

# SECURE THE FUTURE® Manual: Seven Steps to Involve the Community in HIV/AIDS Treatment Support Programmes

First Edition



BRISTOL-MYERS SQUIBB  
SECURE THE FUTURE®

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## Message from the Bristol-Myers Squibb Foundation

In 1999, Bristol-Myers Squibb Company and Bristol-Myers Squibb Foundation launched a programme called *SECURE THE FUTURE*® (STF) to support the development and evaluation of cost-effective, sustainable and replicable models for providing care and support to people living with HIV/AIDS in Africa.

Initially focused on five highly affected countries in southern Africa—Botswana, Lesotho, Namibia, South Africa and Swaziland—STF expanded in 2001 to four countries in West Africa—Burkina Faso, Ivory Coast, Mali and Senegal—and in subsequent years to Malawi and Uganda. From its inception, the programme supported and championed the roles of community-based organizations and communities in response to the HIV/AIDS crisis.

In 2001, the World Health Organization (WHO) started promoting a public health approach to assist scaled-up access to antiretroviral treatment (ART) in developing countries. Under this programme, standardized and simplified treatment protocols and decentralized service delivery were proposed to facilitate treatment of large numbers of HIV-positive adults and children by the public and private health care sectors. Still, as ART rollout plans were being put together, communities in resource-limited settings were often regarded as too challenged by poverty, low education, limited health care infrastructure and workers, and high levels of stigma to implement efficacious treatment programmes.

To address these issues, STF and its government and community partners in Botswana, Lesotho, Namibia, South Africa and Swaziland looked to bring community mobilization and supportive services together with a public health approach to ART and HIV care and announced the Community-Based Treatment Support Programme in 2003.

Through this programme, STF and its partners proposed, piloted and rigorously evaluated a way to overcome the challenges to ART rollout in resource-limited communities by implementing a continuum-of-care model that went beyond referrals to fully integrate community mobilization and supportive services with medical care. It was about providing and integrating the “half hour” of medical treatment and care received in the clinic with the “23 1/2 hours” of disease management and psychosocial support that takes place in the patient’s home and community until the next clinic visit. With great support from community leaders, community-based groups and the governments, this model was successfully implemented at each of the five sites.

For HIV treatment and care to be scaled up and effective over the long term in resource-limited settings, community mobilization and supportive services must be fully integrated with treatment programmes and adequately resourced. Our hope in preparing this manual is to share our experiences and lessons learned for broadly and robustly engaging communities in the fight against HIV/AIDS.

John L. Damonti

President, Bristol-Myers Squibb Foundation

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## Acronyms

AIDS	acquired immunodeficiency syndrome
ANC	antenatal care
ART	antiretroviral therapy
ARV	antiretroviral
BMS	Bristol-Myers Squibb
CBO	community-based organization
CBTS	community-based treatment support
FBO	faith-based organization
HBC	home-based care
HIV	human immunodeficiency virus
IGA	income-generating activity
NGO	nongovernmental organization
OVC	orphans and other vulnerable children
PHC	primary health care
PLWHA	people living with HIV and AIDS
PMTCT	prevention of mother-to-child transmission
PORECO	Swaziland Pilot Operational Research and Community-Based Programme – PMTCT Plus Concept
SINAN	Swaziland Infant Nutrition Action Network
SOP	standard operating procedure
STF	<i>SECURE THE FUTURE</i>
STI	sexually transmitted infection
TAC	technical advisory committee
TBA	traditional birth attendant
VCT	voluntary counselling and testing

## Introduction

### The *SECURE THE FUTURE* Programme

In 1999, Bristol-Myers Squibb Company and Bristol-Myers Squibb Foundation launched a programme called *SECURE THE FUTURE* (STF) to support the development and evaluation of cost-effective, sustainable and replicable models for providing care and support to people living with HIV/AIDS (PLWHA) in Africa. The programme was first launched in southern Africa (Botswana, Lesotho, Namibia, South Africa and Swaziland) and by 2002, had expanded to East and West Africa (Burkina Faso, Ivory Coast, Mali, Malawi, Senegal and Uganda) .

The programme engaged an international Technical Advisory Committee composed of representatives from ministries of health, nongovernmental organizations, PLWHA, academia and international HIV experts to evaluate and recommend proposals for funding and to provide ongoing guidance on the programme's focus and direction.

During the first three years of the programme, funding was provided for more than 160 projects addressing critical areas of need such as community outreach and education as well as medical research. This phase of broad-based grant making put resources directly into the hands of small, community-based organizations that were the "first responders" to the HIV/AIDS crisis and created innovative models of care. The programme also supported African researchers who studied the development of low-cost diagnostic and disease-monitoring tools and conducted trials on locally relevant topics such as diagnosis of smear-negative tuberculosis (TB) and the efficacy of PMTCT medication given to the newborn infant only in cases when the mother presented at the hospital after delivery.

### Proposing a New Model of Care for People Living with HIV and AIDS

By 2002, the international community and many national governments in sub-Saharan Africa began working towards providing free antiretroviral therapy (ART) for the HIV-infected population. At its biannual meeting in April 2002, the Technical Advisory Committee endorsed the STF staff recommendation that the programme redefine its role and join this effort.

In the following months, STF staff consulted extensively with national governments in southern Africa on their challenges and gaps in rolling out ART. A common challenge that was raised was rollout to remote communities where health care infrastructure, capacity and other resources were limited. Many regarded these communities as too challenged by poverty, lack of health care infrastructure and health care worker capacity, lack of food security, unemployment and high levels of stigma to establish and sustain long-term efficacious treatment. These challenges raised not only issues of equity in ART rollout but also the need for innovative models and comprehensive actions to make sure ART could also be provided in these communities. Using these consultations and drawing on lessons learned from the grants made in the first three years of the programme, the community-based treatment support (CBTS) model was developed.



The CBTS model has been validated through a five-site demonstration project as effective for providing comprehensive care, for increasing access to medicines and medical monitoring and for establishing broad-based community support in resource-limited areas. This model places equal emphasis on the need for both clinical and community services to optimize the quality of life and the health outcomes of HIV positive patients. The model is delivered as a partnership involving government, the private sector and nongovernmental organizations (NGOs) by using a seven-step implementation process.

By late 2002, five communities and primary hospitals had been identified by each of the health ministries and departments to pilot the CBTS model: Ladysmith Provincial Hospital, Uthukela District, KwaZulu-Natal, South Africa; Senkatana Clinic, Maseru, Lesotho; Mbabane Referral Hospital, Mbabane, Swaziland; Bobonong Primary Hospital, Bobirwa District, Botswana; and Katima Mulilo Hospital, Caprivi Region, Namibia.

At each of the facilities, it was agreed that the government would co-invest in the sites with BMS and sustain the implementation after a three-year start-up phase. Implementing partners were assembled at each site to jointly plan implementation of the model, and, from 2003 to 2004, communities were mobilized and services were launched at the sites.

Since the launch of the CBTS programme in 2003, more than 17,000 clients have enrolled for antiretroviral treatment, care and support. More than 8,000 clients have received ART. As of June 2007, requests for replication of this model of care have been made by the governments of Mali, Namibia, Swaziland and a community in the Eastern Cape and Limpopo of South Africa.

## Purpose of This Manual

The overall purpose of the manual is to guide any group in how to integrate community mobilization and supportive services provided by community-based organizations (CBOs) (including faith-based and other nongovernmental organizations) to patients in their homes and communities with those patients' medical care.

This manual describes in detail:

- The implementation of the CBTS model to ensure delivery of effective and comprehensive care and support for PLWHAs in resource-limited settings. This includes:
  - Rationale and principles of the approach
  - An operational road map for adapting, implementing and managing the programme
  - Technical tools and resources for partner collaboration to provide quality services for clients: some were developed by STF and its partners, while others were developed by other organizations, but utilized by STF and the CBTSP teams.
  - Profiles of five southern African community-based treatment sites, outlining their experiences in adapting and implementing the CBTS model. These implementation stories illustrate the flexibility of the model.



## Audience for This Manual

The manual is intended for public health officials, project managers, service providers, AIDS service and community organizations, funders and communities seeking to initiate, enhance or expand comprehensive HIV/AIDS treatment and care programmes in resource-limited settings.

- For **public health officials**, the manual offers a continuum-of-care model and multi-sectoral partnership model to leverage resources for community-based HIV/AIDS care.
- For **project managers**, the manual provides a road map for adapting, implementing, monitoring and evaluating, and managing a CBTS programme.
- For **service providers**, the manual offers a wealth of resources and tools for training, record-keeping and documentation, patient monitoring, establishing referral systems and implementing project monitoring and evaluation strategies.
- For **communities and community organizations**, the manual provides information on the critical role they play in reducing stigma and building an environment of support for PLWHA and their families.
- For **funders**, the manual reinforces the importance of supporting partnerships that integrate services and community-based care and provides resources for partner capacity building.

## Organization of This Manual

- **Section II:** This section outlines the major elements of the CBTS model, the approach to its implementation and data collected during one demonstration study to date on its effectiveness.
- **Section III:** This section is a description of the implementation of the model and includes:
  - Lessons learned from the African pilot sites, field examples, key tools and resources according to a seven-step approach:
    - Step 1: Engage Government and Community
    - Step 2: Establish Leadership and Management Structure
    - Step 3: Adapt the CBTS Model
    - Step 4: Build Partner Capacity
    - Step 5: Deliver Services
    - Step 6: Monitor and Evaluate
    - Step 7: Improve and Revise Services
- **Section IV: Key Lessons Learned**
- **Section V: Library:** This includes a list of tools and resources referenced in the manual.
- **Section VI:** This includes five complete implementation stories detailing the experiences of the communities that implemented the CBTS model and other STF initiatives, and key challenges and lessons learned during this pilot phase.
- **Section VII: Annexes:** These include the list of members of the Technical Advisory Committee, a list of the grantees of the *SECURE THE FUTURE* programme and an overview of the programme.

## II The Community-Based Treatment Support Model

### The Community-Based Treatment Support Model Defined

The community-based treatment support (CBTS) model emphasizes that people living with HIV/AIDS (PLWHA) in resource-limited settings need both clinical services and community services to effectively enhance their quality of life and clinical outcomes. The model also places equal emphasis on supporting the needs of PLWHA receiving anti-retroviral treatment (ART) and patients whose disease has not yet progressed to warrant treatment.



Instead of focusing solely on anti-retroviral treatment as a means of reducing mortality rates, this model

*More than 5,000 people attending the public launch of the ACHIVA/Mplohle project at Uthukela District in KwaZulu-Natal, South Africa, in 2004.*

stresses cost-effective supportive services like nutrition support and home-based care to help PLWHA manage their chronic HIV disease outside the clinic and in their homes and communities. The programme leverages the strengths of government, the private sector and community-based organizations to offer true continuum of care or, as *SECURE THE FUTURE* refers to it –“23 1/2 hours” (between clinic appointments) of disease management and psychosocial support that take place in the patient’s home and community following a “half hour” of medical care in the clinic.

As shown in Figure 1, all providers in this approach, whether serving clients in the clinic or the community, act as members of an integrated implementation team. This group shares information about the health and well-being of patients to comprehensively address their needs and optimize treatment outcomes. Each element and partner of the CBTS model is further outlined below.

### Clinical Services

Clinical services include the essential medical interventions needed by PLWHA—diagnosis confirmation and disease monitoring, management of opportunistic infections, antiretroviral treatment and prevention of mother-to-child transmission (PMTCT) of HIV.

### Community Services

Community services include activities that facilitate a patient’s understanding of HIV, disease management, adherence to therapy and overall quality of life. These services include home-based care, food security, psychosocial support, buddies, orphan care, prevention education, voluntary counselling and testing, and income-generating activities.

## Government

Government-run district hospital clinics serve as the focal point of the model, providing voluntary counselling and testing, laboratory services, clinical services (treatment), specialist services and antiretrovirals (ARVs). Such clinics both refer to and receive referrals from community-based organizations and primary health care centres. They encourage households to access clinical and community services to help ensure adherence to treatment and to provide psychosocial support. The government plays a critical role in programme sustainability.

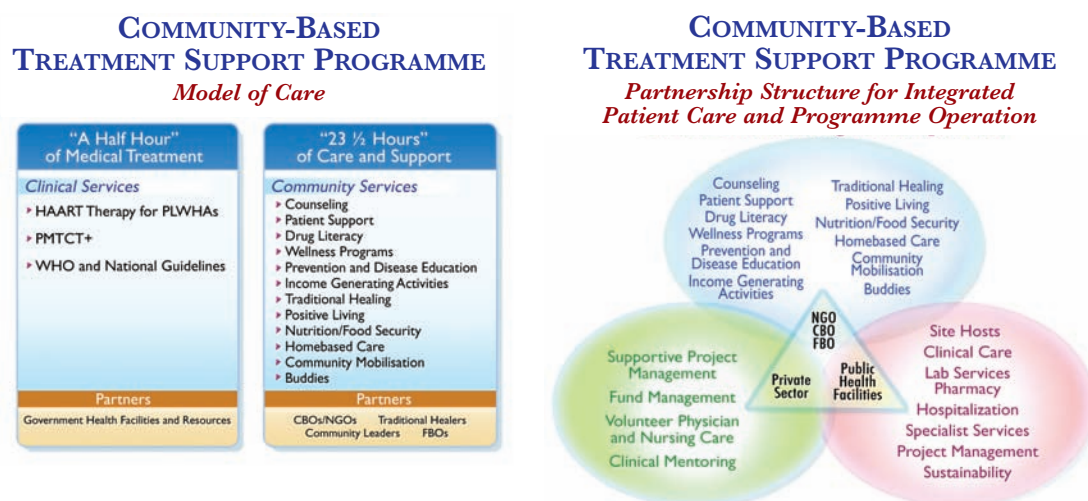
## Private Sector

In the model, the private health sector—which includes private physicians, general practitioners (GPs) and traditional healers, private funders, HIV/AIDS service consultants and trainers—plays a variety of caregiving and supportive roles. GPs refer patients as appropriate to the district hospital or primary health care centres. General practitioners and private physicians can be approached to spend time in state hospitals to augment human resource shortages. The private sector also includes businesses who donate funding or support; e.g., supermarkets can donate food to those in need, and corporate funders such as BMS can leverage their core competencies such as drug procurement and distribution and business skills such as finance, complex project management and quality assurance.

## Community-Based Organizations

Community-based organizations (including faith-based and other nongovernmental organizations) supply counselling and patient support, including buddy programmes, drug literacy, positive-living education, nutritional advice, food security, income-generating activities, home-based care and other outreach services to communities.

FIGURE 1 COMMUNITY-BASED TREATMENT SUPPORT MODELS OF CARE AND PARTNERSHIP



## Effectiveness of the CBTS Model

The effectiveness of the CBTS model has been demonstrated by a five-site, three-year public health demonstration project with compelling results.

Clinical outcomes and the added value of community support were evaluated by rigorous collection of data according to protocols developed by BMS (clinical) and Family Health International (Enhanced Patient Evaluation). Full details of the methodology and analysis are to be found in **Resource No. 1**. The results are summarized below.

An intent-to-treat analysis from the first 941 patients on ARV therapy for 12 months at sites in South Africa, Namibia, Botswana and Lesotho showed an overall efficacy of 64%, where efficacy was defined as a sustainable, greater-than-50 increase in CD4 count. The data also demonstrated adherence rates similar to or better than those in the United States as well as the best adherence rates in Africa.

For a separate cohort of 578 patients, the Enhanced Patient Evaluation investigated the added value of community support. They found that CD4 counts increased to significantly higher levels in patients on ARVs who accessed community support than in those who did not: 326 vs. 268.

Findings from the programme also include:

- **Increased voluntary counselling and testing (VCT) and clinical uptake:** Overall, the uptake of VCT increased approximately 10-fold within two to three months from the start of community mobilization, according to records kept at VCT centres. Uptake of clinic services mirrored this. By November 2006, more than 16,000 patients had been enrolled.
- **Excellent adherence:** At 12 months, 84.5% of patients were still more than 95% adherent. This is equivalent to missing at most only one dose per month and similar to the best adherence rates in Africa (Peltzer).
- **The added value of community support:**
  - CD4 counts increased to significantly higher levels in patients on ARVs who accessed community support than in those who did not: 326 vs 268.
  - Patients who were satisfied with the level of community support they received also experienced better quality of life and adhered better to their ARV medication than those who were not satisfied.
  - Food security and home-based care were the two services statistically related to better adherence.
  - The lost-to-follow-up rate in *SECURE THE FUTURE* CBTS programmes was only 5.1%. In Swaziland's Prevention of Mother-to-Child Transmission programme, all 224 women and their babies were accounted for up until 12 months of the child's age, thanks to community workers who intensively tracked defaulters.
  - Community services helped prepare patients for antiretroviral therapy and "leveled the playing field" by dealing with psychosocial problems, inadequate nutrition and logistical issues such as transport to the clinic and disclosure of status to family members in order to take medications openly at home.

The programme found that with community mobilization and support, a patient is more likely to present for testing and treatment, will be better prepared to begin and adhere to ARV therapy, is less likely to default and is more likely to have a better clinical outcome.

One of the biggest effects of this programme was simply hope. Not only did HIV/AIDS patients have medicine, but also they had community support for food, counselling and generating income. And people were living. The impact could be felt at community levels as well, as illustrated in the following field story.

## FIELD STORY 1 CLINICAL IMPACT AT BOBONONG PRIMARY HOSPITAL IN BOTSWANA

Approximately 66,000 people live in the Bobirwa Sub-District of Botswana, of whom about 20,000 are in the Bobonong village. Bobonong Primary Hospital, where the CBTS model was established, serves this village. Before the CDC clinic was opened in 2004 in the hospital, the few patients from this village that were on ART had to travel to faraway treatment sites in Francistown and Gaborone. By 2006, two years after the CBTS model was adapted and implemented, 3,782 had been enrolled for care and 1,546 patients were on ARVs and the following notable results were achieved:

- Hospital bed occupancy by HIV patients decreased from 93% to 52%
- Mortality in the hospital resulting from HIV/AIDS decreased from 25% to 13%

Before the programme, a team of dedicated volunteers from the Bobonong Home-Based Care Society (BHBCS) provided care for the dying under the supervision of the Ministry of Local Government. Two years after the programme was started, they were transformed and reinvigorated. They were now looking after people getting well and helping them to live full lives again.

This prompted the Member of Parliament for this area to remark, “I no longer attend funerals every weekend as I used to.”



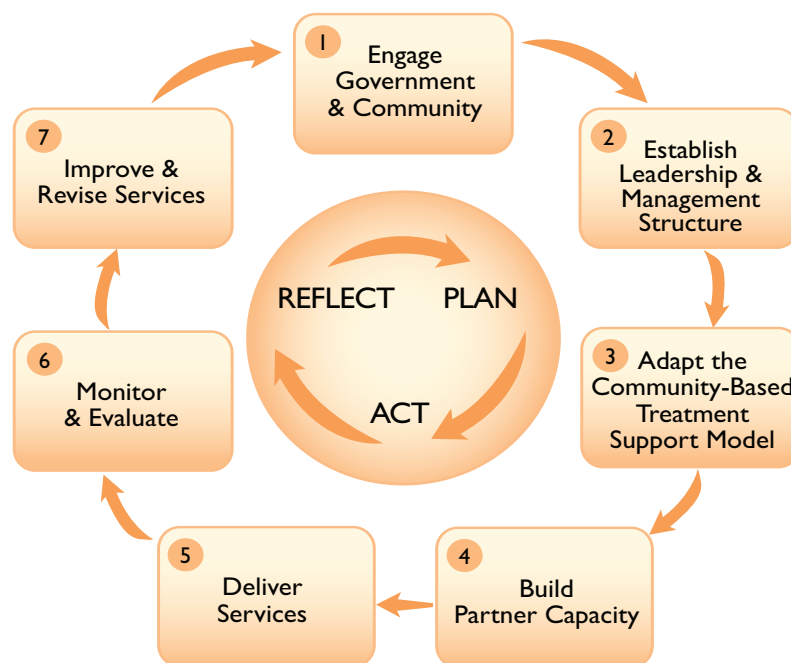
*Mr. Shaw Kgati, Member of Parliament, at the community launch of the Bobirwa ARV Project.*

### III Implementing the Community-Based Treatment Support Model

Applying the CBTS model at a site consists of seven important steps (Figure 2). Readers of this section will find for each step:

- Brief description of each step
- Objectives and expected outcomes of the step
- Outcomes and how to attain them
- Tools and references to best implement the step
- Field stories
- Lessons learned

FIGURE 2 SEVEN-STEP IMPLEMENTATION PROCESS



#### Engage Government and Community (Step 1)

- Step 1 focuses on the participatory assessment and mobilization of both public and private sectors and communities themselves that must take place prior to implementing a CBTS model at a site.

#### Establish Leadership and Management Structure (Step 2)

- Step 2 focuses on the structures needed to effectively lead and manage a CBTS programme.



### **Adapt the Community-Based Treatment Support Model (Step 3)**

Using the CBTS model as a guide, Step 3 discusses how to select which clinical and community services to offer and how to prioritize services based on the level of resources, infrastructure, referral systems and current programmes.

### **Build Partner Capacity (Step 4)**

Step 4 examines developing human capacity for the CBTS programme (who needs to be trained and how) and infrastructure or site capacity (inputs and processes).

### **Deliver Services (Step 5)**

Step 5 outlines how a CBTS model is implemented at the service level.

### **Monitor and Evaluate (Step 6)**

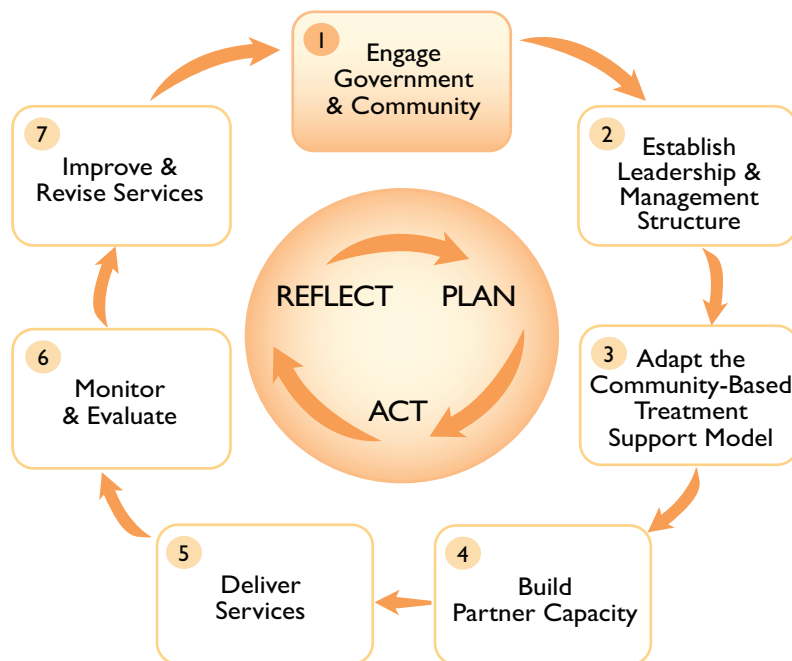
Step 6 addresses the critical challenge of measuring for impact and monitoring for quality.

### **Improve and Revise Services (Step 7)**

Step 7 addresses the importance of reflection on best practices and lessons learned and explores the importance of fine-tuning a site's services.



## Step 1: Engage Government and Community



This step focuses on the mobilization of the public, private and community sectors to engage with and take ownership of the project in order to ensure effective implementation.

### Objectives

- Advocate for establishment of an integrated, community-based approach for HIV/AIDS care and treatment that includes the government, private sector and community in multidisciplinary teams
- Obtain government support for introduction of a CBTS model
- Identify resources from the public health, civil society and private sector that can help deliver a CBTS model of care to people living with HIV/AIDS in a community and that understand the need for HIV/AIDS services to be delivered in the community itself

### Expected Outcomes

- Engage government and secure its support
- Develop a business case for adapting the model in a community

### Engage Government and Secure Its Support

Most communities and governments may still need to be convinced of the merit of implementing the CBTS model. Governments are more likely to support efforts to adopt the CBTS model when they understand how community support services can amplify the resources available to support antiretrovirals and treatment option programmes. Governments will also appreciate evidence of community services' value in such an

approach. A case should be presented to them that explains the rationale for the model, the need, problems and opportunities. This advocacy tool should also qualify and quantify, wherever possible, the need and cost implications.

To develop the case, review the contents of this manual, case studies, country policies and treatment guidelines. Emphasize the following:

- The description of the CBTS model featured in this manual
- The evidence base for the model that demonstrates the value of community services to patients' quality of life, the level of stigma they experience and their clinical outcomes

**Tool No. 1** is a slide set to support outreach and presentations to partners on the rationale for and benefit of the CBTS model. This advocacy and engagement tool should also quantify wherever possible the need and cost implications for the specific community.

## FIELD STORY 2 ENGAGING GOVERNMENT SUPPORT IN BOTSWANA

Botswana had already initiated a universal ART programme called MASA (a Setswana word meaning “new dawn”) when *SECURE THE FUTURE* started consulting with the government in 2003 regarding the relevance and acceptability of implementing a CBTS model.

The Ministry of Health’s member on the Technical Advisory Committee championed the selection of Bobonong village in the Bobirwa Sub-District as a good pilot site for a CBTS model, as the village had a dedicated community-based organization, the Bobonong Home-Based Care Society, which had pioneered home-based care in the country.

Because Botswana already had a policy supporting community-based organizations and experience in ART provision, this enabled the development of a strong and relevant CBTS programme in Bobonong. The national AIDS and STD Unit took the lead in engaging with intergovernmental, district and local stakeholders to develop a proposal based on the agreed upon model and project components.

Through consultations between *SECURE THE FUTURE* and the government, the government’s various roles were defined to best harness its capacity and then outsource other tasks to other partners. The government committed to providing all medication for opportunistic infections and ARVs. The Ministry of Local Government opted to second its staff rather than hire new project staff. This was in order to ensure staff development and retention of experience and expertise. *SECURE THE FUTURE* funding was prioritized for human resource provision, infrastructure enhancement for Bobonong Primary Hospital and Borotsi Clinic and strengthening of the community organization. A private accounting firm, KPMG, was engaged to manage funds for the programme on the government’s behalf.



*Ministers of Health from Lesotho, South Africa, Botswana, Namibia and Swaziland with their officials at a meeting with Bristol-Myers Squibb SECURE THE FUTURE executives and personnel.*

## Develop a Business Case

To achieve this, you should:

- Conduct a baseline survey
- Set the goal
- Identify the implementing partners
- Identify all available resources
- Calculate the cost

## Conduct a Baseline Survey

The starting point for a (CBTS) programme is a baseline survey including) a situational analysis and an assessment of existing resources. A comprehensive understanding of the current situation and the existing resources will define how to adapt a CBTS model to your location. Such an assessment will define the problem and determine where existing community resources can be enhanced and strengthened and where additional resources can be leveraged to successfully address gaps in the programme.

A situational analysis defines the need and situational factors contributing to gaps in the continuum of care. Data and descriptions should be collected on the following:

- Epidemiology, including local disease summary, incidence and prevalence of HIV and other relevant diseases
- Population distribution
- Factors affecting access to health care, including geography, transportation, education and other socioeconomic factors

A resource assessment defines existing strengths that can be enhanced, united and leveraged to address the identified need. Data and descriptions should be collected on the following:

- Local health care infrastructure (including hospitals, clinics, laboratory facilities and pharmacy services)
- Health personnel in both public and private sectors (including physicians, nurses, counsellors, pharmacists and lab technicians)
- Inventory of existing community services, community-based organizations and nongovernmental organizations that provide or could potentially provide critical care and support services
- Opportunities for collaboration and sharing of activities
- Community leaders and gatekeepers who can be engaged in community mobilization and greatly assist in the reduction of stigma

Some of the data might be available in existing reports and documents—for example, the annual district health planning reports, local CBO/FBO/NGO association membership listings, etc. Other data will need to be collected during this stage.

**Tool No. 2** is a Baseline Survey checklist including situational analysis and resource assessment.

Depending on available resources, conducting a more detailed survey may be helpful. This could include the population's educational level, its knowledge of HIV and the level of stigma in the community. As an example, a questionnaire (Sexual Knowledge, Attitudes, Practices and Beliefs) to collect this information is to be found in **Tool No. 3**, and the resulting survey conducted in the Caprivi strip of Namibia is to be found in **Resource No. 2**.

### Set the Goal

Once the need has been established, it is important to set the overall goal. In a resource-limited setting, it is best to set acceptable goals without being constrained in the process by what appear to be the available resources. Resources include funds, personnel, infrastructure, community organizations and their existing skills and capacities.

However, the *SECURE THE FUTURE* sites demonstrated many times the innovative and leveraged approach of teams in these situations in finding solutions to resource constraints. The involvement of the community itself is often overlooked, but it can increase very substantially the available resources above those usually considered.

A sample goal for a CBTS programme could be the following:

*Provide both community and clinical care for ( ) patients with HIV for testing, ( ) patients with HIV for follow-up without ARVs and ( ) patients with AIDS with treatment with ARVs in the (NAME) district. Strengthen the (NAME) community's social response to the epidemic.*

### Identify the Implementing Partners

The goal outlined above will be important in the choice of implementing partners. One of the greatest challenges is selecting partners who will be compatible with the CBTS model's goal and vision. As described earlier, the CBTS model is based on a partnership between the government, the community and the private sector.

### Community Partners

The assessment of community resources will help with the identification of potential partners to provide the community-based components of care. The partners selected should be intimately familiar with the community's circumstances and needs and be well accepted by the community. Depending on the community's needs, CBOs can provide home-based care, food security interventions, PLWHA support groups, buddy programmes and income-generating activities. Some organizations may have the potential to take on more services than they currently offer, but may need increased capacity. Programme implementers should try to include such organizations and then build their capacity accordingly.

A questionnaire to assist in the evaluation of NGOs and CBOs is to be found in **Tool No. 4**.

### FIELD STORY 3 ENGAGING AND SUPPORTING COMMUNITY PARTNERS IN KATIMA MULILO, NAMIBIA

At 43%, the Caprivi Region has the highest HIV prevalence rate in Namibia. In a naming competition at the beginning of the CBTS project, the community selected Mapilelo, which means “place of survival.” The name Mapilelo has become, therefore, a potent form of branding for the project.

At least three NGOs (Africare, Namibia Red Cross Society and Social Marketing Association) and five CBOs (Caprivi Youth Development Association, Caprivi Home-Based Information Assistants, Caprivi Community Theatre Group, Lironga Eparu and Caprivi Hope for Life) were the community service partners. With the establishment of an antiretroviral clinic in the town’s hospital, these organizations were galvanized to collaborate toward a common aim.

*SECURE THE FUTURE* personnel provided guidance and assessed what resources would help create an effective collaboration between the groups. Because the region was severely poor, many of these CBOs had no or inadequate space in which to work. *SECURE THE FUTURE* funded the construction of a small complex of offices for the organizations that became known as the Mapilelo NGO Village. Each CBO has its own space, and additional rooms are available for joint meetings. The NGO village has also become a landmark in the town, partly because of its distinctive appearance.



*In Namibia, an NGO village was constructed inexpensively by employing indigenous construction techniques.*

Partnering organizations sometimes focus on their respective activities and pay limited attention to those of their partners. The CBTS programme, however, emphasizes how the implementing partners integrate and add value to each other's work as they share information about their clients' progress and needs through case management tools. For example, home-based-care workers can be alerted when a patient defaults from a clinic visit, as they are the best partners to visit the patient at home. Similarly, when the clinic nutritionist identifies a malnourished patient, the partner providing food parcels is contacted.

### Private Partners

Private physicians and traditional healers should be informed about the programme so they can refer patients as needed and appropriately treat their regular patients who are enrolled in a CBTS programme.

It is known that in many developing countries, particularly in Africa, traditional healers provide an important community service and are an integral part of its way of life. Traditional healers should be engaged in a community where ARVs will be provided. They should be able to talk to their clients about HIV and its symptoms. They should also be educated about how ARVs work, how they should be taken and what their side effects are, so that they can identify symptoms and refer community members to the clinic, when appropriate. At some CBTS programme sites, they also reinforce the importance of adherence to ARVs and of good hygiene practices to reducing infections (Peltzer).



*Traditional healers such as this South African Sangoma should be actively engaged in the community-based treatment support programme.*

### Government Partners

Although senior government officials may not always be involved in daily management of the programme, the government provides overarching policies and guidelines. Any CBTS programme should be aligned with government policies and priorities. To best engage government, meet one-on-one or in groups with key stakeholders from health, social services and other relevant government departments in order to:

- Share information on the CBTS model and its evidence base
- Formally request partnership and, if necessary, request resources

It is important to know which levels of government and agencies are appropriate for partnership based on their responsibility for the public health policies and resources, e.g. primary hospitals, district hospitals, ARV procurement, etc. Will it be a national-, regional-, district- or local level-partnership or a combination?



If there is no clear policy in the national-level AIDS plan to guide community and nongovernmental involvement in ART rollout, advocacy should be directed to policy makers. In this case, it may be effective to request or offer doing a small scale pilot and use information in this manual to support your case.

### Identify All Available Resources

Additional resources should be mobilized wherever possible to help supplement any gaps found in the assessment of available partners and other resources. Suggested approaches for filling in any gaps include the following:

- Upgrade the skills of existing personnel
- Foster innovative approaches to project design that increase productivity
- Challenge NGOs, CBOs and FBOs to take on new or additional roles
- Foster community ownership of the project and increase the number of individuals engaged
- Lobby for additional targeted funding or support from, among others:
  - Government
  - International donors and local donors
  - Local private sector

### Calculate the Cost

The costs associated with the programme obviously vary from country to country. They include both start-up costs related to the baseline survey, infrastructure upgrading and training of personnel and the running costs associated with providing the clinical and community services. **Tool No. 5** can be used to calculate budget and display the costs in a simple format. **Resource No. 3** details as an example the running costs of the STF programmes in Ladysmith, South Africa, and Katima-Mulilo, Namibia.

In the STF programme in Ladysmith, South Africa, the average annual cost per patient for community services was \$209, while the annual clinical cost was \$495. What then is the added value of the community support that justifies its additional cost?

- Better clinical outcomes as demonstrated by the STF Enhanced Patient Evaluation will translate into lower costs because of fewer opportunistic infections and better control of HIV-related symptoms.
- Lower rate of patients lost to follow-up translates into lower cost due to fewer treatment failures and, therefore, fewer complications, fewer hospitalizations and fewer patients progressing to more costly second-line therapy.
- Better adherence also translates into fewer treatment failures and lower costs.
- Other benefits which cannot be assigned monetary values, e.g., community support services, bring the patients to VCT in the first place, prepare them for ARV therapy, and sustain their psychosocial status on therapy, creating an enabling environment for living positively and openly with HIV/AIDS by reducing levels of stigma through community mobilization and education.

## Lessons Learned

- Governments can be engaged if the CBTS programme and model align with national policies and address critical challenges.
- Align to national vision and set broad goals before a detailed assessment of the available resources.
- Broadly consider the community resources that can be mobilized in a CBTS programme, including resources that have not been considered before or are not currently engaged in HIV/AIDS. For example, an effective, well-managed organization can expand its mission and scope of work to also address HIV/AIDS.
- Understand the role of various government bodies and units to ensure inclusive consultation and buy in, and determine what provisions in the national policy allow for alignment with the CBTS model.

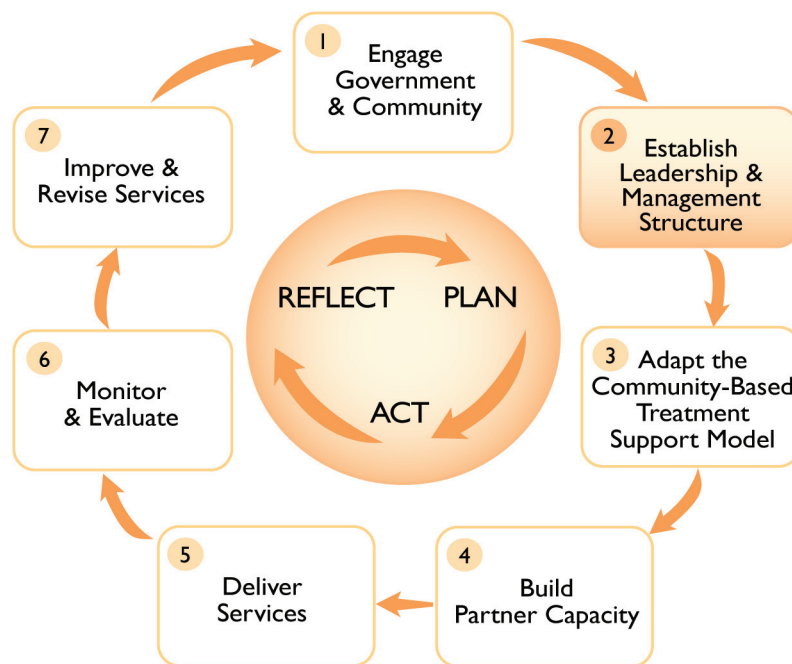
## Tools for this step

- Tool No. 1 Slide set for engaging and consulting with government and other partners
- Tool No. 2 Baseline survey checklist
- Tool No. 3 Knowledge, attitudes, practices and beliefs questionnaire
- Tool No. 4 NGO/CBO /FBO assessment questionnaire
- Tool No. 5 Budgeting tool

## Resources for this step

- Resource No. 1 Methodology and analysis used to assess impact of CBTSP
- Resource No. 2 Survey questions used in the Caprivi Region of Namibia
- Resource No. 3 Running costs of the STF programmes in Ladysmith, South Africa, and Katima-Mulilo, Namibia

## Step 2: Establish Leadership and Management Structure



This step involves creating a seamless project team that is responsible for defining and sustaining collaboration, ensuring quality service delivery and managing the programme's human, financial and technical resources. Effective management of the partners and implementation of the model are best ensured by the appointment of a strong and experienced project manager at each site. In addition to the project manager, the basic management team should include a community services leader and a clinical leader.

