKIP TO 1st-Level Screen.]

5. "(I/we) relied on only a few kinds of low-cost food to feed (my/our) (child/the children), because (I was/we were) running out of money to buy food." Was that often, sometimes or never true for (you/your household) in the past 12 months?

   [] Often true
   [] Sometimes true
   [] Never true
   [] DK or refused

6 "(I/WE) couldn't feed (my/our) (child/the children) a balanced meal, because (I/we) couldn't afford that." Was that often, sometimes or never true for (you/your household) in the past 12 months?

   [] Often true
   [] Sometimes true
   [] Never true
   [] DK or refused

1st Level Screen (screener for Stage 2): If AFFIRMATIVE RESPONSE TO ANY ONE of Questions 2 through 6 (i.e., "often true" or "sometimes true") OR response [3] or [4] to Question 1 (if administered), then continue to Stage 2; otherwise, skip to end.

Stage 2: Ask households passing the 1st Level Screen Questions 7 through 11

[IF CHILDREN UNDER 18 IN HOUSEHOLD, ASK Question 7; OTHERWISE SKIP TO Question 8]

7. "(My/Our child was/The children were) not eating enough, because(I/we) just couldn't afford enough food." Was that often, sometimes or never true for (you/your household) in the past 12 months?

   [] Often true
   [] Sometimes true
   [] Never true
   [] DK or refused

8. In the past 12 months, since last (name of current month), did (you/you or other adults in your household) ever cut the size of your meals or skip meals, because there wasn't enough money for food?

[] Yes

[] No (SKIP 8a)

[] DK or refused (SKIP 8a)

8a. [IF YES ABOVE, ASK] How often did this happen: almost every month, some months but not every month or in only 1 or 2 months?

[] Almost every month

[] Some months but not every month

[] Only 1 or 2 months

[] DK or refused

9. In the past 12 months, did you ever eat less than you felt you should, because there wasn't enough money to buy food?

[ ] Yes

[ ] No

[ ] DK or refused

10. In the past 12 months, were you very hungry but didn't eat because you couldn't afford enough food?

[ ] Yes

[ ] No

[ ] DK or refused

11. In the past 12 months, did you lose weight because you didn't have enough money for food?

[ ] Yes

[ ] No

[ ] DK or refused

2nd Level Screen (screener for Stage 3) : If AFFIRMATIVE RESPONSE to ANY of Questions 7 through 11, then continue to Stage3; otherwise, skip to end.

Stage 3: Ask households passing the 2nd Level Screen Questions 12 through 16

12. In the past 12 months, did (you/you or other adults in your household) ever not eat for a whole day, because there wasn't enough money for food?

    [ ] Yes
    [ ] No (SKIP 12a)
    [ ] DK or refused (SKIP 12a)

12a. [IF YES ABOVE, ASK] How often did this happen: almost every month, some months but not every month or in only 1 or 2 months?

    [ ] Almost every month
    [ ] Some months but not every month
    [ ] Only 1 or 2 months
    [ ] DK or refused

[IF CHILDREN UNDER 18 IN HOUSEHOLD, ASK Questions 13 through 16; OTHERWISE SKIP TO END.]

13. The next questions are about children living in the household who are under 18 years old. In the past 12 months, since (current month) of last year, did you ever cut the size of (your child's/any of the children's) meals because there wasn't enough money for food?

    [ ] Yes
    [ ] No
    [ ] DK or refused

14. In the past 12 months, did (CHILD'S NAME/any of the children) ever skip meals, because there wasn't enough money for food?

    [ ] Yes
    [ ] No (SKIP 14a)
    [ ] DK or refused (SKIP 14a)

14a. [IF YES ABOVE, ASK] How often did this happen: almost every month, some months but not every month or in only 1 or 2 months?

    [ ] Almost every month
    [ ] Some months but not every month

[ ] Only 1 or 2 months

[ ] DK or refused

15. In the past 12 months, (was your child/ were the children) ever hungry but you just couldn't afford more food?

[ ] Yes

[ ] No

[ ] DK or refused

16. In the past 12 months, did (your child/any of the children) ever not eat for an entire day because there wasn't enough money for food?

