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THE NEED FOR THE IMPACT PROGRAMME

The effects of the HIV epidemic on children are enormous: hundreds of thousands of children are infected with HIV every year, most are left undiagnosed and therefore do not access treatment and die very young. Those who are not infected may be orphaned, or live in families and communities where AIDS reduces the productivity of their households and aggravates poverty. Only a combination of factors can improve this situation. These include greater access to the medicines that can prevent mother-to-child transmission, wider access to testing, easy access to care and treatment, and support for families and communities that provide the material, social, and emotional foundation for children’s development. The IMPACT programme is intended to stimulate demand for children’s antiretroviral therapy (paediatric HIV treatment) and ensure accessible ART services are provided and promote HIV testing, early infant diagnosis and prevention of mother-to-child transmission (PMTCT) services.

Who is the Guidebook for?

This guidebook is part of the IMPACT Bantwana toolkit developed under the Children First project, which includes training materials for Community-based Organisations (CBOs) to use in training and updating their community health workers (CHWs) in the identification and care of HIV infected children and young people in their communities. There are also reference materials (the Reference Cards) for use by the CHWs, and Fact sheets that can be left with clients for their reference once the CHW has left.

It is meant for non-governmental organisations (NGOs) and District Health Teams interested in implementing the programme, as well as for community health workers working with families and communities. These guidelines are born out of the need to decentralise the programme and create community ownership in addressing the special needs of children living with HIV, preventing new paediatric infections and additional infections in their communities. In addition, it is important to follow up mother-baby pairs once they are discharged from the postnatal clinics. Strategies include enrolling them into the family child health clinic and assigning CHWs to the pair to help with follow up.
PHASE 1: PLACING IMPACT IN THE COMMUNITY

Objectives

- To ensure the IMPACT programme is relevant to local needs and to determine the extent of need
- To identify gaps in paediatric HIV treatment and identify what role the implementing organisation can play
- To generate community ownership.

1. Working with the Ministry of Health and Child Welfare (MoHCW) in implementing IMPACT in your catchment area

Remember to keep your local Ministry of Health and Child Welfare (MoHCW) officials involved in the programme and its progress, and invite them to any initiatives that may emerge from this programme.

2. Assessment to determine the HIV prevalence in the area

If your organisation is already active in the community, and/or working on HIV related issues, you may already know this information. However, the demographic data is very important in being able to show the impact of the programme, so read through and make sure you have the information stated here in a format that is useable for monitoring and evaluating the IMPACT programme.

It is important to conduct a situation analysis to determine the HIV prevalence in your area, and the numbers of children who may require assistance from the programme. This is mandatory, unless your organisation already has the relevant information available, in order to appreciate what services exist and what the gaps are.

Be prepared to establish Internal Savings and Learning (ISAL) Groups if they do not already exist, in order to support further learning within the community and mother and child pair groups, as well as ensuring that psychosocial support groups exist.
Useful information to collect before, or at the stage of introducing services in a particular area, includes the following:

(i) **Demographic data**
   - The size of the population in the area; the number of children under 15; under five; and under two years old. This information should be broken down by sex, if possible.
   - The characteristics of the people who live in the area, e.g. their age, sex, whether they are married or not, etc. (demographic composition), as certain groups have a greater need for HIV and related services, such as young women and children born with HIV infection.
   - The population density in the area (given that the costs of providing health services in areas with few people are generally higher than in urban areas).

(ii) **Socio-economic data**
   - The socio-economic status of the population means the differences between groups of people caused mainly by their financial situation. This is important because it may affect the issues that emerge from the assessment.
   - The profile of vulnerable, under-served and hard-to-reach groups
   - What welfare programmes and other interventions are already taking place.

(iii) **Health statistics**
   - Infant mortality rate
   - Child mortality rate
   - Immunisation coverage:
     - BCG vaccination
   - Diphtheria, Tetanus and Pertussis (DTP) vaccinations 1-3:
     - HIV prevalence (broken down by age and gender if possible)
     - Number of adults undergoing PMTCT (they will need follow up)
     - Number of mothers undergoing delivery at home (they will need HIV testing and follow up).
3. **Mapping of HIV Treatment services and capacity in the area**

Availability of health services, antenatal clinic (ANC) sites and other health related social programmes

- Health centres offering HIV testing and counselling
- CD4 count testing sites Paediatric ART services
- ART initiation centres
- ART follow-up centres
- Counselling and PMTCT
- ART outreach sites.