### Objectives

- Select an experienced project manager
- Develop a project charter that specifies the management structure for the programme, objectives and deliverables

### Expected Outcomes

- Identification of a project manager
- Development of a project charter

### Identification of a Project Manager

The project manager leads the team and should be selected prior to holding adaptation workshops and exercises. Consider selecting among those working in HIV/AIDS and other social service fields who successfully serve populations difficult to reach and engage. It does not matter if the project manager comes from government, from the community or from an outside consulting firm—it is essential only that the project manager treat all partners equally and be qualified and be experienced in project management.

## Profile of an Effective Project Manager

Required skills and experience:

- Strong leadership and governance experience
- Establishing solid policies
- Assigning roles
- Creating incentives
- Ensuring accountability
- Hiring and motivating staff
- Ensuring outstanding staff performance

Primary tasks for the project manager will include:

- Bringing diverse stakeholders together
- Managing project resources efficiently
- Keeping partners focused on program goals and objectives
- Working efficiently with governments, the business sector and community organizations
- Remaining focused on overall project outcomes



*The high-performance team – The Bobirwa ARV Project team members, Botswana, display their awards for being an efficient and effective team.*

An example of a project manager job description and employment contract are found in **Tool No. 6**.

#### FIELD STORY 4 EFFECTIVE PROJECT MANAGERS AT THE FOUR SITES

**Bobonong, Botswana:** Because a strong manager was not identified at an early stage in Bobonong, the CBTS programme initially experienced multiple difficulties and delays in implementation. Approximately six months into the project, a skilled project manager was found, but by this time the goodwill and momentum between partners had decreased. The project manager had to go back to the stages of advocating for the project and igniting the partnership and collaboration. Although she confronted great challenges, she recruited qualified and compatible personnel, revised and clarified roles and responsibilities and built an impressive team spirit among all the stakeholders. Soon thereafter, the team became a cohesive unit and the project made up the time it had lost. The team was awarded the *SECURE THE FUTURE* prize for superior performance at a special awards event in November 2006.

**Maseru, Lesotho:** The project management came from the government. A key doctor with the Ministry of Health was seconded from her post as director of the Disease Control Unit of the national Ministry of Health and Social Welfare to head the programme. Although a clinician herself, she allowed the physicians working in the clinic to take the lead on purely clinical matters. As project manager, she focused on planning, management, documentation, administration, stakeholder management and advocating for the programme. She also listened to stakeholders, resolved conflicts and took responsibility for decisions that impacted several different stakeholders.

**Mbabane, Swaziland:** The government made its own selection for programme management and chose an NGO, the Swaziland Infant Nutrition Action Network (SINAN), which was well established and respected for project management skills and office infrastructure.

**Katima-Mulilo, Namibia:** The project management was outsourced to a private consultancy firm, New Dimensions Consulting. As their offices were in Windhoek—a three-hour flight from the site in Katima-Mulilo—they appointed a project manager based in the Caprivi Region who visited very often, and their active involvement in the project was always felt by the community. This management structure also succeeded in providing both supervision and a voice for the rather large number of community organizations involved in the programme.

## Development of a Project Charter

A project charter is a management tool that articulates the project vision, objectives and scope, as well as the responsibilities of the partners. It describes how the partnership will function, communicate, monitor its progress and report to stakeholders. An example of such a charter is to be found in **Resource No. 4**.

The contents of the charter should include:

- Project goals, vision and objectives
- Project management structure
- Roles, responsibilities and reporting commitments of the partners

The goals and vision have been stated during the development of the business, and the objectives will flow from them.

The project management structure is best determined in a participatory fashion. *SECURE THE FUTURE* found it effective for the project manager to introduce a management structure proposal at one of the workshops to adapt the CBTS model. Broad discussion of the plan by the stakeholders helps to ensure common ownership and compliance. The resulting management structure should specify the roles and reporting relationships between partners. It should also specify how partners will monitor progress and their reporting responsibilities to stakeholders.

The project manager should have sufficient authority to carry out the job effectively. Project managers can also rely on governance boards and management committees composed of local leaders and government representatives for strategic advice and support. These bodies can play an important role in building government and community support for the programme, but they should not be involved in daily management of the project. The project manager might consider developing small technical groups for each major function (e.g., clinic, community services and finance), which in turn form a larger technical working group for decisions on cross-functional activities. Technical working groups can be established to supervise daily activities.

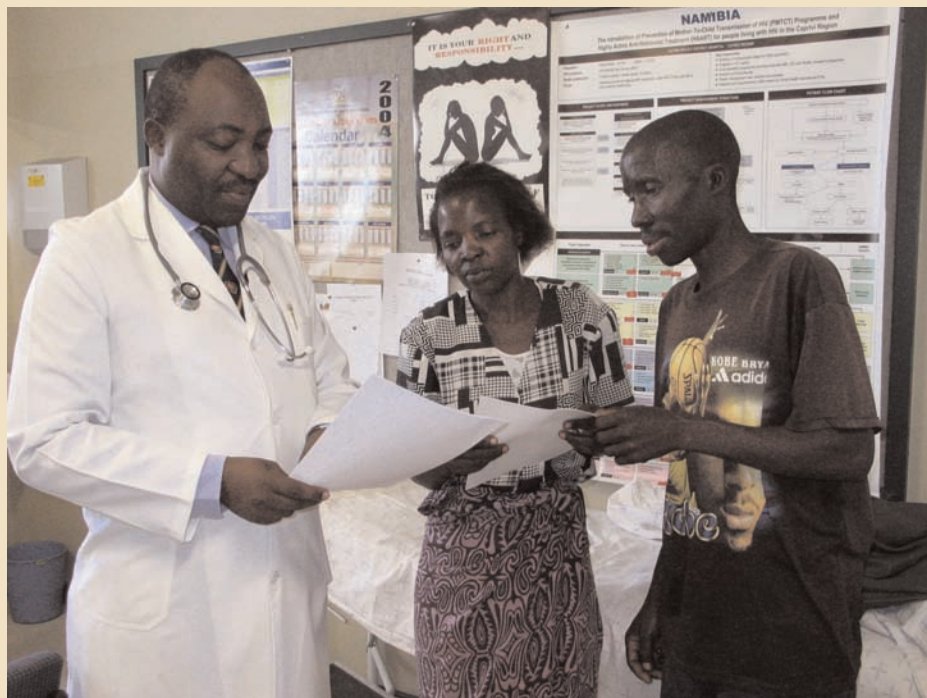
An example of a project management structure from the Senkatana project in Lesotho is explained and shown after Field Story 5 and Figure 3. Note that both direct authority and administrative reporting relationships are detailed.

A series of tools to assist project managers and other project staff are to be found in **Tool No. 7, Tool No. 8, Tool No. 9 and Tool No. 10**.

## FIELD STORY 5 MANAGEMENT TECHNIQUES USED IN LESOTHO AND NAMIBIA

In Lesotho, an Implementers' Forum was created to give a wide range of team members a role in managing the programme. The forum, which meets monthly, provides managers and service providers with a common venue for sharing achievements and resolving problems. All of the key project implementers participate in the forum, including people involved in project management, clinical and community-service providers and people living with HIV/AIDS. The management structure of the site in Lesotho, as shown in Figure 3, had clear roles and assignment of roles.

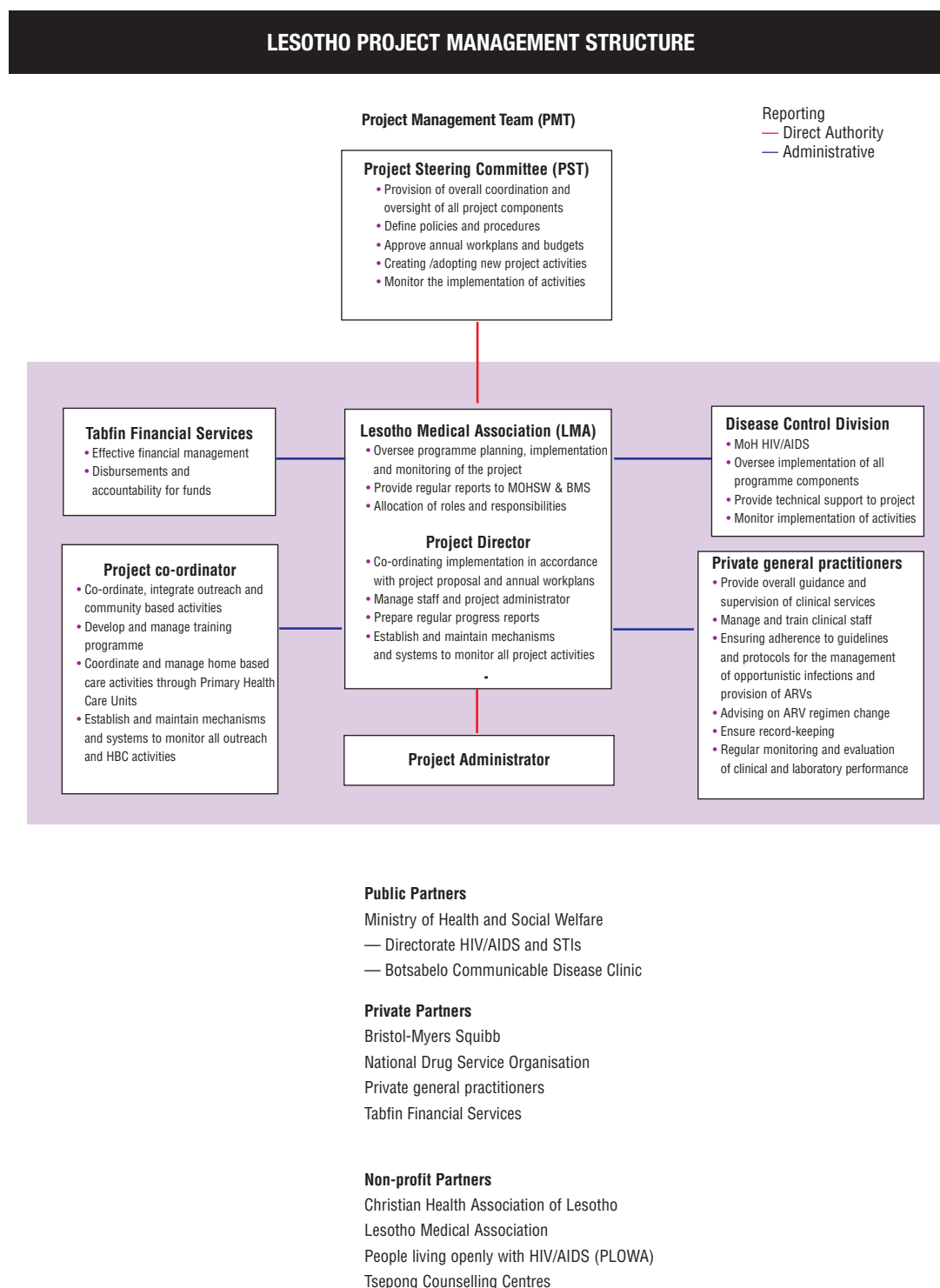
In Namibia, the project team integrated its project with a government structure called the Caprivi Regional AIDS Co-ordinating Committee, which is part of the national AIDS strategy and response. The Caprivi committee and district health teams became key members of the project's management committee and provided policy guidance and alignment with national guidelines.



*Staying close to beneficiaries, Dr. Zengani Chirwa, Mapilelo Chief Medical Officer, and co-chair Caprivi RACOC, consults with his clients Helen and Calvin Myomellow.*



FIGURE 3 MANAGEMENT STRUCTURE AT THE SENKATANA CENTRE IN LESOTHO



Facilitated and funded by the Bristol-Myers Squibb's Secure the Future™ Programme

### Lessons Learned

- Identify a strong project manager trained in project management early in the planning stage and assign that person adequate authority
- Establish a management structure with clear roles, responsibilities and reporting relationships through collaborative and transparent workshops
- Place equal importance on the role of all partners

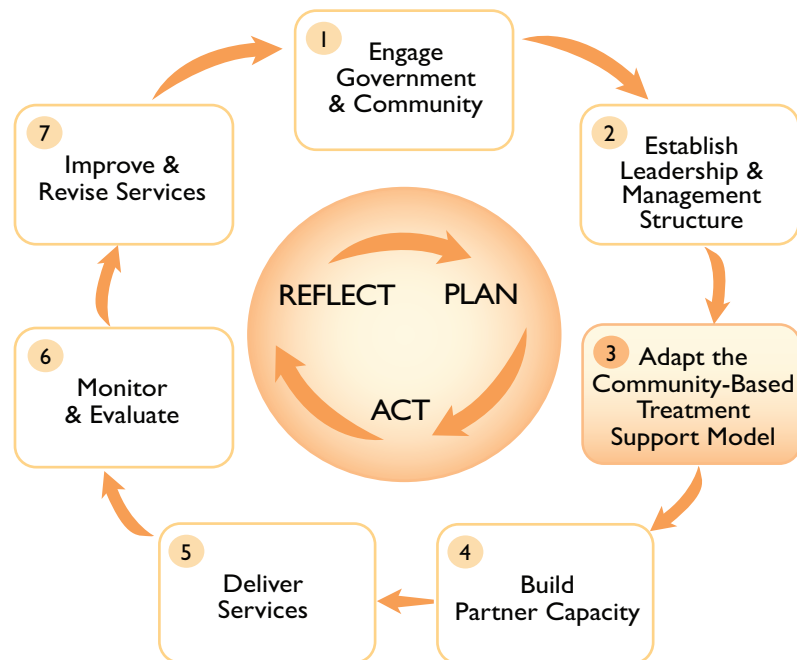
### Tools for this step

- Tool No. 6 Extract from project manager employment contract
- Tool No. 7 Site visit checklist and report
- Tool No. 8 Monthly progress report to all partners
- Tool No. 9 Change request form
- Tool No. 10 Risk management template

### Resource for this step

- Resource No. 4 Sample project charter

### Step 3: Adapt Community-Based Treatment Support Model



This section describes how to adapt the model to a community in terms of the clinical and community services that will be offered and how they will be integrated to create a continuum of care for people living with HIV/AIDS.

#### Objectives

- Identify clinical sites
- Define which clinical and community services to offer
- Identify community-based organizations to offer the services
- Map referral points and patient flow
- Establish a patient documentation system
- Develop an implementation plan

#### Expected Outcomes

- Clinical site selection
- Community services selection
- Map of patient flow
- Patient documentation system
- Implementation plan

## Clinical Site Selection

Clinical services for patients with HIV/AIDS in resource-limited settings can be organized in several ways depending on the resources available, the geography of the catchment area and the degree of stigma in the community. Decisions about this organization may be currently determined by the government as part of a rollout plan, and thus your project may not have flexibility in this area. Since transportation is often a big issue, having more than one site makes it much easier for people to access the services they greatly need. Therefore, some communities may choose to create decentralized services, and this also decreases the burden on one single facility.

### District Hospital

It is probably easiest to initiate and focus service delivery at the district hospital level. Such a clinic is usually located relatively close to other critical hospital services, including in-patient care, surgical care and pharmacy and laboratory services. The clinic can be dedicated solely to HIV/AIDS or jointly provide HIV/AIDS services and other relevant services, such as TB services, care for other sexually transmitted diseases or family planning.

A dedicated clinic enjoys the benefit of focused staff and services. This is probably preferable in areas with a high HIV prevalence because of the large number of patients who will access the services. However, at the same time, this can create a greater risk of stigma because a patient visiting that clinic is identifiable to observers and potentially others who know the patient's identity. Coordinated community mobilization and disease education efforts provided by the CBTS programme can help reduce such stigma.

### General Out-Patient Department (OPD)

HIV/AIDS patients can also receive care in a general out-patient department (OPD). This was not feasible at the model CBTSP sites because focused services for large numbers of patients were required. But in the long term, integration of HIV/AIDS services into regular OPD services will “regularize” the disease and help reduce stigma.

### Primary Health Centre Linked to Central District Hospital

Large, heavily populated catchment areas encompassing remote villages are best served by a network of primary health centres linked to a central district hospital. In that way, patients do not have to travel long distances to a hospital, which is a barrier to care and a disincentive for many patients. Decentralization of services to primary health centres also reduces the burden on the hospital clinic. For example, if there are large numbers of patients, some communities may choose primary health centres to do screening, and the district hospital to treat patients.

However, depending on the resources and personnel available at the centre, services provided at a primary health centre may be less comprehensive or specialized than those at a district hospital.

Key issues to be aware of in relation to the location of clinical services are summarized in Table 1.

TABLE 1 ADVANTAGES AND DISADVANTAGES OF DIFFERENT CLINICAL SITES

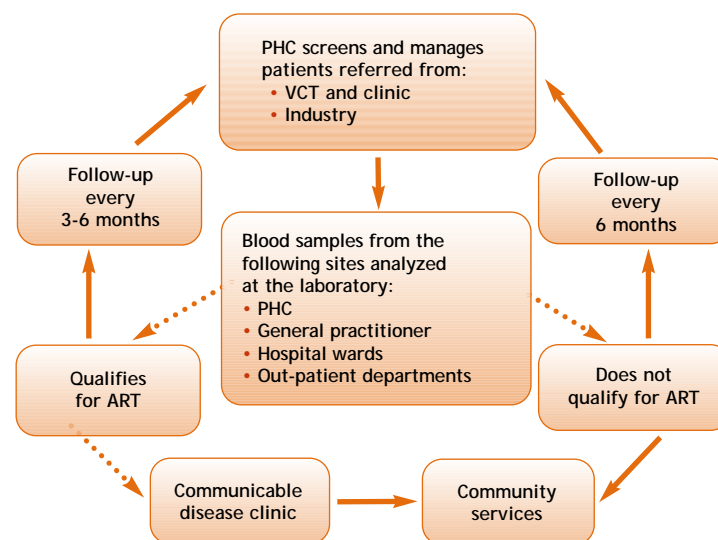
Type of facility	Advantages	Disadvantages
District hospital	<p>Can be dedicated solely to HIV/AIDS or jointly provide HIV/AIDS and other relevant services—TB treatment, sexually transmitted disease treatment or family planning</p> <p>Usually located close to other critical hospital services, including in-patient care, surgical care, pharmacy and laboratory services</p>	<p>Can create a greater risk of stigma for a patient, who is identifiable to observers and potentially others who know the patient's identity.</p> <p>Depending on geography, patients may have to travel long distances to site</p>
General out-patient department	Regularizes the disease and thus reduces the associated stigma	Services not focused and personnel not so specialized in HIV
Primary health clinic linked to district hospital	Close to patients and thus minimizes transport issues	Less comprehensive and less specialized

### Decentralized Service

Decentralization of services is necessary for scale-up HIV/AIDS services, and STF recommends that it be introduced in a gradual manner. Essentially, it is an orderly process of transferring select tasks that are delivered initially at the district hospital to the primary health centres. For example, primary health centres may be used for VCT, the staging of the disease and drawing of blood for CD4 counts. The blood sample is submitted to a central laboratory for analysis (although developments in the technology of CD4 measurement may allow this to be done easily at peripheral sites in the future). Patients qualifying for ARV therapy can then be referred to a secondary health facility for medication and continued laboratory and clinical monitoring. All HIV-positive patients not initially requiring ARVs can also be followed up at the primary health centres until their disease has progressed to a point where ARV therapy is indicated. The primary health centres can begin to care for patients on ARVs as they gain experience and confidence, their pharmacy services develop to the point where they can begin dispensing ARVs, and health authorities gain experience with and develop specific policies for less specialized personnel caring for HIV/AIDS patients.

Figure 4 shows the process of decentralized patient flow after implementation of the model.

FIGURE 4 DECENTRALIZED PATIENT FLOW



Services provided at the primary health centre may be less comprehensive or less specialized than those at the district hospital. This depends on the resources and personnel available at the primary health centre and health authorities' willingness to decentralize and permit less expert personnel to care for HIV/AIDS patients. The exclusive approach often taken toward HIV/AIDS has meant that in many locations even today, only expert personnel can prescribe ARV treatment.

## Define which clinical and community services to offer

### Clinical Service Selection

Clinical services delivered in the CBTS programme include diagnosis, disease monitoring, clinical management including antiretroviral treatment, PMTCT, pharmacy and laboratory services. A description of each of these clinical services is beyond the scope of this manual, because clinical care is determined largely by national guidelines.

### Community Services Selection

In the creation of the CBTS model, the added value of the community services was intuitively understood by SECURE THE FUTURE staff at the outset. Definitive data on the relative value of various services were collected through an Enhanced Patient Evaluation study conducted from 2004 through 2006. The data showed that some community services were accessed by more patients than others (e.g., home-based care, which was accessed by 55%). The study also determined that some services contributed to a better clinical outcome than others such as food security and home-based care.

#### Key Finding: Most-accessed community services

Through experience implementing the model in resource-limited settings in rural Africa, the CBTS site found that the three community services that are most useful and most frequently accessed by patients are:

- Home-based care
- Food security
- Patient support groups

This does not mean, however, that others are not valuable to particular patients or that a particular location may dictate differently. For example, some otherwise very resource-limited settings may have an abundance of readily available food (e.g., rural Thailand) so that food security programmes are not necessary. The enhanced evaluation shows, however, in general in rural Africa, the three most important and impactful community services to support ARV therapy programmes are home-based care, food security and patient support groups.



**TABLE 2 CRITERIA FOR CHOOSING COMMUNITY SERVICES**

Community Support Service	Targeted Outcomes	Activities	Required Resources
Mobilization	<ul style="list-style-type: none"> <li>• Increase community awareness of/access to: <ul style="list-style-type: none"> <li>• HIV/TB/STI facts</li> <li>• Prevention methods</li> <li>• Care services</li> <li>• Treatment</li> </ul> </li> <li>• Increase community involvement and ownership</li> <li>• Reduce stigma</li> <li>• Increase VCT uptake</li> </ul>	<ul style="list-style-type: none"> <li>• Large or small community events</li> <li>• Media campaigns</li> <li>• Project-launching events</li> </ul>	<ul style="list-style-type: none"> <li>• Community leaders</li> <li>• Community participation</li> <li>• Accessible venue</li> <li>• Catering</li> <li>• Distribution materials</li> <li>• Advertisement</li> </ul> <p>Cost: Mid-range Reach: Large groups Impact: High</p>
Prevention and Education Outreach	<ul style="list-style-type: none"> <li>• Minimize new infections</li> <li>• Increase VCT uptake</li> <li>• Reduce stigma</li> <li>• Increase behavior change</li> <li>• Increase access to condoms</li> </ul>	<ul style="list-style-type: none"> <li>• Community events</li> <li>• Education workshops</li> <li>• Youth events</li> <li>• Distribution of health literature</li> <li>• Distribution of condoms</li> <li>• Media campaigns</li> </ul>	<ul style="list-style-type: none"> <li>• Outreach strategies</li> <li>• Distribution materials</li> <li>• Well-developed messages</li> <li>• Accessible venue</li> <li>• Access to media</li> </ul> <p>Cost: Mid-range to high Reach: Broad reach Impact: High</p>
VCT	<ul style="list-style-type: none"> <li>• Individual awareness of HIV status</li> <li>• Reduction of stigma</li> <li>• Increased health education</li> <li>• Increased patient ownership of health</li> <li>• ARV education/awareness</li> <li>• Increased ARV adherence</li> </ul>	<ul style="list-style-type: none"> <li>• Counselling of patients and families</li> <li>• Pre- and post-test counselling</li> <li>• Testing</li> <li>• Risk management counselling</li> <li>• Treatment &amp; adherence counselling</li> <li>• Ongoing psychosocial support</li> </ul>	<ul style="list-style-type: none"> <li>• Training</li> <li>• Counsellors</li> <li>• Remuneration system</li> <li>• Referral system</li> <li>• Testing facilities and materials</li> <li>• Accessible venue</li> </ul> <p>Cost: Mid-range Reach: Potential large reach Impact: High</p>
Home-Based Care	<ul style="list-style-type: none"> <li>• Increase patient well-being</li> <li>• Increase adherence</li> <li>• Minimize defaulter rate</li> <li>• Improve symptom management</li> <li>• Increase health education</li> <li>• Increase community knowledge of prevention, care and treatment services</li> </ul>	<ul style="list-style-type: none"> <li>• Health and social service referrals</li> <li>• Adherence counselling</li> <li>• Management of opportunistic infections &amp; side effects</li> <li>• Assistance returning to full and rewarding lifestyle</li> <li>• Advice on growing food gardens</li> <li>• Ongoing psychosocial support</li> </ul>	<ul style="list-style-type: none"> <li>• Interested community members</li> <li>• Intensive training</li> <li>• Basic health care materials</li> <li>• Referral systems</li> <li>• Remuneration systems</li> <li>• Monitoring systems</li> </ul> <p>Cost: High Reach: Potential large reach Impact: High</p>

Community Support Service	Targeted Outcomes	Activities	Required Resources
Food Security	<ul style="list-style-type: none"> <li>• Increase individual response to treatment</li> <li>• Increase adherence</li> <li>• Increase self-sufficiency</li> </ul>	<ul style="list-style-type: none"> <li>• Nutritional assessment</li> <li>• Short-term food parcels</li> <li>• Training in gardening and animal husbandry</li> <li>• Nutritional education, including selection and preparation of food</li> </ul>	<ul style="list-style-type: none"> <li>• Trained nutritionist</li> <li>• Consistent supply of food parcels</li> <li>• Transportation of goods</li> <li>• Trainers</li> <li>• Training venues</li> <li>• Gardening materials</li> </ul> <p>Cost: High Reach: Targets most needed Impact: High</p>
Support Groups	<ul style="list-style-type: none"> <li>• Increase patient well-being</li> <li>• Increase adherence</li> <li>• Minimize defaulter rate</li> <li>• Reduce stigma</li> <li>• Increase health education</li> </ul>	<ul style="list-style-type: none"> <li>• Weekly group meetings for PLWHA</li> <li>• Discussions of coping skills for challenges</li> <li>• Positive-living activities</li> <li>• Participation in IGAs</li> </ul>	<ul style="list-style-type: none"> <li>• Trained leader</li> <li>• Meeting venue</li> </ul> <p>Cost: Low Reach: Potentially large Impact: High</p>
Positive-Living Workshops	<ul style="list-style-type: none"> <li>• Increase patient well-being</li> <li>• Increase adherence</li> <li>• Increase knowledge, skills, competencies to limit transmission and impact</li> <li>• Reduce stigma</li> <li>• Increase behavior change</li> </ul>	<ul style="list-style-type: none"> <li>• Targeted community workshops on HIV facts, treatment literacy, nutrition etc.</li> <li>• Skills-building workshops in coping mechanisms and life skills</li> </ul>	<ul style="list-style-type: none"> <li>• Trained facilitator</li> <li>• Community participation</li> <li>• Accessible venue</li> <li>• Catering</li> </ul> <p>Cost: Low Reach: Potentially large Impact: High</p>
Buddy Programme	<ul style="list-style-type: none"> <li>• Increase adherence</li> <li>• Minimize defaulter rate</li> <li>• Increase patient well-being</li> <li>• Improved symptom management</li> </ul>	<ul style="list-style-type: none"> <li>• Ongoing psychosocial support</li> <li>• Information on HIV/AIDS</li> <li>• Guidance in recognizing symptoms of HIV progression</li> <li>• Assistance in managing opportunistic infections and medication side effects</li> <li>• Assistance adhering to ART</li> </ul>	<ul style="list-style-type: none"> <li>• PLWHA openly and positively</li> <li>• Intensive training in counselling</li> <li>• Remuneration system</li> <li>• Labor-intensive</li> <li>• Referral systems between clinics and buddies</li> </ul> <p>Cost: High Reach: Low/difficult to offer to all Impact: High</p>

Community Support Service	Targeted Outcomes	Activities	Required Resources
Income-Generating Activities	<ul style="list-style-type: none"> <li>• Increase patient well-being</li> <li>• Increase community-based responses</li> <li>• Increase patient ownership over health and well-being</li> <li>• Provide forum for ongoing psychosocial support</li> </ul>	<ul style="list-style-type: none"> <li>• Forming cooperatives</li> <li>• Identifying markets</li> <li>• Identifying existing skills</li> <li>• Skills training in craft, catering, agriculture etc.</li> <li>• Skills training in small business</li> <li>• Group discussion about positive living, health care access, nutrition, psychosocial support</li> </ul>	<ul style="list-style-type: none"> <li>• Community participation</li> <li>• Facilitators</li> <li>• Training</li> <li>• Ongoing mentoring</li> <li>• Access to start-up capital</li> </ul> <p>Cost: Mid-range to high Reach: Low/difficult to offer to all Impact: Mid-range</p>
Patient Tracing	<ul style="list-style-type: none"> <li>• Minimize defaulter rate</li> </ul>	<ul style="list-style-type: none"> <li>• Community-based tracing of treatment defaulters</li> </ul>	<ul style="list-style-type: none"> <li>• Referral systems</li> <li>• Community health workers</li> <li>• Confidentiality agreements</li> <li>• Transportation</li> <li>• Training</li> </ul> <p>Cost: Low Reach: Low Impact: High</p>
Care for Orphans and Vulnerable Children	<ul style="list-style-type: none"> <li>• Minimize impact of HIV on most vulnerable population affected by HIV</li> <li>• Mobilize community-based responses</li> <li>• Increase patient well-being</li> <li>• Minimize new infections</li> <li>• Increase health education for youth</li> </ul>	<ul style="list-style-type: none"> <li>• Nutritional support, including feeding schemes and gardening projects</li> <li>• Life skills training</li> <li>• Grief counselling</li> <li>• Assistance with access to: <ul style="list-style-type: none"> <li>• Education</li> <li>• Health care</li> <li>• Identification documents</li> <li>• Government grants</li> <li>• Child advocacy</li> <li>• Child support forums</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Community participation</li> <li>• Food</li> <li>• Care venues</li> <li>• Trained child minders</li> <li>• Remuneration systems</li> <li>• Social workers</li> <li>• Referral systems</li> </ul> <p>Cost: High Reach: Potentially large Impact: High</p>

### Identify Community-Based Organizations to Offer the Services

Once the community services to be offered have been determined, it is important to conduct an assessment of community organizations that could provide such services. These organizations are usually well-known in the communities where they operate, but some organizations may not be providing all the services they can or may require capacity building to do so. In choosing community groups to participate in a CBTS programme, be sure to rationalize these groups' activities, avoid duplication and provide an avenue for them to collaborate.

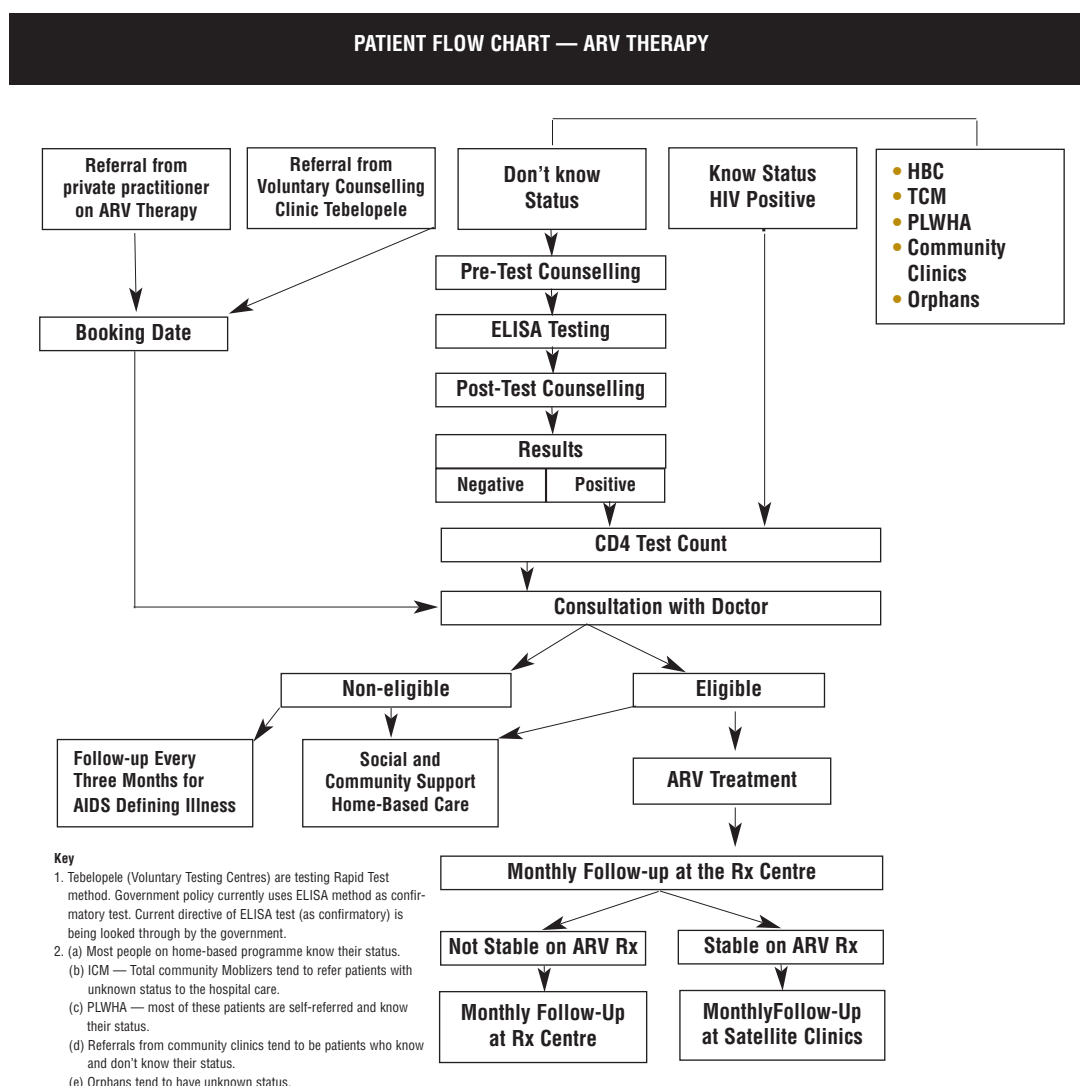
### Map Referral Points and Patient Flow

Developing a clear, detailed diagram of how patients will navigate the continuum of care and be referred between the clinical and community services was one of the most crucial exercises in the design of an effective programme and allocation of resources and personnel. A patient flow diagram should be constructed with input from all stakeholders. Inclusion of patients and family members in this process will help ensure that the proposed flow is patient friendly, and engagement of other stakeholders will help guarantee the system is as effective and efficient as possible. Establishing patient flow between clinical and community services reinforces the crucial linkages between the two and helps create the necessary formal referral processes. Patient flow should be reassessed and adjusted over time as part of an ongoing process of quality assurance and control.

*SECURE THE FUTURE* found that the best way to determine the optimal patient flow is to organize a workshop in which all stakeholders in the patient flow process are invited to participate. The project manager should play a central role in facilitating the workshop and provide the broad perspective of the overall programme. At the workshop, individual groups can be asked to diagram the patient flow into and out of their component (e.g., flow through the pharmacy). All the participants can then collectively examine the Big Picture. As indicated above, the process of defining patient flow also identifies points where referral mechanisms are required. Therefore, this workshop can produce a comprehensive picture of the referral system and the accompanying necessary documentation. A guide to facilitate the workshop on developing a map of patient flow is to be found in **Tool No. 11**.

The resulting patient flow at the STF-funded site in Bobonong, Botswana, is shown in Figure 5.

FIGURE 5 EXAMPLE OF PATIENT FLOW FROM BOBONONG, BOTSWANA



## Establish a Patient Documentation System

Documentation of each patient's history and progress is an essential programme component. The specific method of documentation will depend on local and national requirements. An example of a comprehensive form used to collect such information is shown in **Tool No. 12**. For a CBTS programme, the documentation should ideally include not only clinical data, but information on referrals to and from community services. It then becomes a master record, kept at the clinic and available to both clinical and community personnel, although care must be taken to ensure patient confidentiality.

Referrals from the community to the clinic are as important as those from the clinic to the community. Community workers can raise awareness, mobilize clients to access VCT and treatment, refer patients on ARVs back to the clinic if problems are detected and, perhaps most importantly, trace patients who miss a clinic appointment and reengage them.

