

## Comfort and hope



*Six case studies on mobilizing family and community care for and by people with HIV/AIDS*



Joint United Nations Programme on HIV/AIDS  
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*Cover photo (courtesy of Chirumhanzu Home-based Care Project):*  
**A young AIDS widow in Zimbabwe – the Chirumhanzu Home-based Care Project provides food and other support.**

UNAIDS, 20 avenue Appia, 1211 Geneva 27, Switzerland  
Tel.: (+41 22) 791 46 51 – fax : (+41 22) 791 41 65  
e-mail: [unaids@unaids.org](mailto:unaids@unaids.org) – <http://www.unaids.org>

# Comfort and Hope

Six case studies  
on mobilizing family  
and community care  
for and by people  
with HIV/AIDS





# C O M F O R T   A N D   H O P E

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# Introduction

The case studies included in this collection stem from a UNAIDS presentation entitled *Home and Community Care: It Works!* It documented the experiences and lessons learned by six community-level projects from Africa, Asia, and Latin America. It was given at the Third International Conference on Home and Community Care for People with HIV/AIDS. Subsequently it was decided to publish them.

All the projects were chosen because they reflected most or all of what UNAIDS considers key elements of home and community care, as well as most of UNAIDS Best Practice criteria (discussed below).

All of the presenters were “hands-on” care givers from the community organizations described in the case studies. They were:

- Etta Dendere of Chirumhanzu Home-based Care Project, Zimbabwe
- Janet Frohlich of Tatani Home Care Services, South Africa
- Elizabeth Kyalo of the Diocese of Kitui HIV/AIDS Programme, Kenya
- Americo Nunes Neto of Projeto Esperança (Project Hope), Brazil
- Samboon Suprasert of Sanpatong Home-based Care Project, Thailand
- Yee Khim Chong of Ikhlas community centre, Pink Triangle, Malaysia.

As they each took their turn addressing the conference, the presenters acknowledged or dedicated their talks to the clients in their respective communities. As one presenter put it, the people living with HIV/AIDS and the members of the community who care for them (family members, friends and volunteers) are both “the practical reason and the inspiration for our work”.

## Shared principles and approaches

Prior to the conference in Amsterdam, the six had spent two days in Geneva at UNAIDS headquarters preparing their presentations in consultation with UNAIDS staff. As they compared the various projects with their diverse approaches and environments, the presenters found themselves agreeing on a group of elements they considered key in their work:

- *a shared value* of participation of affected and infected persons;
- *a shared vision* of participation and involvement of family and community;
- *action* aimed at an improved quality of life for infected and affected persons, within their context (i.e., improvement judged according to their perceptions and feelings);
- *systems* and mechanisms for maintaining momentum (i.e., for ensuring the project's sustainability); and
- *synergy* between community members, government departments or agencies, and the facilitating nongovernmental organization (NGO) or community-based organization.

## UNAIDS's *Best Practice* criteria

Community mobilization against HIV/AIDS is being done successfully all over the world. The activities carried out in community projects are as diverse as the peoples and cultures that make up these communities. Some are entirely “home-grown” and self-sufficient, while others have benefited from external advice and funding. Some are based in religious centres, others in medical institutions, and still others in neighbourhood meeting places—including people’s kitchens. Many concentrate on public education, others on providing care, and still others on prevention or other goals.

With such geographical and organizational diversity, how can we know if a community mobilization project is “best practice” or not? This is an important question in the expanded response to HIV/AIDS. In order to answer the question, it is first important to understand what UNAIDS means by the term.



One of the main roles of UNAIDS is to “identify, develop, and be a major source of international best practice, that is, to identify effective and ethical policies and strategies for prevention and care, and promote and support relevant research to develop new tools and approaches to HIV/AIDS.” This role is best understood as being part of UNAIDS’s overall mission of “leading and catalysing an expanded response to the epidemic to:

- improve prevention and care;
- reduce people’s vulnerability to HIV/AIDS; and
- alleviate the epidemic’s devastating social and economic impact.”

Once an initiative is identified as doing any or all of the above well, the following are used as “core criteria” for best practice: relevance, efficiency, effectiveness, sustainability, and ethical soundness. (A brief assessment of each project against these criteria is included at the end of each chapter.)

## Applying *best practice* to a complex field

“Best practice” is a difficult concept to apply to a field as complex—or perhaps more accurately—as *human* as community mobilization. Analysis of community mobilization experiences can only be done when the specifics of each community are understood. These specifics include:

- traditional culture and its adaptation or resistance to outside influences;
- formal and informal power structures;
- local weather and geography;
- important personalities and interactions between these personalities;
- economy and infrastructure;
- educational levels;

and a host of other factors. Few of these are measurable or controllable (in rigorous research terms of social or medical science).

Data collection is also a challenge. Record-keeping in community-level organizations is frequently rudimentary and

inconsistent, quantitative data are partially or entirely unavailable, and sample sizes are, in any case, too small or ill-defined to give reliable results. Even when changes can be measured, it is often difficult to link them to the practice being evaluated. And replicating the result in another community (if a “comparable” community can be found!) may be impossible, not only for methodological reasons but for practical ones such as finding a willing community partner.

## So how do we know what is “best”?

In community mobilization, we rarely know what is best—if by “best” we mean “most relevant, most effective, most efficient, most ethical, and most sustainable, all the time and in all places”. This is particularly true if the rigorous measures of quantitative analysis and the controls of research design are demanded.

On the other hand, we can often say with some confidence that a practice is “good”—certainly in a particular place—and possibly in many other places. Sometimes we can go so far as to judge that one practice is “better” than another, again, in a particular place and possibly in many other places.

For judging best practice in community mobilization projects, the general criteria of *relevance, efficiency, effectiveness, sustainability, and ethical soundness* can be clarified by considering them against a set of characteristics that mobilized communities either exhibit or strive for. These characteristics were discussed in the first of UNAIDS’s Technical Updates on “Community Mobilization and AIDS”. As described in that document, UNAIDS understands a “mobilized community” to exhibit most or all of the following characteristics:

- members are aware—in a detailed and realistic way—of their individual and collective vulnerability to HIV/AIDS;
- members are motivated to do something about this vulnerability;
- members have practical knowledge of the different options they can take to reduce their vulnerability;
- members take action within their capability, applying their own strengths and investing their own resources—including

money, labour, materials or whatever else they have to contribute;

- members participate in decision-making on what actions to take, evaluate the results, and take responsibility for both success and failure; and
- the community seeks outside assistance and cooperation when needed.

Second, the Technical Update states some of the major principles that community mobilization projects should adhere to. These principles can be seen at work in projects that:

- uphold the rights and dignity of people infected with and affected by HIV/AIDS;
- ensure active participation by as broad and representative a group of community members as possible;
- provide for equal partnership and mutual respect between the community and external facilitators;
- build capacity and ensure sustainability;
- build on the realities of living with HIV and AIDS while maintaining hope based on community collective action; and
- maximize use of community resources while identifying and using additional external resources as needed.

## Diversity and commonalities

To return to the six case studies presented here: although they as diverse in origins and activities as in geographical location, a number of common points can be seen. It should be noted that these common points are not common to all but to at least two of the six. Again, this simply illustrates our point that, in so human a field as community mobilization, many different approaches can and do work—not necessarily for everyone all the time, but frequently enough that they are worth considering when creating or modifying one's own project.

Some of the points shared by two or more of the projects are:

- **Spiritual motivation or guidance.** Three of the projects—Projeto Esperança in Brazil, Kenya's Kitui Project, and Zimbabwe's Chirumhanzu—began with, or were greatly aided by, the

initiative of Catholic clergy. In Brazil, the project was started by a nun, and support from the local bishop was crucial in finding a building for the group to work out of. In the two African experiences, staff at mission hospitals provided the impetus and expertise that permitted the projects to start. The spiritual connection is also very strong in the Thai project. There, Buddhist monks and teachings play an important role in helping persons infected with HIV/AIDS “live positively”, and in encouraging families members and others in caring for them. They have also helped greatly in reducing stigmatization of PLWHAs in general society.

- **Participation of a well-known or particularly well-connected individual.** In many places, it is important for someone with a great deal of local respect to publicly support or participate in a project if it is to achieve success. Such was the case in South Africa’s Tateni Home-based Care Services, where the participation of the well-known retired nurse Mama Khoza was important in gathering a successful team. Similarly, Thailand’s Sanpatong Home-based Care Project benefited greatly from the wide professional connections and long experience of organizer Samboon Suprasert.
- **Importance of getting moral support of local leaders and authorities.** As mentioned above, a crucial “helping hand” was provided to Projeto Esperanca in Brazil by the moral and material support of the local bishop. In very different contexts, but illustrating the same principle, the projects in Thailand and Kenya emphasize the importance of careful relationship-building with village chiefs, without whose support few local people would be prepared to openly seek services. In Malaysia, an essential part of the success of Ikhlas community centre’s drug user programme was to reach an agreement with local police, since the members of IDU community are by definition engaged in an illegal activity.
- **Focus on marginalized groups:** in Brazil and Malaysia the project focus reflected the local course of the epidemic which, in both cases, was most prevalent among specific groups of people. In Brazil, Projeto Esperanca’s earliest clients were gay males and intravenous drug users (IDUs). In Malaysia, Ikhlas community centre’s drug user programme was the result of one marginalized group with high prevalence (gay males) reaching out to an even more marginalized group, IDUs. In contrast, the projects in Thailand and Africa took a more general focus

on a geographical area rather than a particular sub-community, since the epidemic has a more general incidence in the areas concerned.

- **Top-down compared with community-initiated approaches:** three of the projects reflected a top-down start, where an existing organization or professionals from a particular institution initiated the project. In Zimbabwe and Kenya, the initiating institutions were mission hospitals, while in Thailand the organizers were professionals from the local Red Cross Centre, Chiang Mai University and public health staff. In contrast, the Brazilian and Malaysian and South African projects were primarily organized based on the participation of community members (this has been called by one community organizer a “bubble-up” approach, rather than the more standard “bottom-up” term).

The South African example of Tateni represents a sort of mix, with the impetus coming from retired nurses who quickly involved both community members and the provincial health authorities.

## In conclusion

UNAIDS is very pleased to present these, the first in a series of case studies of community-based projects that provide care and prevention to people where they live, work, and play. We hope that they will provide food for thought to other existing projects, and useful advice for people who are planning to create their own projects. In addition, we hope these case studies will be useful to policy-makers and public health officials. We believe the experiences described here show how much valuable work can be accomplished by communities determined to look after people living with HIV/AIDS, and to support the family members and others who care for them.



The project's first centre in São Paulo's Eastern Zone was provided rent-free with the help of the local bishop.

# Project Hope

## Projeto Esperança

### de São Miguel Paulista, Brazil

#### Background

##### Facts about Brazil

Total population (1995):  
161 790 000

Urban population:  
79%

Annual population  
growth rate:  
1.6%

Infant mortality rate  
(per 1 000 live births):  
53.00

Life expectancy (years):  
Male: 65  
Female :70

Illiteracy rate:  
Male: 18%  
Female: 29%

Per capita GNP (US\$):  
2 770.00

Surface area (km<sup>2</sup>):  
8 511 965

Borders:  
Eastern half of South  
America bordering French  
Guiana, Surinam, Guyana,  
Venezuela on the north;  
Colombia, Peru, Bolivia,  
Paraguay, Argentina  
on the west;  
Uruguay on the south

Administrative divisions:  
26 states, 1 federal district

#### HIV/AIDS in Brazil

*Brazil has the fourth highest reported number of AIDS cases in the world, with 116 389 cases of AIDS reported by the end of 1997. Over two-thirds of these cases have been reported in the industrialized southeastern portion of the country.*

*About half of cases to date have been found among homosexual and bisexual men. At the same time, the male-to-female ratio of AIDS cases has fallen from 9:1 in 1987 to the current 3:1.*

*In 1996, the Brazilian government passed a law to provide AIDS patients with free combination therapy and other medication, with poor and hospitalized patients given priority. This followed several lawsuits in which Brazilian courts ruled the government should pay for the treatment of people living with HIV/AIDS.*

# Project Hope—Projeto Esperança de São Miguel Paulista, Brazil

*“Hand in hand with life”*—Project Hope’s motto

In 1988, Sister Gabriela O’Connor began to work on the problem of AIDS in Eastern Zone II of Brazil’s largest city, São Paulo. The local bishop, Dom Angelico Sandalo Bernadino, gave his support to her work and provided a small building in the working-class neighbourhood of São Miguel, which still functions as one of the project’s centres.

Following a period of information-gathering on the HIV/AIDS situation, Sister Gabriela had made a large number of personal contacts in the area and brought together a group of volunteers. These volunteers were already well organized and making house visits to people living with HIV/AIDS and their families by the time the project was legally constituted in 1991. Three years later, two new centres were formed in Guaianases and Vila Esperança with the support of Brazil’s National Programme on STD/AIDS.

Project Hope was the first NGO in São Paulo to provide home care. Their initiative has been acknowledged as an important factor in sensitizing government health authorities to the feasibility of home care, and changing the authorities original scepticism of this approach to AIDS care.

## Goals and principles

From the beginning, the goal of Project Hope has been to improve the quality of life of people living with HIV/AIDS by:

- changing the behaviours and attitudes of people living with HIV/AIDS, and
- involving the community.

The motto, “hand in hand with life”, expresses Project Hope’s philosophy of solidarity and positive living, which informs everything it does. In addition, the project bases its home-care work on the following principles:



- the ideal environment and best therapy for a person infected with the virus is to be with his or family;
- families should be helped to accept and face up to the reality of living with HIV/AIDS; and
- infected individuals and their families should be helped to demand and fight for their rights as citizens.

## Working with HIV/AIDS in a poor urban area

São Miguel is home to about 103 000 people, and covers an area of about 7.5 square kilometres. Most of the inhabitants are members of the working class, and many live in poverty.

While statistics for São Miguel itself are not available, the epidemiological profile for the state of São Paulo may give a rough idea of patterns of HIV/AIDS in São Miguel. As of December 1997, the state of São Paulo reported 65 350 cases of AIDS. Three-quarters of these cases are men. Sexual transmission accounts for just under half of all cases, while almost a third are the result of injecting drug use. Mother-to-child transmission accounted for just under 3% of cases.

Among the 28 417 reported cases of sexual transmission, the official statistics attribute 39% to homosexual exposure, 46% to heterosexual exposure, and the remainder to bisexual exposure. To date, over 40 743 000 people in the state of São Paulo have died of AIDS.

Currently, Project Hope provides services to approximately 480 people who are living with HIV/AIDS. Of these, approximately 10% are seriously ill while 30% are asymptomatic, with the rest showing some symptoms of the virus. At a recent count of people being served, there were 212 men, 189 women, and 68 children. In addition, the project was helping 94 orphans through its “godparenting” programme.

## Major elements of the project

Project Hope is structured around four programme areas:

- Health programmes, including support and orientation for people living with HIV/AIDS and their families, nursing care, occupational therapy, and mutual help groups for emotional

and psychological support. Two professional nurses on staff provide care both at the project's centres or in patients' homes.

- Social programmes, including a Campaign for Orphans.
- Educational programmes, including training of volunteers, production of educational material, and public talks aimed at specific groups such as students, young people and housewives.
- Mobilizing financial support, including fundraising from local donors and from national and international agencies.

Within these programmes, several activities can be further detailed as major elements of the project.



Home visits by Project Hope volunteers to persons living with HIV/AIDS and their families are an important part of the project's work.

### Home visits

An average of 183 new cases are taken on by the project every year. Initial contact with the person living with HIV/AIDS is made in several ways, most frequently through the initiative of the person or his or her family. Some introductions are arranged by the social services unit of the local hospital.

