This first volume contains significant community outreach and education projects as well as important applied research initiatives that have resulted from Secure The Future™. These efforts have provided important new insights and helped illustrate innovative approaches to prevent transmission of HIV, reduce the impact of HIV/AIDS, expand access to treatment and build capacity in resource-limited settings. We hope they will provide useful examples and serve as models, whose elements can be replicated in other communities and countries.
Acknowledgments

We’re proud that so many people have been responsible for building Secure the Future™, implementing its vision and creating its legacy. We acknowledge them all, our Technical Advisory Committee members, our grant recipients, our partners, our colleagues in government, at NGOs and CBOs, and in the medical and research community and especially the many people of Bristol-Myers Squibb. They deserve our heartfelt thanks, our deepest appreciation and our greatest admiration. In communities large and small, Secure the Future™ has made a difference and will continue to do so because of the efforts and dedication of all these people. Most of all, we must acknowledge the millions of women and children affected and infected by HIV/AIDS in the Secure the Future™ countries. Their courage and perseverance and indeed their suffering as well as their triumphs in the face of tremendous odds and untold difficulties offer the greatest reasons for all of us to continue to find ways to inspire them, to help them and to serve them.

John Damonti
President, Bristol-Myers Squibb Foundation
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<td>Acquired Immune Deficiency Syndrome</td>
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<tr>
<td>ARV</td>
<td>Antiretroviral</td>
</tr>
<tr>
<td>BMS</td>
<td>Bristol-Myers Squibb Company</td>
</tr>
<tr>
<td>BMSF</td>
<td>Bristol-Myers Squibb Foundation</td>
</tr>
<tr>
<td>COE</td>
<td>Community Outreach and Education</td>
</tr>
<tr>
<td>CBO</td>
<td>Community-Based Organisation</td>
</tr>
<tr>
<td>CIRA</td>
<td>Centre for Interdisciplinary Research on AIDS, Yale School of Public Health</td>
</tr>
<tr>
<td>FBO</td>
<td>Faith-Based Organisation</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>HBC</td>
<td>Home-Based Care</td>
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<td>IEC</td>
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<td>KAP</td>
<td>Knowledge, Attitude, Practices</td>
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<td>KAPB</td>
<td>Knowledge, Attitude, Practices and Behaviour</td>
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<td>MEDUNSA</td>
<td>Medical University of South Africa</td>
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<tr>
<td>MRC</td>
<td>Medical Research Council of South Africa</td>
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<tr>
<td>NGO</td>
<td>Non-Governmental Organisation</td>
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<td>PEP</td>
<td>Post-Exposure Prophylaxis</td>
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<td>PLWHA</td>
<td>Person/People Living with HIV/AIDS</td>
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<tr>
<td>PMTCT</td>
<td>Prevention of Mother-to-Child-Transmission</td>
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<tr>
<td>RFP</td>
<td>Request for Proposal</td>
</tr>
<tr>
<td>STI</td>
<td>Sexually Transmitted Infection</td>
</tr>
<tr>
<td>TAC</td>
<td>Technical Advisory Committee</td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
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1. Secure the Future™ – The Background

It was early 1999. Even as much of the world was preparing to greet the promise of the new millennium at year end, in Africa the reality of the staggering HIV/AIDS pandemic continued to turn hope into overwhelming despair. As former South African president Nelson Mandela once said, the HIV/AIDS pandemic was a threat that put in the balance “the future of nations. AIDS kills those on whom society relies to grow the crops, work in the mines and factories, run the schools and hospitals and govern countries... It creates new pockets of poverty when parents and breadwinners die and children leave school earlier to support the remaining children.”

Indeed, since the start of the pandemic until the end of 1999, some 14.8 million people in sub-Saharan Africa had died – the equivalent of the combined populations of New York City and Los Angeles. More than 20 percent of those deaths were children. And even though sub-Saharan Africa accounted for one-tenth of the world population, it accounted for almost 80 percent of all AIDS deaths worldwide and about 70 percent of all those living with HIV/AIDS. AIDS was turning back the clock on the life spans of large segments of the African population, creating extraordinary numbers of orphans, wreaking economic havoc and civil disorder and decimating the population at every level.

By 1999, Bristol-Myers Squibb, as a leader in the global pharmaceutical industry, with a large HIV/AIDS antiretroviral franchise and a significant business presence in Africa, was searching for an appropriate role to play in fighting the pandemic. Even as considerable controversies surrounded the issue of pricing and availability of HIV/AIDS pharmaceuticals and even though it was clear to most that infrastructure concerns, political considerations as well as many other concerns could stand in the way of meaningful actions, it was also clear that doing nothing was not an acceptable option. At the urging of UN Secretary General Kofi Annan, the company did act, with the largest corporate philanthropic commitment up to that time in the fight against HIV/AIDS.

Bristol-Myers Squibb’s Secure the Future™ programme was announced in May 1999 initially in five countries in southern Africa and then, in late 2001, in four additional countries in West Africa. It is a five-year, $115 million commitment that focuses on two areas:

- Community outreach, education and empowerment; and
- Medical research and care.

Its aim is to develop private/public partnerships to help the hardest hit populations in the region – women and children. This is appreciated because 58 percent of all infected adults in the region are women aged 15-49; in some countries more than 25 percent of pregnant women are infected. Over 90 percent of all AIDS orphans are African.

From the beginning, a number of principles have guided the programme. Firstly, it would not be simply a free or low-cost drug distribution programme. More was needed. Nor would it be directed and controlled centrally, with ideas for projects coming from a distant corporate headquarters. Instead, local personnel was hired; local independent advisory committees were formed. And the active participation of ministries of health of the affected countries, people living with HIV/AIDS, local medical and educational institutions and local NGOs would all become integral elements of project creation and funding. What is more, independent auditors would ensure financial and other controls in funded agencies, and the Yale University Centre for Interdisciplinary Research on AIDS would work with local evaluators to assess programme efforts on the ground. The effort sought to be ethically unassailable. Finally, all grants would focus on innovation, replicability and sustainability.
Simply stated, the aims of this programme – from its beginnings and until today – are sustainability and capacity building. What models could be developed that would endure long after this programme ended? How could sustainable institutions be created and fostered that would allow the people themselves in the region to learn to cope with the challenges of HIV/AIDS? How could small organisations grow into larger organisations, attracting additional funders? How could programmes be appropriately evaluated by independent professionals? Secure the Future™ sought to prevent HIV/AIDS and STI transmission; reduce the impact of HIV/AIDS on individuals by empowering infected and affected women and children and expand access to treatment by informing public health policy.

By 2002, about 130 grants had already been made in southern and West Africa, totalling approximately US$65 million. They run the gamut from drama groups 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 the millions of AIDS orphans in the region. New lower-cost tests to monitor HIV blood levels have been developed. 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 left behind. New approaches to prevent mother-to-child HIV transmission have been explored. Home-based care solutions have been developed; counselling programmes funded; orphans have been cared for; capacity has been built and various forms of community outreach encouraged.

“I deal with lots of funders and I find that Secure the Future™ is one of the easiest to work with. They are different because they actually want to give the money out so they facilitate access to funding, by providing capacity building and assisting civil society and NGOs in the formulation of projects. They give good guidelines on how to access the funds, and they hold your hand so the money is put to good use. In three years Secure the Future™ did an excellent job. They’ve been able to fund a lot of projects in the five countries and have actually extended the project to West Africa, taking models that have been piloted in this region. I think they have learnt so many lessons that they can be one of the best models that can be copied by other funders.” Senator Constance Simelane, a Swazi parliamentarian and national project co-ordinator for Khulisa Umfwana, a grant recipient.

In its fourth year Secure the Future™ began to consider its legacy. It established the roots of a new NGO Training Institute, where the best practices of leading and established NGOs in the five southern African countries were assessed and developed into training modules for existing and emerging community-based organisations. And it is developing a number of community-based treatment sites in the region that will serve as models for integrated treatment, care and disease management at the community level – particularly in resource-limited settings.

The success of Secure the Future™ will be measured by the criteria set at the beginning of each of the 130+ grants and by evaluating how far they have come. It will be measured by the good that these organisations and groups do in contributing to their villages and the people they help. It will be measured by their ability to sustain their efforts, expand them and replicate them elsewhere – and eventually, by the public/private partnerships that will be created to begin to reverse and eventually help defeat the pandemic over time.
2. Why document case studies?

“Ultimately our actions will not be measured in dollars alone, but in the sustainability of the programmes we support and in the enduring empowerment we provide to the people, the communities and the countries we seek to help.” John McGoldrick, Executive Vice President, Bristol-Myers Squibb.

When measured against the scale of the AIDS epidemic, Secure the Future™ is a relatively swift, short term intervention, providing seed funding, capacity building and technical support. However, its longer term impact includes the replication funding and impact of projects that demonstrate they are sustainable over time and those that will help answer important research questions that can then be applied to treatment in community settings. Documenting these approaches enables others to replicate them, adding effective new dimensions to the global response to the HIV/AIDS pandemic.

This set of case studies is part of a broader advocacy kit providing accessible information about the most impactful models to emerge from the Secure the Future™ programme in southern Africa. These projects are notable for their innovation, outcomes, replicability and sustainability. Our aim in documenting and disseminating their work is to encourage others to use what has been learned in the four years that Secure the Future™ has been active in five southern African countries.

If others are inspired to use the processes and access the training materials to expand and build on their responses, then the value of Secure the Future™’s efforts and the number of people that have been assisted will be enhanced far beyond what the five-year programme alone could ever hope to achieve.

“I would say that Secure the Future™ was really the programme that raised the bar with respect to what both public and private sector responses to HIV in Africa should be. Not only other institutions, but also United States and European governments were challenged to step up to the plate after Secure the Future™ was announced. It was some time ago that Bristol-Myers Squibb made this commitment, and I would say that they were head and shoulders above what others were doing for AIDS in Africa.” Dr Richard Marlink, executive and research director, Harvard AIDS Institute.
3. Why consider Secure the Future™’s case studies?

Secure the Future™’s case studies are examples of how key elements of the response to the epidemic in southern Africa – namely prevention, care and support, access to treatment and building capacity – could be developed. They can be of great value to governments, funders, corporations, NGOs or CBOs involved in creating effective responses to the HIV/AIDS epidemic for several reasons. From the beginning:

- Each project underwent a careful and consultative selection process before being offered funding. This was designed to ensure that the project was relevant to local conditions, in line with local government priorities and that it furthered Secure the Future™’s aims of providing support for women and children infected and affected by HIV/AIDS;
- Each project had to meet the criteria of being innovative in its context, sustainable, affordable and, in most cases, replicable, and therefore could be considered a new and worthwhile initiative;
- Each project was independently monitored and evaluated; and
- Each project was selected to be documented based on set criteria for the appropriateness of the work and/or findings when applied to resource limited settings where the pandemic is most prevalent.

The details in these case studies are taken from final reports and evaluation materials compiled by Manto Management and local independent evaluators under the direction of the Centre for Interdisciplinary Research on AIDS (CIRA), located in Yale University’s School of Public Health, which was contracted to provide independent monitoring and evaluation services. Other material was drawn from project records, organisational evaluation material commissioned by the projects themselves or academic reports and publications in peer-reviewed journals.

The grant amounts, scale of work, and subjects covered encompass a wide range of efforts. These case studies range from one-on-one support for people living with HIV/AIDS (PLWHA), the impact of the epidemic on older women caregivers, the potential of faith-based initiatives and participatory community theatre all the way to laboratory work, drug trials and international collaborations, such as the Baylor HIV curriculum, which has been delivered to health professionals in more than 47 countries. But they share two essential features: each has produced powerful, innovative tools to deal with aspects of the epidemic that have not yet been adequately addressed and each has addressed the challenges faced and implemented actions on a scale and in a way necessary to make a meaningful impact.

Enriched through partnerships – The case studies also provide insights into how the responses can be enriched through partnerships allowing, for example, faith-based organisations, academic institutions, and laboratory researchers to create a rich and unique collaborative contribution to real-life interventions.

Individually the case studies demonstrate how carefully selected proposals, nurtured through collaborative work and consultations or assisted by capacity building efforts and professional monitoring and evaluation, can make a significant impact on the individuals and communities they serve, while at the same time strengthening the institutions providing the services.

Collectively, the case studies further demonstrate how a consultative funding process, and ongoing support and development assistance, have helped to expand the key elements of Secure the Future™’s response to the southern Africa epidemic in terms of prevention, care and support, access to treatment and mitigation of the serious effects of the disease itself.
4. Community Outreach and Education – Empowering Communities

Why these projects were selected

Evaluations have revealed that each of these projects has performed strongly in the following areas:

- **Partnerships developed**: the project has developed strong working relations with the community, with staff and volunteers, and with other local organisations and institutions such as universities, hospitals, faith-based organisations or other local AIDS response groups. These have brought the necessary blend of skills and important contributions to the development process;

- **Community ownership**: communities contribute to decisions about the project and see it as a valuable resource within the community;

- **Organisational capacity and leadership**: the project has shown strong leadership, strong internal organisation, broad vision, and the ability to expand its services and reach; and

- **Unique technical input**: the project has developed and used unique technical skills or training materials.

The intervention areas they address

This selection of case studies addresses the broad areas of research and development, prevention, care, support and mitigation and capacity building, adapting proven strategies from other settings and regions of the world and also offering a variety of new approaches.

**Prevention** is addressed by focusing on a Buddy project for HIV positive women in Botswana’s prevention of mother-to-child-transmission (PMTCT) treatment programme, as well as through participatory theatre and peer educator programmes in border towns of Lesotho and South Africa.

**Care and support** is demonstrated through a project that uses an established church to attract retired nurses into home-based care in Swaziland, by addressing the needs of older women faced with caring for infected and affected children and grandchildren, with a new model to link community-based care with Johannesburg’s metropolitan hospital clinics, and through the experience of starting a community-based home care project from scratch in a desperately under-resourced areas of the Eastern Cape in South Africa.

**Capacity building** is illustrated through groundbreaking work educating pre-school children and their teachers about HIV/AIDS, by using the existing church infrastructure to establish a national counselling service in Botswana and standardising training in home-based care in Namibia.

