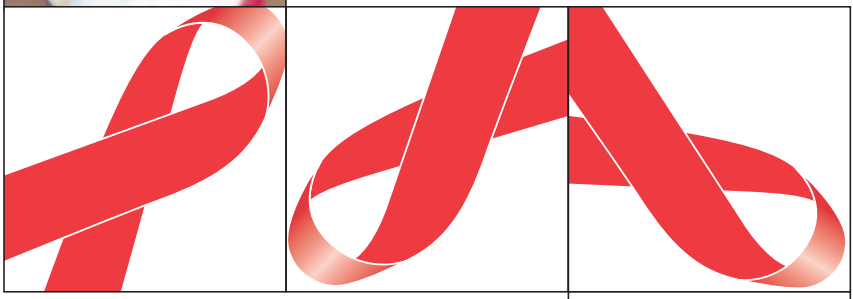
Reaching out, scaling up

Eight case studies of home and community care for and by people with HIV/AIDS



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Case Study

September 2001

Photos courtesy of:

Home Care Programme, Phnom Penh, Cambodia
CASM, Abidjan, Côte d'Ivoire
Programme for AIDS Initiatives, Ecuador
Continuum of Care Project, Manipur, India
Kariobangi Programme, Nairobi, Kenya
Rose Smart, Bambisanani, Eastern Cape, South Africa
Claire Wheatcroft, Mildmay Centre, Uganda
Joy Mukaire, Uganda

Cover photo courtesy of Claire Wheatcroft (Mildmay Centre in Uganda)
Palliative care is provided by a nurse at the Mildmay Centre.

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UNAIDS – 20 avenue Appia – 1211 Geneva 27 – Switzerland
Tel. (+41) 22 791 36 66 – Fax (+41) 22 791 41 87
E-mail: unaids@unaids.org – Internet: http:/www.unaids.org

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2001

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Acknowledgements

The case studies in this report stem from a presentation given in December 1999 at the 4th International Conference on Home and Community Care for Persons living with HIV/AIDS, held in Paris. Like those documented by UNAIDS[1], these case studies document experiences and lessons learned in Africa, Asia and Latin America.

The presenters at the Paris Conference were:

- Mean Chhi Vun of the National Centre for HIV/AIDS, Dermatology and STDs[2] (Phnom Penh, Cambodia)
- Marc Aguirre, Hope Worldwide (Abidjan, Côte d'Ivoire)
- Margarita Quevedo, Kimirina (Quito, Ecuador)
- Vikramjit Singh Nepram, Continuum of Care Project (Lamphelpat, India)
- Charles Thumi, Kariobangi Community Health Centre (Nairobi, Kenya)
- Rose Smart, Bambisanani (Eastern Cape, South Africa)
- Wilson Kisubi, Pathfinder International (Nairobi, Kenya)
- Sophie Mukasa-Monico, TASO (Kampala, Uganda)
- Catherine Sozi, Mildmay Centre (Kampala, Uganda)

UNAIDS thanks them for their participation at the conference and their patient follow-up while this report was being written.

[1] *Comfort and hope. Six case studies on mobilizing family and community care for and by people with HIV/AIDS.* Geneva, 1999 (UNAIDS/99.10).

[2] Note that except where the term is part of an organization's name, the term sexually transmitted infection (STI) is used in this document.

1. Reaching out, scaling up

"AIDS is not curable, but it is careable." Charles Thumi, Kariobangi Community-based Home Care and Home-based AIDS Care Programme, Nairobi, Kenya

The theme of this report, *Reaching out, scaling up*, reflects a concern that has become increasingly important in the past few years. All too often, good local-level responses to HIV/AIDS—best practices, in other words—have remained local and small-scale. The many lessons learned have not been translated into bigger projects or wider coverage.

For a variety of reasons—human or resource constraints, the terms under which donors operate, etc.—action in many countries remains sporadic and patchy rather than comprehensive. 'Boutique' projects may provide services for one or two communities, while large areas of the countryside have nothing.

This is tragic, because the HIV/AIDS epidemic continues to spread. Moreover, infection levels are generally highest where access to care is lowest, and social and economic safety nets that might help families cope with the impact of the epidemic are badly frayed. In sub-Saharan Africa, for instance, the incidence of the disease is increasing three times faster than the money needed to control it.

Lessons from eight initiatives on three continents

This report focuses, therefore, on projects and programmes that have been able to scale up or reach out, and in doing so have brought an improved quality of life to people living with or affected by HIV/AIDS. The initiatives are widely spread geographically, with five from Africa, two from Asia, and one from Latin America:

- Cambodia's *Home Care Programme* is a collaboration of the Ministry of Health, the coordinating committee of Cambodia's NGOs involved in AIDS, and the World Health Organization (WHO). Home Care Teams, made up of staff from government health centres and community-

focused NGOs, have created strong links with community resources such as local community leaders (*phum*), traditional healers and the members of Buddhist temples (*pagodas*). Referral systems link the Teams with health centres, hospitals, and the three government-run HIV Voluntary Testing and Counselling (VTC) Centres. Piloted during 1998-99 in Cambodia's capital city, Phnom Penh, the programme is being extended to other parts of the country.

- In Côte d'Ivoire, the *Centre for Socio-Medical Assistance* (CASM) is an outpatient clinic for persons living with HIV/AIDS—most of them extremely poor residents of the capital city, Abidjan. Initiated in 1991 by HOPE worldwide, an international faith-based NGO that continues to support it, CASM works in close collaboration with the Ministry of Health, the National AIDS Programme, and the University Hospital. Persons living with HIV/AIDS play an important part in the centre's prevention and advocacy activities.
- Ecuador's *Programme for AIDS Initiatives* provides no services directly itself, but instead funds, trains, links and supports community HIV prevention and care programmes. Run by a national NGO called Kirimina, the programme works to increase the organizational and technical capacity of NGOs and CBOs, not just regarding care itself but dealing with issues such as external relations, financial management, and micro-enterprises. Since its beginnings in 1995, the programme has funded 41 organizations in 14 provinces around the country.
- *The Continuum of Care Project (*COCP) in the State of Manipur, India, evolved out of a series of discussions and workshops with the government of Manipur, the National AIDS Control Organization, Oxfam, WHO, the British Council, and representatives of 28 local NGOs. Among other innovations, the Project has created multidisciplinary 'core groups' within hospitals, NGOs and communities. These core groups are designed to improve quality of service, and also to help these care providers better understand the needs of persons living with HIV/AIDS and reduce their prejudices about vulnerable populations.

- *The Kariobangi Community-based Home Care and Home-based AIDS Care Programme* operates in a large, extremely poor area of Nairobi, Kenya. The programme grew out of a community health programme begun there in 1986 by Medical Mission Sisters, and delivers many of its services through the volunteer work of community health workers supervised by a professional staff. Responding to the conditions prevailing in the area, the programme has begun to focus many of its efforts on HIV-positive children and on children who have been, or will be, orphaned by the epidemic.
- *Bambisanani* is a health programme established in South Africa's Eastern Cape province by government, NGOs and the private sector. It provides a coordinated approach to the problems of HIV/AIDS among migrant workers and their families, tuberculosis and HIV, and the growing numbers of children affected by the epidemic. The partners include the state and national governments, major gold mining companies and trade unions, and several NGOs. Along with care and prevention, income-generating activities and community capacity-building are emphasized.
- *The Mildmay Centre for Palliative HIV/AIDS Care* offers a range of specialist referral services near Uganda's capital, Kampala. As well as relieving pain, treating symptoms and assisting with the rehabilitation of people living with HIV/AIDS, it acts as a regional centre of excellence with an extensive training programme aimed at increasing the palliative care skills of the health sector, NGOs and communities.
- *The Partnership for Home-Based Care in Rural Areas* brings together the different expertise of four health-related NGOs to improve AIDS home care in rural Uganda. With technical support from Pathfinder International (a US-based NGO), Uganda's Family Life Education Programme (FLEP) operates 46 primary and reproductive health care clinics in areas far from city centres or large institutions. Since 1993, FLEP's village health workers, nurses and supervisors have received training in HIV/AIDS education and counselling from one of Africa's most experienced AIDS-related NGOs, The AIDS Support Organization (TASO), and have linked up with the voluntary counselling and testing facilities of the AIDS Information Centre (AIC).

Representatives from each of these initiatives came together in Paris at the end of 1999, at the 4th International Conference on Home and Community Care for Persons living with HIV/AIDS. There they shared their experiences in two well-attended workshops, both of which sparked lively discussions between presenters and with members of the audience.

Different approaches for different conditions

The countries in which these organizations work are at very different stages of the epidemic[3] . While Ecuador and India both have less than 1% of their respective populations infected with HIV, their situations vary greatly. Ecuador's HIV infection overall is less than 0.3%, but many groups within society are vulnerable, and care needs have been rising.

India's epidemic is highly diverse: while some states show almost no HIV infection, others have reached adult HIV prevalence rates of 2% and more. Some groups are particularly vulnerable. In Manipur, the prevalence of HIV infection among injecting drug users shot up from virtually nothing in 1988 to over 70% just four years later, and it has remained at these high levels ever since.

Cambodia's epidemic is the fastest-growing in South-East Asia. Prevalence is currently estimated to be a little over 4% among adults in the general population, and about 60% among urban sex workers.

Sub-Saharan Africa has the highest prevalence rates in the world. Côte d'Ivoire is already among the world's 15 worst affected countries, with a prevalence rate of just over 10%. In South Africa, 19.9% are infected—up from 12.9% just two years ago (in fact, with a total of 4.2 million infected people, South Africa has the largest number of people living with HIV/AIDS in the world). The prevalence rate among adults in Kenya is almost 14% among adults, and still rising. Uganda has had notable success in responding to the epidemic, having brought its estimated prevalence rate among adults down to around 8% from a peak of almost 14% in the early 1990s. Yet, even this success story (largely due to strong prevention campaigns) cannot negate the suffering generated by HIV infections acquired years ago and their disastrous effects on the economy and social structures.

[3] All figures in this introduction are taken from the UNAIDS *Report on the global HIV/AIDS epidemic.*

Given the wide range of conditions in which these programmes are operating, it is not surprising that they use many different approaches and techniques. Nonetheless, many of the lessons learned are strikingly similar to those of other countries and even continents (see final chapter).

Sources of inspiration

It is interesting to trace the evolution of the global response to AIDS in these practices. The Ecuadorian project adapted techniques developed by its international partner, the HIV Alliance, during the early 1990s in collaboration with the Philippine NGO Phansup. The Cambodian project owes some of its approach to the work by AIDS NGOs in neighbouring Thailand.

Four of the cases—Kariobangi, CASM, and both Ugandan examples—are initiatives of religious organizations, while a fifth—the Cambodian example—works closely with local religious institutions. Some have grown out of individual projects, but others (in Cambodia, Ecuador, India and South Africa) were specifically designed as collaborations of several or many partners.

Many projects—Cambodia, CASM, COCP and Kariobangi—acknowledge their debt to the integrated approach advocated by WHO's *AIDS Home Care Handbook*, first published in 1993[4]. It is noteworthy that the handbook itself was heavily influenced by the early work of TASO, which continues to be in the forefront of AIDS home and community care. The handbook emphasizes the following conclusions, drawn from AIDS home care initiatives in a variety of countries:

- People who are very sick or dying would often rather stay at home, especially when they know they cannot be cured in hospital.
- Sick people are comforted by being in their own homes and communities with family and friends close by.
- Home care means that hospitals are less crowded, so that doctors, nurses and other hospital staff can give better care to those who really need to be in hospital.
- It is usually less expensive for families to care for someone at home (e.g. they don't have to pay for hospital bills or transportation to and from the hospital).

[4] WHO. *AIDS Home Care Handbook*. Geneva, 1993 (GPA/IDS/HCS/93.2).

- If the patient is at home, family members can meet their other responsibilities more easily.
- Hospital care is often simply not possible.

These conclusions have all been integrated into the work of the organizations presented in this report. However, the *Handbook* went further than the lessons learned from practical experience. It also included a conceptual framework to guide home and community care efforts into the future. This framework was not based on experience (the epidemic was too new at the time), but rather on a vision of what care programmes could eventually accomplish. The framework indicated that such programmes could:

- provide not just individual services but *comprehensive* care to people living with HIV/AIDS;
- provide a *continuum* of care, linked with a referral system, spanning home to hospital;
- integrate this model of care into the existing health care system
- facilitate close coordination and cooperation between NGOs, government health services and communities;
- include a prevention component;
- utilize the existing community resources with sustainable support mechanisms.

Today, these cases are fulfilments of that vision. Their experience of scaling up and reaching out illustrate the continuing value of a human, inclusive approach to care.

Lessons learned

The final chapter of this report revisits some of the main lessons learned through the practices, and examines both commonalities and differences.

In presenting the projects themselves in some detail, and extracting the major lessons learned, UNAIDS and the participants in the Paris workshops hope that other organizations will be able to adapt the various approaches and techniques for use in their own countries and conditions.

2. Home Care Programme, Phnom Penh, Cambodia

background

Facts about Cambodia

Total population (1999):	10 945 000
Urban population:	21%
Annual urban population growth:	5.2%
Infant mortality rate (per 1000 live births):	100
Life expectancy (years) at birth:	53
Literacy rate:	64%
Per capita GNP (US$):	300
Surface area (sq. km):	181 040

Borders:
Thailand and Laos to the north,
Vietnam to the east and south.

HIV/AIDS in Cambodia

With a population of around 11 million people, nearly half of whom are under 18, Cambodia is emerging from political isolation and a long civil war. The country's efforts to control the spread of HIV are complicated by the fact that public infrastructure is still weak and a large sector of the population is unsettled. Many people have returned to the country relatively recently, having spent much of the previous decade in refugee camps on the Thai border. Others are newly settled on land previously under Khmer Rouge control, or have joined the recent large-scale migration into the country's urban areas, as improving economic conditions create demand for labour in the towns, and the poverty of the countryside persists.

Widespread poverty is accompanied by low levels of sanitation, hygiene and nutrition, which have had serious effects on the health of the population. Moreover, the borders with Thailand and Vietnam are porous, making it difficult both to contain the spread of the epidemic and to accurately monitor its development in border areas.

The HIV/AIDS Coordination Committee of NGOs working in Cambodia comments that, "Although there is enough general health care personnel in Cambodia, they are not adequately trained or paid, and often no drugs or equipment are available in the hospitals for them to use. Also, most of the health care staff are located in Phnom Penh or provincial towns. There is a lack of attention paid to people suffering not only from HIV/AIDS but from other illnesses as well. In order for adequate health services to be provided, it is vital for a stable and realistic government salary system to be put into effect as soon as possible. The number of HIV/AIDS patients presenting themselves to hospitals is already larger than can be accommodated..."[5].

In 1999, some 170 000 adults and 4600 children were estimated to be HIV-positive[6]. Approximately a third were female. In all 20 provinces surveyed, the prevalence was at levels that would be internationally considered high, and probably the highest in Asia. In 2000, it is expected that 12 000 Cambodians with HIV/AIDS will have sought care and support, putting pressure on a health care system that provides only 8500 beds in total.

The main sector of the population affected by AIDS is young heterosexual adults, and the major cause of death amongst AIDS patients is tuberculosis. An increasing concern is the number of children orphaned as a result of deaths by AIDS (7300 in 1997, of whom 6900 were still living). The majority of patients are between 20 and 35 years of age, of whom half are male and half are female. These people are usually living in unsanitary conditions, and are extremely poor. There is a general absence of welfare services, thus making it necessary to maximize the assistance of support groups and of NGOs.

[5] HIV/AIDS Coordination Committee contribution to NGOs' web page review (http://www.camnet.com.kh/ngoforum/CGPaper/SectoralPapers.htm).

[6] HIV Sentinel Surveillance 1999 in Cambodia, National Centre for HIV/AIDS, Dermatology and STD.

One of the most important factors in Cambodia's AIDS situation is a well-established commercial sex industry. In the capital, Phnom Penh, HIV prevalence among sex workers increased from 10% in 1992 to over 40% in 1996. Outside of Phnom Penh, prevalence in direct sex workers reached 52% in one province in 1999, whilst overall prevalence for 'beer girls' had risen to 20%. Prevalence among patients with tuberculosis who were tested for HIV reached 8% throughout the country[7].

According to the NGO 2000 Consultative Group, "The increasing number of people with AIDS, as distinct from people infected with HIV, is beginning to shift issues of care, particularly the human rights dimensions of HIV/AIDS, more directly into the forefront of the HIV/AIDS response in Cambodia. This will continue as the disease matures in those infected"[8].

Home Care Programme, Phnom Penh

The Home Care Programme began in 1998, following discussions between government and the country's HIV/AIDS Coordinating Committee (HACC), which groups together Cambodia's NGOs involved in AIDS. These discussions led to a pilot project in which a network of Home Care Teams was created in Phnom Penh, employing a mix of government and NGO workers.

The initial pilot phase involved nurses from eight government Health Centres, teamed with community workers from five local and two international NGOs (Indra Devi Association, WOMEN, Hope Cambodia, CUHCA, Khemara, World Vision and Maryknoll). It was coordinated and monitored by the National AIDS Programme and the World Health Organization (WHO). The Home Care Teams were made up of one of two alternating nurses from the government health centres and three staff from the community-focused NGOs. Strong links were first made between the Home Care Teams and community resources such as local community leaders (*mei phum*), traditional healers and the members of Buddhist temples (*pagodas*).

[7] All figures in this introduction supplied by KHANA, Cambodia.

[8] NGO Statement, 2000 Consultative Group Meeting on Cambodia, Paris, 24-26 May 2000 (http://www.bigpond.com.kh/users/ngoforum/ngo_statement_2000/hiv_aids.htm).

Referral systems were then developed back and forth between the Home Care teams, the health centres, hospitals for referral, and the three government-run HIV Voluntary Testing and Counselling (VTC) Centres.

After the pilot year, coordination of the programme was taken over by the AIDS Care Unit of the National Centre for HIV/AIDS, Dermatology and STD of the Ministry of Health, and funding by the NGOs. Two new teams were created in 1999, and there are plans for more.

Goals and principles

Lessons learned from established home care programmes in other countries were key in guiding the creation of the Cambodia programme. The programme also adopted the principles of WHO's Continuum of Care (see introduction).

The initial aims were to:

- pilot and test home care services appropriate for people living with HIV/AIDS and other chronic conditions within the Cambodian context;
- pilot a model of health care wherein NGOs and government act in partnership.

These aims were based upon the analysis of the Cambodian situation; that is, limited existing health services, the needs of increasing numbers of people affected by HIV/AIDS, and a growing community-focused NGO sector. The programme has now become a formal element in the overall Ministry of Health Strategy for HIV/AIDS and it is hoped that resources will be allocated to extend it nationwide.