## Develop a Implementation Plan

At this stage, the project manager should assume overall responsibility for facilitating the development of an implementation plan in consultation with all the partners. The plan includes the following:

- Prioritized clinical and community services
- Clear objectives for each service
- Major action strategies to address the objectives for each service
- Timeline for implementing the services
- Definitions of the planning partners and their roles
- Estimates of the programme costs and funding sources
- Overall achievement targets, including aggregate indicators (or benchmarks) and how they will be measured (see Step 6 for a more detailed discussion of this task)
- Referral systems
- Roles and responsibilities and communication platforms

**Tool No. 13** provides a template for an implementation plan.

The technical working groups should try to manage activities pursuant to the plan, making sure that they are properly resourced and progressing on time. Significant deviations from the plan can be addressed and managed through an Implementers' Forum or a similar team.

## Communication and Documentation Processes

The implementation plan should also include the processes for communication and documentation for the project. Such processes could include the following:

- Learning and sharing session either electronically, in written reports or during local and national meetings
- Monthly reports to all partners
- Monthly programme teleconferences if covering a wide geographical area
- Quarterly reports to governments, donors and community leaders

Projects initiated as pilots should document their processes, outcomes and lessons because this will be important when they report back and want to advocate for new policies and additional resources that would allow the programme to be scaled up or replicated.

An example of a monthly report to all partners is to be found in **Resource No. 5**.

### Lessons Learned

- One size does not fit all. The configuration of clinical services must match the geography and the needs of the patient population targeted.
- Decentralization of services to primary health centres brings services closer to patients and reduces the burden on hospital clinics.
- Not all the community services may be needed. Choose the ones that will have the greatest impact because they address a gap or strengthen currently impactful services.
- Establish a clear patient flow and referral points. Once the patient flow is defined, everything else will fall into place.
- Include all stakeholders in the workshop where the patient flow is established.

### Tools for this step

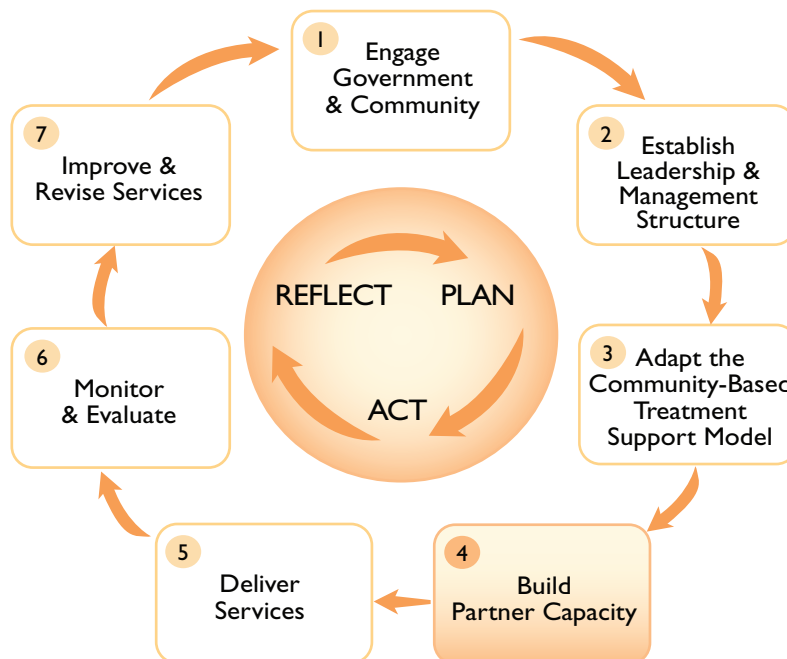
- Tool No. 11 Guide to facilitating a workshop on developing a map of patient flow
- Tool No. 12 Client documentation form
- Tool No. 13 Project implementation plan

### Resource for this step

- Resource No. 5 Monthly status report



## Step 4 Build Partner Capacity



*Capacity building* refers to strategies in which human resources and operational capabilities of organizations are created or improved to perform services better. In the case of the CBTS model, it also refers to preparing partners to integrate their individual services with others and work well together as a team. The overall purpose of capacity building is to ensure effective design, implementation, coordination, management, service delivery and evaluation of the programme.

### Objectives

- Train and build capacity of partners to deliver services and partnership tasks dictated by the shared goals of the project
- Build capacity of physical facilities to adequately deliver clinical services
- Train and prepare partners to integrate their services with one another

### Expected Outcome

- Partner capacity built for effective execution of the implementation plan

### Build Partner Capacity

Bringing diverse organizations together successfully as implementing partners will require capacity building for clinical staff, private physicians and traditional healers, and community organizations both prior to the launch and throughout the programme. In communities where ARVs have not been available previously, training on many aspects of therapy initiation, management and follow-up care is essential. Training and capacity building

opportunities should be presented as both a strict requirement for the program and supportive of the professional development of individual implementers.

### **CBTS Model**

The full cadre of implementers should be educated about the CBTS model so that they can become acquainted with and motivated by its effectiveness and see how their individual contribution fits into a larger continuum of patient care. **Tool No. 1** can be used for this purpose.

### **Human Capacity**

There are many excellent and well-accepted tools and resources for capacity building to provide ART that have been developed by local and national public health agencies as well as major technical assistance and donor programmes like the WHO's 3 by 5 initiative and PEPFAR. The STF sites used a combination of resources.

A series of resources designed to facilitate such capacity building is featured at the end of this section. Particularly broadly used is **Resource No. 6**, an HIV/AIDS curriculum designed by Baylor College of Medicine which is adaptable for all cadres of personnel whether providing clinical or community services. Also STF found **Tool No. 14** on site readiness created by John Snow, Inc. to be a very useful tool for assessing capacity building needs and progress against site preparedness milestones.

### **Physical Infrastructure**

It is also imperative to build the capacity of the physical infrastructure in which the CBTS model will be implemented. If the community doesn't have a facility for ARV treatment, then the groups need to select a site and work with funders on helping to refurbish facilities. For example, in Lesotho, the team selected the site of a government leprosy hospital that was in decline, and *SECURE THE FUTURE* and the World Bank provided funding to refurbish the facilities for the community. In Namibia, funders helped create a low-cost NGO village made of indigenous materials to allow the numerous implementing partners to work together in close proximity to one another.

### **Training for Community Service Delivery**

Capacity building and specific skills training should be provided to all the organizations providing community services. Training for high impact services of home-based care and the buddy programme are described below as examples as they were heavily used by the CBTS programmes.

### **Home-Based Care**

Home-based care is defined as the care given to individuals in their own natural environment (i.e., their home), by their families, supported by skilled social welfare officers and communities to meet their spiritual, material and psychosocial needs, with the client herself or himself also playing a crucial role.

Caregivers should complete a home-based care training course. Volunteers are also recruited and trained to complement the work of caregivers. They perform many

functions, including serving as companions, picking up medications, running errands, and assisting with the care of opportunistic infections, adherence to ARV therapy and management of ARV related side effects.

The basic elements of training are as follows;

- Knowledge of HIV/AIDS, its transmission and prevention
- Myths and misconceptions
- Impact on patient, family, community and economy
- VCT and access to care and treatment
- ARV therapy and adherence counselling
- Management of the chronically ill patient
- Management of common symptoms
- Management of ARV side effects
- Nutritional support
- Psychological and spiritual support
- Helping the recovering patient on ARV therapy reengage fully in life
- Care of the dying
- Management of grief

A manual on HBC training created by the Mpilonhle Project can be found in **Resource No. 8**.

### **Buddies**

The buddy concept is a simple but effective way of providing intensive, individualized support to patients. It entails pairing a newly-diagnosed patient with a trained person who is typically also HIV-positive and helps the patient cope with their disease. Most experienced buddies can support up to four clients at a time.

Buddies must be trained to be effective. An NGO based in Botswana called COCEPWA conducted the training at the STF sites. The training modules for the buddies can be found in Resource No. 9. Buddies do need to be carefully trained as they must protect the confidentiality of their clients, adhere to their time commitments to clients and comply with the policies and procedures outlined during their training.

### **Lessons Learned**

- Training is necessary for CBTSP operation and supportive of professional development of the individual implementers.
- Training to understand the CBTS concept itself is necessary.
- Capacity building is not just about training, but can be facilitated by providing appropriate, sometimes innovative upgrades or modifications to workplaces and other physical structures.

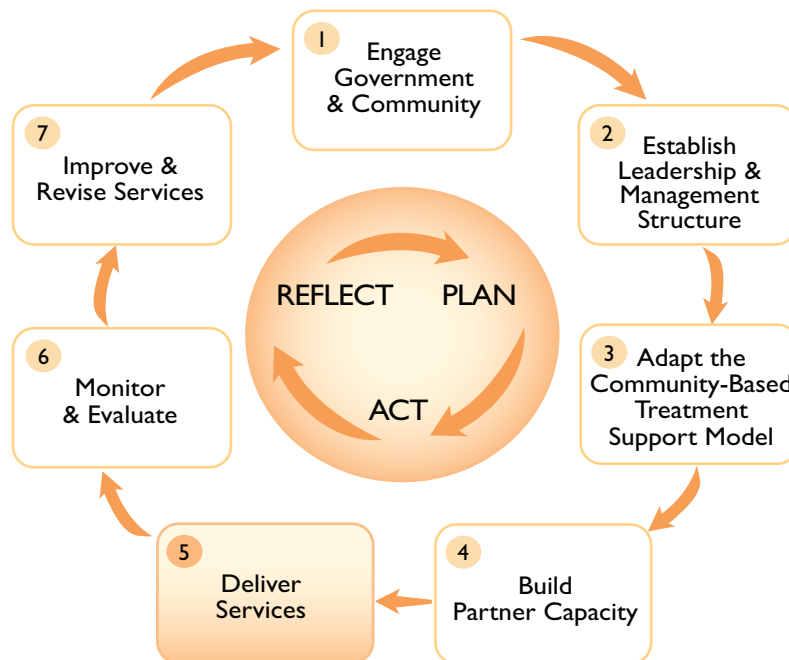
### **Tools for this step**

- Tool No. 1 Slide set for engaging and consulting with government and other partners
- Tool No. 14 Site readiness assessment (John Snow, Inc.)

### Resources for this step

- Resource No. 6 HIV/AIDS Curriculum for the Health Professional (BIPAI/Baylor College of Medicine)
- Resource No. 7 Training curriculum for traditional birth attendants on ARVs (Department of Health, Republic of South Africa)
- Resource No. 8 Training curriculum for home-based care (Mpilonhle Project)
- Resource No. 9 Training curriculum for training treatment “buddies” (COCEPWA)
- Resource No. 10 Training curriculum for community educators (PORECO Project)
- Resource No. 11 Training curriculum in project management

## Step 5: Deliver Services



This step involves putting the programme into action by mobilizing the community, and launching and delivering clinical 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, in other cases community services integrated with ART
- Deliver high quality, accessible and integrated clinical and community services to the targeted numbers of patients
- Track and retain patients in the programme
- Prepare patients who have been prescribed ARVs
- Support patients not yet clinically eligible for ARVs

### Expected Outcomes

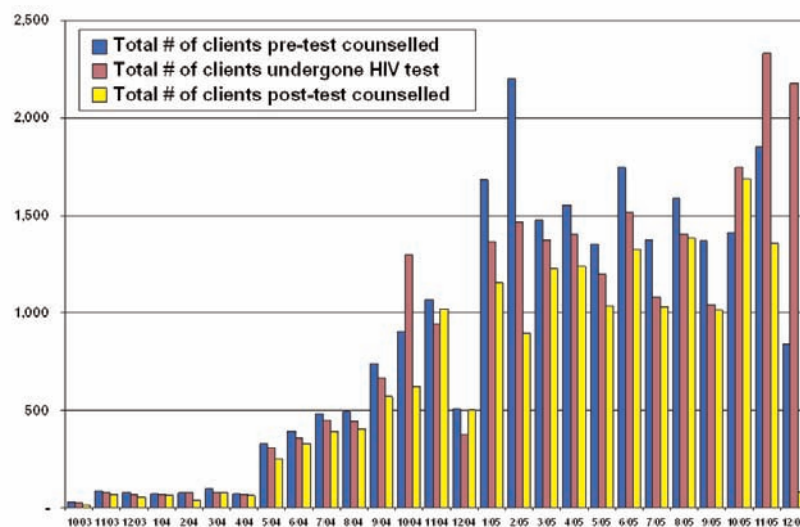
- Community mobilized around HIV/AIDS and the new CBTS programme
- Effective delivery of clinical services
- Effective delivery of community services
- Effective linkage between clinical and community services

### Mobilize Community

Just prior to a CBTS programme and on an ongoing basis, it is critical to mobilize the community to access the enhanced HIV/AIDS services. 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 are often afraid to seek medical care.

Community mobilization is critical to transforming an environment in which HIV-infected and -affected people are ostracized and stigmatized by other community members into one that is nurturing and conducive to positive behaviour change. Community mobilization encourages community members to come forward for testing and treatment. For example, only about 100 patients per month accessed VCT services at the five STF sites in southern Africa prior to community mobilization and establishment of clinics. This increased rapidly after mobilization began in early 2004, and reached more than 1,000 per month in three to six months as illustrated in Figure 6 below.

FIGURE 6 INCREASE IN VCT ACCESS AFTER COMMUNITY MOBILIZATION



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
- Reduction of stigma and discrimination against PLWHAs as a result of increased understanding and compassion
- Provision of information for families, enabling them to support infected family members

## Mechanisms to Mobilize Communities

Several techniques can be used to mobilize the people of a community to access the services of a CBTS programme. 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. **Tool No. 15** created by the Pan African Christian AIDS Network provides a manual for a comprehensive community mobilization programme.

### Radio and Television

Radio public service announcements and educational programming are effective tools for reaching a broad audience of people living in resource-limited settings with basic information. Television is also effective, but households may have limited access to it. Both vehicles can only provide a limited amount of information, do not facilitate interaction and provide no opportunity for interaction with the audience.

### Community Events

Community events permit greater interaction and a means to disseminate more in-depth information to the audience through entertainment, speeches and printed materials like leaflets or pamphlets. These events can also be an effective way of launching the clinical and community services. Such events in CBTS programmes inspired PLWHAs at the five sites in southern Africa to provide public testimony about their HIV status and response to treatment.

### Drama

Drama can be a very effective medium for raising awareness and educating the community about HIV/AIDS. This approach is particularly appreciated in resource-limited settings, because of its novelty and entertainment value. Despite the seriousness of the subject, the effectiveness of the dramatic representations is often enhanced by humour. The humour eases the discussion and enactment of disturbing, frightening or taboo subjects. Examples include representations of seriously ill patients, such as those with HIV-related dementia, images of death or enactment of traditional medical procedures such as the use of enemas. The drama event can be tied to on-the-spot VCT.



*Mapilelo Project community mobilization partners provide "edutainment" in the village.*



## FIELD STORY 6 USE OF DOOR-TO-DOOR CAMPAIGN IN PORECO, SWAZILAND

A team of 42 unemployed graduates from Swaziland University was recruited and underwent an intensive two-week training programme on HIV/AIDS, ARVs and PMTCT. Using a diary card in which they completed the date and 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 Programme 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.



*Community educators use the string game.*

### **Workshops for Community Stakeholders**

It is also suggested to organize workshops that help inform community leaders and encourage them to become involved in mobilization activities. Potential participants include:

- Women leaders in the community
- Youth group leaders
- Traditional healers
- Chiefs and other influential community leaders
- NGO, CBO and FBO representatives
- Public health facility representatives

### **Door-to-Door Campaigns**

A door-to-door campaign presents the greatest opportunity for providing HIV information and interacting with community members. These campaigns should be prioritized to the clients who need it most, e.g., clients of HBC workers who exhibit symptoms of AIDS-defining illness, but have not yet been tested. While labour-intensive and potentially expensive, programme expenses were limited by encouraging the use of volunteers (who may receive small reimbursements for necessary expenses such as food or clothing) to conduct such campaigns.

**Tool No. 16** 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 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 represented by the educator telling the story and connecting the strings between the individuals at the time of infection.

### **Branding the programme**

All of the activities noted above contribute towards branding the programme. They are effective marketing tactics. You can further enhance branding by giving the programme a name; a name which has meaning for the community and thus increases interest in accessing the offered services.

#### **FIELD STORY 7 EFFECTIVE BRANDING OF A CBTS PROGRAMME**

The CBTS programme in Lesotho chose the name Senkatana for its clinic and project. Senkatana is a legendary figure in the country. He was a young boy who killed a dragon threatening to swallow all the Basotho, as the people of Lesotho are known. In selecting this name, the site sought to portray the programme as a savior in the country's fight against HIV/AIDS. And as the first centre to offer ARVs to the general public, the programme catalysed the rollout in the country.

### **Prepare Patients Needing ARVs for Treatment**

Patients must be prepared for ART. In particular, they need to accept that they are embarking on lifelong therapy and must take their medication every day, as prescribed. Research has demonstrated that patients must be at least 95% adherent to ARV therapy to achieve a sustainable response. This equates to missing medication at most only once a month (Paterson, et al).

### **Set Criteria for Enrolment at Outset**

Criteria for patient initiation onto ARVs should follow national treatment guidelines. Where a risk exists of discrimination against certain demographic groups such as sex workers and injecting drug users, however, the project manager may want to establish an ARV committee to supervise enrolment. The committee can review anonymous patient charts, taking into account both labs and physical exam reports that include disease staging. This process facilitates a rational provision of ARVs and protects patients from being denied treatment for non-medical reasons. Social issues are included in the review, but should be considered to determine how to solve such issues and not as a basis for denying ARV treatment to a patient.

## FIELD STORY 8 CREATING AN ARV COMMITTEE IN MASERU, LESOTHO

A dynamic ART committee was established at the CBTS site in Maseru, Lesotho. The committee consisted of physicians, nurses, counsellors and social workers. Initially the entire committee met to review all potential candidates for ART. When it gained experience, the committee set guidelines so decisions could be made immediately about most patients in the clinic, and only difficult cases were reserved for the committee. In that way waiting lists were rapidly reduced and most patients who did not present complications could receive ARVs within five days of diagnosis.

### ***Assess a Patient's Readiness for ARV Therapy***

Before commencing ARV therapy, a patient's personal and social circumstances should be thoroughly evaluated. In some instances, this may reveal issues that must be addressed before therapy begins to maximize the prospects for success. For example, patients with a serious nutritional deficiency may require food supplements. Patients may also have serious social or psychological problems such as alcoholism, mental illness or social isolation. The CBTS programme demonstrated that these problems can be managed so that no patient will be denied ARVs if his or her clinical status dictates need. Community services play the most important role in addressing these issues, proving their value again.

Logistical problems can also be addressed such as ensuring patients can access transportation to the clinic and helping patients disclose their HIV status to a family member or other appropriate person. Transportation is a major issue in resource-limited settings and should not be overlooked. In some instances, patients who cannot afford transportation default from clinic visits and ultimately default from therapy as well.

In some countries, such as South Africa, the Ministry of Health has stipulated that prior disclosure to another person is a prerequisite for ART. Here too, community services can play a major role. *SECURE THE FUTURE* found that patients' outcomes generally improve considerably if people close to them know their condition and are supportive.

### ***Educate Patient about Starting ARV Therapy***

Patients diagnosed with HIV should receive thorough instruction on their condition and how to manage it with medicines, good nutrition and healthy living practices. Once it is determined that ART should commence, patients should be informed about the medication, including how to take it and how to handle side effects. Sometimes clinical staff, particularly counsellors, can provide this information. In some countries, a more structured approach has been adopted. For example, in South Africa patients must attend specially designed classes.

Patients on therapy also require ongoing education. Clinical care and community supportive service partners can provide and reinforce the information. This includes the doctor, nurse and counsellor whom the patients see during their clinic visits. A pharmacist

can also be a valuable resource given his or her knowledge of therapy and the importance of strict drug adherence. In the community, buddies, support groups and home-based care workers can reinforce adherence messages and practices and provide information on positive living.

### Monitor Patients

Apart from standard haematology and blood chemistry investigations, the two widely accepted methods of monitoring HIV patients' progress are a CD4 count and viral load. In resource-limited settings, the latter is expensive and is not feasible when very large numbers of patients are monitored or when samples must be sent a considerable distance for analysis. Results may be reported very late and therefore play little role in patient management decision making.

Viral load results at the CBTS sites were only reliably reported in a timely manner when they were performed by private laboratories, which are often prohibitively expensive. But CD4 counts are usually performed easily and results can be obtained within 48 hours. Where CD4 counts cannot be done, a physician with good clinical acumen can determine the stage of an HIV patient's disease and progress in treatment with reasonable accuracy based on clinical examination alone. The WHO clinical criteria for staging HIV disease are useful in this regard (see **Tool No. 17**).

### Deliver Community-Based Services

#### Home-Based Care (HBC)

Home-based care has emerged as a key strategy in addressing the HIV/AIDS epidemic in Africa and other developing parts of the world (UNAIDS). Many people prefer to receive care at home where they are surrounded by family, friends and a familiar environment. Further, HBC provides an opportunity to inform family members and communities about HIV/AIDS prevention and basic care techniques. Such opportunities are rare for hard-to-reach communities that do not regularly receive prevention and care messages. In this way, HBC workers can now play a new role in encouraging community members to come forward for VCT, by explaining the benefit of knowing one's status and eventually accessing lifesaving ART. Indeed as HIV/AIDS treatment programmes are launched and clients begin to regain their health, the job description of an HBC worker changes dramatically. Most HIV/AIDS patients respond well to ARVs and are no longer very sick or bedridden. When this occurs, the HBC worker can assume the new role of helping the improving client live a fulfilling life. This can include helping the client with drug adherence, management of side effects and returning to work. Eventually, the HBC worker's assistance may no longer be needed.

For patients who are not well or who have mental, physical, emotional and social needs, caregivers provide home-based basic nursing care. The care provided seeks to promote, restore and maintain the individual's maximum level of comfort, function and health, as well as helping people with very advanced HIV disease to die with dignity.

HBC is not a 24-hour service and does not replace the family as the primary caregiver. Families and the patients themselves can be assisted and encouraged to care themselves. A manual for patients and their families to help in management of symptoms is to be found in **Resource No. 12**.

### ***Organizations Providing Home-Based Care***

HBC services are provided by non-profit organizations (NPOs) that are funded by governments and private donors, or by community members volunteering their services through their churches and community organizations. In many countries, nongovernmental and faith-based organizations implement HBC services that are not available through government programmes. Patients who need ongoing care at home upon discharge from a hospital are referred to a primary health care facility in their community. The clinic or primary health centre refers the patient to the NPO partner responsible for HBC services in the area. The NPO can then assess the individual's needs in the individual's home and develop a care plan and assign a caregiver to that person. The structure of an NPO providing HBC is variable. At their most developed, HBC workers start out as volunteers while developing and improving their skills and then advance to paid positions of increasing responsibility. This confers the appropriate sense of HBC as a profession.

A care supporter's monthly report is shown in **Tool No. 18** and an individual patient registration form for HBC purposes is to be found in **Tool No. 19**.

### **Patient Support Groups**

Ongoing patient support is also provided by support groups composed of PLWHA in the community. Either NGO personnel or counsellors and social workers in the programme can guide and coordinate the groups. A support group provides clients with the support, advice and experience of their peers. Such groups should be organized according to the needs and desires of the PLWHA and community organizations. They can serve as forums for discussion or be organized around income-generating activities or food security programmes, reinforcing a sense of common purpose.

### **Wellness and Positive-Living Workshops**

Wellness and positive-living workshops are educational events for patients at which they are provided with information about how to adapt their lifestyle to promote their health in general and more specifically how to slow the progress of HIV/AIDS and maximize the response to ARV therapy. This includes advice on nutrition, smoking cessation, moderating alcohol intake and information on other substance abuse. In addition, ways of enhancing mood and psychological state of mind are explained. These workshops are relatively easy to organize (e.g., in conjunction with support group activities) and can substantially impact a large number of patients.

## Buddy Programme

Like an HBC worker, the buddy provides ongoing psychosocial support, knowledge about HIV/AIDS, guidance in recognizing symptoms of HIV disease progression and medication side effects, and, perhaps most importantly, assistance in adhering to ARV therapy, when necessary. However, the support is more intense, often daily. Although patients may be instructed on the importance of good adherence, the reality of taking medication typically twice a day for life is daunting. Patients with other chronic diseases, such as hypertension or diabetes, are known to have difficulty adhering to medication. The consequences of non-adherence to ARV therapy are particularly severe. Resistance to the ARVs develops quickly, which renders a patient's regimen ineffective and necessitates changing to a new, triple regimen (with the consequent loss of a treatment option). Studies have shown that optimally, patients should be at least 95% adherent to their regimen, which is equivalent to missing at most one dose per month (Paterson, et al). The buddy is a strong proponent for adherence and in some instances may directly observe the patient in taking medications every day.



*Buddies trained by the NGO COCEPWA in Gaborone, Botswana, prepare to go to work.*

Like many peer support models, the buddy is also HIV-positive, and is usually on ARVs. Although that is not essential, the bond between the buddy and the patient is strengthened when the two experience similar circumstances. At the launch of an ARV treatment programme, there may be a limited number of potential buddies, but it grows over time as more patients go on ARVs. Because this is a labour-intensive approach to patient support, it is usually impossible to pair every patient with a buddy. Factors that may determine who will benefit most from having a buddy include a patient's failure to disclose his or her serostatus to a supportive family member (who, in essence, can become a sort of buddy) and the patient's lack of social support systems. Other criteria for selecting patients are detailed in **Tool No. 20**.

## Food Security Activities

A household with at least one HIV-positive person has a reduced capacity to produce or buy food, and is more at risk of food insecurity. HIV-positive people who are malnourished may also be more vulnerable to other infections. As mentioned in Step 3, food security is given high priority among the community services that should be considered in setting up a CBTSP programme. It is intuitively correct that good nutrition is necessary to optimize response to ARVs. In addition, the extensive monitoring and evaluation (M&E) framework implemented at the STF CBTSP sites provided data showing that patients benefiting from food security programmes had better clinical outcomes (see **Resource No. 1**).



A comprehensive food security program includes the following components:

- Nutritional assessment of patients
- Assessment of the patient's access to food
- Provision of vitamins or other micronutrients
- Food parcels for a limited period (usually 3 months)
- Demonstration of how to prepare nutritious meals
- Helping patients and their families to grow their own food in door-sized gardens
- Establishing community gardens to grow larger quantities of food



*Food security in action: ACHIVA/Mpilonhle volunteers tending their community garden.*

Patients who are assessed as requiring food supplements receive food parcels for a limited period, but are simultaneously instructed in how to grow their own food. This is an example of how to empower patients to take greater responsibility for managing their health.

The field story on page 52 is an excellent illustration of the food-growing components of a food security programme established in KwaZulu-Natal, South Africa. This programme also specifically addressed the needs of OVCs in the district.

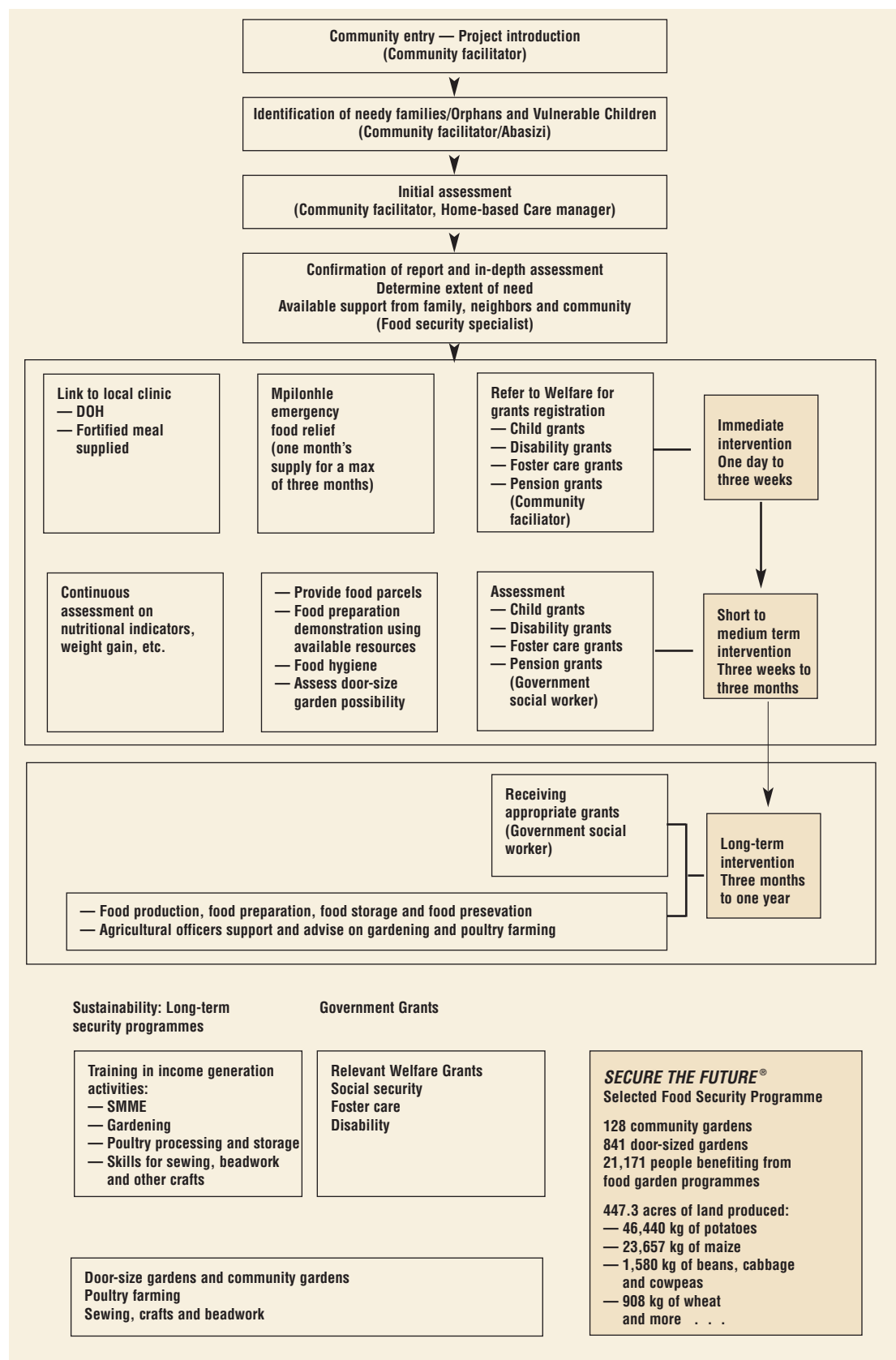


*ACHIVA/Mpilonhle door garden.*

**Tool No. 21** provides a framework for organizing a nutrition project.



FIGURE 7 MPILONHLE PROJECT HOUSEHOLD FOOD SECURITY SUPPORT APPROACH



## FIELD STORY 9 FOOD SECURITY PROGRAMME IN KWAZULU-NATAL, SOUTH AFRICA

At Uthukela District in KwaZulu-Natal, South Africa (population 608,000), more than 34% of the residents are HIV-positive, up to 90% live in poverty and 66% are unemployed.

A partnership between KwaZulu-Natal Department of Health's Ladysmith Provincial Hospital, BMS STF, local private physicians and the NGO MPILONHLE initiated the ACHIVA/Mpilonhle project to support introduction of ART.

MPILONHLE, working through a network of 39 CBOs, led and coordinated community services. One of the programme's key elements is a Household Support, Food Security activities and Orphan and Vulnerable Children Care Protocol that seeks sustainable food and nutrition security in that community. The protocol's key provisions include identification and assessment of family and orphans and vulnerable children nutritional needs, procurement and provision of emergency food, instruction on food and nutrition, and assistance securing government grants. Assessment of nutritional needs is important because not all households require assistance. MPILONHLE also provides demonstrations on preparation of nutritious meals with available food resources in the home and community.

One of the programme's long-term goals is helping households grow their food. But the cultivation of a sustainable crop of vegetables or establishment of a self-sustaining poultry farm takes time. Therefore, households receive food parcels in the interim, usually for at least three months. Household members can simultaneously be instructed on growing vegetables in door-sized gardens beside their houses.

The food security programme also provides food to more than 2,020 orphans and vulnerable children on school days at 15 halfway houses in the Uthukela communities. Children go to a halfway house on their way to and from school. They receive two warm meals, assistance with homework and life skills training there.

## Income-Generating Activities

The type of income-generating activity, i.e., local craftwork, catering businesses and food production, selected should be based on whether the products are authentic, and the available expertise is in the community (or ability to train patients) and the identification of and access to markets. Attempts to import craftwork not indigenous to the community were problematic at CBTS sites. Local expertise is essential, although these skills can also be cultivated through training.

Identifying and creating access to markets for the products can be the most difficult factor. The patients' community is unlikely to prove a viable market because of poverty and other resource limitations. This requires seeking markets elsewhere. Therefore, funders might support initiatives to determine the best markets for these products, and partnerships to get goods and services to market, potentially including other countries.

Income from IGAs can be partially reinvested in other IGAs. Also, patients can either receive income from IGAs or food supplements in lieu of money. Food security programmes can serve as IGAs once production exceeds patient needs.

It is important to understand that IGAs should not be viewed only in terms of their economic value. Bringing patients together around an IGA is a means of fostering communication and mutual support as well as reinforcing public health messages. It also restores patients' dignity, improves their self-esteem and gives them a source of pride.

### FIELD STORY 10 CATERING BUSINESS IN BOTSWANA

The Bobonong HBC Society in Bobonong conducted market research in the district and determined that a catering business constituted a good prospect. The local government and other funders in the village became the principal customers. Vegetables and other crops grown in a large communal garden owned by the project provided a nutritious source of food. The catering business was soon turning a profit of up to 1,200 pula (\$180) per month. This profit could be reinvested in other IGAs such as craftwork.

## Lessons Learned

### Clinical Services

- HIV patients need to be prepared for ARV therapy because of the need to take the drugs diligently every day.
- Selection of patients for ARV therapy should be based largely on clinical criteria and remain uninfluenced by social discrimination.
- Social and psychological problems can usually be managed.

### **Community-Based Services**

- Home-based care is one of the most important community services for HIV/AIDS patients and has been shown to impact clinical outcomes.
- The job description of home-based care workers has been transformed with the advent of ARV therapy from palliative care to supportive care.
- A buddy programme is an ideal way of providing individualized community support to a patient, but it is not feasible to attach buddies to all patients. Therefore, provide buddies for those patients who need them most, e.g., those initiating treatment but who have poor family support, patients who have defaulted and need help maintaining therapy, etc.
- Adequate nutrition is essential for optimal response to treatment of patients with HIV/AIDS.
- Encourage self-sufficiency by teaching patients how to grow their own food rich in nutrients to bolster their immune systems.
- Income-generating activities are not easy to implement but the results often justify the effort. Focus on skills and expertise found in the communities. Do market research upfront and identify your market for selling goods and services.

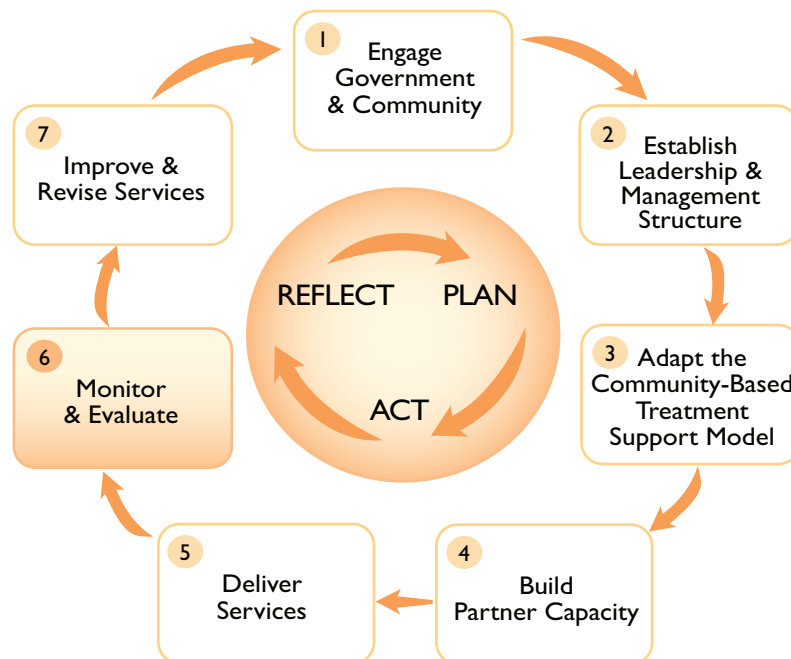
#### **Tools for this step**

- Tool No. 15 Manual for a comprehensive community mobilization programme (Pan African Christian AIDS Network)
- Tool No. 16 String game (UNICEF)
- Tool No. 17 WHO staging system for HIV infection and disease in adults and adolescents
- Tool No. 18 A care supporter's monthly report
- Tool No. 19 Patient registration form for HBC
- Tool No. 20 Buddy programme information
- Tool No. 21 Sample framework for nutrition project

#### **Resources for this step**

- Resource No. 1 Methodology and analysis used to assess impact of CBTSP
- Resource No. 12 Symptom management manual (UCSF/School of Nursing)

## Step 6: Monitor and Evaluate



This step stresses the importance of monitoring and evaluating the programme's progress to ensure that patients are receiving the services they need and programme outcome goals are being achieved.