"What is of relevance in the long term is whether Secure the Future™ funding and support enabled innovative interventions to be established, access further funding, and thus grow their efforts and impact. As part of our legacy, Secure the Future™ has drawn lessons, adopted and adapted models from these projects to inform legacy programmes of the BMSF NGO training institute and community-based treatment support programme."

Phangisile Mtshali, director of Secure the Future™ southern Africa.
5. Community Outreach and Education Case Studies

Community Outreach and Education (COE)'s mission is to assist resource-limited countries to find appropriate, cost effective and relevant responses to the pandemic by supporting programmes with a potential to be models that will add to the body of knowledge around sustainable and replicable interventions.

COE has sought to reduce the impact of HIV/AIDS on communities by empowering and supporting infected and affected women and children in Botswana, Lesotho, Namibia, South Africa and Swaziland.

5.1 Prevention and IEC (Information, Education and Communication)

5.1.1 The Coping Centre for People Living with HIV/AIDS (COCEPWA)

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<tr>
<th>ORGANISATION</th>
<th>The Coping Centre for People Living with HIV/AIDS (COCEPWA)</th>
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<tbody>
<tr>
<td>LOCATION</td>
<td>Botswana: the capital Gaborone and three villages 50 kms away – Mochudi, Molepolole, Lobatse – as well as the towns of Maun and Francistown.</td>
</tr>
<tr>
<td>GRANT AWARDED</td>
<td>US$219,266</td>
</tr>
<tr>
<td>BENEFICIARIES</td>
<td>Pregnant women with HIV, and their babies People living with HIV/AIDS (PLWHA)</td>
</tr>
<tr>
<td>AIM</td>
<td>To improve organisational capacity and to set up a support system for HIV-positive women.</td>
</tr>
<tr>
<td>OBJECTIVES</td>
<td>To support HIV-positive women through creating a “Buddy” system, and encourage them to take up PMTCT treatment or enter treatment trials; To destigmatise HIV/AIDS through a programme of public speaking; To improve organisational capacity to support positive staff and enable the organisation to grow to its full potential.</td>
</tr>
<tr>
<td>TIME LINE</td>
<td>Two years, starting October 2001</td>
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</table>
In 1999, Helen Ditsabe-Mhone – who had been living openly with HIV since 1995 – decided to reach out to other PLWHA, and founded the Coping Centre for People Living with HIV/AIDS (COCEPWA). She began working from her own home, before setting up office in the grounds of the Princess Marina Hospital in Gaborone, in a caravan donated by the hospital superintendent.

When it applied to the COE for funding in May 2001, COCEPWA was a small grassroots organisation driven by its 120 volunteers. All were HIV positive, making COCEPWA one of the few organisations in Botswana to promote the internationally accepted principle that people living with HIV have a crucial role to play in the response to the epidemic. COCEPWA’s mission was to provide support, education and services to people living with HIV, especially women.

Secure the Future™ funding was directed at helping COCEPWA expand into a co-ordinated, community-based social support network for positive women, and to set up two key programmes, the Buddy Programme and Women of Action (public speaking). COCEPWA linked up with the AIDS Action Committee (AAC) of Massachusetts, USA, for part of the funding period.

THE PROCESS

Capacity building

COCEPWA anticipated that its work would expand dramatically during the funding period, and so began its capacity building process with an analysis of its strengths, weaknesses, opportunities and threats (SWOT). This examined the strengths, weaknesses, opportunities and threats in six key areas, including organisational structure, financial and administration policies and all aspects of programming.

Staff training was identified as a major need. The Director, Financial Manager and Assistant Manager and, later, all five co-ordinators, were trained on project and financial management. Staff were also trained on strategic planning, programme planning, budgeting, information systems training and grant and report writing as well as on internal management, counselling, HIV counselling and the Buddy Programme.

"Capacity Building objectives have, overall, been met: the Centre has grown from a very small organisation with less than 10 staff members to a professionally run organisation with over 40 staff members," says an evaluator, from Secure the Future™’s Monitoring and Evaluation Unit (MEU), directed by Yale University’s Centre for Interdisciplinary Research on AIDS. COCEPWA staff wrote all reports for donors, and, in 2002, compiled the organisation’s first annual report.

Processes for opening the new branches were also followed, including local networking and community mobilisation to encourage referrals to and support for the new centre.

"The Greater involvement of People Living with HIV/AIDS or GIPA Principle was ratified at a WHO-organised conference by 42 governments in Paris on 1 December 1994."
Innovative social programmes – The Buddy Programme and Women in Action

During the funding period, 50 women were trained as Buddies, double the targeted number and a Buddy Training Manual was produced in 2002. Twenty women from three branches were trained in public speaking and are regularly presenting to NGOs, CBOs, the church, government and private sector.

The Buddy system started as an outreach programme to HIV positive women attending antenatal clinics. It was modelled on the system used by AAC in the USA, adapted for local conditions. “The Buddy Programme involves pairing an experienced COCEPWA member who has undergone Buddy training and has been on treatment with a new COCEPWA member in need of support. In this manner, COCEPWA is enabling PWLHA to take care of each other,” says Helen Ditsebe-Mhone.

How the Buddy system works

Buddies are experienced COCEPWA members, who go through an interview and training process before being matched up with a client.

The Buddy training course defines what Buddies do and teaches how Buddies can support a client and how they can get support for themselves. The training is active. Participants discuss issues among themselves. They also role-play important skills like how to help a client, and how to define the limits of their relationship with their clients.

After training, Buddies are matched up with another PLWHA so that they can provide one-on-one care, support and companionship. Buddies visit or share activities with their partner at least once a week. They can help clients by telephoning them, being a role model, talking about HIV, safer sex and medication, going for a walk, or helping them with their hospital or clinic appointments.

In this way the Buddy system is also a means to offer alternative support and incentives for women to agree to participate in clinical trials, and in the case of Botswana, the national antiretroviral treatment programme. COCEPWA members say:

<table>
<thead>
<tr>
<th>Being a Buddy means:</th>
<th>Having a Buddy means:</th>
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<tr>
<td>“Fulfillment”</td>
<td>“Being helped with referrals”</td>
</tr>
<tr>
<td>“The goodness of reaching others”</td>
<td>“Being accepted”</td>
</tr>
<tr>
<td>“Reducing isolation and stigma”</td>
<td>“Belonging somewhere”</td>
</tr>
<tr>
<td>“Changing families”</td>
<td>“Food parcels”</td>
</tr>
<tr>
<td>“Knowing more about the condition”</td>
<td>“Help when ill and a trusted friend”</td>
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</table>
“Speaking leads to unloading, public speaking makes me strong, and able to reject stigmatisation”

Women in Action

Women in Action is a public speaker programme to destigmatise AIDS by changing social attitudes to HIV positive women. COCEPWA trains speakers how to tell their stories, challenge misconceptions and respond to difficult questions; it also provides essential support groups and counselling. “Speaking leads to unloading, public speaking makes me strong, and able to reject stigmatisation,” says a COCEPWA Woman in Action.

OUTCOMES

By 1 October 2002, COCEPWA had attracted further funding in Botswana, opened five other branches – all between 50 and 200kms from Gaborone, increased its staff complement from seven to 42, and swelled the ranks of its members – and thus the number of people striving for a positive life with HIV – from 120 to more than 1200. Over the funding period COCEPWA also:

- Developed strong relationships with government departments and other NGOs;
- Established a viable support system for PLWHA through the Buddy Programme;
- Helped PLWHA speak openly and develop their sense of self-worth;
- Established a progressive public speaker programme, utilised countrywide;
- Developed training manuals for all training courses offered; and
- Alerted media to the principle of the Greater Involvement of People Living with HIV/AIDS by ensuring public speaker engagements appeared in daily newspapers.

These outcomes were made possible by focusing the work on two main areas:

- Capacity building for staff, volunteers and in the organisational structure; and
- Innovative social programmes to help change community attitudes towards HIV/AIDS by mobilising and supporting PLWHA. These are the “Buddy” and “Women of Action” Programmes.

LESSONS LEARNED

- Creating the opportunity for PLWHA to drive and partner in a programme helps ensure its success;
- Discrimination and stigma are not easy to dispel;
- Enabling PLWHA to speak in public about their status is a useful, and un-intimidating way to motivate people to start thinking about themselves and HIV; and
- Innovative human resource policies offering organisational support and guidance are important when working to build the capacity of PLWHA.
Reetsanang actor directs a community member during a workshop.
“Theatre has clear messages because it’s not everybody who can read - if you give out pamphlets some may just use them to light fire.” Kopong village resident.

### 5.1.2 Reetsanang: using participatory theatre as a tool for community education

<table>
<thead>
<tr>
<th>ORGANISATION</th>
<th>Reetsanang Association of Community Drama Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOCATION</td>
<td>Nine rural communities of Botswana</td>
</tr>
<tr>
<td>GRANT AWARDED</td>
<td>US$32,000</td>
</tr>
<tr>
<td>BENEFICIARIES</td>
<td>Youth, women in rural communities.</td>
</tr>
<tr>
<td>AIM</td>
<td>To use theatre as a tool for community mobilisation and education on developmental issues.</td>
</tr>
<tr>
<td>OBJECTIVES</td>
<td>To train local theatre groups, especially women and young people, to include theatre as part of HIV/AIDS information, education and communication activities; To deliver HIV/AIDS prevention and care messages to nine villages.</td>
</tr>
<tr>
<td>TIME LINE:</td>
<td>One year, starting January 2000</td>
</tr>
</tbody>
</table>

Final evaluation conducted three months after the close of the programme found that community members were still able to vividly recall key AIDS education images from Reetsanang performance workshops.

These strong memories remained because, behind every performance, was a careful, two-phase process to prepare and involve the entire community. First, the umbrella theatre group used community networking to introduce their work, gather baseline information and prepare for the event. Then, on the day of the performance workshop, Reetsanang trainers helped participants create, rehearse, stage and discuss plays offering solutions to HIV-related issues of concern to the local community.

Secure the Future™ funding was granted to enable Reetsanang to extend this community AIDS education using theatre to nine rural communities in Botswana.
THE PROCESS

Community Networking

Reetsanang programme theme:
"Mobilising, organising, educating and training women and young people to respond correctly and effectively to the problem of HIV/AIDS using community theatre."

Community networking is the most effective way to prepare a community for a workshop. It attracts local people to participate in a weekend-long workshop, and it helps to make sure that benefits and ideas generated by the workshops continue into the future.

Reetsanang’s first step in community networking was to obtain baseline information in four broad areas. The theatre groups asked questions about:

- Village demography, covering questions like the historical background of the area and local beliefs;
- Partners and collaborators, such as leadership structures, cultural groups, government structures and District Multi-Sectoral HIV/AIDS Committees;
- Local knowledge, attitudes and perceptions of health and HIV, including local concerns and facilities; and
- Logistics, such as transport, a suitable venue, the best times for an audience to be available, and food.

The organisation developed guidelines to streamline this process. Reetsanang first introduced the concept to the District Health Team (DHT), and set a tentative date for the event. Then the matter was referred to the District Multi-Sectoral HIV/AIDS Committee (DMSAC), to liaise with the local Member of Parliament, council secretary and district commissioner and to set up a working task force at village level to inform local leadership and investigate logistics.

Workshop Programme

"Theatre breaks down barriers between the audience and performers as it shares ideas, looks at options and stimulates creative thinking. The best way to achieve this is by involving people from one's intended audience in defining the issues, developing and pre-testing the plays to be performed and discussing them after the performances," says Reetsanang’s national co-ordinator.
Workshops followed a broad programme:

**DAY ONE**
- A local, senior politician opened proceedings;
- Condoms and printed HIV/AIDS education material were distributed;
- Reetsanang artists performed a specially prepared drama informed by their research of village needs and issues;

**DAY TWO**
- Group discussions, facilitated by resource persons from the District Health Team and Reetsanang artists, were held to help each community look at their own priorities regarding HIV/AIDS;
- Participants were divided into groups and given a theme around which they created a play; and

**DAY THREE**
- The plays were presented and discussed by the entire village audience at a Lekgotla (village meeting place) in the presence of traditional leadership, local government and other key development and HIV/AIDS stakeholders.

**OUTCOMES**

“Reetsanang’s HIV/AIDS education programme showed theatre to be a powerful tool for community education, one which captured the minds of communities and sensitised them to the spread of HIV/AIDS and the need for prevention and imparted skills for care and support,” say evaluators Kegalale J Gasennelwe and Koketso Rantona.

As an umbrella association, Reetsanang proved that it could network, and so could use its position to influence increased use of theatre to deliver prevention messages. Reetsanang’s Community HIV/AIDS Education programme is gradually being integrated into DHTs’ annual action plan in regions across the country.

Using theatre as a tool to influence behaviour produced specific successes:
- Local health facilities areas reported that condom uptake increased after workshops and more requests for counselling and teaching were received;
- General awareness of PMTCT issues also increased and more people wanted to make use of the options available to them – including Reetsanang artists themselves; and
- Sexual violence issues, explained by using story telling, appeared more clearly understood and less intimidating.