Photo: Home Care Programme, Phnom Penh

The burden of care often falls to an elderly female relative. The Home Care team takes time to listen to her worries and answer her questions.

The objectives of the teams themselves are to provide immediate care in the home, to educate individuals and community members both inside and outside the home, and to make referral links.

Main activities

Training

Initially 40 staff were recruited and trained for three weeks, receiving two weeks of theory and one week of practical work. The training was highly participatory in design, and based upon the *WHO Handbook for AIDS Care* (WHO, 1994, reprinted by SEARO, 1996). Trainers were drawn from the Ministry of Health and different NGOs. As the programme expands, the training curriculum and materials will be adapted and formalized into a set curriculum.

The 40 volunteers were, in turn, given 60 hours of training by the teams. Vacancies in staff positions are often filled by former volunteers.

Ongoing training of Home Care Teams includes counselling, prescribing practices, physiotherapy for pain relief, and peer education, drawing on the specific skills, resources and extensive contacts of the Home Care Network of government and NGO partners. To date, staff and volunteer retention has been good, which has helped maintain a high standard of work and stability of service.

Home visits

The teams visit families within the catchment area of the Health Centres in which they are based. Their primary role is to teach families the management of the treatment of symptoms and to give emotional support. They also encourage good hygiene and nutrition, refer patients to hospitals and voluntary counselling and testing, and liaise with other services as required (e.g. schools, neighbours and Buddhist monks).

Each team carries a Home Care Kit comprised of basic medicines and other supplies. These include simple treatments like Paracetamol, oral rehydration salts (ORS) and gentian violet, as well as selected drugs for more serious symptoms, such as oral candida. In addition, each kit includes supplies such as gloves, soap powder, bleach, bandages, cotton wool, etc. Funds for the kits are provided by the different NGOs, but the drugs are centrally procured and distributed through the Home Care Network.

Photo: Home Care Programme, Phnom Penh

The Home Care teams carry a simple kit of medicines and materials.

Currently, the 10 Phnom Penh teams visit approximately 700 patients per month. Depending on the need, the teams will visit one or more times a week. Over 2000 families have been visited since the beginning of the programme. Based on lessons learned from Thailand's extensive experience with home care, the teams also make visits to patients who are not HIV-positive. Currently in Phnom Penh, about 20% of the patients visited by the programme each month are not HIV-positive. This strategy of responding to all chronically

ill people they meet or are referred to by the community avoids stigmatization of people living with HIV/AIDS. Moreover, by performing home-based treatments that involve touch and close contact with HIV-positive people, the members of the team reinforce their educational messages about what activities do or do not carry risk of transmission[9].

Inevitably many patients have died since the beginning of the programme—each team reports an average of three per month. Since many of these patients were parents, this has meant a notable increase in the numbers of orphans. Additionally, the number of children who are being attended to is increasing. The teams have found that, in nearly half the families they visit, children's schooling is suffering severely and, in more than a quarter, one or more children have had to leave home. The team members conduct informal education sessions with families and neighbours, and are developing strategies for community orphan care.

Education sessions

In order to sensitize the community to the needs of persons living with HIV/AIDS, more formal education sessions are held during local special events or with community leaders. Using the links established with religious leaders, the programme is able to mediate with *pagodas* to ensure access of HIV-positive people to traditional funeral services—an important example of tolerance for the greater community.

Cooperation and funding

Six urban and the two rural teams receive financial and technical support from KHANA (the Khmer HIV/AIDS NGO Alliance), and a further three are supported by the international NGO World Vision, with seven more planned. KHANA is a linking organization of the International HIV/AIDS Alliance, and receives funding from various international donors to strengthen and support local NGOs. Currently, support for the Home Care Teams includes the Ministry of Health's World Bank loan, a significant portion of which the Ministry has contracted with KHANA to manage as a set of small grants to local NGOs.

[9] Joanna Busza. Literature Review: Challenging HIV-Related Stigma and Discrimination in Southeast Asia: Past Successes and Future Priorities (see Population Council's web site at http://www.popcouncil.org/horizons/reports/book_report/review.html).

The programme has had to work hard to maximize cooperation between the various participants. For instance, mutual suspicion between NGOs and government has largely been overcome. Much of this has been achieved through the coordination mechanisms established during the pilot year. These mechanisms vary from informal visits between teams, to regular formal coordination meetings involving all partners (the Home Care Network Group), all of which serve to increase the transparency of activities. Also important are personal contacts between individuals in all the organizations. Finally, there is a formal contract between KHANA and the Ministry regarding the management of funds.

However, teams still report inconsistent support from hospital doctors, who sometimes reject their referrals. It is hoped that increasing recognition of home-based care as a viable strategy in the national response to AIDS will assist in its gaining acceptance from hospital doctors. The AIDS Care Unit of the National Centre is also responsible for developing institutional care guidelines, programmes and support, which are increasingly orientating, training and supporting hospitals to strengthen their part in the national response. Provinces are being helped to develop their own AIDS care strategies, which will bring together institutional care, home-based care and other appropriate responses. As the epidemic progresses, community-based organizations are increasingly looking at strategies to integrate care and support into their AIDS prevention programmes.

Monitoring and evaluation

Ongoing monitoring of activities is provided through the Home Care Network Group, representing all project partners, to whom the teams report monthly. Hospital doctors and service managers join the teams twice a month to supervise and guide the activity.

An external evaluation led by the International HIV/AIDS Alliance, but incorporating government, donor and NGO representatives, was carried out in June 2000. It focused on impact, costs and key components of the model. The major findings were that the programme was having a significant impact on the quality of life among families affected by HIV/AIDS, that coverage was good, and that costs were competitive. Some 92% of patients and families felt that without the Home Care Teams their lives would be significantly more

difficult; 63% of patients felt that the Home Care Team had helped to change their outlook on the future, and 33% felt that they had been instrumental in reducing community discrimination. However, recommendations were made to further adapt the model for rural areas, to improve cost-effectiveness[10] .

The future

Since Cambodia lacks large-scale or extensive welfare services that can be made available for patients, the Home Care Teams have huge and growing demands placed upon them for wide-ranging assistance. Unfortunately, rapid expansion of home care is hindered by the demands that the epidemic is placing on both the government and the NGOs. Funding uncertainties also restrict further development, and increase the dependency upon a wider range of volunteers.

The development of current services is clearly needed across the country The adapted home care model already being piloted in rural areas shows potential for expansion elsewhere. The rapid increase in figures over the past five years indicates that the epidemic has by no means reached its peak. In the meantime, existing Home Care Teams and groups representing persons living with HIV/AIDS are planning to advocate micro-credit and welfare assistance. Potential funding from the government through a World Bank Loan for the funding of provincial teams has generated cautious optimism.

For more information:

Dr Mean Chhi Vun
Director
National Centre for HIV/AIDS, Dermatology and STD
70 Preah Sihanouk Boulevard
Phnom Penh, Cambodia.

Tel/fax: (855-23) 722 515

E-mail: Mchhivun@bigpond.com.kh

[10] Wilkinson D et al. *An Evaluation of the MoH/NGO Home Care Programme for People with HIV/AIDS in Cambodia,* June 2000. Available from International HIV/AIDS Alliance (mail@aidsalliance.org).

3. Centre for Socio-Medical Assistance (CASM), Abidjan, Côte d'Ivoire

background

Facts about Côte d'Ivoire

Total population (1999):	14 526 000
Urban population:	44%
Annual population growth:	3.7%
Infant mortality (per 1000 live births):	85
Life expectancy (years) at birth:	47 (and declining)
Literacy rate: male:	50%
female:	30%
Per capita GNP (US$):	710
Surface area (sq. km):	322 460

Borders:
Côte d'Ivoire shares borders with Liberia, Guinea, Mali, Burkina Faso and Ghana.

HIV/AIDS in Côte d'Ivoire

Côte d'Ivoire is currently the country hardest hit by the AIDS epidemic in West Africa. The number of people infected with HIV is estimated at between 610 000 and 910 000 in 1999[11]. By the year 2005, this number will have increased to between 1 million and 1.3 million.

[11] *Report on the global HIV/AIDS epidemic* spreadsheet.

Seroprevalence rates are currently estimated at between 12.8% and 15.1% in urban zones and between 6.7% and 8.4% in rural zones.

The number of new AIDS cases is estimated at between 90 000 and 106 000 (year 2000), with nearly 2000 deaths related to AIDS per week. Life expectancy has dropped significantly, to 47 years, instead of the 60.3 years that might have been expected in the absence of AIDS. The number of AIDS orphans has also been estimated at between 530 000 and 600 000 (year 2000), and is expected to increase to between 811 000 and 970 000 by the year 2005[12].

Despite the accelerating nature and impact of the AIDS epidemic, the epidemic remains largely unseen. Care of persons living with HIV/AIDS remains in essentially urban centres, and ongoing stigma, discrimination and human rights violations continue to add to the suffering experienced by those infected and affected by HIV/AIDS.

The Centre for Socio-Medical Assistance

The Centre for Socio-Medical Assistance (Centre d'Assistance Socio-Médicale—CASM) is an outpatient clinic for persons living with HIV/AIDS.

The motivation for the project came from volunteers (mainly from the Church of Christ) who were taking care of the sick and dying at the Infectious Diseases Unit of the University Hospital of Treichville (Centre Hospitalier Universitaire, or CHU). It soon became apparent that the vast majority of patients being admitted to the unit were HIV-positive, and that many were being abandoned, stigmatized, or neglected by family, friends and medical personnel. After discharge, few had the means to pay for ongoing treatment, and there was an enormous need to provide compassionate psychosocial support for persons living with HIV/AIDS.

The project was initiated in 1991 by HOPE worldwide—an international NGO allied to the Church of Christ, which has projects with similar aims in various parts of the world. CASM works in close collaboration with the Ministry of Health, the National AIDS Programme, and the University Hospital.

[12] Except where noted, figures are from presentation document by CASM in Paris. They quote a document called *SIDA en Côte d'Ivoire, Décembre 1997*.

Goals and principles

Based on these needs, HOPE worldwide, in collaboration with the Ministry of Health, the National AIDS programme, and the CHU hospital, started the Centre d'Assistance Socio-Medicale (CASM).

Because persons living with HIV/AIDS often find that their family and community connections are shattered by the illness and the fear and stigma that accompany it, CASM's guiding principle has been to restore a sense of solidarity between people living with HIV/AIDS (PLWHA) and their community. It emphasizes that the most constructive answer to improving the quality of life lies in home and community care, and the participation of infected and affected family and community members. Encouraging the direct involvement of persons living with HIV/AIDS in counselling, prevention, support, fund-raising, income generation and care are all activities that directly alleviate the immediate situation.

The Centre for Socio-Medical Assistance began its work with the initial goals of:

- promoting decentralized care for persons living with HIV/AIDS
- providing accessible, affordable and compassionate care
- supporting and encouraging patients to live positively with HIV.

Over time, its goals have expanded to include:

- developing a comprehensive continuum of care for persons living with HIV/AIDS through referrals and 'care linking' with other services or institutions
- integrating persons living with HIV/AIDS into care and prevention programmes
- mobilizing community resources to develop and promote sustainable local action.

CASM's approach to much of its work is based on the belief that the most constructive way to improve HIV-positive people's quality of life lies in home and community care, and the participation of infected and affected family and community members. The direct involvement of persons living with HIV/AIDS in counselling, prevention, support, fund-raising, income generation and care can directly alleviate the immediate situation, as evidenced by such quantitative and qualitative indicators as:

- reduced hospital admissions
- reduced morbidity/prolonged productivity
- reduced stigma
- number of associations for persons living with HIV/AIDS
- number of income-generating projects
- strengthened prevention activities
- reduced stress, anxiety and depression
- community resources to develop and promote sustainable local action.

Major elements of the project

CASM carries out a wide variety of activities, of which the main ones are as follows.

Medical care

CASM employs two full-time and two part-time doctors, a pharmacy assistant, and four project and support staff. It also has a four-bed capacity for those requiring HIV treatments and monitoring. A nurse, who is openly HIV-positive herself, also volunteers regularly at the centre.

The centre follows, as far as possible, treatment procedures outlined by WHO, in its *AIDS Home Care Handbook,* as well as those adapted by local government. Most persons living with HIV/AIDS attending the centre are indigent and have little family financial support. Patients pay the equivalent of $2.50 per month for medical consultations and basic drugs, regardless of the number of consultations. These drugs include many of those found on the WHO essential drug list and are, for the most part, procured from the main government pharmacy at almost cost price.

Referrals

The clinic acts as a referral centre for persons living with HIV/AIDS. On average, 25–30 new patients are referred to CASM every month. The ratio of men to women referred is now equal—a major change since the first few years when it was almost 4 to 1. The average age of those referred is 25.

Referrals come from:

- the main infectious diseases hospital (CHU de Treichville), which, through an official agreement, offers the centre tariff reductions on all specialist consultations, laboratory work, and hospitalizations;
- a voluntary testing and counselling centre (CIPS);
- a hospice centre (OASIS) that offers free care and hospitalization to those patients in the terminal phase of their illness and/or those who require prolonged convalescent care;
- AIDS NGOs, associations of persons living with HIV/AIDS, and volunteers who provide support and follow-up at the community level.

It also takes a small proportion of referrals from the private sector and from health services in outlying regions.

Counselling

The centre employs two counsellors (one full-time and one part-time) and one psychologist. Various counselling and support strategies/techniques (such as group counselling, video viewing and picture codes) are used to promote acceptance of seropositive status as well as positive living and coping strategies. Counsellors from the centre also form part of a 'trainer of trainers' group, which is regularly called upon by the National AIDS Programme, institutions and agencies.

CASM has also conducted multicentre research on the impact of counselling on persons living with HIV/AIDS (the results of this project are available in French on the Internet at http://www.refer.org/ivoir_ct/sante/psa/b7.htm).

Home-based support

The centre has a team of approximately 20 community agents who provide home-based support for persons living with HIV/AIDS. The community agents make about 40 home visits to patients every month.

During the home visits, agents assess living conditions, address psychosocial needs and, when necessary, accompany ill persons with HIV/AIDS to the centre or to the nearest hospital. Community agents also spend one day a month at the centre counselling those attending the clinic. All information obtained, needs assessed and services rendered are recorded after the visit to ensure proper follow-up. Community coordinators interact regularly, and community agents meet once a month to discuss relevant cases, issues, problems and ways to improve the programme.

Support for persons living with HIV/AIDS

In 1994, CASM facilitated the development of the area's first support group for persons living with HIV/AIDS—the *Club des amis* (Friends' Club). Its goal was to provide opportunities for persons living with HIV/AIDS to share common experiences, hopes and fears, and to rebuild dignity, a sense of self-worth, hope, and friendships. It strongly promotes responsible sexual behaviour among its members.

The *Club des amis* (CDA) is now a fully fledged association in its own right with over 300 members and has itself facilitated the creation of three other associations for persons living with HIV/AIDS. Daily, a core of club members supports clinic staff with counselling and support issues, fulfilling their desired role as peer educators and counsellors. Club members are also actively involved in joint AIDS prevention programmes (including participating in the centre's theatre group, whose name, *Kazenze*, means *staying together*). The centre has also provided nutritional, material and financial assistance to persons living with HIV/AIDS.

With the support of the Lions Club, a local NGO called Initiative Plus, and a group of four to six volunteers, the centre provides a daily free breakfast to all its clients. The breakfast table also serves as a safe place for discussion and interaction between persons living with HIV/AIDS.

CASM and CDA collaborate on peer education efforts, which have helped increase AIDS awareness at clinic level. For example, peer support

groups have aided problem-solving on psychosocial issues that may inhibit behavioural change. The use of peer counselling has made AIDS education more acceptable to patients who visit the clinic.

Photo: CASM, Abidjan

Richard is the coordinator of CASM's income-generating schemes. Members of the club make cards from donated and recycled materials.

Income generation

Through various income-generating projects and donations, CASM has been able to provide small cash incentives to persons living with HIV/AIDS who have requested financing of viable projects or who need urgent financial assistance. These have been given mainly to support indigent HIV-positive women and children. Patients are encouraged to participate in card-making, earning 20% of the sale price of each card.

Support for orphans

Together with one of the associations of persons living with HIV/AIDS, the centre has been able to support a small number of orphaned children by keeping them in school and providing them with basic support and provisions. The centre also holds an annual Christmas party for orphans and severely affected children. This event has been well supported by a wide range of partners.

AIDS prevention activities

The centre's prevention programmes have, in recent years, targeted four particularly vulnerable groups: women, young people, prisoners, and underserved communities. Peer educators have been trained within most of these target groups. For example, CASM runs a programme at Abidjan's municipal jail (Maison d'arrêt d'Abidjan, or MACA), where an estimated 25% of prisoners are HIV-positive.

Prevention programmes have reached over 200 000 people over the past five years. Group discussions, community conferences, slide shows, theatre, personal testimonies and other strategies have been used to achieve the greatest possible impact. Media support and coverage of CDA activities have further promoted AIDS awareness. Many of these interventions have been designed in collaboration with other NGOs and youth and sports associations, and have included the participation of persons living with HIV/AIDS in their design and execution.

Photo: CASM, Abidjan

At half time in a football match, the theatre group provides entertainment. The story: Father has discovered a condom in his son's room. Mohammed Limine (on his knees) is a well-known TV comedian who is HIV-positive.

According to CASM staff, the use of personal testimonies by HIV-positive persons in prevention work has both humanized and personalized the AIDS epidemic. Visibility of persons living with HIV/AIDS within communities and schools has promoted more open discussion on AIDS and sexuality.

A typical example of such a testimony is the following, given by a CDA member named Albert:

> *"I haven't told any members of my family that I'm HIV-positive," says 32-year-old Albert, "but I've done a will, explaining everything about my situation. I can't tell them I've got HIV because I'm the eldest and the best educated in the family, and it would be like admitting that I can't do anything for them. They would feel betrayed...*
>
> *"I went for a blood test because I'd heard about CIPS (the testing and counselling centre) on the radio. The counselling they gave me before the test was really good. In fact, if it hadn't been for that, I'd never have had the courage to go back for the result... But when CIPS sent me to a hospital for treatment, things were not so good. The first doctor I saw was very nice, but she sent me to another department for treatment. I had to expose myself to some trainee doctors, and afterwards I overheard them talking about me. One was saying 'Hey, did you see that guy with AIDS, with all the lumps on his penis?' It was really humiliating for me, and I complained to the doctor about it.*
>
> *"Because I couldn't pay for the medicines they prescribed, they sent me to CASM (Centre pour Assistance Socio-Medicale), where I was received very warmly. They gave me coffee and bread, the doctor examined me, and I was given the medicines I needed. When the Friends' Club started, I got involved, and now I'm in charge of the small projects to help our members earn some money.*
>
> *"I also started going to church, and that's helped me a lot. I used to feel very bitter and wanted to revenge myself on society, but that's all gone now.*

"But I still have quite a few problems. I stay with a cousin and his family, but they don't know my HIV status. I'm afraid they'd reject me if they knew. My cousin is already suspicious. He says if I've got AIDS I should tell him. I'm desperate for a job too. When you don't work, you think of suicide all the time. But I'm afraid of my HIV status becoming known because employers sometimes test their staff for HIV without telling them"[13].