[ ] Yes

[ ] No

[ ] DK or refused

END OF FOOD-SECURITY CORE MODULE

6-Item Subset (Short Form) of the 12-Month Food Security Scale Questionnaire

[LEAD] These next questions are about the food eaten in your household in the past 12 months and whether you were able to afford the food you need.

Q3. I'm going to read you two statements that people have made about their food situation. Please tell me whether the statement was OFTEN, SOMETIMES or NEVER true for (you/you and the other members of your household) in the past 12 months.

The first statement is, "The food that (I/we) bought just didn't last, and (I/we) didn't have money to get more." Was that often, sometimes or never true for (you/your household) in the past 12 months?

[1] Often true

[2] Sometimes true

[3] Never true

[ ] DK or refused

Q4. "(I/we) couldn't afford to eat balanced meals." Was that often, sometimes or never true for (you/your household) in the past 12 months?

[1] Often true

[2] Sometimes true

[3] Never true

[ ] Don't know or refused]

Q8. In the past 12 months, since (date 12 months ago) did (you/you or other adults in your household) ever cut the size of your meals or skip meals, because there wasn't enough money for food?

[1] Yes

[2] No (GO to 5)

[ ] DK or refused (GO to 5)

Optional Screener: If any of the first 3 questions are answered affirmatively (i.e., if either Q2 or Q3 are "often true" or "sometimes true" or Q8 is "yes"), proceed to the next question. Otherwise, skip to end.

Q8a. **[Ask only if Q8=YES]** How often did this happen: almost every month, some months but not every month or in only 1 or 2 months?

[1] Almost every month

[2] Some months but not every month

[3] Only 1 or 2 months

[ ] DK, refused or X (i.e., question not asked because of negative or missing response to Question 8)

Q9. In the past 12 months, did you ever eat less than you felt you should, because there wasn't enough money to buy food?

[ ] Yes

[ ] No

[ ] DK or refused

Q10. In the past 12 months, were you ever hungry but didn't eat, because you couldn't afford enough food?

[ ] Yes

[ ] No

[ ] DK or refused

Annex 11: Process Guidelines on Micro Enterprise

Why micro enterprise?

Micro enterprise is recognized as a key strategy for enhancing the livelihoods of the poor, which directly contributes to the well-being of poor families.

Access to credit has been considered essential for establishing any micro enterprise, which itself is a major strategy to enhance the livelihoods of the poor.

Choice of micro enterprise

Earnest attempts to promote self-employment through micro enterprise and other income-generating activities are imperative. Within the project, we will select business opportunities from a wide range of "candidate/family-specific" skill-based initiatives. We will also seek financial as well as market linkages before beginning commercial operations.

Strategy

Some of the households may have adult members with skills they can use to earn a livelihood. Others may not. For them, extra support will be necessary. Moreover, debt is prevalent among households affected by HIV, and as a result these households lack access to sources of capital to start (or, in many cases, re-start) enterprises.

The following strategic steps need to be considered:

1. Identify skill-sets, knowledge and introduce ventures with a local resource base.
2. Emphasize skills within the family or ones that have been laid down through generations.
3. Promote enterprises that are based on the core competencies of entrepreneurs.
4. Promote efficient and cost-effective trade.
5. Look at linkage for the product, skill, services with the local market.
6. Encourage enterprises ancillary to major industries in an area, because these can provide good incomes.

7. Promote enterprise that enhances the community and provides local solutions or services.

8. Establish linkages with nationalized banks and local area banks to provide households with extra working capital. Linkages can also be forged with government- and state-supported bodies, such as the District Rural Development Authority, Andhra Pradesh State Corporations and the Khadi and Village Industries Board, to create access to grants and subsidies and also to training and skill-building initiatives.

9. Support young-adult members of households affected by HIV to take advantage of employment opportunities for which they are eligible. Many government departments in Andhra Pradesh, such as the Employment Generation and Marketing Mission (EGMM) and the Mission for Elimination of Poverty in Municipal Areas (MEPMA), offer training and placement services for young people between the ages of 19 and 25.

