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ISSUE 2

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of The International
Partnership against
AIDS in Africa

Best Practices

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Summary Booklet of Best Practices in Africa

Issue 2
of the Summary Booklet series



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Introduction: Best Practices in Africa

AIDS is now the leading killer in sub-Saharan Africa. Whereas 200,000 people died as a result of conflict or war in Africa in 1998, AIDS killed 2.2 million. The progression of the disease has outpaced all projections. In 1991, WHO projected that in 1999 there would be 9 million infected individuals and nearly 5 million cumulative deaths in Africa. The reality in 2000 is two to three times higher, with 34.3 million infected individuals and 18.8 cumulative deaths.

Nearly 70 per cent of the world's HIV infection and 90 per cent of deaths from AIDS are to be found in a region that is home to just 10 per cent of the world's population. In the sub-Saharan region, infection levels are highest, 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. Resources are not keeping pace with the challenge. Incidence of the disease is increasing three times faster than the money to control it.

Current national AIDS activities in Africa must be expanded dramatically to make an impact on the epidemic. African leaders are demonstrating unprecedented leadership in fighting HIV/AIDS; the time is ripe for an extraordinary effort. The International Partnership against AIDS in Africa (IPAA) is such a mobilization. At the same time, the Best Practice process – accumulating and applying knowledge about what is working and not working in different situations and contexts – is crucial within the framework of the Partnership.

The International Partnership against AIDS in Africa

The IPAA is a coalition of actors who have chosen to work together to achieve a shared vision and common goals, based on mutually agreed upon principles and key milestones. Its purpose is to establish and maintain processes by which governments, civil society, and especially the community sector and national and international organizations working against AIDS in Africa, can work together more effectively to curtail the spread of HIV, sharply reduce the human suffering it produces, and reverse the human, social, and economic erosion in Africa.

(For more on the IPAA, see www.unaids.org/africapartnership/index.html.)

The actors in the IPAA are African governments, the United Nations, donors, the private sector,¹ and the community sector.^{2 3} The IPAA can be

¹ The private sector includes diverse groups such as multinational corporations, pharmaceutical firms, foundations, and trade unions.

² Under the Partnership, the community sector will be understood to start from individuals, families, and communities who have organized themselves on basis of geographic, constituent, and thematic areas

understood as a series of overlapping partnerships at different levels, and among different actors, working to common objectives.

At the country level, members of the IPAA undertake to work under the leadership of national governments within a common, strategic framework, frequently called a “national strategic plan for HIV/AIDS.” To be effective, this framework will identify core strategic and programmatic areas for intervention, and the role of different actors.

- ◆ At the regional and subregional level, members will build on existing mechanisms for collaboration in strengthening and developing regional resources, such as technical resource networks, available for rapid drawdown by national programmes seeking technical advice and training.
- ◆ At the global level, the IPAA will identify processes and products in which to invest collectively. These will include intensifying action in areas ranging from international public goods to political processes, focusing on those areas where coordinated efforts are likely to have an impact as well as those that are likely to result in greater visibility and resources to fight the epidemic.

The benefits of partnership

The partners believe that the synergy created by working with others will dramatically enhance the impact of individual actions, allowing the participants to continue to build on Best Practices at every level.

As designed and agreed to by the partners, the value added by the IPAA lies in the following features:

- ◆ A coordinated response: In most countries there is immediate scope for improved coordination. Introducing the flexibility to identify gaps and improve efficiency in nationally negotiated plans will be a significant step forward in many countries.
- ◆ A scaled-up response through more resources and better use of existing resources: Resources are more likely to flow towards well-designed, clearly costed, and well-implemented programmes, especially where it is clear that mechanisms are in place for moving resources to district and community levels.
- ◆ A linked response: The IPAA will ensure that countries are properly linked to subregional, regional, and international resources and initiatives. By improving communications and the quality of information and, where necessary, ensuring that brokering functions are performed, the Partnership will ensure that countries are able to benefit from other international and regional investments

to respond to the epidemic. The community sector includes national and international non-governmental organizations (NGOs), community-based organizations (CBOs), religious organizations, traditional healers, youth organizations, women’s networks, networks of people living with HIV/AIDS (PLWHA), media houses, and special interest groups.

³ Participating actors in the Partnership include national academic and research institutions.

in addressing the epidemic, including through Best Practice development, information, commodities, or technical expertise.

- ◆ A response based on the Best Practices learned from two decades of experience with the epidemic: Experience from two decades of the epidemic has generated a considerable body of good practice.

A vision of action

The International Partnership against AIDS in Africa proceeds from the vision that, within the next decade, African nations, with the support of the international community, will be implementing larger-scale, sustained, and more effective multisectoral national responses to HIV/AIDS. Through collective efforts, promotion and protection of human rights, and promotion of poverty alleviation, countries will:

- ◆ substantially reduce new HIV infections
- ◆ provide a continuum of care for those infected and affected by HIV/AIDS
- ◆ mobilize and support communities, NGOs, the private sector, and individuals to counteract the negative impact of the HIV/AIDS epidemic in Africa.

Best Practice in the response to AIDS

Identifying practices around the world that work in responding to the AIDS epidemic, and examining how and why they work, is one of the UNAIDS Secretariat's main tasks. UNAIDS and its cosponsors promote the sharing of these practices, including through such means as documentation and widespread distribution of the lessons learned.

The concept of Best Practice is not reserved for "ultimate truths" or "gold standards." For UNAIDS, Best Practice means accumulating and applying knowledge about what is working and not working in different situations and contexts. In other words, it is both the lessons learned *and* the continuing process of learning, feedback, reflection, and analysis (what works, how and why, and so forth).

At its most basic, Best Practice suggests a simple maxim: Don't reinvent the wheel; learn in order to improve it, and adapt it to your terrain to make it work better.

The process of Best Practice is manifested in three ways:

- ◆ exchange of experience, including sharing between individual experts and Technical Resource Networks (TRNs)
- ◆ pilot testing, operations research, and other projects and programmes
- ◆ documentation including formats such as audiovisual cassettes, CDs, and presentation graphics (however, it is important to remember that Best Practice is not simply documentation, but an approach to sharing and using knowledge).

Identifying Best Practice that provides useful “lessons learned” means making judgements. To arrive at such judgements, two approaches may be used, each reflecting a different level of analysis.

The first approach is based on a simple description of the practice's accomplishments. From this point of view, Best Practice can be anything that works, in full or in part, and that can be useful in providing lessons learned.

The second approach is to carry out a thorough analysis using specific, established criteria that look at strengths and weaknesses, successes and failures. UNAIDS uses a set of five criteria as a guide: effectiveness, efficiency, relevance, ethical soundness, and sustainability. While candidate Best Practices should meet one or more of the criteria, they do not need to meet them all.

In summary, the Best Practice process helps to identify and describe the lessons learned and the keys to success of any given project, programme, or policy.

Why document Best Practice?

Our UNAIDS cosponsors, in-country staff, and Secretariat in Geneva are constantly asked to provide brief and up-to-date information – “snapshots” might be a good description – about the constructive and creative things that people and organizations around the world are doing about HIV/AIDS. This is a practical illustration of one of the main reasons we document and disseminate Best Practice. Without access to existing knowledge and experience from the field of things that work, whether fully or in part, mistakes may be repeated and valuable time may be lost. Lessons learned must be widely shared and adapted to local conditions in order to enable an effective response to the epidemic.

The formal objectives of Best Practice are:

- ◆ to strengthen the capacity to identify, document, exchange, promote, use, and adapt Best Practice as lessons learned within a country and between countries as a means to expand the national response to HIV/AIDS
- ◆ to promote the application of the Best Practice process for policy and strategy definition and formulation
- ◆ to collect, produce, disseminate, and promote Best Practice.

In this Summary Booklet, UNAIDS attempts to capture details of a range of Best Practices in order to provide useful lessons and offer references for those working in HIV/AIDS-related activities.

In this booklet, UNAIDS attempts to capture details of a range of Best Practices in sub-Saharan Africa in order to provide useful lessons and offer references for all actors of the IPAA. *It is by no means comprehensive or complete: there are many other Best Practices in Africa that have been documented in the previous issue of the Best Practices Summary Booklet or will be documented in upcoming issues.*

Where do Best Practices come from?

Sources of Best Practice are wide. They include UN system staff, non-governmental organizations, government representatives and agencies, community groups, and individuals. Sometimes Best Practice is identified through small or mass media. UNAIDS gratefully acknowledges the work of its staff, but especially acknowledges the diligent efforts of the field staff of its cosponsors (UNDCP, UNDP, UNESCO, UNFPA, UNICEF, WHO, and the World Bank), the chairs of the United Nations Theme Groups on HIV/AIDS, and other partners to provide the lessons learned for the summary booklet.

Submissions usually arrived in electronic files, often with detailed supporting documents. Others, sometimes hand-written, arrive in the mail from non-governmental and community organizations and from independent researchers – that is, from people working on the front lines of the response to HIV/AIDS. Some of these have been accepted for publication almost verbatim. Still others have been gleaned from journals, project reports, and even from newspapers and magazines.

While some of the practices have been the subject of formal evaluation processes, most have not. This may seem odd in a publication devoted to Best Practice, but there is a reason for it that is based solidly in the reality of the HIV/AIDS epidemic. Formal evaluation of the type practised by academic and government institutions is often a slow, complicated, and expensive process that can take more professional time and cost more than the actual process being evaluated – and that should be planned as part of a practice's life span. The majority of practices detailed in this summary were oriented towards action rather than methodological “purity”; many were formed by grassroots organizations and individuals, few of which have the resources or in-house expertise for formal evaluation.

For this reason, many of the practices do not present evaluation information *per se*. In all cases, however, the outcomes and lessons learned provide whatever information is available on outputs and impacts.

Using the Summary Booklet

Currently, UNAIDS collects and publishes information on over 50 topic areas related to HIV/AIDS. The practices described in this summary are organized, first, according to their main topic areas. Each practice is preceded by a brief introduction to the topic. Since most practices are relevant to more than one topic area (for instance, a national fund for high-cost drugs would be categorized first under access to drugs, but it is also related to human rights, ethics, and law), an index is provided at the end of the summary. This permits practices to be found by their secondary topic areas, as well as by country.

We have tried to provide complete contact information so that readers can get additional information on practices that interest them. Where possible, each practice contains a section called Further Reading, in which readers will find bibliographic references for obtaining more information (some of this is available on the Internet, and full electronic addresses are provided. An electronic version of the full Summary Booklet database is available at www.unaids.org/bestpractice/collection/summary/index.html.)

We welcome your proposals

The entries in this booklet deal only with sub-Saharan Africa, and represent only some of the many reports and suggestions that we received. Later issues will, like the first volume in 1999, cover Best Practices from all continents. We thank all those who submitted proposals, whether they were included in this issue or not.

This publication includes a proposal submission form at the end, which readers can use to propose other practices. The form can also be downloaded from the UNAIDS' web page. Submissions have the best chance of being accepted for publication if they are sent via the UN Theme Group on HIV/AIDS or the UNAIDS Country Programme Adviser in each country (with a copy to the UNAIDS Best Practice Coordinator at the UNAIDS Secretariat in Geneva). Annex 2 contains the relevant addresses in sub-Saharan Africa.

As well, UNAIDS welcomes any comments and suggestions that will help us make this summary better and more complete. Please address these to the Best Practice Coordinator, PSR, at the UNAIDS Secretariat in Geneva.

Best Practices

Children and young people

Young people are key to the future course of the HIV/AIDS epidemic. The behaviours they adopt now and those they maintain throughout their lives will determine the course of the epidemic for decades to come.

At the end of 1997, over one million children around the world were estimated to be living with HIV and suffering the physical and psychological consequences of infection. Of the estimated 16,000 new infections daily, about 1,600 are in children under the age of 15 years. Young people between the ages of 10 and 24 account for more than 50 per cent of new post-infancy infections worldwide. As well, this age group constitutes more than 30 per cent of all people in the developing world, where the epidemic is concentrated. If HIV prevention in this huge population fails, developing countries will have to face the staggering human and economic costs of vast numbers of adult AIDS cases.

Increasingly, young people are being appreciated as a resource for changing the course of the epidemic. They are responsive to HIV prevention programmes and are effective promoters of HIV prevention action. Investing in HIV prevention among young people is likely to contribute significantly to a more sustainable response to HIV/AIDS. Several lessons have been learned over the past years that can be applied to planning effective actions to focus more on young people in the HIV epidemic.