### Objective

- Establish a framework and tools for collection of data and indicators
- Train personnel on the means of collecting the data
- Identify which programme elements are working and which are not

### Expected Outcomes

- A monitoring and evaluation plan
- Increased capacity in monitoring and evaluation

### Monitoring and Evaluation Plan

An effective monitoring and evaluation plan is required to determine how well the programme meets its objectives and serves its patients. Monitoring and evaluation is a way of systematically measuring and tracking programme activities and results. It is often viewed as something only done by “researchers” or to satisfy the requirements of donors, but all programme managers conduct monitoring and evaluation to some degree. To avoid wasting resources, you should decide the minimum amount of data you need to collect to monitor and evaluate your programme. The data derived from monitoring and evaluation are also critically important for the ongoing improvement and eventual optimization of the programme. Finally, it bolsters transparency and demonstrates good governance of the programme, two qualities important to funders. **Tool No. 22** is a template for developing a monitoring and evaluation plan.

Monitoring and evaluation has many uses:

- **Management tool:** Monitoring inputs and outputs can help determine whether programmes and services are reaching their target audiences, or whether issues related to content, program scope, defined coverage areas or target audiences should be re-examined. Monitoring also helps in formulation of new annual plans of action by detailing what has or has not been accomplished by previous ones.
- **Accountability to beneficiaries:** Information from monitoring systems provides feedback to all project levels, including the community. This feedback may encourage grassroots support from the beneficiary population.
- **Advocacy:** Monitoring provides credible information about programme progress, problems and potential. Advocates can use this information to mobilize greater personal commitment and financial support for improved HIV/AIDS policies and programmes.
- **Reporting requirements:** Most donors require some form of reporting so that they can assess whether their resources are being used for agreed-upon objectives. When programmes or projects are funded by several different donors, this often requires writing different reports, each according to a particular donor's specifications. Having good monitoring systems in place will provide managers with ready access to the basic data they will need to share in different formats with different donors.

**Monitoring** is defined as the routine collection and use of data to assess progress in achieving programme objectives. These data are generally derived from programme records.

**Evaluation** involves collecting special data on a periodic or "as needed" basis to address issues that cannot be examined using routinely collected data, like a project's cost-effectiveness or overall impact.

The development of a monitoring and evaluation plan consists of several steps:

- Defining a programme's goal, objectives, inputs, activities, outputs and outcomes (also called a "logframe" or "logic model")
- Identifying indicators or data points and other information to collect and measure critical programme components
- Determining the sources of the data, the frequency of their collection and how they will be analyzed
- Developing a monitoring and evaluation implementation plan

**TABLE 3 EXAMPLE OF M&E COMPONENTS, WITH ANALOGY**

M&E Components	The Soup Analogy	HIV/AIDS M&E Pipeline
Inputs	Carrots, potatoes, chicken broth, spices	Condoms, test kits, drugs, staff, money, facilities, etc.
Processes	Act of cooking the soup	Training, delivery of services, conducting community education events
Outputs	The finished soup	People receiving services (VCT, clinical, care and support), condom availability, trained staff, knowledge of HIV transmission
Outcomes	Level of satisfaction obtained from eating the soup	Attitude changes, behaviour change (increased condom use, sexual abstinence, monogamy), changes in STI trends, increase in social support
Impact	Improved nutritional status of person eating the soup	Changes in HIV/AIDS morbidity and mortality, changes in social norms, coping capacity of communities, economic impact

**Resource No. 13** is a guide to monitoring and evaluation.

### Increased Capacity in Monitoring and Evaluation

Programme partners may require technical assistance to establish strong monitoring and evaluation systems. This may be particularly needed for designing and implementing monitoring plans, tools, questionnaires, outcome studies, qualitative research and costing analysis. Have project validation workshops with health stakeholders where the team can assess the relevance, importance, feasibility and levels of monitoring indicators and identify best practices for adaptation and replicating by other programme partners.



## Collect Data

**Step 3 Adapt the CBTS Model** highlighted the importance of developing a monitoring and evaluation plan. Once the CBTS programme has been implemented and services launched, it is critical to collect data on the elements outlined in the plan.

Many tools are used in data collection. Quantitative tools include:

- Patient sign-in registration logs
- Checklists of services provided to the patient
- Programme activity forms
- Patient charts
- Questionnaires

Qualitative tools include:

- Focus group discussion guides
- Observation checklists
- Detailed interview guides

The following table is an example of the sort of data you might collect with regard to home-based care.

TABLE 4 HOME-BASED CARE INDICATORS

# of HBC volunteers CUMULATIVE
# of trained HBC volunteers CUMULATIVE
# of HBC providers/village health workers trained CUMULATIVE
# of refresher trainings provided to the HBC volunteers MONTHLY FIGURE
# of HBC volunteers who received refresher training MONTHLY FIGURE
# of active HBC volunteers this month MONTHLY FIGURE
# of family members trained in HBC CUMULATIVE
# of HBC volunteers tested CUMULATIVE
# of HBC volunteers positive CUMULATIVE
# of HBC volunteers on treatment CUMULATIVE
# of clients CUMULATIVE
# of ongoing positive clients MONTHLY FIGURE
# of new positive clients MONTHLY FIGURE
# of clients who have left the HBC programme (dropped out, relocated) MONTHLY FIGURE
# of clients who have graduated from HBC MONTHLY FIGURE
# of tested clients CUMULATIVE
# of male positive clients CUMULATIVE
# of female positive clients CUMULATIVE
# of clients married CUMULATIVE
# of clients single CUMULATIVE
# of clients cohabiting CUMULATIVE
# of clients 15-19 years CUMULATIVE
# of clients 20-39 years CUMULATIVE
# of clients 40+ years CUMULATIVE
# of clients who have disclosed their status (# of clients on ARV treatment attached to HBC) CUMULATIVE
# of deceased clients who tested, are positive and/or are on treatment MONTHLY FIGURE
# of clients on HBC on ART CUMULATIVE
# of clients on ART attached to HBC CUMULATIVE
# of clients on HBC receiving food parcels MONTHLY FIGURE
# of clients provided with home care services MONTHLY FIGURE
# of clients provided with ongoing counselling MONTHLY FIGURE
# of clients provided with health education and training MONTHLY FIGURE
# of clients provided with medical care services MONTHLY FIGURE
# of clients attached to buddy programme CUMULATIVE
# of clients received from ART clinics MONTHLY FIGURE
# of clients received from hospital/clinic MONTHLY FIGURE
# of clients received from buddy MONTHLY FIGURE
# of clients received from private practitioner MONTHLY FIGURE
# of clients received from traditional healer MONTHLY FIGURE
# of clients received from traditional birth attendants MONTHLY FIGURE
# of referrals made to ART clinics MONTHLY FIGURE
# of referrals made to hospital/clinic MONTHLY FIGURE
# of referrals made to buddy MONTHLY FIGURE

**Tool No. 23** provides a sample data collection tool appropriate for community services offered in a CBTS programme.

The data may be collected by numerous people. A designated person, or even better, an M&E officer, will then collate the data and calculate other indicators derived from the data (e.g., the number of patients benefiting from HBC in one month as a percentage of the target).

The collected and reported data is then available for any partner or stakeholder to review. The project manager should have primary responsibility for reviewing the data. He or she can utilize the data as a management tool and as a tool for quality control. Simple corrective steps may be sufficient, but the data can also be reviewed by other groups within the management structure or by all partners at an Implementers' forum. More complex issues, for example, defects in systems which involve several partners, may then be tackled and resolved.

### Lessons Learned

- Develop your monitoring and evaluation plans at the beginning of the programme as part of your planning phase.
- While monitoring is an internal management, ongoing function evaluation should be conducted by independent, objective parties at specified times.
- Make sure everyone understands why it is so important to collect data, analyze it and use it to plan next actions.
- Align an M&E plan with the government's and capture the same indicators.

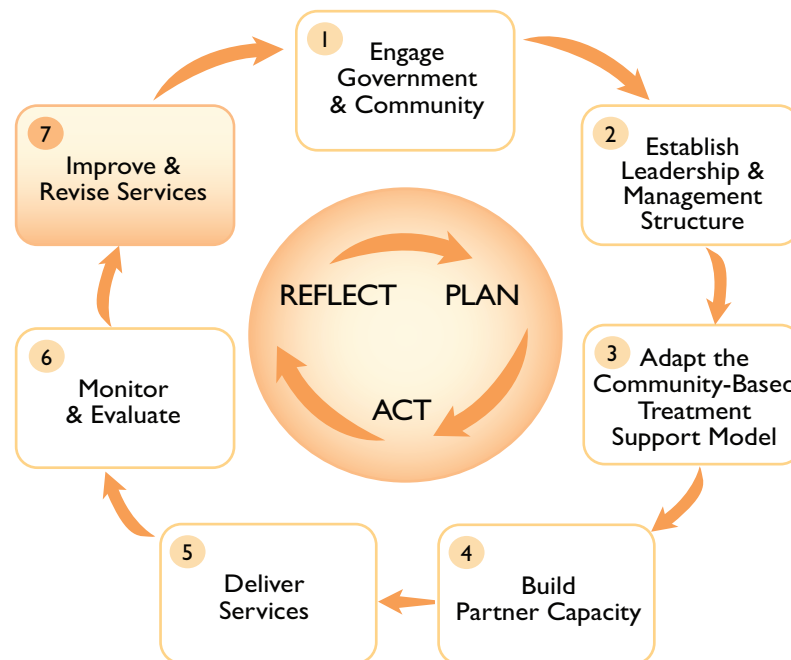
### Tools for this step

- Tool No. 22 Template for monitoring and evaluation
- Tool No. 23 Data collection form for community services

### Resource for this step

- Resource No. 13 STF Guide to Monitoring & Evaluation

## Step 7: Improve and Revise Services



It is important to reflect on successes, challenges, risks and current and future needs and then prepare what needs to be done next. This can be achieved through reviewing plans, processes and actions against their goals and objectives. The major input for this step is the monitoring and evaluation data as well as additional assessments. This step should also be seen as an opportunity to report back to stakeholders and get their input and assessment on the way forward.

- Assessments can be conducted to determine the impact programmes have had on patients, their families and their communities. For an HIV CBTS programme, these could include a facility assessment and patient satisfaction survey, a community household assessment and qualitative surveys of PLWHA. The STF programme employed all of these plus a rigorous study of the added value of community services for a group of patients receiving ARVs. This was measured by patient adherence to medication, quality of life, clinical improvement and decrease in stigma and discrimination. **Resource No. 14** contains a set of relevant questionnaires and assessments:
  1. Quality of life Impact questionnaire
  2. Adherence questionnaire
  3. Household Assessment questionnaire
  4. Health related Quality of Life questionnaire
  5. Indepth interviews with patients living openly with HIV/AIDS
  6. Overview of the enhanced patients evaluation, and
  7. Stigma and Discrimination questionnaire.

## Objectives

- Review monitoring data and document successes
- Conduct programme and specialized evaluations
- Identify problem areas and assign parties and resources to address the problem areas
- Reflect and revise your plan at three levels
- Celebrate successes and harness motivating actions
- Disseminate findings

## Expected outcomes

- Active use of M&E data to identify problems and address them throughout the programme timeline
- Success and lessons identified and disseminated
- A revised business case and programme that are relevant to the needs of the next period

## Review Monitoring Data

More than just tracking what is being done, monitoring data is an early warning sign of things that are not going as planned. Such data can also be a great motivator for the team, if all targets are met or exceeded.

Therefore, in reflecting about the programme, monthly, quarterly, semi-annual and annual monitoring data should be used when it is still current. Also, track new resources and policies that can support the project.

As stated in Step 6, monitoring is a management tool; it validates advocacy initiatives, ensures accountability and also helps to build the business case.

## Conduct Programme and Specialized Evaluations

Unlike monitoring, programme evaluation occurs at specific times and aims to build a Big Picture of the programme's progress at a specific point in time. Evaluation reports should be seen as opportunities to improve services and intervention. Therefore, these reports should be timed well and welcomed.

Complex evaluations conducted to determine the impact of programmes should always be planned for to answer unforeseen questions.

Questions to ask at this step are the following:

- Was the CBTS programme vision achieved and is it still relevant?
- Could the CBTS implementation have been done better and is it still relevant?
- Are the partners still relevant or are new partners needed?
- Are there new needs for the patients served?

## Revise Plan at Three Levels

There are three levels of reflecting and reviewing services.

**Level 1: Monthly revisions are limited to tactical teams and action plans.** These revisions do not result in major service revisions, and they are done at the implementation level by service providers and technical teams. They are about paying more attention to raw monitoring data and field experience, which indicates tasks that are lagging behind or are more challenging.

**Level 2: Quarterly or semi-annual revisions are about objectives and targets.** Reviews and reflection involve broader technical teams and management teams and respond to process and output indicators. The major informants for this level are:

- Baseline reports
- Quarterly and semi-annual cumulative monitoring data and trends
- Responses from donors and governments on submitted reports

If objectives are not achieved and targets are not met, the affected service should have a thorough review or even be subjected to operational research. This may result in revised targets, improved processes or reallocation of resources.

**Level 3: Annual or mid-point and end of programme revisions are about strategy and processes employed by the programme.** The reflection focuses on reviewing progress against the vision and goals of the programme by all programme governance, management and beneficiary structures. Time should be invested in preparation and deliberations, which can be over two or three days. The purpose is to reflect on goals, strategy, processes, priorities and allocation of resources and how to serve future needs. **Tool No. 24** is a tool to help facilitate such a reflection process.

## Celebrate Successes and Harness Motivating Actions

It is also important to highlight what has been done well and to celebrate successes.

During the annual review it is important not to dwell on challenges and what could have been done better. This is also the time to document best practices that can be incorporated when services are being revised. It is also important to capture activities, processes and experiences that energized and motivated individuals and teams.

The simple way is to ask each individual or team to record their most rewarding experience or most exciting time during the programme.

## Disseminate Findings

The first people entitled to the monitoring and evaluation findings, reflection report and revised service plan are the programme teams, from implementers to steering committee members.

All programmes, but especially projects initiated as pilots, should document their processes, outcomes and lessons because this will be important when they report back to government and funders and want to advocate for their model to be scaled up or replicated.

A plan to disseminate programme outcomes at key milestones and at the end of the project should also be developed early on during the programme life cycle as dissemination always has budget implications.

## Lessons Learned

- Use monitoring and evaluation data to help with critical reflection at different levels throughout the programme life cycle.
- Do not wait for formal evaluations to reflect and improve your activities. Each team member should do so on a monthly basis, each project on a quarterly or semi-annual basis and the whole programme annually, at mid-point and at the end of the programme.
- It is important to celebrate successes, and monitoring data and reports are a good way to show that the programme and the team are moving in the right direction.

## Tool for this step

- Tool No. 24 Reflection Tool

## Resource for this step

- Resource No. 14 Questionnaires for specialized monitoring and evaluation: Sample clinical and QOL impact questionnaire

## IV Key Lessons Learned

### Step 1 Engage Government and Community

- Governments can be engaged if the CBTS programme and model align with national policies and address critical challenges of community-based HIV/AIDS care.
- Align to national vision for HIV/AIDS care delivery and scale up and set broad goals before a detailed assessment of the available resources.
- Broadly consider the community resources that can be mobilized in a CBTS programme, including resources that have not been considered before or are not currently engaged in HIV/AIDS. For example, any effective, well-managed organization focused on services for pregnant women can expand its mission and scope of work to also address HIV/AIDS.
- Understand the role of various government bodies and units in HIV/AIDS care and services to ensure inclusive consultation and buy in, and determine what provisions in the national policy allow for alignment with the CBTS model.

### Step 2 Establish Leadership and Management Structure

- Identify early in the planning stage a strong project manager trained in project management and assign that person adequate authority.
- Establish a management structure with clear roles, responsibilities, and reporting relationships through collaborative and transparent workshops.
- Place equal importance on the role of all partners.

### Step 3 Adapt the CBTS Model

- One size does not fit all. The configuration of clinical services must match the geography and the needs of the targeted patient population.
- Decentralization of services to primary health centres brings services closer to patients and reduces the burden on hospital clinics.
- Not all the community services may be needed. Choose the ones that will have the greatest impact because they address a gap or strengthen currently impactful services.
- Establish a clear patient flow and referral points.
- Include all stakeholders in the workshop where the patient flow is established.

### Step 4 Build Partner Capacity

- Training is necessary for CBTSP operation and supportive of professional development of the individual implementers.
- Training to understand the CBTS concept itself is necessary.
- Capacity building is not just about training, but can be facilitated by providing appropriate, sometimes innovative upgrades or modifications to workplaces and other physical structures.



## Step 5 Deliver Services

### *Clinical Services*

- HIV patients need to be prepared for ARV therapy because of the need to take the drugs diligently every day.
- Selection of patients for ARV therapy should be based largely on clinical criteria and remain uninfluenced by social discrimination.
- Social and psychological problems can usually be managed.

### *Community-Based Services*

- Home-based care is one of the most important community services for HIV/AIDS patients and has been shown to impact clinical outcomes.
- The job description of home-based care workers has been transformed with the advent of ARV therapy from palliative care to supportive care.
- A buddy programme is an ideal way of providing individualized community support to a patient, but it is not feasible to attach buddies to all patients. Therefore provide buddies for those patients who need them most, e.g., those who have initiated treatment but who have poor family support or patients who have defaulted and need help maintaining therapy.
- Adequate nutrition is essential for optimal response to treatment of patients with HIV/AIDS.
- Encourage self-sufficiency by teaching patients how to grow their own food rich in nutrients to bolster their immune systems.
- Income-generating activities are not easy to implement, but the results often justify the effort. Focus on skills and expertise found in the communities. Do market research up front and identify your market for selling goods and services.

## Step 6 Monitor and Evaluate

- Develop your monitoring and evaluation plans at the beginning of the programme as part of your planning phase.
- While monitoring is an internal management, ongoing function evaluation should be conducted by independent, objective parties at specified times.
- Make sure everyone understands why it is so important to collect data, analyze it and use it to plan next actions.
- Align an M&E plan with the government's and capture the same indicators.

## Step 7 Improve and Revise Services

- Use monitoring and evaluation data to help with critical reflection at different levels throughout the programme life cycle.
- Do not wait for formal evaluations to reflect and improve on your activities. Each team member should do so on a monthly basis, each project on a quarterly or semi-annual basis and the whole programme annually, at mid-point and at the end of the programme.
- It is important to celebrate successes, and monitoring data and reports is a good way to show that the programme and the team are moving in the right direction.

## V Library

### Tools

- Tool No. 1 Slide set for engaging and consulting with government and other partners
- Tool No. 2 Baseline survey checklist
- Tool No. 3 Knowledge, attitudes, practices and beliefs questionnaire
- Tool No. 4 NGO/CBO/FBO assessment questionnaire
- Tool No. 5 Budgeting
- Tool No. 6 Extract from project manager employment contract
- Tool No. 7 Site visit checklist and report
- Tool No. 8 Monthly progress report to all partners
- Tool No. 9 Change request form
- Tool No. 10 Risk management template
- Tool No. 11 Guide to facilitating a workshop on developing a map of patient flow
- Tool No. 12 Client documentation form
- Tool No. 13 Project implementation plan
- Tool No. 14 Site readiness assessment (John Snow, Inc.)
- Tool No. 15 Manual for a comprehensive community mobilization programme  
(Pan African Christian AIDS Network)
- Tool No. 16 String game (UNICEF)
- Tool No. 17 WHO staging system for HIV infection and disease in adults and adolescents
- Tool No. 18 A care supporter's monthly report
- Tool No. 19 Patient registration form for HBC
- Tool No. 20 Buddy programme information
- Tool No. 21 Sample framework for nutrition project
- Tool No. 22 Template for monitoring and evaluation
- Tool No. 23 Data collection form for community services
- Tool No. 24 Reflection tool

### Resources

- Resource No. 1 Methodology and analysis used to assess impact of CBTSP
- Resource No. 2 Survey questions used in the Caprivi Region of Namibia
- Resource No. 3 Running costs of the STF programmes in Ladysmith, South Africa, and Katima-Mulilo, Namibia
- Resource No. 4 Example of a project charter
- Resource No. 5 Monthly resource report
- Resource No. 6 HIV/AIDS Curriculum for the Health Professional (BIPAI/Baylor College of Medicine)
- Resource No. 7 Training curriculum for traditional birth attendants on ARVs (Department of Health, Republic of South Africa)
- Resource No. 8 Training curriculum for home-based care (Mpilonhle Project)
- Resource No. 9 Training curriculum for training treatment "buddies" (COCEPWA)
- Resource No. 10 Training curriculum for community educators (PORECO Project)
- Resource No. 11 Training curriculum in project management
- Resource No. 12 Symptom management manual (UCSF/School of Nursing)
- Resource No. 13 STF Guide to Monitoring & Evaluation
- Resource No. 14 Questionnaires for specialized monitoring and evaluation

## VI Case Studies

### Bobirwa ARV Project, Bobonong, Botswana

#### Background Data

#### Country Demographics, Social and Economic Indicators

**Population:** 1,680,863 (2001, Central Statistics office (CSO))

**Life expectancy:** 39 years (UNDP)

**Percentage of people living on less than US \$2/day**  
50.1 % (2005, UNDP Human Development Reports)

**Per capita gross national income:** \$5,180 (2005, World Bank)

**Per capita government expenditure on health:** \$387 (2002, UNDP Human Development Reports)



#### Local Demographics (Bobirwa)

**Population:** 66,964 (2001, CSO)

**Sentinel surveillance:** 29.8% prevalence among pregnant women (2005, surveillance report)

**Health infrastructure:** Two primary hospitals, 18 clinics, 8 health posts, 16 mobile stops

## PLANNING

#### Situation Analysis

Before the provision of free antiretroviral therapy, Bobonong was one of the villages most affected by the scourge of HIV/AIDS. The small village in the eastern part of Botswana had multiple socioeconomic challenges, such as poverty, high unemployment, illiteracy and HIV/AIDS.

Unemployment in the Bobirwa Sub-District, which includes Bobonong, increased from nearly 25% in 2001 to 33% in 2003, according to the Government of Botswana. In 2003, the HIV prevalence in the sub-district was 19% and the HIV prevalence rate among pregnant women was 43.3%, according to the Botswana Second Generation HIV/AIDS Surveillance 2003. Many residents left Bobonong in search of jobs and a better life in the mines in Selibe-Phikwe, Botswana, or in South Africa.

What's more, the social and economic impacts of the pandemic were reversing the remarkable economic gains the country had achieved since independence in 1966. United Nations economic experts anticipated that Botswana would experience a 32% reduction in economic growth by 2010 due to HIV/AIDS.

The government of Botswana recognized the profound impact the growing HIV/AIDS epidemic had on communities throughout the country and began providing antiretroviral drugs to its citizens in January 2002. The initial beneficiaries of this internationally lauded campaign were the larger cities, such as Gaborone, Francistown, Maun and Serowe. The provision of ARVs was implemented in phases based on the primary health care model. Therefore, communities such as Bobonong were earmarked for the third phase of the rollout plan. The government of Botswana put up stringent measures to ensure that patients who required ARVs based on the clinical eligibility criteria accessed treatment from one of the pilot sites. Therefore, residents of Bobonong and its catchments area traveled for about 200 kms (125 miles) in a single journey to either Serowe or Francistown for both medical checkups and monthly drug supply.

"Those who made the trip had to factor in the time and some incidental expense. This was not easy for people here. It was demoralizing," said Gabaitse Marope, treasurer of the Borotsi Ward AIDS Committee in Bobonong.

## ENGAGING WITH GOVERNMENT AND COMMUNITY

### How Did *SECURE THE FUTURE* Engage with the Government of Botswana?

*SECURE THE FUTURE* (STF) established and maintained an excellent relationship with the government of Botswana and with the Ministry of Health (MOH) in 1999, when STF first launched. This relationship extended to the president of the Republic of Botswana, who has consistently demonstrated unfailing commitment to the fight against HIV/AIDS in his country. Among the first STF projects to be approved was the building of an HIV/AIDS reference laboratory in Gaborone and the funding of a Children's Centre of Excellence, also in Gaborone. The former helped catalyze the country's national ARV rollout, while the latter has provided a state-of-the-art facility for treatment of children. There were also a number of community outreach and education projects provided by faith-based and community-based organizations such as Botswana Christian Aids Intervention Programme (BOCAIP) and Holy Cross Hospice. Because of this good relationship and STF's credible record as a funding partner, the CBTSP idea was welcomed by the MOHs, which appreciated STF's emphasis on and unique approach to the community support component.

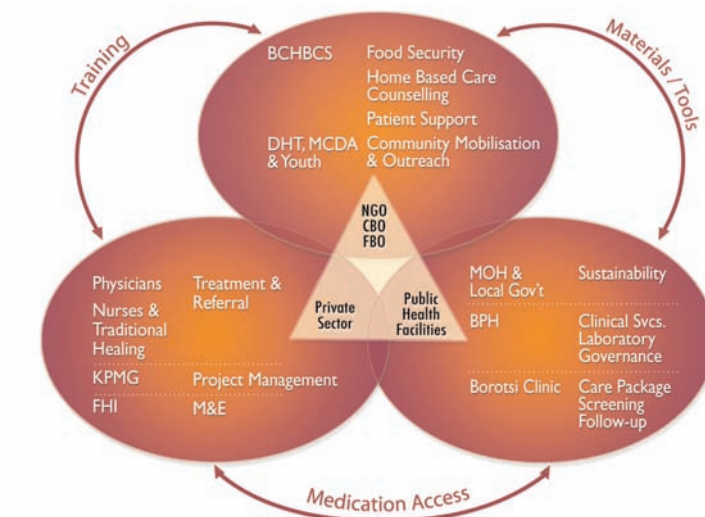
The MOH wanted the initiative to be located in Bobonong to address its dire need for ARVs and to recognize the commitment shown by Botswana Community Home-Based Care Society (BCHBCS) volunteers, who provided care and support services. A memorandum of agreement was signed in December 2003 that included specific clauses about the respective responsibilities of the government and STF. For example, the government committed to provide the ARVs and to cover the cost of laboratory monitoring, while the community

components and infrastructure development were largely funded by STF. The memorandum also addressed the sustainability of the programme after the initial three years of BMS funding.

Overall, the project was aligned with the government's vision to have an AIDS-free generation by 2016 and to provide its citizens living with HIV/AIDS access to high-quality care and support. The programme was further aligned with the country's National Strategic Framework for HIV/AIDS (2003-2009) that sought to increase access to care and support services in Botswana by 50% and usage of HIV/AIDS treatment and support services by 25% by 2009.

However, once the memorandum of agreement had been signed, the local partners in the programme took the lead in adapting the CBTS concept and designing a programme to meet the specific needs of the Bobirwa Sub-District. The following figure illustrates that overall adaptation.

FIGURE 8 THE COMMUNITY-BASED TREATMENT SUPPORT PROGRAMME IN BOBONONG, BOTSWANA



BCHBCS: Bobonong Community Home-Based Care Society  
 BPH: Bobonong Primary Hospital  
 FHI: Family Health International  
 MOH: Ministries of Health  
 MCDA: Matshelo Community Development Association  
 DHT: District Health Team

“So far so good, I was thinking,” recalled Dr Sebastian Wanless, Senior Medical Director of STF. “However, as planning continued, delays in obtaining approval for such things as use of facilities, recruiting personnel, redeployment of personnel, etc., became evident. What was the cause?”

“Despite our excellent relationship with the MOH, we were not well acquainted with the Ministry of Local Government,” admitted Dr Wanless.

The Ministry of Local Government was important in terms of engaging Borotsi Clinic as well as the BCHBCS. Once this ministry was properly consulted and engaged, things moved rapidly and the programme was launched in November 2004.

### How Did STF Engage with Local Community Organizations?

Engaging with local community and its organizations was relatively simple in Bobonong compared with some of the other CBTS sites, because of the strong NGO partner, the BCHBCS. This group had established a solid home-based care practice in the village and was serving a large number of clients. The BCHBCS was a natural choice of partner and stood to benefit from an infusion of funds, resources and training, including ultimately the construction of new premises to house their offices and provide space for programme activities, such as training of staff as well as for patients’ support groups and income-generating activities. Other community groups would subsequently become involved, but BCHBCS, under the supervision of the Ministry of Local Government, was the coordinating body and an enthusiastic community partner.



*Bobonong Community Home-Based Care Society volunteers at the centre built for their organization with funding from STF.*

## **BUILDING THE TEAM, LEADERSHIP AND MANAGEMENT STRUCTURES**

**KPMG Management Services**, a private firm, was a fund manager and acted as a programme office, coordinated consultative meetings among the implementing partners and other stakeholders and set up the Project Secretariat in July 2004. KPMG also nurtured good financial management principles among the implementing partners and the Project Secretariat.

In addition, BMS helped build the institutional capacity of the project by funding new facilities, equipment and staff, conducting recruitment and training and providing technical assistance.

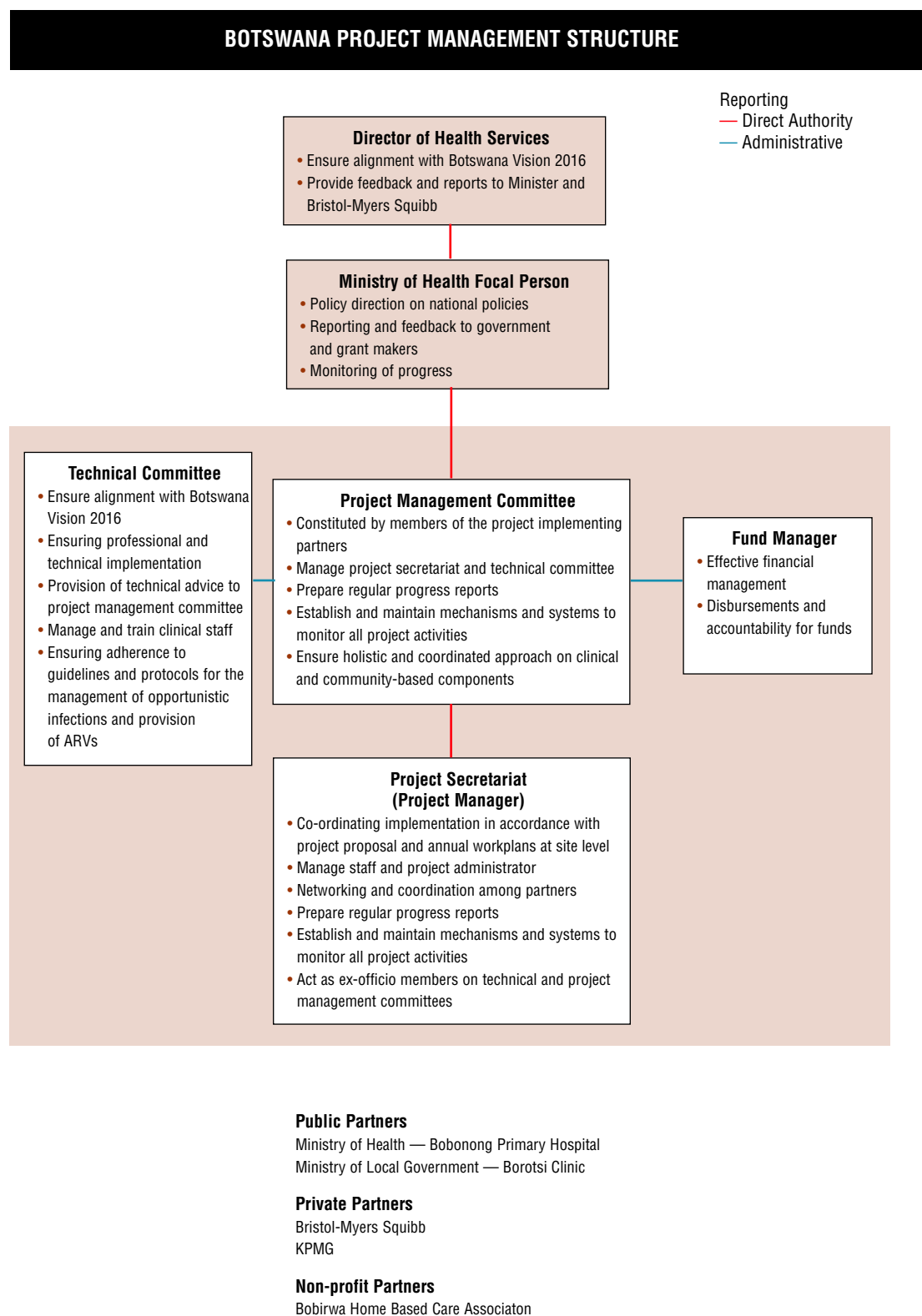
### **Project Management Structure**

The overall management structure and reporting relationships are illustrated in the following diagram. This diagram shows that supervision took place at the government level, but the teams on the ground directed daily programme activities. As emphasized in Step 2 of the manual, the project manager became the key player in this respect.

A strong manager was not identified at an early stage and consequently the programme initially experienced multiple difficulties and delays in implementation. Approximately six months into the project, a very professional and competent project manager, Mrs Botswelelo John, was hired. Although she had to expend considerable effort to rectify the situation, she completed the recruitment of qualified and compatible personnel, revised and clarified roles and responsibilities and created an impressive team spirit among all the stakeholders. Within a short period, the programme had caught up on lost time, and the cohesiveness of this team became truly superior. The Bobirwa ARV team was awarded the CBTSP prize for superior performance at a special awards event in November 2006.



FIGURE 9 PROJECT MANAGEMENT STRUCTURE



Facilitated and funded by the Bristol-Myers Squibb SECURE THE FUTURE™ Programme and the Ministry of Health



## ADAPTING THE CBTS MODEL

### Project Goals and Objectives

The project's overall goal was to improve the quality of life of PLWHA in the Bobirwa Sub-District through the acceleration of the provision of ART. The initial target was to treat up to 1,250 patients with ARVs over three years. This target was exceeded within the first year.

The programme sought to meet the following objectives:

- Build and strengthen the institutional capacity of programme partners for effective implementation of ART
- Mobilize, educate and sensitize the community in general, and PLWHA in particular, on ARVs and HIV/AIDS in general
- Provide ARV therapy for PLWHA in the project site and improve accessibility, availability and effective utilization of ARV services by PLWHA
- Improve food security at both the household and community levels
- Monitor and evaluate the implementation and impact of the project

### Implementation Plan

The key components of the programme were:

- Strengthening the hospital's partnership with filter clinics and home-based care
- Training health care and community workers
- Providing community mobilization services, including a buddy programme and information, education and communication activities
- Conducting patient management data collection and analysis
- Developing an objective and comprehensive M&E system

### Implementing Partners and Their Roles

The national Ministries of Health and local government provided antiretroviral drugs and related drugs, supervised institutional coordination and ensured that the monitoring and evaluation system met the national ARV guidelines. Focal persons were appointed by the two respective ministries to work closely with fund manager KPMG and the project team.

**Bobonong Primary Hospital, representing the Ministry of Health**, the only hospital in Bobonong and one of only two in the sub-district, provided the ARVs, laboratory and radiology services, social work and dietetic services and conducted operational research associated with the project. BPH also housed the Project Secretariat and served as chair for the Project Management Committee.

**Borotsi Clinic (BC), representing the Ministry of Local Government**, also located in Bobonong, conducted community outreach activities, screened and referred patients to the hospital, provided psychosocial support and patient follow-up and participated in the operational research on patients who did not require treatment after an HIV-positive diagnosis based on a CD4 count above 200 without any AIDS-defining illnesses. The District Health Team oversaw community outreach and education on all public health programmes and served on the Project Management Committee as well.

**Bobonong Community Home-Based Care Society, representing community-based organizations,** conducted community mobilization and counselling, peer education and patient follow-up, income-generating activities, home-based care, psychosocial support and food security services. The organization, formed in 1996, began with only 12 volunteers and grew to 70 and is viewed as one of the best community-based organizations in southern Africa.

## **ACTION**

### **BUILDING PARTNER CAPACITY**

The main clinic was established at Bobonong Primary Hospital, one of only two hospitals serving the Bobirwa Sub-District. Initially, the clinic was housed in a temporary structure, while a new spacious clinic and associated offices were being constructed within the hospital grounds. There was also a new building for Borotsi Clinic.

A community member provided land at a nominal cost to BCHBCS to build its offices which also functions as a conference centre and catering business.

There were a series of training sessions conducted by the government, STF and project managers for various cadres of the project.

To increase capacity for treating children, a preceptor agreement was made with Children's Centre of Excellence.

### **DELIVERING SERVICES**

#### **Integration of Services**

As at all the CBTS sites, the linkages required to integrate clinical and community services did not exist prior to the programme and required a dedicated effort to be properly instituted. The patient flow, elaborated on below, was an important guide in this respect. Whereas, in many sites, the community component is often initially not viewed with sufficient respect by clinical colleagues, the fact that the community services, especially HBC, were well established and very well recognized as a pioneer in the field, both in Botswana and elsewhere in southern Africa, meant that most clinical colleagues saw them as equals from the start. This helped integration a great deal. Once a full-time project manager came on board, any remaining issues about integration were rapidly resolved as described above in the section on management.

