Step 5: Implement Service Delivery

**Step 5** involves putting the program into action by launching and delivering clinical, psychosocial and community services to clients and their families.

**Objectives**

- Mobilize community to support and engage in new and improved services—in some cases newly accessible ART.
- Deliver high quality, accessible and integrated clinical, psychosocial and community services to the targeted numbers of patients.
- Track and retain patients in the program.
- Prepare patients who need antiretroviral therapy for treatment.
Mobilizing the Community

It is important to mobilize the community to access the enhanced HIV/AIDS services, prior to starting a new ART program focused on children and their families as well as on an ongoing basis after implementation. In many resource-limited settings, knowledge among the general population of HIV/AIDS and its prevention and treatment is limited and sometimes inaccurate or distorted by local beliefs and myths. Those infected with HIV are subject to stigma and discrimination and may be afraid to seek medical care. In addition, it is important to raise awareness among the general population about the need to bring ill children to the attention of health services at an early stage. This will help to diagnose those who are HIV-positive at an early age, which is critical given a 50% rate of infant mortality by the age of 2 years without ARV therapy.

The objectives of community mobilization include:

- Provision of basic information about HIV/AIDS prevention, transmission and treatment
- Motivation of clients to access VCT and treatment thereafter, if required
- Motivation to bring infants and children to the service’s attention at an early age in order to allow timely initiation of ARV therapy
- Reduction of stigma and discrimination against PLWHAs as a result of increased understanding and compassion
- Provision to families with information enabling them to support infected family members

In those countries in which routine testing is acceptable, aggressive efforts should be made in that direction. This will also help to diagnose infected children at an early age. The following approaches are suggested:

- Training of counseling and testing personnel on routine testing procedures
- Institution of routine testing at the program centers and at all referring hospitals
- Strengthening of referral processes to the program centers
- Extensive education of health professionals about routine testing and the need for early infant diagnosis
- Raising awareness of routine testing among the general population

Mobilization of the community should lead to a rapid increase in uptake of PMTCT for women and VCT for children. Moreover, often the child can be an entry point for an entire family to be tested. Prior to the opening of the BIPAI COE’s in Africa, critics frequently predicted that stigma was still so entrenched in the community that parents would be reluctant to bring their children to a facility that was so obviously named as providing HIV/AIDS services. This proved quite unfounded as illustrated in the graph below of patient uptake at the COE in Lilongwe, Malawi, which was opened in February 2006. This trend has been mirrored at all of the BIPAI COE sites in Africa.

Figure 5: Patient enrolment following the opening of the BIPAI COE in Lilongwe, Malawi.

Mechanisms to Mobilize Communities

Several techniques can be used to mobilize the people of a community to access new HIV/AIDS services. They include radio and television, community events sometimes very effectively utilising drama as a medium of expression and door-to-door campaigns and workshops for community stakeholders, such as chiefs, traditional healers, public health facility representatives, youth and women group leaders and other influential men of the community. It is particularly difficult to motivate men to be involved in HIV/AIDS programs, but their inclusion can yield big gains. Therefore, gaining support and endorsement from influential men of the community other than traditional leaders, such as chiefs of police or well known local ministers and priests is worth the effort. It is critical that the services promised through any mobilization actions can meet
client demand. Mobilizing a community for services that are unavailable or not fully in operation damages the programme’s credibility. Please refer to Resource No. 2, the STF Manual for a comprehensive guide to these forms of community mobilization.

**Door-to-Door Campaigns**

Special mention is made here of the value of a door-to-door campaign, because it presents the greatest opportunity for providing detailed HIV information and interacting directly with community members. While labour-intensive and potentially expensive, the costs can be limited by encouraging the use of volunteers (who may receive small reimbursements for necessary expenses such as food or clothing) to conduct such campaigns. The Field story below illustrates a successful door-to-door campaign in Swaziland.