**LESSONS LEARNED**

- Community networking is a critical part of introducing programmes to communities;
- Stronger organisational development – such as a small, permanent office to manage activities – is critical if the association of drama groups is to continue and expand its work;
- To have impact, programmes that aim to change behaviour should be run for a longer period;
- Community mobilisation is key for collaborative and relevant multi-sectoral HIV/AIDS interventions; and
- Formative research enhances the outcome of community-based interventions.
5.1.3 CARE – Lesotho: innovative methods to target groups at high risk of infection

<table>
<thead>
<tr>
<th>ORGANISATION</th>
<th>Co-operative for Assistance and Relief Everywhere (CARE) Sexual Health and Rights Promotion Programme (SHARP!)</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOCATION</td>
<td>Lesotho, specifically the border towns of Maseru, Mafeteng and Maputsoe, with complementary activities in the South African border towns of Ficksburg and Ladybrand.</td>
</tr>
<tr>
<td>GRANT AWARDED</td>
<td>US$233,609</td>
</tr>
<tr>
<td>BENEFICIARIES</td>
<td>School children (10-14) young people (15 – 25), women in high risk groups, and their families, and community-based organisations.</td>
</tr>
<tr>
<td>AIM</td>
<td>To develop innovative, replicable, sustainable models to protect the financial security of households affected by HIV/AIDS in border communities of Lesotho.</td>
</tr>
<tr>
<td>OBJECTIVES</td>
<td>To use peer education to destigmatise HIV/AIDS and increase knowledge of safer sex among school children, young people, women (including low-income women and women at high risk), men (including migrant labourers ) and migrants such as long distance truck drivers; To develop community-based systems for comprehensive care by strengthening CBOs, setting up Resource Centres and supporting home-based care.</td>
</tr>
<tr>
<td>TIME LINE</td>
<td>Two years, starting March 2001</td>
</tr>
</tbody>
</table>

SHARP! aimed to help those vulnerable to HIV infection to choose safer sex and help care for infected and affected individuals. The programme was designed in the light of CARE’s 30 years of experience in Lesotho, its work with HIV/AIDS since 1994, and the country's national HIV/AIDS policies. SHARP! was aimed at priority groups in selected border areas: young people aged 10 to 14 and 15 to 25, women (including low-income women such as those waiting outside factories to seek employment, wives of migrant labourers or street vendors), women at high risk, such as sex workers, men (including migrant labourers and fathers of children aged between 8 and 25), and community-based organisations.

Secure the Future™ funding was sought to extend peer education to these groups, to include care into community-led responses in Maputsoe, Maseru and Mafeteng, and to cover the cost of a programme office in Mafeteng and Maputsoe.

THE PROCESS

Formative assessments to guide the development of interventions took place at the end of 2000. These showed that many myths around HIV and AIDS still existed. They also highlighted the crucial role of traditional healers as most people turned to them for treatment. SHARP! recruited staff in April 2001, and began work on launching the programme by contacting chiefs in two prime sites – Maputsoe and Maseru – from May 2001 and, later, Mafeteng. Community meetings (lipitso) were held with chiefs and other stakeholders including town councils, policy makers, schools, teachers and traditional healers.
“This committee was the basis for SHARP!’s success, says Mamello Moleli, SHARP!’s Project Manager in Lesotho.

From these consultations the communities were advised to select HIV Community Committees to work with SHARP! to run the peer educator programme. The HIV Community Committees selected individuals to undergo peer educator training according to whether they were interested in the community and of acceptable character. The volunteer peer educators were trained in a four-day training course from July to September 2001. Training followed participatory methods like group work, brainstorming and role-playing and training women to protect themselves against violence and rape. Peer educators then went on to give outreach talks in industrial areas, the communities, cities, schools and border posts. The CBO capacity building and strengthening in targeted communities took place from January 2002.

OUTCOMES

- By August 2002 peer educator training focusing on different cohorts, supported by training manuals, had been established and a strong, committed Community Committee had been established at Maputsoe that was used as a role model for other communities.
- By June 2003:
  - A total of 821 volunteer peer educators among school children, young people and low income fathers and mothers had been trained and 584 were actively involved in community-based peer education activities;
  - Twenty CBOs had been screened to assess their weaknesses and strengths and 12 had been selected and trained in HIV/AIDS information and institutional capacity building. Eight groups received further training in home-based care management and support and five in providing services in orphan care, nutrition, and herbal garden development.
  - Four community resource centres had been established in Maseru, Maputsoe, Ficksburg and Ladybrand. They are staffed by peer educators and have developed into areas of learning about HIV/AIDS and centres for social interaction;
  - An assessment of knowledge, attitudes and practices of service providers had been conducted and training on HIV/AIDS awareness and prevention was planned; and
  - Community level comprehensive care strategies were underway with communities focusing on economic empowerment, home-based care, and strengthening referral systems to the district health centre and hospital.

LESSONS LEARNED

- Using Community Committees is key for projects to be accepted by most community members;
- Training different cohorts of peer educators is a useful way to reach and communicate with different groups of people in the community on sexual and reproductive health issues; and
- Provision and sustainability of allowances for volunteers should always be carefully considered to ensure that the project does not attract only those interested in earning an income.
5.2 Care and Support

5.2.1 A New Robe – Community-Based Parish Nursing

<table>
<thead>
<tr>
<th>ORGANISATION</th>
<th>Maternal Life International / Roman Catholic Diocese of Manzini, Swaziland</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOCATION</td>
<td>Manzini region: Gebeni, Mafutsene, Kakhoza, Mzimpofu, Malkerns, Fairview; Hhoho region: Mpolonjeni, Fonteyn, Nkhaba, Siphosicini, Lobamba, Ntjonjeni; Lubombo region: Lonhlupheko, Maphatsindvuku, Mhlatuze; and Shiselweni region: Kamfisane, Newhaven, Hlathikhulu.</td>
</tr>
<tr>
<td>GRANT AWARDED</td>
<td>US$275,240</td>
</tr>
<tr>
<td>BENEFICIARIES</td>
<td>Isolated and impoverished families affected by HIV/AIDS.</td>
</tr>
<tr>
<td>AIM</td>
<td>A faith-based programme to show how countries can tap into existing resources, skills and infrastructure, such as retired nurses, and through their parishes draw them into community work pertaining to HIV/AIDS.</td>
</tr>
<tr>
<td>OBJECTIVES</td>
<td>To use the church to bring skilled health workers into home-based care initiatives by training retired nurses to work with their community priest in providing HIV/AIDS awareness and care services; To hold a spiritual dimension central to nursing practice, and encompass the physical, psychological and social dimensions; To support lay health workers.</td>
</tr>
<tr>
<td>TIME LINE</td>
<td>Three years, starting May 2000</td>
</tr>
</tbody>
</table>

The Bishop of Swaziland led the launch of the Parish Nurse Programme as part of the Catholic Church’s response to the HIV/AIDS pandemic facing the country. The programme is a partnership between USA-based Maternal Life International, which provides training, support and medicines, and Caritas Swaziland which is the development arm of the Diocese and leads operational management.

Secure the Future™ funding of the Parish Nurse programme meant that – using parish structures – the church was able to reach into communities across the country to galvanise retired skilled nurses into action.

Parish nursing borrows from the United States model where Parish Nurses are health counsellors, educators, leaders and facilitators and links to community services, as well as a source of theological reflection. The model supported by BMSF in Swaziland was tailored to AIDS prevention and care in Africa by adding a specific element of nursing care for HIV/AIDS.

This is known as the “Five S’s”: Specific, Supportive, Symptomatic treatment, as well as Social and Spiritual Care. The Catholic Church introduced the programme, and it swiftly expanded to other denominations; the example of the elderly nurses entering homes attracted the attention of neighbours and extended families, drew them into the work and so also expanded the pool of lay carers.
"I am Sizwe Masilela, a young adult aged 21, residing at Siphocosini area under the Motjane Inkhundla ... My grandmother Veronica Mabuza, who is a retired nurse, influenced me and now I am working as a volunteer in the Parish Nurse programme. I would see her suffer when moving from one homestead to the other visiting her clients due to the fact that she is old and cannot walk long distances. Also the clients would come in large numbers in her place and the work became too much for her. Having a loving heart and compassion I thought of joining her. I then began to move from one homestead to the other, visiting our clients. I became a known somebody."

THE PROCESS

Parish Nurses brought an immediate improvement in the quality of care provided through home-based care. They worked in collaboration with priests to assist the community with spiritual health and healing. They also strengthened the capacities of the individuals, families and the congregation to care for one another as a faith-based community.

Work began in earnest in January 2001, after extensive training of the 16 Parish Nurses – most of whom were retired nurses from the Catholic Church. "In the first year of the programme, the number of deaths was frightening," says Programme Co-ordinator Thandiwe Dlamini. "All clients visited at home were in the terminal stages of the illness." The situation improved in 2002 as the Parish Nurses had already seen clients in the early stages of illness, and been able to assist them to manage opportunistic infections and speak to the family. The most common ailments addressed included painful knees, feet and back, headaches, high blood pressure, diabetes and opportunistic infections for HIV positive clients, including thrush, weakness, itchy skin and coughs.

Evaluation processes conducted by Manto Management on behalf of the MEU have confirmed that through the Parish Nurses, pregnant mothers have been counselled on mother-to-child-transmission, families have been educated in taking care of HIV/AIDS patients without being at risk of infection and community members have been counselled, which has resulted in them going for voluntary counselling and testing. For partners such as the local clinic these services have lessened their already mammoth task of HIV/AIDS care and prevention.

"Parish Nurses are teaching about prevention of HIV/AIDS, STI; to antenatal mothers they stress how HIV is transmitted." Public Health Unit Sister

The material support provided by Parish Nurses, most importantly the over the counter medications that treat opportunistic infections, has gone a long way in helping patients recover and to return to productive lives. The programme reported in March 2003 that, by providing medication for opportunistic diseases, it was able to record a slight decrease in the number of deaths each month as more clients recovered and resumed their normal occupations.
OUTCOMES

“The Parish Nurse Programme has successfully trained retired professional nurses in parish nursing. The trained nurses have taken on their responsibilities with great professionalism and with courage. The programme has to a large extent achieved its planned goals and more through the structuring of partnerships and through mobilising community volunteerism,” says the evaluation by Manto Management.

- The Programme is implemented in 13 Catholic parishes and a few non-Catholic churches and is one of the few NGOs in Swaziland which have a national foothold. Churches from eight other denominations have requested support from the PNP to implement similar programmes in their parishes;
- By March 2003, 30 Parish Nurses had been trained in collaboration with Maternal Life International and 125 volunteers in five parishes had been trained in community home-based care through the Project Support Group;
- The second, user-friendly edition of the training manual – “A New Robe – Parish Nursing in AIDS Prevention and Care” – has been printed for distribution to the nurses. The curriculum and material is sensitive to the Swaziland context and the needs of the Swazi people; and
- Working relationships have been established around referrals to and from public health units, rural clinics and hospitals, civil society organisations, government projects, Secure the Future™ grantees and programmes working on poverty alleviation.

“When I first discovered and attended to Patient T on 20 May 2002, she had sores all over the body, thrush on her tongue, generalised body pains and weight loss. She looked miserable and co-workers did not want to mix with her. I treated her monthly and to my surprise the patient improved gradually, and by 18 September her sores and diarrhoea had stopped and she had gained weight and was cheerful. This client encouraged me to see that our efforts are not in vain.” Lina Dlamini – Parish Nurse

LESSONS LEARNED

- Community-based programmes require good administrative infrastructure and support at all levels, not just for co-ordinators, as home-based care cannot be provided effectively without documenting and reporting;
- Community-based programmes draw on community strengths but at times – as with Swaziland which is now facing a drought and HIV/AIDS – also need to draw on external support for immediate material relief;
- Community-based programmes should have quality assurance mechanisms to ensure that volunteerism and community mobilisation genuinely contribute to the well-being of all community members;
- The church can play a greater role in community development and can help to mobilise communities to respond to community issues;
- Community-based programmes should build partnerships with government, national, and international civil society organisations so as to access best practice models, training and capacity building opportunities, credibility and access to additional resources;
- Community-based programmes should adapt models to meet the needs of their beneficiaries and social and environmental contexts; and
- Community-based programmes should also take into consideration the poverty of the affected families and plan accordingly, for example mobilising and referral for food parcels when necessary.
“The children are hurting so much and they are affecting me because it is not nice for me, but what am I supposed to do.”

5.2.2 Supporting older women caring for children and grandchildren affected by AIDS

<table>
<thead>
<tr>
<th>ORGANISATIONS</th>
<th>Institute of Aging in Africa, Faculty of Health Sciences, University of Cape Town, in partnership with the SA Red Cross Society: Western Cape, Ikamva Labantu, Wola Nani, and Neighbourhood Old Age Homes (NOAH) Project.</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOCATION</td>
<td>Gugulethu, Crossroads, Nyanga, Khayelitsha on the Cape Flats of the Western Cape, South Africa</td>
</tr>
<tr>
<td>GRANT AWARDED</td>
<td>US$172,000</td>
</tr>
<tr>
<td>BENEFICIARIES</td>
<td>Older women affected by HIV/AIDS.</td>
</tr>
<tr>
<td>AIM</td>
<td>To generate and apply research knowledge to enable and support grandmothers in their caregiving responsibilities.</td>
</tr>
<tr>
<td>OBJECTIVE</td>
<td>To empower elderly women – a group which has been largely neglected in HIV/AIDS programmes – to support kin affected by HIV/AIDS.</td>
</tr>
<tr>
<td>TIME LINE</td>
<td>One year, eight months, starting June 2000</td>
</tr>
</tbody>
</table>

The grandmothers of Africa are bearing the heaviest and most difficult burden of caring for their adult children with AIDS and their co-resident grandchildren, some of whom may have AIDS or are orphaned as a result of it. Yet, these elderly women have been paid very little attention in local programmes rolled out in response to the epidemic. There has also been little specific research on how the epidemic impacts on older African women and thus little information has been available to inform the development of government policy in the field.

The need to understand how the epidemic affects older women and their family dynamics drove the University of Cape Town’s Institute of Aging in Africa to research the situation. The researchers linked up with the SA Red Cross Society, Western Cape, which runs a home-based care programme on PWLHA on the Cape Peninsula, to access a sample of households which matched the research criteria1. Initially, difficulties were experienced in accessing a sufficient number of households to meet the sampling criteria in Crossroads, Gugulethu and Nyanga, the three study areas specified in the study design.

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1 Namely a multigenerational household in which a grandmother aged 55 and older, adult child or children with HIV/AIDS and grandchildren reside.
The Institute then expanded the sampling frame and lowered the age cut-off to 50 years. They also linked up with three other CBOs – the Neighbourhood Old Age Homes Project (NOAH) which provides sheltered housing and services to social pensioners; Ikamva Labantu, which operates service programmes aimed at development and Wola Nani, a community AIDS care project in Khayelitsha – so that they could reach a sample of 43 households in four areas in the Cape Flats in which older women living with infected and affected children and grandchildren resided, and who were willing to participate.