Make sure you highlight any services that do not exist locally, or areas that do not have easy access to particular health services. Find out from the MoHCW where is the nearest facility that provides those services not currently available in the community.

4. **Assess if there are institutional policies and procedures to protect confidentiality of clients**

If these do not exist then you must put them in place before the programme is started.
PHASE 2: COMMUNITY AWARENESS AND MOBILISATION

Objective

This phase is critical to ensure buy-in for the IMPACT model from relevant stakeholders. You may not need to follow all the steps here if your organisation is already active in the community.

1. Involve MoHCW, Ministry of Women and Gender and other relevant government officials (Ministry of Local Government) of planned community awareness and mobilisation activities

Following up on the initial communication, it is important to keep MoHCW informed of the activities of the programme, and to assess whether they are able to commit staff to participate in the process.

2. Conducting stakeholder meetings to bring the community on board

“Community mobilisation is the bringing together of members of the community to become aware of the importance of your issue – in this case, HIV testing, PMTCT, paediatric AIDS and HIV care and treatment”.

Stakeholders to involve are indicated in the diagram below. It may be necessary to have several stakeholder meetings to ensure that all levels of community feel free to participate. For instance, it may be advisable to meet with more senior members of the community first, before engaging community members and families, so that they can be assured that community leaders have buy-in to the project.
Community members may feel freer to speak out in a meeting held without the presence of community leaders in the first instance. Then a second meeting can be held with both community leaders and members.

(i) Community Mobilisation

Community mobilisation involves giving information to the community and gathering information from them to create community knowledge and buy-in to the project.

When the community works together to solve problems they have identified, it is possible to achieve much more. Once the community is aware how a problem such as HIV in children affects everyone they begin to take responsibility for it. Finally, involving the community means individuals receive more support and no one gets left alone with a problem.

(ii) Steps in community mobilisation
(iii) **Suggestions on how to get people to come to the meeting:**

- Make announcements in churches, mosques and schools
- Word of mouth - moving from home to home
- Drumming and drama groups, songs, poems, stories
- MoHCW outreaches e.g. Child health days, immunisation campaigns
- Market days
- Poster, leaflet, banner, signboard, billboard
- Loudspeakers
- Hold a gala day
- Radio, television, cinema, newspaper
- Popular drama
- Posters at strategic places

(iv) **Preparing for the meeting:**

Involving people with different skills will make your meetings more valuable. See if there are any health NGOs in the area that are willing to support the meeting.

- Work together with important members of the community, such as health workers and teachers, to develop a plan that will help them share their knowledge for the benefit of the whole community
- Invite local health providers to attend and give technical advice in areas where the community needs more information.

(v) **Structuring the community mobilisation meetings**

1. Introductions: Allow all members at the meeting to introduce themselves
2. State the objectives of the meeting - why the meeting has been called
3. Assess community understanding and knowledge of the Issue: Hand out pieces of card and ask each member of the community to list down anything they know that relates to paediatric AIDS and HIV care, treatment and PMTCT, and also to list down any questions they may have
4. Input (from key speaker). Ensure that the key speaker has all the facts of the current situation of children and the importance of paediatric AIDS/HIV care, treatment and PMTCT. Provide this information to the speaker if necessary, based on the assessment conducted prior to the meeting
5. Community Mapping of area and also services and resources available to address the issues. The community draws a map showing clinics, NGOs, information and other places relevant to the issue. Match this with the information you gathered during your assessment.

6. Identify the way forward: This is an important session as it allows the community to identify how they would like to be involved in addressing the situation. Identify some of the key activities that are part of the IMPACT model and also note that community outreach and education are critical components of the model. Ask the community to identify strategies, as well as to nominate some champions/motivators who can be called upon to provide ongoing input and guidance to the process.