The first home visit is generally aimed at collecting information. It is carried out by a nurse accompanied by a volunteer. The visit begins with learning about the background of the person with HIV/AIDS, and is followed by evaluating his or her clinical condition. Finally, the social and economic situation of the person is discussed in order to make an assessment of needs.

Whether there are follow-up visits depends on the decision of the person with HIV/AIDS. Every effort is made to establish a relationship of trust and friendship during the visits, and there is strict observance of the person's right to privacy. Between first visits and follow-ups, approximately 360 home visits are made per month. In approximately 90% of the cases attended by Project Hope, the families undertake to look after the person living with HIV/AIDS.

### Multiplying agents

An important job is carried out by paid staff who are known as "multiplying agents". These are young people (average age is 15 to 20) whose job is to promote awareness of HIV/AIDS and of the ways that individuals can prevent infection by or transmission of the virus. Examples include role-playing of how the condom use can be negotiated within a couple.

## Services of volunteers

Project Hope could not do its job without the voluntary contribution of time by a variety of different people. They include:

- 74 volunteers who work daily or weekly in the health programmes;
- 97 “godmothers” and “godfathers” who help with orphaned children; and
- 40–50 people who help from time to time with particular events such as fundraising bingos, raffles or bazaars.

The volunteers represent a cross-section of the Eastern Region’s population. The youngest to date is 18 years old, while the oldest is over 70. Fewer than 5% of volunteers have attended university, though 40% have finished secondary school. The majority are women. A variety of religions are represented in the group. Many are persons who have received services from the project.

### Recruitment and training

Volunteers are recruited in various ways, including campaigns on community radio, articles in local newspapers, contacts with the neighbourhood association, and word of mouth. Each candidate is interviewed to find out their personal history, why they got in touch with the project, and what their expectations are. At the same time, the interviewers describe the project and explain its objectives.

If both sides are still interested, the volunteer enters an orientation period, learning in greater detail about Project Hope’s activities and philosophy. The volunteer is free to choose a programme area to work in, based on this orientation. If his or her choice is to work in the health programme, then the volunteer begins to accompany staff and more experienced volunteers on home visits. During these visits, the new volunteer acts only as an observer, and learns that everything divulged during the visit is confidential.

This period of learning-by-experience lasts two months. If all goes well, the volunteer receives formal training on:

- HIV and sexually transmitted diseases (STDs);
- medicines related to HIV/AIDS and STDs;
- the role of volunteers in home care; and
- the benefits of home care for people with HIV/AIDS.

Only then is the candidate considered a full-fledged volunteer who is authorized to do home visits alone.

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## Keeping morale and motivation high

Americo Nuñez Neto is a long-time member of Project Hope. He says:

*“I’ve been HIV-positive for seven years now. I came into Project Hope as a client for their services in 1990. It was a good thing for me, as I really needed the support and also something to re-build my life around. After a while, I became a volunteer in the project and an activist in the struggle for the rights of people with HIV/AIDS. Today I’m vice-president of the project.*

*In my work of coordinating activities, I have to keep in mind the needs of the group. Our work can be very hard on people emotionally, so maintaining balance and harmony is extremely important in motivating our volunteers and staff. You can’t just hope for that to happen, you need mechanisms for the organization to follow. We have a variety of these mechanisms.*

*One is simply good, consistent supervision. I know that sounds obvious, but you have to think about it to do it well, especially when everyone is so busy. Just telling people what to do and leaving them to it doesn’t work—not just because you need to monitor the quality of what they do, but because they need the support and personal communication with someone knowledgeable. As well, our supervision of volunteers isn’t just watching what they do: it includes updating them on what the project is doing, and ongoing training.*

*In formal terms, we schedule weekly meetings where we evaluate progress on individual cases and discuss what the client’s needs are—and the needs of the volunteer, which as a coordinator I always have to keep thinking about. But we also do a lot of group reflection on issues that come up, especially concerns of the volunteers. Being included in decision-making and having your ideas listened to is a great motivator for a volunteer. It certainly was for me.*

*Another important point: even if you can’t pay people for the work they do, you can be creative about compensating them in one way or another. Project Hope organizes things like games, group recreation, trips together—those are obvious, and people like them and they don’t cost much. And they encourage friendships within the group, which is very important. We also can provide public transport passes so people can get around easily and cheaply on the city buses. Less obvious is therapeutic massage and psychological support. These are two services we offer to our clients, and we have professionals who do them, so it makes sense that volunteers should benefit from such supports as well if they need them.*

*Finally, we recognize people’s limits. Everybody needs a rest sometime, and ‘burnout’ is a high risk in this kind of work. So we make sure people take a month’s holiday from their volunteering duties every year.”*

## Partnerships and alliances

An important component of the project is to find financial support for its activities. This work is carried out in several ways, including promoting fundraising events with the local community, identifying and maintaining relationships with local donors, and contacts with supporting agencies both in Brazil and internationally.

### Community support

Project Hope benefits from a great deal of community support, which is often expressed in contributions of materials or services. Fundraising or recreational events often receive free food from local businesses, for instance. Local people with cars or trucks donate their time to do whatever driving is necessary, including driving patients to medical check-ups or treatment and delivering donated food and clothing to people unable to come to the centres.

### Government health-care system

In recent years, Project Hope has worked closely with the Brazilian Ministry of Health's National Programme for STDS/AIDS through an agreement that is subject to review on a yearly basis. The opening of the two new centres in Guaianases and Vila Esperanca was strongly supported by the Programme, which has maintained its financing for the centres' operations since they opened.

### Donor agencies

Donations and other support from outside Brazil have been very important to Project Hope over the years. The British agency CAFOD has supported some of the activities at the San Miguel centre for many years now, while CARITAS-Holland provides funding for Guaianases and Vila Esperanca. In addition, the Austrian agency DKA funds part of our education and prevention activities.

### Other organizations and NGOs

Project Hope participates with about 30 other NGOs in the São Paulo NGO Forum on AIDS. This association carries out state-level advocacy on behalf of people with AIDS. It deals with issues such as public health policy and prevention measures, hospital bed availability, and provision of medicines.

### Monitoring and evaluation

Project Hope holds weekly meetings of paid staff and volunteers to evaluate and follow up on individual cases. Activity reports are written daily and added to each patient's file, along with monthly reports written by agents, volunteers or staff coordinators. Summary information based on these files is provided to supporting agencies for evaluation and planning.

### Strengths of the project

The single most important strength of Project Hope has been its ability to improve the quality of life of people living with HIV/AIDS. This is measured in terms of numbers of people visited, medical attention given, etc. However, there are other indicators that show success of a different kind. An important indicator has been the project's ability to attract volunteers who do not have a direct "stake" in HIV/AIDS. For example, in addition to people living with the virus and their relatives, the project has attracted the participation of a number of volunteers who are not seropositive and have no family members living with the virus. This solidarity indicates success in the project's participatory, community-based approach.

### Weaknesses of the project

Project Hope's internal evaluations recognize several weaknesses. An important weakness is the lack of professional management training within the organization. Project Hope has also had difficulty in managing the relationship between paid and volunteer work, which has occasionally led to misunderstandings or conflict.

On a broader level, the project shares the sense of many NGOs that encouraging true behaviour and attitudinal change among people living with HIV is a highly difficult goal to achieve.

.....  
***For more information:***

**Projeto Esperança**  
**Rua Comandante Carlos Ruy 75**  
**08410-130 São Paulo – SP, Brazil**  
**Fax: 5511 968 6670**

## Best Practice Criteria



The Project Hope logo

■ **Project Hope** is an example of an organization which has been successful in creating systems which are both effective and contribute to the organization's sustainability. These systems have permitted the project to create and maintain a strong corps of volunteers and supporters in its local community. It has also been able to negotiate secure funding from outside sources and create linkages with both government and non-governmental institutions or groups working in the same field. These achievements highlight how Project Hope fulfils several of UNAIDS's best practice criteria.

■ **Relevance:** Project Hope's activities align closely with UNAIDS's goals of prevention, care and reduction of impact of HIV/AIDS. The project's institutional arrangements with the National AIDS Programme are an important guarantee that it will continue to remain relevant to national strategies while responding to the local conditions in San Miguel.

■ **Effectiveness:** Project Hope's effectiveness in operational terms is indicated by the numbers of people visited and levels of service provided. The project takes on approximately 180 new clients per year and makes about 360 home visits per month. Its strategy of involving the community has clearly been successful, given that nearly 200 people are involved on a voluntary basis. Project Hope acknowledges that it has been less effective in its other principal goal of changing behaviours and attitudes of people living with HIV—a not infrequent finding in reviews or evaluations of CBOs.

■ **Efficiency:** there are no indicators currently available on the efficiency of Project Hope's activities. However, the teaching strategy of "learning by observing" for home-visit volunteers appears to be highly cost-effective.

■ **Sustainability.** Project Hope has existed for a decade, indicating both that it responds to a need and that it has found ways to sustain itself. The organizers clearly recognize that sustainability is not only a question of securing financial resources but of paying attention to human issues such as morale, enthusiasm and communication. Having been successful in gaining relatively stable financial support from a variety of sources including local donors, Brazil's National AIDS Programme, and international donors, the project has placed a great deal of thought and energy in sustaining its volunteers who are such an important part of its activities.

■ For example, social activities such as dances and outings are used specifically to build morale and to recognize contributions by the volunteers in a non-monetary way. The limits of people's energy is recognized by the use of "holidays" in order to prevent volunteer burnout and the provision of massage and other relaxation techniques. Regular meetings aid in communication between volunteers and between staff and volunteers by explicitly discussing volunteers' needs and perceptions. Finally, the project coordinators are highly aware that their responsibilities include looking after the volunteers as people rather than as tools to provide services.

Sustainability has also been pursued through contacts with the local religious authorities, businesses and community members. These have led to a significant amount of in-kind services and goods such as driving services and the donation of food and clothing. The Catholic Church's support through provision of the project's first premises was crucial to getting Project Hope started.

■ **Ethical soundness:** Project Hope has proved successful at involving people living with HIV in its work as volunteers and in its management as staff members. This is one of UNAIDS's main indicators of ethical soundness. In addition, the project is socially inclusive, bringing together people from all walks of life within the community and serving clients, regardless of their lifestyles. Finally, Project Hope emphasizes a holistic, active approach to HIV/AIDS that encourages seropositive people to live their lives as independently as possible.



# Kitui

## Kenya

### Background

#### Facts about Kenya

Total population (1996):	29 137 000
Urban population:	28%
Annual population growth rate:	3.5%
Infant mortality rate (per 1 000 live births):	61.00
Life expectancy (years):	Male: 53 Female: 55
Illiteracy rate:	Male: 20% Female: 42%
Per capita GNP (US\$):	310.00
Surface area (km <sup>2</sup> ):	580 367
Administrative divisions:	7 provinces

#### HIV/AIDS in Kenya

*The true number of HIV/AIDS cases in Kenya is not known. In 1997 it was estimated that about 2.1 million people were infected with HIV, of which some 200 000 people had developed AIDS. The number of HIV cases is estimated to be growing at a rate of 7.5% per year.*

*The HIV/AIDS epidemic in Kenya is likely to have a significant impact on the demography of the country. Demographic projections show that AIDS could potentially reverse gains made in increasing child survival and life expectancy.*

*According to one analysis, the number of orphans will increase from the 1990 estimate of 25 000 to roughly 600 000 by the year 2000.*

*An analysis carried out on the socio-economic impact of HIV/AIDS in Kenya by Family Health International/ AIDSTECH reveals that:*

- 1. By the year 2000, the cost of caring for people with AIDS could consume the MOH's entire recurrent budget unless appropriate alternative forms of health-care and health care financing are immediately promoted and adopted;*
- 2. On average, AIDS causes the loss of three-fifths of an infected person's productive life, or approximately 22 years;*
- 3. The total direct and indirect costs of AIDS to the country could reach 15% of GDP by the year.*

# Diocese of Kitui

## HIV/AIDS Programme, Kenya

The diocesan HIV/AIDS programme evolved from the initiative of Dr. Frank Engelhard, from the Dutch organization Memisa, who came to Mutomo Hospital in 1989 following work in Uganda. Observing that some PLWHAs were presenting with symptoms of AIDS, he arranged for a visit to Kikova Hospital in Uganda by six diocesan representatives, including Mutomo Hospital's chief medical officer, Dr. Marian Dolan. Soon after, nurses were selected from the two Mission hospitals of Mutumo and Muthale to be trained in basic counselling by the Kenyan Red Cross.

In 1992, a pilot project was started. After the project was in progress, the need for further training in counselling was identified and it was decided to include the staff of the two government hospitals of Kitui and Mwingi. This led to collaboration with the Ministry of Health, and the evolution of the HIV/AIDS programme with outreach, home care and group counselling.

### Goals

The goals of the programme are:

- to reduce the incidence of HIV infection; and
- to enable people infected and affected by AIDS to live positively.

These goals are pursued by two means. The first is to provide counselling and holistic care to people infected and affected by HIV/AIDS. The second is to cause behavioural change by increasing public awareness of both the impact of the epidemic and methods to prevent its spread.

The programme provides an important service to the local health system as it helps reduce the bed occupancy rate in the area's four hospitals. With home care offered as an effective alternative in a familiar environment, people living with HIV can be discharged as soon as they learn their sero-status and have been given counselling.

## HIV/AIDS in a poor rural area

Kitui and Mwingi are two districts in eastern Kenya that make up the diocese of Kitui. Together they cover an area of 29 389 miles and have a total population of over 812 000 people. There are no industries in this arid and semi-arid area, and most of the people depend on small-scale farming and livestock. Unfortunately, intermittent droughts result in frequent food scarcity and famine.

Poverty is widespread, and there has been a marked migration of men between the ages of 16 and 50 years to the larger Kenyan cities in search of employment. Many return home during the Christmas and Easter holidays. Some women visit their husbands in town during these holidays or at the end of the month.

The population in the catchment area of Mwingi and Muthale Hospitals numbers about 102 000 people, of which 46% are male and 54% female. Of the estimated 43 000 people in the sexually active age group (16–60 years), about 10% are in primary school and 26% are secondary school students. In the catchment area of Kitui Hospital, the population is 138 000 and the sexually active age group contains 36 800 people. Both catchment areas are situated on the lorry routes from Mombassa to Kitui and Nairobi to Garissa, with stop-off points in small towns along the way.

The HIV/AIDS situation in the area is very serious. Some 40% of beds in the area's four hospitals are occupied by people living with AIDS. Owing to poor nutrition, which is the result of frequent droughts in the area, resistance to infection is low, and people living with HIV present with many opportunistic diseases. Most cannot afford the treatment such diseases require.

A 1996 sentinel study survey conducted in Mutomo hospital found 10% of mothers to be HIV-positive. The estimated number of HIV-positive adults (male and female) in the district was estimated at 30 695. At the 7.5% rate of growth in infections nationally, it is expected that this number will have grown to almost 33 000 by the end of 1997.

## Major elements of the project

### Pre- and post-test counselling

Some clients are referred for testing by doctors at the hospitals, while others simply arrive and ask to be tested. In both cases, counselling is given in all four hospitals both before and after tests are done. The home-care clinic provides the following standard services, the first three of which apply to all clients:

- introduction of people living with HIV to counsellors;
- ongoing counselling on living positively with HIV;
- clinical check-up;
- provision of drugs for opportunistic infections and STDs as required;
- preparation of people living with HIV for home visits and group therapy; and
- preparation of family members and friends for roles as care givers.