A four-phased research and intervention project was designed. The exploratory study was funded by the University and was designed to identify the nature of the problem and to develop a research instrument. Secure the Future funded the main survey of 43 women directly affected by HIV/AIDS and two series of follow-up interviews. It also contributed funds for the intervention.

Survey participants were interviewed on three occasions over a six month period between August 2000 and February 2001. The women were relatively young, aged on average 59.7 years; 88 percent lived in households with five or more residents and almost half, where they were age eligible to receive one, relied on social pensions as their main means of income.

The main findings from the interviews paint a picture of pain, and often hopelessness. They include:

- Pervasive, desperate poverty in the households;
- A lack of resources and bureaucratic barriers to accessing entitlements such as grants: “... helped with a support grant for the children. I have been trying to get it but with no success, so if you can give me a plan on how to apply for it;”
- Food poverty: “Starving is the worst thing. I am trying my best to struggle so that there is something to eat.”
- Difficulty in paying for schooling for grandchildren, transport for PLWHA to obtain medical care, and membership fees for a funeral society for dying PLWHA: “I am struggling because their mothers are not working, therefore I am trying my best. It is food .. and I would like to take them to the crèche but there is no money and clothes for them to wear.”
- Emotional trauma for the grandmothers: “The children are hurting so much and they are affecting me because it is not nice for me, but what am I supposed to do.” and
- The physical burden of caregiving and deteriorating health on the part of the grandmother.

Overall, the greatest needs were for money and food for the household, and the most frequent request was for training in business skills to help augment household incomes. Other findings were that:

- Poverty is made worse by joblessness, as neither grandmothers with caregiving responsibilities nor PLWHA incapacitated by illness were able to secure or hold down a job;
- In South Africa grandmothers younger than 60 are not eligible for a pension grant, so half of the older participants in the study did not benefit from one;
- There was a need for information on HIV/AIDS, advice on where to go for help, and business skills;
- Problems with accessing child support grants for grandchildren were common because of the lack of birth certificates; and
- Money for food was a constant problem.

Following on the research results, a pilot intervention was designed and implemented between July and September 2001.
“The future of the country depends on the ability of the older population to cope with the AIDS epidemic and to raise healthy children.” Kathleen Brodrick, GAPA project manager.
Continued growth and expansion

Encouraged by the success of the pilot intervention, people involved with GAPA are committed to continuing and expanding its work. Secure the Future™ agreed to transfer the balance of funds in the research grant to GAPA as seed funding. GAPA was registered as a non-profit organisation early in 2002. The organisation has secured funding from local and provincial governments, elected a management committee and employed a full time project manager. Twelve dedicated and trained grandmothers volunteer to run support groups in their houses in different areas of Khayelitsha. There are 17 GAPA support groups reaching more than 150 women throughout Khayelitsha.

The GAPA trading store – which sells goods crafted by women in the support groups and acts as a temporary meeting place – has been erected in the Mandela Park area. GAPA has also bought land and plans to build a multipurpose centre and a second trading store by the end of 2003.

LESSONS LEARNED

- Researchers and communities need to form strong partnerships with one another to ease the researchers’ entry to the target community, to ensure relevance and legitimacy in the community and to ensure that the research work yields relevant knowledge for implementation;
- Research results should be translated into action, but an intervention should be designed with local beneficiary input so that it is sensitive to community needs;
- Communities need to take ownership of any intervention for it to become sustainable; and
- Soliciting donations and sponsorship to continue a pilot intervention needs to be done early on in the project.

It is worth noting that, having seen how well the pilot project worked, other organisations that were part of the research are now also taking up the challenge of building awareness and support mechanisms for older women. Secure the Future™ for example, also funded the Neighbourhood Old Age Homes (NOAH) to run a one-year programme training older women as peer educators in HIV/AIDS. The first training session, for 17 women, was held in July 2003.
5.2.3 Community AIDS Response – linking metropolitan hospital HIV/AIDS clinics with community care and material support

<table>
<thead>
<tr>
<th>ORGANISATION</th>
<th>Community AIDS Response (CARE)</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOCATION</td>
<td>Johannesburg, South Africa</td>
</tr>
<tr>
<td>GRANT AWARDED</td>
<td>US$76,114. Co-funded by Southern African Catholic Bishops’ Conference and the Catholic Medical Mission Board by the same amount.</td>
</tr>
<tr>
<td>BENEFICIARIES</td>
<td>PLWHA attending metropolitan clinics, their families and caregivers.</td>
</tr>
<tr>
<td>AIM</td>
<td>To support people with HIV and AIDS, their families and caregivers.</td>
</tr>
<tr>
<td>OBJECTIVES</td>
<td>To provide an innovative model of professionally-driven NGO support for HIV/AIDS clinics within metropolitan hospitals – at the hospital, into the community and into the home;</td>
</tr>
<tr>
<td></td>
<td>To provide material assistance for PLWHA, and a specially developed fortified food, “E-pap” – and to use this to facilitate income generation and support projects;</td>
</tr>
<tr>
<td></td>
<td>To provide training to meet patient and carer needs.</td>
</tr>
<tr>
<td>TIME LINE</td>
<td>Two years, starting February 2001</td>
</tr>
</tbody>
</table>

CARE was started by an informal group of volunteers as an initiative to provide a proper programme of support to patients and caregivers at the HIV/AIDS clinic at the Johannesburg Hospital. Today, CARE considers itself a family of caregivers, and has developed a holistic set of innovative services to fulfill its objectives and build an invaluable and professional NGO link between hospitals, clinics, communities and patients.

CARE has focused its services on supporting people living with HIV/AIDS through four interlinked areas of activity: counselling support, home-based care, material support and income generation.
THE PROCESS

To meet these service commitments CARE has also focused on developing a professional volunteer structure. Interested community volunteers are uplifted through: professional screening; initial and ongoing skills training; professional mentoring, supervision and debriefing. CARE also created a career path structure for volunteers to gain skills and resources.

The career path motivates volunteers and provides them with opportunities to advance. It comprises:

- Pure volunteers, who offer befriending and informal help to clients. These volunteers are usually in the process of being screened by CARE to receive counsellor training and receive incentives, or are professionals volunteering their expertise;
- Incentivised volunteers who have gone through the six-day counselling training course and counsel and educate clients two days a week;
- Field workers, who are selected from the above group, receive an honorarium for working four days a week and serve both as counsellors and home-based carers after training; and
- Team leaders, who are full time employees and head a volunteer team.

Volunteers are well supported including weekly group supervision.

CARE has been able to use the volunteer system to professionalise a model of providing a link between community and different levels of institutional care.
CARE services are run from five locations in Gauteng province:
- Two metropolitan hospitals (Johannesburg and Helen Joseph); and
- Three community centres (Yeoville, Alexandra and Soweto Hospice).

Each location offers a range of support services, including pre and post-test counselling, befriending, home-based care referrals, information, support groups, wellness programming, food and training. The services are interlinked; a client introduced to CARE through post-test counselling services will be referred to other needed services including support groups, material support and income generation.

In hospitals and clinics CARE is a formal part of the clinic process; clients often make their first contact with CARE when doctors or nurses refer them for post-test counselling and home care. This is considered crucial for the project’s success since patients take referrals from professional health care workers seriously.

Counselling
Counselling services for clients include pre and post-test counselling, ongoing counselling, support groups, wellness programmes and bereavement support. Some of the main issues discussed in support groups and counselling sessions include: acceptance of diagnosis, disclosure, discordant couples and the impact on relationships, stigma and discrimination and poverty.

Home-based Care
Home-based care services are offered to terminally ill patients who are bedridden or housebound. Most live in township hostels or shacks. A nurse accompanies the volunteer for the first visit and a follow-up visit within six weeks. This ensures a proper introduction, medical assessment and appropriate instructions for the volunteer. Volunteer caregivers make between one and three visits a week, and receive individual and group supervision once a week and compulsory training.

“CARE staff and volunteers provide a consistently high standard of service. There are very few other organisations I can praise as highly.” Sharon Ekambaram, AIDS Consortium.
Material Support

When the Secure the Future™ funding was received in early 2001, CARE requested support from a commercial company to develop a nutritionally fortified product for their clients. In 2003 CARE took a decision to limit its material support to “E-pap” for greater service efficiency and to encourage income generation rather than a culture of dependency. “E-pap” is a nutraceutical blend of maize and soy and includes vitamins and essential minerals.

In the past two years, the product has contributed to CARE’s activities by providing sustenance and nutrition to clients, a structured income generation activity for clients and volunteers, and a supplemental income for CARE, particularly to cover unanticipated costs. CARE receives five percent commission of all sales of “E-pap”, which is now being sold, even outside South Africa.

The product has not been independently evaluated or clinically tested but has been approved by the South African Bureau of Standards. According to CARE’s investigation, clients reported increases in strength, concentration, energy, sleep and bowel habits after using it.

Income Generation

Members of CARE’s income generation groups are referred through the material support or counselling programmes. CARE makes an effort to give each client a referral to an income generating activity because of the pervasive problems of poverty and unemployment. Income generating activities include embroidery, beading, sewing and making teddy bears.

OUTCOMES

- During the first year of operation, CARE supported 1,498 people who were living with HIV and AIDS through 10 volunteer counsellors, 12 volunteer befrienders and five volunteer professionals. The number of people supported trebled in the second year and in the year to September 2002, reached 10,312;
- By June 2003 CARE employed six full time staff, seven team leaders in charge of 25 volunteers and operated six support groups. It had developed a strong referral system and was closely networked with 58 organisations, including hospitals, clinics, NGOs and universities – which meant that multiple needs could be addressed.
- Activities were extended beyond the Infectious Disease Clinic at the Johannesburg Hospital to the Helen Joseph Hospital in western Johannesburg and also to three satellite community-based centres to avoid travel time and costs to clients, most of whom came from Soweto, which lies about 20 kms to the south of Johannesburg;
CARE's administration and training facilities were moved to a donated house in the north-eastern suburbs; and

By developing organisational structures in consultation with outside experts, including a Secure the Future™-sponsored financial auditor, CARE was enabled to develop sound financial and monitoring systems which underpinned its work to secure funding from other sources.

LESSONS LEARNED

- Strong leadership and strategic planning activities help to define objectives and activities such as befriending, counselling and care, as well as strengthen monitoring and guide growth;
- Strategic planning and networking is key to securing additional funding;
- A clear volunteer structure with opportunities for growth and ongoing supervision helps to maintain volunteers’ motivation and make them feel appreciated;
- Supervision is essential to protect the quality of counselling and home-based care services in the face of enormous demand;
- Strong referral systems and a multi-disciplinary approach mean that a wide range of client needs can be addressed;
- NGOs can successfully use outside experts to build internal financial and monitoring systems and plan strategically for growth; and
- NGOs can successfully link institutional and community care through trained volunteers and strong partnerships with hospitals.
5.2.4 Bambisanani: starting a partnership for community-based care

<table>
<thead>
<tr>
<th>ORGANISATION</th>
<th>Bambisanani HIV/AIDS Project</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOCATION</td>
<td>South Africa, Eastern Cape covering Umzimkhulu, Bizana, and Lusikisiki</td>
</tr>
<tr>
<td>GRANT AWARDED</td>
<td>US$353,366</td>
</tr>
<tr>
<td>BENEFICIARIES</td>
<td>Women and children affected by HIV/AIDS in the local communities.</td>
</tr>
<tr>
<td>AIM</td>
<td>To develop a model for establishing a new partnership project to enable poor, rural communities to respond to emerging needs for HIV/AIDS related care and support.</td>
</tr>
<tr>
<td>OBJECTIVES</td>
<td>To train 60 care supporters to provide home-based care for terminally ill people;</td>
</tr>
<tr>
<td></td>
<td>To identify, monitor and support orphaned and abandoned children;</td>
</tr>
<tr>
<td></td>
<td>To establish drop-in facilities to run support groups, youth activities and income generating activities;</td>
</tr>
<tr>
<td></td>
<td>To advocate for the project and mobilise partners;</td>
</tr>
<tr>
<td></td>
<td>To build community capacity around home-based care.</td>
</tr>
<tr>
<td>TIME LINE</td>
<td>Three years, starting January 2001</td>
</tr>
</tbody>
</table>

**BAMBISANANI’S STORY**

Until Bambisanani was set up, the women and children of the impoverished areas of Bizana, Umzimkhulu and Lusikisiki were being left to care for their dying relatives alone. Their men have for decades sought migrant labour in the sugar and mining industries. But by March 2000 many of those who had been cane cutters and mine workers were debilitated by HIV and were being repatriated weekly to their rural homes in what is one of the poorest regions of South Africa. Unemployment in this part of the Eastern Cape is 65 percent; there is one doctor for 16,592 people and less than one nurse per 1,000 of the population.

Responsibility for the care of returning migrants fell on the shoulders of older women and children who often had little or no access to appropriate resources and support and resorted to “dumping” terminally-ill relatives in local, over-burdened hospitals. The community had been discussing how to respond to this problem for more than a year. Two community meetings had been held, with the assistance of local development...
consultants, to articulate local needs. These formed the outline of Bambisanani, a project which started from scratch to provide an integrated response to HIV in a hard-to-reach and resource-limited setting.

Bambisanani was planned to comprise a package of interventions guided by a focus on women and children, a commitment to partnerships between all sectors and a recognition of the severe problem of poverty and the heavy economic pressures faced by households affected by HIV/AIDS. Interventions covered:

- Advocacy, marketing and partner mobilisation, mainly to lobby the public and private sector to support the project;
- Community capacity building to create a suitable environment for home-based care and support for children in distress;
- Support groups and income generating activities, to ensure that affected people, children in distress and their families received support and skills development;
- Home-based care to provide holistic care for the terminally-ill; and
- Identifying and including vulnerable children in a “safety net” so that children in distress access adequate care and support.

**THE PROCESS**

Bambisanani aimed to build a model of creating comprehensive community care where nothing existed before. It developed slowly, driven by the determination of the partners and community to act.