**Tool No. 12** provides a game to raise consciousness about how HIV can quickly spread in the community. The String Game, created by UNICEF, is a highly effective visual aid, designed to educate the general public including illiterate patients on the modes of transmission of HIV. Community Educators carry a stand up display to the clients’ homes. Cardboard cut-out figures of men, women and children are applied to the board and connected by strings to indicate particular modes of transmission. For example, a man contracts the infection from sleeping with a commercial sex worker and subsequently passes the infection on to his wife, who is pregnant and delivers a newborn child infected by the mother to child route of transmission. This scenario is presented by the educator telling the story and connecting the strings between the individuals at the time of infection (see Field story No. 5.1).

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**Field Story No. 5.1: Use of Door-To-Door Campaign in the Poreco Project in Swaziland**

A team of 42 unemployed graduates from Swaziland University was recruited and underwent an intensive two-week training program on HIV/AIDS, ARVs and PMTCT. Using a diary card in which they completed the date, how many people they saw, the graduate community educators went door-to-door in pairs to inform community members around Mbabane about HIV/AIDS and the soon-to-be-opened Pilot Operational Research and Community-Based PMTCT Plus Concept (PORECO) clinic. Within six months, they reached approximately 20,000 residents. For a lighthearted demonstration, these community educators used a visual aid known as the string game consisting of a board on which cut-out figures of men, women and children are pinned and connected by strings representing the path of HIV infection from person to person.
Effective Delivery of Clinical Services

The Clinic

The following constitutes the basic package of amenities and services you will need to launch the clinic.

- Clinics should have access to clean water or another method for maintaining good hand hygiene.
- Space should be provided for the following activities: patient waiting and registration, patient care, counselling/testing, pharmacy, and medical records. The exact makeup of these areas will be dictated by the availability and location of such space.
- Booking systems and medical records: clinics may be run with booking systems or on a walk-in basis. Those with booking systems are thought to be superior because follow-up contact can be made for those patients that miss their appointments. Documentation of the patient visits and the treatment plan is essential for both the clinic and the patient. These may be as simple as a paper card or chart or as complex as an electronic medical record.
- Counseling and testing: the clinic should have the ability to offer HIV counselling and rapid testing for all patients that attend.
- Care and treatment guidelines: clinicians and other health professionals that work in the clinic should be familiar with all of the HIV guidelines in their area so they can counsel and initiate ARVs medications and other prophylactic medications (e.g., cotrimoxazole) for all that attend.
- Equipment: taking care of children can be made easier with equipment that is made for newborns and children of all ages. Appropriate sized needles for drawing blood, catheters (e.g., intravenous, urinary), and blood pressure cuffs. Weight scales and height boards for both babies and older children can help clinicians provide adequate care since antiretroviral medications are dosed based upon the patients weight or body surface area.
- In addition, practitioners working in these centers should be comfortable working and dealing with sick children and their family members.

As stated in the introduction, this Toolkit is not intended to provide details of treatment of HIV/AIDS in children. The WHO has developed a series of guidelines on provision of treatment of HIV/AIDS in resource-limited settings, (see Resource No. 6 for the WHO publications: “Antiretroviral Therapy for HIV Infection in Infants and Children” and “Guidelines on Cotrimoxazole Prophylaxis for HIV-related Infections among Children, Adolescents and Adults.”)

In Step 2 the advantages of decentralized services located at primary health centers were explained and in Step 4, Field Story No. 4 an example was given of how to build capacity at such sites in terms of personnel skills, physical infrastructure and equipment. If this is the route you decide to take, you will find a series of tools designed to assist actual implementation in Tool No. 13. These are simplified protocols for the care, treatment and monitoring of children, which can be utilized by nurse practitioners or other non-physician health professionals. The tools included are:

1. Initial site assessment
2. Pediatric patient mastercard
3. Pediatric ARVs register
4. Checklist for excellence in pediatric HIV care
5. Checklist for health providers in HIV clinic
6. Exposed infant follow-up form
7. Cotrimoxazole dosing guide

Adherence

It is no exaggeration to say that one of the fundamental objectives of all the services that are described in this toolkit is promotion of adherence to ARVs. Good adherence, after all, is the key to sustained optimal response to ARV therapy. Some factors you might like to take into consideration in this regard are as follows:

