

## SECURE THE FUTURE: SEVEN STEPS TO INVOLVE THE COMMUNITY IN HIV/AIDS TREATMENT SUPPORT PROGRAMMES

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In this issue of the *Southern African Journal of HIV Medicine*, Secure the Future is pleased to present in CD form the manual, *Seven Steps to Involve the Community in HIV/AIDS Treatment Support Programmes*. The manual is the product of 4 years of intensive work on the implementation of a programme of community-based treatment support for patients with HIV/AIDS. Its overall purpose is to guide any group in how to integrate medical care with the power of community mobilisation and community services provided to patients in their homes and communities.

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 for people living with HIV/AIDS (PLWHA) in Africa. The programme was first launched in southern Africa (Botswana, Lesotho, Swaziland, Namibia and South Africa), and by 2004 had expanded to East and West Africa (Burkina Faso, Cote D'Ivoire, Mali, Senegal, Uganda and Malawi).

During the first 3 years of the STF programme, funding was provided to more than 160 projects addressing critical areas of need in community outreach and education and medical research. This phase of broad-based grant making put resources directly into the hands of small, community-based organisations 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 prevention of mother-to-child transmission (PMTCT) medication given to the newborn infant only, in cases when the mother presented at the hospital after delivery.

By 2002, the international community and many national governments in sub-Saharan Africa began working towards providing free antiretroviral therapy (ART) to the HIV-infected population. At its biannual meeting in April 2002, the Technical Advisory Committee endorsed the recommendation of STF staff 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 challenges and gaps in rolling out ART. A commonly raised issue related to roll-out to remote communities where health care infrastructure, capacity and other resources were limited. Many regarded these communities as too challenged by

poverty, lack of healthcare infrastructure and healthcare worker capacity, lack of food security, unemployment, and high levels of stigma to establish and sustain long-term efficacious treatment. There was not only concern about how to guarantee equity in ART roll-out, but also the need for innovative models and comprehensive actions to make sure ART could also be provided in poor communities. Using these consultations and drawing on lessons from the grants made in the first 3 years of the programme, the **Community-Based Treatment Support (CBTS) Programme** model was developed.

The CBTS model (Fig. 1) emphasises that PLWHA in resource-limited settings need both **clinical services** and **community services** to effectively enhance their quality of life and outcomes. The model also places equal emphasis on supporting the needs of PLWHA receiving ART and patients whose disease has not yet progressed to the need for treatment.

The model, therefore, employs 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 model leverages the strengths of government, private sector and community-based organisations to offer a true continuum of care, or as STF refers to it, '23½ hours' of disease management and psychosocial support that takes place in the patient's home and community following a 'half hour' of medical care in the clinic.

The resulting STF programme was launched at five sites in southern Africa, chosen after consultation with the respective governments. And the effectiveness of the CBTS model has been demonstrated by a 3-year operational research study conducted at the five sites: namely Katima-Mulilo in Namibia, Bobonong in Botswana, Maseru in Lesotho, Mbabane in Swaziland and Ladysmith in South Africa.

## COMMUNITY BASED TREATMENT SUPPORT PROGRAM

*Partnership Structure for Integrated  
Patient Care and Program Operation*



## COMMUNITY BASED TREATMENT SUPPORT PROGRAM

*Model of Care*

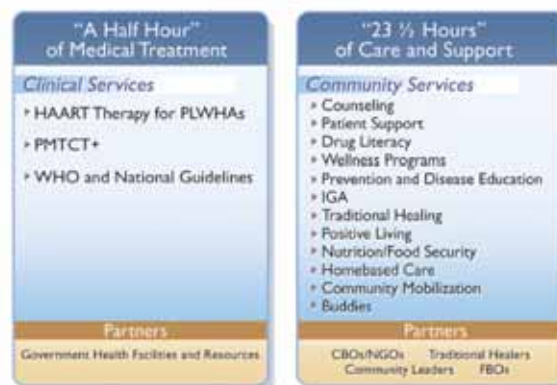


Fig. 1. Community-based treatment support model of care.

Clinical outcomes and the added value of community support were evaluated by rigorous collection of data according to protocols developed by BMS and Family Health International. Full details of the methodology and analysis are to be found in the manual itself, but the following is a summary of key findings.

- **Increased voluntary counselling and testing and clinical uptake.** Overall, the uptake of VCT increased approximately 10-fold within 2 - 3 months from the start of community mobilisation. 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.
- **The added value of community support:**
  - CD4 counts increased significantly more and to significantly higher levels in patients on ARVs who accessed community support than those who did not: from median values of 129 and 127 to medians of 326 and 268 respectively.
  - Patients 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 STF CBTS programmes was only 5.1%. In Swaziland's PMTCT 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 ART and 'levelled the playing field' by dealing with psychosocial problems, inadequate nutrition and logistical issues, such as transport to the clinic and disclosure of status to a significant other.