Initially it was conceptualised as a partnership project between:

- Bristol-Myers Squibb Foundation Community Outreach and Education;
- EQUITY Project, a USAID-funded programme to support the South African government to provide integrated primary health care services to all;
- Gold mining companies;
- Mineworkers Development Agency, the development arm of the National Union of Mineworkers;
- The Employment Bureau of Africa (TEBA), originally the recruitment arm of the mining industry increasingly focusing on facilitating development in rural communities;
- Planned Parenthood Association of South Africa: Eastern Cape;
- Hospice Transkei and South Coast Hospice;
- National Education, Health and Allied Workers Union (NEHAWU), which represents civil servants.

A Project Support Committee was established at a community workshop in November 1999, which was attended the BMSF. The committee comprised representatives from health, welfare, education, NGOs, mining industry representatives, PLWHA organisations, unions, traditional healers and provincial and local governments. A small Project Management Committee was elected to be responsible for overall management.

Because the Bambisanani Project was only registered as a legal entity in July 2002, the BMSF contracted with partners who provided services, namely South Coast Hospice, on behalf of the partnership.

Progress was slow. One of the main challenges was that the project struggled to keep pace with its anticipated time frames, for example setting up support groups and drop-in centers did not move according to project time-lines. Focus on community mobilisation and buy-in, the shortage of supplies and the long distances to be travelled also impacted on progress. However, communities supported the project. In Lusikisiki, for example, a committee was formed to support Bambisanani. The fact that many communities still associated HIV with witchcraft also proved a challenge. But, by July 2003, care supporters trained through Bambisanani were tending to 900 patients a month.
OUTCOMES

- By May 2002 Bambisanani had been able to prove that a community-based home care programme could improve people’s lives because communities were beginning to accept that they were able to care for terminally-ill family members and would be helped to access social services. Research was conducted early in the programme into caring for children in distress, community attitudes to HIV/AIDS, community-based care and poverty alleviation;
- Working partnerships had been set up with government, NGOs and the private sector and a referral system between health services, mining companies and the project was built;
- By July 2003, 60 care supporters had been trained and each attended to around 15 patients per month, though battled to travel the long distances necessary to reach some villages;
- Replication programmes had been initiated in two areas. Secure the Future™ funded the Sibambisene programme at Umkhanyakude in Health District 27 in the north eastern part of KwaZulu Natal and the O R Tambo District Municipality in the Eastern Cape replicated and expanded existing work into Ntabankulu and Flagstaff;
- Children were being helped through delivery of food parcels and applications for support grants, but emotional, educational and other support had still to be made available; and
- Many requests were received to replicate the project and roll it out to more districts. Three years after inception Bambisanani is recognised by the National Department of Health and has managed to attract additional funding of R1,5 million from O R Tambo Municipality and R400 000 from Old Mutual in support of its replication programmes.

Bambisanani Model

1 Senekal, Community Development Unit, University of Port Elizabeth. Gcina Radebe, Health Systems Trust November 2002.
LESSONS LEARNED

- With community involvement a lot can be achieved. For a community-based project to succeed it is critical to first consult, engage with and maintain support from community leadership, then ensure community involvement and especially acknowledge the role of local traditional leadership;
- Community mobilisation alone will not deliver consistent services: organisational development structures, adequate staffing, programme management skills, and clear reporting and support mechanisms are essential to manage the interests of all parties and delivery on the objectives;
- Community-based projects need time, patience, advocacy and mobilisation before consistent delivery is achieved;
- The enormous demand for care and support is worsened by poverty; and
- Accessing social grants from rural areas is deeply complicated. Developing clear systems to access grants with relevant government departments will have significant impact.
5.3 Building Capacity

5.3.1 Cotlands Baby Sanctuary HIV Infant Care Programme

<table>
<thead>
<tr>
<th>ORGANISATION</th>
<th>Cotlands Baby Sanctuary HIV Infant Care Programme</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOCATION</td>
<td>South Africa – Gauteng, Western Cape, Northern Province, Free State.</td>
</tr>
<tr>
<td>GRANT AWARDED</td>
<td>US$76,607</td>
</tr>
<tr>
<td>BENEFICIARIES</td>
<td>Pre-school children and Early Childhood Development (ECD) practitioners.</td>
</tr>
<tr>
<td>AIM</td>
<td>To create HIV/AIDS awareness and empower Early Childhood Development practitioners with HIV/AIDS prevention and management skills.</td>
</tr>
<tr>
<td>OBJECTIVES</td>
<td>To train at least 400 ECD practitioners in previously disadvantaged communities in HIV/AIDS prevention and management; To develop a workbook dealing with HIV/AIDS and universal precautions.</td>
</tr>
<tr>
<td>TIME LINE</td>
<td>One year, starting March 2001</td>
</tr>
</tbody>
</table>

Cotlands is one of the leading NGO organisations in South Africa providing care for children from birth to six years who are infected with HIV/AIDS. It was founded in 1936, opened the first hospice for children living with AIDS in 1996, and runs a nursery school, a foster care programme and a community outreach programme. The experience gained from this daily work enabled Cotlands to develop a unique hands-on, five-day training course for Early Childhood Development (ECD) practitioners. ECD practitioners are dispersed throughout communities in South Africa and it will often be their task to cater for the growing number of children affected by HIV/AIDS.

“Our experience was that once ECD practitioners had been made aware of the magnitude of the problem of HIV and AIDS, and their fears and misconceptions had abated, they demonstrated a sincere willingness and urgency to play a valuable role in combating the disease in their communities,” says project manager Christel Kleingeld.

Secure the Future™ funding was requested to help Cotlands use its training material to train ECD practitioners around the country and to support the development of a workbook for pre-school children on HIV/AIDS.
“The programme is a model because its materials address universal problems and issues regarding early childhood development and care, and can be used in any place, urban or rural,” says the evaluator for Secure the Future™’s MEU.

PROCESS

Training practitioners

Cotlands divided the training process into five phases. They:

- Partnered with colleges and other organisations to recruit ECD practitioners in five provinces to take part in the programme;
- Held 25 training courses and three train-the-trainer courses around the country;
- Followed up training sessions with focus group meetings eight weeks after the event to discuss issues like sharing information, problems and successes with this and formulating and implementing HIV/AIDS policies in the workplace;
- During the follow-up focus group meetings assessed to what extent the participants spread information to their colleagues, parents, children and communities;
- Analysed all the data to assess the effectiveness of the process; and
- Ensured that all ECD centres which participated in the training received sufficient workbooks for their children.

Developing the workbook for pre-school children

Why was the material developed?

The HIV workbook was developed because Cotlands realised in 1997 that staff, children and the community needed to learn about universal precautions. Staff spent two months checking to see if there were any materials already on the market that focused on teaching pre-school children and their teachers about HIV. When they realised that nothing existed, they started to develop their own.

What did they aim to do?

Their aim was to develop materials especially for the under-sixes and their teachers to:

- Stamp out the fears around contracting HIV/AIDS in the educational environment;
- Teach pre-school children about what AIDS is, how it is spread and how they needed to protect themselves against it;
- Teach acceptance of children and people with HIV and teach PLWHA to live positively; and
- Show children that learning something complicated can be fun and easy.

How was it developed?

The staff of Cotlands nursery school developed a pilot set of materials between 1998 and 2000. Then they checked if children could understand the materials and how long it took them to work through the exercises by giving the material to children at the nursery school and from the community to try out.

The first edition was printed in 2001 and the second edition, with updated information, in 2002. The workbook is distributed to all teachers who attend the training on HIV/AIDS through Cotlands and is also available at Cotlands for other interested parties.
Work on these projects set in motion a number of valuable spin-off processes:

- Relationships were established with the local organisations who set standards for ECD qualifications, so that ECD practitioners will in future be able to use the course to earn credits for a formal qualification;
- ECD practitioners who were trained are constantly conducting various Information, Education and Communication (IEC) activities in their own communities;
- The workbook created an income-generating opportunity for Cotlands; and
- Response to the workbook also encouraged staff to explore the idea of developing a series of workbooks for young children on an array of issues. Cotlands is currently developing a book for four to nine year olds on death and dying.

**OUTCOMES**

- The project trained 404 practitioners in five South African provinces and produced and distributed 4 000 user-friendly and practical workbooks with graphics for ECD practitioners and children;
- Interviews with ECD practitioners after the training showed that they are now comfortable working with infected children, that the care centres they run provide a non-discriminatory service, first aid kits have been made available, practices around treating wounds and cuts have changed and children have been taught about universal precautions;
- The response to the workbook was overwhelmingly positive; and
- The Cotlands training course is now accredited as an elective by the National Qualifications Authority.

**LESSONS LEARNED**

- Community networking through local organisations and colleges is essential to recruit ECD practitioners into interventions;
- Government departments responsible for ECD such as Social Development, Education and Health must be consulted about the training process;
- Trainers must be flexible enough to use the language of the area that is well understood by trainees;
- Principals or directors of ECD centres should be the first staff members to be trained, or should understand the content of the training, so that they can influence policy decisions; and
- The workbook should be translated into at least two local languages so that as many children as possible can use it.
5.3.2 Botswana Christian AIDS Intervention Programme (BOCAIP)

<table>
<thead>
<tr>
<th>ORGANISATION</th>
<th>Botswana Christian AIDS Intervention Programme (BOCAIP)</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOCATION</td>
<td>Botswana – Maun, Molepolole and the border towns of Lobatse and Ramotswa.</td>
</tr>
<tr>
<td>GRANT AWARDED</td>
<td>US$430,800</td>
</tr>
<tr>
<td>BENEFICIARIES</td>
<td>Women, children and orphans.</td>
</tr>
<tr>
<td>AIM</td>
<td>To use the faith-based community to mobilise membership to provide counselling and home-based care and so reduce the impact of HIV/AIDS.</td>
</tr>
<tr>
<td>OBJECTIVE</td>
<td>Set up community focus points to co-ordinate, monitor and evaluate counselling and home-based care services, support counsellors and provide AIDS information and training.</td>
</tr>
<tr>
<td>TIME LINE</td>
<td>Three years, starting March 2000</td>
</tr>
</tbody>
</table>

**BOCAIP's STORY**

The Christian community in Botswana began co-ordinating its ecumenical response to HIV/AIDS in 1996 in response to a government plea to help mitigate the havoc wreaked by AIDS among the people of Botswana. Pastors and churches were mobilised through a series of awareness and motivation workshops that were conducted from 1995 to early 1996, which resulted in a month of prayer and Christian mobilisation. The major success of this initiative was the birth of the Botswana Christian AIDS Intervention Programme (BOCAIP) which was launched in May 1997 as a network of local Christian HIV/AIDS initiatives. The church commands an unrivalled audience in Botswana, and so is well placed to develop a community-based network of support services.

BOCAIP requested funding for three existing community counselling centres and to set up a new one. This was part of its drive to develop a country-wide network of community focal points to implement and manage counselling and home-based care services, a project which had started in 1997 with the opening of a Counselling Centre in Maun.
With the Secure the Future™ grant, BOCAIP was able to start activities and demonstrate its capacities, which enabled it to secure further funding from a number of other sources. This helped it to expand exponentially, increasing both the number of centres and the range of services. BOCAIP now operates a national office and ten centres and employs more than 130 people, of which around 90 are full-time staff. Each of the ten centres is run by a management committee, drawn from the local community.

BOCAIP COUNSELLING MODEL

“The BOCAIP intervention offers a sustainable Christian intervention and a model of holistic and integrated counselling, that is community based and owned and has a collaborative relationship with other local stakeholders. The model is cost effective and sustainable because it operates from a broad volunteer base from within the Christian community. Its strength derives from the training received by counsellors and facilitators,” says the then BOCAIP National Co-ordinator, Rev Edward Baralemwa.
Services offered at the centres include:

- Community mobilisation, focusing on youth and prevention, protection and supportive care;
- Training;
- Community outreach to clinics, schools and the workplace to raise awareness, empower community members, and encourage VCT;
- Counselling for issues including pre and post-test counselling, rape and relationships. Home visits for ongoing supportive counselling remains BOCAIP’s core business;
- Support groups including income generation, group counselling and spiritual healing;
- Caregiving to families caring for children affected by AIDS in the form of transport to school and material assistance; and
- Monitoring and evaluation.

OUTCOMES

- BOCAIP excelled in technical training in the area of HIV/AIDS and held 14 training workshops training 259 counsellors between January and June 2002, compared with 4 and 96 during the previous six months;
- By March 2003 BOCAIP had 139 staff and ran ongoing support groups focusing on PLWHA and youths, with meetings in the ten centres being attended by 129 PLWHA and 770 youth. It also provided the following services in the first quarter of the year:
  - A total of 4,561 counselling sessions, mostly in homes across the country, but also at sites in hospitals, clinics and counselling centres. Most of the counselling activities were either on-going or addressing HIV information and prevention needs;
  - Assisting 3,002 regular clients, of which 1,548 were women, and 878 were orphans; and
- BOCAIP’s management committees held 30 meetings in the last quarter of the grant to monitor service provision and give feedback on community perceptions and involvement. They also conducted 701 community outreach activities, reaching 32,406 people.

LESSONS LEARNED

- Rapid growth in a model of this nature must be accompanied by strong organisational development and community participation in order to sustain the work;
- As an organisation grows and decentralises, there is a need to communicate clearly over roles and responsibilities to ensure standards of care;
- Decentralised organisations and services require a dedicated monitoring capacity at national level;
- Human resource development and capacity building must be ongoing, especially for the volunteer centre management boards, because they drive community outreach activities and devise services to meet community needs and must monitor and evaluate these programmes;
- With the devolution of responsibilities from national to community centres, management committees should be empowered to raise funds to support the centre operations and ensure sustainability; and
- Community outreach activities are the mechanism by which counselling centres can reach and contact new clients.