Volunteers

In most of its activities, the centre benefits enormously from a large pool of volunteers. Many of the CASM staff first began working as volunteers, coming from AIDS NGOs and associations, religious groups, international institutions and agencies, and the community at large.

Volunteers support the centre in a number of ways and at different levels. Within the centre, they provide counselling and support, help with the daily functioning of the centre (cleaning, typing, filing, etc.), cook and serve breakfast, make greetings cards for sale by the centre, and decorate the centre in order to make it a pleasant and inviting place. Outside in the community, the volunteers carry out home and hospital visits to patients; help with AIDS prevention campaigns, marches, and conferences; sell cards made at the centre; and carry out fund-raising and publicity.

The volunteers, particularly those assisting at the clinic level, receive small financial and material rewards as well as free medical services. Coordinators, who meet regularly with volunteers, organize volunteer activities at both the clinic and community level.

Financial support

Financial support comes from a variety of sources, including:

- HOPE worldwide, USA
- agencies and institutions that fund specific ongoing projects (prison, youth, counselling)
- income-generating activities (card-making)

[13] Extracted from *Filling the Gaps: Care and Support for People with HIV/AIDS in Côte d'Ivoire*. Strategies for Hope No 10. ACTIONAID. London, 1995.

- participation by those with HIV/AIDS ($2.50 per month)
- donations.

Material support is also obtained through local donations by individuals and businesses, as well as food and clothes drives.

Finally, technical support and training through workshops and conference attendance assistance has come from international agencies such as USAID, UNICEF, UNAIDS, UNDP and Coopération Française. This support has come through training workshops, conference participation (local and international), seminars, research projects, consultant visits and collaborative programmes. The centre also has a library, with resource documents, manuals and videos, covering a wide range of subjects.

Monitoring and evaluation

The programme has conducted its own internal reviews over the years as a means of improving its work. According to these reviews, CASM's strengths include:

- a large pool of committed volunteers;
- strong collaboration with associations of persons living with HIV/AIDS;
- care links with centres that act to strengthen the care continuum;
- expertise/trainers in certain fields (such as counselling and prevention).

The programme's challenges and weaknesses include many problems common to home and community care programmes in sub-Saharan Africa: inadequate funding (notably an inadequate budget for the purchase of basic drugs), dependence on external funding, and lack of managerial staff and capacity to raise funds.

Many of these weaknesses result from the severity of the epidemic and the fragile economic condition of the area. Potential support from local resource mobilization is clearly extremely limited, and for this reason the project is highly dependent on external funding. This also prevents it from hiring trained managerial staff or purchasing all the basic drugs it needs to meet patient demand.

Project staff believe that there are untapped local resources that might be used to reduce its dependence on outside donations, but the centre has been unable to gain entry to these resources.

The programme considers it urgent to conduct further capacity-building and training, especially in programme management, fund-raising and programme evaluation. At the same time, it requires larger premises in order to provide better counselling and administrative services.

The future

There are many plans for the future. One is to increase CASM's networking 'reach' in order to create multi-level partnerships (i.e. beyond its current, mainly local ones) to promote sustainability, continuity, synergy and greater participation in the fight against AIDS. One extremely important aspect of this will be to strengthen links with the private sector by marketing AIDS training programmes in exchange for financial and material assistance.

Other projects for the future include:

- an orphan support programme (currently being developed with UNICEF);
- the expansion of the production and sale of greetings cards to enhance income generation (authorization has been granted by the Ministry of Health to sell the cards in public locations);
- the development of closer links with the legal services in order to more effectively protect the rights of persons with HIV/AIDS and their families;
- the further promotion of greater involvement (and training) of family patient care and support;
- expanding the home visit programme to include home care;
- obtaining access to more HIV-related drugs including antiretrovirals.

For more information:

Dr Marc Aguirre
Hope worldwide
B.P. 1021 Cedex 1
Abidjan 06, Côte d'Ivoire.
Phone: 225 41 80 83
Fax: 225 41 80 83

E-mail: 105223.3613@compuserve.com

Website: www.hopeww.org/

4. Programme for AIDS Initiatives, Ecuador

background

Facts about Ecuador

Total population (2000):	12 646 095
Urban population:	64%
Annual population growth:	2.1%
Infant mortality rate (per 1000 live births):	30
Life expectancy (years) at birth:	70
Literacy rate: male:	92%
female:	88%
Per capita GNP (US$):	1390
Surface area (sq. km):	283 560

Borders: Colombia to the north, Peru to the east and south, and the Pacific Ocean to the west.

HIV/AIDS in Ecuador

The first HIV/AIDS case in Ecuador was detected in 1984, and although the prevalence of HIV infection and AIDS cases in Ecuador is relatively low, there has been a rapid increase over the past few years. Reported HIV/AIDS cases rose 94.8% between 1996 and 1999[14]. In particular, the number of women as a percentage of the total number of people living with the virus rose rapidly in the 1990s. The total number of officially reported HIV/AIDS cases, as of December 1999, was 2457, but estimates suggest the number might be as high as 18 000[15].

[14] Figure provided by Kirimina.

[15] *Report on the global HIV/AIDS epidemic* spreadsheet.

Ecuador is a multicultural and multi-ethnic country, which complicates the task of providing prevention and care. People from most vulnerable groups (such as migrants, sex workers and men who have sex with men) are reluctant to be tested, and official estimates of the incidence of HIV/AIDS may be quite inaccurate. Furthermore, few persons living with HIV/AIDS are willing to make their serostatus public, for fear of losing their jobs and because of potential discrimination and stigmatization both from their families and society in general. For these same reasons, few have been willing to become publicly involved with prevention or care projects.

As well, Ecuador's population is relatively young, with 7.9 million of the total population of 12.6 million under 30 years of age. During 1999, there was a 110.5% increase in the number of cases of HIV/AIDS in the population under 20 years old, when compared to the cumulative 1984-1998 number[16] .

The national AIDS response

Although a National AIDS Programme was set up in Ecuador as early as 1987 with the help of WHO/PAHO, its resources were focused on acquiring materials for HIV testing. In 1994, the programme lost most of its financing, which has not been restored. At the same time, the Ministry of Public Health (MPH) has seen its budget cut drastically, and has been unable to acquire antiretrovirals and other treatments for persons living with HIV/AIDS.

Recognizing that the problem was beyond the resources and capacity of the MPH to deal with alone, the government created a National AIDS Council (CONASIDA) in 1995. The Committee includes representatives from the MPH, Ministry of Education, Ministry of Government, Ministry of Public Welfare, a representative of PLWHA and a representative of NGOs.

The origins of the programme

The Programme for AIDS Initiatives originated with an Ecuadorian development NGO called Comunidec, which was founded in 1985 to create dialogue and solidarity between various ethnic and disadvantaged social groups, and to increase these groups' ability to define their problems and act to solve them. It also facilitated the creation of local and regional networks of NGOs and community-based organizations (CBOs) to promote local development

[16] Figures provided by Kirimina.

initiatives. Over the years, it gained a great deal of experience in working with international partners and adapting their techniques and expertise in its development projects.

In 1995, Comunidec started its Programme for AIDS Initiatives (Programa de Initiativas frente al SIDA) as a means of linking and supporting community HIV prevention and care programmes throughout the country. This coincided with, and benefited from, an international programme of the London-based International HIV/AIDS Alliance. In cooperation with nationally-based partners in several developing countries, the Alliance created a series of workshops that aimed to establish or improve HIV-related NGOs' relationships with business, media, government, local health services and other nongovernmental organizations. Partners in developing countries are chosen on the basis of their ability to act as a national-level 'linking organization' able to transfer the methodologies to local or regional groups.

Following testing of these workshops in the mid-1990s with an NGO partner in the Philippines called PHANSUP (Philippine HIV/AIDS NGO Support Programme), the Alliance worked with Comunidec to apply them in Ecuador. Through its own programme of AIDS initiatives, Comunidec not only adapted the workshops to local conditions but added new elements, such as church relations and building of NGO/CBO solidarity.

Comunidec was the Alliance linking organization from 1995 until March of 2000, when it dropped its AIDS programming to concentrate on its original areas of focus. Starting April 2000, a new organization, called Kimirina, became the new Alliance linking organization. (*Kimirina* is a word in the indigenous Quechua language meaning *getting together to accomplish something*.)

Goals and principles

The programme was initially conceived as a means of linking and supporting community HIV prevention and care programmes throughout the country. Its overall goal is to help reduce both the advance and the impact of the epidemic in Ecuador.

The basic principle of its approach to care and support projects is the belief that home and community care are fundamentally important for persons living with HIV/AIDS. There is also a strongly-held view that there is a need to mobilize those directly affected (PLWHA, family and friends) and the immediate community (e.g. neighbours, members of same parish, etc.) of the persons living with HIV/AIDS in planning and implementing activities.

In doing so, it focuses particularly on the following groups:

- broad populations including men and women in the 'popular' sectors (in Spanish, generally designating people with relatively low incomes), peasant and indigenous women, and young people outside the formal education system
- especially vulnerable groups such as transvestites, prisoners, truck drivers, sex workers, men who have sex with men, and migrants
- health workers
- people living with HIV/AIDS, their partners and families.

Rather than working directly with individuals, however, the Programme seeks to increase the organizational and technical capacity of NGOs and CBOs (whether AIDS-related or not) who are already working with these various populations. Such NGOs and CBOs include:

- organizations originating in or working with communities on broad issues such as development, health, gender, human rights, sexuality and citizen participation
- AIDS-related organizations that work either in prevention or in caring for persons living with HIV/AIDS
- organizations working with populations considered especially vulnerable to HIV infection (listed above)
- organizations with strong links to local or national governments, which have the ability to influence policy-making at various levels.

In the first year, because of the low levels of HIV infection reflected by existing epidemiological research, the Programme supported only preventative projects. However, during implementation of these projects, the need for care and support for people living with HIV/AIDS became apparent. Accordingly, the programme began to work with care and support projects. It also began to create opportunities for PLWHAs and members of the country's few AIDS groups

to take part in the prevention workshops and other capacity-building activities mounted for NGOs and CBOs.

Major elements of the project

Once it has identified a partner organization, the Programme provides technical assistance and small grants that allow the partner to improve or expand its current activities, or take on new ones related to AIDS.

Partner selection

The selection process starts with a Request for Proposals (RFP), which can be of two types: open or closed. An open RFP is meant to bring in organizations that are new to HIV/AIDS work, or whose work needs to be strengthened. Any organization is free to present a proposal. In contrast, a closed RFP is one in which specific NGO or CBOs are invited to present a proposal. Usually, this is for organizations that have previously had grants from the programme, and the resulting grant is awarded in order to support ongoing work.

In both types of RFP, proposed projects must demonstrate their potential to:

- generate knowledge that can be applied by other organizations
- provide prevention and care services in geographical areas or with specific populations where there is an unmet demand, or where need is determined by epidemiological data
- become a technical reference centre in their region, thereby increasing the sustainability of HIV/AIDS work in that area.

Additionally they have to:

- demonstrate motivation and interest in working in sexual health and HIV/AIDS
- have a transparent organizational structure and management
- be open to sharing their experiences and lessons learned with other NGOs
- be a non-profit organization.

Their needs are determined by the observation of their work in the monitoring visits, review of their reports and by the requests made by the NGOs themselves. For the organizations that do not have previous

experience in HIV/AIDS, the Programme provides a set of workshops with the basic information (HIV/AIDS, sexuality and STIs) and tools they need to get started.

Capacity-building

The technical assistance (TA) includes:

- information on sexuality and HIV/AIDS (participatory workshops)
- training in counselling (participatory workshops)
- project planning and evaluation methods (workshops and TA one on one)
- participatory community assessments (workshops and monitoring field visits)
- institutional strengthening, through financial management training, including accounting (TA visits by the programme's financial person—training based on specific needs)
- more recently, operations research and gender analysis (national-level workshops as well as smaller workshops for each NGO).

Photo: Programme for AIDS Initiatives, Ecuador

In a follow-up to a workshop, a home visit is made by the Grupo Despertando.

While some training is given to workers in national workshops, perhaps more significant is that given to teams locally. The smaller workshops, which include approximately ten participants, have been very effective in building a sense of 'ownership' or belonging that has motivated teams to continue their work. Training such as project planning has been given in participatory exercises that determine objectives, indicators and activities to be fulfilled during the year.

The training is mostly given once the grant agreement has been signed. Additionally there are monitoring visits once a trimester, with more technical support visits scheduled as needed. There is also close telephone contact on a regular basis.

Care and support

The programme currently gives technical assistance and grants to several organizations that provide home and community care for persons living with HIV/AIDS in Quito and Guayaquil. Some examples are:

- Fundación Dios, Vida y Esperanza (God, Life and Hope Foundation) was founded by people living with HIV/AIDS and by health professionals as a response to the lack of HIV-specific care and support services. Medical doctors and psychologists (members of the foundation) provide care to people living with HIV/AIDS and their families on a voluntary basis. The medical care is limited to treating opportunistic infections, as they do not have access to antiretrovirals. They also have a home-care programme in which a team made up of a HIV-positive volunteer and a health professional (if available, otherwise another volunteer) do home visits. During these visits, they provide psychosocial support to the whole family and teach them basic information on HIV/AIDS, first aid, nutrition, and tips on what to do when the HIV-positive person is in a crisis; however, they refer to the professional services provided by the Foundation or elsewhere when needed. In a recent project, they trained women living with HIV/AIDS and women health professionals to provide prevention training workshops to women in poor urban areas of Guayaquil (the largest city in Ecuador with the largest number of HIV/AIDS cases in the country). This is an effort by the women living with HIV/AIDS to give something back to

the community and thus feel useful in helping other women stay HIV-negative. At the same time, it makes the seropositive women feel useful and productive, enhancing their self-esteem.

- Fundación Siempre Vida (Life Forever Foundation) is an NGO based in Guayaquil that concentrates on providing counselling to HIV-positive people by HIV-positive people. They also do home and hospital visits on request and help persons living with HIV/AIDS by accompanying them to doctors and hospitals when they first find out about their HIV status. They also have one of the few working self-help groups in Guayaquil, which meets regularly. On average, they serve around 140 people per year.
- Fundación Vivir (Life Foundation) is based in Quito, and was created by persons living with HIV/AIDS in response to the lack of services available for HIV-specific care and support. They offer medical, dental and psychological care with the assistance of volunteer doctors, dentists and psychologists. They have two self-help groups—one for men and another for women. They also accompany HIV-positive people to get paperwork done, or go to laboratories or hospitals for services.

Quality improvement

The Quality Improvement Project started in early 1999 and will continue until October 2000. This project is being carried out with support from the World AIDS Foundation (WAF) and the Alliance. The project seeks to improve the quality of services provided by 11 NGOs through operations research and gender analysis. These 11 projects are part of the 23 currently being financed.

Monitoring and Evaluation

To date, the evaluation of projects has been done by the Programme through reports from the NGOs, and then again in national workshops where the results of programmes are shared and compared. As many of the NGOs are directly involved with home and community care, they have created their own parameters to measure the quality of their work, which may include such elements as technical expertise, empathy with clients, and gender differentials.

However useful reports and national workshops may be in providing an overall picture, and in facilitating the exchange of views between different NGOs, the monitoring of programmes in the field is indispensable. Observing the organizations in action has provided a greater understanding of the nature of the work, thereby allowing for the identification of specific areas that need priority technical support. In addition, the workers in the field, who provide care and support to persons with HIV/AIDS, are themselves supported in their work by these visits. For the betterment of the monitoring, the evaluation, and the effectiveness of the community care programmes, at least three visits a year are recommended in order to service a sufficient programme.

Photo: Programme for AIDS Initiatives, Ecuador

Educational material is developed at Foro Permanente de la Mujer en Esmeraldos.

Results

The programme has supported 110 projects within 41 organizations in 14 provinces over the five years it has been working in Ecuador. The following table gives a sense of the range of target populations served and their geographical spread.

Projects supported by Kimirina in 1999-2000

Organization	Population served	City and province
Fundación Esperanza	Clandestine sex workers	Quito, Pichincha
Fundacón Guazhalán	Schoolteachers and parents of schoolchildren	Gualaceo, Azuay
Centro Cultural Pájara Pinta	Peasant women and young people	Deleg, Cañar
Habitierra	Peasant and indigenous women	Cañar, Cañar
Clínica de Nar	Peasant women	Cañar, Cañar
Asociación Niños Pichincha	Young people in Felices	Quito, poor urban areas
Fundación Dios, Vida y Esperanza	Women (both HIV-positive and HIV-negative) in poor urban areas	Guayaquil, Guayas
Fundación María Guare	Women and their partners in poor urban areas	Guayaquil, Guayas
Fundación Siempre Vida	People living with HIV/AIDS	Guayaquil, Guayas
Club social J. Forever	Young people in poor urban areas	Esmeraldas, Esmeraldas

Organization	Population served	City and province
Fundación SOGA Manabí	Young people in secondary school	14 cantons in Province
CEMOPLAF – Riobamba	Young people in school	Riobamba, Chimborazo
CEMOPLAF – Lago Agrio	Sex workers and their clients	Lago Agrio, Sucumbíos
Cruz Roja de Loja	Young people in school	Vilcabamba, Loja
Fundación Vivir	People living with HIV/AIDS	Quito, Pichincha
CEDIME	Peasant and indigenous women	Puyo, Pastaza
Colectivo de Alternativas Humanas	Young people in school	Guayaquil, Guayas
Grupo de Mujeres Despertando	Women and men in poor urban areas	Guayaquil, Guayas
CEPAM Guayaquil	Health workers	Guayaquil, Guayas
Fundación Nuestros Jóvenes	Young people in jail	Quito, Pichincha
Fundación José de Arimatea	People living with HIV/AIDS	Guayaquil, Guayas
Cocinelle	Transvestites and sex workers	Quito, Pichincha
Foro Permanente de la Mujer en Esmeraldas	Young people and women in poor urban areas	Esmeraldas, Esmeraldas

The major local benefit has been in the increase of the number of care and support groups. There are eight NGOs that provide care and support with which Kimirina has worked. Comunidec and Kimirina have not helped them get established as an organization, but have helped them provide better, more professional services. In the beginning, the majority

of them had the motivation and interest, but the programme gave them the know-how. They worked largely on an empirical basis before. They, in turn, provide the psychosocial support so important to those living with HIV/AIDS. With a general lack of funding, this is often the only help provided, and the establishment of self-help groups and counselling has been most beneficial.