(vi) Following up

After the community meeting, it is important to organise regular meetings with the champions and motivators identified at the community meeting. Check with them if this can be done monthly. Use this time to assess the situation and to proactively problem-solve, but also to identify any further opportunities for community engagement.

3. Implementing an outreach campaign

There are three major steps involved in raising awareness of the benefits of the programme.

1. Understanding the different audiences within your community and how they receive information
2. Preparing a strategy to raise community awareness
3. Implementing the strategy.

The following information will support the development of your outreach strategy.

(i) Understanding Your Audiences

Effective outreach begins with identifying your target audience so that public education and outreach activities can be customized to meet situation-specific needs.

Each community - no matter how large or small - has several different ‘audiences’ consisting of different people. These will vary from community to community, but in general, may include: children not in school and students in school; business people, social groups, church groups, adults and elders, community and traditional leaders, visitors to your community, and of course individual families. Understanding these groups and how they receive information is important in developing an outreach strategy.
Some of the questions that may have been answered by the assessment in Phase 1 are:

- What different target audiences exist (e.g., children, adults, community leaders, etc.)?
- How much do people already know about paediatric AIDS and HIV treatment, care and PMTCT?

In developing the strategy, the following questions may be useful:

- Do community members respond to newsletters and public notices?
- Are they interested in participating in informational events such as workshops, community lunches and others?
- What groups within your community are interested in becoming actively involved in implementing the outreach and awareness campaign? For example, school teachers, students, church leaders?

After identifying your target audience, expand your efforts to include community members who are respected and will be listened to by other community members. Be sure to educate people who can pass your information on and maximise the impact of your message.

Building broad community support through outreach and education helps sustain momentum so your target audience may include your entire community.

ii) Preparing an Outreach Strategy

The next step is to develop a formal plan for implementing your public education programme and community outreach. Your plan should include the following components.

- **Identify Issues and Challenges to be Addressed.** To be effective, you must clearly identify specific issues to be addressed. These may come from the Phase I assessment I, or from input from the community meetings. For example, it could include:
  - HIV in children and families
  - Children living with HIV – paediatric antiretroviral therapy and health practices
  - PMTCT - HIV testing for all pregnant women
  - Psychosocial support for children living with HIV
  - Nutrition for children living with HIV
  - Counselling, testing and confidentiality
  - Addressing stigma and discrimination.
The strategy should also outline any challenges to effective implementation of the IMPACT programme. Common challenges include: successfully delivering educational messages, maintaining programme participation, and providing adequate funding for activities. Identifying these challenges at the beginning of your programme and making sure they are considered as you develop the plan, is crucial to the success of the IMPACT programme.

- **Identify goals for your programme.** Identify outreach goals, while keeping in mind the overall IMPACT programme objectives. For example, the objectives of your outreach might be to:
  - educate community members about the facts of HIV infection in children - highlighting the issues around children who have not yet been diagnosed - and create awareness of critical issues facing children living with HIV;
  - encourage community members to participate in reducing stigma and discrimination against PLHIV;
  - encourage community members to support the needs of children living with HIV and
  - increase community awareness about the success of PMTCT and how they can contribute to zero new infections in children.

Set goals carefully, making sure to choose those that are achievable given your available resources, timeframes and other constraints.

- **Create and deliver a powerful message.** Once you have defined your goals and target audience, consider the messages you want to get across so you can achieve your objectives. Messages are simply the ideas or information you want to communicate to community members. They should be clear and simple, and be ones to which your target audience can relate. It is best to limit yourself to three or four simple messages, using language that is easily understood. In developing the messages, ask yourself:
  - Why do you want to educate your community about this topic?
  - What do community members need to know about your programme?
  - What would they like to do or be willing to do?
  - What other information can you provide that might encourage them to do what you would like them to do?

Keep in mind who you will be sharing your messages with and how they will understand and respond to your messages. Consider issues such as: What are their beliefs? How do they absorb and understand information? What motivates them to take action?

Also think about any other factors that might affect how easily your audience will accept your message. For example, are there particularly sensitive areas surrounding the issue in the community? Are there greater priorities or other sources of information that could take away from or weaken your message?