Feasible opportunities for micro enterprises and other income-generating activities

A complete spectrum of trades and skills needs to be looked at as part of the promotion of micro-enterprises. The economic status, skill sets and geographic location (rural, peri-urban and urban) of households affected by HIV vary widely. Exploring both farm and non-farm based initiatives is essential. Examples of some feasible activities are:

- Service sector: tailoring and embroidery; cleaning and ironing clothes
- Business sector: petty shops, eateries, pickle making, confectionary making, and selling fruits, vegetables, fish and poultry
- Industrial sector: leaf plate making (in rural areas), rope making (in areas with high availability of coir) and detergent making (in peri-urban areas)

Feasible opportunities for skilled people to secure paid employment

To the extent possible, help household members — especially those in the 19-to-25-year-old age group — to gain skills through the EGMM and MEPMA and to use these same government agencies to find paid employment. Mobilizing young adults should be done in a manner to prepare them to explore new possibilities of earning a living.

Annex 12: Guidelines for Establishing a Kitchen Garden

- The households should receive orientation on the concept of a kitchen garden.
- Consult with households, and base the choice of plants on a household's preferences and on growing conditions.
- Fence the kitchen garden with fencing species such as *glyricidea* (a green-leaf manure plant) or *jatropha* (a bio-fuel plant).
- Choose species to suit the seasons and procure all the seeds well before the season for planting.
- Channel all of the household waste (non human waste) water to the kitchen garden plots.
- If possible, maintain a pit or small tank to store waste water as well as to catch and store rainwater for irrigation.
- In a corner of the garden, dig another pit for making compost — especially vermi-compost, because organic manure is preferable.
- Before making a plot, loosen or hoe the soil thoroughly, to a depth of 20 to 25 centimeters, and remove the pebbles and stones.
- Mix the soil with farmyard manure or any farm waste. Raise the plot to avoid stagnant water and level it to avoid runoff.

The species that will help to meet a family's nutritional needs can be established in multiple plots. Diagram 1 shows an effective layout.

Plot 1

This plot should be used as a nursery to raise seedlings. Multiple households can tend this plot jointly. Seedlings of brinjal, tomato, cabbage, cauliflower and so forth can be raised. After 25 to 30 days seedlings should be transplanted.

Plot 2

In this plot brinjal and tomato species can be transplanted, with a spacing of 50 centimeters x 50 centimeters. These species can be cultivated in all three agricultural seasons (*kharif, rabi* and summer)

Plot 3

In this plot Lady's-finger (okra, *bhendi*) is planted by dibbling seeds at a spacing of 50 centimeters x 30 centimeters. It can be grown in the *kharif* and summer seasons. During *rabi* (winter) other green leafy species need to be planted in this plot.

Plot 4

Here only *amaranthus* may be grown. It is essential to mix the seed with some sand (8:2) and sow it by broadcasting. Then cover the plot with a thin film of farmyard manure (fym) or fertile soil. Water by sprinkling. This species can be cultivated in all three seasons (*kharif, rabi* and summer)

Plot 5

Here spinach (*palak*) can be planted. This is also sown by broadcasting the seeds or by dibbling them 10 to 15 centimeters apart. Spinach can be grown all year.

Plot 6

Solely G*ongura* (a green leafy vegetable of the *hibiscus* species) may be grown. Mix the seed with sand (5:5) and sow it by broadcasting. The seed must be scattered, not piled in heaps. Cover the plot with a thin film of fym or fertile soil. Watering is done by sprinkling. This plant can be grown in all seasons.

Plot 7

Tuber species such as carrot, beet root and radish can be grown in this plot. Mix the seed with sand (8:2) sow it in small furrows at a depth of 1.5 inches and a spacing of 30 centimeters x15 centimeters. Cover the furrows with soil.

Plot 8

Use this plot to transplant cabbage and/or cauliflower at a spacing of 45 centimeters x 45 centimeters. These vegetable varieties are grown in *kharif* and *rabi*. Some leafy vegetable can be grown in summer.

Plot 9

In this plot, French beans, cluster beans and the bush variety of *dolichos* can be grown all year. Seeds are sown at a spacing of 45 centimeters x 20 centimeters.

Fruit and tree species

Multiple fruit and tree species can be planted around the garden's perimeter. A good combination is two papayas, two drumsticks, one lemon, and two bananas.