- Preparation of prospective patients to begin ARVs is critical. The DOH in South Africa has developed a specific one day training course for patients, which could be administered to a child’s caretaker. This training provides education to patients and/or their caregivers on HIV/AIDS, ARVs and adherence in particular (Resource No. 7 - Module 1, Module 2 and Module 3).
- It is useful to make an assessment as to the “neediness” of the family in which the child lives. This can identify families which may require more attention and close supervision as the child goes on to therapy. A tool to assist this assessment is to be found in Tool No. 14.
- For quantitative ongoing measurement of adherence, use a combination of pill counts and pharmacy refill records. Appropriate refill counts, in particular, have been correlated with good response in adults [Low-Beer, S. et al. J. AIDS: 23(2000),...
Photographs of patients with their doctors at the BIPAI COE in Gaborone, Botswana

360-1]. These pose logistic problems because of the time required to perform them, but they are worth the effort. The calculation of adherence should be ingested drug as a percentage of prescribed drug. If the percentages are different for each of the ARVs taken, document the lowest one as that patient’s adherence rate.

- Nonetheless, pill counts and refill records can be deceptive if the caregiver or older child tries to “correct” for non-adherence, because they are afraid of telling the truth. This is where the personal relationship between patient/caregiver and health professional can be especially helpful. A non-judgmental approach should be taken, encouraging the truth to be told. When a problem is suspected, you might want to consider using the PACTG Pediatric Adherence Questionnaire, which can be found at the following website (http://www.fstrf.org/qol/peds/pedadhere.html).

- Good adherence can be facilitated by using the simplest regimens and finding ways of reminding patients when to take the medication etc. A system of rewards for the child who is adherent is also very effective. At BIPAI COEs, children are given different colored stars to recognize their good adherence.

- In addition to these activities at the clinic, an effective tracking system to trace patients who default clinic visits is necessary to ensure the patients do not run out of ARV medication (see Step 6 under community services).

- All the members of your team can be useful in assessing and encouraging adherence, including the pharmacist. Ultimately, however, any sign of clinical immunologic or virologic failure is usually linked to non-adherence and that is where the skill of a physician becomes crucial.

Logistical Considerations Regarding TB Co-infection

Clinicians providing HIV/AIDS services should be familiar with providing care for other problems that are common to their community such as tuberculosis (TB). It is important to remember that young children (< 4 years of age) are at the greatest risk for the development of the extra-pulmonary forms of TB (e.g., meningitis).

In addition, children do not spread TB to other family members because they do not usually develop cavitary lung disease. Therefore, the greatest risk for TB to any child is an infected adult that lives in the home. Since these young children do not usually develop cavitary
lung disease, they also do not usually produce sputum and do not have positive sputum smears. Therefore, contact with an infected, untreated adult is often enough to begin anti-tuberculosis therapy.

In countries where anti-TB medications can be provided by the clinic, stocks of fixed dose combination medications are essential. In countries that require a referral to a TB center, a good working relationship with the center is required. Patients have the greatest chance for cure if they receive directly observed therapy.

Clinicians should also be aware of the side effects of the TB medications and the interactions that occur between these medications and antiretroviral medications. Care should be taken within the clinic in dealing with TB infected adults or in any patient required to provide a sputum sample. Since TB can be extremely difficult to treat in an immunocompromised patient, attention to the prevention of spread to other patients or the staff is extremely important. If patients arrive to the clinic with active untreated pulmonary TB or if they have an unexplained chronic cough, especially with a history of coughing up blood, these patients should be taken directly back to a well ventilated examination area or should be asked to wait outside. Practitioners should also take every precaution to improve the ventilation in the areas where such patients will be seen or wear masks when examining the patients. In addition, obtaining sputum samples from TB patients should only be done in a well ventilated area designed for such activities or outside, away from other patients waiting to be seen.

Please refer to the handbook Tool No. 15 for details on the clinical management of co-infection of HIV and TB.