Effective messages relate to people on their own terms and in their own language - methods that work for educating business owners are unlikely to work with small schoolchildren. So adapt your message so that it appeals to each group you are trying to educate. For example, keep your message simple if you want children to understand it; you may need to deliver your message in a culturally appropriate way if you want to reach elders.
Choose an outreach method.

Determine the best way to get your message out to community members. You may already have a clear sense of the best way to get information out in your community. For example, posting notices at the post office or in local schools and through school and teachers.

Consider using more than one method to get your message out. Outreach and educational messages will have more impact if they are heard more than once. Make an initial announcement and then follow up a month later with another message, such as an article in a community newsletter.

Options for distributing your message will also be affected by your budget and any technical requirements. Consider ways of using existing community outreach programmes and tools to get your messages out.

If you need to create educational outreach materials, consider using low-cost creative ways of producing them. For example, if you want a poster, you can have your school sponsor a poster contest and have schoolchildren design and produce the poster. If you need flyers, you might be able to get your Village Committee or local non-profit organisation to produce the flyer for you. When designing any outreach products for your public education and outreach programme, always consider ways to incorporate elements of local culture and traditional knowledge. This will help people feel a connection to your programme.

Public education and community outreach methods.

Public education and community outreach can take a variety of forms, including written materials (fact sheets, newsletters, articles, flyers, inserts in newspapers and newsletters, booklets, and brochures); visual materials (signs, posters, charts, and pictures); and events (community meetings, community dinners, workshops, school events and programmes, public briefings and presentations, media events, and special gatherings).

The following list gives ideas on the types of tools, activities and events that you can use to educate and reach-out to your community. Remember this is not a comprehensive list of things you can do. The number of possible activities and events is only limited by your imagination.

- **Signage** - signs placed in strategic locations are a low-cost, low-effort way of educating community members.
- **Community Newsletters** - newsletters can provide community members and businesses with specific information about the IMPACT programme and its key issues.
- **Inserts, flyers, and other written materials** - these are another low-cost method of spreading information. By developing a simple message and distributing to households and businesses in your community, you can quickly and easily inform everyone about the

"Get support from community leaders – they can deliver powerful outreach messages."
programme. Also, putting certain information such as local VCT and PMTCT services in writing is useful, because people can keep and the information and refer to it when needed.

- **Door-to-Door Campaigns** - Door-to-door campaigns allow outreach workers to talk directly to people in the community. It can be more time-consuming and labour-intensive than other public education programmes, but is invaluable in reaching people, especially where rules and guidelines have changed, or where you anticipate resistance to a new programme, perhaps because of stigma. A door-to-door campaign also lets you hear directly what issues are important to community members and answer any questions or concerns they may have regarding the programme. It has the added benefit of enabling you to track everyone you contact, making it easier to estimate the effectiveness of your programme.

- **Briefings and Presentation** - Briefings and presentations can be used throughout your planning and public education process to keep local officials, agencies, and other groups informed about the programme. These public education tools not only provide information, but also allow these groups to express opinions and concerns about the programme.

- **Media Coverage** - Media coverage of your programme and relevant issues can take the form of feature stories in local papers and provide the most visible media coverage. Send a news release or make personal contact with a reporter from the community newspaper. News conferences, radio talk shows, and public service announcements are also effective methods of providing local people with information about your programme and any community activities.

- **Workshops, Meetings, Special Events** - These are valuable ways to educate community members and provide a hands-on learning experience for participants, as well as provide an opportunity to ask questions.

- **School Activities and Events** - Educating students helps develop a positive attitude among both students and parents regarding the issues and encourages community involvement that will contribute to the success of your programme. Some outreach programmes are specifically focussed on schools. High-profile events quickly and dramatically increase community awareness. All community gatherings are outreach opportunities even when are not directly related to your programme. For example, community festivals and other events draw large crowds where you can set up a booth or make a presentation.

A successful outreach strategy includes several different activities and events. A plan that combines several activities and events as part of a comprehensive programme will reach more people and is likely to be more effective. Different activities and events can also complement one another. For example, public announcements and newsletters can be used to publicise special events. Keep in mind the information needs of the community, your established goals, and any resource or time constraints.