Priority actions to be considered in the light of situation and response analysis in various countries, and feedback from youth organizations and young people, include:

- ◆ establishing or reviewing national policies to reduce the vulnerability of young people to HIV/AIDS and ensuring that their rights are respected, protected, and fulfilled
- ◆ promoting young people's genuine participation in expanding national responses to HIV/AIDS
- ◆ supporting peer and youth groups in the community to contribute to local and national responses to HIV/AIDS
- ◆ mobilizing parents, policy-makers, media, and religious organizations to influence public opinion and policies with regard to HIV/AIDS and young people
- ◆ improving the quality and coverage of school programmes that include HIV/AIDS and related issues
- ◆ expanding access to youth-friendly health services including HIV and STD prevention, testing and counselling, and care and support services
- ◆ ensuring care and support of young people living with HIV/AIDS

Two particular groups of children and young people will require a special emphasis: AIDS orphans and young people living with HIV/AIDS. UNAIDS estimates that, as of December 1998, the total number of AIDS orphans (defined as children having lost their mother or both parents to AIDS before the age of 15) since the start of the epidemic totalled at least 8.2 million. In many developing countries, extended family systems have traditionally provided support for orphans. However, AIDS, combined with other pressures such as migration, is pushing the extended family system to the breaking point in the worst-affected countries.

Like older HIV-positive adults, children and young people living with HIV infection require increasing health care as their immune system weakens and their health declines. However, they may face special obstacles in exercising their right to health. Young people may be too poor to buy care, or too afraid of disclosure by health providers who might not respect their confidentiality. The absence of youth-friendly services is an obstacle. In line with the United Nations Convention on the Rights of the Child, all children living with HIV/AIDS must have access to treatment, counselling, education, recreation, and social support, and must be protected against any form of discrimination.

Tsa Banana Adolescent Reproductive Health Programme (Botswana)

Starting Year: 1995

Main Topic Area: Children and young people

Other Topic Areas: Reproductive health

Contact Person:

Dominique Meekers, Guy
Stallworthy, John Harris

Phone: +1 202 785-0072

Fax: +1 202 785-0120

Email: generalinfo@psiwash.org

Web Site: www.psiwash.org

Address:

Population Services International
Social Marketing and
Communications for Health
1120 19th Street, NW, Suite 600
Washington DC 20036
USA

Implementers

Population Services International

Funding

USAID

Objectives

The Tsa Banana adolescent reproductive health programme was designed to:

- identify, develop, and promote reproductive health information, products, and outlets that are youth-friendly
- encourage young people to visit clinics, pharmacies, and youth centres for advice on how to avoid teen pregnancy and protect themselves against HIV/AIDS
- train retailers and clinic workers to respond to the special needs of their young clients.

Background

Premarital sexual activity is common among the Tswana, often before the age of 17, and it is common for both young men and women to have more than one sex partner. Young people in Botswana believed that reproductive health services were not intended for adolescents, and many were intimidated by clinics and staff. Yet Botswana has a high and increasing incidence of adolescent reproductive health problems, including pregnancy and infection with HIV and other STDs.

Tsa Banana, which means "for adolescents" in Tswana, was launched to test the effects of a promotion campaign targeting young adults in the medium-sized town of Lobatse.

Main Activities

The one-year project was implemented in Lobatse from March 1995. It included the following:

- a communications campaign
- youth-oriented social marketing of condoms
- community outreach through peer sales educators
- development of adolescent-friendly outlets for distribution of condoms and information.

Peer educators taught adolescents condom-negotiation skills, correct condom use, and ABC: Abstain, Be faithful, and Condomize. Condom demonstrations were held to instruct adolescents about the correct use of condoms. The programme also provided peer education sessions in primary and secondary schools. In secondary schools, the education sessions targeted all students and addressed topics related to AIDS, HIV transmission, teen pregnancy, and condoms. In primary schools, the education sessions targeted only those over 13, and mainly provided information on puberty and encouraged abstinence.

Outcomes

Research showed that 68% of female and 71% of male adolescents had heard of the Tsa Banana programme. Most (59% of females and 64% of males) had been exposed to Tsa Banana promotional items such as T-shirts, stickers, and pamphlets. More than 20% had heard about or seen a Tsa Banana condom demonstration. Some 41% of female adolescents and 33% of males were directly involved in Tsa Banana activities.

Evaluation Findings

Pre- and post-intervention surveys were conducted in both the intervention location (Lobatse) and a comparison location (Francistown) by Social Impact Assessment and Policy Analysis Corporation (SIAPAC) Africa. Analysis is based on the health belief model (HBM), which attributes changes in individuals' health behaviour to their beliefs about 1) the severity of the health threat, 2) their susceptibility to it, 3) the benefits/effectiveness of protective measures, 4) the barriers/negative implications of taking protective action, and 5) a trigger that leads individuals to act on these beliefs.

All changes in health beliefs were statistically significant. Females in the follow-up survey were 0.6 times as likely as women in the baseline survey to believe that it is hard to convince a partner to use a condom. At the same time, males were 2.2 times more likely to be shy about buying condoms in a public place, and 1.8 times likelier to be shy about obtaining them from a health workers.

After the intervention, males were 1.5 times more likely than before to believe that people use condoms to avoid sexual risks, and only 0.7 times as likely to believe it is hard to convince a partner to use a condom. Females were 2.7

times more likely than before the intervention to believe that AIDS cannot be cured, 3.4 times more likely to believe that people use condoms, 1.5 times more likely to believe people abstain from sex, and only 0.2 times as likely to believe that sex is good because it can lead to marriage.

There were a number of changes, both desirable and undesirable, which took place in both the intervention and the control location and that were not attributable to the intervention. Desirable changes are that males are more likely to believe that sexually active people are at risk of HIV/AIDS, that people reduce risk by abstaining from sexual activity, and that many of their friends use condoms. They are less likely to believe that sex is good because it can lead to marriage. There were undesirable changes as well. Females in both locations are more likely to feel shy about purchasing condoms in public, believe that women lose the respect of males if they initiate condom use, and believe that few of their friends use condoms. They are less likely to believe that people avoid casual and multiple partners to avoid risks. Among males, there is increased belief that sex is good because it enhances one's status.

However, the study demonstrates that the programme had a positive impact on several adolescent health beliefs. Within eight months, the intervention resulted in significant increases in the beliefs that AIDS cannot be cured, that people use condoms or abstain to protect themselves, and that it is easy to convince a partner to use condoms.

Lessons Learned

Males and females differ both in their responses to the Tsa Banana campaign and in societal trends. Future interventions should be designed to allow for these differences. Moreover, additional emphasis may be needed to counter undesirable changes.

Growing awareness that condoms protect against the risks involved in having casual and/or multiple partners may simultaneously tend to stigmatize condoms – through the associations with high-risk behaviour – even as it increases the perception of benefits that accrue from using them. This enhanced understanding of the complexity of the factors that affect programme impact will help programme managers improve ongoing as well as future AIDS prevention programmes.

Further Reading

Meekers D, Stallworthy G, and Harris J. *Changing adolescents' beliefs about protective sexual behavior: The Botswana Tsa Banana Program*. PSI Research Division, Working Paper No. 3, 1997.

AIDS prevention through The National Union of Youth and Students (Eritrea)

Starting Year: 1998

Main Topic Area: Children and young people

Other Topic Areas: Communications programming • Reproductive health • Male condoms

Contact Person:

Ms. Eden Asghedom

Project Manager

Phone: +291 1 120 488 or +291 1 124 751

Fax: +291 1 125 981

Email: nueyspro@eol.com.er

Address:

Ms. Eden Asghedom

National Union of Eritrean Youth and Students (NUEYS)

HIV/AIDS Focal Point

P.O. Box 1042

Asmara, Eritrea

Implementers

National Union of Eritrean Youth and Students (NUEYS)

Funding

UNFPA, Population Services International (PSI), UNICEF, and Family Planning Service Expansion and Technical Support Project (SEATS), a US NGO.

Objectives

The programme seeks to improve health for all young people 14 to 30 years of age by training volunteers in reproductive health and family planning so that they can establish peer education programmes in their schools and share their knowledge with their peer group.

Background

In 1993, following a 30-year struggle, Eritrea became the most recent independent nation in Africa (Africa's 52nd nation). It faces many serious problems. Nearly a quarter of Eritrean women marry before they are 15 years old and many bear children before their bodies are fully developed. Total fertility for the whole country is 6.1 children per woman (3.7 for the city of Asmara). The large number of births, spaced very closely, contributes to both maternal and infant mortality. The contraceptive prevalence rate is only 26 per cent in Asmara and 8 per cent for the country. As well, Eritrea suffers from an illiteracy rate of over 80 per cent, an acute shortage of schoolteachers and

instructional materials and equipment, uneven distribution of educational resources, and the absence of vocational training opportunities. About 5,787 cases of AIDS had been reported by the National AIDS Control Programme (NACP) of Eritrea by late 1998, and it is believed that HIV prevalence is growing rapidly, doubling every 18 months.

The youth of Eritrea (aged 14–24) account for approximately 30–35 per cent of the total population. There are insufficient school places and jobs, leaving many young people untrained and with few ways to contribute productively to their society. It is estimated that 20,000 young people are in school and 700,000 are out of school.

In Eritrea, it has traditionally been difficult for young people to get information on sexual and health matters. The family is often unprepared to deal with the educational, informational, and social needs of its children, and a traditional Eritrean family does not normally discuss sexual issues with children. Nor has the school system traditionally provided sex-related education. Similarly, there are few other institutions that cater to the physical and psychological needs of the young. Consequently, the youth of Eritrea tend to be ignorant on issues related to sexuality and adolescent/reproductive health.

The National Union of Eritrean Youth and Students (NUEYS) is a national non-governmental organization whose goal is to advance education and improve employment opportunities for youth. It has evolved into a strong, nationwide network, with a membership of over 138,000 young people, a paid staff of 269 within 51 urban and rural offices and sub-offices, and an even larger volunteer workforce, about half of which are women. NUEYS has a cooperative relationship with both local and foreign NGOs, UN agencies, and government ministries, and has participated in the implementation of a broad range of activities and projects throughout Eritrea, including four health centres.

Main Activities

Given the prevailing situation and indications of an increase in the problems of young people and their poor awareness about reproductive health and responsible sexuality, NUEYS and the Planned Parenthood Association of Eritrea (PPAE) in 1994 designed a project of comprehensive reproductive health education and services. In recent years, HIV activities have taken on a larger profile in the overall effort. They include.

- Regular sensitization seminars for high school students: These basically cover topics of population dynamics, anatomy and physiology of reproductive organs, what adolescence is, changes in adolescence, how pregnancy occurs, methods to prevent pregnancy, and STDs with emphasis on HIV/AIDS.

- Training for adolescent reproductive health counselling: The topics in the training courses on adolescent reproductive health include population dynamics, pretest counselling procedures, the AIDS situation in Eritrea, adolescents' and parents' perceptions about pregnancy, psycho-dynamics of counselling, sexual maturation, gender and sex, methods to prevent pregnancy, female genital mutilation, consequences of unprotected intercourse (i.e., pregnancy, abortion, infection with STDs or HIV/AIDS).

- Peer education programme: The trained youth are encouraged to hold meetings with their peer groups in their schools, at NUEYS health centres, and at NUEYS rural and urban offices.
- Workshop on how to involve men in family planning and introducing female condoms: Part of the messages given to men here is that using the female condoms would both facilitate family planning and prevent infecting partners with STDs including HIV/AIDS.
- Condom distribution: Condoms are distributed through the centres to STD clients and others. They are also distributed in the various sites where health orientation seminars are given and health training is done.
- Provision of clinical STD case management and family planning services, reproductive health counselling, library and recreational services for young people: These are the services that the youth-friendly centres provide to clients on a daily basis. In each of the services mentioned above there is an HIV/AIDS component. In the library and recreation centres for instance, there are IEC materials and other health booklets that speak specifically about HIV/AIDS. Part of the recreation provided is video shows that include movies that are HIV/AIDS-specific.
- Drama and film production: Several drama shows have been organized and shown to youth and the public, some only in Asmara and others throughout the country using a mobile drama group. These shows are always accompanied by the distribution of condoms and different campaign materials. NUEYS recently coproduced a film on HIV/AIDS and youth. Using language young people understand, it deals with the current behaviours of and problems facing Eritrean young people. This film was launched in the presence of many collaborating NGO representatives, youth leaders, MOH officials, and others and was broadcast on national TV on the World AIDS-Day Campaign launching day.
- Radio and newspaper: NUEYS is using one of its three newspapers to publish HIV/AIDS and other reproductive health-related articles addressing questions from youth on social issues like dating, friendship, love and sex, school and peers, peer pressure, and so forth. The articles are published every other week, with an overall goal of promoting healthy and safe sexual behaviour in young people. As well, NUEYS, in agreement with the Ministry of Information, has national radio airtime every Saturday from 2 to 3 P.M., during which youth issues are broadcast. Health messages are incorporated into these radio programmes, presented in drama, poems, and other forms. NUEYS organized a two-hour live radio programme for the 1999 World AIDS Day activities.

Outcomes

A review of the cumulative achievements of the four health centres shows strong growth of services from 1996 to 1999. It is difficult to separate the HIV/AIDS component from other activities, but the following figures have been collected. Note that the clients are people between the ages of 14 and 35, in Asmara and other towns in which the centres are found. They are served

regardless of their membership in the union and their sex, religion, ethnic group, or other characteristics.