While some features of the counselling are general, some types of clients are handled in specific ways, according to their particular needs:

- TB patients who are referred for HIV tests are given pre-test counselling before they receive treatment with TB drugs. This is because the drug Thiazine has many side effects on people living with HIV and may result in death.
- Children who may be infected with HIV are not tested until they are two years old. Their growth is monitored, and their mothers are taught how to maintain their children in good health. This includes education about opportunistic infections and the importance of getting immediate treatment for children if they fall sick.
- Elderly care givers who are taking care of orphans are given supportive counselling and are supplied with limited material support such as second-hand clothes and food such as maize, beans, sugar, and tea leaves.

### Home visits

Following the people living with HIV's discharge from hospital, a home visit is made by the counsellor. This visit serves to introduce the counsellor to these people's family and begin

to develop trust with them. Again, home visits include some standard services:

- assessing home conditions and family needs;
- assessing physical, emotional, psychological, and physical condition of people living with HIV;
- supportive counselling for persons living with HIV and family members;
- identifying or meeting guardians (described below);
- providing simple curative medicines; and
- schedule next visit.

A variety of issues are discussed in home visits. The person living with HIV is encouraged to identify a guardian from among close family members (mother, father, sister or brother) who will be responsible for the orphans. This guardian will also act as a contact person if the person living with HIV becomes ill and cannot visit the hospital. At these times, the guardian will go to the hospital to report on this person's condition to the counsellors. In addition, the guardian and other family members are given training in home care of people with HIV/AIDS.

All information that comes up at these visits is kept confidential. Notes and other information are available to all counsellors and doctors associated with the project, but no one else.

### Group counselling sessions

Group counselling sessions or workshops for people living with HIV is an important way to assist people to come to terms with their condition. Typical activities at the sessions include:

- sharing experiences, both positive and negative;
- encouraging people living with HIV are encouraged to express their feelings and learn how to deal with them;
- helping people living with HIV to identify their own strengths and talents; and
- discussing small-scale businesses and other income-generating activities.

Group counselling discussions have also been useful in identifying the need for workshops on health maintenance and ongoing education for personal growth.

### Community education

The project attempts to provide members of the community with basic HIV/AIDS awareness, and to encourage the community to take responsibility for persons living with HIV and for orphans. To this end, HIV education visits are frequently made by counsellors (including persons living with HIV) to schools, hospitals, workplaces, churches, and public gatherings. Depending on the audience, the information is given in a variety of forms, including Training of Trainers (TOT), seminars and workshops. The project also encourages competitions in drama, poetry, and songs on AIDS.

Health education visits also target behaviour change in specific audiences. These have included teachers, youth groups, primary and secondary schools, men's and women's groups, traditional healers, traditional birth attendants, sex workers, and hotel and bar workers. It is recognized that such change is a gradual, ongoing process because there is still a stigma associated with the disease and some fear of programmes and personnel working in HIV/AIDS prevention.

### Recruitment of persons living with HIV as volunteers

Recruiting people living with HIV to act as volunteers is a recent and very important step of the programme. Denial and stigma are still very strong in Kenya, and this is an effective way to educate the community at large. To date, two persons living with HIV assisted by counsellors have made educational visits to locales away from where they live. In these visits, they have spoken of their sero-status and experiences.

This activity is supported by group counselling which, in addition to helping people living with HIV come to terms with their condition, has encouraged them to see the need to assist in the education of the community. It is hoped that this activity will expand and develop in the near future.

### Services for people with STDs

The programme provides treatment and counselling to people who have sexually transmitted infections (STDs). This is an important service in this area, which has a high incidence of such infections.

### Preparing people for death

A variety of services are provided to people who are dying. These include helping them identify guardians for their children, and helping them write wills to ensure that their land and belongings are passed on to their children. Efforts are made to help people with AIDS spend their remaining days in familiar surroundings, and to die with dignity.

### Encouraging economic activity

Some people living with HIV are helped to identify their existing talents and skills that might enable them to set up small businesses. Examples of products which might people living with HIV be taught to sell include second-hand clothes, utensils, and groceries. Skills that are taught include marketing and sales skills, book-keeping and simple accounts, stocktaking, and interpersonal customer relations.

This activity is carried out in collaboration with the Ministry of Health, Catholic Diocese, Church of Province of Kenya, the municipality and the Kitui county council.

### Provision of simple curative medicines

Persons living with HIV/AIDS are provided with simple curative medicines, including anti-malarials, anti-diarrhoeal, and anti-fungal drugs, multivitamins, and antibiotics.

### Basic supports for needy clients

Very needy clients are assisted with their food needs such as beans, maize, flour, eggs, and milk. This assistance is assessed on the individual level in order not to encourage dependency. During the current famine conditions, seeds have been given to people living with HIV in each area.

## Staff training and support

All staff in the project are nurse/counsellors. Some are qualified as trainers of trainers, while others are trained as facilitators of groups, workshops, and seminars. Regardless of their origin, all receive ongoing training in counselling and topics such as personal development, education for life, and behaviour change.

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## Hope for the Chende family

This story was provided by a nurse/counsellor

*Mr Chende\* is a local man who, like many in the District, often works in other parts of the country. In 1986 he was working in Mombasa for a large company. One day he began to feel fever, chills, and pains in the joints. The fever subsided for a while, then reoccurred. That went on for years, and during that time he received frequent treatment for malaria, joint pains, and colds.*

*In 1990 Mr Chende was admitted at Mutomo Hospital with herpes zoster, and a blood-screening test for HIV was ordered. He received pre-test counselling before that test was carried out, and then post-test counselling when the results came back. It was bad news: Mr Chende had HIV.*

*The post-test counselling session made it easier for Mr Chende to come to terms with his condition. He was discharged from Mutomo with a referral to Kitui Hospital, which was nearer to his home. He also was invited to join in group counselling.*

*For the next few months, Mr Chende received treatment for the herpes infection and attended the group counselling sessions. There were many issues to think through, since he was not only married but had three children. As well, since he was seriously ill, he was counselled to tell his wife about his HIV-status. He agreed, and soon shared the information with her.*

*Mrs Chende came into the Hospital with her husband for counselling, and agreed after the session to be tested for HIV. Two weeks later she came back for her results and post-test counselling. She too was positive. After that, she began to go with her husband to group counselling sessions.*

*With both parents sick and three children to support, the family was very poor and needed help. They decided to share their HIV status with their close relatives, but requested that they be supported by nurse/counsellors when they did so. A meeting of relatives was called, and the nurse/counsellors informed them in confidence of the Chendes' condition. They also asked the clan and family members to support and care for the Chendes. This request was accepted, and today they receive a great deal of support from these relatives. Additional help came when Mrs. Chende asked the programme coordinator for help to build a small house. Having very limited funds at her disposal, the coordinator organized a small fundraising in the community. Neighbours donated iron sheets and some of the young people in the Chendes' village made bricks for the house.*

*Mr Chende's condition remains poor due to severe skin cancer (Kaposi sarcoma), but he and his family are much more comfortable in their new house. They are also very happy with the services provided by the community and by home-care staff.*



*Mr and Mrs Chende continue to attend group counselling sessions, and have become more involved in the programme. Both help prepare food for the group, and both give encouragement to other people living with HIV. They continue to enjoy the support of their clan and family members.*

\* Not the real name. Shortly before printing, UNAIDS was informed that Mr Chende had died.

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Staff are supported by central office as needed. However, all participate in meetings held every six months to plan, evaluate, and implement the project's activities.

## Confidentiality

Confidentiality is essential to the programme, since it is the only way to maintain trust in the relationships between counsellor and person living with HIV and between people living with HIV themselves. Already part of the code of nursing ethics, confidentiality is emphasized to people living with HIV from the moment they join the programme.

At the same time, candour between people living with HIV is essential to group counselling, since the practice of people living with HIV acknowledging their status at each group session is vital in their acceptance of their status. It is part of their education in self-awareness, and in acknowledging and accepting their feelings. Along with spiritual care, these elements help people living with HIV greatly in personal growth and overcoming stigma.

## Partnerships and alliances

### Government health-care system

The programme collaborates on an ongoing basis with Ministry of Health personnel. This collaboration began in 1993 with the secondment of two Diocesan nurse/counsellors to the Government Hospitals at Kitui and Mwingi.

The Ministry has financed some of the programme's World AIDS Day activities and the National AIDS Programme has provided it with educational materials. Recently, all four

hospitals have been accepted by the Ministry as Sexually Transmitted Infections centres, which will greatly assist the programme in its work against HIV infection.

The government hospitals supply the programme with some nursing materials such as gloves and disinfects, while others are bought by the programme. In addition, some free drugs are distributed to people living with HIV/AIDS in the government hospitals and the Mutomo Mission Hospital.

## Monitoring and evaluation

Group counselling sessions are held once every two weeks, and use self-evaluation.

Monitoring of the programme's activities in home care clinics and hospitals is carried out on a monthly basis by supervisors.

Every three months, programme personnel meet with Ministry of Health personnel. Evaluation and planning sessions for programme staff are held every six months.

### Strengths of the programme

Self-assessment by the programme indicates that staff are well trained and motivated, with the concrete benefit that minimal supervision of staff is needed. Provision of group counselling for staff is an additional source of strength for staff.

Communication between the various groups in all four hospitals is good, as is collaboration with the Ministry of Health.

### Weaknesses of the programme

Our self-assessment is that two important elements in the programme itself need reinforcing:

- more effort is needed in education aimed at changing attitudes and increasing acceptance of sick people by families and the community; and
- there is not enough coordination between our programme and other NGOs, government departments, and the community. Regular meetings, even on a half-yearly basis, might help ensure that all necessary activities are being covered and to avoid overlapping of efforts.

Otherwise, the main weaknesses appear to be directly related to the increasing gravity of the epidemic and the lack of resources available to deal with it. For instance, with 200 new orphans being identified each month, the programme is unable to serve all orphans being left without caretakers. Similarly, there are not enough counsellors or material resources to meet the rising demand for counselling services, which are very time-consuming activities. This results in increasing physical and emotional stress on counsellors. It has also caused a problem of confidentiality because it is impossible for only one counsellor to follow each person living with HIV, so information must be shared between counsellors. And it has made it difficult for counsellors to keep abreast of new practices in the field of HIV/AIDS.

## The future

The programme has resolved to fortify itself and improve its services in the following ways:

- increasing emphasis on mobilizing extended families to take care of orphans;
- running a workshop on behaviour change and education for life;
- continuing education for counsellors to keep up with HIV/AIDS developments globally; and
- increasing networking at local and national levels.

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***For more information:***

**Office of the AIDS Coordinator  
Diocese of Kitui – P.O. Box 123 – Kitui, Kenya  
Fax: 0141 22899**

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## NGOs/CBOs role

Kenya AIDS NGO Consortium was established in 1990 with over 320 member organizations (UNAIDS in Kenya, 1996).

Important role played by NGOs and religious groups. Religious groups emphasize awareness and prevention activities. NGOs focus primarily on high-risk populations, emphasizing IEC, condom distribution and training for community-based workers.

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## Best Practice Criteria

The HIV/AIDS Programme of the Diocese of Kitui exemplifies the types of action that can be undertaken to improve the quality of life for infected and affected persons.

The project illustrates UNAIDS best practice criteria in the following ways:

- **Relevance:** the programme is focused on two UNAIDS priorities: prevention and care. A wide variety of needs are provided for within this programme, from individual needs to care and counselling to community education.
- **Effectiveness:** from a top-down perspective, the programme takes a highly organized and professional approach to its activities, as could be expected when all staff are trained nurse/counsellors who are employed by a well-equipped mission hospital. Effectiveness also appears to be enhanced by a high degree of cooperation with the government health services, allowing collaboration between four hospitals in the area.

On the level of services, the programme has clearly taken into account the diverse needs of specific groups of people living with HIV, and appears to have devised effective strategies for each. Different groups include PLWHAs with HIV-relevant medical conditions such as TB and STDs, seropositive or potentially seropositive infants, elderly care givers, and people who are in the terminal stages of AIDS.

Programme staff express concern that success in changing attitudes and behaviour in the greater community has so far been limited, particularly with regard to increasing acceptance of people living with HIV/AIDS. It seems likely

that effectiveness in these areas of endeavour will remain limited unless greater resources become available for community education.

■ **Efficiency:** There are currently no indicators available of the project's efficiency.

■ **Ethical soundness:** the Kitui programme is run by trained nursing staff with a strong grounding in their profession's ethics. Awareness of the need to safeguard confidentiality is solid, although the limited number of staff makes it necessary for counsellors to share information among themselves.

■ **Sustainability:** the sustainability of the programme appears to be guaranteed by the support of both the mission and government hospitals, and the Ministry of Health. It is to be hoped that greater involvement with local community (i.e., a less top-down approach to services) may become possible as more volunteers are recruited and the growing impact of the epidemic reduces the current stigma attached to it.



# Drug user programme, Ikhlas Community Centre, Pink Triangle, Malaysia

## Background

### Facts about Malaysia

Total population (1995):  
20 140 000

Urban population:  
47.20%

Annual population  
growth rate:  
2.00%

Infant mortality rate  
(per 1 000 live births):  
11.00

Life expectancy (years):  
Male: 70  
Female: 74

Illiteracy rate:  
Male: 14%  
Female: 30%

Per capita GNP (US\$):  
2 790.00

Surface area (km<sup>2</sup>):  
329 749

Administrative divisions:  
13 states and  
2 federal territories

The capital is Kuala Lumpur

### HIV in Malaysia

*The first case of HIV in Malaysia was detected in 1986. Up to the end of 1996, the total cumulative number of HIV infections reported was 19 019. Out of this number, 580 were AIDS cases.*

*The major mode of transmission of HIV is through sharing of HIV-infected injection equipment among injecting drug users (IDU): this accounts for 77.4% (or 14 713 cases) of the total cumulative number of infections. Sexual transmission accounts for 5.9% (or 1 116 cases). (These figures probably contain a data collection bias since active HIV screening tests are carried out among injecting drug users incarcerated in the drug rehabilitation centres and prisons, whereas the number of people from other sectors of the population coming forward voluntarily for testing is still low.)*

*Of the total HIV infections reported, 83.4% occur among those in the 20–49 years age group and 95.7% of the infections are among males.*

*The national AIDS programme budget includes provision of drugs, including antiretrovirals. Public health officers, health clinics, and the rural health clinics are involved in provision of care for AIDS patients, along with district hospitals and general hospitals.*

# Drug user programme, Ikhlas Community Centre Pink Triangle, Malaysia

*Ikhlas is a Malay word that means “sincere”*

The Ikhlas community centre’s drug user programme was created in 1991 by an NGO called Pink Triangle Malaysia. Operating in a drop-in centre and through outreach workers, it works with the intravenous drug user (IDU) population in a Chow Kit, a poor community of Malaysia’s capital city, Kuala Lumpur.

Chow Kit is a bustling, traffic-congested area of Kuala Lumpur. Its ethnically mixed population is mainly composed of working class Malays, Chinese, Indians, and a significant migrant population of Indonesians. Chow Kit is a shopping and business area, with a thriving retail and petty trade, but it is also a red-light district. Several of its side streets are lined with seedy brothels, and are ‘home’ to drug users. According to one estimate, there are about 8000 IDUs, sex workers, and transsexuals living and working in the area.

Each month, an average of 1040 contacts with clients are made by programme staff and volunteers. Contacts include such activities as providing basic medical care and food, handing out and discussing information on HIV and harm reduction, and making referrals to other care and support services.

## Goals

From the beginning, the goal of Pink Triangle Malaysia in creating the drug user programme was to serve the IDU population of Chow Kit by:

- providing information on health, harm reduction, and HIV itself;



- providing care and support, including medication, nutrition, shelter, employment, and psycho-social support; and
- advocating for IDUs' needs and concerns.