Papaya: The dwarf *pusa* and *thaivan* varieties can grow well in a backyard and fruit within one year. It is essential for water not to stagnate at the base of the plant to avoid root rot disease.

Drumstick: *Pkm-1* is the best variety of drumstick for a backyard garden. This variety can be established by dibbling seeds but transplanting a seedling is more successful. When the seedling is in the ground, nip the tip for more branches. This variety will bear first fruit in 6 to 7 months and thereafter will fruit twice a year (from March to June and from September to October). After each harvest, the plant should be cut back to a height of 1 meter so that new sprouts can establish themselves and start flowering.

Banana: *Dwarf Cavindish* and *potti pacha aarati* are the varieties best suited to a backyard. From each plant, 3 to 4 new suckers generate each year and these can be used for further propagation.

Lemon: Smaller and early yielding varieties such as *balaji* and *kagji* are the varieties most suitable for the backyard.

Planting: Plant fruit trees at least 3 meters apart, increasing the distance between trees if space allows. The pit should be 45 to 60 centimeters wide and deep and fym should be applied when planting. The basin for each plant should be prepared so that it can hold water. Mulch the root zone around the plant with grass or dry leaves to conserve moisture.

Gourds and creepers

Along the garden's perimeter, short duration gourds can be raised. They can be trained to creep over the fence or supported on poles made from dried branches. Ridge gourd, bottle gourd, bitter gourd, round gourd and snake gourd are especially successful during the summer months.

Compost/vermi-compost

As the model kitchen garden in Diagram 1 shows, it is advisable to dig a small pit for vermi-compost in a corner of the garden. If space is lacking, a small clay pot can also be used to prepare the vermi-compost. This compost can be harvested every 45 days. All sorts of kitchen waste and farm waste can be used as composting material.

Seed production

With the exception of green leafy vegetables, all vegetable species and gourds that can be cultivated in a kitchen garden will produce seeds. One or two healthy, disease-free fruits with desirable traits

should be preserved/sun-dried and their seed extracted for the next growing cycle. In this way families can minimize their dependency on the market for seed.

Role of the family case manager

In working with moderately or severely food-insecure families, the FCM may:

- Assess the client's level of interest in a kitchen garden and the availability of land, fencing and water
- Provide technical support to beneficiary families on methods of seed-bed preparation, handling of manure and seed collection.
- Make regular follow-up visits to the garden and ensure crop rotation

Annex 13: Types of Demonstration Plots

A. Demonstration of high-yield varieties

Crops suited to the area's ecology should be grown in a segment of the demonstration plot. The choice of crop and the amount of land set aside for it should be determined in accord with the season and the availability of water and in consultation with government extension workers. The food consumption pattern of the community should be considered. To the extent possible, high-yielding varieties should be grown. Examples of species that could be demonstrated are jowar, paddy, red gram, pulses, groundnut, ragi and maize.

B. Demonstration of cropping systems

Innovative systems such as intercropping, multiple cropping and mixed cropping should be demonstrated in order to provide a community with a variety of cropping system that residents can apply to specific climatic and soil conditions. Innovations such as incorporating a combination of poultry units, piggeries, beehives and fishery farms may also be suggested.

C. Demonstration of technology

Soil moisture-conservation techniques should be demonstrated to lessen the burden on a community to arrange for a constant source of irrigation. One model is a technique called "SRI Vari" for the cultivation of paddy; it requires less water and increases the yield many times. Low-cost technology and water conserving techniques such as drip/sprinkler irrigation can also be demonstrated.

D. Demonstration of horticulture/fruit species

The techniques of intercropping (with vegetable cultivation) should be demonstrated. Some of the species that could be used for intercropping are mango, guava, papaya, pomegranate and vegetables such as tomato, brinjal, cabbage, cauliflower, tubers and leafy vegetables. In a demonstration of mixed farming techniques, mushroom cultivation can also be pursued.

E. Floriculture demonstration

Flowers are important in the cultural practices of Andhra Pradesh. As a result there is always high demand for flowers — especially marigolds, jasmine, chrysanthemums, gladioli and asters. These species and other cut flowers can also be grown for commercial purposes. In addition to demonstrating floriculture, information about linkages to local markets can also be provided.