Year	1996	1997	1998	1999
Clinical and counselling services clients	86	577	1,219	1,700
Training activities trainees	145	158	87	154
Library and recreational services users	984	15,282	19,974	70,832
Sensitization activity/orientation seminar participants	3,210	25,730	25,570	33,400

However, NUEYS faces serious limitations in funding and other resources, and has been offering all of its services for free. Although free services may be appropriate given the general levels of poverty, the fact remains that NUEYS must find new sources of funding if services are to be enhanced, or even sustained.

Lessons Learned

The programme illustrates the potential of a national, mass-based organization like NUEYS to participate in a major public health effort – in this case, to mobilize young people against HIV/AIDS and reach out to them with services. The national union's size allows it to participate as a partner with government ministries and major international NGOs, possibilities that would be denied an organization with fewer members or a smaller geographic coverage.

An important lesson learned by NUEYS in all its activities is that different populations of young people must be reached in different ways. It is relatively straightforward to bring HIV/AIDS information and activities to young people in school, but the difficult situation of the country means that concentrating only on school-based activities would miss large numbers of potential beneficiaries. Therefore, the strategy of diversity – attacking the problem of HIV/AIDS and the lack of reproductive health knowledge from multiple directions and using various media – is the most effective way to reach all young people, including some of the most vulnerable such as those who are out of school but living in or near urban areas.

Life Skills Programme: "My Future Is My Choice" (Namibia)

Starting Year: 1997

Main Topic Area: Children and young people

Other Topic Areas: Communications programming • Reproductive health

Contact Person:

Mr. Rick Olson

Project Officer

Phone: +264 61 229220

Fax: +264 61 224413

Email: rolson@unicef.org

Web Site: www.un.na/unicef

Address:

c/o UNICEF

P.O. Box 1706

Windhoek

Namibia

Implementers

Youth Health Development Programme (YHDP), through multisectoral committees, and the Ministries of Youth, Health, and Education

Funding

UNICEF, Sida, Irish Aid, World AIDS Foundation, UNICEF Committee of Germany

Objectives

The main objective is, by the year 2001, to provide life-skills education to 80 per cent of the country's young people, aged 10–18 years. The project is designed to:

- inform them about sexual health, pregnancy, STDs, alcohol and drug abuse, and HIV/AIDS to help them make positive decisions
- improve communication skills between boys and girls, friends, and young people and their parents by providing them with information and communication or decision-making skills on sexual health.

Background

My Future Is My Choice (MFMC) is a programme that provides life-skills training specifically for HIV/AIDS prevention, teen pregnancy reduction, youth empowerment, and behaviour change among young people, as well as information on sex as a decision for two, alcohol and drug abuse, and rape. The programme uses a highly interactive approach to inform young people while allowing them to explore their feelings in a safe environment.

Main Activities

My Future Is My Choice is a ten-session programme that aims to give young people the information and life skills they need to think and make choices about their future. This involvement in their own development allows them to think for themselves and take responsibility for their future. In other words, the programme tries to give young people the courage, confidence, and skills to make informed choices about how they behave.

Young people who have completed secondary school receive ten days of training as MFMC facilitators. They then facilitate MFMC groups of 20–22 young people who voluntarily sign up for the programme. The ten two-hour sessions are spread over three to five weeks and are held at schools after regular classes or in the community for out-of-school youth.

Young people, trained as master trainers, supervise the facilitators. The programme's 622 facilitators and 45 master trainers are responsible to a regional or subregional YHDP committee, which includes young people. Each facilitator works through the MFMC training manual, which has six or seven activities each session. The opening and closing activities are short and often include a game. There are at least three 20–25 minute participatory or skills-development activities each session.

All participants have workbooks, with information from the session and space to take notes. Each session is evaluated by three participants. In the last session, each participant does a peer education action plan. In addition, each school has a contact teacher who provides some oversight of the facilitator's activities.

Outcomes

In 1997, approximately 7,500 young people went through the course, followed by 21,000 in 1998. In 1999, the manual was revised and made more participatory and focused. Just over 20,000 young people went through MFMC in 1999. The target for 2000 is a minimum of 40,000 young people to receive 20 hours of peer-facilitated life-skills education on sexual and reproductive health.

Evaluation Findings

In 1998, a longitudinal study was done comparing the reported sexual behaviour of young people who went through MFMC with young people who had not. Those who had gone through MFMC were delaying sexual intercourse longer and significant numbers were using condoms.

Lessons Learned

An important lesson learned is that building the "ownership" of the activity in the communities where it takes place is a key component of success. Building such ownership is not only a matter of good will and openness, but also of organizational structure.

This lesson was recognized fairly early on in the programme's life, with the result that MFMC was decentralized in 1999 to allow the regions to manage and monitor project implementation. This has been successful, with increased

inclusion of young people in the management and supervision of the activities – as equal partners with the staff of the Youth, Health, and Education Ministries. This has been a learning experience for both the adult and youth committee members. One concrete application of this experience was that the revision of the training manual in 1999 involved young people and experts.

Capacity development for partners is a long-term process, and skills still need to be strengthened in project management and monitoring and evaluation. Nonetheless, by listening more to the young people, the project partners believe they have produced a training programme that more closely meets the needs of its participants.

Further Reading

See the website www.un.na/unicef for the training materials.

Community mobilization

Community-level action – much of it initiated by persons infected or affected by HIV – has always played a major role in the global response to AIDS. In many countries, community response preceded the official national response. It has proved essential to many components of a successful national response, most notably awareness, prevention, policy and legal changes, impact alleviation, advocacy, and family or community care and support.

UNAIDS defines “community” in its widest and most inclusive sense: a community is a group of people who have something in common and will act together in their common interest. Many people belong to a number of different communities – the place they live, the people they work with, and their religious group, for example.

A community becomes mobilized when a particular group of people becomes aware of a shared concern or common need, and decides together to take action in order to create shared benefits. A community's ability to act together may have existed for centuries, or it may be triggered in a very short time by some urgent problem. In the past, community mobilization has usually meant initiatives at a neighbourhood, village, or local district level.

Today, however, the AIDS pandemic and modern communications technology have challenged traditional ideas of community. National and even global communities have emerged, with shared concerns to prevent the spread of the virus, to care for those affected by HIV and AIDS, and to advocate for health and human rights. While the concept of community has been widened, the need to design culturally and epidemiologically specific responses to help particular groups of people has created a corresponding need to define individual communities more closely.

In terms of HIV/AIDS, a mobilized community exhibits most or all of the following characteristics:

- ◆ Members are aware – in a detailed and realistic way – of their individual and collective vulnerability to HIV/AIDS.
- ◆ Members are motivated to do something about this vulnerability.
- ◆ Members have practical knowledge of the different options they can take to reduce their vulnerability.
- ◆ Members take action within their capability, applying their own strengths and investing their own resources, including money, labour, materials, or whatever else they have to contribute.
- ◆ Members participate in decision-making on what actions to take, evaluate the results, and take responsibility for both success and failure.
- ◆ The community seeks outside assistance and cooperation when needed.

Starting a community effort is generally much easier than sustaining it. Many community organizations and programmes have been at work for years, and continue today with the same enthusiasm. Others have withered and lost their former energy; some have disappeared. For national responses to be effective, existing community initiatives must be reinforced, and new ones must be nurtured as they establish themselves. This will require flexible partnership arrangements with governments and other forces in the campaign against HIV/AIDS, particularly in developing countries.

A huge range of activities has been found effective in the field of community mobilization projects for HIV/AIDS. However, experience indicates that Best Practice in this field is distinguished by the following basic principles:

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

Centre for Socio-Medical Assistance (Côte d'Ivoire)

Starting Year: 1991

Main Topic Area: Community mobilization

Other Topic Areas: Palliative care • Religion • Resource mobilization

Contact Person:

Dr Marc Aguirre

Phone: +225 41 80 83

Fax: +225 41 80 83

Email: 105223.3613@compuserve.com

Web Site: www.hopeww.org/

Address:

Hope Worldwide

B.P. 1021 Cidex 1

Abidjan 06

Côte d'Ivoire

Implementers

HOPE Worldwide is an international, faith-based NGO. It works in collaboration with the Ministry of Health, the National AIDS Programme, and the University Hospital (Centre Hospitalier Universitaire – CHU).

Funding

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); person with HIV/AIDS participation (\$2.50 per month); donations.

Material support is also obtained through local donations by individuals and business, 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.

Objectives

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.

Background

The Centre for Socio-Medical Assistance (Centre d'assistance socio-médicale – CASM), an outpatient clinic for persons living with HIV/AIDS, opened its doors in February 1991. The motivation for this initiative 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 CHU de Treichville. 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 persons living with HIV/AIDS with compassionate psychosocial support.

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. The guiding principle of CASM has been to restore a sense of solidarity between 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 help the immediate situation.

Main Activities

CASM's main activities are as follows.

1. 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 IV 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 the World Health Organization (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 near cost price.

2. Referrals

The clinic acts as a referral centre for persons living with HIV/AIDS. Referrals come from:

- the nearby (main) infectious diseases hospital (CHU de Treichville) (the hospital, through an official agreement, offers the centre tariff reductions on all specialist consultations, labs, 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 that provide support and follow-up at a community level.

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

3. 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.)

4. Home-based support

The centre has a team of approximately 20 community agents who provide home-based support for persons living with HIV/AIDS from the centre. 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 and needs and services rendered are recorded after the visit to assure 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.

5. 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. 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. 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 persons living with HIV/AIDS with nutritional, material, and financial assistance. With the support from 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.

6. 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 per cent of the sale price of each card.

7. 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.

8. AIDS prevention activities

The centre's prevention programmes have in recent years targeted four particularly vulnerable groups: women, young people, prisoners, underserved communities. Peer educators have been trained within most of these target groups. Group discussions, community conferences, slide shows, theatre, personal testimonies, and other strategies have been used to achieve the greatest possible impact. 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.

9. Volunteer contributions

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. Volunteers come from AIDS NGOs and associations, religious groups, international institutions and agencies, and from concerned members of the community. 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, and so on), cook and serve breakfast, make greeting 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 within 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.

Outcomes

- 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.
- The community agents make about 40 home visits to patients every month.

- The Club des amis 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.
- Prevention programmes have reached over 200,000 people over the past five years.

Lessons Learned

CASM's experience with resource mobilization provides some important lessons. Over the years, the centre has developed important local resources that underpin its activities and allow it to meet many of its objectives. The most notable of these are:

- a large pool of committed volunteers
- strong collaboration with associations of persons living with HIV/AIDS
- formal links with other services and institutions that strengthen the care continuum available to patients.

Developing such resources is essential for any project with CASM's goals and target population.

Given the severity of the epidemic and the fragile economic condition of the area, the centre at the same time has learned the limitations of local resource mobilization. Despite the development of local resources, the project is highly dependent on external funding, and lacks the resources to hire trained managerial staff. It does not have sufficient funds to purchase all the basic drugs it needs to meet patient demand. Project staff believe that untapped local resources exist that might be used to reduce its dependence on outside donations, but the centre has been unable to find entry to these resources.

Further Reading

See www.hopeww.org/Where/Africa/africa5.htm for a general description of this project.

Kariobangi Community-Based Home Care and Home-Based AIDS Care Programme (Kenya)

Starting Year: 1986

Main Topic Area: Community mobilization

Other Topic Areas: Palliative care • Counselling • Religion

Contact Person:

Mr Charles Thumi

Sister Gill Horsefield, MMS

Phone: +254 793 266/793 288

Address:

Kariobangi Community Health Programme

P.O. Box 53376

Nairobi, Kenya

Implementers

The organization in charge of the project is the Medical Mission Sisters Health Programme.

Funding

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.

Objectives

The goal is to enable the people of Korogocho to cope with AIDS physically, socially, and psychologically by:

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

Background

Korogocho, the slum in Kariobangi in which the programme is set, is 12 km east from the centre of Nairobi. It has a population of over 100,000 (recent unconfirmed statistics suggest it is now 130,000). Most people live in single room shanties made of plastic, tin, or mud. Sixty 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 showed that 32 per cent of the population was HIV-positive; 14 per cent of

those infected had AIDS. Due to their poverty, some 22 per cent had never sought medical attention.

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

Main Activities

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 TB in the Deanery of the local Catholic church.

The programme has six main activities:

1. Care for the sick

The programme recognizes and attempts to build on the fact that most of the care that persons living with HIV/AIDS will receive, realistically, will be provided by relatives (not just adults, but 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.

2. 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.

3. Crisis care for persons with AIDS

An aim 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.

4. 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, moral support, and emotional support.

5. 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.

6. Recruitment and training of community health workers

The community health workers are chosen from the small Christian communities of the neighbourhood. These communities are mutually supportive groups who 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. The CHWs are regarded with great respect in the neighbourhood, and are regarded 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.

Outcomes

The programme's current patient load is 787 persons, with a cumulative total of 3,746 persons served since 1990. There were 537 new patients in 1999.

In 1998, 68 volunteer health workers provided medical care and moral support to 1,880 persons living with AIDS, including 172 babies and children.

Evaluation Findings

Analysis of the programme budget for approximately 2,000 patients found an expenditure of \$13.40 per patient per year (this sum includes the cost of medicines, staff salaries, transport, running a car, and administration). Of this, \$2.20 represents the cost of medicine per patient per year. The cost of training per community health worker was calculated to be \$7.00.