## Reaching out from one marginalized community to another

Pink Triangle was already an experienced organization in 1991, being the first NGO in Malaysia to work at the community-level on HIV and sexuality issues. It had begun to work on behalf of a marginalized community—the gay community of Kuala Lumpur—in 1987, shortly after the first cases of AIDS were diagnosed in the country. By the early 1990s it was well established, with its own HIV education and support programmes. One of the best known is Positive Living, a support and care project especially for people living with HIV.

Today, Pink Triangle has 18 staff and about 100 volunteers involved in its HIV prevention and support programmes. One of the first services provided by Pink Triangle, and which is still being provided, is a telephone information and counselling service addressing issues of HIV and sexuality. The funding for its programmes came from various sources—AusAID, HIVOS, the European Commission, the Malaysian AIDS Council, corporate bodies and its own fund-raising activities such as theatre shows, sale of merchandise (e.g. T-shirts, badges).

As their work evolved, members of Pink Triangle Malaysia were strongly aware of the fact that the gay community was not the only marginalized group of people who were especially vulnerable to HIV. They identified groups such as injecting drug users, transsexuals and sex workers as particularly vulnerable. This was borne out by government statistics demonstrating the increasing number of HIV infections in Malaysia, particularly among IDUs.

According to official statistics, sharing of HIV-infected needles and syringes among injecting drug users accounted for almost three-quarters of the total number of infections. In contrast, sexual transmission caused less than ten percent. Little information was available about infection rates among transsexuals and sex workers, but Pink Triangle guessed that they too had high

infection rates. (This guess has been borne out by the number of HIV-positive transsexuals and sex workers who have made contact with Pink Triangle. The official reported figure for HIV-positive female sex workers in the country is 393, as of 31 July 1997. No official statistics are available for transsexuals.)

Encouraged by their success among gay men, Pink Triangle Malaysia resolved to do something about the vulnerability of these other marginalized groups. The result was the drug user programme, based in an area of Kuala Lumpur known as Chow Kit.

## Getting organized

Pink Triangle Malaysia recognized the importance of proceeding cautiously and systematically. Volunteers began by making contact with drug users and consulting them about their needs.

Having learned a great deal from its own organization and continued operations since 1987, Pink Triangle Malaysia based its work on the following principles:

- trusting relationships had to be established with the IDU community;
- the IDU community had to be consulted about what they wanted and needed;
- the immediate, basic needs of the IDU community had to be addressed before HIV education would take place;
- care and support services had to be provided in safe spaces and be client-centred (that is, concentrate on meeting the needs of the client);
- members of the IDU community could be motivated to take action to address their vulnerability to HIV/AIDS, and could participate actively in the project according to their own capacities;
- supportive relationships with other affected communities and concerned parties had to be established and maintained.

These principles continue to guide the project today, more than five years after its birth. Even before the first care and support work was undertaken, Pink Triangle applied the first three principles in order to understand their intended client group.

### Establishing relationships with the IDU community

The IDU community is not an easy one to get to know. IDUs in Chow Kit form close-knit peer groups or 'comradeship'. For example, one group that has stopped shooting drugs may exclude people who are still shooting drugs.

Fortunately, however, prior to the start of the drug user programme, certain volunteers of Pink Triangle Malaysia had already established contact and developed a good relationship with several members of the IDU community in the Chow Kit area. These contacts had been formed through the volunteers' work with the gay community there.

### Consultation with the IDU community

Through the initial contacts, an informal needs assessment was carried out among IDUs in Chow Kit. This was accomplished through outreach and discussion with the drug-using population in the area, who were consulted about the needs and concerns of the community.

The informants were visited on their terms, in places where they felt most comfortable, including "shooting galleries" and meetings on the street. Key informants were chosen during the outreach activities, based on their knowledge of the IDU community and on their contacts in Chow Kit. They included the so-called "IDU doctors" (themselves IDUs) who help other IDUs inject drugs for a fee, and who were identified as key agents of change. Demographic data was collected using a questionnaire. Later on, Ikhlas used the same techniques to create project components especially for transsexuals and sex workers.

### Addressing the client group's priority needs

The informal needs assessment gave the Pink Triangle volunteers a clear sense of what IDUs in Chow Kit saw as priorities for improving their lives. These priorities were extremely basic, emphasizing the extreme marginalization and vulnerability of the IDUs:

- basic medical care;
- shelter;
- food;
- jobs;
- children's welfare; and
- obtaining identification papers and birth certificates.

## Major elements of the project

Guided by the information obtained in the needs assessment, Pink Triangle moved to set up the major elements of the drug user programme. They were, and remain the Ikhlas community (or “drop-in”) centre, outreach services, and the ongoing motivation and participation of the IDU community.

### Drop-in centre

The drop-in centre was conceived as a “safe space” in which many of the clients needs could be met efficiently but without intimidating them or making them feel unwelcome. It is located on one of the side streets in Chow Kit, not far from the brothels and where the IDUs spend much of their time. It’s located in one of a row of three-storey shop-houses. The building is rented from a landlord. A variety of activities are carried out there, most of which reflect the original needs assessment.

Medical care and treatment is provided by para medics, with referrals to hospitals/drug treatment centres given as needed. Counselling and psychological support are also available.

As well as care and treatment, the drop-in centre has a strong education and prevention role to play. Information on harm reduction and on HIV and other STDs are available to anyone who want it. The centre also provides condoms and lubricant. Finally, the drop-in centre offers its clients a variety of services not specifically related to HIV or STDs, but which respond to their stated needs and priorities:

- bathroom/toilet facilities are provided so that clients can maintain basic hygiene (bathe, wash clothes, etc.);
- food is served;
- referrals to job placements are done.

### Outreach services

Drug programme workers do not only work in the drop-in centre, waiting for clients to come in to them. It has always been clear that the project must seek out and support clients in their everyday living and working environment. In addition to encouraging the involvement of clients in the project’s work, outreach is the most effective way to maintain first-hand understanding of people’s needs and problems.

Outreach workers, both staff and volunteers, meet clients at home, in bars or on the streets—wherever the clients are most comfortable. The outreach workers also make visits to hospitals and to drug rehabilitation centres. Among the services provided by these workers are:

- transporting clients to hospitals;
- assisting with getting identification papers, birth certificates.

### **Building trust**

This story was told by a drug programme volunteer:

*It is very hard to build trust sometimes, but if it is done well it is something that is very strong. The programme didn't build trust among IDUs in one day—it took a long time. In fact, you have to keep building it, you can never just assume trust because you've been helpful in some way. But we see evidence of it under very tough circumstances sometimes, and that's how we know we're on the right track.*

*We had one fellow I remember well, a guy who was a single parent. Now, Raju was both HIV-positive and addicted to heroin, so he had lots of problems. But as a parent his greatest need was to keep his job and shelter in order to care for his child. So that's what we helped him with: work and housing. For instance, we got him a job as a labourer through personal contacts of an Ikhlas volunteer, and also raised money for the deposit for his rented room.*

*There came a time when Raju had to go to jail, and knew he had to make arrangement for his kid. He had nowhere else to go, so he came to the staff and asked us to help to take care of his child while he was incarcerated. That was the kind of trust he had in us, or rather, the trust we had earned with him.*

*We found a place for the child, and it worked out fine. With Raju's approval, we are arranging for the child to be adopted.*

### **Motivation and active participation of the IDU community**

Motivation and participation of the clients was always a key element in the IKHLAS strategy, and has evolved as the project has gained acceptance in Chow Kit.

The process began with the members of the IDU community who were involved in the initial needs assessment and early

consultations. They not only contributed their knowledge but also became more aware of their vulnerability to HIV/AIDS. This provided some with the motivation to get involved more actively, and the programme was ready with ways for them to do so.

As time went on, IDUs who became known to the project were recruited as community health outreach workers. This recruitment included training in HIV education, harm reduction approaches and facilitation skills. The training was provided by HIV educators/trainers and health care professionals from local hospitals.

There are many ways for clients to participate on a more basic level, and to take “ownership” of the project. For instance, clients are encouraged to take responsibility for the nutrition programme and maintaining the cleanliness of the drop-in centre. Under supervision from the staff, they handle the shopping for food, do the cooking, and clean the bathroom/toilet facilities. This not only helps the project itself by making it more cost-effective, but is part of the process of “re-socialization” and self-esteem-building among the clients.

An unexpected benefit from the interaction of clients with volunteers from hospitals, nursing schools, the corporate sector, and colleges in the programme is that it has stimulated some IDU clients to participate more actively in the programme. Apparently, the feeling of being accepted by people from the “general community” is important to these clients for their re-socialization and self-esteem-building.

## Partnerships and alliances

Pink Triangle has always known that efforts to “go it alone” are not only difficult but usually ineffective. It has therefore made strong efforts to find allies and make common cause with a variety of groups and organizations outside the IDU population.

### Other affected groups

The programme is aware of the benefits its experience can offer to other groups, and the benefits that can be gained from the experience of others. Therefore, it has always made an effort

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### **The power of self-esteem: Ruby educates “the professionals”**

This story was told by a volunteer and illustrates the type of enabling, supportive environment that the project has worked to create:

*Ruby passed away only a few months ago and we miss her greatly. In her 30s, she was a small, frail-looking but gutsy and lucid-thinking woman and an extremely warm personality.*

*Ruby was HIV-positive, an injecting drug-user and an early client of the drug programme. Despite her difficult circumstances, she always insisted that she had received so much from the project and she felt very strongly that she had to give something back. And she really did, in her own special way.*

*I remember when she was very ill with TB, and went into hospital. Well, she educated the hospital staff! A doctor told me afterwards that she raised hell during that one week she was there because staff were not giving services in an appropriate manner. Not treating people respectfully and gently. I asked her about it later on, and she said, “I acted like that because I wanted people who come after me into that hospital to get better services.” That was her way of giving something back.*

*Another time, we had a workshop on law and ethics and HIV, and Ruby was there. It was pretty soon after she got out of the hospital, having been cured of her TB. There were a couple of doctors from private practice attending the workshop, and one of them told the other not to sit beside Ruby because she might still be infectious. This lady should have known better, being a doctor. Anyway, Ruby let her have it.*

*“I can’t believe that this is happening in a workshop where we’re talking about ethics and HIV!” she said. “I’m cured, I’m recovered, SO I CAN’T SPREAD THE TB!” And then she added, “I see I’m going to have to educate you professionals so you don’t treat other people badly.” And she did.*

*A great person. I think about her a lot.*

.....

to be open to volunteers from other affected marginalized communities who have a shared concern and similar vulnerability such as the transsexual, sex worker, and gay communities. Members of these are recruited and trained to do outreach work, and to provide support in the drug user programme.

To date, six persons have been recruited in this way. One of them is a gay student who decided to give up his tertiary studies

to work on the programme. Staff greatly appreciate his language and street skills, which have proven very useful for outreach work.

### **Other social and medical organizations**

The programme cooperates closely with all other organizations that can be of help to its clients. For instance, clients are frequently referred to drug treatment and rehabilitation centres, to other NGOs working with IDUS, to churches and to shelters. Such referrals go both ways, as many new clients come to the programme via referrals from these organizations. In addition, about 40 clients come to the Ikhlas drop-in centre daily.

Local hospitals regularly refer their IDU patients once they are able to leave institutional care. Finally, many other NGOs working in the field of HIV/AIDS refer their clients and their affected families to the programme when it is clear that they could benefit from our services.

### **Donors**

The drug user programme could not do the job it does without donations—in-kind and cash from a variety of sources. Major donors include the European Commission (EC) and the Dutch agency HIVOS. Locally, great help has been received from:

- the Malaysian AIDS Council (MAC);
- theatre companies that have dedicated specific performances to the community centre. These have contributed not only funds but have given valuable publicity to their work. (A great deal of publicity was also generated a few years ago by the participation of Miss Malaysia in one of their events.);
- pharmaceutical and health-care companies that have contributed medicines and nursing materials (e.g. treatment drugs, gauze, bandages); and
- hotels and food manufacturing companies that have donated food to the nutrition service.

### **Governmental agencies**

As well as gaining access to government services for clients and making its work better known, the programme cultivates relationships with a variety of government agencies for reasons of advocacy. In particular, its aim is to create awareness and understanding of the needs and concerns of IDUs and to stimulate change at the policy- and decision-making level. This includes work



with the National Anti-Narcotics Task Force, drug rehabilitation programmes, the police and prison authorities. In particular, staff have facilitated HIV education and counselling training sessions with personnel in prisons and drug rehabilitation centres.

The project also maintains a close relationship with the Ministry of Health and hospital staff, from whom we receive the assistance of doctors to provide testing and counselling services at our drop-in centre.

## Monitoring and evaluation

The mechanisms employed for monitoring and evaluating the work are fourfold:

- seeking programme beneficiaries' feedback (stories);
- regular meetings for peer review and evaluation among clients, volunteers, and staff;
- monitoring referrals to and from other agencies; and
- obtaining feedback from affected families.

### Strengths of programme

These various evaluation methods indicate that the main strengths of the programme are as follows:

- *Client-centred*: In the project's six years of operation, it has been able to keep the focus on what the clients want and need. There are probably many reasons for this, but an especially important one is that the project is structured so that the ongoing involvement and feedback of clients obliges staff and volunteers to keep this focus. Structurally, the programme is: community-based; located within the area where its clients live, work and congregate; and largely run by IDUs/persons with HIV/AIDS for IDUs/persons with HIV/AIDS.
- *Ability to show real care and concern for clients*: This is related to the previous point, but probably has more to do with recruiting. In particular, the concentration on immediate needs and the outreach component that meets clients in their own preferred places (homes, shooting galleries, street) provide clients with concrete evidence of concern.
- *Peer support system*: nobody can relate to an IDU living with HIV/AIDS in the same way as someone who shares the same challenges and the same lifestyle. Providing a space and a structure in which people talk, share experiences and problems,

and receive both good information and positive advice, is key to effective work at the individual level.

- *External relations:* Development of a good working relationship with governmental agencies and NGOs has paid off in a variety of ways (described earlier).
- *Fund-raising:* the programme has been able to generate good support from Malaysia's corporate sector, both in cash and in kind.

### Weaknesses of programme

Weaknesses identified by monitoring and evaluation mechanisms include the following:

- *Stress experienced by staff and volunteers:* The work can be very intense emotionally. A high-risk, high-vulnerability population like IDUs presents special challenges. For instance, the fact that clients and colleagues get sick and sometime die is very hard. The personal and legal problems faced by clients inevitably affect the work of the project, and can get very complicated. The project's main way of dealing with such stress is to hold regular sessions among staff and volunteers for discussion of problems, "ventilating" and counselling.
- *Volunteer recruitment:* As in any difficult activity that is heavily dependent on volunteers, the programme has trouble getting interested and committed volunteers on an ongoing basis. One of its most effective techniques for recruiting has been to recruit drug users and ex-drug users from the community.
- *Lack of management training:* Better skills in management, administration, and so on are particularly necessary.
- *Challenges to programme focus:* Although the programme has been able to remain client-focused, it often faces internal debate on how much effort and resources should be devoted to the collective needs of IDUs versus the individual needs of clients.
- *Treatment resources:* Despite fund-raising success and good relations with outside agencies, the project frequently experiences difficulty in getting access to adequate treatment facilities and drugs for our clients. Pharmaceutical companies are regularly approached for treatment drugs and nursing materials, sometimes through the programme's hospital contacts.
- *Police raids:* Despite its efforts to maintain good relations with the police, the drop-in centre services are sometimes affected by police raids in the area. The project tries to deal with this

problem through dialogue with the police at the decision-making level (i.e., not by trying to confront the police officers carrying out the raid but by speaking with their superiors).