**Establish a timeline.**

Your outreach strategy should include a timeline which will coordinate your schedule for implementing outreach activities with the implementation schedule of the IMPACT programme. It should also take into account any seasonal activities and events.
iii) Implementing the Strategy

Public education and community outreach programmes should become a regular part of your community and should evolve to meet the needs of community members. The IMPACT programme is a long term one and requires on-going public education and outreach.

Once your outreach programme is in place, it is important to take steps to: 1) create partnerships, 2) address comments and complaints, and adjust and 3) maintain your education and outreach programmes. Remember to carry out programme measurement activities.

1. Partnerships and outreach campaigns - these activities complement one another. Outreach generates support and creates partnerships. In turn, partnerships are crucial to conducting further outreach and sustaining your programme. For example, if you want community leaders to promote your programme, you need to convince them that it is worth promoting. So outreach begins with educating your potential partners

2. Address community comments and complaints - When developing your community outreach strategy, it is important to anticipate questions that community members may have so that they can be addressed early on

3. Adjust and maintain your education programme to fit your needs - When educating community members, be sure to use educational materials and outreach methods appropriate for the people you are trying to reach. Whenever possible, use culturally appropriate methods of communicating and sharing information.

OUTREACH TIPS

- Identify your target audience.
- Create clear and simple messages.
- Incorporate culture and traditional values when appropriate.
- Be creative and explore a variety of outreach options.
- Obtain support from community leaders and respected members of your community.
- Perform outreach to build partnerships and use them to increase the success of your outreach efforts.
- Take advantage of high-profile events, such as community functions and school programmes.
4. Implementing the IMPACT programme

Identify a list of priorities for IMPACT implementation in your community. It should be possible to determine these from the results of your assessment from Phase I and input from the community meetings.

**Identify goals for your programme.**

For example, it should include:

- HIV in children and families
- Children living with HIV – paediatric antiretroviral therapy and health practices
- PMTCT
- Psychosocial support for children living with HIV
- Nutrition for children living with HIV
- Counselling, testing and confidentiality
- Addressing stigma and discrimination.

**Identify any challenges to address**

The community meetings should have highlighted any challenges in implementing the programme in your community. The programme implementation strategy must clearly identify specific issues to be addressed.

Common challenges include: maintaining programme participation, and providing adequate funding for activities. Identifying these challenges at the beginning of your programme and making sure they are considered as you develop the plan. This is crucial to the success of the IMPACT programme.

Sensitisation of programme staff in the implementation of the IMPACT model

A suggested programme for sensitising programme managers and officers on implementing the programme can be found in the Facilitators Manual, which also describes the training.

**Selection and training of community health workers (CHWs)**

You may already have CHWs whom you intend to use in the programme. They will need to be trained in all the information and support areas they are expected to provide. CHWs will also be responsible for increasing community support as they go about their tasks within the community.

See the Facilitators Manual for suggested training programme.
PHASE 3  TRAINING CHWs TO LEAD THE IMPACT PROCESS

Objectives

- To ensure that local home based caregivers or community health workers (CHWs) and others are familiar with basic child communication skills, paediatric HIV care and child friendly ways to educate children and young people on ART and adherence, using games.
- To encourage CHWs to involve the community in identifying and supporting HIV positive children.

1. Keep MoHCW informed and involved in training activities as appropriate

It is important to keep open communication with MoHCW and to solicit their involvement throughout the roll-out of the programme. Responsible programme officers need to determine from MoHCW what services around PMTCT and pediatric treatment are available at local centres, so that this information can be provided to CHWs during their training.

Where certain services are not available, you will also need to find out where CHWs should refer to. You may also begin to advocate for services to be brought to local health facilities.
2. **Determine the number of home based carers or community health workers needed to roll out the programme**

Using the assessment conducted in Phase 1, the programme officer should determine how many community health workers will be needed to implement the programme. Factors to consider include number of households/CHWs, distance between households, comfort of communities with particular CHWs.

3. **Training of CHWs to deliver home-based paediatric HIV care**

There are two objectives of the CHW training:

- To provide basic education on health and wellness as it relates to children and their parents and HIV, as well as on PMTCT services
- To provide the CHWs with appropriate and relevant tools to assist them in educating community members; enable them to screen potential clients and to refer them to appropriate services.