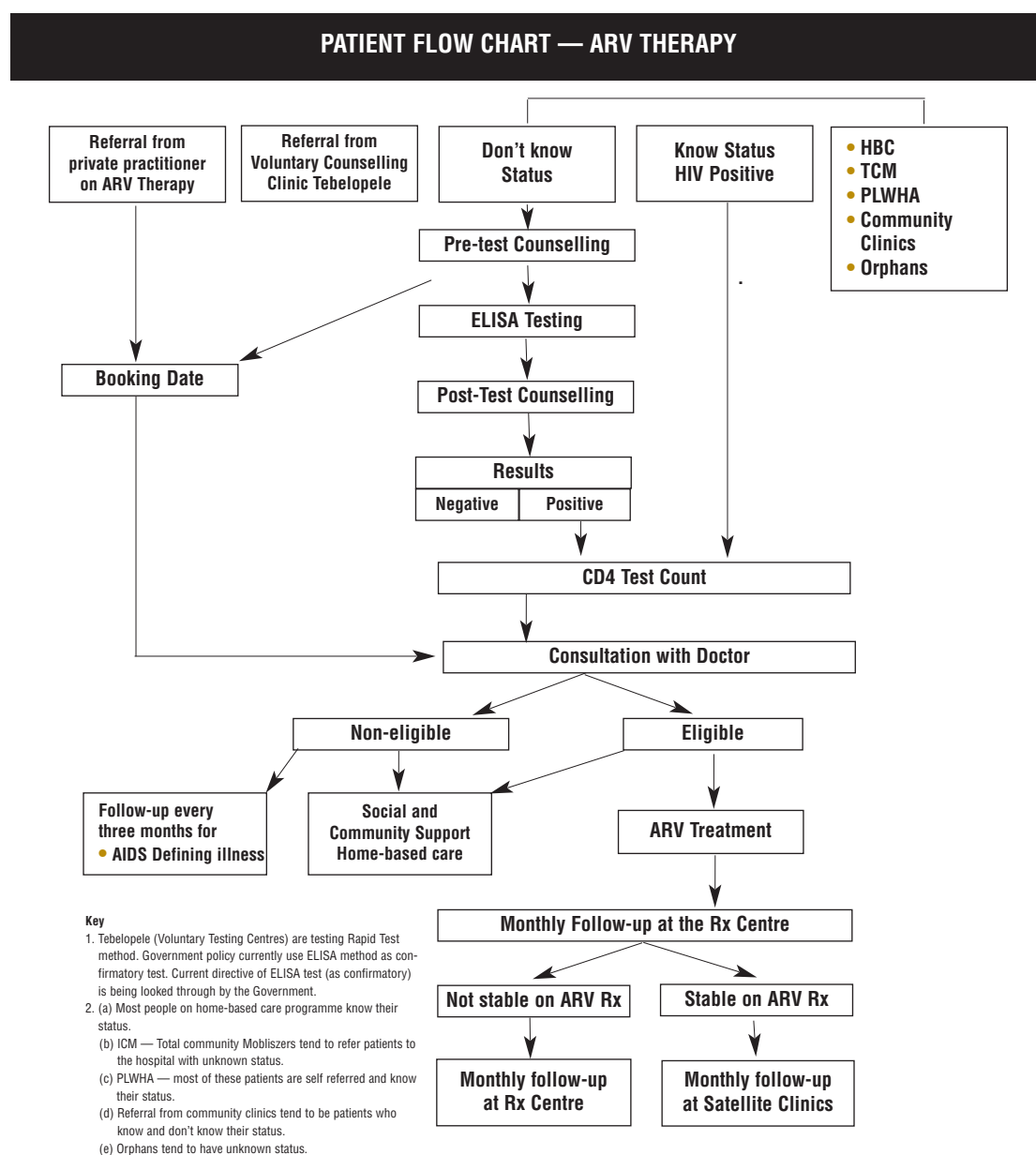
#### **Bobonong Primary Hospital**

Initially, the hospital screened and treated patients. But a more decentralized system was soon established, and the Borotsi Clinic (also a recipient of a spacious screening centre) started screening patients in September 2004. "At first we did both [screened and treated], but this created confusion and was inefficient," said Dr Jean Kabengele, acting Chief Medical Officer at the hospital.

In recognition that it was also difficult for many sub-district residents to access Borotsi Clinic, additional satellite clinics were opened in Mathathane, Semolale and Tsetsebjwe. Like Borotsi, they provided counselling and testing, referred clients to the hospital and monitored those clients who did not yet require ARV therapy. “Transportation is a big issue here, and the additional facilities made it much easier for people to access the services they greatly needed,” said Dr Kabengele.

Therefore, quite rapidly a decentralized service was instituted and the burden on the hospital substantially reduced. The following diagram illustrates the patient flow in detail.

FIGURE 10 PATIENT FLOW CHART FOR ART



Of note, patients who tested HIV+ but whose CD4 was found to be at a level not yet qualifying for ARV therapy were monitored at the satellite facilities, such as Borotsi Clinic. This reduced the patient load on BPH, but initially it also fostered a sense in the hospital that the non-ARV patients required less attention. This was not the intention of the CBTS programme, but the emphasis of treatment goals and getting as many patients as possible on therapy, which tended to sideline the non-ARV patients. These patients, however, needed community support services as well in order to cope with their diagnosis and to keep them healthy for as long as possible before they actually come to need ARVs.

Borotsi Clinic, which was not collecting the data required for the operational research, was supported with training and better processes, and soon the patients were fully reintegrated into the system and the setting up of a special database for monitoring and follow-up of clients who do not need ARVs. The social worker at Borotsi Clinic intensified follow-up of patients not on ARVs with the assistance of the patient follow-up volunteers and family welfare educators.

The project leaders also recognized from the start the importance of integrating traditional healers into the programme. “People in our community have a strong belief in traditional healers. You cannot overlook them. We therefore needed to train them on HIV/AIDS issues,” said Dr Kabengele.

While recognizing that he and other traditional healers take a very different approach to HIV/AIDS than the health professionals in the community, traditional healer Ngwako Nkawana, a member of the Botswana Dingaka Association, said he was viewed none the less as a member of the team from the outset. “Here people are appreciative of traditional healers, and I have worked well with others in the programme,” he said. “When I cannot handle the problem, I have always urged people to go to the hospital for follow-up. I have also encouraged people to take ARVs and not to mix them with traditional medicines.”

BCHBCS community-based activities included going to the homes of community members living in the most remote areas of the community. BCHBCS set up some coordinating structures for community mobilization. The PLWHA support group has also been empowered and developed. They have received training on leadership and governance, basic counselling, the buddy system and community mobilization.

“The organization’s community education and mobilization effort is reaching members of the sub-district who have never been informed about HIV/AIDS issues before,” said Hildah Nkhori, secretary of BCHBCS. “We are encouraging entire families to go for testing and other services. The word seems to be getting out because people now seek services because they hear from others that this is a good programme.”

And as a result, members of the community play an active role in the execution of health projects, including distribution of HIV/AIDS information.

Other local groups also worked with the BCHBCS and the medical facilities to address community needs. Five HIV/AIDS ward committees, the Community Capacity Enhancement Committee and the Men Sector were established in 2005 to inform residents about HIV/AIDS issues and encourage them to access the project's services. In addition, other groups such as the Religious Ministers' Fraternal, Business Community Committee and youth groups were also strengthened to mobilize the community. The strategies used included door-to-door campaigns and workshops, public/kgotla campaigns and football tournaments. HIV testing public campaigns were conducted during some of the activities. The Botswana ARV Project is recognized by the District Multi-Sectoral AIDS Committee (DMSAC).

## REFLECTION

### MONITORING AND EVALUATION

#### Community-Based Services Results

BCHBCS also initiated four small-scale income-generating activities—a catering service, a community garden, a poultry farm and bead work. Clients participating in the IGAs keep 12% of their profits. The most successful one so far has been the catering service started in 2005, which generates a profit of up to 1,200 pula (US \$1,800) per month. The sub-district council, the CBTS programme and government departments have been the service's principal customers. The catering initiative forms an integral part of the organization's internal mechanism for sustainability.

Since the programme began, the job description of a home-based care worker has change dramatically. "When we began, home-based care was associated with people who were about to die," said Nkhori, secretary of BCHBCS. "That has changed dramatically. Many of our clients are not even bedridden now. Our volunteers do not visit the clients as often as they did before. In fact, some clients no longer need home-based care. They have gone back to work now and care for their own children."

#### Clinical Services Results

The clinical component has also produced impressive results. Its impact has been easy to measure because the programme services are provided to a circumscribed population.

- "When we started, we sought to enroll a limited number of patients. However, we have gone well beyond that and have already enrolled 3,193 [as of June 30, 2006]. The linkage between the clinical and community services has definitely empowered individuals in the community," Botswelero said.
- Out of 3,193 clients assessed for CD4 count, 1,428 of them were on ARVs and no clients were on a waiting list for treatment. In addition, 19,503 clients had been reached through community mobilization and 337 were on home-based care.
- Further evidence of the clinical component's impact is the decline in the HIV/AIDS bed occupancy rate at the hospital—from 93% in 2003 to 52% in 2005; and the drop in the mortality rate at the hospital due to HIV/AIDS—from 23% to 13% during the same period, according to Tlhaloganyo Kaisara, the project's monitoring and evaluation officer.

This impressive outcome could be demonstrated because of the relatively circumscribed population in the catchments area of the Bobonong Primary Hospital.

“People are more aware of and accepting of HIV and more are receiving services now. My ward AIDS committee does not have as much to do now,” said Gabaitse Marope, treasurer of the Borotsi Ward AIDS Committee in Bobonong.

Ngwako Nkawana, a member of the traditional healers group Botswana Dingaka Association, said he and others can attest to the reduced mortality in the community because “in the past, six to eight people in the community were buried per weekend whereas only two are now.”

- Government officials have also observed the reduction in the mortality rate. “I am no longer attending funerals as I used to, thanks to BMS,” said the Honorable Shaw Kgathi, Bobirwa’s representative in Parliament.

## IMPROVING AND REVISING SERVICES

### Challenges and Lessons Learned

Despite the programme’s numerous achievements, serious programme challenges remain.

- **Finding a way to engage more men in the programme.**

Only about one-third of those being tested and receiving ARV therapy in the programme are men. A Men’s Sector Committee was established in 2005 to address men’s reluctance to access the programme’s services.

Dennison Legopelo, an executive committee member, said it was a struggle at first to elicit interest among men. Legopelo said his group explored a variety of ways to take its message about the pandemic and the programme to men in the community. This included visiting men on their farms and at bars and other frequent gathering places.

“We even organized a football tournament in Bobonong in 2005. This created an opportunity for us to talk with men about the importance of being tested and of positive living,” he said.

He said many of the men whom the committee contacted were afraid to access the project’s services. “Some even asked for separate testing for men. I think many of them were afraid of encountering their multiple partners,” he said.

One of the biggest challenges the committee faced, he added, was changing men’s attitude about women. “We encouraged men in the community to look at women as partners rather than subjects.”

- **Stigma in the community has also been a significant problem, but staff members and clients maintained it has declined since the BMS programme began.**

“I do not believe there is stigma now in the community like there used to be. People understand that when you point a finger at somebody, you are pointing a finger at yourself,” Legopelo said.

- **Increasing PLWHA participation in income-generating activities (IGAs).**

As of June 30, 2006, 16 clients were participating in food security/IGAs, and only 8 clients had been trained in IGAs. Several clients said they would like the programme to provide more support, training and follow-up in this area.

One beneficiary, Lesedi John, a resident of the sub-district, said she was proud of her backyard garden of carrots, tomatoes, cabbage and other vegetables, made possible by the Bobonong Community Home-Based Care Society.

The project reviewed and revised its processes on an ongoing basis but major revisions were done during the annual CBTSP review conference where all sites met for three days to report on progress, learn from each other and incorporate monitoring and evaluation findings.

## Senkatana Centre, Maseru, Lesotho

### Background Data

#### Country Demographics, Social and Economic Indicators

**Population:** 1.8 million (2006, World Development Indicators database)

**Life expectancy:** 34.4 years (2006, CIA Fact Book)

**Percentage of people living on less than US \$2/day:** 56.1% (1990-2003, UNDP)

**Per capita gross national income:** \$960 (2005, World Bank)

**GDP per capita:** \$2,619 (2004, UNDP)

**Per capita government expenditure on health:** \$106 (2003, UNDP)

#### Local demographics (Maseru District)

**Population:** 477,599 (MOH)

**Sentinel surveillance:** 42% (2000, KFF fact sheet)

**Health infrastructure:** Queen Elizabeth II, Scott and Roma Health Service Areas, Makoanyane Military Hospital, Maseru Private Hospital and more than 60 clinics

## PLANNING

### Situation Analysis

According to Lesotho mythology, a brave boy named Senkatana used a spear to kill a huge dragon-like monster who had been swallowing all the people in the country. That is why the CBTS team in Lesotho christened their clinic with the same name. Now the Senkatana Centre is giving the country hope in its struggle to contain the public health crisis threatening the country's survival.

"In our present situation, the monster is the HIV/AIDS pandemic and the Senkatana Centre becomes the saviour and salvation of Basotho from the gripping effects of HIV and AIDS," Prime Minister Pakalitha Bethuel Mosisili declared at the centre's dedication in May 2004.

Maseru, the national capital, had a population of about 477,000 when the programme began. About 35% of its residents were HIV-positive, and an estimated 10% required ART, according to government agencies. At the end of 2003, the country as a whole recorded the third highest HIV/AIDS prevalence rate (ranging from 28.9% to 31.7%) in the world after Botswana and Swaziland, according to UNAIDS. An estimated 55% of the PLWHA in Lesotho were women.



Before the BMS-funded facility opened in Lesotho, residents could obtain ARVs only from private sector doctors and the Maluti Adventist Hospital, a private institution managed by the faith-based Christian Health Association of Lesotho. Many PLWHA in the country consequently were unable to afford the drugs.

“HIV/AIDS programmes in the country had been focused mainly on prevention,” said Dr Pearl Ntsekhe, the Project Director of Senkatana Centre in Maseru. “ART was long overdue. ART rollout in Lesotho was not taking off, and was desperately needed.”

Before the programme could start it had to overcome a significant obstacle by finding a site. The programme identified a government leprosy hospital in Maseru that was in declining use, and BMS and the World Bank provided funding to refurbish the facilities for the programme.

## ENGAGING WITH GOVERNMENT AND COMMUNITY

### How Did STF Engage with the Government of Lesotho?

The relationship of STF with the government went back to 1999 when the programme was first launched. It had been nurtured on the basis of mutual respect and continuous consultation. When STF explained the concept of a community-based approach, Ministry of Health officials were intrigued by the possibility of tapping into the potential of the community to augment the resources available to fight HIV/AIDS. Because their own ARV rollout had not yet begun, they requested that STF establish a centre in Maseru, the capital.

Although not rural, Lesotho is relatively poor, with limited resources throughout the country. Engaging with the government was easy because it was mutually beneficial. The government understood that this initiative would accelerate the start of their national rollout of community-based ART. And to facilitate this, they agreed to the use of the buildings within a former leprosy hospital on the edge of the city.

STF also engaged with the government through the hiring of Dr Ntsekhe, the Director of the Disease Control Unit of the national Ministry of Health and Social Welfare (MOHSW), because she had co-authored the CBTSP proposal to BMS for Lesotho. She left her government post to head the programme once it began. Her transition from an MOHSW post to Director of the Senkatana Centre further cemented the relationship with the government.

### How Did STF Engage with the Community?

In some ways, the health care system in Lesotho lent itself easily to the CBTS model because community and social services are supervised by the country's Health Service Area (HSA) management. The full benefit of this arrangement may not have been realized previously but the Senkatana project provided a unique opportunity to develop the relationship between clinical and community services. This arrangement also meant that STF did not have to go seeking community involvement. The required partners were already there. Later in the project a very competent community coordinator, Mrs Agnes Kalaka,

was appointed. She drove the development of appropriate services and ensured that training of personnel proceeded properly and on schedule.

## **BUILDING THE TEAM, LEADERSHIP AND MANAGEMENT STRUCTURES**

### **Project Management Structure**

A structure on paper is one thing, but effective management of a programme as complex as CBTS requires that the structure and reporting relationships be actualized. Part of the success of Senkatana can be attributed to a strong project manager. Doctors are not natural managers, nor are they trained to be managers. However, Dr Ntsekhe was unusual in that respect, possibly because of her experience working in the Ministry. She understood her primary role as manager of a diverse team. Although a clinician herself, she allowed the physicians working in the clinic to take the lead on purely clinical matters. As project manager, she listened to all stakeholders, resolved conflicts and took responsibility for decisions which impacted several different stakeholders.

It is important to make a distinction between direct authority and administrative reporting relationships. This level of sophistication can be very helpful as it can effectively reduce workload on the project manager.

Whatever the details of such a structure, they should all contribute to and be aligned ultimately with the strategy of the programme. In the Senkatana programme, the most important aspect of the strategy, namely linking community service with clinical management to optimize outcomes, is reflected in the management structure, with the project director bridging the two.

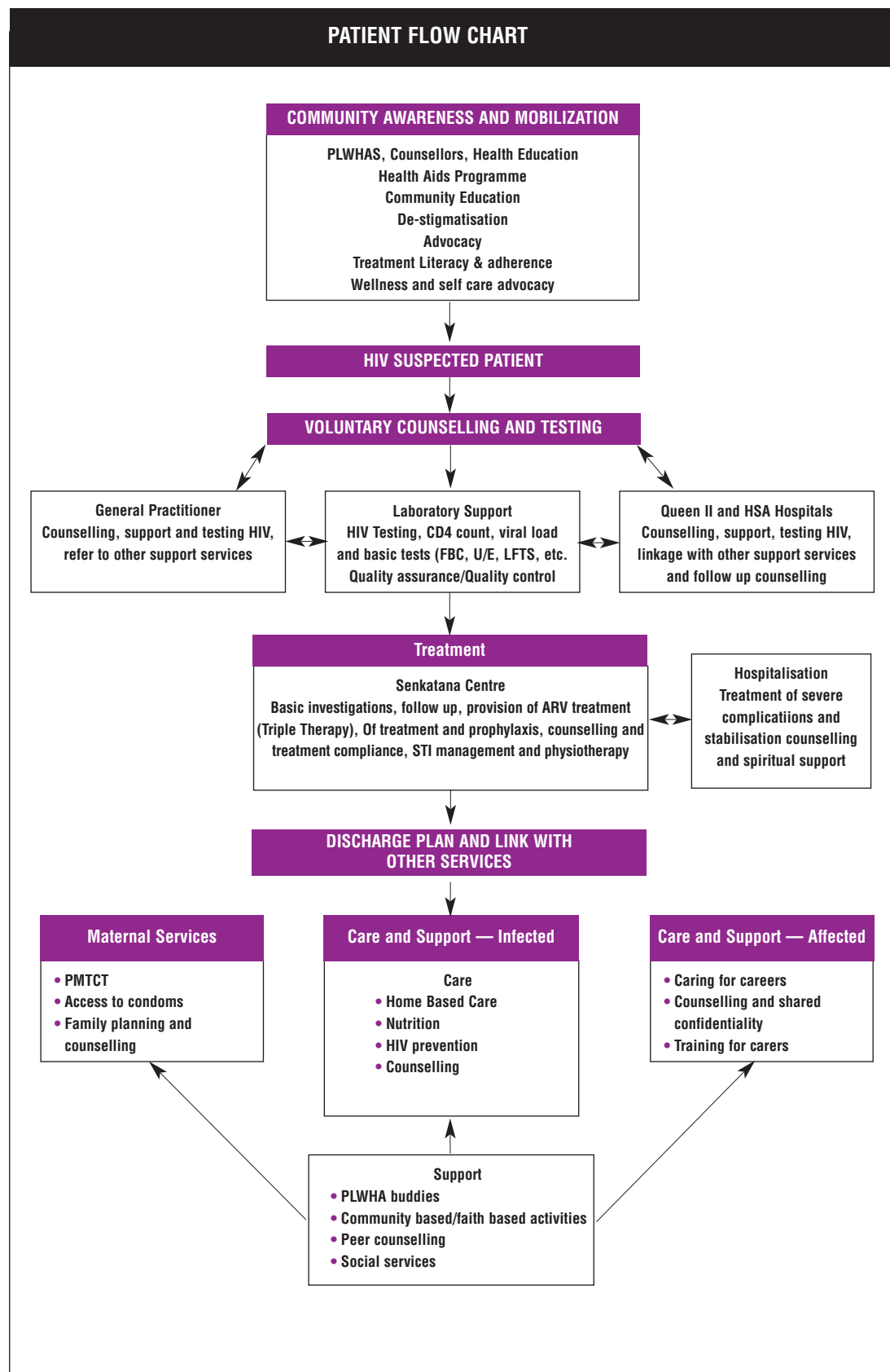
### **The Implementers' Forum**

The implementing partners provided comprehensive clinical and community-based services, including home-based care, counselling, community mobilization, food security, income generation, support groups and a buddy programme. They established an effective Implementers' Forum to foster collaboration in delivering such broad services. The forum, which meets monthly, provides managers and service providers with a common venue for sharing achievements and resolving problems. All of the key project implementers participate in the forum, including members of project management, clinical, voluntary counselling and testing, home-based care, laboratory and pharmacy teams, PLWHA, and fund managers.

### **Integration of Services**

The integration of services was eased by the established relationship between clinical and community services at the HSA level. Creating strong and appropriate linkages, however, still required considerable effort. Dr Ntsekhe played a key role in this respect, because she understood that this was critical to success and she insisted on giving community stakeholders an equal place at the table with clinical representatives.

FIGURE 11 PATIENT FLOW CHART



This diagram shows patient flow in the Senkatana project. It shows the close relationship and bilateral referral systems between clinical and community services.

## ADAPTING THE MODEL

### Programme Goals and Objectives

The project's chief goal was to provide equitable access to quality care and support for HIV-infected and affected people in the community through a tripartite partnership of the public health sector, private sector and community-based organizations. An initial target of 1,200 patients over a three-year period was initially set. As described below, this target rapidly became obsolete as large numbers of patients responded to the community mobilization effort.

The project objectives included:

- Strengthening Senkatana Centre's institutional capacity for effective management of HIV/AIDS and related illnesses, and ART
- Building partnerships between clinical services, home-based care and private practitioners to give holistic care to those infected with and affected by HIV/AIDS
- Providing HIV/AIDS management skills to health care workers and caregivers in the public and private sectors
- Mobilizing, educating and sensitizing the community in general, and PLWHA specifically, on ARVs and HIV/AIDS management
- Strengthening and increasing community usage of VCT services
- Collating and analyzing client data collected at the clinic and partnering institutions to determine how to provide affordable and comprehensive services

### Implementing Partners

An impressive team of national agencies and organizations with complementary responsibilities partnered with BMS to implement this ambitious programme.

- **Ministry of Health and Social Welfare** provided technical coordination of clinical services at Senkatana, overall programme supervision and accountability, and drug procurement and management.
- **Lesotho Medical Association** was appointed as project managers and recruited project management and clinical staff.
- **TABFIN Financial Management Services** provided fund management services for the project.
- **Christian Health Association of Lesotho (CHAL)** had responsibility for the primary health care units in private hospitals Roma and Scott, the home-based care programme and client referrals to Senkatana.
- **Tsepong Counselling Centre (TCC)** handled community mobilization and counselling, voluntary counselling and testing promotion, HIV/AIDS awareness and chaplaincy. The organization later shifted from awareness to behavioral change.
- **People Living Openly with HIV/AIDS (PLOWA)** was responsible for client advocacy, the buddy programme and treatment literacy and peer counselling.

## ACTION

### Building Partner Capacity

In addition to playing a critical role in infrastructure development, BMS assisted with drugs, equipment and transportation procurement; staff training and personnel costs; and other technical assistance. Although ARVs were procured centrally by the government, BMS put in place an agreement for emergency procurement of drugs through the private sector. This contingency was felt necessary to avert any possibility of stock-outs. And in the event, it proved very useful on two occasions when stock-outs were imminent.

Pan African Christian Aids Network (PACANET) and COCEPWA were also brought in to train on community mobilization and the buddy programme. Family Health International (FHI) provided ongoing support on monitoring and data collection and analysis.

## DELIVERING SERVICES

### Project Implementation

Key components of the programme included:

- Building collaboration between filter clinics, health centres and home-based care in the district
- Training health care and community workers
- Conducting community mobilization, including information education campaigns, a buddy programme and counselling
- Conducting patient management data collection and analysis
- Developing an objective and comprehensive M&E programme

### Community-Based Services

At the outset, the programme mounted an ambitious and effective community mobilization and information dissemination effort led by the TCC and the primary health care departments of the national referral hospital, Queen Elizabeth II, and CHAL-affiliated hospitals Scott and Roma. This included working with leading figures and institutions in the community, such as church leaders, chiefs, traditional healers, community organizations, schools and businesses.

“The programme employs a wide range of tools to build community awareness and usage of the programme’s services. These include public awareness forums, peer groups, door-to-door campaigns, mass media, informational materials and dramas,” said Agnes Kalaka, the community coordinator. “One of the greatest successes we had was community mobilization. It has created significant demand for services. Originally, some in the community delayed coming, but more are coming now who want treatment, support and better quality of life. We are also getting clients now at an earlier stage of their illness than before.”

The mobilization effort is complemented by a comprehensive, integrated package of care and support services to CBTS clients. This includes support groups that provide PLWHA with care, support, peer counselling and improvements in their socioeconomic status. Forty support groups had been established as of July 2006. These embolden PLWHA in the community to open up about their serostatus and share their feelings and experiences with others who are HIV-positive. They also provide information about HIV and help to fight stigmatization and encourage the people in their communities to access VCT service.

Members of the support groups participate in a range of income-generating activities (IGAs), including poultry farming, handicrafts, bead work and candle making. The clients who take part in these activities are at different stages economically. Some are unemployed, so the income earned is critical to some of the members. It is important to note that support groups are usually much more effective if they are organized around IGAs. The communal activity fosters a sense of solidarity and it eases discussion. Conversation is more spontaneous when the members are engaged in work than in the somewhat artificial setting of a support group consisting of people who do not really know each other, being asked to talk openly about many difficult subjects. The groups also engage in food security activities, and a part-time nutritionist at Senkatana provides nutrition advice to clients and conducts demonstrations on proper food preparation, preservation and gardening.

The programme also sought from the start to work with local institutions that were providing community services. “The design of the project provided a need for collaboration with local community structures. For example, we wanted to get input from all of the existing support groups in the area and work with them,” said Agnes Kalaka, coordinator of the programme’s community services.

### **Clinical Services and Patient Flow**

The CBTSP Support Programme became a learning centre and catalyst for subsequent ARV rollout by several public and private hospitals in the country, including Queen Elizabeth II, Roma and Scott. The programme also became a model for the way it organized and managed its clinical services and patient flow. Programme managers noted, for example, that in contrast with some ARV providers in the region, Senkatana has effectively eliminated patient waiting lists through its efficient provision of patient care. Approximately six months into the programme, patient waiting lists for ARV therapy were beginning to grow uncomfortably long, approaching three months. It is true that initiation of ARV therapy is very rarely an emergency. However, in the case of Lesotho, a significant proportion of the patients were already very sick when they first came to the clinic; 34% of the patients had a CD4 of less than 50 at baseline, more than any of the other CBTSP sites.

A three-month waiting list could be detrimental for these patients. Senkatana clinical staff initially introduced prioritization of patients. Thereafter, a very dynamic ARV committee was created to accelerate patient review for initiation of therapy. Eventually the approach to patient review became systematic, such that formal meetings of the committee were seldom necessary. The waiting list time dropped to five days.

## REFLECTION

### MONITORING AND EVALUATION

#### Community-Based Services Results

The community mobilization effort had already reached close to 51,000 people in the community as of June 30, 2006. Moreover, it helped create a greater demand for services than programme leaders originally anticipated. Instead of the 1,200 clients they expected to be on ARVs by May 2007 (three years after the programme began), 1,899 were already in treatment by June 30, 2006. And 1,195 clients not on ARVs were receiving community-based services.

Lay and outreach counsellors are also assisting clients with drug adherence, positive-living skill development, drug literacy, nutrition information and IGA establishment. “Counselling has helped show the clients alternative ways to live. It helps them to change their behavior, which is a major focus now of Tsepong (Counseling Centre), ” said Rev James Morojele, a pastoral counsellor in the programme.

These initiatives are giving an increasing number of clients the confidence to disclose their HIV status, and some are even conducting mobilization and destigmatization for other clients, according to programme officials. One client, who is also a peer counsellor at the Senkatana clinic, has been on ARVs since 2004. He is a member of a support group and counsels 30 other clients per day. He talks with his fellow clients about how HIV is transmitted and how to avoid infection, how to care for family members who are sick, and the importance of ART.

“Clients need to know they are in a supportive environment. Here they lose their fear, can live with their illness and talk about it freely,” he said. “Also, here they open up because they are sick and they have to talk about it. They cannot hide from it at the centre.”

Majola said when he disclosed his status to others in the community he lost some old friends but made new ones, especially in the support group. He has also referred several people to Senkatana for support, care and treatment services.

The PLWHA organization People Living Openly with HIV/AIDS (PLOWA) also supports Senkatana clients. PLOWA operates the buddy programme at the site, which pairs a client living openly with HIV/AIDS with a newly diagnosed HIV-positive client.

#### Clinical Services Results

The clinical component works closely with the community-based services provided by the centre and is building relationships with the primary health care units of hospitals in the community. It has also established a dynamic ARV committee consisting of key stakeholders in the programme that reviews each client’s eligibility for treatment.

Dr Appolinaire Tiam, who works at the Senkatana Centre, said that 83% of the 1,899 patients on ARVs as of June 30, 2006, are adhering well (i.e., more than 95% of the time) to their drug regimens, and achieving and sustaining good clinical outcomes.

“Most of our patients are stable on ARVs. The response of the patients to treatment has been excellent. People on the ARVs are able to resume work and their daily routines,” said Dr Tiam.

For example, one male client started on ARVs at Senkatana in 2004 after undergoing treatment for tuberculosis at the Adventist hospital. Initially, the young man had a CD4 count of only three, weighed 38 kilograms (around 84 pounds) and was bedridden. But after initiating ART, his CD4 count catapulted to 567 as of July 2006, his weight increased to 65 kilograms (around 143 pounds) and he could resume his normal daily activities.

“I have been very pleased with the level of services here,” said the client. “They have been very supportive. I never even thought about stopping [my drug regimen].”

The client also said that the improvement in his health also motivated him to change his lifestyle. “I was drinking and smoking before I came here. Now I am taking much better care of myself,” he said.

The clinical programme at Senkatana has also received strong laboratory support from the Health Service Area. Scott’s lab is conducting lactic acidosis tests for the centre’s patients, and Queen Elizabeth II provides other lab support services for Senkatana, including CD4 counts, as part of the government’s contribution to the national ART rollout.

## IMPROVING AND REVISING SERVICES

### Community Challenges and Lessons Learned

- One of the biggest challenges programme leaders have confronted is the hopelessness and fear people feel once they learn they are HIV-positive. “Early on some of our clients did not give us correct IDs [identifications] or locations. People were afraid. They felt there was a finality of eventual death if you were positive,” lamented Agnes Kalaka, the project coordinator.
- Stigma persists in key community institutions, but as communities see patients on ART regain health, stigma is reduced. “Some teachers did not even want to address the issue in the schools at all,” said Dr Ntsekhe. “Some denominations were very resistant. They felt people were bringing HIV/AIDS upon themselves and would be judged by God,” said Rev. Morojele.

As a programme such as Senkatana is implemented and patients begin to recover, sometimes dramatically, the surrounding community witnesses this and the level of stigma usually falls quickly. This was observed at all five of the CBTS sites and was corroborated by the Enhanced Patient Evaluation study.

The reluctance of men in the community to access the services also posed a serious challenge. “Men have always been our biggest problem. They might be willing to come to community activities, but they have been reluctant to get tested,” said Flory Kolobe, coordinator of Tsepong Counselling Centre.



To address men's reluctance to access programme services, a male support group was established at Senkatana. The group is addressing such key issues as men's role in fighting HIV/AIDS, the importance of supporting the members' wives and partners and reasons for the limited usage of programme services by men. The support group is also developing an action plan to increase male involvement.

### Clinical Challenges and Lessons Learned

- **Limited staff experience in providing high-quality care**

Senkatana has only three doctors, one nurse clinician and nursing assistants to care for the patients. The staff sees more than 100 patients per day and puts almost 90 patients on ARVs per month. "A ratio of 500 clients to one doctor is optimal in resource-limited settings. The ratio is 1,000 clients to one doctor. "We cannot deny treatment, but this is becoming a problem," said Dr Tiam.

- **Lack of an on-site laboratory facility to handle the increasing number of specimens requiring analysis**

- **Maintaining a reliable, adequate drug supply**

The MOHSW allocated ARVs donated by the government of India, but as other public hospitals initiated ART, the pharmacy unit at Senkatana was not able to implement the system of providing stable patients with two months' supply of ARVs as demands for drugs increased. Consequently, Senkatana received only monthly stocks of ARVs beginning in April 2006. "With support from BMS and activating the contingency plan, the centre purchased supplemental stock, and stock-out was avoided," said Dr Tiam.

- **Patients on ARVs experiencing treatment failure**

As of July 2006, 20 patients were on second-line regimens. Failure is attributed to a number of causes, from poor clinical management by private physicians with limited ART experience to transportation being a barrier, to refilling prescriptions, to patients not adhering to their regimens. In some cases, patients stop adhering because they feel better and believe they have been cured. One of the measures needed to address this problem, according to Dr Tiam, is intensified patient education on adherence.

- **A significant number of patients not yet requiring ARVs were clinic defaulters who had to be traced.**

The bulk of the defaulters at Senkatana are HIV-positive clients who are not eligible for ARVs. "When they are only offered follow-up services, they take it badly," said Dr Ntsekhe. "That is why the community services are so important for these patients."

STF staff noted early in these programmes that a significant number of patients not yet requiring ARVs were clinic defaulters who had to be traced. Often these clients either stated that they felt demotivated by first being told they were positive and then being told to come back in six months. Others feel relieved and so do not understand the importance of continued monitoring. In either case, the provision of community services to help these patients live positively keeps them engaged so that they are not lost to follow up.

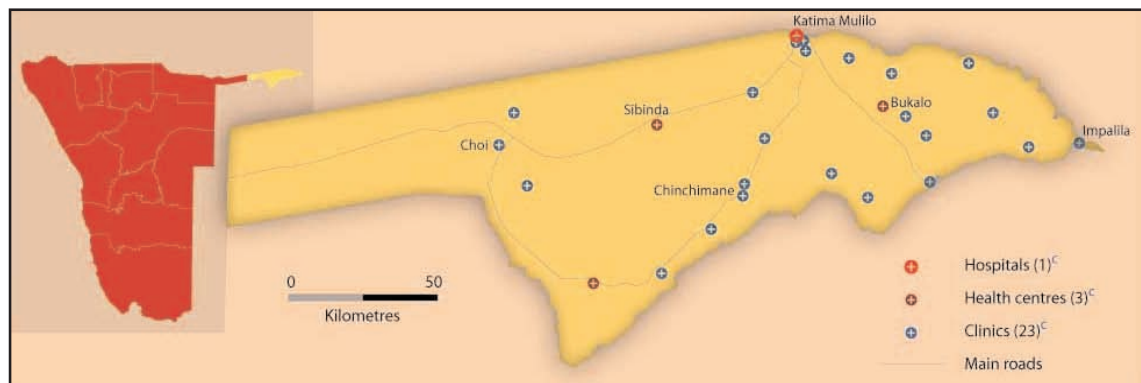
Dr Ntsekhe said that the necessity of including defaulter tracing in the programme was not foreseen when the programme began. During year two, two PLWHA field workers came on board mainly to trace both those on ARVs and those not on treatments, who have defaulted.

### Celebrating Successes

Cross-fertilization of ideas and best practices was made possible by the existence of five sites and by the active advocacy of the STF programme office staff. Such cross-fertilization also took place during monthly project management teleconferences at which all sites were represented and at Annual Review Meetings, which took place in different countries on a rotating basis. These were off-site meetings where intensive presentation, dialogue and brainstorming assisted all the teams to chart the best way forward.

Now that Senkatana is a mature programme, the stakeholders are proud of the project's service to the community and believe it has been a great success. "I think that what we have demonstrated is that HIV care is possible in resource-limited settings," said Dr Tiam.

## Mapilelo Project, Caprivi Region, Namibia



### Background Data

#### Country Demographics, Social and Economic Indicators

**Population:** 2.0 million (2006, World Development Indicators database)

**Life expectancy:** 47.2 years (UNDP, 2006)

**Percentage of people living on less than US \$2/day:** 55.8%

**Per capita gross national income:** \$2,990 (World Bank)

**Per capita government expenditure on health:** \$366 (UNDP, 2006)

#### Local Demographics (Caprivi)

**Population:** 88,900

**Sentinel surveillance:** 42.5% (2004 sentinel surveillance)

**Health infrastructure:** One District Hospital, 3 health centres and 25 clinics

## PLANNING

### Situation Analysis

The Caprivi Region is the only point in Africa where five countries (Angola, Botswana, Namibia, Zambia and Zimbabwe) meet. As such, it represents a major crossroads, transit centre and point of transmigration of multiple populations.

The Caprivi Region has some major development challenges due to its location and due to the prevalence of natural disasters. Some areas in the Caprivi Region are inaccessible in the wet season, making it difficult for some essential services to reach the people in these areas. Other main development challenges are the high unemployment rate and malaria.