“BOCAIP’s strengths in service delivery lie in its capabilities and demonstrated leadership in helping communities develop and implement comprehensive mitigating and preventive strategies in the area. BOCAIP’s national office spearheaded and facilitated service delivery … the result has been visible and accessible projects at community level,” says the evaluator from Manto Management.
5.3.3 Catholic AIDS Action (CAA) / Namibian Catholic Bishops’ Conference

<table>
<thead>
<tr>
<th>ORGANISATION</th>
<th>Catholic AIDS Action (CAA) / Namibian Catholic Bishops’ Conference</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOCATION</td>
<td>Namibia, the largely rural Oshana region in the north, and the farming-based Hardap region in the south.</td>
</tr>
<tr>
<td>GRANT AWARDED</td>
<td>US$82,624. Co-funded by Southern African Catholic Bishops’ Conference and Catholic Medical Mission Board with the same amount.</td>
</tr>
<tr>
<td>BENEFICIARIES</td>
<td>PLWHA, orphans and affected children.</td>
</tr>
<tr>
<td>AIM</td>
<td>To develop a model and standards for a quality driven, nationally operated system of home-based care.</td>
</tr>
<tr>
<td>OBJECTIVE</td>
<td>To provide ongoing oversight, supervision and support for community-based volunteer groups who provide HBC.</td>
</tr>
<tr>
<td>TIME LINE</td>
<td>Three years, starting October 2000</td>
</tr>
</tbody>
</table>

CAA’s STORY

Catholic AIDS Action was founded by the Namibian Catholic Bishops’ Conference in February 1998, as the first national church based response to HIV/AIDS. There was a history of church leadership in Namibia as the Council of Churches supported the country’s pre-independence struggle for liberation. CAA built on that legacy and quickly grew to become Namibia’s largest NGO-based response to the epidemic, working in nine of the country’s 13 political regions. Its work is to inspire and support programmes of HIV/AIDS prevention, home-based care, spirituality, empowering PLWHA, and support for orphans and vulnerable children.

CAA has a national network of 91 parishes, more than 300 small Christian communities, 15 Roman Catholic hospitals and health care institutions, and 31 affiliated schools and hostels. Its work in home-based family care started after an HBC train-the-trainer session in 1998 by the Ministry of Health and Social Services. Lack of follow-up and support however, meant that actual home-based care activities resulting from this were limited and variable.

Secure the Future™ funding was requested to develop and implement a comprehensive system of home-based care, to be piloted in two under-served regions, Oshana in the north and Hardap in the South.

THE PROCESS

Using trained volunteers to provide home-based care across the country was a new approach, and considered to be an important model for government and other organisations. CAA believed that, to ensure quality, it needed to standardise the training and methodology for training of trainers as well as the recruitment, training and support of volunteers. Implementation needed to be systematic, with CAA staff, maintaining the standards of supervision and administration, and supporting volunteers to prevent burn-out and loss of quality.

The Secure the Future™ funding was used to develop training methodology and a training manual specifically to support volunteer training in home-based family care and counselling. CAA used the material to train more than 1,000 community-based volunteers in the first two years. As a result, during the first quarter of 2002
CAA provided tangible and emotional benefits to more than 2,500 clients and 6,200 orphans and vulnerable children. Volunteers also reached 33,000 people through outreach activities in that quarter. CAA staff and the formal evaluation commissioned by CAA gave some insights into why the church was able to motivate action on such a wide scale and why volunteers were prepared to become involved:

CAA’s training courses have been expanded since the beginning of the programme and now include:
- A four-module training of trainers course in home-based family care;
- A training of trainers course for professionals in psycho-social support of orphans and vulnerable children;
- Refresher courses;
- Peer education for youth; and
- A training course for community volunteers in psycho-social support of orphans and vulnerable children, although this is still being finalised.

The courses developed by CAA have contributed to community-based care standards for Namibia, and impacted directly on the lives of its citizens.

CAA’s commitment to provide community care has enabled it to provide direct support to government initiatives. Government’s February 2003 pledge to roll out antiretroviral treatment saw the opening of three community-level voluntary testing and counselling sites; two of these sites were on CAA sites in Katutura (Windhoek) and at Oshakati. The CAA is also working closely with an increasing number of community-based organisations that provide care and support to orphans and vulnerable children, which is another key area of government activity.

_Says Elaine Pienaar, CAA co-ordinator for training:_ “Above all faith works as a great motivator for people to become involved in social development of their community. Moreover the organisational structure of churches – the fact that they offer a national infrastructure combined with an almost ubiquitous presence in every village and neighbourhood of the country – means that increasingly, others expect them to take a constructive leadership role with regard to human crisis.”
OUTCOMES

- The third group of trainers, trained in psycho-social support for orphans and vulnerable children graduated in February 2003. The 27 trainers were professionals drawn from government, NGO and faith-based organisations and returned to their jobs and organisations after the course. Another 27 trainers would have graduated from a similar course by the end of the year;
- By June 2003 CAA had trained over 1,700 volunteers and 100 peer educators for youth;
- In the two regions supported by Secure the Future™ CAA ran 27 volunteer groups with 384 volunteers between January and June 2003, providing tangible and emotional benefits to 858 clients a month and 3,865 registered orphans. Volunteers also reached 6,308 people through community outreach activities; and
- Currently there are three soup kitchens operating in Oshana and Hardap, serving a total of 200 clients including orphans and vulnerable children.

LESSONS LEARNED

From an independent organisational review conducted in August 2002 CAA learned that:

- Support offered to active volunteers should be spiritual, emotional and contribute to poverty alleviation, for example in the form of volunteer “retreats”, a funeral benefit for volunteers and income generating opportunities;
- All elements of the programme should emphasise prevention, care and empowerment of PLWHA, and community-based care and psycho-social support of orphans and vulnerable children; and
- Monitoring and evaluation should be integrated into a programme plan and implementation.
The Medical Research and Care component was created to provide grants to facilitate medical research focusing on women and children affected by HIV/AIDS in Botswana, Lesotho, Namibia, South Africa and Swaziland. The objective was to expand medical research and training, and develop model programmes for those who manage HIV/AIDS.

Why these projects were selected

The projects detailed here were selected for their methodological excellence, impactful results and their significance to public health in local settings and in resource-limited settings in particular. The quality of research generally is indicated by publication of results in peer reviewed medical and scientific journals.

Their results are documented in case studies so that they can be disseminated, and further applied in the communities in which they were generated, and to the benefit of public health worldwide.

“If we can translate all that we have funded into action and if the benefits are really applied in the settings within which they are appropriate, then we will have had a true impact on public health,” says Dr Sebastian Wanless, Director, Medical Research and Care, Secure the Future™, “We are currently investigating the best means of applying the results of our research outcomes at both the hospital and community levels”.

Every project recorded here was subjected to a careful process of selection before it received any funding, to make sure it would help women and children, impact on public health policy, and/or produce results relevant to resource-limited settings. Some of the projects selected were also responses to a specific funding methodology, in which Secure the Future™ solicited responses to themes it had identified as critical, namely prevention of mother-to-child-transmission, tuberculosis and specific local needs for capacity building. The selection process was conducted by a Technical Advisory Committee of local and international experts, and all decisions were ratified by the Department or Ministries of Health of the relevant national governments.

If a proposal met the abovementioned main criteria it was then checked against the following factors:

Significance: Does this study address an important problem? If the objectives of the study are achieved, how will scientific knowledge be advanced and what will be the effect on the concepts or methods that drive this field?

Innovation: Does the project employ novel concepts, approaches or method? Are the aims original and innovative? Does the project challenge existing paradigms or develop new methodologies or technologies?

Approach: Are the conceptual frameworks, design and analysis adequately developed, well integrated and appropriate to the objectives of the project? Does the applicant acknowledge potential problem areas and consider alternative tactics?

Researcher: Is the investigator appropriately trained and well suited to carry out this work? Is the work proposed appropriate to the experience level of the principal investigator and other researchers?

Capacity Development: Does this proposal focus on research capacity development? Is capacity development aimed at promoting equity and development?

Institution: Does the scientific environment in which the work will be done contribute to the probability of success? Do the proposed experiments take advantage of unique features of the scientific environment or employ useful collaborative arrangements? Is there evidence of institutional support?
The research questions answered

The main questions addressed by these case studies are the:
- Need to find cost effective means of conducting HIV laboratory monitoring methods;
- Prevention of mother-to-child-transmission (PMTCT);
- Development of resistance to treatment in PMTCT – work solicited to meet Secure the Future™’s focus on prevention of mother-to-child-transmission; and
- Capacity building in terms of laboratory facilities and operational skills, research expertise and clinical skills.

Technical terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>3TC</td>
<td>A NRTI eg Epivir or lamivudine</td>
</tr>
<tr>
<td>CD4+ lymphocyte</td>
<td>A measure of the concentration of the T helper cell in the blood</td>
</tr>
<tr>
<td>d4T</td>
<td>A NRTI eg Zerit or stavudine</td>
</tr>
<tr>
<td>ddC</td>
<td>A NRTI eg HIVID zalcitabine</td>
</tr>
<tr>
<td>ddl</td>
<td>A NRTI eg Videx, didanosine</td>
</tr>
<tr>
<td>HAART</td>
<td>Highly active antiretroviral therapy</td>
</tr>
<tr>
<td>HIV-1 Subtype C</td>
<td>The virus type commonly circulating in southern Africa</td>
</tr>
<tr>
<td>Leucocyte</td>
<td>White blood cell</td>
</tr>
<tr>
<td>Lymphocyte</td>
<td>One of the five main types of white blood cells; T lymphocytes help protect the body against viral infections</td>
</tr>
<tr>
<td>Nevirapine</td>
<td>A NNRTI</td>
</tr>
<tr>
<td>NNRTI</td>
<td>Non nucleoside reverse transcriptase inhibitors, a second major group of antiretroviral drugs which also block the HIV protein called reverse transcriptase, but do so in a slightly different way to NRTIs</td>
</tr>
<tr>
<td>NRTI</td>
<td>Nucleoside reverse transcriptase inhibitors, the first class of antiretroviral medications to be approved by regulatory authorities. NRTIs block the HIV protein called reverse transcriptase, and so prevent HIV RNA from changing into DNA</td>
</tr>
<tr>
<td>PI</td>
<td>Protease inhibitor: a third major group of antiretroviral drugs. PIs prevent the protease enzyme from cleaving HIV proteins into smaller functional units</td>
</tr>
<tr>
<td>RT</td>
<td>Reverse-transcriptase</td>
</tr>
<tr>
<td>Viral load</td>
<td>A measure of the concentration of virus in the blood</td>
</tr>
<tr>
<td>ZDV</td>
<td>A NRTI i.e. zidovudine</td>
</tr>
<tr>
<td>Short Course</td>
<td>A treatment regimen with ART developed to prevent mother-to-child-transmission</td>
</tr>
<tr>
<td>HIVNET 012</td>
<td>A Ugandan study examining the effectiveness short course intervention in PMTCT with nevirapine</td>
</tr>
<tr>
<td>SAINT</td>
<td>The South African Intrapartum Nevirapine Trial, which confirmed the effectiveness of a short course nevirapine regimen for PMTCT</td>
</tr>
</tbody>
</table>
7. Medical Research and Care – Impactful Research Outcomes

7.1 Prevention

7.1.1 HIV drug resistance in pregnant women and their infants: Effects of Short Course Antiretroviral treatment to prevent perinatal transmission

<table>
<thead>
<tr>
<th>PRINCIPAL INVESTIGATOR</th>
<th>Prof Lynn Morris, AIDS Virus Research Unit, National Institute for Communicable Diseases (South Africa).</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOCATION</td>
<td>Johannesburg, South Africa</td>
</tr>
<tr>
<td>GRANT AWARDED</td>
<td>US$99,113</td>
</tr>
<tr>
<td>ROLEPLAYERS</td>
<td>AIDS Unit, National Institute for Virology; Perinatal HIV Research Unit, Chris Hani Baragwanath Hospital, South African Institute for Medical Research</td>
</tr>
<tr>
<td>TIMELINE</td>
<td>Three years, starting July 2000</td>
</tr>
<tr>
<td>AIM</td>
<td>To investigate whether the failure of antiretroviral therapy to prevent HIV-1 transmission from mother to infant is due to the presence of antiretroviral drug resistance mutations; To investigate whether the natural history of HIV infection in children acquiring a drug resistant virus is different from those infected with drug sensitive viruses.</td>
</tr>
<tr>
<td>OBJECTIVE</td>
<td>To determine whether HIV positive pregnant women who were given short course treatment with ZDV, 3TC, d4T or ddi, developed drug resistant mutations of HIV; To determine whether HIV infection in their infants was related to the transmission of any drug resistant variants of HIV; and To determine the natural history of HIV infection in children with the resistant form of the virus.</td>
</tr>
</tbody>
</table>
METHODOLOGY

The HIV-1 reverse transcriptase genes from 37 HIV-1 positive pregnant women attending an antenatal clinic in Soweto, South Africa, were sequenced and analysed to check if any drug resistant mutations were present. The women had never been exposed to antiretroviral drugs (drug naïve) but were being screened as potential participants in clinical trials of antiretroviral drugs aimed at preventing mother-to-child-transmission.

RESULTS

Sequence analysis revealed that all genes belonged to HIV-1 subtype C, the subtype of the virus which predominates among heterosexual populations in South Africa. A total of 23 amino acid loci associated with resistance to ZDV, 3TC, ddI, d4T and NVP were examined. It was found that they did not encode mutations that would confer resistance to these drugs. Polymorphisms at these loci were infrequent, with three patients harbouring the A98S and V179I polymorphisms. An additional three patients harboured V118I, which can function as an accessory resistance mutation, but is considered in this context likely also to be a polymorphism.

SIGNIFICANCE

The research data contributed to the knowledge and debate around monitoring drug resistance mutations in the HIV-1 subtype C, particularly with regard to affordable treatment regimens for the prevention of mother-to-child-transmission.

Using a short course of antiretroviral drugs for PMTCT is becoming part of the standard medical response to the epidemic in southern Africa. The drug of choice is nevirapine, which is affordable, easy to administer and highly effective, even following a single dose to both mother and child.

This treatment regimen is associated with the selections of mutations associated with drug resistance. The mutations do not compromise the ability of nevirapine to prevent mother to child transmission. However, further follow-up research is necessary to determine whether the induced mutations may compromise use of nevirapine at the time of the mother's subsequent delivery of another child. This follow-up should also be able to determine if the resistance really "fades" over time, as preliminary work from Dr. Morris's laboratory and others suggests.