The CHW reference cards form the basis of the training curriculum. Upon implementation, this training course should enable CHWs to implement the IMPACT programme at community level through engagement with communities, households and children.

The services they deliver will lead to increased access to health, paediatric HIV treatment, care and PMTCT, as well as identification of children and young people living with HIV but as yet undiagnosed. Their actions and its results will play a significant role in the promotion of a preventive service that will also engage communities in looking after their own health.

At the end of the training the CHWs should be able to:

- Complete a household assessment using the household profiling tool
- Establish the needs of children and families in households
- Undertake and complete appropriate education, assessment of families’ needs (screening) and referral
- Adhere to established follow-up mechanisms children, families and communities
- Communicate clear-cut preventive and health promotion messages, specifically to mitigate the multiple burdens of HIV in communities.

Combined with the other elements of the overall programme, this will ensure that the overall objectives of the IMPACT programme are met.
**Format of the training**

The training material and curriculum provide the building blocks necessary to understand and deliver consistent and accurate information that focuses on the current issues related to children and HIV. The central theme - HIV prevention, care and treatment - runs through the content and should be reflected in the training.

The training encompasses both the theoretical and practical aspects of their work to ensure that the CHWs are equipped to fulfill their role successfully through:

- A 5-day theoretical and practical training course (the content for which is given in the accompanying Facilitators Manual).
- A 3-month post training assessment in the field with household visits, testing skills acquisition and competency.
- Refresher training courses in the various Reference Cards

The set of tools provided to equip CHWs to effectively implement the learning are:

- Reference cards, including IMPACT Awareness poster and Home Visit record tool
- Community booklets in local languages to be left as reference for households as needed.

**Training content**

The course consists of five modules, each of which should take a day to complete. Remember that much of the information will be new to CHWs and it is important not to overload them with too much information at once. The course may be given as a 5-day course, or in separate days as suits the time and availability of CHWs and facilitators.

**Module 1:** The purpose of the IMPACT Programme. The role of the CHWs: This module covers the purpose of the training, the role of the CHWs, skills development and how the CHW should record, report and follow up.

**Module 2:** The Basics of HIV: This module covers all the basic information on HIV infection, prevention and treatment. It particularly focuses on children, and PMTCT.

**Module 3:** Assessment of children for HIV (screening): This module covers everything to do with the symptoms and assessment of children as they pertain to HIV.

**Module 4:** The comprehensive care of children living with HIV and AIDS. This module covers treatment, care, nutrition, psychosocial support etc.

**Module 5:** Community care and support: This module explains how to access services such as support groups, nutrition gardens and how to care for those living with sickness and disability.
Supporting Resources

The Reference Cards provide the CHWs with a quick and easy reference for use in the household and community, as well as the Home Visit record tool that will assist CHWs perform their assigned tasks at household and community level.

CHWs need to be made aware that they may be required to employ more than one tool per visit, if their organisation requires different tools for different family circumstances.

It is important that the need to make use of these tools is emphasised during the training.

The services they deliver will lead to increased access to health, paediatric HIV treatment, care and PMTCT...
PHASE 4: IDENTIFYING AND CONNECTING HIV+ CHILDREN WITH ACCESS TO ART SERVICES

Objectives

- To identify previously undiagnosed children and help them access ART
- To address bottlenecks in accessing ART and accelerating the initiation of children on ART
- To emphasise importance of adherence to treatment for a successful ART programme.

Below is a flowchart of key components of this phase

1. Connecting HIV+ Children with Access to ART services
2. Child is tested at nearest health institution and receives pre/post test counselling
3. If child is positive the CHW refers parent and child to ART initiating site and opens case file
4. Provide transport assistance to children and guardian
5. Establish specific time that paediatric clients can be seen by a paediatrician or health care professional
6. Set up system to deal with lengthy initiation process
7. Establish community bleeding and transport system to ferry blood samples to CD4 test centre
8. Request specific time for CD4 samples of paediatric clients to be processed
9. HBC provide treatment adherence support by counselling children and parents. (Also nutritional advice)
Steps to support this process for the implementing organisation can be guided with the checklist below.