Another benefit is that NGOs and CBOs already working with women and local development (but with no experience in AIDS) have been able to assess the AIDS-related needs of their communities, and begin, or take over, existing AIDS work. In particular, these organizations have been able to move beyond basic AIDS awareness-raising campaigns to programmes addressing (a) individual and social vulnerability and (b) behavioural change. At the same time, experienced AIDS groups have been able to take on a development perspective and expand their support network through relations within the newly mobilized nongovernmental sector.

For example, CEMOPLAF is one of the leading reproductive health NGOs in Ecuador. It had not formerly focused on AIDS prevention, except to provide some basic information. Today, however, one of the CEMOPLAF clinics with which Kimirina is working includes STI and HIV prevention in all its education programmes and it has incorporated it into its family planning counselling. Similarly, the women's organization CEPAM has developed, with the Programme's support, a training programme on STI diagnosis and treatment for health professionals in Guayaquil.

Another example is Asociación Niños Felices—a neighbourhood organization in northern Quito. The Programme helped them start a set of training workshops for teenagers in the area, which are given by young people. They were so successful that a local school asked them to give training sessions to regular classes as well. They subsequently received funding from a Christian children's fund to hold similar workshops for adults.

This has led to the general strengthening of the institutions. For example, following assistance given in project planning, some organizations have been able to find their own funding from donors. Fundación Vivir was able to find external donors to help them buy computer equipment and a house where they can work. The Municipality of Portoviejo Fundación was persuaded by SOGA to donate a piece of land in order to build a hostel for PLWHA, and is also receiving building materials from different sources.

The Future

While work with the groups seen as more vulnerable to HIV/AIDS will continue, the programme feels that it is necessary to begin to attend to the groups who are considered 'core transmitters' of HIV. In Ecuador, this includes not only male and female sex workers, but also patients of clinics that diagnose and treat sexually transmitted infections and, even more specifically, men who work away from their families (e.g. vehicle drivers, petroleum workers).

This would be a role for the NGOs, who have expressed a need for further technical support to enhance their work, not only in the direct support of a person living with HIV/AIDS but also in areas such as external relations, financial management and micro-credit and micro-enterprise. This latter information would enable them to enhance their present activities.

With the creation of Kimirina, the Programme has placed its central emphasis on working with larger NGOs that already have an established network of services. Through alliances with them, the Programme helps them incorporate HIV/AIDS into their existing work, thus expanding their coverage. The objectives until now have dealt almost exclusively with the immediate needs of persons living with HIV/AIDS. It is now necessary to broaden the impact of these contributions through strategic alliances with cooperative facilities, while still remaining a centre of technical support and a developer of appropriate tools and methods for work on AIDS care and prevention in the region.

For more information:

Margarita Quevedo
Corporación Kimirina
Ramírez Dávalos 258 y Páez
Quito, Ecuador

Telefax: (593-2) 543-246, 568-767, 556-750

E-mail: mquevedo@quik.com.ec

5. Continuum of Care Project, Manipur, India

background

Facts about India

Total population (1999):	998 056 000
Urban population:	27%
Annual urban population growth:	2.2%
Infant mortality rate (per 1000 live births):	70
Life expectancy (years) at birth:	63
Literacy rate: male:	66%
female:	38%
Per capita GNP (US$):	370
Surface area (sq. km):	283 560

Borders: shares borders with Pakistan, Afghanistan, Nepal, China, Bhutan and Bangladesh.

HIV/AIDS in India

In testing for HIV prevalence among antenatal clinic women tested in the major urban centers of Calcutta, Mumbai and New Delhi, median HIV prevalence has increased from 0% in the late 1980s to 2% in 1999. In Mumbai, the major urban area in western India, HIV prevalence has increased from 1% in 1993 to 3% in 1999. Outside the major urban areas, median HIV prevalence among antenatal women tested in 1999 was 0.3%. HIV prevalence was 0% in 34 of the 86 reporting sites. Among sex workers tested in Mumbai, HIV prevalence had reached 51% in 1993. In Calcutta, 12% of sex workers tested in 1997 were HIV-positive. In 1999, 58% of sex workers tested in Vellore and 11% of sex workers tested in Agra were HIV-positive. In 1998 and 1999, HIV testing among STI clinic patients became

part of the National AIDS Control Organization sentinel surveillance system. In 1999, 4% of STI clinic patients tested in the major urban areas were HIV-positive, however the range was from 1% in New Delhi to 64% in Mumbai. Outside the major urban areas, a median of 2% of STI patients tested at 71 sentinel sites were HIV-positive with a range of 0-45%.

The State of Manipur

Manipur is a small North Eastern state whose capital is the city of Imphal. The state has a population of just over 18 million in an area of 22 327 square kilometres. Topographically, it is divided into two parts—the valley and the hills—with 64.4% of the population living in the four valley districts of Imphal East, Imphal West, Bishnupur and Thoubal. The remainder of the population resides in the five hill districts of Ukhrul, Senapatti, Tamenglong, Chandel and Churachandpur[17].

Manipur has the highest HIV prevalence in India, with some parts of the state approaching the levels found in sub-Saharan Africa. The table below indicates an overall level approaching 2.7% of the screened population, who are mostly adults from urban areas. It is estimated that seropositivity among injecting drug users has stabilized at 67.51% (see Table 'Risk Categories', opposite).

Epidemiological analysis of HIV/AIDS in Manipur: September 1986 to June 2000

Number of blood samples	Sero-surveillance	Sentinel surveillance	Total
Screened	48 063	20 830	68 893
Number of positives	7565	2634	10 199
Number of females	1045	—	1045
Number of AIDS cases	669	—	669
Number of deaths	139	—	139
Seropositivity rate per 1000 samples screened	157.4	126.5	148.0

Source: Epidemiological Report, MACS

[17] Note that the project described here does not reach the entire population of the state. The population within the project area is about 3.6 million.

Risk categories among people testing positive

Risk category	Number of HIV-positive cases	% of total HIV-positive cases
Injecting drug users (IDUs)	5107	67.5
STI clinic attendees	363	4.8
Suspected AIDS cases	229	3.0
Blood donors	218	2.9
Relatives of AIDS patients	95	1.2
Antenatal mothers	74	1.0
Blood recipients	48	0.6
Others	1431	18.9
Total:	**7565**	**100.0**

N.B. These figures were rounded before addition.

The institutional health system (i.e., hospitals and clinics) suffers from inadequate knowledge about, and skills related to, HIV/AIDS, as well as an overall lack of resources. There are insufficient supplies of medicines useful in HIV/AIDS care such as antifungals, antidiarrhoeals, Bactrim-DS, dextrose, etc., and treatments for specific opportunistic diseases. In addition, basic biosafety is often compromised due to inadequate levels of basic supplies (gloves, disinfectant, syringes, clean linen) and infrastructure (regular supply of water and electricity, incinerators and proper sanitation).

The cultural context in Manipur has a significant effect on the epidemic. In general, society is not open to discussion about HIV/AIDS and the behaviour that puts people at risk. This is particularly the case among the Hindu people of the plain, for whom talking openly about sex and sexuality is taboo. Another obstacle is that the state is ethnically and linguistically diverse. For instance, Churachandpur district is inhabited by eight major ethnic groups, each of which speaks its own dialect.

Finally, as a result of the epidemic, a rapid rise in the numbers of widows and orphans is becoming apparent. This poses a serious potential threat to the socioeconomic structure of society, and to the State's under-resourced social services.

Continuum of Care Project

Starting in 1994, the Continuum of Care Project (COCP) evolved out of a series of discussions and workshops with the Government of Manipur, the National AIDS Control Organization (NACO), Oxfam, WHO, the British Council, and representatives of 28 local NGOs.

This project was launched to bring about a concerted and integrated effort by the government, NGOs and relevant sectors of society, to rally their support and services for persons living with HIV/AIDS in three geographically distinct areas of Manipur. The programme initially concentrated on reaching intravenous drug users from a socioeconomically deprived population of indigenous peoples. Recently, however, the programme has begun to address the additional, complex challenge of meeting the care needs of former IDUs, their partners and their children.

Goals and principles

The COCP is in its fifth phase, for which it has received financial assistance from the National Lottery Board (NLCB). The main objective of this phase has been to extend services in order to establish a continuum of comprehensive care services for persons living with HIV/AIDS, as outlined in WHO's *Handbook of AIDS Home Care* (see Introduction). The following specific objectives were developed, of which the first three directly concern hospitals and health institution:

- create core interdisciplinary teams within health facilities, and provide them with relevant training for providing care to HIV-positive patients
- create an NGO core group and train its members to provide emotional and social support to persons living with HIV/AIDS
- further develop the existing referral network linking health services with NGOs

- create and distribute a culturally-specific AIDS home-care handbook for use in local languages
- improve the monitoring system to ascertain the impact of the programme.

Major elements

Core groups are one of the main innovations of the programme. They are designed to help members (and the institutions or sectors they represent) better understand the needs of persons living with HIV/AIDS, reduce their prejudices about at-risk populations, and provide better care and support to them. Each core group selects representatives who sit on a joint coordination team in their respective project areas.

Core groups at hospitals

The first objective was to form multidisciplinary core groups among the hospitals. In order to achieve maximum acceptance by the institutional hierarchies, the heads or directors of the respective hospitals were the first people officially contacted by COCP. These contacts were followed by frequent conversations explaining the concept of the care continuum for HIV/AIDS. Only when a solid level of trust had been built up were the core groups formed.

The hospitals' core groups bring together doctors, nurses and laboratory technicians in quarterly meetings chaired by the head of the institutions and facilitated by COCP staff. The groups were organized as follows:

- In Imphal, core groups were established at the Regional Institute of Medical Sciences Hospital (19 members); Jawaharlal Nehru Hospital (20 members); the Tuberculosis Hospital (11 members); and the Tuberculosis Clinic (12 members).
- In Kakching, one core group was created at the area's Community Health Centre (8 members). Another was created to involve traditional healers who use herbal and other natural cures but, to date, this only has one member.

- In Churachandpur, a core group was established at the Churachandpur District Hospital (9 members).

Focus group discussions were held as part of the process of creating the core groups, and were very useful in identifying problems that needed attention. In a discussion about why HIV/AIDS patients are often badly served in the institutional health system, the system's general lack of resources was found to be an important factor in 'de-motivating' service providers. The inability to follow basic biosafety measures, due to lack of equipment and materials, is the main reason hospital staff gave to explain why they ignore AIDS patients. The groups also agreed that hospitals needed discharge plans to ensure the proper care and follow-up for persons living with HIV/AIDS. As a result, formal discharge planning was adopted by all hospitals.

As the core groups started meeting, it was soon observed that the nurses had difficulties in expressing their problems concerning HIV/AIDS care in the presence of their superiors (i.e. doctors). This was recognized as a serious problem given the pivotal role nurses play in providing care, in referrals between care teams, the difficult role of nurses within health institutions, and the special circumstances they may encounter with HIV/AIDS patients. Hospital matrons and nurses in charge therefore requested that a separate nurses' core group be formed. This was done at the two main hospitals in Imphal—JN Hospital and RIMS Hospital.

Core groups in nongovernmental organizations

Core groups were also created to bring together NGOs and CBOs, which are directly involved in the field of drug abuse, and HIV/AIDS. Examples of NGOs include:

- World Vision, the international NGO, operates a branch office in Manipur from which it provides financial support to HIV-positive people who are otherwise unable to buy medicine for opportunistic infections.
- Sneha Bhavan, a charitable trust organized by the Silesian Sisters in North-east India, provides services such as the detoxification and rehabilitation of female drug users, vocational training, and care for terminally ill female patients
- two hospices are operated by NGOs—one each at Imphal and Churachandpur—with financial assistance from the Manipur AIDS Control Society.

A variety of other NGOs and CBOs already working in HIV/AIDS prevention and health services provide home visits and nursing care.

In Imphal, the core group has representatives from 16 NGOs. The Kakching core group has members from six, while the one in Churachandpur has representatives from eight.

The NGO core group meetings are held either at COCP's offices or the office of the NGOs (this is decided by the members according to their convenience). Their activities include identifying the problems and issues of persons living with HIV/AIDS, experience sharing and problem solving, and working together in the service cells.

Core groups in communities

The three project areas were divided into culturally-specific zones in order to create core groups to serve and represent specific populations. Based on recommendations by the programme partners, nine zones were identified in Imphal, eight in Kakching, and eight in Churachandpur.

In each zone, community core groups were established at 'orientation' meetings to which were invited community leaders, youth leaders, religious leaders, women leaders (Meira Paibis), traditional village chiefs (HAOSHAPU), etc. Also present were representatives from NGO/CBO core groups, local clubs or associations, hospices, HIV/AIDS service centres, self-support groups of persons living with HIV/AIDS, and individual health and social workers. Since then, regular meetings have been conducted in the respective zones.

Community core groups are horizontal in structure, cutting across the zone, with representatives and religious leaders from formal and non-formal sectors. Each core group is supported by a coordination team made up of community mobilizers/volunteers. The groups identify needs in their community, plan activities, and identify volunteers to take part in training. Core group representatives themselves receive training to disseminate information to persons living with HIV/AIDS and help them access existing resources for their support. A great deal of inter-group networking is done at joint core group meetings, which allow people from various walks of life to meet and exchange their experiences.

Service cells

'Service cells' were initiated as a practical and highly visible way for integrating the continuum model of care into the existing health institutions. They have so far been established at JN Hospital, RIMS Hospital and Tuberculosis Hospital in Imphal, and the Churachandpur District Hospital.

A service cell is based in a hospital room accessible to people when they first come to hospital looking for information or treatment. It is attended from 09:30 to 13:30—the hours during which outpatients are normally treated—by individuals from a roster of 40 community mobilizers/volunteers, hospital management staff, and representatives from NGOs. All receive training by COCP to help them provide general guidance about services, referrals and information on preventative measures, and carry out counselling.

Photo: Continuum of Care Project, Manipur

Volunteers provide information and guidance to outpatients at a hospital 'service cell.'

Counselling is carried out in separate rooms by the service cell staff. This marks the first time in the State of Manipur that pre- and post-test counselling, STI counselling, family counselling, etc. have all been provided in one facility.

The service cell model provides a common place for the NGO partners, institutions and community representatives to work jointly, thereby strengthening the network. It is generally felt that this has enhanced understanding between government health care staff, NGOs and communities. Regular meetings are held to identify any problems in the operation of these service cells, and skill-building training programmes are organized whenever needs are raised.

Referral of patients for care and support

The programme has been able to create a referral system spanning the continuum of care from home to hospital. By July 2000, a total of 1844 referrals had been made by health institutions to counselling and home-care services. Just under half of those referred were HIV-positive. This total is broken down by gender and age group across the three programme areas in the table 'Patients referred at the three programme areas (October 1994–July 2000).'

Patients referred at three programme areas (October 1994–July 2000)

Area	Patients	Gender		Age groups					Deaths
	Total (HIV+)	M	F	0-10	11-20	21-30	31-40	41->	
Imphal	1341 (715)	979	362	51	62	770	433	25	150
Kakching	131 (59)	91	40	2	5	54	42	11	46
Ccpur	376 (123)	286	90	4	56	239	67	10	78
Total	**1848 (897)**	**1356**	**492**	**57**	**123**	**1063**	**542**	**46**	**274**

Source: Patients' record files.

Referrals have been made easier by the creation of a resource directory for all three areas. These contain contact details for all care and social support available to persons living with HIV/AIDS in their local community.

In all referrals, confidentiality is maintained through the use of code numbers for record keeping and information is shared only by properly trained community mobilizers and staff. This measure has been vital in gaining and maintaining the trust of the clients.

Training

Improving the level of HIV/AIDS-related knowledge and skills has been a key part of the programme. The programme conducts training in four thematic areas: (1) nursing and palliative care; (2) counselling; (3) gender issues; and (4) sexual health.

All major groups of people associated with HIV/AIDS—health care professionals, CBO and NGO staff, outreach workers, community health workers, family members of persons living with HIV/AIDS, etc.—are targeted, and training is tailored to the needs of the particular group. In training for women's groups, for example, more curriculum emphasis is placed on nursing and palliative care. NGO and CBO members' training is focused more on counselling, gender issues and sexual health. Hospital staff get more information on clinical management of HIV/AIDS.

The programme has given high priority to the training of trainers (TOT), who are selected from NGOs. These are generally volunteers who already have a high level of knowledge and experience in HIV/AIDS care. These local TOTs are an important resource because, unlike external trainers, they speak the local languages. For example, the trainer at Churachandpur speaks all the eight major ethnic dialects in the area.

Home-based care

The majority of patients who have developed advanced symptomatic illnesses prefer to be treated at home, for the following reasons:

- The hospital environment does not appeal to them because of the negative way they are treated by some of the health care workers.
- The family members of these clients face financial, personnel and time constraints when the patient is admitted to the hospital; hence they prefer home-based care.

- Limitation of hospital beds for HIV/AIDS patients.
- Lack of confidentiality in the hospital.

In order to provide good-quality home-based care services, COCP has provided training on nursing and palliative care in the home to nearly 50 community mobilizers, nurses, health workers and social workers. During home visits, they, in turn, pass on these skills to the family members who provide care.

The programme has created a Home Care Handbook for use as a reference in providing home-based care. More than 5000 copies have been printed in English and Manipuri. The Handbook comprises 164 pages with 50 fully illustrated pages, four story lines and a yellow pages health guide. As well as being used as a training tool, the Handbook has been found useful by persons living with HIV/AIDS, whose feedback indicates that they find the handbook very useful in taking care of themselves.

Formation of self-help groups

The Manipur Network of Positive People (MNP+) was created by COCP in 1997, and was the state's first self-help group of persons living with HIV/AIDS. Its main objective is to act as a voice for persons with HIV/AIDS and, as such, it lobbies at the state level for social acceptance and improved health services. Although now organizationally independent as a registered society, it continues to work closely with COCP. At area level, three self-help groups for women have been formed in Imphal, Kakching and Churachandpur. All the members are either infected with, or in some way affected by, HIV/AIDS. The groups meet monthly at COCP's offices to discuss women's HIV/AIDS-related needs and issues. From time to time, the groups hold information sessions on topics such as positive living and home-based care, and other activities such as vocational training and health check-ups are organized periodically for HIV-positive women.