Lessons Learned

The experience in Kariobangi illustrates that a programme built largely on volunteers can make a significant difference in the lives of people living with HIV/AIDS in a very poor community. Three conditions appear to account for much of the programme's success:

- the energy and dedication of the volunteers, most of them highly motivated by religious faith, and the locally appropriate manner in which they are recruited (i.e., the fact that recruitment is based on the respect that the community holds for the candidates)
- support and supervision provided by a professional staff
- a web of local partnerships, including nearby health institutions and other NGOs working in the area.

At the same time, the programme's experience also illustrates the limitations imposed by lack of local resources. 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.

Lessons have also been learned about the difficulty of dealing with AIDS in a culture where there remains considerable stigma attached to the disease (although there appears to be somewhat more openness about the subject than even a few years ago). A staff member comments, "Often people will talk about 'this sickness' and everyone knows what they are talking about, but they don't actually call it AIDS. All the professional staff know the HIV status of all the patients, but keep the information confidential. The community health workers can only know a patient's status if the patient herself/himself shares it with them. Nonetheless, most community health workers have a very good knowledge of the signs and symptoms of AIDS, and are fully aware of any given patient's situation."

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.

Health system personnel and training

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.

A planned programme of education in HIV/AIDS 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.

Educational methods, as well as content, can significantly influence the outcomes of programmes. For example, guided learning based on experience is more effective in both imparting knowledge and changing attitudes than is a didactic, information-giving approach. It is also important to note that training has the potential for capacity-building, as more HCWs become knowledgeable enough to become teachers themselves, provided that they are taught to have and use those skills during their training.

Recent experience in various parts of the world suggests the following among the many lessons learned about HIV-related training and awareness for health care personnel:

- ◆ While health managers and workers often feel in danger of being overwhelmed by the HIV/AIDS epidemic and have neither time nor resources for training, this view is short-sighted. Training can actually strengthen capacity in the health sector, if it is planned as an integral part of health system development.
- ◆ Training programmes in many countries have not only enhanced the knowledge and skills of HCWs, but have also changed their attitudes towards working with people with HIV/AIDS. In some cases, increased knowledge corrects misconceptions, and in that way can change attitudes.

- ◆ HCWs who are HIV-positive can continue to be valuable members of staff, provided they are offered support, and do not fear discrimination from their coworkers. Training can correct misconceptions about risk of infection, and can help to change attitudes too. (At the same time, HIV-positive HCWs need to be protected from opportunistic infections, especially from TB, and both managers and colleagues must be empowered to do this.)
- ◆ HCWs at all levels should be taught counselling skills with HIV/AIDS patients, especially in relation to testing.

Preparing new students in all health sciences to care for people with HIV/AIDS is, of course, essential and will, in the longer term, build the capacity of the health services. As well, there is a continuing need for research into the effects of education on all aspects of caring for people living with HIV/AIDS, and on health workers themselves, and therefore evaluation is a vital component of any training programme.

Partnership for Home-Based Care in Rural Areas (Uganda)

Starting Year: 1993

Main Topic Area: Health system personnel and training

Other Topic Areas: Reproductive health • NGOs and networks • Community mobilization

Contact Person:

Ms. Sophie Mukasa-Monico, TASO

Phone: +256 41 231138

Fax: +256 41 251982

Email: dirtaso@infocom.co.ug

Address:

TASO

P.O. Box 10443

Kampala, Uganda

Contact Person:

Wilson Kisubi, Pathfinder International (East Africa)

Fax: +254-2-224154

E-mail: WKisubi@pathfind.org

Address:

Pathfinder International

P.O. Box 48147

Nairobi, Kenya

Implementers

Family Life Education Programme (FLEP), a community-based organization initiated by the Busoga Diocese in the mid-1980s, provides family planning and other reproductive health services for rural communities in Uganda.

Pathfinder International is a US-based NGO that works to improve the quality of and accessibility to family planning and related reproductive health services in developing countries. It has worked with FLEP for many years, primarily providing training services.

The AIDS Support Organization (TASO) grew out of Africa's first support group for persons living with or affected by HIV/AIDS, and since 1987 has expanded to provide a wide range of related services.

Funding

Funding has been provided by Pathfinder International and USAID, and indirectly by a number of donors that support TASO.

Objectives

The goal of the partnership is to improve the quality and accessibility of HIV/AIDS care and prevention services in rural communities that have few formal health services. The partnership aims to reach especially vulnerable groups (women, young and adolescent children, orphans, and very poor people). This is to be done by:

- delivering services such as counselling, reproductive health care and family planning, and medical care and social support
- building the capacity of other organizations, communities, institutions, and individuals already in the communities to provide HIV/AIDS services
- networking in order to increase information exchange and solidarity among HIV/AIDS organizations, communities, institutions, and individuals
- AIDS advocacy at the local and national levels.

Background

When the Family Life Education Programme was formed, civil war in the 1980s had destroyed much of Uganda's rural infrastructure, leading to widespread poverty and few social services. FLEP was created to provide basic curative health care, family planning, and health education to the war-torn communities of the Busoga Diocese. FLEP was the first community-based organization to provide family planning and other reproductive health services for rural communities in Uganda.

With USAID and Pathfinder International funding training as well as technical and other kinds of assistance, FLEP has conducted extensive information and education campaigns and has established 46 primary health care clinics. FLEP trained medical practitioners to staff the clinics, and also trained many village health workers and village health leaders. As a result of this experience, FLEP developed training expertise and is now providing training and technical assistance to other reproductive health and family planning organizations in Uganda.

In 1993, communities began to demand AIDS-related services from village health workers, who did not have any training about the HIV virus and its impact. For this reason, Uganda's oldest and largest AIDS support group, the AIDS Support Organization (TASO), was requested to train village health workers, nurses, and FLEP supervisors in HIV/AIDS education and basic HIV/AIDS counselling.

The context in which this partnership operates is extremely serious. The AIDS epidemic is confronting Uganda with demands that are far beyond the capacity of its formal health care system, particularly in the rural areas served by FLEP. Hospitals are overcrowded with AIDS patients, most of whom are eventually discharged to their homes in a state of hopelessness, to be cared for by untrained relatives. Simultaneously, village health workers are overwhelmed by the needs of persons with HIV/AIDS and their families, whose demands they must place alongside their usual reproductive health and family planning services workload. At the same time, most AIDS-specific services are concentrated in the country's urban areas.

Main Activities

The Partnership for Home-Based Care has two major sets of activities. One is training and capacity-building; such activities are fairly easily described in terms of tasks and outputs. The other, which can be termed system capacity-building, includes such work as advocacy, negotiation, institutional reform, and networking. Its outputs are difficult to describe, but are essential to support training and capacity-building.

1. Training

The partnership works to improve and expand the skills of FLEP village health workers, nurses, and supervisors in rural communities. Training is aimed at ensuring that persons living with HIV/AIDS are provided with a "package of care services provided to a person living with HIV/AIDS at home by different care providers who may 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.

TASO and Pathfinder International therefore provide FLEP village health workers with the training to:

- (a) assess patients' and families' needs
- (b) provide some of the package of services themselves, particularly counselling and some basic forms of medical care
- (c) train persons living with HIV/AIDS to provide self-care appropriate to their situation
- (d) train family members and friends of persons living with HIV/AIDS to 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)
- (e) 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.

2. 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:

- 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. 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.

Outcomes

To date, about 2,240 village health workers have been trained in 56 rural communities to provide AIDS-related services in addition to their other duties. Furthermore 160 counsellors for 16 other organizations have been trained to provide AIDS services in districts without TASO centres. Through FLEP, the partnership now provides care to an estimated 16,000 clients every year.

Lessons Learned

Perhaps the most important lesson learned is 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 is particularly important in a resource-poor setting. All three 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.

As regards consistent quality of care, an important lesson is that regular refresher courses and frequent motivational interaction with supportive supervisors help maintain enthusiasm and promote a greater level of knowledge.

Another important lesson is that morale-building and motivation must be given serious thought. Due to the gravity of the AIDS crisis and the tough economic situation in these communities, the all-important human factor underpinning these services is fragile. The demands on and local expectations for the village health workers are overwhelming, and it is a major concern of the partners to acknowledge and help with the despair frequently faced by these people who work most closely and most regularly with the patients. In order to reward and motivate village workers, FLEP began by giving them a bicycle every three years and a bar of soap. The bar of soap was changed into a monthly allowance equivalent to the cost of soap, and this was eventually increased to an equivalent of \$10 a month. Other motivations included giving them an annual allowance for bicycle spare parts, and acknowledging them with a uniform.

Further Reading

See Pathfinder International's web page on its activities in Uganda at www.pathfind.org/html/Worldwide/uganda_2.htm

Local responses to HIV/AIDS

Numerous examples of Best Practice in local responses have been identified over the past few years in places such as Burkina Faso (see Gaoua District AIDS Initiative in this section), Malawi, Senegal, Tanzania, Uganda, and Zambia.

A local response to HIV/AIDS means the involvement of people where they live – in their homes, their neighbourhoods, and their workplaces. Such a response aims to enable local communities to acquire what may be termed "AIDS competence." This means that people should become skilled in dealing with AIDS and, in particular, they should be properly informed about the epidemic; be able to assess accurately the factors that may put them personally, or their communities, at risk of infection; and act so as to reduce and mitigate the impact of those risks.

The end goal of the process is to reduce HIV transmission and to enable those living with HIV/AIDS, as well as those affected, to enjoy an improved quality of life. Since there are limits to what people can do on their own, local partnerships can help improve the effectiveness of local responses. Such partnerships bring together key social groups, service providers, and facilitators:

- ◆ Key social groups are those whose members have a particularly important role to play in HIV prevention and care activities, whether because they are at high risk of infection (vulnerable groups) or for other reasons. Examples include young people (particularly those out of school or unemployed), people living with HIV/AIDS, migrants, and members of specific occupational groups, such as sex workers, soldiers, and truck drivers.
- ◆ Service providers may include government bodies (including local government), NGOs, community-based groups, businesses, or religious groups who furnish information, resources, or specific services.
- ◆ Facilitators stimulate interaction between the various partners in local response, helping them become more competent, make choices and set priorities, command greater resources, or articulate their views.

Experience documented in a range of countries suggests that successful local responses employ at least some (and usually many) of the following steps:

- ◆ Creating AIDS competence. Enabling people to assess accurately the factors that may put them or their communities at risk of infection, and to act to reduce those risks, requires a conducive political environment along with an accessible range of interventions, activities, and services.
- ◆ Developing, by consensus, a national strategy on HIV/AIDS, based on local responses. Key elements in developing such a strategy include decentralization of interventions to the most appropriate planning unit close to the communities; multisectoral and participatory approaches; partnerships

from a range of social, cultural, and religious groups, with clearly defined tasks for the various partners.

- ◆ Appointing a national facilitator for local responses to HIV/AIDS. The facilitator's main task is to encourage feedback from lessons stemming from activities at the local level and to set up ways to exchange experiences among communities, sectors, and policy-makers.
- ◆ Establishing, at district level, a local responses support team responsible for expanding partnerships, finding new resources, and documenting and building on the experiences of community projects. The team should have the moral support of local communities and include people such as district officials; religious and traditional leaders; representatives of NGOs, community-based organizations, and the private sector; and people living with HIV/AIDS. The local responses support team can strongly facilitate the local response by:
 - identifying key social groups who may be at particular risk of HIV infection, and whose AIDS competence it is especially urgent to build or reinforce
 - starting a feedback process to collect various lessons from around the district and using these to help local partners adjust the criteria for determining AIDS competence and the means by which it can be achieved
 - encouraging sectoral reforms. In each sector, units should review – with regard to HIV/AIDS – the amount and quality of the services they are providing, their internal organizational structures, their interaction with others, and the planning and development of their human resources. The implementation of sectoral reforms is intended to create a suitable environment in which AIDS competence can flourish.

Note that the sequence in which these steps are performed is not critical. Depending on local circumstances, any of the steps can be the starting point.

Gaoua District AIDS Initiative (Burkina Faso)

Starting Year: 1997

Main Topic Area: Local responses

Other Topic Areas: Resource mobilization • NGOs and networks

Contact Person:

Kekoura Kourouma

CPA Burkina Faso

Phone: +226 31 08 72

Fax: +226 31 04 70

Email: kekoura.kourouma@undp.org

Address:

c/o UNDP

01 B.P. 575

Ouagadougou 01

Burkina Faso

Contact Person:

Geneva: Jean-Louis Lamboray

UNAIDS Geneva

Tel: +41 22 791 4756

Email: lamborayj@unaids.org

Address:

UNAIDS

20 avenue Appia

CH-1211 Geneva 27

Switzerland

Implementers

The Gaoua District AIDS Initiative includes partners at the local, national, and international levels. The main original implementers identified in 1997 were the local partners under the Ministry of Health (MOH) supported by the political structures (local government, préfectures, Gaoua mayors, administrative delegates), the local radio, and some involvement of the Ministry of Education. In the voluntary and private sector, some NGOs (Plan International Burkina), associations (Association pour les femmes de Gaoua (APFG), Association pour les jeunes, Association des femmes chrétiennes), and other groups (Union des transporteurs, Marketing social des condoms/PROMACO) were active.