## Threats and opportunities

The programme, like the population it serves, often finds itself in a position of vulnerability. It is most vulnerable to the withdrawal of government support. While it has achieved a strong profile in its field and can count on help from many professionals and influential people, the overall tolerance and support by government for its work is volatile. A change in the head of a government agency, or the government's need to respond to political or religious pressure can result in support being reduced or even withdrawn. While the project continues to build its profile and cultivate all the relationships it can with other agencies, this vulnerability is simply part of its environment and will continue to be so.

At the same time, the time and effort spent building the programme's profile means that it currently has a highly visible platform from which to speak out. The project is well known to the media, who often give it sympathetic coverage. The project can speak both formally and informally with major players in the Government such as the Ministry of Health, Ministry of Home Affairs, and the Malaysian AIDS Council.

So long as it maintains this profile and these good relations, and so long as it continues to involve and work on behalf of the real needs of IDUs and persons with HIV/AIDS, Ikhlas community centre drug user programme will continue to make its contribution to Malaysian society.

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### *For more information:*

Executive Director, Pink Triangle  
 c/o P.O. Box 11859 – 50760 Kuala Lumpur, Malaysia  
 Tel. 60 3 441 4699 / Fax: 60 3 441 5699  
 E-mail: [isham@pc.jaring.my](mailto:isham@pc.jaring.my)

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## **Other HIV/AIDS agencies and NGOs in Malaysia**

The Malaysian AIDS Council (MAC), an NGO umbrella association, was set up in 1991 with WHO funding. It groups 22 members, although only a few are AIDS-specific. The Council is supported in part with funds from the Ministry of Health (\$400 000 in 1994). Council members generally concentrate on the most vulnerable groups in Malaysian society: women and youth, migrants, IDUs, gay men, and commercial sex workers.

Besides the MAC, the National Council of Women Organization promotes AIDS activities among its affiliate members.

Other NGOs active in HIV work include:

- Tenaganita, a women's group working primarily with migrant workers, in industry, and with sex workers in selected areas of Kuala Lumpur;
- PENGASIH which runs a halfway house for IDUs in Kuala Lumpur;
- Positive Living, another Pink Triangle Malaysia project for people with HIV/AIDS;
- The Malaysian Red Crescent Society, which runs a youth peer education project relating to HIV and reproductive health;
- The Federation of Family Planning Associations of Malaysia;
- Community AIDS Service Penang;
- National Council of Churches.

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## **Best Practice Criteria**

The IKHLAS Project strongly illustrates the community mobilization value of participation by persons living with HIV/AIDS, and the resulting benefits in effectiveness and efficiency which are possible from being guided by such an ethical approach. In fact, the participation of infected persons from the IDU community is probably essential in order to reach this group, which is highly marginalized both socially and legally. The project illustrates UNAIDS best practice criteria in the following ways:

■ **Relevance:** Since injecting drug use is the major form of transmission of HIV in Malaysia, the project's focus on IDUs is extremely relevant to the national response to the epidemic. In terms of the proportion of activities, it can be seen that two of the three project goals and a majority of activities are not devoted strictly to HIV/AIDS but to the more general needs of the target population. However, this in large part is a function of the marginalization of the IDUs, who do not seek or receive the same level of medical and social services as the rest of Malaysian society. It is likely that any other strategy than one that offers a variety of services (not just HIV-related ones) to this particular group would fail to engage their trust and participation and therefore not be effective at all.

■ **Effectiveness:** There are no quantitative measures for the impact the project has had on IDUs in Chow Kit. However, the available evidence suggests that IKHLAS has been highly effective in gaining the trust of its target community (which is likely a function of its effectiveness in providing services this community wants or needs) and in attracting resources (food, medicines, services, funds) from the wider community. The project has also been effective in its advocacy activities through the favourable media profile it has been able to generate and the institutional links it has created with government and NGOs.

■ **Efficiency:** The combination of a drop-in centre and outreach via staff and volunteers appears an efficient application of resources, particularly given the hard-to-reach characteristics of the target population. The cost-efficiency of the drop-in centre is maximized by use of client labour (under staff supervision) in cleaning, cooking and shopping and by securing the services of medical staff on an unpaid basis.

■ **Ethical soundness:** IKHLAS's voluntary and participatory approach to HIV/AIDS is in line with current ethical standards in the field. The project's efforts to create a higher and more sympathetic profile for its clientele among the greater community, and to give them a channel for self-advocacy, supports basic human rights objectives.

■ **Sustainability:** while recognizing the precarious nature of much its support, IKHLAS has made impressive strides in securing a variety of resources from a wide range of donors, institutions, and individuals. This diversity of support has not only permitted the project to survive for over six years but is probably the project's best guarantee of sustainability in the future.



Tateni provides a sincere welcome to all who need its services.

## Background

### Facts about South Africa

Total population (1995):  
41 465 000

Urban population:  
52.40%

Annual population  
growth rate:  
2.20%

Infant mortality rate  
(per 1 000 live births):  
48

Life expectancy (years):  
Male: 62  
Female: 68

Illiteracy rate:  
Male: 23%  
Female: 25%

Per capita GNP (US\$):  
2 670.00

Surface area (km<sup>2</sup>):  
1 221 037

Borders:  
At the southern extreme  
of Africa bordering  
Namibia, Botswana and  
Zimbabwe on the north;  
Mozambique, Swaziland  
on the east;  
surrounds Lesotho

Administrative divisions:  
9 provinces

Government:  
Federal republic with a  
president as head of  
state and government

# Tateni Home Care Services South Africa

## HIV/AIDS in South Africa

*The AIDS epidemic is well established in South Africa and continues to grow at varying rates in all nine provinces.*

*In a November 1996 antenatal survey, 14.07% of women attending public health service clinics were found to be infected with HIV. Over 10% of all adults are estimated to be infected. If the estimates are accurate, this would indicate just over 2.2 million by the end of 1996. The majority of infections are the result of heterosexual transmission.*

*Analysis of reported AIDS cases is currently of limited value due to pervasive under-reporting. However, the current number of AIDS cases is estimated to be 43 000 of whom 10 000 are children born to infected mothers.*

*Levels of infection in Guateng Province, where Tateni Home Care Services is located, were 6% in 1994, 12% in 1995 and 20% in 1996.*

# Tateni Home Care Services

## South Africa

Mamelodi is a former black “township” of about 1.5 million people that lies west of South Africa’s administrative capital, Pretoria. The community contains an estimated 250 000 dwellings (this term includes everything from proper houses to large boxes that people live in), with an average of six people per dwelling. A large proportion of the population is impoverished, and the incidence of HIV/AIDS is high.

Tateni Home Care Services began with a group of retired nurses living in Mamelodi, directed by Veronica Khoza, who identified a need for home-based care in 1995. The group visited some 2 000 dwellings during the first year and identified about 1 000 chronically ill persons, of whom 427 would benefit from home-based care. A consultant to the provincial department of health’s Directorate for AIDS and Communicable Diseases, Janet Frohlich, acted as an adviser to the group in developing home-based care policy and training materials. During that same year, the group began providing home-based care services.

In 1996 Tateni Home Care Services was asked by the department of health to join a team of key role players at the Provincial, Regional, and district/community levels. The team has developed an integrated model of home-based care for the province modelled partly on Tateni’s work. Pilot projects based on the model are now being set up in other locations in partnership with the provincial government.

### Goals and principles

Tateni Home Care Services is a non-discriminatory, non-judgemental organization that aims to ensure that home-based care is provided in Mamelodi. The organization embraces the values of empathy, acceptance, hope, and the removal of discrimination against those infected or affected by HIV/AIDS. Its goals:

- to provide counselling and support services to infected and affected persons;



- to implement home-based care that is affordable, accessible, equitable and efficient;
- to enhance the collective capacity of the community to provide care and support;
- to enable and empower ancillary health careers to care for and cope with the chronically ill persons in their community; and
- to teach, advise, and provide guidance to the seropositive person and family members (or other significant persons in the patient's life) about relevant aspects of health care, infection, and health promotion.

The organization also bases its work on three important principles. The first is the principle of decentralization, under which home-based care and support are decentralized from the provincial government to district and community level. Decentralization takes place through collaboration with other local health and social programmes. The second is the principle of partnership in order to include all stakeholders in policy development, strategic planning, and implementation of home-based care. Finally, the organization recognizes the principle of multisectoriality, which harnesses the knowledge and resources of a broad range of society in the response to HIV/AIDS.

## Collaboration, not competition

In keeping with its basic principles, Tateni's activities complement existing health care services rather than duplicating or competing with them. The multisectoral approach means that, rather than working within the systems set up by the Health Ministry (with its limited and often overburdened human resources of formal care givers and support personnel), Tateni adds new resources:

- the family and kinship network as primary care givers; and
- community resources as support services.

Tateni's approach recognizes that copying models of home-based care from industrialized countries, with their high levels of funding and extensive formal health systems, would lead to failure. First, doing so would set unattainable goals in an area with a large population and limited resources. Second, it would be inappropriate to the social and cultural context of the people of Mamelodi, whose African traditions emphasize complex family

and community relationships of support, obligation, and consensus rather than formal, state-directed services.

However, collaboration with the formal health system is an important part of the approach. When necessary, patients are referred to hospitals and other 24-hour institutions such as clinics for services like short-term admissions to control difficult symptoms, respite for primary care givers (that is, when the family needs a short break from looking after their seropositive member), or admission for more extensive treatment.

## Major elements of the project

Tateni's home-based activities aim mainly at providing and enabling palliative care. However, HIV/AIDS prevention, education, and surveillance are also important parts of the work.

### Referrals

People with HIV and their families come to Tateni in a number of ways. Many arrive in search of services having heard about Tateni through word of mouth. Formal referrals are received from local clinics, general practitioners and the Pretoria Academic Hospital. Finally, Tateni receives clients through contacts with other local NGOs and CBOs, notably those in the Mamelodi coalition of organizations working with Tateni (these include Women Against Abuse, Children's Day Care Centre, and several youth groups).

### Training

Tateni's training activities are carried on at two levels. The first is training of community care workers. These are local people who typically live nearby the clients they will be assigned to work with once training is finished. The training is given by a professional nurse with help from a social worker. Currently, the training is very basic and takes six months, but this is planned to be upgraded to twelve months in order to meet the standards of the National Policy for Health Workers.

The second level of training is carried out by the community care workers, with coordination and supervision by the professional staff. This training is directed towards:

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## We started with a box...

A Tateni nurse:

*When Tateni began, we weren't really anything formal. Not even a registered NGO, just a group of retired nurses and volunteers brought together by Mama Khoza. She's a retired nurse herself, and a very important figure locally.*

*You should have seen our original "centre". It was a big box, a container I think you call it, that we got permission to use. There are pictures of us giving classes outside of it, with an awning to keep the sun off the women who came to listen. Today it doubles as a crèche, where women can leave their babies.*

*When we were starting up we visited a lot of HIV-positive people and their families, and collected a great deal of information about what they wanted and needed. Almost unanimously, chronically ill people said they wanted to be treated at home whenever possible. Many of these people or their family members got involved in the planning and services at that time, and that continues today. We also got women's groups, local churches, and youth organizations to help out.*

*After a while we had a lot of activities going, with many individuals and community groups involved. So we went to the provincial government and said, look, we have something to offer here. Because of our contacts—remember, the original project members are retired nurses—we already had a certain level of access to the clinics and hospital beds. And that was essential, because it's AIDS and at some point you need those intensive professional services. But we were out there in the community, with first-hand knowledge and a "reach" the formal system couldn't offer. Among other benefits, our work reduced the length of in-patient stays in hospital and clinic beds, and gave the formal system a place to refer patients to once they were discharged.*

*So it was a logical match, Tateni doing what it does well and the Department of Health doing what it does well, and everyone working hard to communicate. That way we avoid duplication and get the most efficient use of resources. It's not perfect, and we always need more funds and more volunteers, but it works. It really does. And that's why Tateni is being used as a model in five pilot projects in other parts of the province.*

- .....
- teaching persons living with HIV and their families how to provide effective home care. This includes discussing various aspects of HIV/AIDS itself, a holistic approach to wellness, and accessing the formal system as needed;
  - teaching volunteers to provide services such as counselling and health promotion.

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## Laughing while learning

A Tateni nurse: *We did a lot with very little in the early days, and actually we still do. For instance, we needed some kind of demonstration aid to help in training families to look after someone when he or she gets ill—how to put on a bandage, or how to wash someone, all those basic things. It couldn't be heavy because no one has their own car and so they often have to go by public transport and walk a fair distance. It couldn't just be a diagram on paper because that just doesn't work among people who aren't comfortable with Western-style communication. And it couldn't be expensive. In fact, it couldn't cost money at all.*



*So we created a training doll, full-size, made of foam rubber. It looks funny, but people like it and learn from it. There's no reason you can't have a laugh while learning...*

.....

"It looks funny, but..."  
Tateni staff teach home care using  
a life-sized doll made with foam rubber  
and cast-off clothes.

## Partnerships and alliances

### Government health-care system

The model of home-based health care developed for Guateng Province is based on devolution of decision-making responsibilities from the provincial level to the regional/district level. This creates a "care interface" between organizations at community level with health department officials who actually have decision-making power, with the result that policy development, planning, and monitoring activities are shared rather than handed down from one level to another. These planning and monitoring activities can thus be imbued with the core values of community mobilization since the lines of communication are not exclusively top-down. The arrangement also ensures that home-based care is delivered according to the health system's accepted standards of conduct and practice.

### Local health-care providers

As mentioned earlier, Tateni Home Care Services maintains an ongoing contact with local clinics, hospitals, and general practitioners. Referrals are made by all of these stakeholders both

to and from Tateni. Clinic and hospital beds are used by Tateni clients both for purposes of treatment of patients and to provide respite to family care providers.

### Donors

Financial support for Tateni Home-based Care Services comes entirely from local donors and the provincial government. There are currently no national or international sources of funding. The medicines and nursing materials dispensed by Tateni are only possible because of donors. In some cases, medicines may be supplied by a local clinic if the patient or a family member is able to go to the clinic and collect it.

### Other organizations and NGOs

Tateni maintains relations with a variety of other community-based organizations and NGOs, including church groups, youth organizations, and women's groups. As mentioned earlier, a number of these organizations are loosely grouped in the Mamelodi coalition.

## Monitoring and evaluation

At the end of its first year of operation in 1996, Tateni Home Care Services carried out a qualitative assessment of its work. The retired nurses in the group distributed a questionnaire to 500 participants, of whom 369 responded. In addition to showing overwhelming appreciation of the services provided, the results indicated that most respondents preferred Tateni's home care and training to continue to take a general approach to health care activities rather than focus exclusively on HIV/AIDS.

## Strengths and weaknesses of the programme

Internally, staff feel that the primary strengths of Tateni are twofold: its success at encouraging community participation and its achievement of widespread feelings of community ownership. They believe these are the reasons that Tateni has been able to reach and provide services

to so many people in a relatively short time. These two strengths have given it enough credibility that the government services were willing to enter into a partnership with it.

The other significant strength is the project's successful integration of government and community activities, as modelled in the diagram on the following page.

The organization notes two significant weaknesses:

- resource mobilization is difficult, and the service is dependent on donors. Further partnerships and fund-raising will be necessary if further progress is to be made; and
- although commitment from volunteers is high (some of which may be attributable to the newness of the organization); hours that can be volunteered are extremely limited. This is likely a problem in any impoverished community. The organization would like to add incentives such as travel costs, meals, and “uniform” to its budget as line items, but is unable to do so yet.