Greater involvement of persons living with or affected by HIV/AIDS (GIPA)

The programme has encouraged the employment by NGOs of persons living with HIV/AIDS. This has been accomplished by building skills and confidence among HIV-positive people, and through personal advocacy by COCP staff with various NGOs. While there is no hard

information on this, programme staff observe that the HIV-positive employees have gained knowledge and skills that have enabled them to change their attitudes and behaviours, while improving their quality of life. Some have become role models in society by 'living positively' and productively, by their involvement in providing care to others, and as speakers prepared to give public talks about HIV/AIDS.

Treatment of tuberculosis

As noted earlier, HIV/AIDS and tuberculosis are closely linked, and many of the patients co-infected with HIV and tuberculosis in Manipur were found to develop multi-drug resistance. Recently, however, the Revised National Tuberculosis Control Programme was implemented in Imphal District through the State Tuberculosis Clinic, making antituberculosis drugs available free of charge.

In cooperation with this programme, COCP has opened two centres providing DOTS (Directly Observed Treatment, Short Course) in collaboration with local youth clubs and the State Tuberculosis Clinic.

Monitoring and evaluation

The programme tries to make monitoring a part of regular work activities. At the case level, there are regular evaluation meetings between clients, volunteers and staff, and efforts are also made to obtain feedback from affected families regarding the services they receive. At the organizational level, monthly meetings of the programme partners, core groups, community mobilizers and staff all include reports of their activities, along with discussion of problems and needs. The data are collected as follows:

- The community mobilizers submit their weekly reports to their area project coordinators using a prescribed format. The reports include: detailed information about the persons/patients contacted; types of support and care given to the persons/patients; other activities carried out, such as contact and meetings with the community members and NGO/CBO members; and any meetings or training programmes organized in their respective communities. The report is collected and assessed by the respective community mobilizers with the help of the assistant project coordinators. The data submitted are cross-

checked and monitored by visiting the sites and discussions during weekly meetings.

- The three project coordinators submit their activities report along with the reports submitted by the community mobilizers. The project coordinators' activities include: meeting NGO/CBO core groups, community core groups and hospital core groups; their assessment of the outcomes.
- The reports are finally compiled and documented in the head office. In addition to the above-mentioned information, personal interviews with the key players (i.e. heads of the NGOs/CBOs, nurses and doctors of the hospitals) and focus group discussions are carried out from time to time to gather additional information.

Short- and long-term planning reviews are carried out periodically, generating a certain amount of data useful for monitoring purposes.

Finally, an overall external evaluation has been carried out by OXFAM.

Successes

The programme has been recognized by both the National AIDS Control Organization (NACO) and Indian Network of Positive people (INP+) as having significantly advanced Manipur's response to the epidemic, with improved services for people living with HIV/AIDS.

It has been observed that dialogue between all the major sectors has led to a change of attitude among care providers, particularly in health institutions, and better understanding about the needs and the potential contribution of persons living with HIV/AIDS. One indicator of this change is the fact that complaints about staff attitudes and negative treatment of persons living with HIV/AIDS (once frequent) have been considerably reduced. This has been matched by increased confidence and hope among persons living with HIV/AIDS—as indicated particularly by the increasing number of HIV-positive persons seeking services, publicly discussing their risk behaviour and sero-status, joining self-help groups, and participating in the mainstream of society as change agents and facilitators in the area of HIV/AIDS intervention. Increasing numbers of persons living with HIV/AIDS and their relatives are becoming members of the community core groups.

Attitudes are also changing in society, as revealed by KABP studies carried out in the area. Until the mid-90s, there was a pervasive discriminatory attitude in the community towards persons living with HIV/AIDS, as could be seen in the attendance at funerals and patterns of neighbourhood solidarity for people who were ill. Traditionally in Manipur, it has been a social obligation for at least one member from each family in a locality to attend funerals in their neighbourhood. It was also traditional for neighbours to visit sick people and offer material, monetary and psychological support. But due to the stigma attached to the epidemic, these cultural traditions were not practised when people were known to have, or suspected of having, AIDS.

In the past five years, however, significant changes have been observed. It has been noted that numbers of people attending funerals of people who have died of AIDS have increased significantly. As well, it is increasingly common for neighbours, relatives, friends, local youths and leaders to extend care and support to the HIV/AIDS patients and their families both materially and emotionally, and to provide psycho-emotional support to bereaved families.

As a result of this success, parts of the programme have been replicated in Maharashtra, Chennai, Tamil Nadu, and other districts of Manipur. Nationally, India's National AIDS Control Organization (NACO) recently took up home-based care and COCP's continuum model as an integral component of the National AIDS Prevention and Control Policy. In particular, NACO has stated that "comprehensive care across a continuum is strongly advocated. This means bringing together the medical and social services available within the community. For making comprehensive HIV/AIDS care services accessible to the patients with HIV infection, a total reorientation of health services, social services and community support [is] essential."

Challenges

COCP's success in meeting some of its objectives has resulted in high expectations of the overall project by people who use its services. For example, many people in Manipur believe that clinical care, medicines and other materials are now fully available for persons living with HIV/AIDS, as well as financial support and other services for affected families. They are understandably unhappy when it becomes clear that, despite the improvements achieved by the project, this is not the case.

Several other remaining challenges are highlighted by the programme staff:

- Some groups in Manipur are still seriously underserved. While there has been progress in increasing availability of drugs for patients with the money to pay for them, health centres are often unable to provide even simple drugs and supplies to patients who have no money.
- After a decade of the HIV/AIDS epidemic in Manipur, it has been observed that the death toll has escalated to an alarming level. Consequently, the number of young widows with children, and of parentless children looked after by the grandparents, is increasing day by day. As the State will be hard put to face such an acute socioeconomic impact, COCP has been attempting to organize socioeconomic support mechanisms to enable AIDS-affected families to maintain a sustainable livelihood. As yet, however, COCP has been unable to achieve this objective due to a lack of skills among its team members.

Photo: Continuum of Care Project, Manipur

The number of children affected by HIV/AIDS is increasing daily.

- The project has so far been unable to attract traditional healers to aid in the response to HIV/AIDS, though considerable efforts have been made.

The future

Though still not deeply entrenched, changed attitudes in Manipur towards HIV/AIDS have led to improvements in the lives of persons living with or affected by HIV/AIDS. But programme staff comment that, "Clasping to a faint optimism does not blind us to the fact that political will is lacking, that a negative stigma is still often attached to the patient and family, and that, though there has been a change in the attitude of health professionals, quality treatment is yet to be achieved.

"The instability of law and other problems in the State hamper the implementation of more HIV/AIDS-related activities. Stronger protection of legal rights of women (particularly AIDS widows) is urgently needed. More generally, there has been inadequate focus on the women and children affected by the epidemic, and on low-income groups."

In conclusion, however, the programme staff comment, "Despite all the difficulties and challenges, the past five years of experience have taught that a concerted and collaborative effort by the community, government and nongovernmental organizations in managing the epidemic can create a positive impact in a resource-constrained setting like Manipur."

For more information:

Vikram Singh Nepram
Project Manager, Continuum of Care Project
Lamphhelpat, Imphal - 795004
Manipur, India.

Tel/fax: 91 385 312827

E-mail: cocp@dte.vsnl.net.in

6. Kariobangi Community-based Home Care and Home-based AIDS Care Programme, Nairobi, Kenya

background

Facts about Kenya

Total population (1999):	29 549 000
Urban population:	30%
Annual population growth:	2.6%
Infant mortality rate (per 1000 live births):	65
Life expectancy (years) at birth:	male: 53 female: 55
Literacy rate:	78%
Per capita GNP (US$):	340
Surface area (sq. km):	580 367

Borders: Somalia to the east,
Ethiopia to the north,
Tanzania to the south,
Uganda to the west and
Sudan to the north-west.

HIV/AIDS in Kenya

The estimated number of adults and children who died of AIDS in Kenya in 1999 was 180 000. The national statistics show no indications of reduction in the spread of HIV/AIDS. While around 2.1 million people (half of whom are women) are HIV-positive, the social consequences of the epidemic are also growing exponentially.

The number of AIDS orphans, estimated in 1990 at 25 000 approximately, had risen by 1999 to 730 000. Households headed by children present a whole new set of circumstances for the society to consider. Yet the epidemic does not spare children, of whom 100 000 are HIV-positive at this time.

The major sector of society that is affected by HIV/AIDS is that which is the greatest contributor to the productive development of the country, and the reproductive development of the country—those persons between the ages of 20 and 40.

Evidence provided by researchers shows that the major method of transmission is heterosexual, with high numbers of pregnant women (median rates of 15.9% in major urban areas, and 13.25% outside major urban areas). Prevalence rates were high among certain minority groups (sex workers in urban areas in 1999 were recording 56.2% prevalence), and the poor[18].

Although awareness campaigns by the government and NGOs have made AIDS a more open subject than it used to be, the stigma of AIDS still remains strong in local culture. Often people will talk about "this sickness" rather than AIDS, although everyone knows what they are talking about.

Kariobangi Community-based Home Care and Home-based AIDS Care

Korogocho, the slum in Kariobangi in which the programme is set, is 12km east of the centre of Nairobi. It has a population of over 100 000 (recent unconfirmed statistics suggest that it is now 130 000). Most people live in single-room shanties made of plastic, tin or mud. Sixty

[18] All figures above from *UNAIDS Report*.

per cent of homes are headed by women alone. Most residents have no land and are living as squatters in the slum. As there is little opportunity for work, most try to earn a living by very small-scale trading, and by scavenging on the city dump, or by alcohol-brewing and survival prostitution.

A survey conducted in two large neighbourhoods in the Korogocho slums in 1994 showed that 32% of the population was HIV-positive, of whom 14% had AIDS. Due to their poverty, some 22% of the population had never sought medical attention[19].

The Community Health Programme was begun in 1986 by Sister Gill Horsefield of the Medical Mission Sisters Health Programme, and commenced its AIDS-related activities in 1989–90.

Today, the programme delivers many of its services through the volunteer work of community health workers (CHWs), who are all from Korogocho itself. The CHWs are supervised and supported by a professional staff of five nurses, two counsellors, a social worker who visits mothers with AIDS and helps them plan for the future of their children, and a pastoral worker who serves patients' spiritual needs. There is also a diagnostic laboratory for tuberculosis in the deanery of the local Catholic church.

Goals and principles

The programme's overall goal is to enable the people of Korogocho to cope with AIDS physically, socially and psychologically. It does so by:

- training community health workers to care for persons living with HIV/AIDS
- providing a backup team of medical and social services professionals to enable this to happen.

Major elements of the project

The programme undertakes a variety of activities:

Recruitment and training of community health workers

Community health workers (CHWs) are at the heart of the programme and they are chosen from the small Christian communities of the neighbourhood. These communities are mutually supportive groups who

[19] Figures provided by Kariobangi project.

expect all their members to perform some sort of service within the community. Huduma ya Afya (Service for Health) is one of the services for which members can volunteer. They are trained in community-based health care at Korogocho village school, where they have weekly classes for about five to six months. After working for a year, they receive a badge and a certificate. Cost of training per Community Health Worker is budgeted at about $7.

In 1998, some 68 volunteer health workers provided medical care and moral support to 1880 persons living with HIV/AIDS, including 172 babies and children. The CHWs are regarded with great respect in the neighbourhood, and are viewed as peers by the professional staff, who support them and help them to increase their knowledge. Some of the health workers are trained as counsellors; most of them have supplies of medicines for treatment of symptoms, and some have supplies of antibiotics. Those who work in the hospice have received training in psychological and pastoral care of the dying.

The CHWs are involved in all decision-making about the development of the programme. Their strong Christian motivation is reinforced by the gratitude and support with which they are treated by both patients and professional staff. Some of the CHWs have been working for 12 years and feel that, in spite of receiving no financial reward, they have gained a great deal in terms of increased abilities and confidence.

Photo: Kariobangi Programme, Nairobi

Young community health workers graduate and receive their badges and certificates.

Care for the sick

The programme recognizes and attempts to build on the fact that most of the care received by persons living with HIV/AIDS will be provided by relatives (not just by adults, and frequently by children) and friends of the patients at their own homes. Therefore, the programme improves and supports this existing care resource through voluntary community health workers. The workers provide friendship and moral support, bring medicines, and teach home-nursing skills to the patients' relatives and friends. Where necessary, workers bring food during their visits—either a cooked meal provided once a day, or dry food to be cooked for the patient by family members. If food is provided, it is for the whole family rather than just the patient—a necessity given the difficult circumstances in which most AIDS-affected families live. The budgeted amount per family is $0.50 per day.

The programme's current patient load is 787 persons, with a cumulative total of 3746 persons served since 1990. There were 537 new patients in 1999.

Programme staff calculate that the cost of caring for nearly 2000 patients with AIDS in Korogocho is equivalent to the amount budgeted for the care of one patient in the United Kingdom. The programme budgets about $13.40 per patient per year—a sum that includes the cost of medicines, staff salaries, transport, running a Suzuki car, and administration costs. Some of the costs identified are as follows:

- cost of medicine per patient per year: $2.20
- cost of transport to hospitals, clinics, etc.: $1
- cost of X-rays and laboratory tests: $0.70

Confidentiality is strictly maintained. All the professional staff know the HIV status of patients, but Community Health Workers realize that they can only know a patient's status if the patient herself/himself shares it with them. However, while most Community Health Workers have a very good knowledge of the symptoms of AIDS, and are therefore aware of most patients' situation, they are trained to maintain confidentiality.

Referral system

The community health workers live in the slum, and they are each responsible for a small area. When someone in the area is sick, the CHW will

be told by neighbours. She will visit the person to determine the seriousness of the illness. If it is a minor sickness, she will advise on home treatment or perhaps recommend a visit to the dispensary. If the sickness is serious, or the patient appears to have symptoms of AIDS, she will call the nurse, who will visit the patient with her and make a diagnosis. If the patient has the symptoms of AIDS, he or she will be registered in the programme, and the health worker will then visit regularly, and report every week to the nurse on the patient's condition.

Some patients require additional care in between reporting times. In such cases, CHWs can contact the nurse in the morning when she arrives to visit the area. Once diagnosed as having AIDS, patients are prescribed their medicines by the nurses, and the medicines are delivered by the CHWs.

Crisis care for persons with AIDS

One of the aims of the programme is to help patients to stay at home until they die. When care at home is beyond the abilities of relatives or friends, there is a small hospice, run by the volunteer health workers, where patients can be looked after following a major downturn in their health. The hospice has four beds but usually has only one or two patients at a time.

Photo: Kariobangi Programme, Nairobi

Community health worker Lucy Waithera looks after an AIDS patient in the hospice.

Crisis care for children

The programme provides medical care to children living with HIV, but also runs a Child Crisis Centre where children can stay temporarily when a mother is too sick to cope, or when a mother dies suddenly. This need has emerged as adult mortality due to AIDS makes it increasingly difficult to find family members to care for orphans. The Crisis Centre is also a safe haven where children who are caring for sick parents come to learn, and where they can always come to get advice, and moral and emotional support.

An important problem raised by continuing stigma is that of informing children about their parents' serostatus. Community health workers have been trying to persuade HIV-positive parents to share this knowledge with their children, but so far with little success. Very often the children know, or at least suspect, and the workers feel strongly that if the truth of the situation could be discussed openly within families, it would be easier for the children. However, confidentiality forbids this without the parents' consent.

Children's programme

Child-headed households are becoming more common. Even when a very small child is sent to grandparents, the eldest child usually remains in the family home with the responsibility for caring for the other children. The children's programme was created for children who are healthy themselves but who will in the future be orphaned. They are invited to join in order to prepare for life without parents. They learn how to care for their sick parents and also how to bring up their younger brothers and sisters. While learning, they share a great deal together, and so form supportive groups that, it is hoped, will help them in the future.

Partnerships, alliances and collaboration

One of the programme's strengths is the web of local partnerships it has created. Partners include nearby health institutions and other NGOs working in the area. This helps it avoid taking on work that other organizations are already doing. For instance, the programme does little formal work in HIV/AIDS education and awareness, leaving this to other NGOs working in Korogocho.

On the other hand, there has been little success with support groups for persons living with HIV/AIDS. There are a few informal groupings among the patients who help each other, and there is also a group that meets to pray and share together, but they are only a small proportion of the programme's patients.

The programme is highly dependent on external financing. Without it there would be no administrative budget, no salaries for professional staff, and little money for medical supplies.

The main funding for the programme comes from Memisa Medicus Mundi (Netherlands)/Cordaid. Initial help with publicity materials was received from UNICEF. The programme also receives funds from parish groups overseas and locally. The programme still receives a great deal of moral support from UNAIDS personnel.

The future

The programme plans to increase the number of voluntary community health workers. It also hopes to further develop their skills, and provide them with more of the basic supplies needed to care for patients with AIDS.

For more information:

Mr Charles Thumi or
Sister Gill Horsefield, MMS
Kariobangi Community Health Programme
P.O. Box 53376
Nairobi, Kenya

Phone: +254 793 266, 793 288

7. Bambisanani, Eastern Cape, South Africa

background

Facts about South Africa

Total population (1999):	39 900 000
Urban population:	49%
Annual population growth:	1.7%
Infant mortality rate (per 1000 live births):	60
Life expectancy (years) at birth:	54
Literacy rate:	82%
Per capita GNP (US$):	3210
Surface area (sq. km):	1 221 037

Borders: At the southern extreme of Africa, South Africa surrounds Lesotho, and shares borders with Namibia, Botswana, and Zimbabwe to the north; and Mozambique and Swaziland to the east.

HIV/AIDS in South Africa

South Africa has been beset by the AIDS epidemic ever since the formation of the new democracy in 1994. The devastating increase of HIV/AIDS prevalence continues to wreak havoc throughout the nation. It is estimated that about 250 000 South Africans lost their lives to AIDS in 1999, and the total number of all adults infected with HIV numbered 4.1 million. These facts and figures are difficult to comprehend. Yet they remain statistics on the basis of which government and NGO officials can seek the means to prevent the further expansion of the epidemic, and can begin to improve the lives of those directly and indirectly affected by HIV/AIDS.

Well over 50% of those infected are women, with HIV prevalence among rural antenatal attendees having increased from less than 1% in 1990 to a median of 21% in 1999.

Just one of the consequences of this calamity is the number of children who have lost their mother or both parents to AIDS—the orphans. Those who were alive and under the age of 15 at the end of 1997 numbered 420 000[20].

Eastern Cape Province

Region E, part of the former homeland known as the Transkei, comprises four districts and has an area of over 17 043 sq. km. The population of Region E is between 1.2 and 1.3 million. Although only 2% live in urban settings, the population density is high: 70 people per sq. km.