The research data from the study funded by Secure the Future™ showed that pregnant women who are candidates for receiving antiretroviral drug therapies do not contain naturally-occurring or pre-existing drug resistance mutations, and thus that such drug therapies were likely to be highly effective in this setting. The study results were accepted for publication in the AIDS Research and Human Retroviruses journal in January 2002, under the title "HIV-1 subtype C Reverse Transcriptase Sequences from Drug Naïve Pregnant Women in South Africa".

The authors also reviewed current data on HIV-1 drug resistance mutations and what they might mean in terms of efficacy of antiretroviral therapies to prevent mother-to-child-transmission. This work was published in December 2001 in volume 56 of the South African Dental Journal under the title "HIV-1 Drug Resistance and Mother-to-Child-Transmission."
7.1.2 A randomised 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

| INVESTIGATOR | Dr Glenda Gray |
| LOCATION     | Johannesburg, South Africa |
| GRANT AWARDED | US$600,084 |
| ROLEPLAYERS  | University of Witwatersrand, Perinatal HIV Research Unit |
| AIM          | To compare the efficacy of AZT and nevirapine at delivery in reducing the transmission of HIV from positive, untreated mothers to their infants. |
| OBJECTIVES   | PRIMARY: To compare the efficacy of nevirapine versus zidovudine in reducing mother-to-child-transmission of HIV-1 when administered postnatally to the infant; SECONDARY: To assess the efficacy of post-exposure prophylaxis in infants who are breastfed. |
| TIME LINE    | Six months, starting June 2000 |

METHODOLOGY

Researchers conducted a randomised, open-label, multi-centre clinical trial in three South African hospitals to compare the use of a single dose of nevirapine (NVP) with a six-week course of zidovudine (ZDV) in infants whose mothers had no prior antiretroviral therapy.

A study sample of 1,040 infants was randomly selected between October 2000 and September 2002. All post-partum women who had delivered without prior knowledge of their HIV-1 status were offered voluntary counselling and rapid on-site testing (PP-VCT) within 24 hours of delivery. Treatment for the infants was started within 24 hours of delivery after the mothers had signed informed consent. HIV-1 infection rates were ascertained at birth, six weeks and three months of age. Secondary analysis on infant feeding was done.
RESULTS

By Kaplan-Meier analysis, the overall transmission rate at six weeks of age was 13.1% (95% CI: 10.8; 15.4).

The HIV-1 transmission rates in the NVP and ZDV groups were similar: 7.1% and 5.8% at birth (p=0.4); and 12.3% and 13.7% by six weeks of age (p=0.5).

The maternal factors associated with transmission were a CD4 count of less than 500 (OR = 2.50; 95% CI: 1.16; 5.35); a maternal viral load greater than 50 000 (OR 3.68; 95% CI: 1.98; 6.87); and breastfeeding (OR 1.87; 95% CI: 1.01; 3.47).

In essence, single dose NVP proved no different to six weeks of ZDV in reducing MTCT. NVP post-exposure prophylaxis (PEP) is a valid alternative in settings where there is a need to preserve NVP for the treatment of HIV infected women.

SIGNIFICANCE

The value of post exposure prophylactic antiretroviral therapy in reducing MTCT of HIV in infants whose mothers did not access therapy during pregnancy or labour had not previously been studied. The research findings have implications for both the cost and the design of PMTCT interventions in resource-limited settings.

The fact that a single dose of NVP to neonates is equivalent to six weeks of ZDV therapy in reducing mother-to-child-transmission of HIV is significant as the NVP regimen is easier to implement and is likely to be more cost effective than the ZDV therapy. Adherence to NVP would be easier to ensure than to the ZDV therapy. NVP also has potent antiviral effects and is well tolerated with good oral absorption and bioavailability.

To date MTCT programmes in resource-constrained settings have almost all concentrated on antenatal VCT only. The researchers believe postpartum voluntary counselling and testing and prophylaxis of infants may be an important strategy to reduce vertical transmission in settings where many women do not access antenatal care, where babies are born at home or where women arrive too late in labour to access HIV testing. It may also be useful for women who may access highly-active antiretroviral therapy post-delivery.

Postpartum VCT and postnatal interventions to reduce MTCT would enhance and complement MTCT programmes in labour, delivery and postnatal care of HIV positive women.

“Postpartum VCT, infant feeding counselling and a single NVP dose for the neonate for should be considered part of care for women who had not previously accessed ante-natal care, including VCT and tested positive,” says Dr Gray.

Postpartum VCT could also help address concerns that using NVP exclusively to prevent MTCT could result in the development of drug resistance. This factor may in the long term limit therapeutic options for HIV positive mothers. NVP PEP is a valid alternative in settings where there is a need to preserve NVP for the treatment of HIV infected women.

\* CI – Confidence Interval: an estimate of the amount of error in the data.
\* OR – Odds Ratio: a way to compare whether the probability of an event is the same in two groups.
7.2 Treatment and Care

7.2.1 The cost effectiveness of HIV/AIDS Treatment in the Western Cape, South Africa

<table>
<thead>
<tr>
<th>INVESTIGATOR</th>
<th>Prof. Robin Wood (Project Leader); Mr Brian Haile (Project Co-ordination)</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOCATION</td>
<td>Cape Town, South Africa</td>
</tr>
<tr>
<td>GRANT AWARDED</td>
<td>US$34,054</td>
</tr>
<tr>
<td>ROLEPLAYERS</td>
<td>Prof R Wood; Dr JG Kahn; Mr B Haile &amp; Consultants</td>
</tr>
<tr>
<td>TIMELINE</td>
<td>One year, starting April 2000</td>
</tr>
<tr>
<td>AIM</td>
<td>To provide accurate empirical data to help provincial policy makers in identifying and implementing more cost effective HIV/AIDS treatment strategies.</td>
</tr>
<tr>
<td>OBJECTIVES</td>
<td>To assess the cost of health care per patient per month at different stages of HIV/AIDS disease;</td>
</tr>
<tr>
<td></td>
<td>To estimate the incremental cost per life year gained from different antiretroviral treatment regimens;</td>
</tr>
<tr>
<td></td>
<td>To estimate the anticipated direct public sector costs for persons living with HIV/AIDS in the Western Cape over five years, with and without the provision of antiretrovirals;</td>
</tr>
<tr>
<td></td>
<td>To assess life years gained for different allocations of state health sector funds to the treatment of HIV with antiretrovirals, to treatment of AIDS opportunistic infections and to assess treatment of HIV-related TB;</td>
</tr>
<tr>
<td></td>
<td>To describe practicable and cost effective strategies to deliver HIV treatment within the Western Cape health system, and present these strategies to the Department of Health decision makers;</td>
</tr>
<tr>
<td></td>
<td>To train key staff within the Provincial Department of Health and local clinician-researchers to use our model for subsequent cost effectiveness analyses.</td>
</tr>
</tbody>
</table>

METHODOLOGY

Researchers compared the risk of tuberculosis in 264 patients who received Highly Active Antiretroviral Therapy (HAART) in phase III clinical trials and a prospective cohort of 770 non-HAART patients who were attending Somerset Hospital adult HIV Clinic at the University of Cape Town between 1992 and 2001.

Poisson regression models were fitted to determine risk of tuberculosis and patients were stratified by CD4 count, WHO HIV clinical stage and socio-economic status.
RESULTS
HAART was associated with a lower incidence of tuberculosis (2.4 versus 9.7 cases per 100 patient years), a finding apparent across all strata of socio-economic status, baseline WHO HIV stage and CD4 count. The only exception was in patients with CD4 counts of more than 350 cells.

The number of tuberculosis cases averted was greatest in patients who were at WHO HIV stage 3 or 4 and in those with CD4 counts of less than 200 cells.

SIGNIFICANCE
The research was able to quantify the benefit of antiretroviral therapy for patients at different stages of HIV/AIDS disease, an insight of very significant use to professionals designing treatment strategies for patients with HIV/AIDS.

The research showed that HAART reduced the incidence of tuberculosis associated with HIV-1 by more than 80%, in an area where TB was endemic.

It also indicated that HAART had the greatest protective effect in patients with symptoms, and those with advanced immune suppression.

Results were published in The Lancet, of 15 June 2002, under the title Effect of highly active antiretroviral therapy on incidence of tuberculosis in South Africa, a cohort study. The data was used by the WHO to model the relationship between HIV and TB and was also presented at the Barcelona AIDS Conference as a strategy for treatment of patients with HIV.

Research is continuing and the results from the extended studies have been submitted to other leading journals for publication.

* Lancet 2002; 359: 2059-64
7.2.2 Cost effective laboratory monitoring: CD4+ T cell enumeration – use of CD45, CD3, CD4 and SS parameter gating without the necessity for a Lymphocyte differential

<table>
<thead>
<tr>
<th>INVESTIGATOR</th>
<th>Dr Debbie Glencross</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOCATION</td>
<td>Johannesburg, South Africa</td>
</tr>
<tr>
<td>GRANT AWARDED</td>
<td>US$9,000</td>
</tr>
<tr>
<td>ROLEPLAYERS</td>
<td>Flow Cytometry Unit, Department of Molecular Medicine and Haematology, South African Institute for Medical Research (SAIMR) and the School of Pathology, University of the Witwatersrand.</td>
</tr>
<tr>
<td>TIMELINE</td>
<td>One year, starting 28 February 2001</td>
</tr>
<tr>
<td>AIM</td>
<td>To reduce costs and improve accuracy of CD4 testing in aged adult and paediatric samples.</td>
</tr>
<tr>
<td>OBJECTIVES</td>
<td>To improve current CD4 testing and cut costs by investigating an alternative approach for the generation of an absolute CD4 count. Specific Flow Cytometric gating strategies were investigated including CD45 expression and light complexity (side scattered light / 90 degree) to obviate the need for an Absolute Lymphocyte count (ALC); To improve the accuracy of CD4 enumeration, especially in those peripheral blood samples that are &gt; than 6-8 hours old; To reduce the current costs of CD4 testing by reducing the time technologists currently spend generating an Absolute Lymphocyte Count required for the calculation of an Absolute CD4T cell count.</td>
</tr>
</tbody>
</table>
METHODOLOGY

North American and European guidelines for dual-platform (DP) flow cytometry recommend absolute CD4 T-cell counts to be calculated from two parameters: the absolute lymphocyte counts obtained on a haematology analyser, and the percentages of CD4+ cells among lymphocytes obtained by flow cytometry. This means that CD4 counts are measured by differentiating between the different types of white blood cells, counting them and then working out, mathematically, the number of CD4 cells in each millionth of a litre of blood.

These methods are cumbersome, labour intensive, and error prone. The main source of the inaccuracy comes from the poor match between the common denominators in the two systems. Different pathology laboratories using the same technique can produce results that vary by 15% to 50%.

Dr Glencross’ PLG CD4 technique measures all white blood cells (as opposed to just certain types) and uses this in the mathematical equation to improve the precision of dual platform absolute CD4 counting. Correlations and Bland-Altman tests were used for statistical analysis.

RESULTS

Twenty-two stabilised blood product samples were provided by the UK National External Quality Assessment Scheme (NEQAS). Compared with these samples, a higher accuracy and precision of CD4 counts were documented using PanLeucogating than compared with lymphocyte gating.

Thereafter, 183 fresh and 112 fixed whole blood samples were used to compare dual platform methods and single-platform methodology, including both volumetric and bead-based techniques.

There was a particularly high correlation and comparable precision of absolute CD4 counts between the single platform volumetric method and the dual platform PanLeucogating. The single platform volumetric method showed lower levels of agreement with the dual platform lymphocyte gating and the single-platform bead-based method.

SIGNIFICANCE

The research, published in Clinical Cytometry in 2002\(^4\), indicates that dual platform leucocyte counts should replace lymphocyte counts as the common denominator.

Coupled with quality control for white cell counts on haematology analysers, the dual platform method with CD45 PanLeucogating represents a robust CD4 T-cell assay that is as accurate as the single platform volumetric techniques but lowers the costs of CD4 tests by almost two thirds.

In addition to being disseminated in other publications\(^1\), the research on the technique has been validated by the World Health Organisation and is being used by South Africa’s National Health Laboratory Service (NHLS) in Cape Town and Johannesburg.

On 9 May 2003 the NHLS also signed an agreement with an American based medical equipment developer to license the PanLeucogated (PLG) CD4 T cell enumeration. "We view this license agreement as an important step to enable the dissemination of our affordable technology to our African and other counterpart third world laboratories and, further, as an important step for standardisation of CD4 testing for our organisation," the NHLS Board stated.

Secure the Future \(^\text{™}\) will buy the equipment and implement training to test the functionality of the technique in resource-limited settings as part of its legacy programme to develop community-based HIV treatment sites.


\(^1\) Glencross D, Scott LE. CD4 Cell monitoring for HIV/AIDS, old options; new insights. SADJ, Vol 56 No 12.
7.3 Building Capacity

7.3.1 The HIV/AIDS Reference Laboratory – Gaborone, Botswana

<table>
<thead>
<tr>
<th>INVESTIGATOR</th>
<th>Harvard AIDS/Botswana Government Partnership</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOCATION</td>
<td>Princess Marina Hospital, Gaborone, Botswana</td>
</tr>
<tr>
<td>GRANT AWARDED</td>
<td>US$4.9 million, co-funded by the Botswana Ministry of Health and the African Comprehensive HIV/AIDS Partnerships.</td>
</tr>
<tr>
<td>ROLEPLAYERS</td>
<td>Harvard AIDS Institute, Botswana Ministry of Health.</td>
</tr>
<tr>
<td>TIME LINE</td>
<td>Opened on 1 December 2001</td>
</tr>
</tbody>
</table>

**METHOD**

The HIV Reference Laboratory was an improvement to an initial laboratory facility and was dedicated in February 2000. It was co-funded by the Botswana government, and was closely aligned to the Botswana government’s national HIV/AIDS agenda and strategy.

The three-story, 2 300 square meter facility was designed to provide laboratory support for the Botswanan National ARV Programme as well as to house epidemiologic and laboratory-based research on:

- Prevention of mother-to-infant transmission;
- AIDS treatment; and
- Vaccine design and testing.