Nutritional Services

Ideally you will be able to recruit a nutrition specialist, who can coordinate the activities of all staff involved in the management of children’s nutrition. If this is not possible, ensure that all staff has received the basic training in nutrition they need (e.g., from the The HIV Curriculum for the Health Professional, published by BIPAI: Resource No 3).

Malnutrition (also known as protein-energy malnutrition) is a problem in many areas of the world. Severe malnutrition is associated with a high mortality rate and children may suffer long term developmental or physical side effects as a result of their caloric deficiency. Protein-energy malnutrition (PEM) is often subdivided into two separate entities, kwashiorkor and marasmus. Kwashiorkor is characterized by protein deficiency and commonly presents about the time mothers discontinue breast feeding, although it can develop at any age. The hallmark of kwashiorkor is the development of fluid retention (edema), dry peeling skin and hair discoloration. Kwashiorkor can be difficult to recognize by inexperienced clinicians since the fluid retention often makes the child appear nutritionally normal. Marasmus results from a total caloric deficiency and is characterized by stunted growth and wasting of muscle and tissue. This form of PEM can also occur when mothers wean their children from the breast but like kwashiorkor occurs at all ages.

Patients can be classified as severe malnutrition by weight loss (> 20% of total body weight) or by the use of weight for height charts or mid upper arm circumference charts. Severe PEM usually requires hospitalization in the initial refeeding phase where conditions such as hypothermia, hypoglycaemia, infection and dehydration should be addressed. Once the patient has been stabilized, refeeding can begin with a 20 calorie/ounce formula or a formula made specifically for PEM such as F75 (75 calories/100 ml). Patients should receive approximately 8-100 kcal/kg/day until their appetite returns. After this is accomplished and if the child is doing well, the patient can have the feeds changed to include a 30 cal/ounce formula, F100 (100 calories/100 ml), or ready-to-eat therapeutic foods. Once a goal weight is reached and home and food security issues have been addressed, the patient may be discharged home with close follow-up.

Malnutrition and wasting is often found in children suffering from advanced HIV/AIDS and the presence of this finding places a HIV infected patient in WHO Clinical Stage 3 or 4 based upon the severity of PEM. In places where food security is an issue, differentiating moderate-to-severe PEM from HIV/AIDS induced wasting is impossible and in most incidences the patient is suffering effects from both. Therefore, clinicians working with children in these situations must be familiar with recognizing and diagnosing moderate-to-severe malnutrition and understand how to take care of these patients. It is also important to remember that children suffering from PEM are in the highest risk category for being infected with HIV/AIDS and should undergo counseling and testing. Clinics or clinicians should have good linkages with local feeding centers not only in order to transfer patients to them but also to establish testing protocols for all the children treated there.

Because of the labour intensive nature of the treatment of malnutrition and the shortage of trained nutritionists, BIPAI has developed a program, which trains laypersons as nutrition assistants, thus reducing the workload on other health professionals. The steps
involved in putting the program into action are described below and a series of tools to assist implementation are to be found in Tool No. 16.

**A Stepwise Approach to Designing and Implementing a Nutritional Program Utilizing Laypersons as Nutrition Assistants**

**Step 1: Partner with hospital administration.**
- Engage hospital administration in implementing the program.
- Identify a small room to transform into a basic kitchen

**Step 2: Hiring and training of laypersons as nutrition assistants**
- Laypersons can be recruited and trained as nutrition assistants. Based on BIPAI experience, approximately 5 such individuals can provide the required nutritional services for 3,000 patients.
- Schedule a three day training session for the recruited laypersons.

**Step 3: Training:**
- The training can be done by nutritionists, physicians and nurses. It includes didactic teaching on general principles of growth and nutrition, recognition of acute malnutrition, the basics of treating malnutrition in the inpatient setting, basic infection control/hygiene principles, importance of confidentiality, play therapy, as well as topics such as scheduling, filling in forms, and the day-to-day responsibilities of the job.
- Practical hands-on training in measuring weights/heights/head circumferences, MUAC is best done with experienced nurses.
- A nutritionist should provide practical instruction in making therapeutic formulas.
- Nutritionists and physicians can also review the cases of currently admitted malnourished children at the bedside.
- A complete proposed training schedule is to be found in Tool No. 16.