Since then they have been joined by a larger number of partners (see Outcomes).

Funding

Funding was originally from the MOH, with help from the German Technical Cooperation (GTZ) and Plan International, the latter operating in a few communities. These funders have been joined over the past two years by the World Bank, UNAIDS, UNFPA, UNDP, and WHO. Some medicines are being contributed by the national Projet population et lutte contre le SIDA (PPLS/ World Bank).

Objectives

Operational objectives of the Gaoua District AIDS Initiative were to:

- carry out a situation assessment permitting a coordinated local-level response to HIV/AIDS in the district
- bring together all sectors that could contribute to or benefit from the response
- create a strategic plan for the response
- implement the plan.

On 1 December 1999, the Local Committee on HIV/AIDS (which is in itself one of the outputs of the initiative) created its own definition of the Gaoua vision, which contains the following goals:

- a change in individual sexual behaviour
- a reduction in the stigma against people living with AIDS
- a spontaneous willingness to come forward to be tested for HIV
- an improvement in the quality of hospital care
- an increased mobilization of people against HIV/AIDS
- a reduction or stability in the rate of prevalence of HIV.

Background

Gaoua District in Burkina Faso's Poni province is moving ahead with implementation of support for local HIV/AIDS responses, having obtained authority to mobilize locally and disburse funds. Before the initiative began, AIDS was the responsibility of the health sector alone. In 1997, GTZ, UNAIDS, WHO, and the MOH began a study of how to expand the response.

Main Activities

While the operational activities of the initiative are similar to those found in many local responses to HIV/AIDS around the world (health promotion/information, education, and communication (IEC) activities, social marketing of condoms, testing and counselling facilities, etc.), it is the process by which the initiative was conceived, planned, and implemented that may provide the most useful lessons learned. The main points and timetable of this process are as follows:

- May 1997: situation analysis regarding local socioeconomic situation, social/behavioural determinants of the epidemic, social attitudes towards and knowledge of HIV/AIDS, access to health care, and the institutional environment
- March 1998: three-day pre-planning workshop to create consensus among partners
- July–August 1998: field studies in Gaoua, Kampti, Batie, and Diebougo; situation analysis regarding care and counselling needs; development of lessons learned from this research
- September 1998: preliminary report
- November 1998: four-day workshop to prioritize determinants needing to be addressed; assignment of domains of action to different sectors, based on

these priorities; design of a planning team to propose a strategic plan and specific assignment of activities

- December 1998: five-day meeting of the planning team to create detailed proposals for sectoral responsibilities and actions
- December 1998: four-day workshop at which the proposals of the planning team were debated, directing principles for the initiative were adopted, consensus was obtained on sectoral objectives and strategies, and a coordinating procedure was adopted
- January 1999: two-day workshop to finalize the strategic plan and its budget
- January–April 1999: detailed planning by partners on their individual contributions to the initiative, done according to the framework of the strategic plan
- 25 June: meeting of international partners for mobilization of financial resources
- 1 July 1999: official date for implementation of the initiative
- January 2000: first review of activities (internal evaluation, with recommendations for modifications where necessary).

It is important to note that one agency (in this case, UNAIDS) has provided technical support to these activities throughout the local responses. In addition to secretariat functions and transportation, the support was provided in the form of:

1. consultations and coordination of activities
2. documentation of processes and reforms at the district and national levels
3. running meetings, seminars, and workshops for sharing lessons learned
4. production of study papers.

A country broker was hired to facilitate the local response process, articulate lessons learned from action, and ensure global dissemination of the lessons learned.

Outcomes

At the local level, the initiative has engaged the participation of a wide variety of sectors, institutions, and groups. They include:

- religious associations such as Catholic, Muslim, and Protestant lay women's groups
- women's groups such as development associations (APFG), women educators (Association des mères éducatrices), soldiers' wives, Foyer Biboo Yir (Promotion de la jeune fille et prévention du SIDA)
- young people's groups such as l'Association pour la promotion anti-SIDA et planification (APASP), the theatre troupe Pale Nani, and the Sabougnouma orchestra
- the public service sector including different regional directorates (i.e., Direction régionale de la santé (DRS), l'Equipe cadre du district (ECD), and others (DRASF, DRERA, DRJS)), and the Regional Hospital (CHR), the army (22eme Ric), high schools and colleges, the public school inspectorate, and the detention centre
- local divisions of the NGO Plan international Burkinabé (PIB).

National-level participants include the Programme national de lutte contre le SIDA, the PPLS, and the Muraz Centre in Bobo-Dioulasso. Finally, international participants include an international NGO (Plan international Burkinabé/PIB) and bilateral (Coopération Française, GTZ) as well as international agencies (UNAIDS UNDP, UNFPA, WHO, and the World Bank).

As regards external resource mobilization, Gaoua District mobilized US\$ 200,000 (US\$ 1 per inhabitant) from various bilateral sources to implement the district level work plan from 1999 on.

Within the country, the initiative has had an impact on higher levels of government. At the national level, Burkina Faso's Ministry of Health has decided to extend support to local responses to HIV/AIDS in 11 districts (one per province) by mid-2000. Poni Province's High Commissioner has established and chairs a provincial multisectoral AIDS control committee. Finally, 45 high commissioners and 44 mayors of Burkina Faso met in 1999 to share experiences on the implementation of an expanded response to AIDS, using Gaoua District as a concrete example of what can be done.

Evaluation Findings

Preliminary review of the initiative reveals several indicators of impact. Journalistic interviews indicate that considerable enthusiasm and awareness have been generated among the local population for the general response to AIDS and that this awareness has extended to medical staff, health and other governmental authorities, and civil associations. Although numbers of people coming forward for voluntary testing have not risen, awareness that the service exists has become widespread and may yet translate into increased numbers. While there has been some slowness in disbursement of promised funds, the majority of planned activities have received their funding and commenced operation. Most activities have been in the town of Gaoua itself, with less activity (except for radio programming) reaching the more remote areas of the district.

The review also notes weaknesses in the initiative, including a lack of precision in job descriptions for Technical Committee members and a lack of information exchange between the Technical Committee and the provincial AIDS Control Committee.

Lessons Learned

A major lesson that has been learned from the Gaoua experience (and that has been learned in countless other projects in other places) is the importance of situation analysis tailored to HIV/AIDS questions, particularly using existing action-oriented research techniques. This research provides a solid underpinning to all activities, as well as answering many of the questions that external donors or technical partners may have before they will commit to supporting such an initiative. If properly communicated, research findings can contribute greatly to an entire community's AIDS competence by acquainting them with the reality of their situation – a key step towards taking action.

A second lesson learned is that it is necessary for the process to be locally owned and driven and to have a time span of two to three years to develop.

Finally, the establishment of an official body (in this case, the Technical Committee) is of cardinal importance to take responsibility for consensus-building and for coordinating and planning the local response at the district level. This group fulfills an essential role by identifying and bringing in new partners, finding new resources, and documenting the progress of the initiative. It is essential that the team have the moral support of local communities. Membership may be drawn from many sources, but should probably include district officials; religious and traditional leaders; representatives of NGOs, community-based organizations, and the private sector; and people living with HIV/AIDS.

Further Reading

UNAIDS case-study Best Practice on Gaoua District: local responses in Burkina Faso (to be published in 2001).

Ministère de la Santé. *Plan de lutte contre le VIH/SIDA et les MST dans le District Sanitaire de Gaoua*. Burkina Faso, Ministère de la Santé, 1999.

M'Pelé P. *Etude de cas Burkina Faso processus de planification stratégique de la réponse nationale contre le VIH/SIDA dans le domaine spécifique de la prise en charge des personnes vivant avec le VIH/SIDA dans un District Sanitaire*. UNAIDS Care Team, 1999.

M'Pelé P. *Documentation des processus et des résultats, planification stratégique pour une réponse élargie face au VIH/SIDA dans un District Sanitaire Gaoua Burkina Faso*. UNAIDS Care Team, July 1999.

M'Pelé P. et al. The impact of a local response to HIV/AIDS in a rural district of Burkina Faso. 13th World AIDS Conference, Geneva, July 2000.

Salla R. et al. District Response Initiative (DRI): fostering partnership in HIV/AIDS control. Situation analysis in Burkina Faso. Poster no. 34127, Handout supplement. 12th World AIDS Conference, Geneva, July 1998.

Bambisanani: an EQUITY Project (South Africa)

Starting Year: 1999

Main Topic Area: Local response

Other Topic Areas: Migration • Workplace • Health system personnel and training • Community mobilization

Contact Person:

Mrs Rose Smart

Phone: +27 11 465-9803

Fax: +27 11 465-9803

Email: rmart@netactive.co.za

Address:

Bambisanani: An EQUITY Project

P.O. Box 415, Magalies View

2067 South Africa

Implementers

Bambisanani (which means “in partnership to help each other”) has the cooperation of several organizations that provide assistance through funding and other support services:

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

Funding

Seed funding for the first two years is provided mainly by Bristol-Myers Squibb from their Secure the Future initiative, from Goldfields of South Africa, Ltd, and from the EQUITY Project.

Objectives

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.

Background

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 per cent live in urban settings, the population density is high, 70 persons per square kilometre.

In Region E, access to all health and social services is severely limited. There is 1 doctor for 16,592 people and the lowest ratio of nursing staff in the country (less than 1 per 1,000). The infant mortality rate of 58.2 per 1,000 births and the life expectancy of 59.5 years are, respectively, the highest and lowest in the country.

Over 40 per cent of all South African migrant workers working in the gold mines come from the Eastern Cape, and almost all the migrant cane-cutters working in the sugar industry come from Region E. According to the demographic profile of Region E, there are many children and few old people except grandmothers. The absence of adult men is striking. In the age group from 20 to 24 years, there are 50 per cent more women than men. The dislocation of workers' family lives 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 per cent,

40 times what it was in 1990, with a 26 per cent increase from 1997. The figure for Region E was 21.5 per cent. The number of persons estimated to be HIV-positive in Region E was 69,392 (44,948 adult females, 22,207 adult males, and 2,237 infants). TB is a major problem, and is the leading cause of death in HIV-positive persons. In Region E only 17 per cent of clients complete their six-month TB treatment.

More than 70 per cent of the hospital beds in Region E are occupied by patients with HIV (with or without associated TB). All the hospitals report being over-burdened 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.

Main Activities

The project is based on the approach that decentralization (bringing decision-making and administration down to the local rather than national or provincial level) and integration (through partnership of existing players, each doing what they do best and avoiding competition or duplication) of all HIV/AIDS services offer the best chance of sustainability as well as cost-effectiveness.

In November 1999, under the auspices of the EQUITY Project, 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, TB, 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 for the partnership, keeping the plan within reasonably obtainable parameters. A clear articulation of immediate needs became the starting point of this project, summarized under four broad activity categories.

1. 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 TB 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.

2. 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 grassroots-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 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.

3. 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 Welfare 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.

4. Support for groups and income-generating activities (IGAs)

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. IGAs such as building, food-related, 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.

External mid-term and end-of-project evaluations will be conducted. The following expected outcomes at various levels will likely form the basic indicators of much of the evaluative work:

- for patients/clients: reduced suffering and improved quality of life; appropriate treatment, care, and support; enhanced end-of-life care
- for families: improved capacity to cope and to care; practical support; bereavement support
- for caregivers: the capacity, resources, and support to deliver quality care; access to colleagues and community networks of support
- for communities: improved capacity to cope; enhanced environment for care; reduced stigma; skills development and job creation
- for children: early identification of children in distress; access to holistic care and support
- for persons living with HIV/AIDS: skills development; access to networks of support

- for health services: reduced pressure on services; effective referrals between different service providers; cost savings
- for welfare services: improved utilization of social services; better access to grants
- for South Africa: lessons learned; replicable models.

Outcomes

The main outcomes to date are the establishment of a Project Management Committee consisting of Region E representatives, the development of a detailed implementation plan for year one, the mobilization of resources, the appointment of a project coordinator, and the commissioning of baseline research (the latter two are being finalized).

Lessons Learned

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 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 mine workers and cane cutters but also to their families and the communities from which they come.

Further Reading

Though not about the project specifically, the following documents provide useful contextual information: the first about mine workers and their sexual partners, the second about home-based care programmes, and the third about the situation of children in South Africa.

Campbell C, Williams B. Understanding the impact of a community-led HIV prevention programme in South Africa: context, conceptual framework and methodology. *Australian journal of primary health interchange*, 1999, 15, 4.

Russell M. Schneider H. *A rapid appraisal of community-based HIV/AIDS care and support programmes in South Africa*. Centre for Health Policy, 2000.

Smart R. *Children living with HIV/AIDS in South Africa – a rapid appraisal*. Save the Children (UK in SA), 2000.

Mother-to-child transmission

Mother-to-child transmission (MTCT) is the overwhelming source of HIV infection in young children. Without preventive intervention, the probability that an HIV-positive woman's baby will become infected ranges from 15 to 25 per cent in industrialized countries and 25 to 35 per cent in developing countries.