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***For more information:***

**Veronica Khoza, Tateni Home Care Services  
P.O. Box 77980 – Mamelodi 0101, South Africa  
or Janet Frohlich, CERSA. Medical Research Council  
Private Bag X385 – Pretoria 0001, South Africa  
Fax: 27 35 550 1674  
E-mail: [jfrohlic@mrc.ac.za](mailto:jfrohlic@mrc.ac.za)**

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## **The role of NGOs/CBOs in the National AIDS Programme**

The work of Tateni Home-based Care Services takes place in a context of important changes to South Africa's health system. At the time of writing, a document called the White Paper for the Transformation of the Health System has been brought before the national legislature.\*

The document states that, "nongovernmental organizations should continue to play an important role in the delivery and management of services". It also proposes that community involvement be guided by the following principles:

- "All South Africans should be equipped with information conducive to caring for themselves or those in their community.
- People should be afforded the opportunity to participate actively in various aspects of the planning and provision of care counselling and support and preventive strategies.
- Civil society and the government sector will be involved mutually in containing the spread of HIV/AIDS.
- People living with HIV or AIDS will be involved in all prevention, control, and care strategies.
- The emphasis will be on adequate capacity-building at all levels, including NGOs to accelerate HIV/AIDS prevention and control measures".

The White Paper goes on to say that, in order to "improve the effectiveness and ensure the implementation of the National AIDS Programme, government will develop partnerships with key NGO/CBO stakeholders and benefit from the collective experience of civil society". It also proposes the creation of a committee to coordinate support for NGO/CBO activities in HIV/AIDS prevention and control. Among other tasks, the committee will develop an NGO funding policy for the National AIDS Programme, process NGO applications for government funding, and review progress by NGO/CBO organizations.

*\* In British parliamentary tradition, a White Paper is a detailed discussion document presented to the legislature by the government, usually proposing significant changes to some aspect of government activity.*

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## Best Practice Criteria

■ **Tateni Home Care Services** exemplifies the community mobilization value of synergy, as achieved through shared planning and day-to-day collaboration between community-based organizations, local institutions, and government. This synergy has made possible significant benefits in both effectiveness (the impact on the target population) and efficiency (the use of available resources in the most effective way).

■ **Relevance:** All of Tateni's stated goals are relevant to an enhanced response to HIV/AIDS. However, its goal of enhancing the collective capacity of the community to provide care and support is especially appropriate in an area where high HIV prevalences mean a large impact on the community as a whole. The creation of a CBO, even when the community has few financial or physical resources to contribute, is also extremely appropriate given the provincial and federal governments' adoption of decentralization. Finally, the relevance of the project to real needs in the community appears to have been ensured by the fact that the project began with a survey (in effect, a needs assessment) based on home visits to over 2000 dwellings.

■ **Effectiveness:** Tateni has only been providing services for two years, and formal measures of its effectiveness in terms of impacts are not yet available. Anecdotal evidence indicates that the project's activities have reduced the lengths of some patients' hospital stays, which is an important benefit both to individuals and to the health care system.

■ **Efficiency:** The project has adopted an efficient strategy of collaborating with clinics, general practitioners, and the local hospital ensures. This allows the project to avoid tasks already carried out by other organizations or institutions (particularly those better equipped for those tasks). A second efficient strategy is its two-level training activities. This permits formal, resource-intensive training of community care workers (selected from within the community) to be carried out at the same time as less formal but much more widespread training of infected and affected persons. The project has also made a virtue of its lack of financial resources by being creative in acquiring or adapting premises (a vacant container used as a crèche for parents receiving training) and equipment (a home-made training doll for demonstration of palliative care).



■ **Ethical soundness:** Tateni's ethical standards are safeguarded by its multiple interfaces with government, medical practitioners, and other community organizations (many of which are themselves involved in human rights activities such as reducing violence against women). This ensures that community values and wishes are not overwhelmed by the priorities of other levels of government or by the medical profession.

■ **Sustainability:** Tateni's sustainability appears to be supported by the fact that the project is highly relevant to needs as defined by the community. Linkages with the formal health care system are another important element in its sustainability over time, particularly given the federal government's apparent support for the encouragement of community-based organizations in South African health care. However, the project acknowledges that it is highly dependent on outside donors for material resources, and that the poverty of the local community makes recruitment of volunteer labour extremely difficult.



A Tateni nurse provides palliative care at the home of an older patient.



Meeting place of the Sanpatong Home-based Care Project.

# Sanpatong, Home-based Care Project Thailand

## Background

### Facts about Thailand

Total population (1995):  
58 791 000

Urban population:  
25.10%

Annual population  
growth rate:  
1.00%

Infant mortality rate  
(per 1 000 live births):  
34.00

Life expectancy (years):  
Male: 65  
Female: 72

Illiteracy rate:  
Male: 5%  
Female: 9%

Per capita GNP (US\$):  
1 840.00

Surface area (km<sup>2</sup>):  
513 115

Administrative divisions:  
72 provinces

### HIV/AIDS in Thailand

*By the end of the century, mortality due to AIDS could become the leading cause of death in Thailand, according to the Thai Ministry of Public Health. Two-thirds of the approximately 800 000 persons currently living with HIV/AIDS reside in the northern part of the country.*

*Rates of infection have historically been high among women who are or have been sex workers, but recently the greatest rates of increase have been among women in stable relationships who have never been sex workers. HIV prevalence in the north among women attending antenatal clinics is between 4% and 8%.*

*Based on current prevalence rates among pregnant mothers, by the year 2000 there will be approximately 120 000 AIDS orphans, and more than 60 000 cases of infants with AIDS. Increasing AIDS-related mortality among infants and young children may reverse many of the gains made by effective national child health programmes, such as the Control of Diarrhoeal Diseases and Expanded Programme on Immunization.*

# Sanpatong

## Home-based Care Project, Thailand

The Sanpatong Home-based Care Project works in the Sanpatong area some 25 kilometres south of Chiang Mai City. A joint project of the Thai Red Cross Society health centre in Sanpatong and the district hospital, it currently works with about 600 people living with HIV/AIDS.

The project aims to make it possible for families to support and care for persons living with HIV/AIDS at home. (Note that the concept of home care is different in Southeast Asia than in Western countries, where it generally refers to home visits by doctors and nurses for purposes of treatment or monitoring. In contrast, people served by this project are taken into a hospital or clinic by their families when they need medical attention.) Services include training for family members, health care visits and referrals, provision of some basic necessities, meditation and spiritual instruction in the Buddhist tradition, and support activities, including a weekly club with visiting speakers and doctors.

### Goals and principles

It is traditional in the Buddhist culture of Thailand for several generations of a family to live together, and to look after one another when one member is sick. The goal of the project is to reinforce this traditional value through home care training and other supports that will:

- permit primary health care for people living with HIV/AIDS to be provided at home;
- change negative attitudes of family members, friends and the community to HIV/AIDS; and
- promote self-care and self-reliance of families and individuals infected or affected by HIV/AIDS.

As a secondary goal, it is hoped that this strategy of care will reduce costs both to individual families and to government health services.

## A holistic approach to home and community care

The Sanpatong area is one of the hardest-hit by the AIDS epidemic in Thailand. Since the late 1980s, the hospital system has been increasingly hard-pressed to provide care for all of those who needed it, with as many as 60% of beds being occupied by persons with HIV/AIDS in recent years. The majority of these cases are of people in their most economically productive years.

Families in which a member has HIV/AIDS face a variety of devastating challenges, including:

- social stigma and discrimination;
- conflict between the desire to have children and the fear of infection;
- enormous emotional loss when family members die; and
- economic hardship.

In 1992, a group made up of staff nurses from Sanpatong's Red Cross health centre, volunteers from the faculty of medicine at Chiang Mai University, and Chiang Mai public health staff perceived an opportunity to create a new kind of care project. Coordinating the group was Somboon Suprasert, a family health nurse practitioner and AIDS researcher and lecturer in the Department of Family Medicine, Faculty of Medicine, who had just retired as head of the department's research unit. Mrs. Suprasert (better known as "Auntie Boon" to her patients and students) was continuing to work as a consultant with both the university and the Red Cross, and had extensive community contacts, and so was well placed to bring the group together.

Pooling its wide variety of practical and academic experience, the group was able to agree on several fundamental ideas, the first of which was the importance of a holistic approach to care.

As they saw it, a holistic approach should be one that provided "bio-psycho-social support":

- *bio*: treatment of symptoms;
- *psycho*: helping to deal with stress and worry, solve problems, improve attitude; and
- *social*: improving ability to cope with, participate in, and be accepted by the community and greater society.

Their main idea was to help people living with HIV/AIDS be treated at home, a strategy that would reinforce all three parts

of the holistic approach. Such a project, they knew, would require education and skills training for many people: family members, volunteers from the community, and even village leaders. It would also require funding and resources in order to get started and to sustain itself.

At the same time, the group, an NGO supported by a number of agencies recognized the importance of providing support for people who are HIV-positive but have not developed full-blown AIDS. In addition to meeting these people's needs for emotional support, the group's strategy included providing training on practical matters of self-care and self-reliance before the people get sick. Again, it was intended that this preparation would eventually reinforce all three parts of the holistic approach.

## Major elements of the project

In the years since the project began, the group has pursued its holistic approach to care by creating a continuum of activities. These begin by dealing with the needs of individuals (health care, psychological reinforcement, etc.) and extend to community mobilization and creating money-making opportunities for people living with HIV.

An essential ongoing activity is recruitment and training of volunteer medical personnel. The latter was facilitated by the creation of a manual for these personnel.

Recruitment of people living with HIV generally occurs either through word of mouth among community members or by doctors' referral. In addition, the testing programme at the Sanpatong Hospital refers all persons found HIV-positive to the project, usually to the HIV club that gets together once a month.

Currently, there are approximately 600 persons living with HIV served by the project, about 60% female and 40% male. The age range is from 25 to 45. About 60% of people living with HIV are asymptomatic, with 20% presenting some symptoms and 20% having full-blown AIDS.

### Thursday Club

Modelled on the well-known Wednesday Friends Club in Bangkok, the Thursday Club is a monthly lunch gathering and support group for men and women with HIV/AIDS. It regularly

attracts 40–50 people to its lunches, which includes meditation, exercise and talks from a wide variety of guests. Visiting speakers and presentations have included actors from a visiting international musical show, a Tao Yoga master from Korea, the White Line dance group (an AIDS education performance troupe) and vegetarian cooking classes from a Buddhist meditation centre. A particular highlight, and evidence of support from the highest levels of Thai society, was a visit by one of the King’s cooks to prepare a meal for the club.

Medical attention is available at each meeting, and food and herbal medicines (including honey tablets) are also offered. The lunches are also used as occasion for the home care team to monitor the health of club members. Finally, the club is the first stage in the project’s strategy of educating people living with HIV/AIDS about self- and home-care before serious illness has reduced their mobility and normal functioning.

### **Training of people living with HIV and family members**

The project conducts regular one- and two-day training sessions about home care each month, mostly in Chiang Mai City. Thirty group sessions, each comprising 30 participants, have been held each year since 1994 and have thus reached about 900 persons since their inception. The sessions are open to all members of the public, and follow a format that has been worked out over time:

- “icebreaker” exercise to reduce participants’ initial nervousness;
- individual introductions so that people get to know each other; and
- group meditation.

The sessions then break into small training groups based on two methodologies: problem-based learning and focus group technique. These smaller groups also follow a set format:

- HIV/AIDS education: all members are encouraged to tell their story and express their feelings, fears, and questions about HIV/AIDS. This leads to discussion and provision of information about the disease, its symptoms and what can be done about it. A particular focus is on practical ways to live with HIV/AIDS in one’s life, including the importance of regular exercise, proper nutrition, condom use, etc.



Group training is an important part of Sanpatong's efforts.

- practicalities of home care: subjects discussed and demonstrated include universal precautions, dressing wounds, taking medication correctly, changing bed sheets, use of bed pans, bed baths and sponging, and utensils needed.
- developing confidence: the final part of the session aims to help participants gain confidence in themselves and their capabilities. In particular, they are shown how to feel strong and capable of self-care.

In all cases, home visits are made by both volunteers and nursing staff in order that people living with HIV and caretakers can be supervised and monitored.

### **Extension of club and training of health-care volunteers**

Once members have received the home care training and have had time to get experience doing it at home, they are encouraged to set up an HIV club in their own village. There are currently six such clubs in outlying villages. Not only people living with HIV but a variety of other people have aided in organizing these clubs, including village headmen, health system personnel, health volunteers and Buddhist monks.



Health care volunteers are also recruited to receive orientation and the home-care training. Once these activities are completed, the volunteers receive medicine boxes to use in their home-care visits. The medicines are for primary care of conditions such as diarrhoea, fever, cough, skin diseases, headaches, and stomach aches.

### Support groups

The project helps bring together small support groups of about 30 persons living near each other in sub-districts. These support groups help people living with HIV to share their experiences and concerns with each other. In order to create a family feeling, sightseeing trips and overnight camping at resorts are organized for these groups.

### Meditation and spiritual care

Spirituality has always been important in Thai life, and so spiritual care is a well-accepted and necessary part of the project's work. In particular, meditation is taught by local Buddhist monks as a means of helping hard-hit people find tranquillity and the mental strength to continue. As well as teaching meditation techniques, the monks provide people with spiritual guidance on how to protect themselves from suffering and how to put life and death into perspective.

The project arranges for groups of persons living with HIV to spend week-long retreats at the Wat Sangu temple in Ampur Hot. There they receive training in meditation, and benefit from a healthy diet and exercise.

As well, the Brahma Kumaris World Spiritual University runs free workshops for people living with HIV on such topics as positive thinking, self-esteem and meditation. It also does workshops on vegetarian cooking.

### Material support to families

This activity was initiated as a way of providing practical support to families looking after people living with HIV. School funding (i.e. children's fees to attend school) blankets, clothing, food and milk are provided to these families, using donated funds and foodstuffs. A donation of 600 000 baht (approximately US\$ 17 000) from the Thai Red Cross Society enabled the project to provide these amenities for two years. Some medicines donated by private companies is also distributed.

### Community care

This activity was begun in 1995. Its goal is to get whole villages to accept and participate in the care both of persons living with HIV and their families. In coordination with existing Red Cross activities in villages in the Sanpatong area, the project holds monthly sessions in local houses. In particular, the sessions aim to involve village leaders in ensuring care for relatives of the deceased, and to encourage neighbours to help each other. Currently, sessions are held in houses, village halls and health centres and have involved 300 people living with HIV and their families. A key element in the success of this activity is preparatory visits before the date of the session. These preparatory visits are used to explain the project to village leaders and gain their support, and to encourage participation by neighbours.

### Cooperative shop

The project has set up a self-supporting cooperative shop as a joint venture between the Red Cross health care centre and the Sanpatong Hospital. The shop sells food and crafts produced by people living with HIV/AIDS, and also provides work for some such people as shop attendants.

### Supporting the special care role of grandmothers

In northern Thailand, HIV infection has often resulted in the illness of women who are wives and mothers. In a very special way, and particularly among poorer families who cannot afford hospital care, this places the entire stability of the family at risk.

Care-giving responsibilities in these situations often fall to the grandparents, and particularly grandmothers. Although Thai grandmothers have always had important roles in the care and upbringing of children and the running of households, this unexpected burden in their later years is a heavy one. This is particularly true if they have no previous knowledge of HIV/AIDS or of basic home care techniques such as universal precautions. In addition to the physical effort involved in home care, grandmothers are also faced with significant emotional stress from the illness of their children and HIV-infected grandchildren, and often from the social stigma surrounding such illness.