**Step 4: Clearly define responsibilities/ongoing daily activities for nutrition assistants:**
- Providing and documenting feeds: All feeds and rehydration fluids are best prepared by the nutrition assistants in the kitchen. The nutrition assistants then ensure that each malnourished child that they are following is given the appropriate amount of formula/feed at the correct time as prescribed by the doctor during that day. At night they wake the caregivers at the appropriate time to ensure the feeds are given. For each feed they document on an intake form the type of feed, the amount offered, the amount taken, and whether or not there has been any vomiting or diarrhea since the last feed. These forms are kept in the nutrition assistants’ kitchen and available to physicians to review before their daily rounds.
- Measuring patients and monitoring progress: The primary responsibility for measuring patients should remain with nurses.
  - The nutrition assistants can also help in this important output by ensuring that the weights measurements are done and documented daily.
  - They can also ensure that measurement of heights is carried out at a minimum of every 3 weeks.
  - Nurses should measure MUAC on all admitted patients.
  - Nurses should measure temperatures 3 to 4 times daily.
- Assisting with family education: The nutrition assistants can participate daily in education of the caregivers – including on basics of general nutrition, basics of treating malnutrition, and the importance of adhering to the feeding schedule as prescribed. They can also demonstrate to caregivers how to do both oral and nasogastric feeds appropriately and model and encourage the importance of appropriate hygiene/hand washing.
- Fostering communication between families and medical staff: This is one of the most crucial functions of the nutrition assistants. Because of large patient loads, the physicians and nurses are often able to spend only a short amount of time with each patient. Because they are constantly with the malnourished children, nutrition assistants can notify nurses and doctors when a patient is getting sicker or needs immediate attention. They can also explain the feedings and management that the doctors prescribe each day and can reinforce the messages that the doctors give.
Other activities/updates: Two of the nutrition assistants can be given the additional responsibilities of record keeping and administrative duties.

– One should be responsible for creating and disseminating the work schedule, disseminating messages from the coordinators to the rest of the group, and ensuring that necessary materials—such as forms, dish soap, binders—are kept adequately supplied.
– The other should be responsible for data collection and data entry. She should collect the monitoring forms and enter the information into a specially created database. An example of such a database is also included in Tool No. 16.

Pharmacy

Organizing the Pharmacy

You may decide to have ARVs dispensed at the outpatient department’s general pharmacy. This obviates some risk of patients experiencing stigma. Alternatively you may wish a dedicated ARV service in order to provide a faster and more efficient service. In the latter case, if possible, an additional service window should be created to provide an express service to patients on ARVs, who may initially be sicker than other outpatients obtaining their medications at the pharmacy. This express service could also be used for other patients who would benefit from a faster dispensing service so HIV patients are not singled out. In addition, an express window could be created for children.

The first step in setting up the pharmacy service is to appoint at least one qualified pharmacist or certified pharmacy technician before the program begins. The generally accepted ratio is one pharmacist per 500 patients. Ideally the pharmacist should have an assistant. (I.e. one pharmacist and one pharmacist’s assistant for every 500 patients). The pharmacist’s assistant normally performs such tasks as pre-packing ARV drugs, labeling drug packs and, importantly, collecting data. The latter should ideally be conducted with a personal computer loaded with pharmacy/drug management software to facilitate the monitoring of ARVs stored in the pharmacy and dispensed to the patients.

Training the Pharmacy Personnel

As soon as the staff members have been selected, they should be trained in HIV and AIDS, focusing on the mechanisms of the disease and its treatment. The training should also include information on all ARV drugs, their pharmacology, expected side effects and dispensing information. Since drug adherence will inevitably become an issue, staff should also be trained on adherence counseling. Access to a recommended training curriculum is “Medunsa; Pharmacist in HIV” to be found in Resource No. 8. In fact pharmacists and their assistants often play a critical role in aiding good adherence. Not only can they do pill counts to determine if the correct number of pills is being returned to the pharmacy, but they can give invaluable counseling when the patient first receives ARVs and on an ongoing basis thereafter.