The virus may be transmitted during pregnancy, labour, delivery, or after the child's birth during breastfeeding. Where breastfeeding is the norm, it may account for more than one-third of all transmissions. Since the beginning of the pandemic, about 90 per cent of all HIV-positive infants have been born in Africa. However, cases in India and Southeast Asia appear to be rising rapidly.

In 1994 a regimen using the antiretroviral drug zidovudine (ZDV, also called AZT) was shown to reduce MTCT by about two-thirds in the absence of breastfeeding. This ACTG 076 regimen is now widely used in industrialized countries, but, at an average cost of US\$ 1,000 per pregnancy, it is too expensive for widespread use in poor countries. In a trial concluded in Thailand in February 1998, a short regimen of zidovudine pills in the last weeks of pregnancy cut the rate of MTCT during childbirth by half, at less than a tenth of the cost of ACTG 076. Because the women were also given safe alternatives to breast milk, MTCT in the study population was reduced to 9 per cent. Testing of newer, less costly regimens is ongoing (see below).

Any national strategy to prevent mother-to-child transmission should be part of broader strategies to prevent the transmission of HIV and STDs, to care for HIV-positive women and their families, and to promote maternal and child health. The ability to quickly make interventions to reduce MTCT widely available depends on political will, affordability of the interventions, and the strength of existing human resources and infrastructures. Powerful means of effecting change lie in demonstrating the success of interventions to reduce mother-to-child transmission of HIV, as well as the costs of not acting to prevent this kind of transmission.

Essential infrastructure and support services

Four factors that affect the affordability of interventions to prevent mother-to-child transmission are: the cost of drugs; the cost of safe alternatives to breastfeeding; the cost of HIV tests; and the cost of service delivery. WHO has added ZDV for mother-to-child transmission to the Essential Drug List. Glaxo-Wellcome has recently offered ZDV at substantially reduced prices. Further negotiations are planned to minimize the cost of the first three of these factors.

The following parameters describe the optimum context in which to implement effectively the interventions necessary to reduce transmission of HIV from mother to child:

- ◆ All women should have knowledge about HIV and access to the information necessary to make appropriate choices about HIV prevention and about sexual and reproductive health and infant feeding in the context of HIV.
- ◆ HIV counselling should be available for pregnant women and those contemplating pregnancy. Such counselling should address reproductive health issues such as family planning and safe infant feeding. Active referral and/or networking for follow-up counselling, comprehensive care, and social support should be available for HIV-positive women and their families.
- ◆ Pregnant women, and those contemplating pregnancy, should have access to voluntary HIV testing, to test results with the least possible delay (requiring that appropriate laboratory services be available to process such tests), and to counselling.
- ◆ All pregnant women should have access to antenatal, delivery, and postpartum care, and to a skilled attendant at birth.
- ◆ There should be follow-up of children at least until 18 months, especially for nutrition and for childhood illnesses.

Recent trials of antiretroviral regimens against MTCT

In 1999, three existing randomized controlled trials of short-course zidovudine monotherapy conducted in Thailand and West Africa were concluded. Although the risk of transmission of HIV from mother to child was greater in the breastfeeding populations, the relative decrease in transmission risk was similar for all three trials, between 40 and 50 per cent.

Concurrently, another study, the PETRA trial, conducted a randomized controlled trial of HIV-positive pregnant women from three countries in Africa. There were four arms to the trial, three using various regimens of ZDV and 3TC (lamivudine), the fourth using a placebo. Arm A of the trial included antenatal, intrapartum, and postpartum treatment; arm B intrapartum and postpartum treatment; arm C intrapartum alone; and arm D the placebo. In September 1999, the risk of transmission in each group was: Arm A 8.6%; Arm B 10.8%; Arm C 17.7%; Arm D 17.2%.

In July 1999, a joint Uganda-US study compared the efficacy of a single dose of the antiretroviral drug nevirapine with a short regimen of ZDV given in labour to the mother and administered to the baby for one week after delivery. HIV infection was reduced from 25 to 13 per cent in infants about three months of age (see HIVNET 012 study in this section).

HIVNET 012 study on effectiveness of Nevirapine in prevention of mother-to-child transmission (Uganda)

Starting Year: 1998

Main Topic Area: Mother-to-child transmission

Other Topic Areas: Antiretroviral therapy • Access to drugs

Contact Person:

Care and Support Team

Phone: +42 22 791-4808

Fax: +42 22 791-4741

Email: summaryreply@unaids.org

Web Site: www.unaids.org

Address:

UNAIDS

20 avenue Appia

CH-1211 Geneva 27

Switzerland

Contact Person:

Department of Reproductive Health
and Research

Email: reproductivehealth@who.ch

Web Site: www.who.int/rht

Address:

World Health Organization

20 avenue Appia

CH-1211 Geneva 27

Switzerland

Implementers

HIVNET 012 was undertaken at Mulago Hospital by researchers from Makerere University in Kampala and Johns Hopkins University in Baltimore, Maryland, USA.

Funding

The study was sponsored by the HIV Prevention Trials Network of the US National Institute of Allergy and Infectious Diseases (NIAID). Glaxo-Wellcome and Boehringer-Ingelheim Pharmaceuticals provided the drugs used in the study.

Background

A variety of trials of short-course zidovudine (ZDV) and/or nevirapine regimens are being conducted in Thailand and Africa. One, the PETRA study, is a randomized controlled trial that has recruited HIV-positive pregnant women from five sites: two in South Africa, two in Uganda, and one in Tanzania. There are four arms to the trial, three using various regimens of ZDV and 3TC (lamivudine), the fourth using a placebo. Another study, ACTG 316, is ongoing in the United States, Europe, and Brazil. It compares a combination of zidovudine and nevirapine with zidovudine monotherapy.

Finally, a trial called SAINT (South African Intrapartum Nevirapine Trial) in South Africa aims to recruit 1,200 HIV-infected mothers and compare the HIVNET 012 nevirapine regimen with arm B of PETRA. Results should be available by June 2000. (For more on ongoing research trials into MTCT, see www.unaids.org/publications/documents/mtct/prevmtct.html.)

Main Activities

The study was a randomized controlled trial enrolling 645 mothers (average age 24) and their infants living in and around Kampala. The dosage regimen for nevirapine was a single dose of 200mg given to the mother to take at the onset of labour, followed by 2mg per kg given to the neonate within 72 hours of birth. This was compared with a ZDV regimen of 600mg started by the mother at the onset of labour, followed by 300mg of ZDV every three hours during labour and a further course of ZDV of 4mg per kg given to the infant for seven days after birth.

Outcomes

The primary measures were of HIV infection and HIV survival at 6–8 weeks and 14–16 weeks. Of 609 mother–infant pairs, data were available for 529 at 14–16 weeks. At 6–8 weeks, 11.9 per cent of infants in the nevirapine group were HIV-infected, compared to 21.3 per cent of those in the ZDV group. At 14–16 weeks, the figures were 13.1 and 25.1 per cent, respectively.

Lessons Learned

A technical working group composed of experts from WHO, UNICEF, UNFPA, and the UNAIDS Secretariat reports consensus on the following points:

1. Nevirapine is cheap and simple to administer. Uganda has made relatively simple calculations of the costs of buying drug to treat all HIV-positive pregnant women in the country. For nevirapine, this would amount to \$640,000 per year. With zidovudine, the cost would be \$21,450,000 per year, and if the PETRA trial arm B were adopted this would cost \$29,250,000 per year. With this overwhelming cost difference, it is likely that nevirapine will be widely seen as the drug of choice for this indication.
2. The low price of nevirapine must not blind decision-makers to the fact that effective MTCT interventions are not simply a matter of finding the right drug at the right price. Although drugs are a substantial element of the pilot projects, many of the additional components of the projects are independent of which drug is used. This includes the infrastructure of voluntary and confidential testing, many aspects of antenatal and postnatal care of women, psychosocial support to HIV-infected women, and the follow-up of babies to determine their HIV infection status. These elements need to be initiated and maintained regardless of what drug is recommended, now or in the future. Other elements of the infrastructure, however, such as laboratory testing (mainly haemoglobin measurement), the frequency of antenatal clinical attendance, and the monitoring of women for drug toxicity would be more extensive with short-course zidovudine than with nevirapine.

3. Voluntary counselling and testing are necessary. Although there has been discussion about using nevirapine in settings with high HIV seroprevalence without voluntary and confidential testing for HIV, there is consensus that this was not a desirable strategy. Even if nevirapine is safe for use in women who are HIV uninfected, the importance of women being aware of their HIV status offers substantial additional benefits. These include improved decision-making and the ability to plan for future health and well-being of families, and prevention of subsequent sexual transmission.

4. Considerations of risk and of drug resistance must continue to be examined. The beneficial effect of antiretrovirals given for MTCT prevention (a significant reduction in the baby's risk of infection with a fatal virus) far outweighs any risk to the infant. However, these risks have been and must continue to be researched. One serious risk – that of developing drug-resistant strains of HIV – is considered to be minimal when antiretrovirals are used for a short period of time. Research and extensive experience with ZDV since 1987 indicate that the virus takes at least three months to develop resistance to the drug when used as monotherapy. On the other hand, HIV has been shown to develop resistance to nevirapine monotherapy very quickly. Since only a single dose of nevirapine has been given to mother and baby in the study of MTCT prevention, resistance is not expected to be a problem, but no data are yet available to confirm this. If antiretroviral drugs are used in combination, resistance is even slower to develop than with monotherapy, as they offer the virus a more complex challenge. At present, however, the risk of developing drug resistance if a woman is treated with the same drug over several pregnancies is not known.

Further Reading

For more on HIVNET 012, see www.Nlaid.nih.gov/newsroom/simple/qa.htm.

For more on ongoing research trials into MTCT, see the UNAIDS website at www.unaids.org/publications/documents/mtct/prevmtct.html.

Palliative care

The medical management of HIV/AIDS is a balance between acute treatment and trying to control symptoms. For relatively long periods, people with HIV infection may suffer a variety of opportunistic infections or cancers, experience multiple symptoms, and face a myriad of psychosocial issues. Moreover, the disease progression is unpredictable: declining health may alternate with periods of physical and emotional stability, resulting in chronic uncertainty. As people reach the end of their illness, testing and treatments may have little long-term benefit and merely add to the distress of the patient.

Fortunately, many HIV-associated illnesses – or their symptoms – are relatively easy to treat with basic drugs. Doing so can greatly improve the quality of life of HIV-positive people, as well reducing stress on the people caring for them. Major symptoms include:

- ◆ pain, often increasing in severity as the disease progresses
- ◆ diarrhoea and constipation
- ◆ nausea, vomiting, anorexia, and weight loss
- ◆ cough and shortness of breath
- ◆ malaise, weakness, and fatigue
- ◆ fever
- ◆ psychological problems
- ◆ brain impairment.

The importance of pain relief

No one should have to suffer from uncontrolled pain. Treatment of the underlying condition is important but in all cases 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. Pain medication should be reviewed frequently and increased when needed.

Access to analgesics and palliative care drugs

In many countries, analgesics such as codeine and other opiates can be prescribed only by doctors. This can strongly reduce access to analgesics in settings where most palliative care is delivered by nursing staff or community caregivers. A balance between increasing access to adequate pain medication and careful supervision and record keeping of prescriptions of opiate analgesics is needed.

The special needs of children with HIV

Since children often do not verbalize their problems, their palliative needs are frequently ignored, particularly in resource-poor health systems. As well, counselling children about death and dying is often avoided on the grounds that it causes more harm than good.

Organizing care in different settings

There are many ways of organizing palliative care delivery, depending on such factors as health sector resources and social organization. They include:

- ◆ Home care: Community-based home care has proven cost-effective in many settings, with the added benefit of helping communities come together, raise awareness, and promote tolerance and acceptance.
- ◆ Day centres: Patients remain living at home while going out for palliative care, counselling and emotional support, and such services as cooked meals, child care, and even income-generation activities. Family or hired caregivers also benefit by receiving time off during the day.
- ◆ Hospice care: Facilities for people in terminal stages of AIDS are particularly helpful for people who live alone, have poor symptom control, or suffer from difficult-to-manage symptoms such as severe brain impairment. Hospices may also provide respite periods for caregivers.

As well, traditional healers and alternative systems should not be ignored in places where they are widely accepted and can provide symptomatic treatment or pain relief with herbal remedies or practices such as acupuncture. In these settings, therefore, such healers and alternative practitioners may be included in the palliative side of care planning and practice.

Give palliative care recognition

In countries with limited drug budgets, palliative care medicines are not always seen as a priority compared to curative drugs. Yet many of the drugs and services that can benefit people with HIV are cheap, readily available, and listed as WHO essential drugs. Political commitment, backed by increased resources, is essential to care for the increasing numbers of people with HIV, and to train caregivers and health care workers. Because palliative and supportive care needs are often overlooked, they must be emphasized in national strategic plans. There is also need for coordination with donors to ensure that palliative care is seen as a priority; resource mobilization is essential to strengthen these efforts.