In Region E, access to all health and social services is severely limited. There is one doctor for 16 592 people and the lowest ratio of nursing staff in the country (less than one per 1000). The infant mortality rate of 58.2 per 1000 births and the life expectancy of 59.5 years are, respectively, the highest and lowest in the country.

Over 40% of all South African migrant workers in the gold mines come from the Eastern Cape, and almost all the migrant cane-cutters in

[20] All figures above from UNAIDS Report spreadsheet.

the sugar industry come from Region E. According to the demographic profile of Region E, there are many children who are cared for by a few old people, especially grandmothers. The absence of adult men is striking. In the age group from 20 to 24 years, there are 50% more women than men. The disruption of workers' family lives caused by the migrant labour system, inherited from apartheid, creates a unique obstacle to containing the AIDS epidemic, and to establishing family care and support for AIDS patients.

Figures from the end of 1998 show that the HIV prevalence rate among antenatal clients for Eastern Cape Province as a whole was 15.9%—40 times what it was in 1990—with a 26% increase from 1997. The figure for Region E was 21.5%. The number of persons estimated to be HIV-positive in Region E was 69 392 (44 948 adult females, 22 207 adult males, and 2237 infants). Tuberculosis is a major problem, and is the leading cause of death in HIV-positive persons. In Region E, only 17% of clients complete their six-month tuberculosis treatment.

More than 70% of the hospital beds in Region E are occupied by patients with HIV (with or without associated tuberculosis). All the hospitals report being overburdened yet admit that there are no services available to support the discharge of patients with chronic or terminal conditions into the care of their families and communities[21].

Bambisanani

Although home-based care has been identified as a provincial priority, the experience of people and organizations working in HIV/AIDS is that 'home care' can become 'home neglect' if appropriate planning, capacity-building, community participation and support are not in place. Given the growing needs for care and support, government and NGOs recognized that innovative, integrated, public-private-NGO partnerships would be required, with the partners taking on non-traditional roles.

In November 1999, a consultative meeting was attended by representatives of all the potential partners in Region E. The intent was to consolidate their experiences regarding HIV/AIDS, tuberculosis, the care and support of children in distress, and repatriated workers. To implement a thorough plan, they had to analyse potential partners and develop guidelines

[21] All numbers from Region E area reported by project.

for the partnership, keeping the plan within reasonably obtainable parameters.

As a result, several organizations came together to create Bambisanani (*in partnership to help each other*). The lead partner, which convoked the November consultative meeting, was the EQUITY Project—a seven-year, $50-million USAID-funded project created to support the South African Government in providing integrated public health care projects to all South Africans. The project reports to the Eastern Cape Department of Health (ECDOH) and the South African Ministry of Health (MOH). Phase One of the project (1997–2000) focuses on Eastern Cape.

Other partners include the Employment Bureau of Africa, the development agency of the National Union of Mineworkers, major gold mining companies, the Planned Parenthood Association of South Africa, and the Transkei and South Coast branch of the international NGO Hospice. (More details on the participation of each are given below.) Seed funding for the first two years is provided mainly by Bristol-Myers Squibb from their Secure the Future initiative, Goldfields of South Africa, Ltd, and the EQUITY Project.

Goals and principles

The goal of Bambisanani is to enable selected communities in the Eastern Cape's Region E to provide comprehensive care that will contribute to the improved quality of life of persons living with HIV/AIDS, their families, and the communities in which they live. (Comprehensive care, as the term is used by the project, encompasses not only the physical needs of the patient but also spiritual, emotional, nutritional and social needs.)

In more concrete terms, Bambisanani aims to provide an organizational framework that can, cost-effectively and without introducing a new bureaucratic structure:

- coordinate available services with government, businesses, NGOs, health care workers and volunteers
- establish adequate training for social service providers and home-based services
- ensure that the special needs and concerns of groups such as persons living with HIV/AIDS, women and children are attended to.

Bambisanani is based on the principle that decentralization and integration of all HIV/AIDS services offer the best chance of sustainability as well as cost-effectiveness.

Major elements of the project

The first meeting quickly led to the following actions:

- establishment of a Project Management Committee consisting of Region E representatives
- development of a detailed implementation plan for year one
- mobilization of resources
- the appointment of a project coordinator
- the commissioning of baseline research.

With these in place, the project started its work, which is organized under four broad activity categories. The responsibilities of the major partners are described within these categories.

Community capacity-building

In order to create an environment conducive to home-based care and support for children in distress, there is an urgent need for capacity-building among a broad base of constituencies (e.g. community leaders, such as church leaders and traditional leaders; women's and youth groups; traditional healers; and community structures such as Community Health Committees).

Capacity-building will be accomplished through community meetings and participatory training workshops with an emphasis on HIV/AIDS and tuberculosis within the context of community development. A questionnaire to measure attitudes and perceptions about home-based care will be administered at the initial workshops, to serve as a baseline and then subsequently to measure changes over time. Follow-up in-service updates will take place quarterly.

Home-based care

The project will identify the minimum resources required for effective home-based care and establish a system to provide these to the primary caregivers. Training is required for all categories of caregivers, professionals, and health workers in both the public and private sectors as well as for

traditional healers. The project will therefore coordinate the training of care-supporters (a kind of grass-roots-level supervisor/trainer) who will operate in their communities, each one supporting a number of primary caregivers. Support, in the form of regular meetings, monitoring and in-service training, is planned to ensure that the quality of care is maintained.

Bambisanani takes seriously the widely confirmed experience that volunteers working in poor communities remain active, and function best, when they are provided with some form of incentive. The project accepts this position and will provide volunteers with incentives in the form of transportation reimbursement, uniforms or distinguishing attire, record-keeping materials, and token payments.

Photo: Rose Smart

Zweli is a migrant worker who returned home to his wife when he became sick.

Care and support for children in distress (CINDI)

Despite the recognition that increasing numbers of children are being severely affected by the epidemic, there are currently no means to identify these children, nor is there a safety net for them. The initial part of this component will be intervention-linked research to establish mechanisms for identifying children in distress. Care and support services

to be provided for identified children will be linked both with the relevant Department of Health and Department of Social Development programmes (e.g. nutrition and grants) and with the drop-in centres for life-skills and job-skills development. Also provided will be training for professional social service providers and for youth lay counsellors.

Support for groups and income-generating activities

Given the prevailing reality of extensive poverty, people living with HIV/AIDS and children in distress require special support groups and methods by which they can generate an income. Income-generating activities (IGAs), such as building, food-related activities, farming, and other micro-enterprises, will be available at each of the drop-in centres. The choice of IGAs will be identified through a research process.

Partnerships and alliances

In keeping with its decentralized approach, Bambisanani is built on cooperation between different organizations that apply their specific expertise or comparative advantages:

- The EQUITY Project will provide training for staff in the public health sector.

Photo: Rose Smart

The Employment Bureau of Africa supports Bambisanani as a referral and support source and as a link with the mining companies.

- The Employment Bureau of Africa (TEBA), whose major function was formerly to ensure an adequate supply of 'economical' labour to the mining industry, has significantly refocused its activities in the new South African society. TEBA will support Bambisanani by serving as a referral and support source (with a focus on repatriated migrant workers) and as a link with the mining companies. In addition, TEBA will assume the leadership role in the support group and income-generating element of the project.
- The Mineworkers Development Agency (MDA) will support the job-creation and income-generating aspects of the project. MDA is the development wing of the National Union of Mineworkers (NUM).
- The gold mining companies have agreed to support home-based care services with resources (such as home-based care packs). There is a growing awareness of the need to broaden their commitment into the sphere of care in the areas from which their mineworkers are drawn.
- The Planned Parenthood Association of South Africa–Eastern Cape (PPASA-EC) will oversee and run the community capacity-building and the children in distress (CINDI) components of the project.
- Hospice (Transkei and South Coast) is an international NGO providing palliative and terminal care. It will oversee and run the home-based care element of the project, including the provision of training for care supporters.

Monitoring and evaluation

A successful programme should fulfil the needs of many, from those of the patient to those of the nation. Should it be perceived to be successful, and indeed *be* successful, it is hoped that it may serve as a replicable model for other programmes.

External mid-term and end-of-project evaluations will be conducted. A set of expected outcomes at various levels has been adopted as the basic indicators of much of the evaluative work. These are summarized in the table, 'Expected outcomes by target group', overleaf.

Expected outcomes by target group

Target group	Expected outcomes adopted as indicators of programme success/failure
Patients/clients	• reduced suffering and improved quality of life • appropriate treatment, care and support • enhanced end-of-life care
Families	• improved capacity to cope and to care • practical support • bereavement support
Caregivers	• the capacity, resources and support to deliver quality care • access to colleagues and community networks of support
Communities	• improved capacity to cope • enhanced environment for care • reduced stigma • skills development and job creation
Children	• early identification of children in distress • access to holistic care and support
Persons living with HIV/AIDS	• skills development • access to networks of support
Health services	• reduced pressure on services • effective referrals between different service providers • cost savings
Welfare services	• improved utilization of social services • better access to grants
South Africa as a whole	• lessons learned • replicable models.

The future

Bambisanani represents the application of a large number of lessons learned in various settings, both within and outside South Africa. However, in the process of putting together the initiative, an important new lesson has been learned: the existence of great problems in seemingly separate sectors (in this case, the business, labour, welfare and health sectors) can give rise to creative responses and new resources (or the most cost-efficient application of existing ones) if multisectoral approaches are applied.

In itself, the AIDS epidemic represents an enormous challenge to South Africa's fledgling democracy. The requirements of projects such as Bambisanani must vie with many other high-priority transformation demands such as redressing the migrant labour system. However, by finding common or complementary activities, the Region E project offers benefits not only to the migrant mineworkers and cane-cutters but also to their families and the communities from which they come.

For more information:

Mrs Rose Smart
Bambisanani: An EQUITY Project
P.O. Box 415, Magalies View
2067 South Africa

Phone: +27 11 465-9803

Fax: +27 11 465-9803

E-mail: rsmart@netactive.co.za

8. Mildmay Centre for Palliative HIV/AIDS Care, Uganda

background

Facts about Uganda

Total population (1997):		21 143 000
Urban population:		13%
Annual population growth:		2.8%
Infant mortality rate (per 1000 live births):		103
Life expectancy (years) at birth:		40
Literacy rate:	Total:	62
	Male:	74
	Female:	50
Per capita GNP (US$):		330
Surface area (sq. km):		236 040

Borders: The Congo to the west, the Sudan to the north, Kenya to the east, and Tanzania and Rwanda to the south.

HIV/AIDS in Uganda

Uganda is one of the countries making up the Great Lakes Region in Eastern Africa. Of a total population of 22 million people, it is estimated that 1.9 million have been infected with the human immunodeficiency virus (HIV), of which 67 000 are known to be children. Deaths as a result of HIV/AIDS have been estimated at 500 000, and 1.7 million children have been orphaned. These figures indicate that 1.4 million people are currently living with HIV/AIDS.

However, trends indicate that, in the urban sentinel sites, new HIV infection rates have declined by about 50%. At one urban antenatal clinic, the rates dropped 29.5% in 1992 to 13.4% in 1998, the reduction being predominantly among 15–19-year-olds. There is also ongoing evidence of changes in sexual behaviour: between 1989 and 1993, it appears that the proportion of those who had ever had sexual intercourse fell from 69% to 44% among young adult males, and from 74% to 54% among young adult females. However, the rates are still high, and there remains a need for increased effort to improve, and sustain, existing AIDS control initiatives.

The Mildmay Centre for Palliative HIV/AIDS Care

In 1993, Mildmay International was invited by the Ugandan Ministry of Heath to help establish the country's first AIDS palliative care and training centre. Mildmay International is an NGO, based in the United Kingdom, that has gained wide experience in HIV/AIDS care and training. Connected with the Mildmay Hospital in England, it traces its roots back to the previous century, when religious lay women organized themselves to provide home care to people infected by the London cholera epidemic of 1866.

The Mildmay Centre, which has been operational since September 1998, is situated 14km along the Entebbe Road from Kampala City within the Mpigi District. It provides comprehensive outpatient palliative care, and rehabilitative services for men, women, adolescents, and children living with or affected by HIV/AIDS.

The project is funded by the United Kingdom's Department for International Development (DFID) and received initial support from the World Bank for the procurement of equipment.

Goals and principles

Mildmay Centre's objective is to provide palliative care and rehabilitation for persons living with AIDS in the local community.

The centre defines palliative care as "the active total care of someone with an incurable illness, where the control of pain and other physical, psychological, emotional and spiritual needs are paramount, and where the goal is an improved quality of life. The relief of pain and other distressing symptoms can lead to prolonging life, which, in turn, benefits the immediate community both socially and economically. It is also intended to facilitate a comfortable death with both peace and dignity".

One by-product of this type of care is expected to be that the country benefits from the prolongation of the individual's economic and social productivity and that children benefit from a longer period of parental care.

Major elements of the project

Mildmay does not become the patient's primary carer, which remains the role of the referring doctor, nurse or counsellor. Rather, Mildmay is a specialist referral centre, which aims to support existing services and to actively support the principle of rehabilitation.

Its main activities are:

Care

The centre provides holistic, high-quality care and advice, and emphasizes the fact that respect for the concerns, rights and beliefs of each individual must be an important part of that care.

It uses multidisciplinary therapies involving a team of professionals including doctors, nurses, nursing assistants, counsellors (including those skilled in working with children), a physiotherapist, occupational therapist, aromatherapist and a nutritional adviser. It also has pastoral care workers, laboratory personnel, pharmacy staff and a volunteer workforce to accompany patients around the centre. There are currently just over 80 staff—both full- and part-time—and 11 volunteers at the centre.

Mildmay has no in-patient services, and patients must arrive with a letter of referral from a local doctor, medical institution or health-related NGO. Outpatient clinics are held four days a week. Patients pay for the care through a registration fee and a small follow-up fee, but provision is made for serving children and adults who are unable to pay (see below). The majority of referrals (90%) are from within and around the Kampala and Entebbe area. Mildmay receives these referrals from home-care organizations (e.g. Hospice Uganda and the Joint Home Care Team); HIV-related NGOs (e.g. the AIDS Support Organization and the AIDS Information Centre); traditional healers; private doctors, practitioners, and hospitals; and government organizations such as the Mulago Hospital and Health Centres.

Outpatient clinics are held four days a week, and between 40 and 60 patients are typically seen each day. Tuesday is paediatrics day, when mothers bring children for treatment.

Children who are awaiting their own examinations or waiting for parents to be seen are invited into the Noah's Ark Children's Centre free of charge. The children's play is supervised by personnel trained in working with traumatized or sick children.

Children with HIV/AIDS enjoying a meal at the Children's Centre.

Photo: Claire Wheatcroft

The major problems of referred patients were persistent or recurring pain (47%), cough (39%) and skin problems (38%). Of the 980 patients, the female-to-male ratio was 4:3.

In its first year, the Mildmay Centre registered a total of 980 patients, and provided services to thousands more. By the end of March 2000, over 10 500 people had been served since the opening of the centre, and there were 1450 new registrations, of whom 230 were children under the age of 19. The average age of the children was 8.5, with about one-quarter between 10 and 19 years of age.

Mildmay has found it extremely useful to hold weekly interdisciplinary meetings in which patients are discussed, and staff members share their different perspectives on the patients. This helps overcome the fact that patients often communicate only part of their story, symptoms, or problems to each team member they see. At these meetings, the whole picture is clearer, and more effective plans may be applied. These meetings also help staff members share their feelings and emotions about the situations they are presented with—a useful technique for countering staff burnout. Special counsellors, independent of the centre, visit Mildmay twice a month to counsel staff.

Training of carers

Holistic care involves not only the staff and volunteers at the centre, but also the caregivers (mostly family members of patients) at home, who are recognized and valued as the main source of most patients' care. Workshops for caregivers were started in response to the need of the caregivers to acquire appropriate nursing and psychological skills to give them confidence as they care for a patient at home. The workshops, coordinated by the nurses, take place at the end of every month and are run by the interdisciplinary team.

Some of the topics covered during the workshops are: simple nursing techniques; bed bathing; care and prevention of pressure sores; mouth care; patient toileting; lifting and handling of patients; feeding techniques; diets suitable for HIV/AIDS patients; drug administration; will-making; issues of death and dying; handling a difficult patient; communicating with children; modes of HIV transmission; positive living; and income-generating activities.

One of the lessons that Mildmay (like so many other community care projects) has learned is that burnout among caregivers is an ongoing problem that must be addressed. This means that projects must plan for the fact that

caregivers, like patients, need emotional and psychological support. In order to help deal with caregiver and staff burnout before individuals reach crisis stages, a counselling service is provided, which is independent of the centre.

Capacity-building in AIDS palliative care

Mildmay has a variety of educational programmes to help improve care throughout the region, with an emphasis on building local capacity in AIDS palliative care. It has its own Training and Education Centre, complete with a lecture hall and simple hostels where trainees can stay during courses.

Workshops, which include core components, are adapted for each audience. Participants include: health workers and health professionals (doctors, nurses, counsellors, social workers, volunteers, community health workers); government and NGO staff, including policy-makers and media; students and teachers in schools; workers; men, women, children, and adolescents living with HIV/AIDS (for example, workshops for HIV-positive fathers and mothers); employers and employees in businesses or institutions; journalists and religious leaders.

Some courses given in 1999

Date	Category of persons trained	Numbers
Feb. 1999	Carers of persons living with AIDS	30
Mar. 1999	AIDS palliative care for community health workers (Plan International)	47
Mar. 1999	AIDS palliative care for nurses	80
April 1999	ARVs for nurses and counsellors	20
June 1999	AIDS care for school development workers	14
Sept. 1999	Management development for a health NGO's executives	8
Oct. 1999	Care and management of HIV/AIDS for rural nurses	16
1 Saturday each month	AIDS care for doctors and clinical officers	

Mildmay also has a Mobile Clinical Training Team that takes training to the rural districts. The team, which spends two weeks of each month in the field, visits agreed-upon health centres run by the MOH, conducts a needs assessment, and develops a training programme. Trainees spend one week at the Mildmay Centre and then, over a period of a year, are given follow-up and further training by the mobile team. The team currently works in ten districts of Uganda.

Support for HIV-positive young people

Children are now living longer with HIV/AIDS—occasionally up to 16 years of age. Some, who are suffering from chronic disabling conditions, have special care needs that families and communities have great difficulty meeting. Since the HIV-positive individuals fall sick often, have left school, or are orphans, their needs are very rarely recognized and planned for. In addition, the transition from childhood to adolescence is a difficult time, during which the HIV-positive adolescent is undergoing exactly the same social and emotional stresses as those who are HIV-negative. To assist these young people, Mildmay has formed an adolescents' club called Our Generation Mildmay Adolescent Club (OGMAC). It teaches adolescents how to improve or cope with various aspects of their lives (e.g. nutrition, reproductive and sexual health, positive behavioural change) and to encourage them to seek health services.