Patient Bookings

When patients are booked for prescription refills, bookings for their next clinic visit should occur at the same time. Patient scheduling is important because pre-packing should be done in advance of a patient’s next visit. Pre-packing may be necessary since some medications need to be specially packed for dispensing.

Dispensing to Children

It is more difficult and time-consuming to prepare prescription ARVs for children than for adults. A detailed algorithm (see the Baylor College of Medicine tables in Tool No. 17) should be prepared for ARV preparation for children factoring in their age and weight. Children should be weighed frequently (usually every three months) because their weight can change significantly during treatment, thereby necessitating a change in ARV prescription. As mentioned above it is advisable to have special arrangements for rapid dispensing of ARVs to children.

ARVs Stock-Outs

Stock-outs of ARVs are to be avoided at all costs. Inability to furnish a continuous and reliable supply to patients will result in treatment failures. In the case of private donors or some NGO’s, you may be buying ARVs yourself. Otherwise you may be reliant on a centralized system for procurement of ARVs, i.e., under government control. For both situations we recommend that contingency plans be drawn up. There exist private procurement and distribution companies with which you may wish to enter into an agreement. They can usually find sources of ARVs albeit at higher cost than you are usually paying. Although costs may be higher, this contingency approach is less expensive than dealing with the consequences of patients failing their ARV regimen.
Laboratory Monitoring

The availability of laboratory testing in resource-limited areas is varied. However, at a minimum, it is desirable that clinics should have access to laboratories that can provide the following tests:

- Rapid HIV testing
- Complete blood count
- Liver function tests
- CD4 testing
- HIV DNA PCR

The complete blood count will provide a hemoglobin level and a white cell count with differential. In areas that do not have access to CD4 counts, the absolute lymphocyte count can be used as a surrogate marker for a CD4 count and can be used to aid clinicians in starting antiretroviral therapy. In addition in many countries, absolute CD4 counts are the only information provided while issues related to pediatric HIV/AIDS therapy should ideally be based upon the CD4 cell percentage. With the absolute CD4 number and a percentage of lymphocytes provided by the complete blood count, the CD4 percentage can be calculated.

Liver function testing is helpful in monitoring for adverse drugs reactions from the antiretroviral or anti-tuberculosis medications.

Many countries have protocols for routine laboratories written into their HIV care and treatment guidelines. In areas without specific guidelines, routine laboratory testing with a complete blood count, liver function tests and CD4 counts should be done at the initial evaluation and once every six months. If patients develop treatment or medication complications, they may require testing more often.

HIV DNA PCR obtained with the use of dried blood spot testing is critical in establishing the diagnosis of HIV in patients as young as 6 weeks old. The methodology to allow use of dried blood spots for performing PCR has been developed and validated. This technique is particularly useful at remote clinics, from which the dried blood spots can subsequently be transported to a laboratory for analysis.

The use of quantitative RNA viral loads can also be used for the initial diagnosis in infants and young children similar to the HIV DNA PCR, and this also provides information to the clinician about the activity of the virus. In addition to the CD4 count, the quantitative HIV RNA viral load are best obtained once every 6 months unless patient complications require more frequent testing.

The WHO guide on laboratory monitoring of HIV in resource-settings is to be found in [Resource No. 9].

Lessons Learned

- Mobilization and education of the community are critical to ensure acceptance of a new pediatric HIV service and hence rapid uptake of the service.
- Pay a lot of attention to methods of attaining good adherence to ARVs.
- Tuberculosis and malnutrition are such common concomitant problems in children that your clinic should address them vigorously.
- Avoid stock-outs of ARVs at all costs.
- You can still monitor children’s response to ARVs even if you do not have access to “standard” laboratory tests such as viral load and CD4, by measuring absolute lymphocyte count and good clinical assessment skills.