The Caprivi Region has the highest HIV prevalence rate (43%) in Namibia. Traditional practices, cultural beliefs, polygamy, migrant labour, truck drivers and prostitution are some of the contributing factors in the region and the belief that witchcraft can induce HIV/AIDS is widespread and complicates education, diagnosis and treatment of the disease. The needs of the Caprivi Region with regard to HIV/AIDS are further complicated by specific developmental challenges due to its location far from the capital city ( $\pm 1,200$  km from Windhoek), high HIV prevalence rate, high unemployment rate and transit point to four countries.

## ENGAGING WITH GOVERNMENT AND COMMUNITY

The government of the Republic of Namibia has recognized the need for a quick response to the HIV/AIDS problem in the Caprivi Region. The strategic plan (Medium Term Plan II) compiled during 1998 and launched by His Excellency President Sam Nujoma (former President of Namibia) in March 1999 has strongly emphasized the HIV/AIDS Chapter in the National Development Plan II (NDPII) and formed the basis for the national response to the pandemic.

Bristol-Myers Squibb's *SECURE THE FUTURE* (STF) programme made the government's planned activities a reality when staff approached the Ministry of Health and Social Services (MOHSS) in 2002 to establish a CBTSP in a resource-limited setting. The Caprivi Region was identified by the Ministry as the most remote and most resource-limited region, making it an ideal target area to test the hypothesis that community support is the key to optimizing response to ARV treatment in such settings. A project proposal together with implementation plans was developed through the MOHSS with the active involvement of local partners and stakeholders. A baseline survey was conducted and the proposal resubmitted in July 2003. The Mapilelo project started in October 2003 and has made a significant impact in improving the lives of people living with HIV/AIDS (PLWHA). The project is aligned to meet the NDPII policy objectives.

"Namibia was one of the most challenging countries in terms of putting the implementing partners together because it had many organizations, parastatals, NGOs and CBOs and government departments to mobilize and pull together," said Phangisile Mtshali, Director of STF Southern Africa. "However, this was assisted by a very clear government plan and mature multi-disciplinary structures to guide a collaboration we had in mind. There was still significant investment of time in workshops between nongovernmental and community-based organizations."

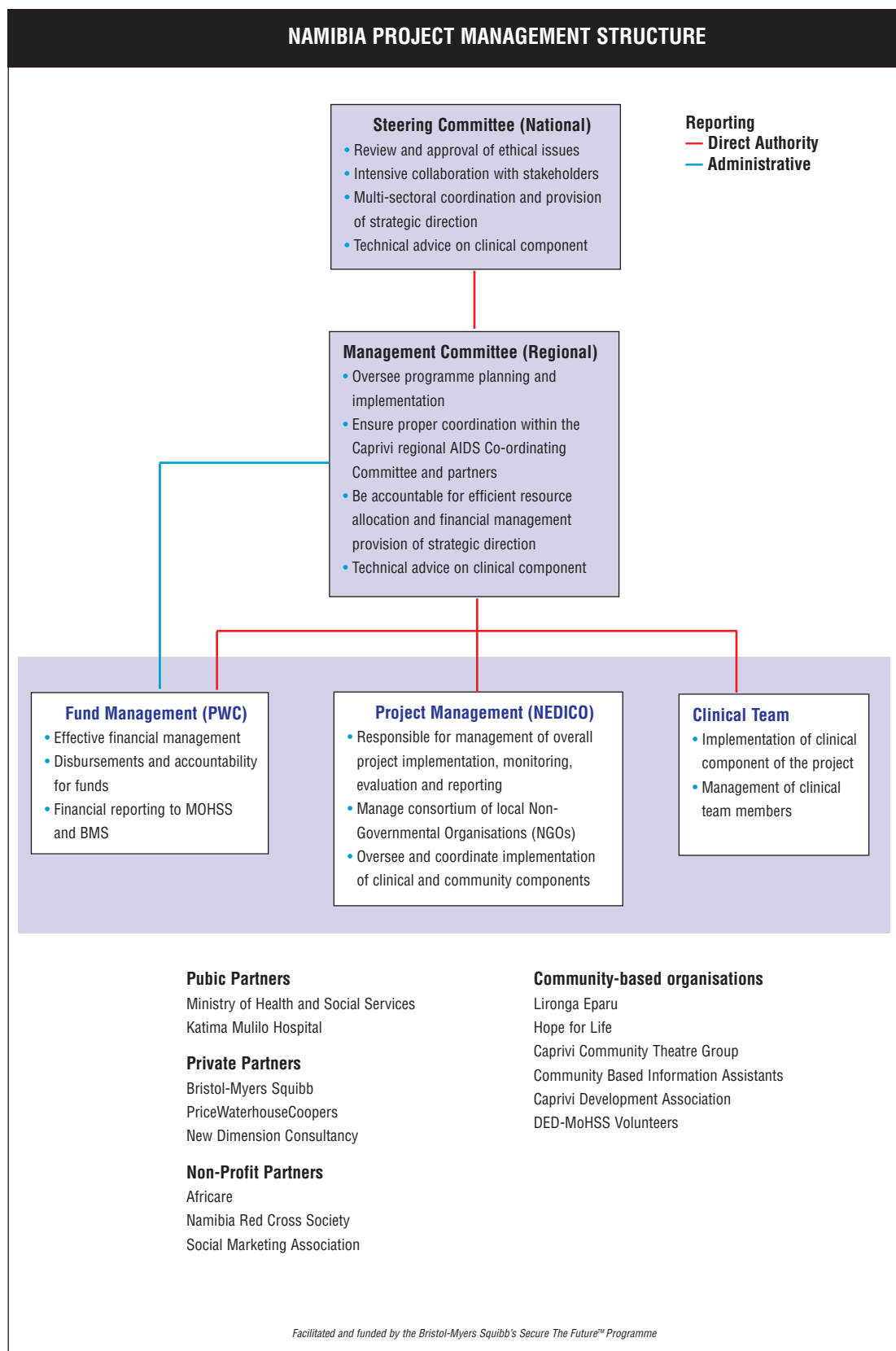
The name Mapilelo means "place of survival" and it was coined by the community in a naming competition held in the Caprivi Region at the beginning of the project. It meant that the community realized that HIV/AIDS was taking its toll and the project was the only means of survival. The name Mapilelo has become, therefore, a potent and well-recognized branding for the project.

## BUILDING A TEAM, LEADERSHIP AND MANAGEMENT STRUCTURES

### Project Management Structure

As with all the sites, strong project management was provided by a private company, NEDICO. Despite their offices being located in Windhoek, a three-hour flight from Katima-Mulilo, they visited often and their active involvement in the project was always felt. The management structure also succeeded in providing both supervision and a voice for the large number of community organizations involved in the programme.

FIGURE 12 MAPILELO PROJECT MANAGEMENT STRUCTURE



## ADAPTING THE CBTS MODEL

### Project Goals and Objectives

The goals and objectives of the project were enunciated using a classic approach; namely (1) establishing the needs, (2) setting goals to satisfy these needs, (3) assessing the available resources at baseline, and (4) determining the additional resources required to meet these goals as well as the means to procure them.

### Needs

The Mapilelo project was aimed at satisfying the need for prevention of mother-to-child transmission (PMTCT) and antiretroviral (ARV) services for HIV-positive people and people living with AIDS. But in order to do this effectively, it was necessary to understand the need for community support services.

### Goals

The overarching goal of the project was to reduce the prevalence of HIV infection and HIV/AIDS morbidity and mortality, with subsequently mitigated social and economic impact of the HIV/AIDS epidemic in the Caprivi Region. The project started off with the overall goal to put 750 clients on treatment, but that was later increased to 2,500 as the initial 750 were enrolled in the programme during the first year of implementation. This goal was to be attained by implementing effective community mobilization and civic education programmes through house-to-house visits, mass meetings, dramas, radio slots, and the development and distribution of information education materials.

### Assessment of Available Resources at Baseline

A selected number of volunteers from identified community-based organizations (CBOs) were trained on conducting baseline and impact assessment research. A quantitative survey as well as secondary data collection and review was carried out that informed the implementing partners about the available community support services and other important information critical for the effective implementation of the project in the Caprivi Region.

### Project Objectives

- Establish a project management structure
- Improve knowledge and attitudes, and change behaviours related to HIV/AIDS, through a targeted civic education programme
- Reduce the transmission of HIV from pregnant women to their children and improve the quality of life for the parents and children infected with HIV/AIDS, through establishment of a regional comprehensive PMTCT Plus programme in Katima Mulilo hospital. (PMTCT Plus implies triple ARV therapy when indicated for the mother and newborn child.)
- Increase access for people living with HIV/AIDS to ARVs, other therapeutic interventions and palliative care through a regional network of the regional hospital, 3 health centres and 25 clinics in partnership with the PMTCT programme
- Improve and expand home and community-based care, support groups and other support services for people living with and affected by HIV/AIDS

- Improve food security and nutrition at the household and community levels, including income-generating activities

### **Project Implementing Partners**

- **Ministry of Health and Social Services (MOHSS)**

The MOHSS was the primary player. At the national level it was the National AIDS Executive Committee and the Technical Advisory Committee on PMTCT, ART and Case Management, which supervises the project. At the regional level, the Regional AIDS Coordination Sub-Committee (RACOC), the Regional Health Management Team and the Katima Hospital Management implemented the project.

- **New Dimensions Consultancy (NEDICO)**

The project management functions were outsourced to NEDICO, an external agency that was responsible for ensuring smooth functioning, efficient delivery of services and timely implementation of activities. The overall goal of the management agency was to facilitate and coordinate the planning, reporting, coordination, accounting, resource allocation and direct supervision of the social mobilization, home-based care and food and nutrition components of the project.

- **PricewaterhouseCoopers provided fund management services.**

- **The National Institute of Pathology (NIP)**

NIP provided services for bioclinical diagnosis and monitoring of the clients and patients.

- **Namibia Red Cross Society (NRCS)**

NRCS, an affiliate of the International Red Cross operating in the Caprivi Region, was engaged in the local community-based initiatives to provide comprehensive support and complement the RACOC community programmes in the six constituencies. These initiatives included home-based care and ensuring a continuum of care from clinic to community.

- **Social Marketing Association (SMA)**

SMA provided voluntary counselling and HIV testing services to the residents of the Caprivi Region.

- **Africare**

Africare was another partner that was tasked with coordinating the component on food security and nutrition.

- **Lironga Eparu**

The Lironga Eparu branch of PLWHA in Namibia engaged its members in education about adherence to medication. It was also responsible for the buddy programme which offered psychosocial support for clients and intensively promoted adherence.

Other partners at the local level included various local community-based organizations involved in community mobilization through the media, meetings, drama performances and house-to-house counselling:

- Hope for Life
- Caprivi Cultural Theatre Group
- Community-Based Information Assistants
- Community Youth Development Assistants

This rather long list of implementing partners initially posed a problem of coordination. Most of them had not worked together before and many had no offices to work from, which is why a low-cost NGO village was constructed.

## **ACTION**

### **BUILDING PARTNER CAPACITY**

#### **Determination of Additional Resources Needed to Meet These Goals and of the Means to Procure Them**

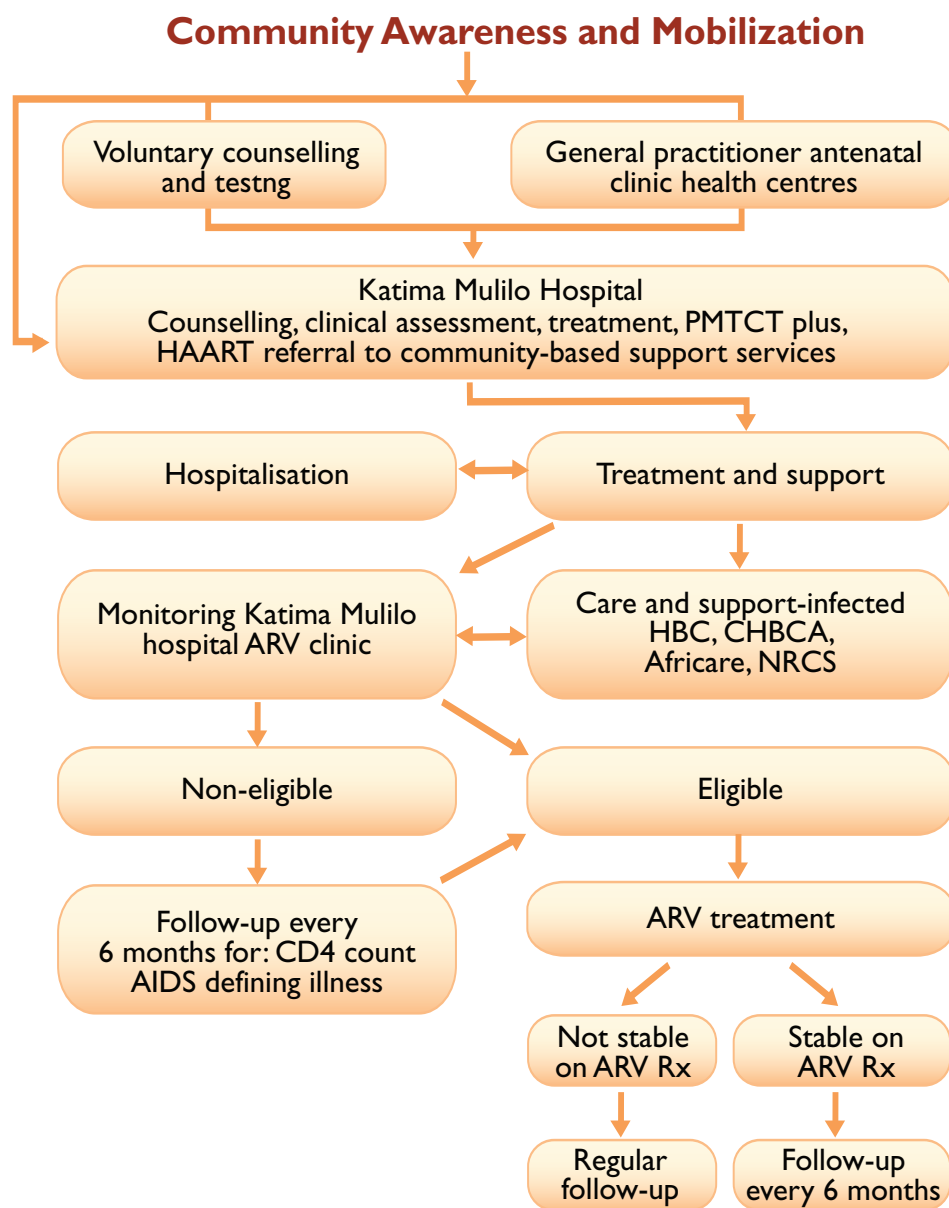
Prior to the implementation of the project-specific capacity building, human resource and material needs were identified for the effective implementation of the project as follows:

- Appointment of a project management agent and a fund manager
- Recruitment of additional staff
- Construction of a multipurpose NGO village and VCT centre
- Procurement of equipment and materials, e.g., boat and vehicles
- Renovation and construction of counselling rooms, consultation rooms and relevant infrastructures at the Katima Mulilo Hospital Complex
- Training of health professionals, NGO/CBO members and other key players
- Establishment and social marketing of VCT services

As the programme progressed, to complement the funding supplied by the *STF* programme, the Mapilelo project successfully accessed additional funds from the Centre for Disease Control and Prevention (CDC). This allowed all the above tasks to be carried out. Innovative and inexpensive approaches were taken whenever possible. For example, the NGO village was inexpensive to build because it made use of traditional materials and innovative techniques.



FIGURE 13 PATIENT FLOW CHART



### Community-Based Services

Community-based services in Caprivi built on and enhanced existing activities by national NGOs and local community organizations.

“In the Community-Based Treatment Support programme model, some form of support was offered to all. However, certain services such as food supplements were reserved for patients who were assessed to be malnourished or have inadequate access to food. To avoid these patients’ becoming dependent on food parcels, they were also involved in food security programmes such as vegetable cultivation,” said Jerry Mameja, Mapilelo Project Director.

The Food Security and Nutrition component trained clients on treatment in goat rearing, poultry farming, crop production and vegetable gardens. The Vita Goat project used raw materials such as fruits and soybeans to process into soy milk, yogurt, and fruit juices. In addition, there was a hatchery for processing eggs as part of the poultry projects. Various support groups participated in these projects, with assistance from their family members. “A balanced diet and availability of food are essential for clients on treatment,” said Dr Zengani Chirwa, Mapilelo Clinic Chief Medical Officer.

The introduction of treatment supporters and the buddy programme were milestones for the project, as they contributed to the reduction of defaulter rates and increased adherence in the region. The mass public disclosure by 25 buddies on World AIDS Day 2006 was a huge step in addressing stigma and discrimination in the region. The Minister of Health commended the buddies for taking such an unprecedented step, which he said would encourage others not only in the Caprivi Region but in the whole nation.

### Clinical Services

The clinical component started screening patients in October 2003 and set a targeted enrolment of 750 clients, a number that was reached within the first year of implementation.

When the programme started, most clients were brought to the clinic by their relatives when they were already very sick. However, with the reduction of stigma, testing uptake has increased as most of the clients started coming to the clinic voluntarily. Soon demand for testing and treatment increased to the point that there was an urgent need to increase the medical staff at the clinic. With demand also coming from villages outside Katima Mulilo, transportation still presented a barrier to patients seeking VCT. At the same time, blood sampling for CD4 measurement and ARVs also needed to be taken so clinic staff started outreach activities to clinics. This outreach also contributed to increased adherence and reduced defaulter rates in the areas reached.

“The outreach team delivers antiretrovirals to Chetto, an area designated for the disadvantaged San people. The nurse in the outreach team has been trained to dispense antiretrovirals to the chronic stable clients. This will be extended to other health facilities as part of a decentralization process now under way,” explained Dr Chirwa.

## REFLECTION

### MONITORING AND EVALUATION

In-depth interviews conducted as part of Family Health International’s (FHI’s) monitoring and evaluation framework proved the buddy programme to be effective in promoting adherence through peer interaction. Where there are many buddies they graduate into a support group. Formation of support groups has made it easier for the project implementers to target people in need of services and income-generating activities.

Initiation of ARV treatment has prompted people who were previously unable to work due to HIV/AIDS related illness to request medical documentation of ability to work again.

“Clients who came and requested retirement on medical grounds due to HIV/AIDS are now coming back after six months on ARVs and requesting to be certified fit so that they can go back to work,” observed Dr Chirwa. “This has encouraged a lot of clients to come forward for testing. It has brought hope where there was none.”

### **Clinical Services Results**

As of December 2006, the clinic pre-test counselled over 5,250 clients for HAART and enrolled 2,570 clients in the programme, of which 1,718 were on HAART. Over 3,000 pregnant women were pre-test counselled for PMTCT. Rapid testing centres were introduced at 10 district health facilities, including the maternity ward, and training was also conducted on dry spot testing of infants in the PMTCT programme.

### **Community-Based Services Results**

Residents of the Caprivi Region are now accessing voluntary counselling and testing, treatment and other services including home-based care, food security and nutritional supplementation, income-generating activities, buddy programmes and support groups.

Overall, the programme increased knowledge and awareness and changed attitudes about HIV/AIDS treatment services available through a strong community mobilization team. Involvement of community-based organizations increased community ownership resulting in a positive community response. The programme’s three-year target enrolment of 750 clients was reached within the first year of implementation. Due to high demand, a new target for programme enrolment of 2,500 clients was later set. The community mobilization team reached all constituencies in the region, and the effectiveness of their work significantly decreased HIV/AIDS related stigma and discrimination.

The home-based care component benefited 2,314 clients. This component of the programme trained 928 community volunteers who are caring for clients on treatment as well as terminally ill patients. Other benefits to clients included distribution of food parcels, blankets, umbrellas, T-shirts and caps, and participation in food security projects.

“More and more people are dropping out of the HBC programme because they feel they are well and strong enough to take care of themselves after they have started treatment,” said Erich Afrikaner, project manager.

## **IMPROVING AND REVISING SERVICES**

### **Challenges and Lessons Learned**

- Although significantly reduced, stigma and discrimination still pose a challenge in the fight against HIV/AIDS in the region. Some people fear that their households will be shunned and do not access the available services. Some spouses refuse to get tested even when they find that their partners have the virus. The medical staff at the clinics created letters which they gave to the spouses (mainly male) to invite them for counselling services, but for the most part, male partners tended not to access counselling and testing services.

- Male involvement was and still is a challenge. The project established a soccer team to attract male involvement through recreation. However, this did not bring about a great change in terms of males becoming involved in HIV/AIDS issues.
- Traditional beliefs reinforce practices that can contribute to increasing the infection rate. “The project has to some extent changed the attitudes of the people in the region, but it is very difficult to change the practices of the people due to their strong cultural beliefs,” said Erich Afrikaner. For example, some people use natural herbs to practice dry sex without a condom. Involvement of traditional healers in the programme helped to address some of these beliefs.
- Perennial seasonal flooding is a major challenge because it renders access to services virtually impossible for four to six months in certain areas, especially in the eastern part of the Caprivi Region. These clients can only be reached using a canoe during this period. The Mapilelo project purchased a boat for the outreach team to try and alleviate this problem.
- Many HIV-positive women of childbearing age who were on ART for more than six months commonly expressed the desire to have children. At a client workshop where women discussed the issue, most had lost a child or children and had a great desire to replace these children. Others felt that getting pregnant was the ultimate proof of recovery and womanhood. Still others mentioned pressure from their husband and relatives. The project’s initial strategy was to encourage clients up front not to become pregnant. Currently they are asked to consult with project staff if they want to have children, so that staff can ensure as safe a pregnancy as possible.

## **ACHIVA/MPILONHLE Project, Uthukela District, KwaZulu-Natal, South Africa**

### **Background Data**

#### **Country Demographics, Social and Economic Indicators**

**Population:** 42.2 million (2006, World Development Indicators database)

**Life expectancy:** 42.7 years (2006)

**Percentage of people living on less than US \$2/day:** 34.1% (1990-2003, UNDP)

**Per capita gross national income:** \$4,960 (2005, World Bank)

**GDP per capita:** \$13,000 (2006, CIA World Fact Book)

**Per capita government expenditure on health:** \$669 (2003, UNDP)

#### **Local Demographics (Uthukela District)**

**Population:** 680,333 (2001, census data)

**Sentinel surveillance:** 33.5% (2001, UNAIDS)

**Health infrastructure:** Three hospitals, 15 provincial clinics

### **PLANNING**

#### **Situation Analysis**

When the programme began, the pandemic was decimating communities in Uthukela and the rest of the province. Moreover, government officials estimated that:

- Nearly 2 million residents of KwaZulu-Natal would be infected with HIV by 2005
- Life expectancy would fall from 48 years to 38 years by 2007
- The number of maternal orphans would climb from approximately 85,000 to 440,000 by 2010

Government officials attributed these alarming statistics to widespread lack of information in the community about HIV, the presence of trucking routes through the province, poor and inconsistent use of condoms, migration, sexual violence and poverty.

“Like the province as a whole, the picture of the epidemic in the district was one of increasing deaths among young adults, ever-greater numbers of orphans and growing burdens on affected families and communities, in particular on women,” programme officials stated in a 2003 assessment of the pandemic. “And, despite the daily reality of the epidemic, the stigma associated with HIV/AIDS remains pervasive and represents an enormous challenge to effective interventions and service delivery.”

## ENGAGING WITH GOVERNMENT AND COMMUNITY

In 2003, the South African government and leading foundations started to plan programmes to provide patients throughout the country with antiretroviral therapy—including the province of KwaZulu-Natal. But none of those initiatives were covering the province's Uthukela District when Bristol-Myers Squibb approached the government about the possibility of developing a CBTS programme there. The Department of Health agreed, and STF started consultations in Ladysmith Provincial Hospital and engaging local community groups to provide the necessary community services in the surrounding district of Uthukela. The Uthukela District is a rural area of around 600,000 people with high HIV prevalence, poverty and unemployment.

BMS partnered with the local, provincial and national Departments of Health in establishing the Augmented Community HIV Action (ACHIVA)/MPILOHNLE project. Ladysmith Provincial Hospital (LPH), the largest in the district, managed the clinical component and collaborated with private physicians to oversee operational research.

### How Did STF Engage with the Government?

As in all five of the southern African countries in which STF operated, consultation with the government and, in particular, with the National Department of Health had been instituted from the beginning of the programme in 1999. Although there were some issues initially in gaining the Department's trust, by the time the CBTSP was conceived, the relationship was smooth. The details of the partnership in KwaZulu-Natal were negotiated with the Provincial Department of Health, based in Pietermaritzburg, and the local authorities in Uthukela.

There was some "give and take" in these negotiations. For example, the Department requested that STF place the equipment required to measure CD4 count in a nearby town rather than in Ladysmith, because it was felt to be a more logical geographic location. On the other hand, considerable effort was made to accommodate the project needs within Ladysmith Provincial Hospital, and LPH management was more accommodating to integrate community support services there.

"This site started about six months behind as it had to wait for the national government policy to provide comprehensive care and treatment and LPH had to be accredited according to guidelines of the programme," said Phangisile Mtshali, Director, STF Southern Africa. "LPH was initially not in the first phases of the provincial ART accredited sites, but the partnership with STF assisted them to jump the queue."

### How Did STF Reach Out to Community Organizations?

Mpilonhle, a local nongovernmental organization in Ladysmith, submitted the community component of the proposal to BMS and became the manager of the community-based services in the programme. Mpilonhle went about in the community to identify community-based associations and home-based care volunteers. Extensive consultation and engagement with traditional leaders was an important part of this site and was necessary to ensure ownership of the programme and support for volunteers.

## BUILDING THE TEAM, LEADERSHIP AND MANAGEMENT

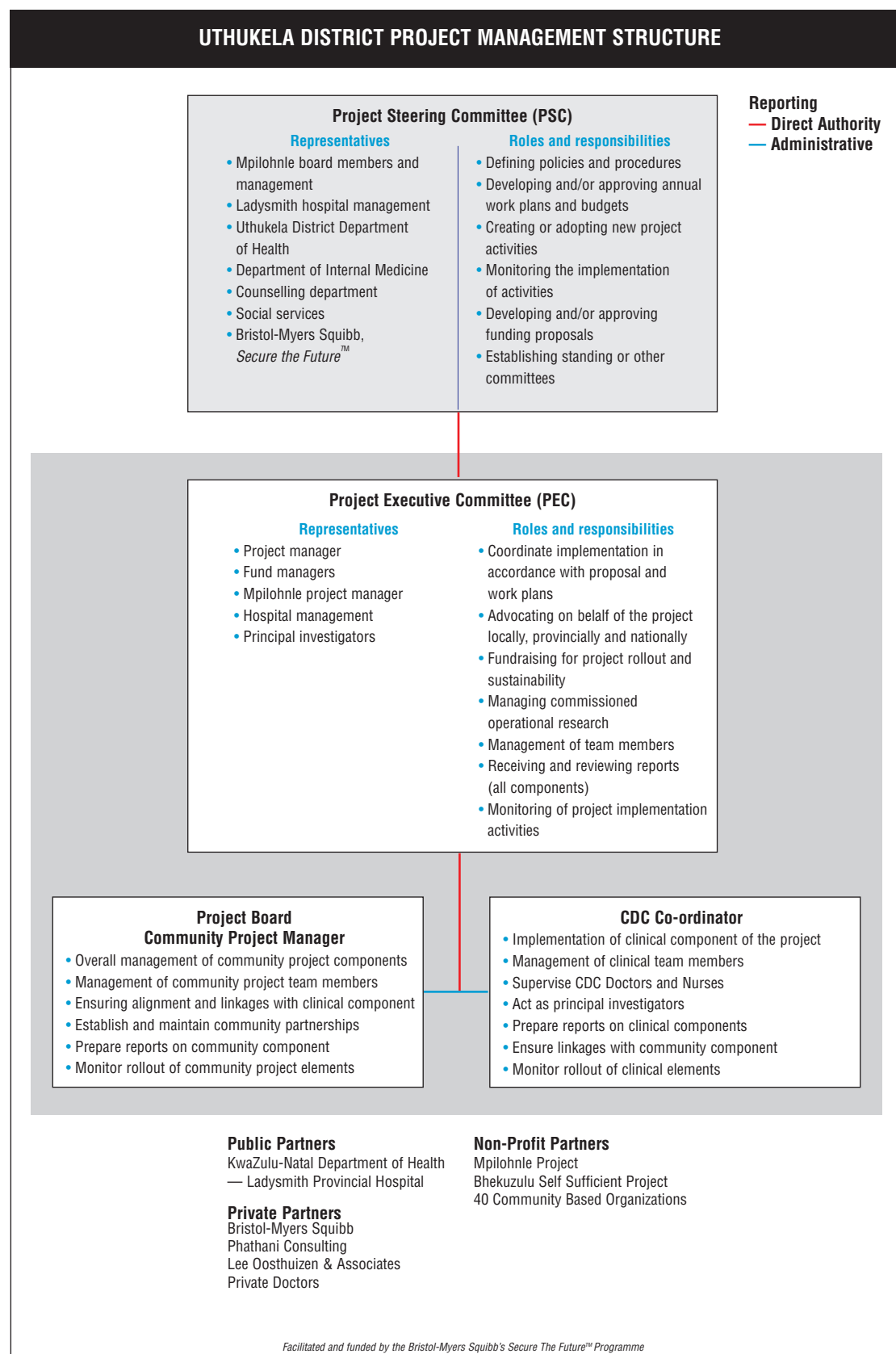
### Project Management Structure

Just as Mpilonhle had dedicated and skilled staff and volunteers, Ladysmith Provincial Hospital already had a small group of highly committed health professionals, who were already running a small clinic for HIV-positive patients, although ARVs were not yet available.

They formed the core of the new programme. Initially, activities were directed very competently by the hospital medical manager, Dr Nambassi. He very effectively led the planning stages and was invaluable in negotiations with the Provincial Department of Health. However, it was not appropriate to expect him to continue in this role when implementation began, given his considerable other important responsibilities. Thereafter, project management was entrusted to a private company. The project manager assigned by this company was not physically located in the Ladysmith area. Although the professionals working in the clinic and at Mpilonhle were individually very competent, overall project management was not as good as hoped. This is highlighted here simply to point out again how important it is to identify a strong project manager as early as possible, preferably working daily with the teams at the site.

The project management structure is illustrated in the following diagram. The individual committees functioned competently; however, in the absence of strong project management, a programme of this complexity with many stakeholders cannot operate optimally.

FIGURE 14 ACHIVA/MPILOHNLE PROJECT MANAGEMENT STRUCTURE





## ADAPTING THE CBST MODEL

### Project Goals and Objectives

The ACHIVA/MPILONHLE project decided to pursue the dual goals of (1) determining how ART can be administered to HIV/AIDS patients in a resource-limited setting at minimal cost and (2) improving the quality of life of communities in the district by promoting and supporting a holistic approach to all health-related challenges, particularly HIV/AIDS. The initial goal was to provide this holistic care to approximately 1,000 patients.

The project also established several ambitious objectives:

- Mobilize and involve communities in specific community groups in all project activities
- Initiate and sustain support for affected households in food security and care of orphans and vulnerable children
- Establish systems to monitor and sustain all elements of the project
- Develop a continuum of care and support for clients with HIV/AIDS and other terminal conditions
- Build facility infrastructure, including clinics and laboratories
- Strengthen prevention of mother-to-child transmission and sexual violence post-exposure prophylaxis programmes and provide antiretroviral therapy

### What Were the Roles of the Implementing Partners?

After identifying the partners, their roles were determined as follows:

- **The National, Provincial and Local Departments of Health** assisted with provision of treatment literacy, training materials and HIV/AIDS-related media. They also used existing government structures to ensure treatment compliance, access to resources and project coordination.
- **Ladysmith Provincial Hospital's Communicable Disease Clinic (CDC)** coordinated patient follow-up, managed the project and provided daily clinical services.
- **Ladysmith Provincial Hospital's Social Work Unit** provided psychological support and stress management, facilitated and developed support groups, and provided ongoing counselling and family therapy.
- **Mpilonhle** (a Zulu word meaning holistic wellness) supported and provided wide-ranging community-based services and treatment literacy. And, crucially, they put in place an efficient system of tracking those patients who defaulted from clinic visits **using 39 community-based organizations**. They also partnered with **Bhekuzulu Self-Sufficiency Project (BSSP)**, an NGO that was already active in one part of the district.

### Project Implementation

Key components of the programme managed by these organizations included:

- Providing psychosocial services and linking clinical and community-based activities
- Conducting community mobilization, including training and advocacy
- Providing home-based care and household support

- Providing comprehensive HIV/AIDS management
- Conducting an operational study assessing how antiretroviral therapy can be implemented
- Monitoring and evaluation

## **ACTION**

### **BUILDING PARTNER CAPACITY**

LPH benefited greatly from infrastructure upgrade, equipment, enhanced personnel and training that ranged from Good Clinical Practice to side effect management. As originally envisaged in the tripartite partnership model, training for health professionals was open to those in the public and private sectors throughout the district.

The programme took an empowerment approach when it came to community partners. Mpilonhle staff, leadership and board were supported with training on good governance, project management and resource mobilization. Mpilonhle in turn employed the same approach with its 39 CBO partners, providing them technical, life skills and livelihood training.

### **DELIVERING SERVICES**

#### **Integration of Services**

Under Dr Nambassi's guidance and with significant input from the STF team, the roles and responsibilities of the clinical team and of Mpilonhle's personnel were established. A continuous effort was required to maintain effective communication between the clinical and community components. A patient flow diagram had been developed at the time of initial proposal writing. On the basis of this patient flow, lines of referral were developed so that patients could be effectively referred between the two components. To facilitate this referral process, a comprehensive client documentation tool was developed. This tool provides for extensive documentation of both clinical and community services and results. At a glance, all interested personnel could gain a complete picture of any patient's history and management within the programme.

One of the most effective aspects of the integration was the system developed to trace clinic visit defaulters. Mpilonhle staff were immediately informed when a client defaulted, and a community worker was dispatched to find the patient to reengage him or her if necessary and get the patient back to the clinic. This system contributed to the programme's low dropout rates—less than 5% of patients were lost to follow-up.

In order to formalize interaction between the various stakeholders, an Implementers' Forum was created, an idea shared from the Lesotho site.

#### **Patient Flow**

The clinical component of the ACHIVA Mpilonhle project evolved quickly. When Ladysmith Provincial Hospital's HIV/AIDS centre, the Communicable Diseases Clinic (CDC), opened in 2002, it provided limited services to predominantly female patients, maintained a limited schedule and was not widely known in the community. This began to change, however,

when the clinic began providing ARVs to patients in 2004. “People started hearing about the clinic from other patients. They started coming here in greater numbers,” said Dr Fazila Amod of Ladysmith Hospital.

The resulting large increase in patient registration under the programme placed a significant strain on the CDC’s limited staff and space, leading to the decentralization of the clinical programme in October 2005. Under this new structure, primary health centres in the community began to manage all patients with a CD4 count greater than 200, and refer patients to the CDC clinic when their CD4 count fell to less than 200 or they experienced an AIDS-defining illness (both criteria for initiating ARV therapy). The primary health centres were also expected to issue ARVs to patients in the next phase of the decentralization plan, said Dr Mohamed Khan, head of internal medicine and the HIV division at the hospital.

In addition to reducing the burden on the hospital, decentralization made services more easily accessible to the patients, some of whom had previously travelled up to 50 km (31 miles) to get to the hospital. Patient flow before and after decentralization is illustrated in Figure 15.