F. Nursery management

Households engaging in floriculture and/or horticulture must know how to manage root stock and scion block. Simple techniques that community members can learn are grafting and budding, which improve the crops of mango, guava, citrus fruits, custard apple and local berries. Grafting and budding of roses and other species of crotons can be used to prepare saplings for beautification projects and avenue plantation. These improved saplings have a huge local market.

G. Organic farming/vermi-compost units

This could be an essential feature of a demonstration garden. Because vermi-compost can be harvested every 45 days, it is a good source of natural fertilizer. All sorts of kitchen waste and farm waste can be used as the composting material.

Annex 14: Formation and Management of a Grain Bank

In the project operational area, self-help groups (SHGs) of women affected by HIV can come together to start and manage a grain bank. To avoid social exclusion and stigma, other vulnerable groups such as elderly people, widows, people with disabilities and poor families should also be given access to the grain bank. Each bank would be managed by a grain bank committee consisting of two groups: the ethical group and the entitled group.

The ethical group

This group shall include:

- Women-headed households (especially households headed by women whose HIV status is known to be positive) that are moderately or highly food-insecure
- Adolescent girls in child-headed households whose members are HIV-positive or otherwise affected by HIV
- Pregnant and lactating mothers who are HIV-positive or otherwise affected by HIV
- Grandmothers, elderly people and people who are chronically ill

To the extent possible, members of the ethical group should be given priority for loans from the grain bank.

The entitled group

This group shall include families who are entitled to and/or are accessing the benefits of government schemes such as the Public Distribution system and the *Antodaya & Annapoorna* schemes

Modalities for establishing a grain bank committee

At the village/cluster level, a grain bank committee needs to be formed to manage the grain bank. The ideal tenure of such a committee is two years. The committee should be led by women, with priority given to those whose households are affected by HIV. This committee shall decide on the loan-quantity of food grains per family, capacity of savings and the duration and mode of repayment (cash, grain).

Savings and stock management

Initially, the grain bank members will start saving grain at a common place and the project will provide a one-time grant to the grain bank committee's account for the purchase of food grains. The grant will

cover the cost of the grain and the costs of transportation. The president of the grain bank will furnish receipts for donations from external support agencies — institutions, individuals, IKP (the state-run scheme) and so forth. Weights, measures and balances will be established by the grain bank committee or by external sources. Arrangements will be made for proper storage of the grain. Group members will decide on the place of storage, the quality of the grain and the price of grain for purchase in the local market.

Members of the families of the grain bank will be entitled to loans of food grains and repay the loans in installments on terms subject to agreement. The family case management team for the area whose households are bank members will work with the grain bank committee on purchases of grain, weights, balances and storage bins and structures. The team will also help the committee manage its meetings and bookkeeping, at least during the initial period.

Loan/credit/recovery

Priority for loans will be given to grain bank members who are highly food-insecure — especially households affected by HIV and headed by women or children. The size of loans shall be gauged to the size of the family. In the event of a shortfall of grains and if the grain bank has funds, the committee may buy grain and loan it to households in need.

Grain shall be given by the bank to bank members, and recovery in kind may also be made by the group. Depending on the situation of a recipient family, the committee may adjust the period for repayment and make the loan on low–interest or no–interest terms. In addition, through a resolution, the committee will have the authority to provide grain to any family in dire need in the form of a grant or a loan that is nonrefundable.

The type of grain used to repay the loan will preferably be the same type as the grain that was loaned. It need not be, so long as the committee approves. If no repayment is made within the stipulated period, continuation of the family's membership in the bank would be contingent on the committee's decision.

Storage of stock

Low-cost traditional storage methods such as bamboo bins and large mud pots, which can be procured or prepared locally, are best. *Neem* leaf and sun-hemp seed shall be used to prevent infestation by pests. To keep the grain dry, the storage structure should be erected in a sunlit place.

Monitoring

The grain bank committee will meet at specified intervals or as and when required in order to discuss the issues at hand. With the help of family case managers, the committee will maintain such records as a book of minutes of the meetings and the loan and stock register. If possible, every bank member should have a passbook with current information about her or his grain savings and loan status.