Mildmay Centre for Palliative HIV/AIDS Care (Uganda)

Starting Year: 1998

Main Topic Area: Palliative care

Other Topic Areas: Community mobilization • Health system personnel and training

Contact Person:

Dr Catherine Sozi
Director of Clinical Services
Phone: +256 41 200862/5/6/7
Fax: +256 41 200861
Email: mildint2@infocom.co.ug

Address:

The Mildmay Centre
P.O. Box 24985,
Kampala
Uganda

Implementers

Mildmay International is a UK-based NGO that has gained wide experience in HIV/AIDS care and training. It is connected with the Mildmay Hospital in England.

Funding

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.

Objectives

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."

Background

With antiretroviral therapy out of the financial reach of most Ugandans, Mildmay was invited by the Ugandan Ministry of Health to establish an AIDS Palliative Care and Training Centre, in the belief that this form of care can reduce the suffering and improve the quality of life of those infected with the virus. 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.

The Mildmay Centre, which has been operational since September 1998, is situated 14 km 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.

Main Activities

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:

1. Care

The centre provides holistic, high-quality care and advice, and emphasizes that respect for the concerns, rights, and beliefs of each individual is 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. 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 Funding for care and treatment).

2. 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

3. Capacity-building in AIDS palliative care

Mildmay has implemented educational programmes to help improve care throughout the region, with an emphasis on building local capacity in AIDS palliative care. 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, and so on); 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. The Mobile Clinical Training Team takes training to the rural districts – the team 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 provided follow-up and further training by the mobile team.

4. 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 providing. Since the HIV-positive individuals fall sick often, have left school, or are orphans, their needs are very rarely recognized and planned for. As well, 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, 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.

5. Funding for care and treatment

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 England) to help pay for the care and treatment of all children and adolescents, as well as for a few adults.

Outcomes

In its first year, the Mildmay Centre registered a total of 980 patients, of whom 80 per cent had referral letters, and provided services to thousands more. The majority of referrals (90 per cent) 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. 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.

By the end of March 2000, over 10,500 people had been served since the opening of the centre, and there were 1,450 new registrations, of whom 230 were children under the age of 19 years. The average age of the children was 8.5, with about one-quarter between 10 and 19 years of age.

Evaluation Findings

Every three months, clients (the patient and/or their caregiver) fill out 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 that is 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 improved by the end of four visits to the centre. In this study, most patients (70%) had at least one investigation, with microbiology being the most frequently requested investigation (microscopy, Ziel Nielson, and gram stain). 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.

Lessons Learned

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.

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.

On the clinical side, 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 problem 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 towards the situations they are presented with – another useful technique for countering staff burnout.

Religion

In many countries, HIV/AIDS continues to be perceived and treated exclusively as a health or medical problem. However, it is becoming increasingly evident that successful national AIDS programmes are those that have broadened their focus from the urgency of encouraging individual behavioural change to include the necessity of addressing how societies behave towards persons living with or affected by HIV/AIDS, and towards vulnerable individuals in general.

A number of institutional settings provide opportunities for collective action to strengthen HIV/AIDS prevention and care efforts. These include schools, health care facilities, the military, and the workplace. One of the most important, however, is religious institutions. This is because of the moral leadership that such institutions provide to hundreds of millions of people worldwide, the trust they have gained over generations, and the excellent channels of communication and organization that many have built up.

Around the world, individual places of worship within communities (including churches, mosques, synagogues, temples, and hospitals with religious affiliations) have undertaken their own initiatives to deal with HIV/AIDS and its impact at a local level. These initiatives have included advocating changes in local community attitudes, speaking out against prejudice, raising money, and organizing home-based care.

At the same time, regional and national religious hierarchies in some countries have undertaken wide-ranging activities, sometimes moving well ahead of many local members. In Africa, religious leaders confronted HIV/AIDS early on in the epidemic, and religious institutions were among the first to care for the sick and dying. In many parts of Asia, Buddhist monks and nuns and other religious groups are very much involved in caring for people living with HIV/AIDS. Many spiritual leaders have grappled with the difficult questions that the epidemic poses to theology, and have found that discussion of these questions can have beneficial effects on faith and religious teaching.

A two-pronged focus appears to be developing in the engagement of the religious sector in various parts of the world:

- ◆ To promote the exchange of ideas and training for community-based prevention and care programmes. This has been done through conferences and symposia, as well as the creation of interfaith alliances both at local and higher levels.
- ◆ To encourage religious institutions to strengthen life-skills training for HIV/AIDS education in schools operated by their congregations.

Treasuring the Gift (Zambia)

Starting Year: 1998

Main Topic Area: Religion

Other Topic Areas: Children and young people • Reproductive health

Contact Person:

Ms. Robie Siamwiza

Phone: +260 1 221314, 228118/9

Fax: +260 1 225741

Email: robie@zamnet.zm

Address:

Project Concern International

P.O. Box 32320

Lusaka

Zambia

Implementers

Lusaka Interfaith HIV/AIDS Networking Group (Christian Council of Zambia, Evangelical Fellowship of Zambia, Makeni Islamic Community, Zambian Episcopal Conference, Bahai Community, independent churches, and the Salvation Army) with support from Project Concern International (Zambia)

Funding

Project Concern International (Zambia)

Objectives

The aim of the project is to support, strengthen, and sustain leaders of youth groups attached to religious organizations, using their religious values and traditions to promote good sexual health.

The project's operational objective was to develop sexual health learning materials that require little or no literacy among participants, and that enable youth groups attached to religious organizations to:

- gain relevant and accurate information on sexuality, reproduction, and HIV/AIDS and other STDs
- develop values and attitudes that will promote sexual health
- practise skills necessary for good sexual health
- support their members in promoting their sexual health
- take action in their communities to promote sexual health.

Background

The project was designed to provide sexual health learning activities to religious youth groups, and especially to youth no longer in school. There are many myths about HIV in Zambia, and many young people lack adequate information and life skills. This is especially the case among out-of-school

youth, who, in addition, are hampered by low literacy. Religious groups have recognized the need for new ways of preparing youth for adolescence and adulthood and are asking for support in this area. In many communities, in the cities as well as in the countryside, religious groups are the only form of organization with links outside the community. They are therefore an ideal channel for communication of sexual health messages.

A number of conditions and concerns are particular to Zambia and to specific faiths, and these had to be dealt with and taken into account:

- The gap between puberty and marriage in Zambia can be ten years or more. Social and religious rules still ask that young people abstain from sex until marriage.
- Dating has been one outlet for adolescents wanting premarital contact with the opposite sex, although in some cultures, such as Islam, it is expressly forbidden. This social invention did not exist when most religions were founded, nor does it exist in traditional Zambian society, so there is very little guidance on the subject. Even when acceptable, the culture of dating is different in Zambia than in the West. In the West, young people can have boyfriends or girlfriends without engaging in sex. In Zambia, most young people understand boyfriends and girlfriends to mean someone you have sex with. In those religious communities that allow dating, efforts should be made to change this understanding, so that dating without sex becomes established as a norm for young people.
- Studies of sexual behaviour in Zambia have found that people with “stricter” religious beliefs are less likely to use condoms, even though many of them may have sex outside marriage, increasing the risk of HIV for many religious believers. Religious communities have a responsibility to tackle this issue.

Main Activities

A consultant writer was assigned to produce a book aimed at religious communities to help them prepare youth for adulthood in a world with AIDS (Zambia has one of the highest HIV rates in the world). The book production process involved:

- recruitment of a production team, made up of professionals, NGO representatives, and youth from a variety of religious organizations; the production team consisted of 14 young school leavers in their early twenties; the Lusaka Interfaith Networking Group identified youths to work with the consultant, who trained them to prepare the materials
- training for the team, involving information about sexual health and religious attitudes to sexual health; the dominant training methodology was use of participatory learning activities
- choosing topics for inclusion in the learning pack (personal values, communication skills, risky situations and self-control, dealing with negative peer pressure, interpersonal relationships, puberty and masturbation, reproduction, pregnancy, abortion, STDs, HIV prevention, living with HIV/AIDS, and breaking traditional barriers)

- participatory research by production team members upon return to their youth groups, using participatory learning and action (PLA) techniques including mapping, flow diagrams, and focus groups.

The production cycle involved a series of meetings designed to test the activities as well as graphics, diagrams, and other elements, and adapt them as needed. That information was then fed into the writing process.

Representatives of the Interfaith Group were consulted at each stage of the process and met with young people from the production team and the facilitators to make suggestions for improvement. There was agreement that there should be only one book for all faiths, rather than separate versions for Christians, Muslims and Bahais.

Outcomes

Treasuring the Gift: How to handle God's gift of sex, is a 142-page book for leaders of religious youth groups. It contains 18 participatory learning activities, supported by 47 pages of background information. The material is suitable for children and youth from the age of 10 upwards and can be used by mixed or single-sex groups. The instructions are clearly laid out and written in simple English to facilitate translation. It is fully illustrated with diagrams, line drawings, and photographs. Users of the book need only a minimum of training in facilitation and participatory approaches.

The activities are designed to encourage honest discussion about the realities of sexual behaviour among young people, religious and non-religious, and to allow youth to practise the skills they need to avoid emotional hurt, unplanned pregnancy, or infection with STDs, including HIV. Each topic is supported by information and advice, to enable facilitators to lead discussions and answer questions with confidence.

Among other, more indirect outcomes:

- an Islamic youth group has been created that plans to continue after the end of the programme, broadening its activities beyond sexual health and HIV prevention;
- the Salvation Army (a Christian group) is planning a youth HIV-prevention workshop to share the work of its two participants in the programme;
- one participant has been asked to facilitate a day's workshop on sexual health and HIV prevention with one of the youth groups where she was conducting pretests.

One of the programme objectives was to produce a resource that did not require literacy from participants. It was thought that PLA techniques might be suitable, as they do not require literacy. The book is very easy to use: the instructions are simple, and a young person with only a few days' training can use it successfully. During the pretesting, some young people who were not part of the programme, and had had no training at all, used the book to lead groups.

Lessons Learned

The project clearly demonstrates how using young people themselves to disseminate messages is highly effective. In addition, the following lessons were learned:

- Participatory approaches increase the confidence and experience of those who use them, and being involved in all phases of a production process ensures that facilitators will find it easy to teach the materials they helped design.
- Interfaith approaches to sensitive topics do work as long as representatives of religious groups are brought in at the beginning of the process and consulted throughout.
- High levels of literacy are not essential to use text-based sexual health information materials.
- Using outside consultants is often necessary, but their work can be made more effective by including target groups in the process from the outset. The consultant recruited for the project had worked in Zambia before and had previous experience in producing reproductive health materials for a Zambian audience. These considerations encouraged cooperation with the Interfaith Networking Group and enhanced their willingness to collaborate. The consultant was identified by Project Concern International, and was immediately accepted because of the strong existing relationship between Project Concern and the Interfaith Group.

School-based interventions and services

There are more than one billion adolescents in the world. Their number in developing countries – over 800 million – will increase by 20 per cent in the next 15 years. Young people are society's future, and it is essential to invest heavily in them so that they can protect their own health and influence and educate their peers. This requires effective AIDS education programmes in school alongside preventive efforts in the community and the media.

Education is a national concern in all parts of the world, and so cooperation at the highest levels of government is important in making school AIDS education programmes work. Experience in various parts of the world indicates that, working in collaboration with ministries of education and with health and social services, each country's national AIDS programme should aim to provide all schoolchildren with AIDS education.

Effective AIDS education includes information on prevention, care, and support for people with HIV/AIDS, and on non-discrimination. Education of this kind has been shown to help young people to delay sex and, when they become sexually active, to avoid risk behaviour. However, children and young people are often denied AIDS education in school. Reasons for this include the sensitive or controversial nature of the subject in some societies, and the difficulty of finding time for AIDS education in an already overcrowded curriculum. In some places, schools may teach information on AIDS but not the behavioural skills needed for prevention and support.

Best practices in school-based interventions include:

- ◆ partnerships among policy-makers, religious and community leaders, parents, and teachers to set sound policies on AIDS education
- ◆ designing a good curriculum and/or a good extracurricular programme, one that is adapted to local culture and circumstances and that focuses on life skills rather than biomedical information
- ◆ teaching primary and secondary students to analyse and respond to social norms, including understanding which ones are potentially harmful and which ones protect their health and well-being
- ◆ good training, both for teachers and for peer educators (that is, young people from the same age group, specifically selected to educate their friends and acquaintances about AIDS)
- ◆ starting HIV-prevention and health programmes for children at the earliest possible age, and certainly before the onset of sexual activity. Effectively, age-appropriate programmes should start at the primary school level.

Straight Talk (Uganda)

Starting Year: 1993

Main Topic Area: School-based interventions and services

Other Topic Areas: Communications programming • Reproductive health • Male condoms • Children and young people

Contact Person:

Ms. Anne Akia, Programme Director
Ms. Catherine Watson, Editorial Director

Phone: +256 41 543 025 or 543 884

Fax: +256 41 543 884

Email: strtalk@swiftuganda.com
or strtalk@imul.com

Web Site: www.swiftuganda.com/~strtalk

Address:

Straight Talk Foundation
P.O. Box 22366
Kampala
Uganda

Implementers

Straight Talk Foundation is a communications NGO based in Kampala.