Photo: Claire Wheatcroft

Palliative care is provided by a nurse at the Mildmay Centre.

Funding for care and treatment

As a Christian NGO, Mildmay cares for patients whether they can pay or not. At the same time, it attempts to recover some of its costs from patients who can pay something. Those who arrive as private patients are charged at a rate that covers all costs and helps subsidize rates for the very poor. The sliding scale of fees is as follows (1999):

- Private patients pay a fee of Sh30 000 which covers the initial consultation, including counselling and physical therapies. Follow-up monitoring, counselling and physical therapies cost an additional Sh10 000. Tests and drugs are charged according to their cost.
- Ordinary referrals are charged Sh7000 for the initial consultation (as above) and Sh 2000 for the follow-up. Tests and drugs are charged at a subsidized rate.
- Persons with no income are charged only a registration fee of Sh500.

It became apparent very early on in the project that caregivers were unable to pay for all the services needed, not only for themselves but for all the children infected or affected. The Hardship Fund was set up by Mildmay International (the parent NGO in the United Kingdom) to help pay for the care and treatment of all children and adolescents, as well as for a few adults.

Monitoring and evaluation

Every three months, clients (the patient and/or the caregiver) fill in assessment forms so that the centre can monitor their views. Similarly, staff make presentations at audit meetings, and every department within the centre carries out three-monthly audits of the care provided. Quarterly reports are forwarded to DFID and to Mildmay International for scrutiny.

One audit, taken after six months of operation, indicated that a patient-centred approach using multidisciplinary therapies was both appropriate and beneficial to patients reviewed: 42% of symptoms were gone and 18% of symptoms were significantly reduced by the end of four visits to the centre. In this study, most patients (70%) had at least one investigation, with microbiology (microscopy, Ziel Nielson, and gram stain) being the most frequently requested investigation. Therapies or services prescribed by the doctors included medication (88% being at least on

Cotrimoxazole prophylaxis, particularly the children), counselling (41%), spiritual support/counselling (16%), physiotherapy (24%), including those with skin complaints being referred for aromatherapy, nutritional advice (31%), and occupational therapy (5%). Ten per cent were referred to hospital and 0.5% to home care through a referral system that has been developed with the Joint Home-Care Teams.

The future

In a phase of the epidemic when the need for palliative care is insufficiently recognized, the activities of the Mildmay Centre show that such care can be provided in a way that complements and even strengthens the existing systems of medical services and home and community care. Palliative care does indeed improve the quality of life for people living with HIV/AIDS, and can be managed so that clinical staff and home caregivers work together rather than in isolation. The educational and capacity-building components of the project serve to reinforce the understanding of palliative care's benefits among a much wider group of people than would otherwise be the case.

According to Dr Catherine Sozi, Director of Clinical Services, "Advanced HIV disease is going to be with us for a long time yet and as a doctor who is very much involved in these patients' care, the value of my fellow colleagues is immeasurable. Partnership with the patient and his/her carers or family members means that we do not see ourselves as authority figures, rather that we offer advice, information and knowledge of the options available to the patient, and they make a valid and informed choice. Interdisciplinary care and communication is paramount in order to give the best care for this disease, for which there is no cure yet. It is important that even if our people cannot afford anti-viral therapy we can still care for the whole person and improve the quality of life of an individual and enable them to live as positively as possible to the end".

For more information:

Dr Catherine Sozi, Director of Clinical Services or
Ruth Sims, Chief Executive,
The Mildmay Centre
P.O. Box 24985
Kampala, Uganda

Phone: +256 41 200862/5/6/7

Fax: +256 41 200861

E-mail: mildint2@infocom.co.ug

9. Partnership for Home-based Care in Rural Areas, Uganda

background

As the name suggests, Partnership for Home-based Care in Rural Areas is a collaborative effort between several organizations:

- Family Life Education Programme (FLEP) is a community-based organization that provides family planning and other reproductive health services for rural communities in Uganda.
- Pathfinder International is an NGO, based in the United States, that has worked with FLEP for many years, building its capacity to provide integrated reproductive health services and technical assistance to other groups with similar aims.
- The AIDS Support Organization (TASO) grew out of Africa's first support group for persons living with or affected by HIV/AIDS. Since 1987, it has expanded to provide a wide range of services in eight Ugandan districts.
- The AIDS Information Centre (AIC) has been providing voluntary HIV testing and counselling in Uganda since 1990.

The early years of FLEP

Although the partnership began in 1993, its roots go back to the previous decade. In the 1980s, civil war had destroyed much of Uganda's rural infrastructure, leading to widespread poverty and few social services. FLEP was created to provide family planning, health education and expanded immunization services to the war-torn communities of Busoga Diocese. It was the first community-based organization in Uganda to provide family planning and other reproductive health services for rural communities.

Initially, FLEP was often criticized by Church members who felt that the Church should not be involved with 'worldly' concerns such as family planning. Many rural people associated contraception with prostitution; they believed that having many children was a good substitute for financial wealth, and worried that FLEP's activities would disrupt the social fabric of the community. Nonetheless, FLEP continued its work with the full backing of Busoga's Bishop.

With USAID funding and Pathfinder International providing training and technical assistance, FLEP established 47 primary health care clinics and two voluntary surgical contraception (VSC) referral centres (in Jinja and Kamuli districts respectively). FLEP and Pathfinder trained medical practitioners to manage the clinics and clinical outreach services, and also trained village health workers, village health management committees, peer educators and quality-of-care monitors.

By 1993, it had become an independent NGO with a strong network of village health workers, health centres and local health committees. It currently has memoranda of understanding with four Ugandan district governments to provide a variety of health services. In addition to village health workers, FLEP employs information, education and communication (IEC) specialists to train local drama groups (and sometimes village health workers) to write and produce songs and dramas that make family planning information more accessible to local audiences. The skits are produced at schools, community meetings, church gatherings and health fairs.

As a result of its rich experience, FLEP is now providing training and technical assistance to other reproductive health and family planning organizations in Uganda [22].

The need for HIV/AIDS services

Starting in the early 1990s, hospitals in Uganda became increasingly crowded with chronic AIDS patients. Most were eventually discharged to their homes in a state of hopelessness, to be cared for by untrained relatives. Inevitably, communities began to demand AIDS-related services from the village health workers, who till then had no training in this field. Many found themselves becoming overwhelmed by the needs of persons with HIV/AIDS and their families, whose demands they had to place alongside their usual workload.

In response, FLEP and Pathfinder worked during 1992 and 1993 with community groups to identify HIV-related needs. The resulting list included the need to train existing staff, but also to provide appropriate IEC materials and activities, tools such as a risk assessment checklist, a HIV testing system, capacity for treatment of opportunistic infections, and improved clinic facilities.

To meet the first of these needs, FLEP requested that TASO train its village health workers, nurses, and supervisors in HIV/AIDS education and basic HIV/AIDS counselling. This fitted TASO's emerging policy at that time to limit its own growth, and instead lend its expertise to help other HIV/AIDS service groups in the country[23]. As a basis for the training, TASO and FLEP jointly developed a curriculum tailored to the needs and knowledge level of village health workers, and translated it into the local language. (This curriculum has since been adopted for training in other districts of Uganda.)

[22] See Population Communications International's discussion of reproductive health services in rural Uganda. This can be found in *Population and Development, Sexual and Reproductive Health, and the Environment*, No. 10, October 2, 1999 which can be consulted at http://www.population.org/Glissue10.html.

[23] TASO has attempted to limit both its growth and its mission, despite many pressures to get bigger, on the grounds that its effectiveness and responsiveness to its clients will be reduced if it expands greatly. For instance, TASO has always referred clients to the AIDS Information Centre for testing, and invited government doctors to its clinics rather than employ its own medical staff. In 1995, it formally decided to limit its physical presence to the TASO centres already working in 7 of Uganda's 47 districts.

Funding for the initiative was provided by USAID to FLEP, with budget and administrative support furnished by Pathfinder International. An agreement was made whereby FLEP paid TASO for the time and other costs of TASO staff who travelled to FLEP clinics to give the training.

Goals and principles

The partnership's central goal is to improve the quality of life for persons and communities affected by HIV/AIDS, and to reduce the incidence of HIV through prevention work. However, all of its activities follow the principles established by TASO early in the epidemic as guides to help persons living with and affected by HIV/AIDS to 'live positively' within their communities. These principles include:

- the rights of persons infected or affected by HIV/AIDS to be supported emotionally, medically and socially;
- the responsibility of people infected or affected by HIV/AIDS to cultivate self-esteem, hope, respect for life, respect for and protection of their community, care for self, and care and support for dependants;
- the rights of the community to protect itself from, and its responsibility to curb, the spread of HIV;
- the responsibility of the community to support persons infected or affected by HIV/AIDS so that they have access to emotional, medical and social services and can live responsibly with HIV/AIDS.

The philosophy of the TASO movement affirms that the above-mentioned rights and responsibilities should be fulfilled through education, counselling, dialogue, acceptance and togetherness, not through coercion and stigmatization.

Major elements of the project

FLEP's needs analysis was reinforced by its experience in the first year. It eventually settled on a model that included the following key service delivery components:

- STI/HIV risk assessments for all clients receiving reproductive health/family planning services from clinics in the project area;
- STI/HIV screening of all clients receiving services, using a diagnostic checklist;
- identification and referral of clients for HIV testing, using administrative procedures that protected client confidentiality;

- diagnosis and treatment of clients with STIs, using syndromic management;
- IEC materials and activities (such as public meetings, seminars, plays, songs and school programmes) to inform and educate all clients, in-school youth, and persons living in the Busoga Diocese about STIs and HIV/AIDS[24].

Within that model, the partnership took on two major areas of activity:

Training and capacity-building for village health care workers

The partnership works to improve and expand the skills of FLEP village health workers, nurses and supervisors in rural communities.

Photo: Joy Mukaire

A community health worker travelling to work.

Village health workers are on duty an average of three days a week, carrying out a variety of tasks in different community zones assigned to them. Their primary work involves making informational visits to village women in their homes, giving group talks, and following up with women who have

[24] Some of this text was adapted from PATH's Reproductive Health Outlook at http://www.rho.org/html/rtis_overview.htm (PATH = Programme for Appropriate Technology in Health)

discontinued a family planning method. They distribute condoms and oral contraceptives and make referrals to FLEP clinics, VSC clinics and hospitals. Their work also includes family planning with growth monitoring for children under five, and immunization.

The training strategy conceived by TASO and Pathfinder International is aimed at enabling village health workers to ensure that HIV-infected persons receive a 'package' of care services at home, the various components of which can be clinic-based, health unit-based, village-based, family- or home-based. The components of the package are: medical care (both nursing and clinical); support and counselling; psychosocial support (including spiritual support); AIDS education; health education; nutrition; hygiene and sanitation.

The curriculum created by the partnership trains FLEP village health workers to:

- assess patients' and families' needs;
- provide some of the package of services themselves, particularly counselling and some basic forms of medical care;
- build skills among persons living with HIV/AIDS to provide self-care appropriate to their situation;
- build skills among family members and friends of persons living with HIV/AIDS so that they can be home-based caregivers, and thereby meet the patients' day-to-day care needs (making them comfortable, ensuring better nutrition and hygiene, changing dressings, administering simple medications, keeping their spirits up);
- work with the local hospital and with doctors, counsellors, spiritual leaders, and social workers (this includes knowing the capacities of these other service-providers and making referrals as necessary);
- work with legal aid programmes of other NGOs (for example, the Women Lawyers Association) to help persons living with or affected by HIV/AIDS to plan their future. Activities include preparing a will, burial arrangements, and linking to grass-roots organizations affiliated to FIDA (the Ugandan widows' association) to assist with property inheritance issues, especially securing land, ensuring orphans' care and education, and discouraging 'widow inheritance' in order to reduce in-family HIV transmission.

In order to reward and motivate village workers, FLEP began by giving them a bicycle every three years and a bar of soap. The soap incentive was changed to a monthly allowance for bicycle maintenance, currently the equivalent of $10 a month. Other motivations included supplying them with major spare parts for their bicycles and a uniform.

The partnership also took into account the need to maintain morale (as well as improve knowledge). It therefore emphasizes regular refresher courses, and frequent motivational interaction with supportive supervisors. The further development of village health workers' communication and leadership skills also enhances the quality of care they provide.

Other incentives include the possibility of promotion to supervisor, and courses to enable them to become trainers or IEC specialists. These, in turn, can lead to other interesting possibilities for those who show skill and initiative: the chance to be employed training other organizations, and to host visitors from inside or outside the country (this is fairly frequent, since many organizations are interested in FLEP's work).

System capacity-building

The project recognizes that HIV/AIDS care is delivered at four levels, which frequently work independently, in ignorance, or in distrust of each other. These four levels are:

- clinic-based service providers (doctors, nurses, counsellors);
- community-based service providers (village health workers or AIDS community workers);
- home-based caregivers (relatives or friends);
- self-care by persons living with HIV/AIDS.

The partnership aims to help build bridges between the different levels, making their efforts consistent with, and conscious of, the efforts of others, and improving the quality of care provided by each. This, in turn, improves the entire system of health care available in rural communities.

This system capacity-building is done through meetings and workshops to plan, implement or evaluate activities, negotiate financing, and examine and improve training curricula. Advocacy is another important part of this activity set, and is carried out both at the local level (i.e. with local government and institutions), to ensure cooperation with the activities of village health workers, and at the provincial or national level with appropriate authorities

such as the Ministry of Health. Pathfinder International also continues to build FLEP'S institutional capacity to increase its prospects for sustainability.

Photo: Joy Mukaire

The community health worker training and supervising a carer in her home.

Monitoring and evaluation

Under the arrangement arrived at by the partners, monitoring of activities was undertaken by Pathfinder International. This was a natural role for the latter, since, as a contractor to USAID, it already had responsibility for financial supervision of FLEP's activities. Among other tasks, Pathfinder hired auditors annually to check the project's books, and monitored disbursements during the year.

Accomplishments

FLEP currently provides care to about 16 000 clients every year. There have been 2240 volunteers trained in 56 rural communities in order to provide intermediate AIDS services. Furthermore, 160 counsellors for 16 other organizations have been trained to provide AIDS services in districts without TASO centres.

The partnership has produced an effective training curriculum, and its home care handbook has proved both useful and 'friendly' to its readership. FLEP now has sufficient in-house capacity to carry out most of its training, and therefore only needs TASO to help with special projects rather than with basic village health worker training or training of other organizations.

Challenges

Through monitoring and discussion, several ongoing problems have been identified over the course of the project:

- As yet, there is no formal contract or memorandum of understanding between FLEP and TASO. While good communications have so far kept the relationship reasonably smooth, it is felt that a more formal written arrangement would help ensure clarification of each organization's roles and responsibilities. Also, this would ensure that activities are jointly planned and institutionalized so that unilateral cancellations of planned activities (the only serious problems to date) are discouraged.
- Standard guidelines are now available in Uganda for management of STIs but not, as yet, for risk assessments to be used in the management of HIV/AIDS. This has made it difficult for FLEP to standardize its own protocols.
- While well informed about the basics of HIV/AIDS, FLEP staff are not yet sufficiently trained in the management of opportunistic infections. Plans are under way to solve this critical problem, since it is expected that increasing numbers of patients will be seeking help with HIV/AIDS-related illnesses.
- The same concern about rising demand for services applies to the fact that clinics are inconsistently stocked. The situation varies from clinic to clinic because drug purchases depend on provider requests and resources available. They generally have few drugs available to treat opportunistic diseases (this is also true for STIs).

The future

The partnership's experience to date confirms the significant potential benefit of cooperation between existing services—each contributing its own expertise and practical experience—and the feasibility of doing so without creating new levels of bureaucracy. The latter feature is particularly important in a resource-poor setting. All of the partners have been strengthened, but the real benefits are felt by rural communities and people living with HIV/AIDS, who would otherwise have fewer, lower-quality AIDS-related services.

Pathfinder, TASO and FLEP are working on a proposal for a community-based essential drug kit, to ensure that the minimum necessary to assist persons living with HIV/AIDS is readily at hand. They are also exploring the possibility of social-marketing such a kit to raise motivational support for the community-based service volunteers, village health workers or AIDS community workers. In addition to the training curriculum and home care handbook already produced by the partnership, they are creating a flipchart training tool for use in the villages.

The programme feels it is important that the status of village health workers be increased, through the recognition of their work by the community. Furthermore, the workers should be given active roles to play in major national and international events. The formation and registration of an association, of which all village health workers are members, has facilitated community exchange visits and study tours, as well as entitling them to engage in micro-enterprise projects.

For more information:

Wilson Kisubi
Pathfinder International (East Africa)
P.O. Box 48147
Nairobi, Kenya

Fax: +254-22-24154

E-mail: WKisubi@pathfind.org

Sophie Mukasa-Monico
Executive Director, TASO
P.O. Box 10443
Kampala, Uganda

Phone: +256-41-231138

Fax: +256 41 251982

E-mail: dirtaso@infocom.co.ug

Phyllis Joy Mukaire
Family Life and Education Program
31 Baxi Road
P.O. Box 2010 Jinja

Phone: +256-43-120990

Fax: +256-43-120073

E-mail: jmukaire@pathfind.org

10. Lessons learned and common strategies

The eight cases described in previous chapters are each very different in setting and origin, yet a variety of parallels and similarities can be seen between them. Each provides valuable lessons about how home and community care operations can be scaled up to reach new clients, or provide a more complete continuum of services to people living with or affected by HIV/AIDS.

Putting the WHO Home Care Framework into practice

As mentioned in the introduction, many of these cases studied and applied the lessons presented in WHO's 1993 *AIDS Home Care Handbook*. However, most have gone beyond the book's lessons, and have actually put into practice the conceptual framework for scaling up and reaching out. This framework was not based on experience (the epidemic was too new at the time), but rather on a vision of what care programmes could eventually accomplish.

It is worth looking briefly at the objectives that made up the conceptual framework, and seeing how they fit with the cases in this report

1. Provide not just individual services but *comprehensive* care to people living with HIV/AIDS

Six of the eight cases have made this an important objective of their activities, within the limits of the resources available to them. All six emphasize building the skills of care providers to recognize and deal with a variety of medical conditions or counselling needs. India's COCP and the Cambodia's Home Care Programme have increased the comprehensiveness of the services they offer by creating multidisciplinary teams. On a more mechanical level, standardized home care kits are an important part of this effort, for they provide caregivers with the materials necessary to do the job.