FIGURE 15 PATIENT FLOW PRIOR TO DECENTRALIZATION

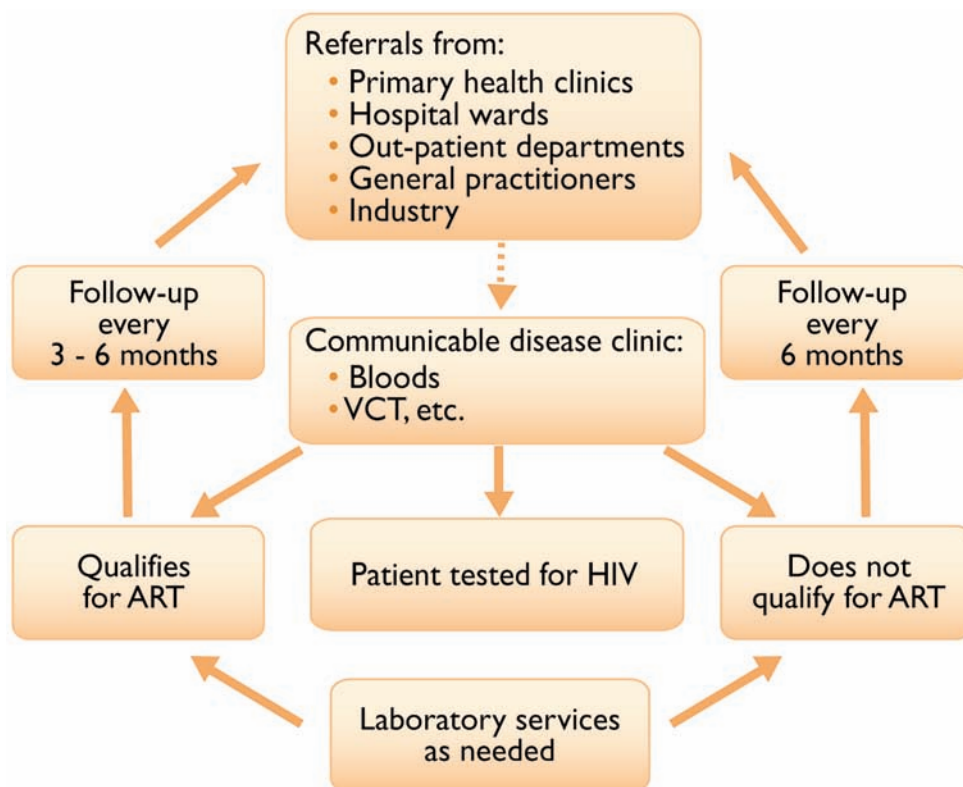
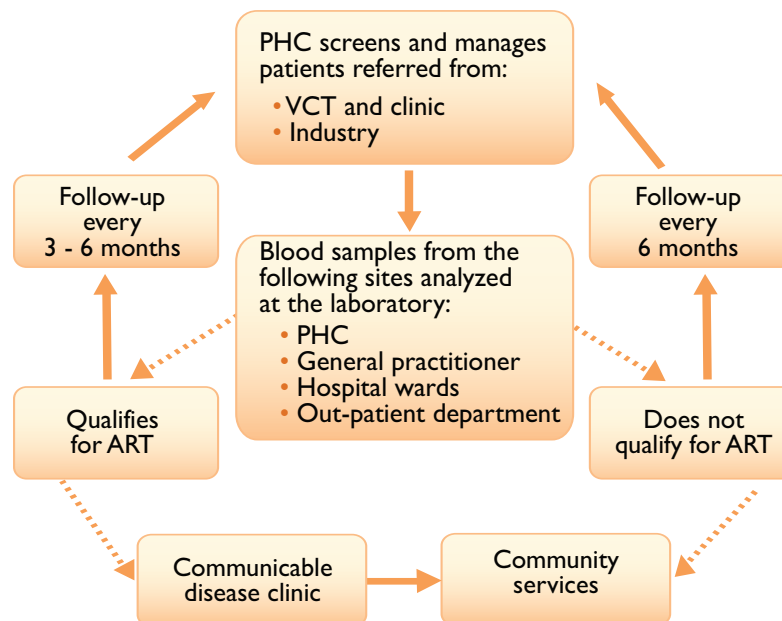


FIGURE 16 PATIENT FLOW AFTER DECENTRALISATION



“As the ARV rollout has escalated, the hospital staff has become overburdened,” said Dr Amod. “It is therefore important that services be decentralized so that at the grassroots level, clinics are empowered to manage patients requiring palliative care as well as to manage patients on ARVs, recognize a problem and refer to the hospital in a timely manner.”

Dr Amod emphasized the role of decentralization in maintaining high-quality patient care. “We cannot cope with everyone here and provide high-quality service at one site,” he said.

A CDC patient who went on ARVs in 2005 commented on the benefits of the new system. “I am glad I will be able to collect my medicines at a clinic. I would prefer to go there to get them. It will make it much easier for me,” she said.

### Community-Based Services

Mpilonhle has addressed community needs in such key areas as food security, home-based care, community mobilization and services for orphans and vulnerable children (OVC). The organization mobilized 600 community volunteers to help provide these services. For Mpilonhle, home-based care was the centrepiece of their programme, and many of the volunteers were devoted to these efforts.

### Home-Based Care

Community-based organizations provided home-based care services to residents of the district before the BMS programme began. These volunteers, who reported to community health workers, typically cared for people who were either in advanced stages of AIDS or had other terminal conditions.

When the CBTS programme got under way, Mpilonhle trained their volunteers and forged partnerships with other CBOs to provide comprehensive home-based care services to the programme clients, including those who were HIV-positive. Services included providing clients with information on HIV/AIDS and how to take their drugs properly, encouraging them to be tested and accompanying them to clinics for testing as indicated.

“Years ago I did not think home-based care was a necessity,” confessed Nomusa Sithole, the home-based care manager at Mpilonhle. “But I came to see what a dire need there is to care for the sick and to educate people. Home-based care workers do that.”

Furthermore, the scope of the programme’s care reaches beyond the clients themselves, and home-based care officials say their role has changed as the programme has evolved.

“When we visit people’s homes, we must not focus just on the sick person,” said Hlengiwe Happiness Shabangu, a home-based care worker and support group leader. “We must educate all members of the family....I feel I am more effective now. People are more open at home now than they used to be.”

Also, with the increasing number of clients accessing and adhering to antiretroviral therapy, home-based care volunteers are no longer caring primarily for clients on the brink of death.

Home-based care volunteers and buddies help organize support groups for PLWHA in the district. The programme started with only five mixed male-female groups, but has since grown to more than 30 groups as PLWHA have become increasingly comfortable disclosing their HIV status to others. Some of the support groups in the community are engaged in such income-generating activities as gardening, bead work, poultry farms and crafts. Home-based care workers and buddies have helped organize these activities and train participants. The poultry project, in particular, was a profitable IGA.

Mpilonhle employs many vehicles to mobilize community members and inform them about programme services, including community meetings, special events, brochures, musical bands and theatre. The project works closely with community leaders in that effort, including schools, churches and government agencies. Mpume Zwane, Mpilonhle project manager, said the organization has not used radio or television yet in its mobilization campaign. The project’s biggest mobilization activity was its launch, which was broadcast live by Ukhozi FM, South Africa’s biggest indigenous-language station.

### **Food Security**

The household support, food security and orphans and vulnerable children (OVC) Care Protocol is another key component of the programme that works towards sustainable food and nutrition security in that community. This component was included based on the recognition that accessible information on good nutrition and knowledge about how to prepare nutritious meals are needed for treatment and care efforts to be most effective for people living with HIV/AIDS. The protocol’s key provisions included identification and assessment of family and OVC nutritional needs, procurement and provision of emergency food, instruction on food and nutrition, and assistance in securing government grants. Assessment of nutritional needs was important because not all households require

assistance. Mpilonhle also provides classes in how to prepare nutritious meals with products either available or grown.

A long-term goal of the programme is to help households grow their own food. But the cultivation of a sustainable crop of vegetables or establishment of a self-sustaining poultry farm takes time. Therefore, households receive food parcels in the interim, usually for at least three months. Household members can simultaneously receive training in growing their own vegetables in door-size gardens beside their houses.

The food security component also provides food to more than 2,020 OVC on school days at 15 halfway houses in the Uthukela communities. A halfway house is a place where the children go on the way to and from school. They also receive two warm meals, assistance with homework and life skills training.

“Some people in the community could have died due to malnutrition,” said Hlengiwe Happiness Shabangu, a home-based worker and support group leader in the programme. “These activities have played an important role in helping people to live longer.”

“Unemployment is high and people need and appreciate self-help activities,” said Nomantshali Mtshali, Household Support Food Security Specialist at Mpilonhle. She cautioned, however, that the gardening programme confronts serious challenges. “The weather can be severe here. Also, water that can be used for the gardens is limited here. What’s more, livestock sometimes destroy gardens.”

Nutrition is central to Mpilonhle’s OVC programme, which also includes training the children in life skills. Halfway houses in the district provide free meals to local OVC both before and after they attend school. Some of these facilities draw upon adjoining gardens to feed the children.

“Nutrition is a big problem for many of the kids. We try to help meet that need at the halfway house,” said Sibongile Thabede, chairperson of the St. Chads halfway house, which cares for 50 children ranging in age from 1 through 16.

Most of the 16 halfway houses are funded by BMS. The others are supported by private community benefactors Richard Tarlow and Alexander Forbes. The facilities care for approximately 500 children, most of whom are orphans. Happiness Mohlakoane, the OVC coordinator and community facilitator at Mpilonhle, reported that some of the children who attend the halfway houses care for younger siblings, but most live with older family members, including grandparents. The programme trains the community volunteers who operate the halfway houses in counselling, home-based care and nutrition.

Happiness reported that the programme has received contributions of clothes, books, toys and blankets from several sources, including BMS employees in the U.S., government agencies and local businesses. “We always inform the communities about the halfway houses before they open. They have been very supportive,” she said.

## REFLECTION

### MONITORING AND EVALUATION

#### Community-Based Services Results

Mpilonhle partnered with the Department of Agriculture in providing food security services to district residents. This included funding and training for door-sized and community vegetable gardens. According to programme officials, 277 door-sized gardens and 75 community gardens consisting of such staples as carrots, spinach, broccoli, beetroot and cabbage had already been planted as of July 2006.

Programme officials have also conducted workshops on nutritious food preparation throughout the district, she said. The Department of Agriculture also staged a traditional foods competition. The programme had trained 2,158 clients in food security activities as of June 30, 2006, far exceeding the totals of other community-based HIV/AIDS programmes in the region. Mpilonhle has also procured and distributed food parcels to eligible families that have not received them from the Departments of Health and Social Welfare.

Sibusiso Ndebele, a buddy programme trainer, said he has worked with more than 100 clients and trained more than 70 buddies since he joined the programme three years ago. He has witnessed an increasing willingness by the community to embrace PLWHA, but remains concerned about stigma and discrimination against them. “I want to defeat stigma and fear,” he said. “I want to stay in the programme until these problems are defeated.”

#### Clinical Services Results

The clinical component of the ACHIVA Mpilonhle project has produced impressive outcomes. Patient registration at the clinic increased dramatically from only 176 in 2002 to 2,535 in 2005. Dr Khan reported that the number of patients receiving antiretroviral therapy rose from 143 in 2004 to 1,020 in 2005. By the end of 2006, 2,276 patients were receiving ARV treatment. The number of clients accessing counselling and testing services also increased from 192 in 2002 to 1,890 in 2005. At the end of 2006, the number had climbed to 5,700.

A CDC patient said she has gained strength and weight since she went on ARVs, and feels more confident now about disclosing her HIV status to others.

“It is much better since I started taking the drugs there,” she said. “I have accepted HIV and am moving on with my life.”



## IMPROVING AND REVISING SERVICES

### Challenges and Lessons Learned

Despite impressive gains, ACHIVA/MPILONHLE faces some serious challenges.

- The OVC programme needs to be substantially expanded. There are insufficient halfway houses to meet the needs of OVC in the district.
- OVC in the halfway house programme currently receive nutritious meals only on school days.
- Communication needs to be increased and improved between the community volunteers at the halfway houses and the children's caregivers. Currently, they do not consult on a regular basis about the children's problems and progress.
- Volunteers in the programme receive training in child counselling. "These children need a lot of psychological care, and we need to put more emphasis on that," said Ms. Zwane.
- Some HBC clients are uncomfortable receiving care from people whom they do not know well.
- A limited number of men have accessed clinical services so far and this is attributed to stigma. "The culture perpetuates this problem," said Elize van der Merwe, social work manager at LPH. "Those here are greatly influenced by other men. We need more men to work with men and to touch upon issues that are sensitive to them, like promiscuity." The programme recently addressed this problem by forming a support group for men at the clinic.
- CDC officials said most patients adhere to their treatment programmes. But some are defaulting, they said, for a variety of reasons including:
  - switching to traditional medicines;
  - difficulty keeping appointments;
  - pressure from family members to stop taking ARVs; and
  - mistakenly believing they no longer need ARVs once they start to feel better.
- Clinical staff is receiving ongoing training about possible adverse reactions to drugs, especially as decentralization continues.
- Prevention of mother-to-child transmission services need to be strengthened and delivered as a comprehensive programme for mother, child and partner.



## PORECO Project, Mbabane, Swaziland

### Background Data

#### Country Demographics, Social and Economic Indicators

**Population:** 1.1 million (2006, World Development Indicators database)

**Life expectancy:** 36.6 years (2005, World Bank)

**Percentage of people living on less than US \$2/day:** Statistics not available

**Per capita gross national income:** \$2,280 (2005, World Bank)

**Per capita government expenditure on health:** \$324 (2003, UNDP)

#### Local Demographics (Hhohho District)

**Population:** 247,539

**Sentinel surveillance:** 40.3% (2004)

### PLANNING

#### Situation Analysis

During the 1990s, babies born HIV-positive were dying at a steadily increasing rate in Swaziland. In that period, the infant mortality rate rose from 72 to 87 per 1,000, according to government agencies. Moreover, the country's adult HIV infection rate of more than 25% in 2002 was one of the highest in the world, and the prevalence among pregnant women was close to 43%, according to UNAIDS reports.

In late 2002, the Ministry of Health and Social Welfare (MOHSW) was considering how best to launch an antiretroviral (ARV) programme for the country. Until then the only focus of ARV usage in the public health system was prevention of mother-to-child transmission (PMTCT), using nevirapine for both mother and newborn child. The Ministry decided to build on that experience. Because nearly 90% of women in Swaziland access antenatal services, according to government agencies, the integration of PMTCT services into maternal health programmes seemed a logical approach to provide triple ARV therapy to pregnant women when indicated.

The NGO Swaziland Infant Nutrition Action Network (SINAN) has led the effort to introduce PMTCT services in Swaziland. The organization, which provides PMTCT-related training to local health workers, is widely recognized as an expert in infant feeding, child nutrition and child health. In 2002, SINAN, in partnership with UNICEF and the Nazarene Church, initiated a PMTCT programme targeting families. SINAN subsequently developed PMTCT guidelines, which were adopted by the MOHSW in 2003.

## ENGAGING WITH GOVERNMENT AND COMMUNITY

### How Did *SECURE THE FUTURE* Engage with the Government and with the Community?

By 2003, the Bristol-Myers Squibb (BMS) *SECURE THE FUTURE* (STF) programme had established a good track record of funding community outreach and education projects in Swaziland. Accordingly, when BMS approached MOHSW about making antiretroviral therapy available to the public in Swaziland, the Ministry suggested BMS take the lead in building upon the existing national PMTCT programme and support a PMTCT Plus component in Mbabane that would provide clinical and community-based follow-up services, including triple ARV therapy when indicated, to the entire family. Negotiations moved very quickly because this was a win-win situation. It allowed the MOHSW to begin an ARV programme earlier than originally feasible and it provided an opportunity to test the Community-Based Treatment Support (CBTS) programme concept in a unique programme in a resource-limited setting. The programme was different from the other CBTS programmes in southern Africa, in that it was focused on PMTCT looking to leverage pregnancy as an entry point to care and a special motivation for a pregnant woman to accept voluntary counselling and testing (VCT) at an antenatal clinic. This approach was also in keeping with the *STF* programme philosophy of consultation with government and alignment with their health policies and priorities.

The resulting innovative community-based treatment support programme, which started in 2003 at the Mbabane Government Hospital, was called the Swaziland Pilot Operational Research and Community-Based PMTCT Plus Concept (PORECO). For everyday project management and to run the community components, the MOHSW selected SINAN, who had infrastructure and an interest in mother and child health. However, SINAN was indeed well established and, as it turned out, brought superior project management skills to the programme.

Bonisile Nhlabatsi, the PMTCT point person in the Sexual Reproductive Health Unit of MOHSW, cited several reasons why the Ministry supported the programme: the positive outcomes of the services provided by SINAN and UNICEF, the strong demand in the country for PMTCT, the excellent clinical services provided by the government hospital, and the high infant mortality rate and resulting political pressure to address this problem.

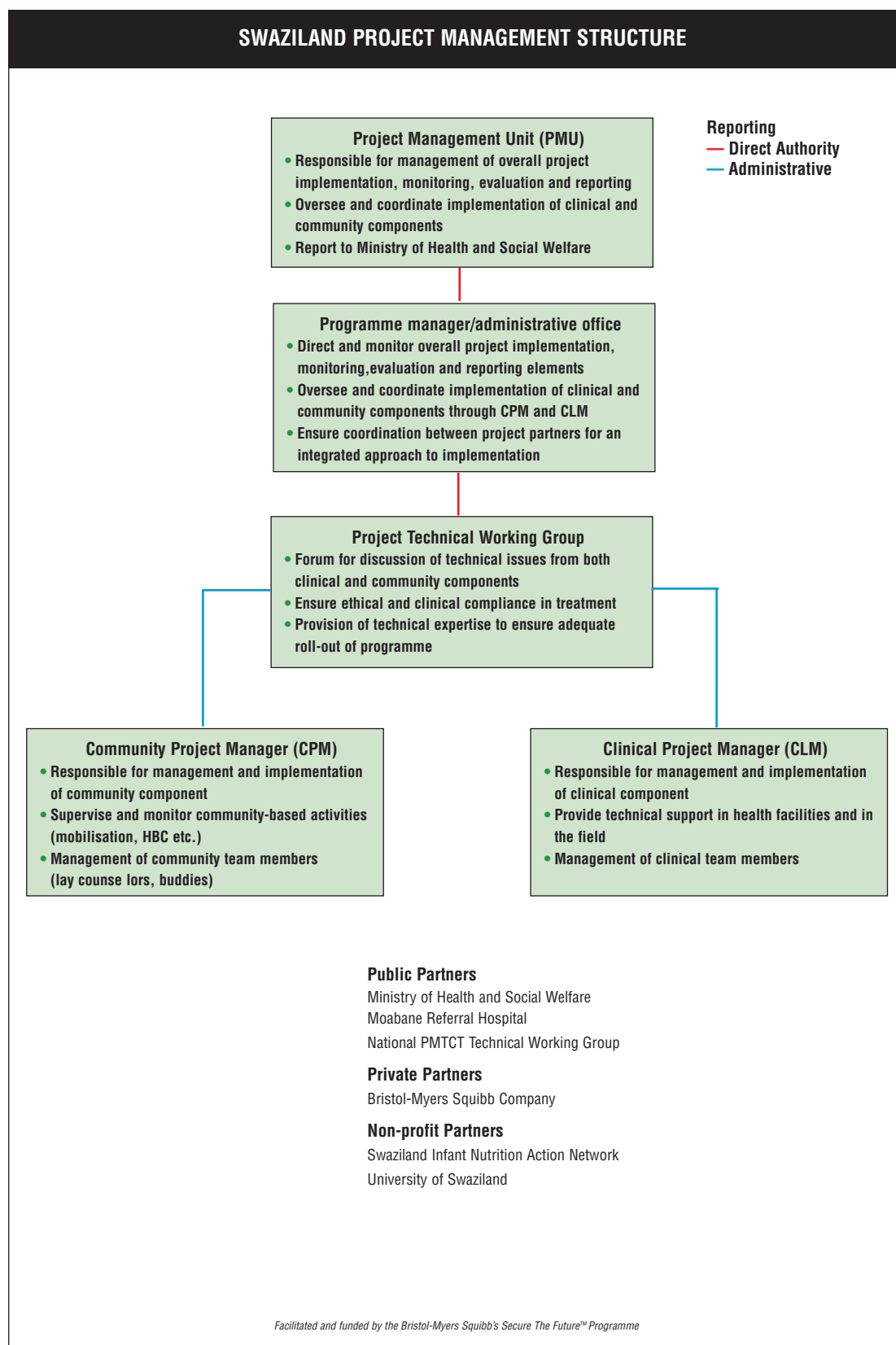
## ESTABLISHING THE TEAM, LEADERSHIP AND MANAGEMENT STRUCTURE

### Project Management Structure

A Project Management Unit (PMU) chaired by the principal secretary of MOHSW was responsible for overall coordination and monitoring of the programme. The PMU met quarterly. SINAN handled daily financial and administrative management. A technical working group consisting of government and nongovernmental stakeholders provided ongoing technical support and guidance to the programme.

The direct involvement of the Principal Secretary and other government officials was unusual, but indicative of the level of importance afforded to the project by the government. “It is important when developing a programme like this to have government buy-in. It has worked well here. The government has been very supportive,” said Nomvuyo Shongwe, PORECO’s community project manager.

FIGURE 17 PORECO PROJECT MANAGEMENT STRUCTURE



Despite this direct government involvement, the structure illustrated earlier gave a very prominent role to the project management services provided by SINAN. Project management had direct authority over both the clinical and community components, very much in keeping with the Principal Secretary's emphasis on the necessity for strong project management of a CBTS programme. Planning and implementation proceeded rapidly. In fact, PORECO, being launched at the end of 2003, was the first of the *SECURE THE FUTURE* CBTS programmes to start because of several factors, among them:

- Strong project management
- Political engagement in the HIV/AIDS epidemic by the government
- Evident government ownership (as seen by their involvement in the management structure)
- The circumscribed nature of the programme design in terms of target patient population and sample size

## ADAPTING THE CBTS MODEL

### Programme Goals and Objectives

The project's chief goals were to integrate PMTCT care and support in maternal and child services at the Mbabane Hospital, strengthen community capacity to reduce stigma and discrimination and fear of testing, and enhance client care and support. Because the project was conceived as a pilot, with an aim to guide future PMTCT services in the country, it was limited to 200 mothers, their newborn children, their partners and other siblings. To strengthen the interpretation of the outcomes, the *SECURE THE FUTURE* programme suggested an operational research component to which the MOHSW readily agreed. The programme's key objectives were:

- Creating community awareness and readiness for PMTCT and ART programmes
- Building the capacity of community volunteers, buddies, traditional birth attendants and lay counsellors to effectively implement community-based activities
- Providing comprehensive mother and child health services (antenatal care, delivery and postnatal care)
- Providing PMTCT medication
- Establishing and maintaining support systems, such as psychosocial and nutritional care
- Providing palliative care and support to symptomatic mothers and children
- Providing nutrition and ongoing counselling and support to mothers and children
- Managing the PMTCT model, including provision of triple ART to HIV-infected mothers, newborn babies and partners, when indicated

### Implementing Partners

A team of complementary organizations partnered with STF to implement this programme:

- The Ministry of Health and Social Welfare's Swaziland National AIDS Programme (SNAP) provided policy guidance, clinical facilities and site personnel for the clinic services.
- SINAN handled community-based services and coordination of staff training.

## Implementation Plan

The key components of this programme were:

- Community mobilization, including a large-scale door-to-door education campaign
- Daily clinical services, including VCT, PMTCT Plus and ART, when required
- Infant feeding counselling, nutrition and food security
- Patient data collection and analysis
- Objective and comprehensive monitoring and evaluation

The three-year project started in 2003 seeking to prolong the lives of 200 mothers, 200 partners and 200 babies through an integrated programme of triple ART and sustained comprehensive community support.

“Initially I thought someone on treatment had all their problems solved, but I found out otherwise,” said Mrs Bhembe, the Project Manager. “People need continuous care, psychosocial support and other services. When someone is infected, it is a continuous battle. Unless you actualize the social problems that person faces, you will not succeed in addressing HIV/AIDS.”

The clinical component of the operational research was conducted by principal investigator Dr Priya Mahaliyana-Dissanyake and specialists in internal medicine, paediatrics, obstetrics and gynecology. A key contributor to the operational research component was the research nurse, Marie Hallissey, who excelled in data management and producing relevant reports on time. The community capacity component was implemented by SINAN in collaboration with other stakeholders such as the City Council, NGOs, private clinics and community-based health workers. Funding and technical assistance was provided by BMS.

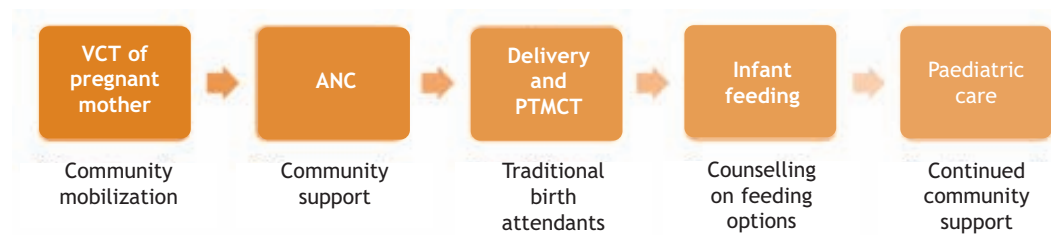
## DELIVERING SERVICES

### Integration of Services

The technical working teams developed a coordinated continuum of care from the time the pregnant woman opted for VCT, through her subsequent pregnancy, delivery and postnatal care and paediatric care of her child thereafter until 12 months of age, when the child’s serostatus was definitively determined.

These clinical services could not be integrated as such. Therefore, to ensure that coordination ran smoothly and to provide comprehensive community support throughout, the various community services were assigned to support appropriate components of this continuum of care. The continuum of clinical services and the relevant community support services are illustrated in the following diagram.

FIGURE 18 CONTINUUM OF CLINICAL SERVICES AND RELEVANT COMMUNITY SUPPORT SERVICES



### Clinical Services and Patient Flow

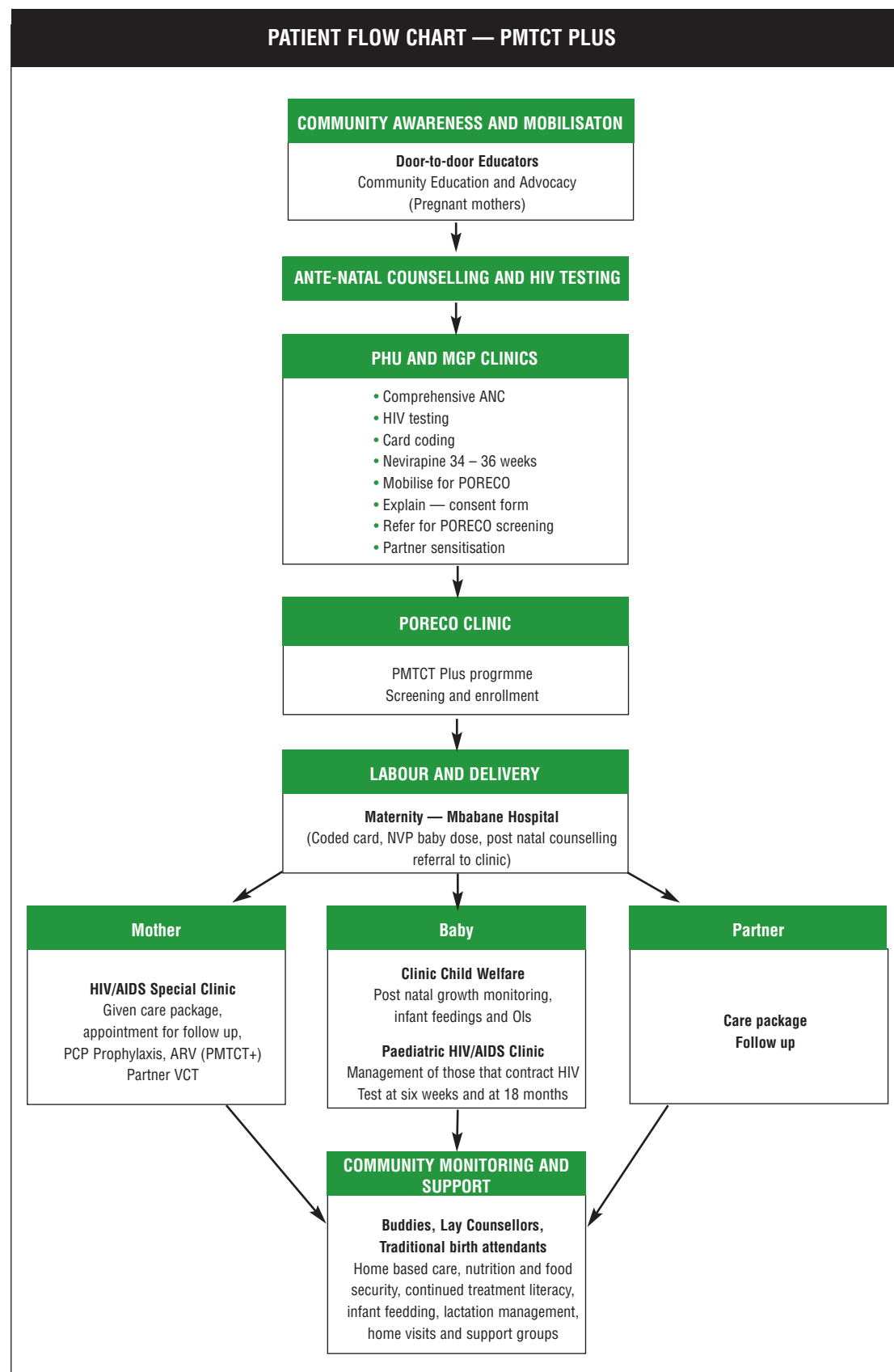
Clinic personnel reported that the majority of potential PORECO clients typically receive antenatal services at one of the five feeder clinics in the community, including the Mbabane Public Health Unit affiliated with the hospital. Women attending these feeder clinics receive information on PMTCT and are encouraged to receive an HIV test.

Those who tested positive and lived in the catchment area were counseled on infant feeding options, received information on the project, and if interested, were referred to the PORECO clinic, where they received care from the PORECO clinic nurse and doctor. PORECO personnel said the women were encouraged to disclose their status to their partners and to invite them to join the project as well. The clients were also encouraged to deliver at the Mbabane Government Hospital maternity ward.

Women in the programme received nevirapine (in accordance with national treatment guidelines) just prior to delivery either in the maternity ward or at home by a traditional birth attendant. Their newborn infants received the paediatric dose within 72 hours of delivery (typically this was accomplished within 24 hours). The women also received intensive infant feeding counselling and advice on contraception and family planning options. The newborn babies received routine care, including immunizations. When discharged from the hospital, the clients were reminded to return to the PORECO clinic in six weeks, or sooner if they were on ARVs.

The babies were also monitored regularly under the programme. All of the babies received PCR (DNA) tests when they were six weeks old and those breast-fed were tested again at nine months. All of the babies' serostatus was checked at 12 months. Testing at six weeks has been followed in the PORECO project for operational research purposes. It is a best practice, but is not feasible in many resource-limited settings.

FIGURE 19 PATIENT FLOW CHART-PTMCT PLUS



## REFLECTION

### MONITORING AND EVALUATION

#### Clinical Services Results

In total, 224 mothers and their 181 newborn children were enrolled in the study. As of February 2007, 202 PORECO babies were born; 181 had reached 12 months of age; 21 had died. The mother-to-child transmission rate at six weeks of age, measured by PCR, was 6.8% which compares with a national average of 10% or more. Encouragingly, and perhaps surprisingly, no babies seroconverted thereafter, whether breast-fed or not. This may be explained in part by the intensive counselling given with regard to exclusive breast feeding, as well as by the fact that 45 of the breast-feeding mothers were receiving triple antiretroviral therapy during breast feeding. Overall, 92 of the mothers were on ARVs. In addition, 92 partners had been enrolled, of whom 32 received ARVs. Six of the babies were on ARVs. None of these babies became maternal orphans. This excellent result is attributed to the clinical care and community support the mothers and babies received in the programme.

Patrick Shabangu, the PORECO monitoring and evaluation officer, noted that, “Of the 224 pregnant women enrolled in the project, all were accounted for by the end of the study in February 2007. This 100% tracking rate was also true of all the babies.”

Follow-up of this standard has rarely if ever been reported from PMTCT programmes in developing countries and was made possible by intensive tracing of defaulters by community workers and by the other supportive services offered by the community component of the programme. STF considers this the most important result of the trial, because tracking of patients in PMTCT programmes is generally very poor, with the result that the overall efficacy of a PMTCT service is usually impossible to calculate. For example, data from the KwaZulu-Natal province of South Africa in 2006 indicated that for every 100 pregnant women entering such a programme, the serostatus of only three of their newborn children was actually determined at 12 months of age.

Project staff reported that about 90% of PORECO patients on ARVs were feeling significantly better than when they started treatment.

- “ARVs have brought hope to people. It gives them a reason for testing, and it affects their behavior in a positive way,” asserted Marie Hallissey, a research nurse in the programme.
- Dr Mahaliyana-Dissanyake said most PORECO patients adhere to their treatment regimens. But she noted some default because they mistakenly believe they do not need to stay on treatment because they feel better.
- Mrs Bhembe concurred, adding, “All patients who are trained on HIV issues are the best in terms of treatment response. Those who have not been are our biggest challenge.”

Based on the success of the PORECO PMTCT Plus model, replication of the programme is now taking place in other parts of Swaziland.



- “PORECO is serving as a lesson learned by the government for replication, and as a lesson learned by other partners,” Bonisile said.

STF, in collaboration with the MOHSW, is funding an extension of the programme to Northern Hhohho, a rural area in the northeast. In that catchment area, it is anticipated that up to 3,000 pregnant women will enroll each year.

Similar models are also being replicated by other organizations such as the Elizabeth Glaser Pediatric AIDS Foundation and its partners in Manzini, and UNICEF in several very remote areas of the country. These organizations are seeking PORECO’s assistance during implementation.

PORECO officials can cite many reasons their model is being adopted so broadly, but Nomvuyo offers a simple explanation. “We celebrate babies’ birthdays here. That these babies have survived and are HIV-negative is the greatest measure to me of the success of this programme,” she said proudly.

### Community-Based Services Results

PORECO is providing wide-ranging community-based services to clients with the help of volunteers. These include 36 buddies, 22 educators, 84 lay counsellors and 35 traditional birth attendants. Mrs Bhembe said PORECO trained its buddies because it was unhappy with the SASO PLWHA group it had originally engaged.

One of the outstanding features of the community component is the mobilization programme. “When we were developing the PORECO model, we talked about outreach. This is an important part of the programme,” said Bonisile.

PORECO employs many vehicles for informing members of the community about HIV/AIDS and convincing them to access counselling and testing services. This includes the door-to-door campaign conducted by community educators, which has been a huge success and has been employed as a model elsewhere, including by an STF-funded CBTSP in Mali, West Africa. Other vehicles include community meetings and events, dramas and media. The programme had already reached 41,920 people in the community as of June 30, 2006.

“We are introducing ART, and people in the community have to be ready for that,” said Nomvuyo. “We have to build support in the community for the programme and for the clients. To that end, the clinical and community services always need to work in tandem. Otherwise, it hurts our credibility.”

In addition, monthly support groups provide PORECO clients with an opportunity to talk openly about their serostatus and the challenges it presents in their lives. Separate groups have been formed to support the specific needs of clients, including a group for clients on ARVs, an exclusively male group to facilitate male behavior change, income-generating activities groups and the general PORECO membership group, which consists mainly of clients who do not fit into one of the more specialized groups.

PORECO has also initiated successful income-generating activities (IGAs) for clients. “Most of those in the programme have limited income. In fact, only eight are even employed. The IGAs empower these people; they sustain them,” Nomvuyo said.

Nomvuyo reported that as of July 2006, 36 clients were taking part in a sewing programme, a collaboration between PORECO and Waterford Kamhlamba United World College of Southern Africa; 15 in a catering service; and 6 in a gardening programme. She added that PORECO also counsels clients on good nutrition and provides them with food baskets. Another group of ten women were recruited by Armstrong Artwork for skills training in sewing and crafts. Their products are sold in Sweden and South Africa.

Bongiwe Mathala, a PORECO client and community educator, said the catering programme had earned 30,000 rand (about US\$4,285) as of July 2006, making it the most profitable IGA in the programme. “It has been very successful for me,” she exclaimed. “I am able to buy anything I want now. And others are motivated now to do what we did.” Since most IGA participants do not have management expertise, PORECO trains clients demonstrating leadership potential. As of July 2006, 20 clients had received such training, Nomvuyo said. “This programme is really helping the master trainers to sustain their projects.”

## IMPROVING AND REVISING SERVICES

### Challenges and Lessons Learned

- **Integration of the clinical and community components of the programme was a problem, but emphasized that communication between the two has improved.**  
“At the start there was a clear wall between the clinical and community components. The doctors focused initially on clinical issues only, but that has changed,” said Mrs Bhembe. “This was overcome as the programme progressed. They have weekly meetings now where there is an exchange of views on issues concerning the clients.”

- **As in other countries, one of PORECO’s biggest challenges has been to convince men to access programme services.**

Men constitute only one-third of those participating in the project. The programme has used numerous means to educate and mobilize them, including going to their workplaces and homes. Women and their partners are also encouraged to come in together.

This effort is starting to produce results. The number of men participating in the programme has grown from four at the programme’s inception in 2003 to 92 as of July 2006. Nonetheless, project staff would like to see more men access programme services.

- **Stigma and discrimination against PLWHA persist in the community.**

A PORECO client and health educator explained that her mother, who lives in a rural community, was not supportive when she first learned the young woman’s serostatus. Her mother is now better informed about HIV and is more supportive, she said.

- **Clients said PORECO has given them the self-confidence to accept their HIV status and to disclose it to others.**

“Until you accept your status, no one will accept you,” said one client. “Anything is possible when you have your hands and mind.”

- **Programme officials are concerned about maintaining community-based services.**

There is not yet a policy to address the community component of ART. PORECO will pursue public and private sources of funding for community services.