The major research initiative supported by Secure the Future™ at the site is focused on HIV-1 subtype C, the viral subtype predominant in southern Africa and the subtype causing the highest numbers of new HIV infection worldwide.

The new laboratory has two critical roles: to support research by serving as a central facility for testing clinical specimens for research studies; and to support the government’s roll-out of anti-retroviral therapy through the Botswana public health system in the National ARV Programme.

Secure the Future™ funding covered laboratory infrastructure, training of technicians, and the launching of the first comparative combination antiretroviral study in Botswana.
RESULTS

The laboratory has the technical capacity to conduct a range of studies including research on the molecular characterisation of HIV-1C, antiretroviral therapy and drug resistance, HIV behavioural components, and the details of the immune response to HIV-1C. The advanced research techniques that it is able to perform include viral genome analysis and infectivity serologic assays.

SIGNIFICANCE

The HIV/AIDS Reference Laboratory was a sustainable and appropriate intervention based on the commitment of the Botswana government.

It also played a significant role in expanding the laboratory capacity necessary to support implementation of the national AIDS response and treatment.

“This laboratory demonstrates that we will not only commit our resources to end the epidemic, but we will place HIV research at the top of our political, economic, and social agendas,” said Leonard Manthe, Assistant Director, Department of Technical Support Services, Ministry of Health of Botswana at the opening ceremony.

The laboratory dramatically expanded Botswana’s capacity to support clinical research in HIV/AIDS and conduct clinical tests. Among the new research projects it supported is the Tshepo study, a study of antiretroviral treatment and resistance with particular relevance to HIV-1 subtype C to be conducted in phases by Dr Richard Marlink, executive director of the Harvard AIDS Institute, and research relevant to HIV Vaccine Design.9

Botswana introduced ARV medication through the public health system at the beginning of 2002. By July 2003 the programme had been implemented at six sites in the country, enrolling more than 9 000 people in 18 months. A further seven sites are expected to open before the end of 20038, including a site in an extremely resource-limited setting, Bobonong, funded by Secure the Future™ and distinguished by strong community support.

7.3.2 Health Professionals Education Programme: Baylor College of Medicine and Nursing School, SADC AIDS Network of Nurses and Midwives, UNAIDS, National Nursing Association

<table>
<thead>
<tr>
<th>INVESTIGATOR</th>
<th>Dr. Mark Kline</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOCATION</td>
<td>South Africa, Swaziland, Zimbabwe, Botswana, Namibia, Lesotho, Malawi, Tanzania, Kenya, the Seychelles, Mauritius, Mozambique</td>
</tr>
<tr>
<td>GRANT AWARDED</td>
<td>US$325,000</td>
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<tr>
<td>TIMELINE</td>
<td>Five years</td>
</tr>
<tr>
<td>ROLEPLAYERS</td>
<td>Baylor College of Medicine and Nursing School in South Africa, Southern African Development Community AIDS Network of Nurses and Midwives (SANNAM), UNAIDS, National Nursing Association</td>
</tr>
<tr>
<td>AIM</td>
<td>To educate health professionals through a training curriculum developed in collaboration with regional partners.</td>
</tr>
<tr>
<td>OBJECTIVE</td>
<td>The development of a dedicated, comprehensive paediatric HIV health professional education and training programme, which is a necessary prerequisite to establishing HIV clinical research capabilities in Africa.</td>
</tr>
</tbody>
</table>

**METHODOLOGY**

The idea of creating a comprehensive curriculum on HIV/AIDS developed from the experience of Baylor College of Medicine's Baylor International Paediatric AIDS Initiative (BIPAI) with health professional education in developing countries including Romania and Mexico.

BIPAI conducted a needs assessment in Africa in June 1999 focusing at that stage specifically on nurses. The assessment confirmed that simply conducting education programmes for nurses dealing with HIV would not have the lasting impact necessary to begin to combat the epidemic.

With the encouragement of African partners and support from Secure the Future™, Baylor took on the challenge of developing a comprehensive curriculum, with the aim of implementing it in schools of nursing throughout Africa. The initial draft was developed from July 1999 to March 2000, in partnership with key collaborating institutions.
Afro-centric
The curriculum was intentionally Afro-centric, with case studies involving typical African settings and addressing African concerns. It was designed in a modular format so that elements can be used collectively, or individually – for example, as a single module to supplement a community nursing course, or a group of modules to give a complete review of factors such as clinical manifestations of HIV. However, with adaptations it could be used in training health professionals world-wide.

Contents
The total course comprises 22 modules, with objectives, key points and written lecture material for each, as well as review questions, exam questions, case studies and overhead transparencies illustrating the material. Areas covered are:

- Epidemiology of HIV
- Pathophysiology of the HIV
- HIV diagnostic criteria
- Management of clinical manifestations of HIV
- Opportunistic infections
- Primary care for HIV infected individuals
- Antiretroviral treatment
- Complementary and alternative medicine
- HIV counselling and testing
- Psychosocial aspects of HIV/AIDS
- Prevention and control of HIV
- Legal and ethical issues

Pilot testing
The first draft of the nursing curriculum was pilot tested in April 2000 in short conferences at the College of the Nazarene School of Nursing in Swaziland and the Medical University of South Africa in Pretoria. Conference content included both didactic presentations and interactive sessions, given by either the Baylor College of Medicine or the local faculty and based on the HIV Nursing Curriculum.

Three interactive sessions were conducted in train-the-trainer format. Selected local participants – including nurses, physicians, public health specialists and hospice workers – met with the Baylor faculty at the end of each conference to provide feedback on curriculum content. Their comments were integrated into the HIV Nursing Curriculum to make it more culturally sensitive and regionally appropriate.

Second edition
The second edition of the curriculum was re-written to reflect BIPAI’s growing experience in conducting training in southern Africa. It was re-named the HIV Curriculum for Health Professionals as experience showed that doctors, counsellors, and other health professionals in addition to nurses could benefit from the material. Other changes included, for example, adding answers to frequently asked questions into the text of the revised modules.
“Thanks so much for the HIV/AIDS Nursing Curriculum material. I have gone through the content and it's great work. I'm a teacher in a secondary school co-ordinating HIV/AIDS initiatives and requested the information for a village clinic. The reason I feel it is also appropriate for both teachers and students is because in Uganda at one time every Ugandan has to act as a nurse for HIV/AIDS infected in one way or another either at home or hospital. Most people cannot afford the hospital costs so they are nursed at home by people who know nothing about HIV/AIDS. I wish there was a way each hospital, clinic, health centre, all personnel addressing HIV/AIDS, would have access to this information.” Olivia Mugabirwe, Namilyango College, Kampala, UGANDA

RESULTS

Over 1 100 copies of the first edition collaborative HIV nursing curriculum binder have been distributed in 47 nations. In 2002 a Secure the Future™ curriculum implementation plan supported train-the-trainer programmes for nurses based on the curriculum and conducted by BIPAI staff in South Africa, Swaziland, Zimbabwe, Botswana, Namibia and for participants from the Democratic Republic of Congo and Angola.

These educational programmes were offered in co-ordination with UNAIDS and the Southern African Development Community AIDS Network of Nurses and Midwives (SANNAM), which comprises representatives from the nursing associations of all 14 SADC nations. Workshop evaluations reflect that they have been very well received in the nations where they have been conducted to date.

“We received the “HIV Nursing Curriculum” a month back. I've gone through the curriculum, it is really an excellent work! Thank you very much indeed for sending us a copy. Looking forward to hearing from you.” Best Regards, Dr. Mohammad Hossain, Medical Consultant, Confidential Approach to AIDS Prevention (CAAP), Dhaka, BANGLADESH.

SIGNIFICANCE

The curriculum is beginning to impact on available training. Countries in which the workshops were offered are eligible to apply for up to $5,000 to be used by their National Nursing Associations to continue to educate nurses using the train-the-trainer approach.

Applications for seed funding received to date have been well documented and well justified.

The nursing curriculum implementation was presented at the XIV International AIDS Conference in Barcelona, Spain, in July, 2002, and a curriculum implementation wrap-up and evaluation workshop was held on February 7th, 2003.

The full text (including illustrations) of the second edition HIV Curriculum for the Health Professional is now available on-line in pdf format. Hard copies of the curriculum are provided free-of-charge to individuals in developing countries.

“Greetings from Zimbabwe. On behalf of the Mnene Nurses Training School staff we acknowledge receipt of the HIV/AIDS Nursing Curriculum. We are using the copy as reference material for the STI/HIV/AIDS topics to the students. The doctors, sisters in charge, and the home-based HIV/AIDS co-ordinators are using it to develop in-depth knowledge about HIV/AIDS. We appreciate the copy. It is very educative. May God bless you all.” Yours truly, W. Chibarabada (tutor-in-charge), Bishop Ambrose Moyo, Mnene Nurses Training School, Mberengwa, ZIMBABWE.
7.3.3 Rapid AIDS Mortality in South Africa

<table>
<thead>
<tr>
<th>INVESTIGATOR</th>
<th>Dr Debbie Bradshaw</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOCATION</td>
<td>Western Cape, South Africa</td>
</tr>
<tr>
<td>GRANT AWARDED</td>
<td>US$174,000, co-funded by the Global Health Forum for Research and UNICEF</td>
</tr>
<tr>
<td>ROLEPLAYERS</td>
<td>Medical Research Council – Burden of Disease Research Unit, University of Cape Town</td>
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<tr>
<td>TIME LINE</td>
<td>Two years, starting 1 May 2001</td>
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<tr>
<td>AIM</td>
<td>To establish a mechanism to rapidly use National Data on registered deaths in conjunction with actuarial and demographic models to provide detailed and timely information on AIDS mortality.</td>
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<tr>
<td>OBJECTIVES</td>
<td>To produce short and medium term projections of AIDS mortality; To refine the methodology to do this accurately in the Southern African context.</td>
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**METHODOLOGY**

Funding was used by the Burden of the Disease Unit and the Centre for Actuarial Research at the University of Cape Town to establish a rapid mortality surveillance system to monitor the age pattern of deaths.

The main source of information on deaths in South Africa is the routine cause of death data compiled and reported by Statistics South Africa. These are based on the medical certification of the cause of death, but are problematic as death registration is well known to be incomplete and the cause of death to be frequently misclassified. The South African government attempted to improve the process of death registration and statistics from 1994 but the most recent year for which full cause of death statistics have been released is 1996.

Researchers obtained permission from the South African Department of Home Affairs to analyse the data on deaths that are included on the Population Register, which is a register of all people who have identity numbers, for June 1999 to September 2000. This data provides information on the age and sex of dead individuals who were on the population register, but does not provide adequate statistics on children as many children are not registered.

The Department of Home Affairs data were supplemented by data from Statistics South Africa from mid 1997 to mid 1998, and from the Department of Health from mid 1998 to mid 1999.

Standard indirect techniques were adapted to estimate the extent of under-reporting of deaths. This allowed for different levels of completeness at different ages which can be expected in South Africa, in order to estimate the extent of under-registration in both the routine vital statistics reported by Statistics South Africa and the data obtained from the Department of Home Affairs.

The work demonstrated the value of supplementing routine vital statistics with rapid mortality surveillance, making use of administrative data from the Population Register.
RESULTS

The Rapid AIDS Mortality Surveillance tool developed by the Burden of Disease Unit in collaboration with, among others, the Centre for Actuarial Research and partially-funded by Secure the Future™ was applied in several different contexts. It produced reports and insights into the impact of HIV/AIDS including: adult death rates in South Africa; the impact of HIV/AIDS on orphanhood in South Africa; the HIV/AIDS profile in the provinces of South Africa; and the burden of disease estimates.

Publications which documented these include:


SIGNIFICANCE

Statistical modelling of epidemiological and mortality data paints a clear picture of a hidden epidemic, and provides the understanding necessary for all elements of planning.

In South Africa the information generated by the research was a breakthrough which helped build the growing body of evidence that the AIDS epidemic was leaving a trail of death and devastation among young and adult South Africans.

This is best illustrated by the first application – reviewing the impact of AIDS on adult death rates – which showed that:

- The pattern of mortality from natural causes in South Africa had shifted from the old to the young since 1991;
- Patterns of mortality differed between men and women in shifts that fitted several AIDS models; and
- The future burden of the epidemic could be predicted with reasonable confidence over the next decade but allowed for different intervention strategies in different parts of the country.

“This report is a chilling reminder of how powerful stereotypes across society have colluded in creating the most explosive epidemic in the history of our country. Comprehensive, powerful and rigorous as these data are, they can be seized upon positively by individuals, government and society to intervene at many levels…” noted Professor Malagepuru William Makgoba, President of the Medical Research Council in the report released in July 2001.
Contents of CD-Rom

1. Secure the Future™ – Technical Support to Grantees
   1) Essentials of Good Clinical Practice
   2) ICH E6 EMEA Guidelines
   3) NGO Financial Management Pocket Guide
   4) Monitoring and Evaluation

2. Community Outreach and Education Case Studies – Additional Material
   1) Coping Centre for People Living with HIV/AIDS (COCEPWA)
      - Buddy Training Manual
      - Women in Action Training Manual
   2) Care Lesotho
      - Peer Educator Training Manuals
   3) A New Robe – Community Based Parish Nursing
      - A New Robe – Training Manual for Parish Nurses
   4) Supporting Older Women Caring for Children and Grandchildren Affected by HIV/AIDS
      - A pilot intervention project.
   5) Community AIDS Response – Linking Metropolitan HIV/AIDS Hospital Clinics with Community Care and Material Support
      - A full introduction to CARE
   6) Cotlands Baby Sanctuary HIV Infant Care Programme
      - Workbook for pre-school children on HIV/AIDS

3. Medical Research and Care – Impactful Research – Additional Material
   1) The Cost Effectiveness of HIV/AIDS Treatment in the Western Cape
      - Published research
   2) Cost Effective Laboratory Monitoring: CD4 and T cell enumeration
      - Published research
   3) Health Professional Education Programme: Baylor College of Medicine and Nursing
      - HIV Curriculum for the Health Professional
   4) Rapid AIDS Mortality in South Africa
      - Published research