<table>
<thead>
<tr>
<th>Step</th>
<th>Action</th>
<th>Notes/date/Update</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparatory tasks</td>
<td>CHWs should:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✗ Establish relationships with local health care centres/service delivery points</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✗ Record service delivery point details in directory of services (see sample at the end of this manual)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✗ Promote formation of ISAL support groups for help with meeting transport needs and other support.</td>
<td></td>
</tr>
<tr>
<td>Make provision for testing of children</td>
<td>✗ Make contact with health institution and make appointment for client (if appropriate)</td>
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<tr>
<td></td>
<td>✗ Ensure that the parent (and child, if old enough to understand) get pre- and post-test counseling</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✗ Support caregiver / child through the testing process and with obtaining CD4 count if necessary.</td>
<td></td>
</tr>
<tr>
<td>For positive children, referral to ART initiating site</td>
<td>✗ Support the caregiver and child in following up CD4 count results and obtaining ART.</td>
<td></td>
</tr>
<tr>
<td>Follow-up of PMTCT babies</td>
<td>✗ Make contact with local antenatal clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✗ Get list of all PMTCT mothers</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✗ Follow up PMTCT mothers and babies 6 weeks after delivery</td>
<td></td>
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<tr>
<td></td>
<td>✗ Ensure PMTCT babies get tested – early infant diagnosis</td>
<td></td>
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<tr>
<td></td>
<td>✗ Follow up clinic for results after 2-6 weeks</td>
<td></td>
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<tr>
<td></td>
<td>✗ HIV positive infants should be commenced on treatment immediately</td>
<td></td>
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<tr>
<td></td>
<td>✗ Determine mother’s ART eligibility through CD4 testing</td>
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<tr>
<td></td>
<td>✗ Develop a case management follow up plan for mother/baby with local clinic</td>
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<tr>
<td></td>
<td>✗ Make contact with local antenatal clinic.</td>
<td></td>
</tr>
<tr>
<td>Step</td>
<td>Action</td>
<td>Notes/date/Update</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Provide transport assistance or support.</td>
<td>✗ In cases where child and parent stay far from a health centre, assess if they need transport support (stipend)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✗ Make financial arrangements for this for all appointments.</td>
<td></td>
</tr>
<tr>
<td>This includes formation/joining of an ISAL group</td>
<td></td>
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</tr>
<tr>
<td>Appointment with OI clinic staff if the client has other medical problems or concerns</td>
<td>✗ Set up an appointment with OI clinic staff</td>
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<tr>
<td></td>
<td>✗ If one not available solicit a volunteer doctor. Approach relevant OI initiating staff</td>
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<tr>
<td></td>
<td>✗ Communicate appointment time with the parent/guardian.</td>
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<tr>
<td>Treatment adherence support</td>
<td>✗ Counsel child and parents to manage intake of ARVs</td>
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<tr>
<td></td>
<td>✗ Provide educational session and material on side-effects and critical signs</td>
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<td></td>
<td>✗ Introduce child/ caregiver to local PSS groups.</td>
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<tr>
<td>Establish support system</td>
<td>✗ Make arrangements for emergency support in cases where children display critical signs.</td>
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<tr>
<td>Follow up</td>
<td>✗ Decide on date of follow up to check progress.</td>
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</tbody>
</table>
PHASE 5: FOLLOW-UP ON TREATMENT OF HIV POSITIVE CHILDREN

Objectives:
- To address the needs of the child
- To coordinate service provision for HIV positive child
- To facilitate the establishment of support networks for children and their families.

See flow diagram below outlining key steps for this phase:

Some guidelines for programme implementing organisations to follow are:

**Step 1: Treatment Programme**
- Refer to Reference card 16 and 17. CHWs inform parent/guardian of the need to take medicines the right way (at the right time, the right number, etc.)
- Agree on a follow-up schedule, times and dates
- Taking medicines regularly. Identify with client ways to do ensure this.

**Step 2: Nutrition**
- Review nutrition programme with client. Refer to Reference Card 21 to identify any changes needed
- If needed – refer parent to a local nutrition garden.