## VII Annexes

### Medical Research Technical Advisory Committee (1999-Jan. 2004)

Akuaake, Matheus, Dr	Chief Medical Officer, National AIDS Coordinating Programme, Ministry of Health and Social Services, Namibia. (2003)
Coovadia, Hussein (Jerry)	Professor of Paediatrics, Medical School, University of Natal, South Africa. (1999 - 2000)
Cotton, Mark, Dr	Senior Specialist, University of Stellenbosch, South Africa. (2002 - 2004)
Diese, Mulamba, Dr	Director, International Association of Physicians in AIDS Care, South Africa. (2002 - 2004)
Gathiram, Vinodh, Prof	Professor of Infectious Diseases, Medical School, University of Natal, South Africa. (1999 - 2000)
Gray, Glenda, Dr	Director, Perinatal HIV Research Unit, Chris Hani Baragwanath Hospital and University of the Witwatersrand, South Africa. (1999 - 2000)
Grimwood, Ashraf, Dr	Principal Medical Officer, City of Cape Town, National Chair of NACOSA, South Africa. (1999)
Herman, Allen, Prof	Dean, National School of Public Health, Medical University of Southern Africa, South Africa. (1999 - 2004)
Kline, Mark, Prof	Professor of Paediatrics, Baylor School of Medicine and Texas Children's Hospital, United States. (1999 - 2004)
Kunene, John, Dr	Acting Deputy Director, Health Services, Ministry of Health and Social Welfare, Swaziland. (1999 - 2004)
Makgoba, Malegapuru, Prof	President, Medical Research Council, South Africa. (1999 - 2004)
Makhema, Joseph M, Dr	Private Practitioner, Gaborone Private Hospital, Botswana. (2001 - 2004)
Makoe, Nthabiseng, Dr	Research Specialist, National University of Lesotho, Lesotho. (2000 - 2004)
Marlink, Richard, Dr	Executive Director, Harvard AIDS Institute, United States. (1999 - 2004)

Martin, Desmon, Dr	President-elect, Southern African HIV Clinicians Society, South Africa. (1999 - 2004)
Matsiliza, Nosisa, Dr	Senior Researcher, Liver Research Centre, Groote Schuur Hospital, South Africa. (2000)
Mazhani, Tumelo, Dr	Dental Specialist, Oral Health Services, Botswana. (2000)
Miller, Steve, Dr	Director, Innovir Institute, South Africa. (1999 - 2004)
Moffat, Howard, Dr	Hospital Superintendent, Princess Marina Hospital, Botswana. (1999 - 2004)
Mokotoko, Maloali, Dr	Physician, Botswana. (2000 - 2001)
Mompati, K, Dr	Private Physician, Botswana. (2002 - 2004)
Moorosi, Thlabi, Dr	Director of Laboratory Services, Queen Elizabeth II Hospital, Lesotho. (2000 - 2004)
Mtetwa, Victor, Dr	Dean of Science, University of Swaziland, Swaziland. (2000 - 2004)
Mugala-Mukungu, Flavio, Dr	Head of Department of Internal Medicine, Head of STD/HIV Clinic, Chairperson of Treatment Advisory Committee of Antiretroviral Therapy, Ministry of Health and Social Services, Namibia. (2001 - 2002)
Saba, Joseph, Dr	Clinical Research Specialist, UNAIDS. United States (1999 - 2000)
Samb, Badara, Dr	Formerly Care Advisor, UNAIDS, currently Advisor to the Director of the HIV Department, World Health Organization, Switzerland. (2002 - 2004)
Sayed, Abdul Rauf, Dr	Biostatistician, University of Cape Town, South Africa. (2002 - 2004)
Simelela, Nothemba, Dr	Director, Directorate HIV/AIDS and STIs, Department of Health, South Africa. (1999 - 2004)
Smego, Raymond A, Jr. Prof	Professor, Infectious Diseases, University of the Witwatersrand, South Africa. (1999)
Sullivan, Louis, Dr	President, Morehouse School of Medicine, United States. (1999 - 2004)

Wainberg, Mark, Dr                      Director, International AIDS Society, McGill University AIDS Centre, Canada. (1999 - 2004)

Zuniga, Jose, Dr                          President-elect, International Association of Physicians in AIDS Care, United States. (1999 - 2002)

**Community Outreach and Education Technical Advisory Committee  
(1999-Jan. 2004)**

As Sy, Elhadji, Dr                      Inter-Country Team Leader for Eastern and Southern Africa, UNAIDS, South Africa. (1999 - 2000)

Bonnecwe, Colin, Mr.                      Director, HIV/AIDS and STIs (NGO Coordination), Department of Health, South Africa. (2002 - 2004)

Burley, Marian, Ms                      International Development Consultant, London. (2000 - 2002)

Chaba, Sinah, Ms                      Manager, HIV/AIDS Unit, Botswana Ministry of Health, Botswana. (1999 - 2000)

Decker, Mark, Mr.                      HIV Consultant, PLWHA, South Africa. (1999 - 2004)

Doro, Thanduxolo, Mr.                      Programme Manager, National Association of People Living with AIDS (NAPWA), South Africa. (2000 - 2004)

Finch III, Charles, Dr                      Director of International Health, Morehouse School of Medicine, Georgia, United States. (1999 - 2004)

Hlatshwayo, Osborne, Mr.                      NGO Capacity Unit Representative, South Africa. (2000 - 2001)

Kgosidintsi, Audrey, Ms                      Executive Director, Institute of Development Management, Botswana. (1999 - 2004)

Kimani, Lillian, Dr                      Formerly of Graduate School of Public and Development Management, University of Witwatersrand, *SECURE THE FUTURE™*, NGO Institute, South Africa. (1999 - 2004)

Kunene, Patrick, Mr.                      HIV/AIDS Advisor, World Health Organization, Swaziland. (2000 - 2001)

Mabitle, Nthabiseng, Ms                      Manager, National AIDS Programme, Department of Health, Lesotho. (1999 - 2004)

Mabuza, Cesphina, Dr                      Director of Health Services, Ministry of Health and Social Services, Swaziland. (2002 - 2004)

Makinwa, Bunmi, Mr.	Team Leader, Inter-country Team for Eastern and Southern Africa, UNAIDS, South Africa. (2002 - 2003)
Mathia, Rabia, Dr	Global Programme Director, CMMB, New York, United States. (2002 - 2004)
Matthew, Debbie, Ms	Fundraiser, AIDS Foundation, South Africa. (1999 - 2000)
Mkhabela, Lolo, Ms	Under Secretary, Ministry of Health and Social Services, Swaziland. (2001 - 2002)
Mnguni, Grace, Ms	Coordinator, Friends for Life, South Africa. (1999 - 2001)
Molosiwa, Kgoreletso, Ms	Director, AIDS/STD Unit, Ministry of Health, Botswana. (2002 - 2004)
Motlhabane, Norah, Ms	NGO Coordinator, Ministry of Health, Botswana. (1999 - 2000)
Nts'ekhe, Pearl, Dr	Director, Infectious Diseases, National AIDS Programme, Lesotho. (2000 - 2004)
Padayachee, Nicky, Prof	Dean, Faculty of Health Sciences, University of Cape Town College of Medicine, South Africa. (1999 - 2004)
Phillip, Rubin, Bishop	Bishop, Diocese of Natal, Anglican Church, South Africa. (1999 - 2004)
Rantona, Koketso, Ms	Botswana <i>SECURE THE FUTURE™</i> NGO Task Force, Botswana. (2002)
Simelane, Constance, Senator	Non-Governmental Sector Rep., Swaziland. (2001 - 2003)
Tobias, Saara K, Ms	National AIDS Control Programme, Ministry of Health, Namibia. (2000 - 2004)
Tselayakgosi, Monica, Ms	Programme Planning Manager, National AIDS Coordinating Agency, Botswana. (2002 - 2004)
Viljoen, Johan, Mr.	Project Manager, South African Catholic Bishops' Conference, South Africa. (2000 - 2004)
Xoagub, Abner, Mr	National AIDS Coordinator, Namibia. (2000 - 2004)
Zwane, Isabel, Dr	Head of Department, Community Health Nursing, University of Swaziland, Swaziland. (2002 - 2004)

## Grants Disbursed as of December 2003

Since 1999, 144 grants have been disbursed, totalling more than US\$70 million. They run the gamut from theatrical troupes that tour villages to promote HIV and sex education and awareness, to programmes that offer economic opportunities and training for the grandmothers who have now become the caregivers for many of the millions of AIDS orphans in the region. New lower-cost tests to monitor HIV blood levels have been developed. New approaches to prevent mother-to-child HIV transmission and treat opportunistic infections as well as operational research involving ARV have been explored. Programmes that help orphans deal with the loss of their parents have been generated. Public health fellowships have been funded, lay health workers have been trained, parish nurses have been given new tools to counsel and care for the sick and dying – and for those they leave behind. Home-based care solutions have been developed; counselling programmes funded; orphans cared for; capacity built; and various forms of community outreach encouraged.

### Medical Research

Grants Disbursed as of December 2003

INSTITUTION	TITLE
<b>Operational Research involving ARV</b>	
1. Botswana-Baylor Children's Clinical Centre of Excellence, Princess Marina Hospital, Botswana	The BANA 2 (Children) Trial. A randomized, comparative trial of continuous versus intermittent highly active antiretroviral therapy in HIV-infected infants and children in Botswana
2. Botswana-Baylor Partnership, Princess Marina Hospital, Botswana	A pilot trial in Gaborone, Botswana, of long-term therapy with Stavudine (d4T) plus Didanosine (ddl) versus Stavudine plus Didanosine plus Hydroxyurea (HU) in HIV-infected infants and children (the Bana Trial)
3. Botswana-Harvard Partnership, Princess Marina Hospital, Botswana	The adult antiretroviral treatment and resistance study (the Tshepo Study): Emergence of HIV-1C nucleoside drug resistance impact on maternal-infant transmission in Botswana
4. Children's Infectious Diseases Clinical Research Unit, Tygerberg Children's Hospital, Stellenbosch University, South Africa	An evaluation of CD4+ and CD8+ T cell apoptosis as surrogate markers for monitoring progression of disease in HIV-1 infected children: a single centre study
5. Department of Paediatrics and Child Health, Red Cross War Memorial Children's Hospital, University of Cape Town, South Africa	Antiretroviral therapy: guidelines for the treatment of a cohort of HIV-infected children and their infected parents at Red Cross Children's Hospital (Study Extension for ARV treatment for patients on both the Micronutrient study RES094-02 and the TB Study)
6. Department of Paediatrics and Child Health, University of Natal, South Africa	Assessment of intermittent and Pulse ARV regimens used for HIV-infected newborns and children in Durban, South Africa
7. Department of Paediatrics and Child Health, University of Natal, South Africa	Induction and augmentation of protective immune responses to achieve effective and durable control of HIV in adult and paediatric infection in sub-Saharan Africa
8. National Health Laboratory Services, UCT Clinical Virology Laboratory and School of Child and Adolescent Health, University of Cape Town, South Africa	Field testing of the use of dried blood spot-based viral load assays to monitor ART in children.
9. South African Institute of Medical Research and the University of Witwatersrand, South Africa	The impact of an early diagnosis of HIV infection status in vertically exposed infants on the management of paediatric HIV: A multi-centre study to explore cost-effective solutions in the South African setting



INSTITUTION	TITLE
<b>Trials in Opportunistic Infections</b>	
10. Botswana-Harvard Partnership, Princess Marina Hospital, Botswana	Pregnant women's acceptance or rejection of the prevention of HIV transmission from mother-to-child programme (PMTCT) in Gaborone, Botswana
11. Department of Obstetrics and Gynaecology, University of Cape Town, South Africa	Management of Abnormal cytology in HIV-1 infected women (MACH-1)
12. Department of Obstetrics and Gynaecology, University of Natal, South Africa	Prophylactic intrapartum antibiotics for delivery in HIV-positive women
13. Department of Paediatrics and Child Health, Red Cross War Memorial Children's Hospital, University of Cape Town, South Africa	The pharmacokinetics of oral cotrimoxazole in HIV-infected children: Phase 1
14. Department of Paediatrics and Child Health, Red Cross War Memorial Children's Hospital, University of Cape Town, South Africa	The pharmacokinetics and efficacy of oral compared with intravenous trimethoprim-sulphamethoxazole (TMP-SMZ) for treatment of <i>Pneumocystis carinii</i> (PCP) in HIV-infected children (Phase 2)
15. Diana Princess of Wales HIV Research Foundation, New Somerset Hospital, South Africa	The cost-effectiveness of HIV/AIDS treatment in the Western Cape, South Africa
16. Diana Princess of Wales HIV Research Foundation, New Somerset Hospital, South Africa	The cost-effectiveness of HIV/AIDS treatment in the Western Cape, South Africa (Extension)
17. Division of Medical Virology, University of Cape Town, South Africa	An investigation into the relationship between HIV-1 injectable progestogen contraceptives, cervical cancer and sexually transmitted infections
18. Perinatal HIV Research Unit, Chris Hani Baragwanath Hospital, University of the Witwatersrand, South Africa	Establishing the prevalence of viral hepatitis B and C infection in newly diagnosed HIV-infected patients so as to support the routine screening of these tests in these patients
19. uMngeni AIDS Centre, KwaZulu-Natal, South Africa	The impact of incorporating relevant health care options into education and counselling programmes
20. University of the Witwatersrand, South Africa	Burden of disease caused by respiratory viruses and <i>Pneumocystis carinii</i> pneumonia in African HIV-infected children hospitalized for acute lower respiratory tract infections
<b>Trials of Self-Care, Nutrition and Other ARV Therapies</b>	
21. City of Tygerberg, Cape Town, and the Child Health Unit, School of Child and Adolescent Health, University of Cape Town, South Africa	The role of tactile stimulation in infants born to HIV-infected mothers in Khayelitsha, Cape Town
22. Department of Community Health Systems, School of Nursing, University of California, United States	Self-care symptom management for persons with HIV disease
23. Department of Paediatrics and Child Health, Red Cross War Memorial Children's Hospital, University of Cape Town, South Africa	The use of zinc and a trace element mixture plus multivitamin supplement to reduce morbidity in HIV-infected children in Cape Town: An efficacy study. (The Micronutrient study)

INSTITUTION	TITLE
24. National Food Technology Research Centre, Botswana	Phase 1: Fortification trials of sorghum flour in Botswana Phase 2: The effect of fortified sorghum meal on weight changes and nutritional related side effects of HIV-positive adults in Botswana
25. Research for the Future, Cape Town, South Africa	How to counsel on infant feeding practices in southern Africa in a time of HIV/AIDS
<b>Trials in MTCT</b>	
26. Botswana-Harvard Partnership, Princess Marina Hospital, Botswana	Male involvement in mother-to-child (MTCT) HIV transmission prevention in Botswana: maximizing support to the programme
27. Department of Paediatrics and Child Health, Red Cross War Memorial Children's Hospital, University of Cape Town, South Africa	Acceptability study of a district health service intervention designed to reduce mother-to-child HIV transmission
28. Department of Paediatrics and Child Health, University of Natal, South Africa	HIV seroconversion among women: prevention, diagnosis and mother-to-child transmission of HIV in KwaZulu-Natal
29. Department of Paediatric, Coronation Women and Children's Hospital and the University of the Witwatersrand, South Africa	Clinical relevance of nevirapine resistance for the treatment of HIV-infected children exposed to nevirapine through prevention of mother-to-child-transmission (PMTCT) programmes
30. National Institute for Communicable Diseases, South Africa	HIV drug resistance in pregnant women and their infants effects of short-course antiretroviral treatment to prevent perinatal transmission (Phase 1)
31. National Institute for Communicable Diseases, South Africa	HIV drug resistance in pregnant women and their infants – effects of short-course ARV: addendum to proposal RES004-02, was previously RES004-12
32. Perinatal HIV Research Unit, Chris Hani Baragwanath Hospital, University of the Witwatersrand and the University of Cape Town, South Africa	A randomized control study to assess the role of post-exposure prophylaxis in reducing mother-to-child transmission of HIV-1 in infants born to mothers without access to antiretroviral therapy – expansion to include a Cape Town site.
33. Perinatal HIV Research Unit, Chris Hani Baragwanath Hospital University of the Witwatersrand, South Africa	A randomized control study to assess the role of post-exposure prophylaxis in reducing mother-to-child transmission of HIV-1 in infants born without access to antiretroviral therapy
<b>Trials in TB</b>	
34. Department of Paediatrics and Child Health, Red Cross War Memorial Children's Hospital, University of Cape Town, South Africa	Natural history of TB-HIV interaction in children
35. E-Agency, Cape Town, South Africa	A pilot study for the development, implementation and evaluation of enhanced informed-consent documentation and processes for smear-negative TB in HIV-positive adults trial in a developing country.
36. Infectious Diseases Research Unit, UCT Lung Institute, University of Cape Town, South Africa	A multicentre study to evaluate an algorithm for the diagnosis of smear-negative tuberculosis in high HIV prevalence settings

INSTITUTION	TITLE
37. Infectious Diseases Research UNIT, UCT Lung Institute, University of Cape Town, South Africa	Deriving an accurate and cost-effective approach to the diagnosis of smear-negative tuberculosis in HIV-infected adults in a developing country
38. Paediatric Infectious Disease Research Unit, University of the Witwatersrand, South Africa	Evaluation of the efficacy of isoniazid prophylaxis in preventing tuberculosis and the effectiveness of cotrimoxazole in reducing the burden of <i>Pneumocystis carinii</i> pneumonia in African children
<b>Training/Education or Capacity Building</b>	
39. Baylor College of Medicine Botswana Government, Princess Marina Hospital, Botswana	Botswana-Baylor Children's Clinical Center of Excellence
40. Baylor College of Medicine, Texas Children's Hospital, United States	Baylor International AIDS Initiative <i>SECURE THE FUTURE™</i> Health Care Professionals Education Programme South Africa, Swaziland, Lesotho, Botswana
41. Baylor College of Medicine, Texas Children's Hospital, United States	Expansion and implementation plan for the fourteen South African Development Community nations
42. Baylor College of Medicine, Texas Children's Hospital, United States	Bi-directional Physician Exchange Programme
43. Baylor College of Medicine, Texas Children's Hospital, United States	Art therapy for treating depression in children orphaned by HIV/AIDS
44. Botswana-Harvard Partnership, Princess Marina Hospital, Botswana	Establishment and staffing of the HIV/AIDS Reference Laboratory in Gaborone
45. Department of Community Dentistry, University of Stellenbosch, South Africa	Oral HIV/AIDS education, diagnosis and training programme for oral health personnel
46. Division of Bioethics, University of the Witwatersrand, South Africa	HIV/AIDS: ethical and legal issues
47. International Association of Physicians in AIDS Care (IAPAC), United States	I-Med Exchange Programme
48. Medical Research Council of South Africa, South Africa	Establishing an information portal as an integrated system incorporating global health information initiatives relating to HIV/AIDS for the benefit of SADC countries, with a view to be rolled out into other African states
49. Swaziland Nursing Association, Swaziland	SNA HIV/AIDS training programme application for implementation fund
50. Youth AIDS Project, Claremont, Cape Town, South Africa	Youth AIDS Project
<b>Laboratory Studies</b>	
51. Department of Medical Microbiology, University of Stellenbosch, South Africa	Antibiotic resistance and strain typing of <i>Pneumocystis carinii</i>
52. Department of Paediatrics and Child Health, University of Natal, South Africa	Cell-associated virus in breast milk of HIV-seropositive women
53. Department of Pharmacology University of the Western Cape, South Africa	The feasibility of performing rapid HIV testing in community pharmacies: a pilot study in the Western Cape

INSTITUTION	TITLE
54. National Institute for Communicable Diseases and the University of the Witwatersrand, South Africa	Pre-clinical studies on the effectiveness of a new class of antiretroviral drugs targeting the co-receptor or binding regions of HIV-1 subtype C viruses
55. National Institute for Communicable Diseases, South Africa	Development of rapid screening method for the detection of NVP resistance mutations in the HIV-1 subtype C reverse transcriptase gene
56. Perinatal HIV Research Unit, Chris Hani Baragwanath Hospital, University of the Witwatersrand, South Africa	Rapid HIV saliva tests for the surveillance and clinical diagnosis of HIV infection in South African children between 12 to 24 months of age
57. School of Child and Adolescent Health, Red Cross War Memorial Children's Hospital, University of Cape Town, South Africa	Novel diagnostic tests for the diagnosis and monitoring of childhood and adult TB
58. South African Institute for Medical Research and the University of the Witwatersrand, South Africa	Affordable and accessible laboratory monitoring for HIV/AIDS
59. South African Institute for Medical Research and the University of the Witwatersrand, South Africa	CD4+ cell enumeration: use of CD45, CD3, CD4, and SS parameter gating without the necessity for a lymphocyte differential
<b>Psychosocial Studies</b>	
60. Bethal Hospital, South Africa	A study to increase partner compliance of STD-diagnosed patients
61. Centre for Social Science Research, University of Cape Town, South Africa	Study of stigma and implications for people living with HIV
62. Department of Psychiatry and Mental Health, University of Cape Town, South Africa	Risk, resilience and the psychosocial adjustment of adolescent AIDS orphans
63. School of Oral Health Sciences Department of Community Dentistry, University of the Witwatersrand, South Africa	Traditional healers in the management of HIV/AIDS
64. University of East Anglia, United Kingdom	An investigation into the nature and extent of the impact of AIDS on orphans: a study of conditions for orphans in rural and urban areas of Botswana and the implications for future poverty levels in Botswana
<b>Epidemiological Studies</b>	
65. Department of Community Health, University of Stellenbosch, South Africa	The impact of TB, HIV, STD, hepatitis and substance abuse in correctional service institutions on women and children
66. Medical Research Council—Burden of Disease Research Unit, South Africa <i>Co-funded by Global Health Forum for Research and UNICEF</i>	Rapid AIDS mortality surveillance in South Africa

## COMMUNITY OUTREACH AND EDUCATION

INSTITUTION	TITLE
<b>Counselling</b>	
1. Botswana Association for Psychosocial Rehabilitation, Botswana	Research and community psycho-education project to educate the mentally ill and train their caregivers on HIV/AIDS
2. Botswana Christian AIDS Intervention Programme (BOCAIP), Botswana	Counselling and home-based care project
3. Lifeline/Childline, Namibia, <i>Co-funded by SACBC/CMMB</i>	Building national lay counselling capacity in northwest Namibia
4. Soweto HIV/AIDS Counsellor Association, South Africa <i>Co-funded by SACBC/CMMB</i>	Counselling support for HIV/AIDS counsellors and institutional capacity building
<b>Home-Based Care</b>	
5. Maternal Life International/Roman Catholic Diocese of Mangini, Swaziland	Community-based parish nursing project
6. Bambisanani, Eastern Cape, South Africa	Community-based HIV/AIDS home care model
7. Bambisanani, Eastern Cape, South Africa	Bambisanani 2 – Community outreach programme
8. Cooperative for Assistance and Relief Everywhere (CARE,) Lesotho.	HIV/AIDS destigmatization through peer education and prevention tactics among women and children on border towns of Lesotho and South Africa
9. The Caring Network/The Care Ministry, Western and Eastern Cape South Africa, <i>Co-funded by SACBC/CMMB</i>	Home-based care and counselling
<b>Home-Based Care and Integrated Approaches</b>	
10. Christian Health Association of Lesotho, Lesotho. <i>Co-funded by SACBC/CMMB</i>	Home-based care and community education
11. Catholic AIDS Action/Namibian Catholic Bishops Conference, Namibia. <i>Co-funded by SACBC/CMMB</i>	Home-based care training and implementation
12. Joy For Life, Cape Town, South Africa <i>Co-funded by SACBC/CMMB</i>	Day care and educational community centre for people living with and affected by HIV/AIDS
13. Holy Cross Hospice, Botswana. <i>Co-funded by SACBC/CMMB</i>	Strengthening home-based care and support for orphans
14. Mission Aviation Fellowship, Botswana. <i>Co-funded by SACBC/CMMB</i>	Home-based care for people with HIV/AIDS and the terminally ill
15. Naledi Hospice, South Africa. <i>Co-funded by SACBC/CMMB</i>	Developing a model for systematic implementation of the approved home-based care model at the provincial level
16. Rhema Christian Service Foundation, South Africa	Mobile primary health care and integrated HIV/AIDS services in informal settlements
17. Sungarden Tetani Hospivision Consortium, Gauteng and North West provinces, South Africa	Research and development of economic models of caring and providing income-generating opportunities
18. The Valley Trust, South Africa and Swaziland	Integrated plant use for community-based health

INSTITUTION	TITLE
19. Lesotho Universal Medicine Men and Herbalist Council, in collaboration with Institute of Extra-Mural Studies (IEMS), Lesotho	Participation of traditional medicine practitioners in the fight against HIV/AIDS
20. Hospice Associationn of the Witwatersrand, South Africa	Sowetho Hospice mini satellite comprehensive home care service pilot project
<b>Prevention</b>	
21. Stellenbosch AIDS Action Group Western Cape, South Africa	Community mobilisation for prevention and care
22. Oasis Rover Crew, South Africa. Co-funded by the SACBC/CMMB	Oasis HIV/AIDS counselling, support and outreach project
23. Baphalali Swaziland Red Cross Society, Swaziland	School-based prevention of new infections project through blood donation programmes
24. Community Aids Response (CARE), South Africa. Co-funded by the SACBC/CMMB	Linking metropolitan hospital HIV/AIDS clinics with community care and material support
25. Reetsanang Association of Community Drama Groups, Botswana	Using participatory theatre as a tool for community education
26. Scripture Union, South Africa	Life skills education and HIV/AIDS prevention in schools
27. Centre for Positive Care, South Africa	Integrating community-based home care with prevention
28. Young Women's Christian Association (YWCA), Botswana	Prevention, HIV/AIDS education targeting parents
29. Scripture Union, Lesotho	Life skills education: Prevention among senior primary and secondary school students
30. Joint Centre for Political and Economic Studies and Schools Health and Population Education (SHAPE), Swaziland and South Africa	Prevention campaign in schools through empowering teachers and classroom activities
31. Empilisweni Woodlands Centre, South Africa. Co-funded by the SACBC/CMMB	King Williams Town Juvenile Prison project educating inmates on STDs and HIV/AIDS
32. Progressive Primary Health Care Free State, South Africa	A behavior modification and sexual violence prevention programme
33. Johannesburg Society for the Blind, Gauteng, South Africa. Co-funded by the SACBC/CMMB	Johannesburg Society for the Blind HIV/AIDS awareness and training project
34. Human Sciences Research Council (HSRC), South Africa	A study to investigate the participation of indigenous African healers in preventing HIV infection and AIDS in KwaZulu-Natal
35. Namibia Development Trust, Namibia	An integrated capacity-building programme for a rural health network with specific emphasis on HIV/AIDS in four northern regions
36. Namibian Tuberculosis Association (NAMTA), Namibia	A sustainable approach to reduce TB and HIV/AIDS in Namibia

INSTITUTION	TITLE
37. Ikaheng Community Association, Eastern Cape, South Africa. <i>Co-funded by the SACBC/CMMB</i>	Integrated programme on prevention, care and support for people living with HIV/AIDS
38. Youth for Christ (Generation Z1, Lesotho. <i>Co-funded by the SACBC/CMMB</i>	Prevention and food security
<b>Care and Support for Orphans and Vulnerable Children</b>	
39. AIDS Foundation of South Africa. <i>Co-funded by the SACBC/CMMB</i>	Coordinated orphan response
40. Beautiful Gate, Lesotho. <i>Co-funded by the SACBC/CMMB</i>	Developing the capacity of support programmes and caregivers
41. Botswana Christian AIDS Intervention Programme, Botswana	Bana Ba Keletso and Motse Wa Tsholofelo orphan care projects
42. Community Paediatric Department, University of the Witwatersrand, South Africa	Home-based care; care and support for orphans and vulnerable children
43. Coordinating Assembly of Non-Governmental Organisations (CANGO), Swaziland	Civic education for children infected and affected by HIV/AIDS
44. Coping Centre for People Living with HIV/AIDS / AIDS (COCEPWA), Botswana	Setting up a support system for HIV-positive women and building organizational capacity
45. Forum for African Women Educationalists, Swaziland Chapter (FAWESWA), Swaziland	Training caregivers for orphans and vulnerable children
46. Groote Schuur Occupational Therapy Department, University of Cape Town, Western Cape, South Africa	Exploring the effect of play therapy between mothers and caregivers and HIV-positive children
47. Institute of Aging in Africa, Faculty of Health Sciences, University of Cape Town, Western Cape, South Africa	Supporting older women caring for children and grandchildren affected by AIDS
48. Kagisano Women's Project, Botswana	Creating the link: pioneering community responses to gender sexual violence and HIV/AIDS
49. Khulisa Ahead, Swaziland	Khulisa Ahead HIV/AIDS teen action programme
50. Namibia Women's Network, Namibia. <i>Co-funded by the SACBC/CMMB</i>	Domestic and sexual violence: prevention, care and support for survivors
51. National Institute of Community Development and Management (NICDAM), South Africa	Development of capacity-building programmes for primary and secondary caregivers of HIV/AIDS affected children
52. Network of AIDS Communities (Netcom), South Africa	Ithembalabantu project: a partnership for progress in HIV/AIDS antiretroviral treatment and holistic care for people living with HIV/AIDS
53. Phillippi Namibia Christian Counselling and Counselling Training, Namibia. <i>Co-funded by the SACBC/CMMB</i>	Programme for orphans and vulnerable children in Namibia
54. Save the Children UK, Lesotho	Children affected by HIV/AIDS care and support programme
55. Save the Children, Swaziland	Children affected by HIV/AIDS care and support programme



INSTITUTION	TITLE
56. Sibambisene Network, South Africa. <i>Co-funded by the SACBC/CMMB</i>	Integrated, community-based response to the HIV/AIDS epidemic in northern KwaZulu-Natal
57. Sinosizo home-based care, Oral History Project, University of Natal, South Africa. <i>Co-funded by the SACBC/CMMB</i>	Child bereavement counselling of AIDS orphans and affected children
58. St. Philomena's Children's Home, South Africa. <i>Co-funded by the SACBC/CMMB</i>	Community care project for orphans and vulnerable children
59. World University Services, Swaziland	Care and psychosocial support for child-headed households
<b>Capacity Building</b>	
60. INara Training Centre, Namibia	Coordinated HIV/AIDS programmes in informal settlements
61. Botswana Network of AIDS Service Organisations (BONASO), Botswana	Capacity building for the networks of AIDS service organizations
62. Cotlands Baby Sanctuary HIV Infant Care Programme, South Africa	Care and support for children living with HIV/AIDS
63. Namibia Housing Action Group/ Cactus Consortium, Namibia	Management capacity building for NGOs and CBOs with HIV/AIDS interventions.
64. National Association of Child Care Workers, South Africa	Comprehensive capacity-building approach to care and management in respect of HIV/AIDS
65. National School of Public Health MEDUNSA, South Africa	Fellowships in public health, with an emphasis on AIDS care
66. Swaziland Institute of Management and Public Administration, Swaziland	Capacity building for HIV/AIDS community-based organizations and non-governmental organizations
67. University of Illinois College of Nursing, Missionary Sisters of the Sacred Heart, Swaziland	HIV/AIDS prevention and home-based care for rural health workers
68. Women's Leadership and Training programme, KwaZulu-Natal and Eastern Cape, South Africa. <i>Co-funded by the SACBC/CMMB</i>	Empowerment of women through training women as rural lay counsellors and as home carers
<b>Independent Monitoring and Evaluation</b>	
69. Yale University, United States	<i>SECURE THE FUTURE®</i> Monitoring and Evaluation Programme



## Overview of *SECURE THE FUTURE*®

### Care and Support for Women and Children with HIV/AIDS

#### Origin and Purpose

*SECURE THE FUTURE* is an innovative, comprehensive public-private initiative to help alleviate the HIV/AIDS crisis among women and children in sub-Saharan Africa, where 25 million people are infected with the disease. Bristol-Myers Squibb and the Bristol-Myers Squibb Foundation launched the initiative in 1999.

The goal of the programme is to prevent HIV/AIDS and STD transmission, reduce the impact of HIV/AIDS, and expand access to treatment by informing public health policy. *SECURE THE FUTURE* was the first and remains the largest single corporate commitment of its kind to fight HIV/AIDS in Africa.

The range of *SECURE THE FUTURE* programmes includes:

- establishing six model community-based treatment centres that integrate community support with medical care in very resource-limited settings;
- funding approximately 90 medical studies and 100 community outreach and education programmes;
- building a network of clinical centres of excellence to treat HIV-infected children; three centres are now in operation, and three are under construction.
- creating and supporting a pediatric AIDS corps to bring doctors to Africa to treat children, train local staff and extend the reach of the children's centres to rural areas;
- funding education and training programmes for physicians, nurses and other public health professionals as well as NGO leaders;
- supporting innovative public education programmes for teens and entire communities; and
- creating support programmes for grandmothers and other caregivers—including nutritional and income-generating projects—and support services for orphans and vulnerable children.

#### Key Programmes and Accomplishments

- **Community-Based Treatment Support Programme** — Pilot centres established in South Africa, Botswana, Swaziland, Lesotho, Namibia and Mali have demonstrated that comprehensive medical treatment and care combined with broad-based community support can be successful in fighting the disease in remote, poverty-stricken areas where health care and other resources are limited. Data from the centres prove for the first time the added value of community services in achieving better patient outcomes. Of more than 15,000 HIV-positive patients enrolled at these centres, 7,000 are on antiretrovirals (ARVs), and adherence rates are over 80%. Plans are under way to open similar programmes elsewhere in southern and West Africa.

- **Children's HIV/AIDS Clinical Centres of Excellence** – *SECURE THE FUTURE* funded the construction and equipping of clinical centres in Botswana, Lesotho and Swaziland, operated by the Baylor International Pediatric AIDS Initiative with the assistance of host government funding. Centres in Burkina Faso, Kenya and Uganda, also funded by the initiative, are under construction. The centres provide multidisciplinary care for children and their families, state-of-the-art infrastructure and education and training for medical professionals.
- **Pediatric AIDS Corps** – *SECURE THE FUTURE* and Baylor College of Medicine have created a programme to send up to 250 pediatricians and family practitioners to Africa over five years – 50 doctors per year – to treat approximately 100,000 children and train local health care professionals. The first wave of 50 doctors began work in Africa in August 2006. The doctors are based in the children's clinical centres and also working in rural hospitals and health centres to treat children and train health care professionals.
- **BMS Foundation NGO Training Institute** – This capacity-building programme develops and builds organizational and individual skills for the delivery of support and care among nongovernmental organizations (NGOs) and community-based organizations (CBOs) working with HIV/AIDS. The Institute creates model training modules and best practices in management, good governance and leadership. The programme – the first of its kind in Africa – is currently in operation in South Africa, Botswana, Namibia, Lesotho and Swaziland.
- **HIV/AIDS Model Curriculum for Health Care Workers** – The initiative supported development of the Baylor College of Nursing's model curriculum on HIV/AIDS and the Health Professional, now in its third edition. The curriculum has been adopted in 51 countries and endorsed by UNAIDS.
- **Public Health Masters' Degree Programme at the Medical University of Southern Africa** – The initiative funded a distance learning public health training programme providing a one-year diploma or masters' degree programme that has educated more than 260 professionals, 40% from the ministries of health. The programme has been replicated at the Cheick Anta Diop University in Dakar, Senegal, and will educate 120 public health specialists by year-end 2007.
- **HIV Reference Laboratory in Botswana** – *SECURE THE FUTURE* co-funded establishment of the first HIV/AIDS Reference Laboratory in Botswana, operated by the Botswana-Harvard Partnership.
- **CD4-Count Test** – *SECURE THE FUTURE* grantee Dr Debbie Glencross developed a fast, affordable test for CD4-count that has been recognized by the WHO, adopted by the South Africa National Health Laboratory Service and approved by the US Food and Drug Administration. This test is important because the cost of monitoring had long been a barrier to treatment in Africa.

- **Landmark Prevention of Mother-To-Child Transmission (PMTCT) Study** – The initiative funded a clinical study that demonstrated that mother-to-child transmission of HIV – from positive mothers who did not access PMTCT medication prior to delivery – can be reduced through post-natal prophylactic antiretroviral (ARV) therapy. Dr Glenda Gray and colleagues received the Nelson Mandela Award for Health and Human Rights for this accomplishment. Their findings have implications for PMTCT interventions in resource-limited settings.
- In conjunction with the 65 clinical studies funded by *SECURE THE FUTURE*, many of which are still under way, more than 600 grantees have been trained in Good Clinical Practices by Bristol-Myers Squibb staff.

The commitment by Bristol-Myers Squibb through *SECURE THE FUTURE* has grown to \$150 million, provided through more than 200 grants for innovative, cost-effective model programmes. These programmes support people living with HIV in clinics and at home; build medical capacity and infrastructure; and encourage development of sustainable programmes that can be replicated elsewhere in Africa and in other parts of the world. The initiative started in five countries in southern Africa and was subsequently extended to West Africa and Central Africa. It now serves people in South Africa, Swaziland, Botswana, Namibia, Lesotho, Malawi, Senegal, Burkina Faso, Mali, Ivory Coast, Kenya and Uganda.

*SECURE THE FUTURE* has developed and funded innovative programmes by creating a unique series of partnerships with government leaders; Ministries of Health; medical institutions in Africa and the US; physicians and other health care professionals; non-governmental, community-based and faith-based organizations; and people living with HIV/AIDS. Programmes were recommended by independent local Technical Advisory Committees with full participation by personnel from national governments. They were aligned with national AIDS plans, developed with sensitivity to local traditions and customs, and designed to meet best-practice standards and demonstrate outcomes and impact.

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