In summary, with community mobilisation and support, a patient is more likely to present for testing and treatment, will be better prepared to begin and adhere to ART, is less likely to default and is more likely to have a better clinical outcome.

And the impact at a community level was dramatic. For example, approximately 66 000 people live in the Bobirwa sub-district of Botswana. The Bobonong Primary Hospital, where the CBTS model was established, is the only hospital serving this population. By 2006, 2 years after the CBTS model was adapted and implemented in the sub-district, 1 546 patients were on ARVs and the following notable results were achieved:

- Hospital bed occupancy by HIV patients decreased from 93% to 52%
- In-hospital mortality due to HIV/AIDS decreased from 25% to 13%.

The model is now presented in the manual as a partnership involving government, the private sector and community-based organisations, using a seven-step implementation process as illustrated in Fig. 2.

The manual also includes 22 technical tools and resources to assist the provision of quality services to clients, as well as case study profiles of five southern African community-based treatment sites, outlining their adaption and implementation of the programme. These case studies illustrate the flexibility of the model.

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

The steps outlined in the manual will allow a logical, optimal and effective path to implementation. The key objectives, expected outcomes and lessons learnt according to STF are detailed below.



Fig. 2. The seven-step process.

### STEP 1: ENGAGE GOVERNMENT AND COMMUNITY

The first step recognises the critical need of obtaining government support for introduction of the CBTS model. It guides the implementer in how to advocate for establishment of an integrated, community-based approach for HIV/AIDS care and treatment, which includes the government, private sector and community in multidisciplinary teams. At the end of this step, a business case for the programme will have been created and government buy-in secured.

STF learnt that governments can be engaged if the CBTS programme and model align with national policies and address critical challenges. Engagement should now be eased because of the positive data included in the manual, attesting to the effectiveness of the community-based approach.

### STEP 2: ESTABLISH LEADERSHIP AND MANAGEMENT STRUCTURE

This step leads to the appointment of a skilled and preferably experienced project manager, as strongly recommended by STF, and to the development of a project charter that specifies objectives and deliverables as well as a management structure with clear roles, responsibilities, and reporting relationships through collaborative and transparent workshops.

Another key learning by STF was that for the CBTS programme to succeed, it is important to place equal importance on the role of all partners and give them equal say in planning and implementation.

### STEP 3: ADAPT THE COMMUNITY-BASED TREATMENT SUPPORT MODEL

The CBTS model is flexible. Indeed adaptation is essential and is described in this step, which leads to selection of clinical sites and of community services, the elaboration of a patient

flow map, the development of a patient documentation system and an implementation plan.

Perhaps the most important learning of this step is that a carefully designed patient flow map is the key to quick and accurate adaptation of the model to any particular programme location.

### STEP 4: BUILD PARTNER CAPACITY

This step describes how to train and build capacity of all stakeholders to deliver services and other skills dictated by the shared goals of the project.

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. STF also learnt that training personnel to understand the CBTS concept itself is necessary for effective implementation.



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

### STEP 5: DELIVER SERVICES

The first objective of this step is mobilisation of the community to support and engage in new and improved services, particularly newly accessible ART and community services integrated with ART. Thereafter attention is paid to how to deliver high quality, accessible and integrated clinical and community services to the targeted numbers of patients, how to prepare patients who need ART for treatment and how to track and retain them in the programme. The manual also



*More than 5 000 people attended the public launch of the ACHIVA programme at Ladysmith Provincial Hospital in KwaZulu-Natal, South Africa, in 2004.*



*A woman in Bobonong, Botswana, proudly tends her door-sized garden.*

addresses how to provide community support for patients not yet clinically eligible for ARVs. STF learnt the importance of this, because inattention to these patients can demotivate them and they may then drop out of the programme. STF also learnt that selection of patients for ARV therapy should be based largely on clinical criteria and remain uninfluenced by social discrimination, because social and psychological problems can usually be managed.

**STEP 6: MONITOR AND EVALUATE AND STEP 7: REVISE SERVICES**

Step 6 guides the development of a monitoring and evaluation framework while step 7 explains how to reflect on progress, successes and challenges, making use of monitoring and evaluation data. Corrective action can be taken with input and agreement from relevant partners.



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

In publishing the manual, it is the hope of STF that the experience gained and lessons learnt can be utilised by others wishing to provide holistic and effective care and support to patients with HIV/AIDS in resource-limited settings.



*Food security in action: Workers in their community garden in Lesotho.*

In terms of community services, home-based care was found to be one of the most important for HIV/AIDS patients and has been shown to impact on 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. In addition, adequate nutrition is essential for optimal response to treatment, but it is important to encourage self-sufficiency by teaching patients how to grow their own food.

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