**Step 3: Exercise and Rest**
- Provide information on education and rest to the parent and child and help them find strategies to address this.
Step 4: Psychosocial support

- See Reference card 20. CHW counsels child and caregiver and advises them about support groups for children and adults. If necessary, assist with establishing support groups locally.

- Follow-up on treatment for HIV+ Children
- Implementing institution and CHW establish follow up schedule for HIV positive child
- Support training for guardian/primary caregiver, on ART adherence medication and warning signs
- HBC completes a comprehensive assessment and ensures linkages with appropriate services to address those needs
- Form psycho-social groups for children and their caregivers

Step 5: Assess other needs

- In conversation with the child or caregiver, use creative methods as described in Reference Card 3 to identify other needs of child (additional counselling etc)
- Make the necessary referrals.
PHASE 6: REFERRAL AND RECORDKEEPING

As per the training of CHWs, identify the needs to keep files and detailed reports on each child for follow up. Each community health worker should be advised to develop a directory of services available locally and further away, to which they can refer, when clients need to be referred for additional services. A sample directory is given below.
CHWs should use a separate page for each support area and follow up on the contact people they have listed regularly in case of staff changes. Remember that additional services may be opened up. The headings in the sample indicate the different services that may be found in the community, though these may not be exhaustive.

A sample referral form is also attached. It can be photocopied. The form has two parts: the top part should be filled in by the referring NGO, and the bottom tear off part should be filled in by the receiving institution, stating services provided. The tear off part should be completed by the receiving institution and returned to the client, to hand over to the NGO who referred them.

The programme officer should ensure that he or she is kept informed of any developments regarding addition or removal of services from the area and inform CHWs of these changes so that they can ensure their directory is up-to-date at all times.
Public Education and Community Outreach,

## SAMPLE REFERRAL DIRECTORY

<table>
<thead>
<tr>
<th>Service Page</th>
<th>NGO/ Health facility</th>
<th>Physical Address</th>
<th>Phone Number</th>
<th>Contact Person</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV Counselling and Testing</td>
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<tr>
<td>Counselling - other</td>
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<tr>
<td>PCR testing</td>
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<tr>
<td>ART initiation / Side-effects</td>
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<tr>
<td>Repeat ART script filling</td>
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<tr>
<td>Food Support and Nutritional Counselling</td>
<td></td>
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<tr>
<td>PMTCT services</td>
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<tr>
<td>Family Planning Services</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Service Page</td>
<td>NGO/ Health facility</td>
<td>Physical Address</td>
<td>Phone Number</td>
<td>Contact Person</td>
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<tr>
<td>STI Services</td>
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<tr>
<td>Youth Friendly Services</td>
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<tr>
<td>Condom Distribution</td>
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<tr>
<td>PEP and Emergency Contraception</td>
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<tr>
<td>Child and Sexual Abuse / Rape</td>
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<tr>
<td>Victim Friendly Unit/ Child Protection Committee</td>
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<tr>
<td>CD4 Count Testing</td>
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<tr>
<td>In the Event of Treatment Failure</td>
<td></td>
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<tr>
<td>Psychosocial Support groups</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Internal Savings and Lending Schemes (ISALs)</td>
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</tbody>
</table>
Service Referral Form (to be completed by the referring NGO)

We are referring our client

Name: ....................................................................................................................................................... 

To your institution for

Service Required: .....................................................................................................................................................
.....................................................................................................................................................
.....................................................................................................................................................

Once you have provided the services needed, please complete the tear off slip below and give it to the client to return to us for our records. Thank you for your assistance.

Date: ................ / ................................ / ....................................
Community health workers Signature: 
.....................................................................................................................................................

We ................................................................................................................................................................. (name of service provider)

confirm that we have provided ...........................................................................................................................
.................................................................................................................................................................
.................................................................................................................................................................
.................................................................................................................................................................

Date: ................ / ................................ / ....................................

(name of client)

with the following services:
.................................................................................................................................................................
.................................................................................................................................................................
.................................................................................................................................................................
.................................................................................................................................................................

(Please return the signed form to your Community Health Worker)
This toolkit was developed under the USAID funded Children First Project.