The project has begun a new activity aimed at improving the ability of grandparents to function as home care givers and

providing support to them as they do so. In particular, the project has identified the special needs of the care-giving grandmother as:

- training in home-care techniques;
- ongoing, regular support from the home-care team to help her look after her sick child or grandchild;
- support from medical personnel to keep herself healthy;
- financial support from the social welfare Ministry;
- emotional support from the social worker or counsellor to help her express grief or cope with stress; and
- support and acknowledgment from neighbours and community.

## Partnerships and alliances

The project has always had a strong orientation towards partnerships and alliance-building, since from its very beginnings it has included people from three distinct organizations: the Red Cross health centre, the Chiang Mai University faculty of medicine, and Sanpatong district hospital (Thai Ministry of Public Health). Links with the all three groups remain strong.

### Local health care providers

The referrals described earlier from the hospital to the project are matched by referrals in the other direction. People living with HIV who come directly to the attention of the project and are in need of medical intervention or testing are first referred to the Red Cross health centre, which is open seven days a week for primary and secondary care. Tertiary cases are referred to the Sanpatong hospital. In most cases, the Red Cross follows up with a home visit, and a letter to the health centre with an update on the case.

In addition, the local public health office has donated 2000 baht per month for the Thursday Club monthly meetings.

### Government Health Care System

The Red Cross works very closely with the local health system. Proposals are made jointly by the health personnel working with villagers.

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## **Grandmother is best**

Somboon Suprasert

*When I was growing up, my mother took care of me  
When I went to work, my mother took care of my children  
When I was away from home, my mother cooked for me and my children  
She was my source of strength.*

*In a small village there are many who can help but  
The one who is available is Grandma  
The one who is acceptable is Grandma  
The one who is accessible is Grandma.  
Grandma cares for children with tender love and kindness because  
She has experience  
She knows them and they trust her  
They know she knows what they need.  
If Grandma can care for her grandchildren why  
Leave them with strangers?  
Put them in a strange house?  
Or send them away to a strange village?*

*As Grandma holds the orphaned baby in her arms  
Together they comfort each other  
Together they comfort each other.  
They are each other's source of strength.*

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## **Donors**

The most important donors of funds, materials, and other resources for the project are:

- the Thai Red Cross Society AIDS programme which provides medications and nursing staff;
- pharmaceutical companies which donate medications, and some prominent members of the industry who have made donations of cash;

- Rotary Clubs: Rotarians have been very generous to the project (this is facilitated by the project's coordinator, who has a long history in the Chiang Mai Rotary Club and is currently its president); and
- milk companies: donations of soya bean milk make possible the distribution of milk to families containing a member living with HIV.

### Other organizations and NGOs

The project has an ongoing relationship with the Brahma Kumaris World Spiritual University, which provides workshops for people living with HIV (described above).

## Monitoring and evaluation

Monitoring of progress is carried out by the home-care team once a month at the lunch club. Feedback from people living with HIV is listened to seriously, and discussed by the group. Project staff have noticed that few families now ask early whether confidentiality will be maintained, as used to be the case. This indicates that as there is an increased feeling of openness among people living with HIV and less fear of stigmatization.

An objective measure of success in many people living with HIV has been the finding of substantial weight gain in people living with HIV after three months in the project.

No formal evaluation has yet been made of the project. Some indication of project success (as well as of demand for the kinds of services provided) has been the speed with which our community care activities have spread from zero to 20 houses in various villages.

### Strengths of the programme

People living with HIV feedback emphasizes the following benefits:

- increased ability to enjoy their lives;
- increased quality of life; and
- increased feelings of being respected, loved, and appreciated.

### Weaknesses of the programme

A significant challenge facing the programme is to maintain sufficient resources in the face of rising needs. Funding from the Red Cross AIDS Programme and the Rotary Club (the two main cash contributors) has not always been sufficient, and staff have sometimes contributed from their own savings when money has been needed.

### The future

Although the actual challenge posed by the high infection rates of HIV in the region is daunting, we believe that the project is actually gaining energy. An important element in this is the increasing help we are receiving from pharmaceutical companies, NGOs, and other organizations. For instance, the Rotary Club and the Business and Professional Women's Club of Chiang Mai recently found a volunteer to work with the project.

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#### *For more information:*

**Ms. Somboon Suprasert**  
**Research Institute for Health Science**  
**Chiang Mai University**  
**P.O. Box 80 CMU – Chiang Mai 50202, Thailand**  
**Fax: 6653 321 969**

## Other HIV/AIDS activities in Thailand

National plans are formulated under the coordination of the National Economic and Social Development Board, which is the national planning authority. This ensures smooth cooperation among the government agencies, the NGOs, and the private sector in formulating a comprehensive action plan.

Programme components assigned to 14 different ministries. Examples include: Public relations/mass media to Prime Minister's Office; AIDS education in schools to Ministry of Education; AIDS programmes for special target groups to Ministry of Interior; medical and counselling services and condom promotion among sex workers to Ministry of Public Health; condom distribution and peer education among the military to the Ministry of Defence; research and evaluation to Ministry of University Affairs.

Thailand Business Coalition on AIDS established in 1993 provides information, technical support and training programmes to Thai businesses. Helps in the development of effective and non-discriminatory measures for AIDS in the workplace policies. A large number of businesses are concerned or involved in HIV/AIDS activities, in particular the sex industry.

Coordinator  
Somboon  
"Aunty Boon"  
Suprasert (left)  
works with  
a group  
of project  
members.



## NGOs/CBOs role

Over 200 development-oriented Thai NGOs are currently participating in work against AIDS epidemic. The large national NGOs include PDA, Thai Red Cross Society, Planned Parenthood of Thailand, and Lions Club. Among the most active international NGOs are World Vision, PATH, Save the Children, and FHI.

The consortium of Thai NGOs Against AIDS, formed in 1991, has 42 members. Member organizations are mainly involved in developing models of AIDS education and social support services where the government sector has been relatively weak, and in consultation on policy issues.

For instance, NGOs work closely with disadvantaged communities and social groups and in supporting community empowerment. They also take the lead in working among stigmatized social groups. Activities include developing participatory forms of AIDS education and client-centred counselling and support services, campaigning for social acceptance of people living with HIV/AIDS and their rights to non-discrimination, and in training and employing people to work as AIDS educators and counsellors.

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### Best Practice Criteria

The **Sanpatong Home-based Care Project** provides an example of how an organization's emphasis on participation and involvement of families in caring for people living with HIV/AIDS can result in efficiency and effectiveness benefits both to individuals and to the public health system. The project illustrates UNAIDS best practice criteria in the following ways:

■ **Relevance:** The goals and operations of the project are fully relevant to the current stage of the epidemic in Thailand, where a large number of people in local communities are presenting symptoms of AIDS. The "bio-psycho-social" approach chosen by the project fits very well with the UNAIDS concept of expanded response (i.e., an approach beyond the traditional goals of public health, which tend to be rooted in a purely medical model). In addition, the goal of reducing the impact on government health services is extremely appropriate in a high-prevalence area where hospital and clinics are hard-pressed by the epidemic. The project's emphasis on support for orphans is similarly relevant given the infection rates among adults of child-bearing age, particularly women in a stable relationship, in the North of Thailand.

■ **Effectiveness:** Measured in numbers of homes visited (600 between 1994 and mid-1997) or reached through home-care training sessions (900) and types of service provided, the project appears to be effective in pursuing its goals of permitting primary health care to be provided at home and promoting self-care and self-reliance. Quality of service is safeguarded by the participation of arms of the formal health system (Thai Red Cross, Chiang Mai



public health staff, and faculty of medicine at Chiang Mai University). While there is no evidence yet available on the effectiveness of using spiritual resources (talks from Buddhist monks, retreats, meditation techniques) to achieve psychological and physiological benefits for people living with HIV, experience from other fields of medicine suggest that this strategy is a beneficial one.

■ **Efficiency:** the project's efficiency appears to be relatively high, in that it permits a large number of people to receive valuable services of useful quality at a low monetary and administrative cost. This is achieved by training unpaid human resources (mostly, though not entirely, family members of the persons with HIV) to assume care responsibilities that would otherwise be carried out by salaried medical staff in overburdened hospitals and clinics—or not at all. Efficiency is also increased by the emphasis on providing training to seropositive individuals and their families before symptoms of AIDS appear. The use of the lunch club, a strategy pioneered in Thailand, is one which has already been proven efficient as a non-threatening, low-cost access point through which infected people can receive services and information.

■ **Ethical soundness:** the project emphasizes an open, non-discriminatory approach to HIV/AIDS that nonetheless safeguards confidentiality. It also emphasizes involvement of persons living with HIV and their family in the project. The simultaneous involvement of qualified academic, government, and non-governmental medical personnel appears to provide a sufficient set of checks and balances to assure that accepted standards of medical ethics are observed.

Looked at from the outside, there may be an ethical concern in the component that supports grandmothers as care providers. This concern arises from the limited energy and increasing frailty of these older women and the assumption that they, rather than grandfathers, will assume this role. However, this concern is mitigated by understanding that the project aims to give grandmothers better skills to carry out a role they willingly assume (both through tradition and links of personal affection) and some measure of assistance through home visits and support groups. It relieves grandmothers of the sole responsibility for care by training other family members.

■ **Sustainability:** the project has only been in existence for three years, and reports difficulty in securing reliable financial resources. It is not yet clear whether the personal commitment and dynamism of some of the founding personnel are necessary for the continued effectiveness and even survival of the project.



A young widow carries food and supplies provided by the Chirumhanzu project.

# Chirumhanzu Home-based Care Project Zimbabwe

## Background

### Facts about Zimbabwe

Total population (1995):  
11 557 835

Urban population:  
31%

Annual population  
growth rate:  
2.5%

Infant mortality rate  
(per 1 000 live births):  
53

Life expectancy (years):  
Male: 59  
Female: 62

Illiteracy rate:  
Male: 14%  
Female: 20%

Per capita GNP (US\$):  
610.00

Surface area (km<sup>2</sup>):  
390 759

Borders:  
Zambia on the north,  
north; Botswana  
on the west;

Mozambique on the east;  
South Africa on the south

Administrative divisions:  
8 provinces

Government:  
Parliamentary democracy  
with a president  
as head of state

### HIV in Zimbabwe

*Zimbabwe is one of the countries most affected by the HIV epidemic. According to recent estimates, almost 22 percent of the adult population (or about 1.2 million people) are currently HIV-positive. To date, the number of persons who have reached the stage of AIDS has totalled 150 000. Some 400 people die of AIDS and its related diseases each week.*

*In parts of the country, between 50% and 70% of pregnant women attending antenatal clinics have been found to be HIV-positive.*

*Only one voluntary counselling and testing centre currently exists in the country, seeing an average of 30 clients per month. Another centre is planned in Harare for the near future.*

# Chirumhanzu

## Home-based Care Project, Zimbabwe

*“Home care, not home neglect!”—Project slogan*

Chirumhanzu District is a farming area in the central Midlands province of Zimbabwe. The HIV epidemic has struck the area hard. At St Theresa’s Hospital, which is the first-level referral centre in the District, just over half of the 253 in-patient deaths occurring in 1997 were due to AIDS, and the numbers are still increasing.

The Chirumhanzu Home-based Care Project started in 1994. It grew out of an initiative of Hospital health workers, including senior nurses, Dominican sisters, and expatriate doctors. Concerned by the overcrowded hospital wards, they were also well aware of the wish of local AIDS patients to stay at home under the care of their families up till, and including, the time of their death.

Since that time, a variety of HIV/AIDS-related services have been created, including home care for over 200 persons living with HIV. The home-based care part of the project is provided primarily by family members under the supervision of home-care volunteers. These volunteers are themselves supervised by the project coordinator and the professional nursing staff of the hospital.

### Goals and principles

The project is based on two main goals:

- to meet the HIV-affected peoples’ needs as close to their homes and relatives as possible;
- to provide the necessary information, skills, care, materials, and support to everybody involved or interested.

From the beginning, the project has taken a comprehensive approach to care that includes not only meeting medical needs but also social and emotional needs. It promotes HIV awareness and prevention, both among the general public and among target groups within the public such as sex workers, students, and STD patients.

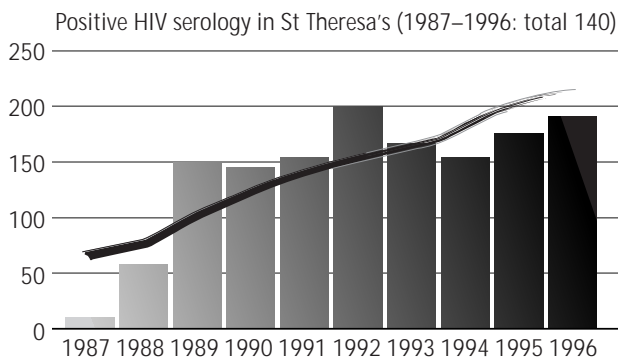
The project strongly believes in, and builds on, African traditions of family support and mutual obligation, including consensus to designate a direct care giver within each family. As project coordinator Etta Dendere puts it, “Family is the most important resource for our clients”. At the same time, Etta stresses that “home care cannot be home neglect”—in other words, home care must be supported because it meets patients’ needs effectively and not because it reduces demand on the local hospital beds.

A final principle is the participation of persons infected or affected by the virus in all aspects of the project. This principle is important not only in itself, but also because it increases the profile of persons living with HIV in the community and thus serves to reduce stigmatization.

## Some background

The population of Chirumhanzu District is approximately 70 000 people, of whom almost half are under the age of 16. The dry, hilly area is quite poor. Its economy is based on subsistence farming, mostly of maize, and is highly dependent on adequate rainfall from year to year.

The epidemic arrived in the District later than in the urban areas of the country, but since the late 1980s between 150 and 200 people have tested positive each year at St. Theresa’s Hospital (see table below). About half of all beds occupied, and of all in-patient deaths, are HIV-related. Moreover, HIV/AIDS statistics at the hospital (admissions, in-patient deaths) are still increasing, at a time when the hospital is already over-crowded.



Analysis of these statistics indicates that of all admissions ending with the patient's death while in hospital, AIDS patients stay longer in hospital than non-AIDS patients: Of the non-AIDS patients, the average stay before death was 8.2 days, with half dying after 4 days. In contrast, AIDS patients stay on average 14.6 days before dying, half of them dying after 8 days.

The project began on the initiative of hospital staff who, realizing that home care would be essential to look after the growing number of AIDS patients, went out to churches and communities looking for people willing to be trained in this task. The staff began giving workshops for trainers of home care givers in 1994. (Some groundwork had already been laid for this initiative. The Ministry of Health had earlier provided some training in counselling and home care to hospital staff in 1991, and the staff had also consulted the World Health Organization's AIDS Home Care Handbook.)

## Major elements of the project

The project is organizationally separate from the hospital but collaborates fully with it in referrals and has space in the hospital wing built by the Dominican Sisters. A full-time nurse paid by the hospital works with the project, while the group's full-time coordinator is paid a small honorarium from project funds provided by the Swiss NGO Solidarmed. A smaller honorarium is also provided to a volunteer who helps the nurse and coordinator.

The project's comprehensive approach includes three main elements:

- home-based care for AIDS patients;
- support groups for HIV-positive people; and
- awareness and prevention for general public and target groups.

The first two are aimed at meeting the medical, social, and emotional needs of persons with HIV/AIDS. The third focuses on encouraging local society to take greater responsibility in accepting and caring for its HIV-positive members.