2. Provide a *continuum* of care, linked with a referral system, spanning home to hospital

Seven of the eight work to either widen the range of care offered to patients by home care programmes themselves or plug gaps in the existing services available to patients. Côte d'Ivoire's CASM, Kenya's Kariobangi, and Uganda's Partnership for Home-based Care all operate at the health front line, providing the basic home care that the health system cannot afford or is not organized to offer. However, they refer patients for more complicated treatment to the hospital system or to private doctors, thereby extending the continuum of care available to patients.

In contrast, the Mildmay Centre fills in a gap (provision of specialized palliative care services) between Uganda's highly experienced home care providers, health care clinics, and hospital systems. Ecuador's Programme for AIDS Initiatives, operating in a low-prevalence environment where AIDS is not a national priority, aims to fill an almost complete vacuum in HIV/AIDS care.

3. Integrate model of care into the government health care system

A continuum of care can be created by individual organizations identifying and plugging gaps. However, in cases such as Cambodia's Home

Care Programme and South Africa's Bambisanani, new initiatives were designed by a set of partners—government, NGO and community—who decided together how best to integrate home care with existing HIV/AIDS and other health services. This type of planning could provide a valuable model for use in other countries.

4. Facilitate close coordination and cooperation between NGOs, government health services and communities

Ecuador's Programme for AIDS Initiatives provides an example of how a national-level NGO can take up a coordinating role as it (a) strengthens other NGOs and CBOs already doing some AIDS work and (b) enables other NGOs and CBOs to extend their services to people with HIV/AIDS. As part of its coordinating activities, the national NGO can develop cooperation among partners or seek new partners as opportunities present themselves.

A different approach was taken by Cambodia's Home Care Programme, India's COCP and South Africa's Bambisanani; these initiatives included all or most partners from the beginning, including government. In Uganda, the Partnership for Home-based Care started out as a coordinated effort between the NGO partners, and only later developed formal ties to the district governments.

5. Include a prevention component

Most of the cases in this report include some prevention activities as part of their work, often in quite innovative ways. For example, some of CASM's most effective prevention work in Côte d'Ivoire is done through the Friends' Club, a support and advocacy group for HIV-positive people which grew out of (but still works closely with) CASM's clinical work. In South Africa, Bambisanani tackles prevention from several directions: through its community mobilization activities, through condom distribution, and through extensive information, education and communication (IEC). In contrast, Kenya's Kariobangi has decided to leave prevention to other NGOs or government programmes, judging that the best use of its own expertise and resources is in care.

6. Utilize the existing community resources with sustainable support mechanisms.

All of the cases attempt to use local resources as much as possible, but their approach depends very much on the relative wealth of the community and country. In the poorest settings, the most important local resource is people, and therefore volunteer labour is a key input (often this is achieved with the assistance of local religious authorities). Bambisanani, in contrast, has been successful in gaining the financial and material support of industry, with participation by both the mining and pharmaceutical sectors. In Ecuador, which is considerably better off per capita than most other cases, many of the AIDS efforts supported by the Programme for AIDS Initiatives have achieved notable resource mobilization successes, gaining funding or material support from sources such as municipal governments and church groups.

The following table summarizes how each of the cases described in this report has taken on the objectives set out by the conceptual framework.

Conceptual framework objective	Home Care, Cambodia	CASM, Côte d'Ivoire	AIDS initiatives, Ecuador	Kariobangi, Kenya	COCP, India	Bambisanani, South Africa	Mildmay, Uganda	Partnership, Uganda
Provide comprehensive care to people living with HIV/AIDS	✓	✓		✓	✓	✓		✓
Provide continuum of care spanning home to hospital	✓	✓		✓	✓	✓	✓	✓
Integrate with gov't health care system	✓	✓	✓	✓		✓	✓	✓
Cooperation between NGOs, government, services and communities	✓	✓	✓	✓		✓	✓	
Strong prevention component		✓	✓		✓			✓
Utilize existing community resources with sustainable support mechanisms.			✓	✓	✓		✓	✓

Obstacles to scaling up

In the context of HIV/AIDS home and community care, 'going to scale' is about bringing services to more people. Although lack of resources is often a main challenge to this goal, several other obstacles also stand in the way:

- The ambitions of NGOs and local services to expand sometimes run counter to government plans or policy, or do not fit well with a country's administrative structure. For instance, it may be difficult for an NGO based in one district to receive support (or even permission) to work outside that district's boundaries if the national health system is very rigid in its administrative procedures (e.g. if drugs supplied by government pharmacies can only be distributed in their district of origin).
- Institutional competition may arise if one organization expands into places that other organizations consider to be their territory. Similarly, friction may arise if one professional group (e.g. clinical staff, social workers, administrators, traditional healers, pharmacists) feels that another is encroaching on its area of professional expertise.
- People who are good at one activity, such as home care or counselling, are not necessarily good at administration. For this reason, organizations that function smoothly while small, often run into serious problems once they get bigger. This is a problem of organizational capacity, often due to lack of management expertise or experience.

It is instructive that TASO, though one of Africa's most successful AIDS NGOs, made a decision to limit its own growth because of fears of over-extending itself. In 1995, TASO was operating in eight of the country's 49 health districts, and was often tempted to respond to the obvious need in other districts by expanding. However, instead of widening its institutional presence within Uganda, it decided instead to help other NGOs who were attempting to do home care, providing the benefit of its experience to these newer organizations.

Creating bridges and breaking down barriers

Some successful partnerships have evolved over time without formal planning, contracts or memoranda of understanding. The relationships of Kariobangi and CASM with local health providers and other NGOs are examples of this kind of growth, the success of which depends greatly on the interpersonal skills of staff and mutual goodwill between organizations.

In other places, effective scaling up is the result of carefully-designed cooperation between existing services. The partners must have similar goals and objectives in AIDS responses, or recognize a potential to capitalize on synergies between AIDS-related activities and those working in different fields. Then each partner contributes its own comparative advantage and practical experience.

This sounds easy and logical, yet such partnerships are the exception rather than the rule. Although the word 'partnership' is almost a cliché in the fields of health and development, it is often forgotten that a successful partnership takes *work*. Effective partnerships often have to overcome different ways of doing things, organizational politics, and sometimes even outright hostility before they begin to work.

The Ugandan home care partnership of four NGOs—FLEP, Pathfinder International, TASO and the AIDS Information Centre—is a prime example of how scaling up can be achieved without creating a new level of bureaucracy when a group of organizations contributes their comparative advantages. FLEP brought its system of clinics and rural health centres as the main service provider; Pathfinder and TASO each contributed technical expertise and training; the AIDS Information Centre supplies the essential component of HIV testing. From the beginning, however, the partners recognized that the partnership was not necessarily a 'natural' one, and that bridge-building (across organizational, professional and even political boundaries) would be necessary. For this reason, it is worth repeating the following text from our chapter on the Partnership for Home-Based Care, which is an explicit statement of what often remains unsaid:

The project recognizes that HIV/AIDS care is delivered at four levels, which frequently work independently, in ignorance, or in distrust of each other. These four levels are:

- *clinic-based service providers (doctors, nurses, counsellors)*
- *community-based service providers (village health workers or AIDS community workers)*
- *home-based caregivers (relatives or friends)*
- *self-care by persons living with HIV/AIDS.*

The partnership aims to help build bridges between the different levels, making their efforts consistent and conscious of the efforts of others, and improving the quality of care provided by each.

A similar lesson is emphasized by the Home Care Programme in Cambodia:

> *The programme has had to work hard to maximize cooperation between the various participants. For instance, mutual suspicion between NGOs and government has largely been overcome. Much of this has been achieved through the coordination mechanisms established during the pilot year. These mechanisms vary from informal visits between teams, to regular formal coordination meetings involving all partners (the Home Care Network Group)—all of which serve to increase the transparency of activities. Also important are personal contacts between individuals in all the organizations. Finally, there is a formal contract between KHANA and the Ministry regarding the management of funds…*

COCP in Manipur has tried to 'build in' such cooperation through the mechanism of core groups and service cells (see Chapter 5 for details). Whatever the strategy used to build such partnerships, a common lesson learned seems to be that clarity and transparency are key.

The benefits of decentralization

An important lesson learnt over the past decade in a wide variety of settings is that national HIV/AIDS responses cannot reach the necessary scale, maintain quality, or provide the necessary flexibility by acting solely through the centrally operated programmes. A decentralized, participatory approach—

i.e. with involvement of all sectors—is the only way to get wider coverage and enable programmes to reach all those who are hard to reach, especially at the grass-roots level.

For example, most National AIDS Programmes have not been effective in reaching people—especially youth and women—in the rural areas. However, when they are willing to work in partnership with NGOs who have special expertise with these populations, a great deal can be accomplished.

COCP is a good illustration of this. Its cooperative approach linking NGOs and CBOs to formal health services permits people from the hilly areas of Manipur Province and injecting drug users to access services they would otherwise shun or perhaps not even know of. Similarly, the Partnership for Home-based Care in Uganda works formally with the district health governments, linking their hospital and other services to the NGO health clinics and village care workers. Finally, the Ecuadorian Programme for AIDS Initiatives has supported a wide range of client groups—from indigenous peoples to children in school—none of which were receiving adequate services from the under-funded national programme.

Building management capacity

In many developing countries, HIV/AIDS projects are held back by a number of administrative challenges. Some of these are the legacy of colonial times and some are of more recent origin; most are not peculiar to HIV/AIDS, but to all aspects of public administration and governance:

- lack of institutional capacity, including lack of trained managers and insufficient administrative infrastructure to manage given projects;
- slow, out-of-date bureaucratic procedures that choke initiative and reduce effectiveness;
- lack of procedural transparency, allowing inefficiency and corruption to 'eat' scarce resources;
- lack of follow-up, either because short-term political priorities 'hijack' carefully planned programmes or because monitoring and evaluation are not built into planning cycles.

Two of the cases in this report have responded specifically to these problems. The Home-based Care Partnership in Uganda partly addresses these problems in its 'system capacity-building' function, which includes a focus on improving health care partners' planning, implementing and evaluating activities. In Ecuador, the Programme for AIDS Initiatives includes an activity aimed at "institutional strengthening" that provides partners with training in project planning and financial management, including accounting.

Special lessons from Ecuador

Over the years, the Programme for AIDS Initiatives in Ecuador has gained special experience working with partners and subcontractors. It functions as a granting and technical support organization, helping other organizations to carry out their local-level HIV/AIDS activities. This model may be useful in other parts of the world.

The programme staff emphasize the following lessons learned in managing relationships with nongovernmental organization (NGO) and community-based organization (CBO) partners in HIV/AIDS care:

- Staff need to know and understand the candidate NGO or CBO well before signing grant agreements with them. Sometimes the candidate organization's motivation can be simply that of obtaining funds, rather than mounting a serious response to HIV/AIDS. Although it provides no guarantees, an in-depth analysis of each candidate partner can help screen out such organizations.
- Many NGOs and CBOs need support in preparing their initial project proposals to help them be more realistic based on the local situation and the NGO/CBO's resources and experience. A community assessment is very important in this process.
- The NGO/CBO support organization [in this case, the Programme for AIDS Initiatives] should avoid training the target population directly. It should instead carry out training of trainers, to help the NGO or CBO gain technical credibility in the community, rather than always waiting for the 'experts'

to come and visit. On the other hand, this also raises the level of sustainability of their work and the NGO, as they can work independently of the support organization.

- It is important to document the different tools and methods developed, as much of the experience could probably be beneficial to other organizations doing similar work.
- Field visits are crucial to a good monitoring system. Reports and office visits only can give a partial view of reality and must be augmented by direct observation of the work done. Among other benefits, this allows the support organization to better determine exactly what type of support is needed.
- Support organizations should foster a periodic process of reflection and analysis within the NGO or CBO. At certain times they need to stop and evaluate their impact and processes so they can attempt to improve them.

A final word of advice is one that will strike a chord with most people who have worked in community mobilization: "Always recognize the existing knowledge and experience of the NGO or CBO and the target population. No work starts from zero."

Building technical capacity among local health care workers

The knowledge of health care workers (HCWs) about HIV/AIDS varies from place to place, and in many cases is incomplete. Because the epidemic is relatively recent, many HCWs have received little training on HIV/AIDS. Unless in-service training is offered, there is no opportunity to develop knowledge or skills in this area of work.

Nevertheless, most HCWs—nurses, midwives, doctors, dentists, and paramedical personnel—will at some point encounter people living with HIV/AIDS, and may be involved in their care. To do so, they will need new skills and increased knowledge. As well, support staff need to learn about HIV/AIDS if they are to be effective in their work, become educators for health, and protect themselves from harm.

HIV/AIDS education and skills-building can be a cost-effective investment in recruitment and retention of the health care workforce for several important reasons. First, enhanced knowledge and skills lead to improved patient care, in both prevention and treatment. Second, greater knowledge will help HCWs to protect themselves from infection, both professionally and personally. Third, there is growing evidence that improved knowledge of HIV/AIDS positively affects attitudes to caring for people living with HIV/AIDS and reduces levels of discrimination towards them.

Taking advantage of the HIV/AIDS expertise they have built up over the years, almost all of the initiatives in this report make some effort to build the technical capacity of health care workers. Some, like India's COCP, teach a wide range of skills to an equally wide range of health care workers. In the case of Uganda's Mildmay Clinic, the training is in a specific field (palliative care—see below).

Palliative care: an essential part of the care continuum

Palliative care—particularly reducing pain and discomfort—should be central to AIDS care programming. People living with HIV/AIDS face a variety of opportunistic infections or cancers, experience multiple symptoms, and face myriad psychosocial issues. The disease progression is unpredictable: declining health may alternate with periods of physical and emotional stability, resulting in chronic uncertainty.

Unfortunately, too much focus on budgets and systems sometimes results in forgetting the human toll exacted by AIDS. In low-resource settings, pain management is often forgotten as medical efforts are focused on the underlying condition. Obviously, such treatment is important but pain relief is a priority. Health workers should not withhold pain relief for fear that a person will become addicted to pain-killers or taking medication. A balance between increasing access to adequate pain and careful supervision and record keeping of prescription of opiate analgesics is needed. However, it must be remembered that palliative care requires special skills and sometimes a change in attitudes among health staff in order to be effective.

Uganda's Mildmay Clinic has taken a lead in this field, not just in providing palliative care but in spreading its expertise. Mildmay has a variety of educational programmes to help improve care throughout the region, with an emphasis on building local capacity in AIDS palliative care. It has its own Training and Education Centre, complete with a lecture hall and simple hostels where trainees can stay during courses. Mildmay also has a Mobile Clinical Training Team that takes training to the rural districts.

Most of the other cases in this report place a great deal of emphasis on managing pain and other symptoms. For instance, Cambodia's Home Care Teams receive training in physiotherapy for pain relief, and their home-care kits include simple medicines that aim to make patients more comfortable. India's COCP provides its partners with training in palliative care, including a specialized curriculum for community mobilizers, nurses, health workers and social workers who provide palliative care in the home.

Tackling the dual epidemic: AIDS and tuberculosis

AIDS is a serious public health problem in its own right, but it also exacerbates other challenges to national health systems. The increased demand for health care from people with HIV-related illnesses is further testing the already overstretched public health services of many developing countries. Moreover, the development of vaccines and of new therapies for HIV-infected persons will further raise health sector costs in infrastructure, drugs, training and personnel expenditures as demand for these products increases.

The shifting and growing demand on health care systems is underscored by the exploding tuberculosis epidemic in the countries most heavily affected by HIV. Tuberculosis has become the leading cause of death among people with HIV infection, accounting for about a third of AIDS deaths worldwide. Hospital data from Africa show that up to 40% of HIV-infected patients have active tuberculosis, which represents a further cost to the health sector.

Several of the initiatives in this report have responded strongly to the dual epidemic. COCP in India has established core groups within Imphal's Tuberculosis Hospital and also the State Tuberculosis Clinic. It also joined its efforts to that of India's National Tuberculosis Control

Programme, taking advantage of this link to access drugs for its patients and also opening two centres providing DOTS treatment for tuberculosis in collaboration with local youth clubs and the State Tuberculosis Clinic. In South Africa, Bambisanani places great emphasis on tuberculosis in its community mobilization work. On a smaller scale, Kariobangi works closely with a diagnostic laboratory for tuberculosis located in a local Catholic church.

Dealing with the impact of AIDS on families

It is now clear that the population structures of badly affected countries are being radically altered by HIV. What this means for society is hard to predict, since the world has never before experienced death rates of this magnitude among young adults of both sexes across all social strata. But there is one certainty: a small number of young adults—the group that has traditionally provided care for both children and the elderly—will have to support large numbers of young and old people. Many of these young adults will themselves be debilitated by AIDS and may even require care from their children or elderly parents rather than providing it. Inevitably, AIDS-affected households suffer a dramatic decrease in income. Another development is the rising number of families headed by young children or very old persons, who not only have to do the myriad tasks needed to run a household but also have to care for the sick adults.

CASM in Côte d'Ivoire and Kariobangi in Kenya both show the kind of efforts that can be made to reach out to AIDS-affected families in resource-poor settings. Services range from providing food (either in the home or at the programme centre), to income-generating schemes and activities aimed at strengthening the future of these families' children. The Mildmay Clinic in Uganda includes occupational rehabilitation in its range of services, teaching skills to patients that may help them earn an income, despite their illness.

On a larger scale, Bambisanani in South Africa is investing considerable effort in providing families with income-generating activities such as building, food-preparation, farming and other micro-enterprise. Two of Bambisanani's partner organizations—the Employment Bureau of Africa (TEBA) and the Mineworkers Development Agency—will be involved in the job-creation and income-generating aspects of the project.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) brings together eight 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 International Labour Organization (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO), and the World Bank.

UNAIDS, as a cosponsored programme, unites the responses to the epidemic of its eight cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV/AIDS on all fronts. UNAIDS works with a broad range of partners–governmental and nongovernmental, business, scientific and lay–to share knowledge, skills and best practices across boundaries.

Produced with environment-friendly materials

The theme of this report, *Reaching out, scaling up*, reflects a concern that has become increasingly important in the past few years. All too often, good local-level responses to HIV/AIDS—best practices, in other words—have remained local and small-scale. The many lessons learned have not been translated into bigger projects or wider coverage.

This report focuses, therefore, on projects and programmes that have been able to scale up or reach out, and in doing so have brought an improved quality of life to people living with or affected by HIV/AIDS.

Joint United Nations Programme on HIV/AIDS

UNAIDS

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Joint United Nations Programme on HIV/AIDS (UNAIDS)
20 avenue Appia, 1211 Geneva 27, Switzerland
Tel. (+41) 22 791 36 66 – Fax (+41) 22 791 41 87
E-mail: unaids@unaids.org – Internet: http://www.unaids.org