In all grain banks a stock board will be mounted displaying information on the bank's assets and loans. At the start of the intervention period the family case manager may need to support the committee by facilitating its monthly meetings. The personnel from the facilitating agency should also visit the grain bank and attend some of the committee meetings to provide clarity on the bank's processes.

Resource mobilization and external linkages

Linkages with government schemes and other benevolent trusts to access resources are essential to the sustainability of the intervention. These linkages can also be used to document successful practices of grain banks so that other banks can replicate them.

Annex 15: Household Care Referral Form: File Copy

Client name:	**Gender: M ☐ F ☐**
Client number:	**Residence:**
Place referred to:	

REASON(S) FOR REFERRAL:

Education/ cognitive dev.
- ☐ School fees
- ☐ Books/ Materials
- ☐ Uniform
- ☐ Play group
- ☐ Parent group

Psychosocial
- ☐ Specialized counseling
- ☐ Support group
- ☐ Spiritual counseling
- ☐ Other referral

Food security
- ☐ Food support
- ☐ Nutritional counseling
- ☐ Garden/livestock support

Economic strengthening
- ☐ Micro credit support
- ☐ IGA
- ☐ Vocational training
- ☐ Grant
- ☐ Welfare

Child protection
- ☐ Child protection
- ☐ Birth registration
- ☐ Physical neglect
- ☐ Physical abuse
- ☐ Sexual abuse
- ☐ Child labor
- ☐ Abandonment
- ☐ Child prostitution

Legal protection
- ☐ Will writing
- ☐ Selecting a guardian
- ☐ Property protection

Welfare
- ☐ Shelter
- ☐ Clothing
- ☐ Bedding
- ☐ Water

Economic strengthening
- ☐ OPC
- ☐ CHBC
- ☐ VCT
- ☐ PMTCT/ANC
- ☐ Pediatric
- ☐ TB

Referred by (name):_____**Date:**_____ **Signature:**_____

Write remarks/additional comments on the back page

Household Care Referral Form: Client Copy

REASON(S) FOR REFERRAL:			
Client name:			**Gender: M ☐ F ☐**
Client number:	**Residence:**		
Place referred to:			
Education/ cognitive dev. ☐ School fees ☐ Books/ Materials ☐ Uniform ☐ Play group ☐ Parent group	**Psychosocial** ☐ Specialized counseling ☐ Support group ☐ Spiritual counseling ☐ Other referral	**Food security** ☐ Food support ☐ Nutritional counseling ☐ Garden/livestock support	**Economic strengthening** ☐ Micro credit support ☐ IGA ☐ Vocational training ☐ Grant ☐ Welfare
Child protection ☐ Child protection ☐ Birth registration ☐ Physical neglect ☐ Physical abuse ☐ Sexual abuse ☐ Child labor ☐ Abandonment ☐ Child prostitution	**Legal protection** ☐ Will writing ☐ Selecting a guardian ☐ Property protection	**Welfare** ☐ Shelter ☐ Clothing ☐ Bedding ☐ Water	**Economic strengthening** ☐ OPC ☐ CHBC ☐ VCT ☐ PMTCT/ANC ☐ Pediatric ☐ TB

Referred by (name):_____**Date:**_____ **Signature:**_____

Family Case Management - A Handbook for Family Case Managers

The five-year long experience in Balasahyoga has led FHI 360 to believe that the Family Case Management approach is essential to effectively address the vulnerabilities and build resilience among HIV infected and affected families.

The handbook aims to improve the knowledge and skills of those involved in implementing or supporting community based outreach services for vulnerable children, youth, and families affected by disease and trauma. It outlines child focused as well as family centered activities, and promotes the community and facility based integration of care, prevention and treatment services. It recognizes that the needs of HIV infected and affected children go beyond health. Keeping this in mind, the handbook provides practical insights to assess family needs, prioritize families and provide need based support in five domains of care i.e. health, nutrition, psychosocial support, education and food security. The handbook can be used as a personal guide by the outreach worker or as a resource for collaborative learning on this community based approach.

Andhra Pradesh State AIDS Control Society

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