### Home-based care

The home-based care element of the project begins with the identification of clients. This occurs mainly in hospital through the admissions process or as a result of HIV testing. If diagnosed

as HIV-positive, the individual receives counselling sessions that include assessment of individual needs and wishes. This assessment helps identify appropriate follow-up procedures once the patient has been discharged from hospital.

When patients are ready to go home, a letter is provided from the hospital to the patient's nearest local clinic and to the care giver and relatives. This letter confirms that the patient has been discharged for home care.

A volunteer, who has been trained as a community-based care giver, undertakes follow-up at home. Each client is visited once a week. The reports written by the volunteer following the visit are used by the project coordinator at the hospital to decide whether a home visit by a qualified nurse is needed.

Nursing materials and drugs used in the home care service are mostly provided by the Ministry of Health.

### Self-care and family care givers

Many patients diagnosed with HIV are mobile and able to take care of themselves. These people receive self-care training in nutrition, hygiene, and techniques such as caring for HIV-related skin problems. The patient also receives training in "positive living"—taking on a forward-looking, optimistic attitude to life.

When a person needs a greater degree of care and has come to St Theresa's for in-patient treatment, her or his family is asked to send a member over the age of 12 to take home-care training while the patient is in hospital. This relative is usually chosen in the traditional way by decision of the entire family, and is generally a female member relative (wife, mother, daughter or cousin.) About one in ten of the care-giver relatives are male (fathers, husbands or sons. If coming from far away, the relative is able to stay in a guest house operated by the hospital during the training.

Like self-care patients, family care givers receive training in nutrition, hygiene, oral rehydration and control of simple infections.

### Volunteer care givers

Most of the project's volunteer home care givers are recruited through the District's church parish councils and other base-level

religious organizations. Criteria which guide the councils in their recruitment of these volunteers include compassion and willingness to provide spiritual support and care where needed. Most of the volunteers are HIV-positive themselves, though an increasing number are relatives of infected persons. There are currently about 30 volunteers in Chirumhanzu.

Basic training is given in workshops that are supplemented occasionally with refresher courses. The basic course teaches how to provide care and supervise the home care provided by family members.

The supervision of these volunteers is the responsibility of the project administrator and a qualified nurse. Concerns about individual clients are normally included in the reports written by the volunteers after their weekly home visit, and these can be discussed immediately with the administrator depending on their urgency. Meetings of all volunteer care givers are held once a month in order to address more general problems.

Some incentive is provided to volunteers in the form of monthly “pocket money”. Since the actual sum of Z\$8 is only enough to buy a small item such as a bar of soap, most volunteers prefer to receive the year’s pocket money in a lump sum. In addition, refresher workshops and monthly meetings at St. Theresa’s are used partly as a way of thanking and motivating volunteers by providing a good meal and a social gathering.

### Support groups

The project has also created a number of support groups in the district. There are currently six groups with 12 to 22 persons in each group that come together each week on Thursdays. The numbers depend largely on how dense the population is in each group’s village area, since there is no bus service to villages and members must walk to the support group meetings. Members learn about the groups through referral by the hospital or through word of mouth, and membership is, of course, entirely voluntary. One of the focuses of the support groups is to increase the economic self-reliance of members by teaching sewing (by hand and by machine) and gardening skills. People within some groups are also involved in raising chickens together. Where such productive activities are underway, the groups appoint a small committee to oversee the work and to organize monthly meetings of those involved.



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## Living proof

Etta Dendere is the Chirumhanzu Home-based Care Project's coordinator:

*Discrimination and stigma make it very hard for infected people to talk about their HIV-positive status. We need information and counselling, and we need to be able to participate in helping other people. Otherwise, living positively is very, very hard.*

*When I was diagnosed with HIV it was about four years after I had begun living with my husband (we were never officially married). I was pregnant when I found out... It took me a very long time before I had the courage to face my husband, but when I told him he blamed me. We had several quarrels and I went to stay with my parents.*

*There was no counselling available. I was trying to think of my baby in the womb, to plan for the future, but I thought I would be dead soon so I couldn't come to any conclusions. Actually, when I learned the results of my test I thought I would be dead tomorrow. I knew nothing about the difference between HIV and AIDS, so I didn't see why it mattered to think about the future. I wish I'd had better information.*

*When my daughter was born my husband showed up because he wanted the baby. He took her to stay with his parents. She was healthy for over a year, she was even walking, but then she got sick.*

*My daughter died 15 days before her second birthday. No relative showed up to the funeral as people normally do in Zimbabwe. They all wanted to know the cause of death. So I had to explain about HIV/AIDS (by that time I had learned more), and how the mother can pass the virus to her unborn baby. I tried my best, but it did not make any difference. His relatives said, "Etta will also kill our son—she must go". And he listened to them, although we loved each other. We used to visit each other regularly. Later I lost him to another woman. I have since lost contact with him.*

*By that time, I had got a lot of courage from the Dominican Sisters at St. Theresa's Catholic Hospital. I openly went to Sister Kristiana for counselling, and that counselling provided my life with a foundation. She gave me some books about HIV/AIDS, and from this counselling I learned this lesson: you can live longer if you live well. Or as it is sometimes said, "HIV + Good Information = Long Life".*

*In 1994 I went to the Hospital and joined the Kushinga AIDS Support Group. Then I began AIDS education work. I got training to be an HIV/AIDS counsellor and then went to train in home care. Eventually, I started to work with the hospital to implement our home care project, and became its coordinator. Now I can help other people in ways that were not available to me back when I was diagnosed.*

*This job is voluntary. I had no salary from 1994 to 1996. Then we got financial help from Solidarmed and that pays me a small honorarium as an incentive. I like this job very much. It is building me up. Caring for other people gives me back a kind of support, and the courage to go on. That is how I know that involvement of people living with HIV/AIDS in community projects like this one is a key element to success: I'm living proof.*

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### Awareness and prevention

The project's principal tool for awareness and prevention has been its drama group. The group has created a skit which it uses to entertain their public while providing information on HIV/AIDS. The group usually accompanies the nurse and coordinator when they attend village meetings, and performs at these meetings.

Recently, the project has begun to organize public netball and football clubs in the area for the community's young people. Games between clubs are used as an occasion to give talks and to show a video about HIV/AIDS.

Currently, eight women who volunteer with the project have taken on responsibility for prevention work. These women visit popular meeting places where they teach about HIV and sexually transmitted diseases, hand out pamphlets on these subjects, and also distribute condoms.

## Partnerships and alliances

From the early days, the project has been careful to work with traditional leaders in the area in order to gain people's trust, and to overcome stigma and ignorance about HIV and AIDS. The project's initial outreach to villages begins with an invitation to the village chiefs and their advisers to visit the hospital or a clinic and to meet with the project staff. A video on home care and HIV/AIDS is shown during this visit. This is usually followed by a visit from the staff to the village, during which a public meeting may be held. This public meeting may include a presentation about HIV/AIDS by the project's drama group and a talk by the project's nurse or coordinator.

### Local health care providers

The Chirumhanzu Home-based Care Project was initially set up to work mainly in the hospital's catchment area, where there are currently about 150 identified HIV-positive clients. The project also works with five government clinics in the district, with regular visits by the project nurse and coordinator.

### Government health-care system

The project informs the Provincial Medical Director about its activities through its annual report. Recently, the government provided five bicycles for the project to help project members move around the area more quickly and easily.

### Donors

In the 1994–95 period, the project received financing from UNICEF through the Zimbabwean Government. Since 1996, overseas donations have come from the Swiss NGO SolidarMed, and from German parishes and private donors with the help of the Dominican Sisters.

### Other organizations and NGOs

The project is not aware of any other health-related organizations currently working on HIV/AIDS in the immediate region. However, the coordinator has represented HIV/AIDS support groups from the Midlands at capacity-building workshops given by the Zimbabwe National Network for Persons Living with HIV/AIDS (ZNNP+).

## Monitoring and evaluation

Monitoring of the project is carried out in the following ways:

- monthly review of home-based care activities by the project coordinator, augmented by visits to clinics and homes;
- monthly meetings of the project members, which include reports from all activities within the project, discussion of problems, short- and long-term planning, policy review; and
- annual reports, including accounts and a budget are prepared for donor organizations.

These monitoring activities are sufficient for administrative purposes, but the project does not have enough personnel with the necessary skills to carry out the monitoring it would prefer to do. For example, more time to consider patient reports and analyse the issues brought up at monthly meetings would probably allow the project to make some valuable improvements to procedures and policy.

As the decentralization process moves more activities out to the clinics from the hospital, it is anticipated that there will be increased challenges to monitoring. In anticipation of this development, the project has created a standardized monitoring form to be used to monitor the activities of home-based care workers operating from these clinics.

Except for an evaluation of financial accounting systems carried out by the government in 1994–95, no formal evaluation of the project has been carried out as yet.

### Strengths of the project

The Chirumhanzu Home-based Care Project has now existed for almost three years. During this time it has achieved a high degree of continuity in services and a stable financial basis for its operations through its donors.

The connection with St Theresa's Hospital has been a particular source of strength and continuity, particularly because of the availability of trained health professionals to the project when needed.

An important feature of the project is the fact that it is managed by local people. The majority of the project members are either HIV-positive or are directly affected in some way by the virus, such as having had a family member who died of AIDS.

### Weaknesses of the project

Although the project has stable finances due to its donors and support from health professionals in the hospital, this dependence on overseas donors and foreign medical staff is far from an ideal state of affairs. Yet the area is a poor one, and there are few options for greater resource mobilization locally or nationally.

As yet, the project has not been able to get a great deal of active involvement or support from local chiefs or village health

workers (passive support or tacit acceptance, however, is essential to the project's work). Some of the local chiefs feel they should receive payment for supporting the project, as do the health care workers whose regular salary is very low. The project does not have the financial resources to provide any such payment, and this lack of involvement has partly resulted in less community involvement in the project than the project feels is possible. (A promising sign, however, is that while the chiefs are not inclined to talk publicly about AIDS, many of their children attend public meetings presented by the project.)

Another reason for this weakness may be the fact that the project is too centralized in the hospital. It is hoped that the decentralization of some of its activities to clinics further away from the hospital will have positive results.

## The future

In the short term, decentralization to surrounding clinics is one of the major objectives for the project.

In the longer term, the project hopes to cooperate with other home-based care or HIV/AIDS organizations on a provincial level.

Recently, the project has begun to help set up a similar project in the neighbouring district of Mvuma. Progress to date includes informing local chiefs and selection by the community of designated care givers.

Most important, the project wishes to make it possible for everyone in the area to talk about HIV and AIDS. In particular, it aims to empower all persons living with AIDS to be open about their sero-status if they wish to talk about it.

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### *For more information:*

**Etta Dendere, St-Theresa Hospital  
Private Bag 7015 – Mvuma, Zimbabwe**

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## NGOs/CBOs role in the National AIDS Programme

Zimbabwe currently does not have a National AIDS Committee. All functions of managing the national response to HIV are vested in the National AIDS Coordination Programme, which is located in the Ministry of Health and Child Welfare. The Ministry of Education and the Ministry of Public Service, Labour, and Social Welfare also have had HIV/AIDS-related activities for some years now.

Zimbabwe has over 60 NGOs and more than 83 support groups of PLWHAs who are implementing a wide variety of community-based activities. At national level, the activities of NGOs and support groups are coordinated by the Zimbabwe AIDS Network (ZAN). Activities of NGOs include community-based home care, orphan care, peer education for both in- and out-of-school youth, income-generating projects, etc. The work of NGOs is also coordinated at provincial and district levels.

As well, the private sector implements a wide range of projects and activities. These are mainly in the areas of peer education, benefits management, counselling and condom distribution, STD case management in the workplace, community outreach, and financial support to community projects. However, with the exception of the latter, most of these tend to be in-house arrangements (i.e., only within the specific company.) There is as yet no collective private sector response.

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## Best Practice Criteria

The Chirumhanzu Home-based Care Project exemplifies the community mobilization value of participation by infected and affected persons in their own care, and shows how this provides a guarantee of a project's ethical soundness.

The project illustrates UNAIDS best practice criteria in the following ways:

■ **Relevance:** The project's activities are entirely in line with UNAIDS priorities and guidelines for an expanded response, particularly in their contribution to care. In addition, the project's activities and strategies appear well adapted to the specific local context: widespread poverty, low literacy, and prevalence of traditional political structures.

■ **Effectiveness:** The effectiveness of this project in terms of impact on client health and local levels of HIV-related knowledge is difficult to measure with the data currently available. (There are few other health resources in the area which might permit surrogate measures.) However, the project's affiliation with the hospital has permitted it to be highly effective in terms of numbers of people reached to date in its various activities. All persons in the district who are diagnosed with HIV are referred to the project. Another indicator of the project's effectiveness is found in its success at recruiting volunteers. Since this is usually extremely difficult in areas where poverty is rife and subsistence farming is the economic mainstay, the project's current roster of 30 volunteers (up from 24 in the previous year) is impressive.

Faced with the problem of providing information in an area of low literacy, the project has chosen three forms of communication which are most cost-effective in such circumstances: public meetings, drama, and video showings (where electricity and a VCR are available, such as at clinics or in the hospital). In addition, the creation of sports leagues for young people appears to be a highly effective way of getting public attention in a place where over half the population is under the age of 25.

■ **Efficiency:** In an area with few financial and material resources, it is difficult to see how a home-based care project like Chirumhanzu's could do more with less. Lacking other means of transportation, staff carry out much of their monitoring and information activities by "hitching" rides with doctors from the hospital. Premises are shared with the local hospital and all possible sharing is carried out with the five clinics in the area. Recruitment is carried out through parish organizations.

The project appears to be highly realistic in its approach to local sensitivities and traditional hierarchies. Initial outreach to villages is made first by communication with local chiefs, whose approval must be given to permit public meetings by the coordinator to be held in the village. Only then can the work of home visits and recruiting home care providers be undertaken. This may not be efficient in terms of reaching the greatest numbers of people in the shortest possible time, but it addresses the reality that the local chief's support (or at least neutrality) is essential if the project is to operate in a specific area.

■ **Ethical soundness:** The project's emphasis on combating social stigma and its success in encouraging participation of HIV-positive persons in its activities are strong indicators of its ethical soundness. As well, project staff appear to be vigilant about the danger that faces many home-based care initiatives: that

success in providing home services or training home care providers may allow existing health systems to neglect the needs of HIV-positive people and their families. To date, this has not been the case in Chirumhanzu because of the good relationship enjoyed by the project, the local hospital and the district health system.

■ **Sustainability:** the project is dependent on outside sources for financial backing, but appears to have done everything possible in gaining local support for its activities. The creation of support groups and the ongoing presentation of public activities to reduce the stigma of HIV/AIDS appear to be important supports to the project's continued survival and effectiveness in the future.



The Joint United Nations Programme on HIV/AIDS (UNAIDS) is the leading advocate for global action on HIV/AIDS. It brings together seven UN agencies in a common effort to fight the epidemic: the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations International Drug Control Programme (UNDCP), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO) and the World Bank.

UNAIDS both mobilizes the responses to the epidemic of its seven cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV on all fronts: medical, public health, social, economic, cultural, political and human rights. UNAIDS works with a broad range of partners – governmental and NGO, business, scientific and lay – to share knowledge, skills and best practice across boundaries.



Joint United Nations Programme on HIV/AIDS

**UNAIDS**

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UNESCO • WHO • WORLD BANK

**Joint United Nations Programme on HIV/AIDS (UNAIDS)**

20 avenue Appia, 1211 Geneva 27, Switzerland

Tel. (+4122) 791 46 51 – Fax (+4122) 791 41 65

e-mail: [unaids@unaids.org](mailto:unaids@unaids.org) – Internet: <http://www.unaids.org>