Funding

Funders include UNICEF, Sida, DANIDA, Save the Children Alliance, USAID (through Population Services International), the Ford Foundation, the Department for International Development, UK (DFID), and the European Union (from 2000).

Objectives

The goal is to encourage adolescents to delay sexual activity and to adopt safer sexual behaviours once they do become active. The mission statement includes "keeping adolescents safe" and "communication for better health."

Background

Straight Talk is a monthly four-page newsletter that targets secondary school students between the ages of 15 and 19 as well as young adults in colleges and universities (aged 20–24). The newsletter advocates safer sex, including abstinence, masturbation, non-penetrative sex, and condom use.

Its counterpart for younger people, *Young Talk*, is aimed at upper primary school pupils and young adolescents aged 10–14. Key topics include changes at puberty, a child's rights and responsibilities, and general body health and hygiene. *Young Talk* advocates abstinence, although information about condoms is provided if the children request it. Those who say they are

sexually active are advised to reconsider their actions. In primary schools, teachers are encouraged to use *Young Talk* as a teaching tool.

Both publications take a strong moral stand against exploitative and manipulative relationships and advocate respect for family values.

The publications led to the creation of the Straight Talk Foundation, a communication NGO that produces information, education, and communication (IEC) materials for adolescents. Part of the foundation's mandate is to keep its target audience (Ugandan adolescents, aged 10–19, and young adults, aged 20–24) safe from STD/HIV infection.

Main Activities

The main activities are the publication of the two newsletters, *Straight Talk* and *Young Talk*, which are distributed free of charge throughout Uganda (see Outcomes).

Straight Talk is available in English, but is also translated into two local languages and published four times a year for out-of-school adolescents who have difficulties with English. In April 1999 a *Straight Talk* radio show was launched on two popular English FM stations. It is now on five FM stations and reaches almost countrywide. Local-language programmes are planned.

Both newsletters are published by professionals but are in fact "adolescent-driven." The information published in them is determined by the content of letters received from readers. Message content is periodically pretested among adolescents. The newsletters offer age-appropriate information on reproductive health, life skills, and rights for adolescents. In terms of HIV/AIDS preventive actions, they stress the delay of sexual activity and the importance of safer sex for those who are already sexually active.

The publications are complemented by visits by the Straight Talk team of doctors and other visitors to a dozen schools each term in about six districts. During a school visit, a team of adolescent-friendly doctors and counsellors spends the first two days sensitizing teachers about adolescent behaviour, body changes, and so on. The next two days are spent with 150 students from one school; the last two days with students from a second school. Students decide what topics they want to discuss. These range from love and sex to relationships with parents and the opposite sex, STDs/HIV, body changes (menstruation, wet dreams, breast size, penis size) and life skills. Role plays based on several scenarios are enacted by students. The day ends with one-on-one counselling.

Another activity associated with the project is the almost 200 Straight Talk clubs that have been founded by students in schools throughout Uganda.

Outcomes

Straight Talk has a print run of 150,000 a month and is sent to 1,400 secondary schools. *Young Talk* has a print run of 270,000 per month and is also placed as an insert in the *New Vision* newspaper (40,000 copies); it is sent to 12,000 primary schools. In addition, about 130 large NGOs, 426 tertiary education institutions, 50 community groups and churches, 191 Straight Talk clubs formed by students, and 149 medical institutions receive

the newsletters. The newsletter costs US\$ 0.07 per copy but is distributed free of charge.

In terms of feedback, *Straight Talk* receives over 3,000 letters per year from readers.

Evaluation Findings

An evaluation in 1995 after 16 issues found that all secondary school students surveyed had seen *Straight Talk*. The evaluation found that 8 per cent of the 1,682 adolescents surveyed cited *Straight Talk* as their main source of information on HIV. Radio ranked first at 43 per cent.

Lessons Learned

The project has shown that it is possible for health educators to talk about sex, even in conservative societies. It is crucial to find the right tone, however, so as not to offend the existing culture, and for the information to be backed by correct medical facts. Other lessons learned include:

1. The information given to an audience must be supported by the teaching of practical life skills and values, otherwise it will not be of much use to the recipient.
2. Adolescent involvement in such work must be guided by properly prepared adults. Adolescents do want and need guidance, but at the same time, they and their opinions must be respected.
3. In order to maximize resources, it is important to use the cheapest means possible. In *Straight Talk's* experience, using newsprint instead of glossy paper has been very beneficial. Approximately ten people share a single copy of the newsletter.
4. Producing materials is only half the battle. It is important to place a great deal of effort and thought into the dissemination of materials produced, otherwise they will not reach the audience. To this end, it is important to have contacts with NGOs, newspapers and all forms of distribution outlets to establish a successful distribution network.

Further Reading

See the website at www.swiftuganda.com/~strtalk.

Sex workers and clients

Sex workers have existed since time immemorial, with a long history of moral and socioeconomic conflicts, persecution, stigma, and violence surrounding sex work. HIV/AIDS is a new issue that has fuelled concern over sex work and how societies think about and dealt with it. It has, however, also brought to light many of the underlying factors that feed this trade and make it unsafe.

There are several categories of sex workers among the women, men, and transgendered persons in the trade. Most often the sex trade is thought of in terms of full-time sex workers found in brothels. Those working in these situations are frequently called prostitutes or “call girls,” and are in working relationships with pimps, madams, or owners. A second category comprises “casual” or “indirect” sex workers, who exchange sex for money or for favours or gifts, either on an ad hoc basis or as a second employment. Such sex workers are less inclined to have a “business manager.” In a third category are those sex workers who are forced into sex work and may be held in bondage for short or long periods of time. All of these categories include, to greater or lesser degrees, the sexual exploitation of young people and women. The category that the sex worker finds herself in, as well as her age, may determine the extent to which she can protect herself from HIV and STD transmissions (this is also true for males in the trade).

In many countries, HIV was first identified in the sex work population. As the epidemic grew, international agencies, governments, and NGOs recognized the need to create interventions for this vulnerable group who engage in risk behaviour and do not often have the means or knowledge to reduce their risk of infection. At the same time, negative social and political views of sex work have used and continue to use HIV/AIDS as a reason to create and enforce laws that marginalize and criminalize sex workers.

Initial responses were primarily promotion and distribution of condoms to sex workers, and dissemination of information. Most of these programmes are targeted to the sex worker, ignoring the clients and the brothel owners or managers. Educational and enabling strategies are the two main elements used when addressing sex work and STD/HIV/AIDS, but the most successful projects include components of both. They also involve people who influence commercial sex activity: clients; owners and managers; police and law enforcers; health officials; community leaders; the media; neighbours and families.

The most effective comprehensive projects are frequently those carried out by men or women who are or have been sex workers. This approach is usually referred to as peer education, but can and should go beyond the educational aspects of HIV/STD education. Other important methods used in HIV/STD sex work programmes are:

- ◆ outreach or fieldwork – going to sex workers and their bosses in their workplace, at informal meeting places, or at times in their homes, speaking with clients in bars and clubs
- ◆ group education sessions through outreach work
- ◆ distribution of educational material for sex workers, bosses, and clients
- ◆ promotion and distribution of, and easy access to, condoms and lubricants (again this needs to address all parties concerned and not only the sex worker)
- ◆ creating or strengthening an enabling environment through provision of and access to health, social, and legal services, especially appropriate management of STDs and confidential counselling services
- ◆ networking of sex workers – locally, nationally, and regionally – to advocate for protective laws, safer working conditions, and safer services, and to exchange information and experiences
- ◆ economic development programmes, including skills training, that offer alternative means of employment to sex workers
- ◆ strategies for drug-using sex workers, including needle-exchange, non-injectable drugs, and harm-reduction methods
- ◆ advocacy for a socially and legally supportive environment – working with communities to change social norms and with policy-makers and law-enforcers to address legal issues that affect sex workers.

PPP: Programme for care and prevention among female sex workers (Côte d'Ivoire)

Starting Year: 1991

Main Topic Area: Sex workers and clients

Other Topic Areas: Male condoms • Sexually transmitted diseases

Contact Person:

Dr Ayokoin Michel

Phone: +225 246 856/246 796/
243 013/243 014

Fax: +225 243 119

Address:

Programme national de lutte
contre le SIDA

Implementers

The National AIDS Programme (PNLS – Programme national de lutte contre le SIDA) provides the institutional home for the PPP within the Côte d'Ivoirian health system, and oversees its administrative and financial management. It provides an office, audiovisual support, and access to vehicles and educational materials. However, other organizations are or have been deeply involved with programme, including:

- National Institute for Public Health (INSP – Institut national de santé publique)
- Projet Retro-Ci (a collaborative project of the Ministry of Health and the US Centers for Disease Control and Prevention)
- Institute of Tropical Medicine, Antwerp, Belgium
- Population Services International (PSI)
- WHO and UNAIDS.

Funding

Principal funding over the years has been provided by WHO, UNAIDS, the Institute of Tropical Medicine of Antwerp, UNDP, and UNFPA.

Objectives

The programme targets three main groups: sex workers (both professional and non-professional); their clients and sex partners; and the owners and operators of locations where the sex trade occurs. Its overall objectives have been to:

- increase knowledge of the risks of HIV and STD infection
- improve access to condoms
- improve access to STD and other medical care

Background

The sex trade in Côte d'Ivoire has an ambiguous status: it is illegal, yet it is tolerated by the authorities and widely used by men from all sectors of society. As early as 1990, levels of HIV prevalence among sex workers in the capital, Abidjan, were known to be over 50 per cent and condom use was low. A study of HIV prevalence among clients of sex workers found HIV infection among approximately one-fifth of those tested.

In a pilot project in 1990, the INSP carried out a survey of 130 sex workers and proprietors in the Adiopoume area of Abidjan. This was followed in 1991 by group discussions with sex workers and clients, a KAP (knowledge, attitudes, and practices) survey, and other research that permitted the sex trade to be analysed and mapped. Findings included a high number of migrants among sex workers, low knowledge of STDs and HIV, low condom use, and extremely limited access to medical attention. Based on the needs demonstrated by this research, the programme was instituted by the INSP in July 1991 in three of ten communes (boroughs).

Coverage was extended to all communes in 1993–94, when the programme took on its formal name (Programme de prévention et de prise en charge des MST/SIDA chez les femmes et leurs partenaires), and came under the authority of the PNLS. It has since been extended to four other cities: Bouake, Daloa, Korhogo, and San-Pedro. Staff include health educators, sociologists, and government social workers, along with peer educators recruited from among the sex workers.

In 1992, a separate project called Projet Retro-Ci (a collaboration of the Ministry of Health, the Centers for Disease Control, and the Institute of Tropical Medicine) created a clinic in the borough of Koumassi, where a large number of sex workers were known to live or work. Although created and financed as essentially a research centre, the Clinique de Confiance collaborates with the larger programme by providing salary support to the PPP's 18 health educators and participating in the PPP's monthly meetings. The clinic performs outreach to nine out of ten boroughs of Abidjan, and provides clinical services for STDs and voluntary HIV counselling and testing. It should be noted that the life of the programme has coincided with a variety of prevention initiatives undertaken by the government, including mass media AIDS awareness campaigns and social marketing of condoms (the latter in collaboration with PSI).

Main Activities

The programme comprises three main components:

1. Community mobilization and education. Activities include:

- educating and involving all interested parties in prevention work, including local government authorities, leaders of immigrant communities, owners of bars or hotels in which sex work takes place, and leaders among the community of sex workers;
- educational meetings in places where prostitutes live or work; the meetings' agenda includes information about AIDS and other STDs, prevention methods, testing, and STD services, and a demonstration of proper condom

use (using wooden models of penises) is generally also part of these meetings;

- peer education through recruitment of sex workers who perform outreach to other sex workers in their places of work, as well as organizing educational meetings; training sessions for peer educators are held every two months at the Clinique de Confiance.

2. Promotion of and access to condoms. The programme distributes free condoms in places where the sex trade is carried out and in some health centres. It has also attempted to involve sex workers and hotel or bar owners in this distribution.

3. Access to STD care and to voluntary HIV counselling and testing. The Clinique de Confiance offers free STD examinations and treatment specifically for sex workers.

As well as the services at the Clinique de Confiance, the programme helps direct sex workers to health centres that are familiar with and adapted to their needs and specific conditions. The PPP has also created a network of public and private medical partners who are capable of responding to the needs of sex workers.

Outcomes

A variety of outcomes have been studied, although data are not complete. In the year 1996, for instance, 176 educational meetings were held, with participation as follows: 2,673 men, 1,886 sex workers, 1,550 women who were not sex workers, and 1,213 children. Between October 1992 and December 1998, the Clinique de Confiance was visited at least once by 5,218 sex workers.

An important outcome is the information produced by the programme's KAP research, which was first carried out in 1991 and has been repeated at two-year intervals since then. As well, the Clinique de Confiance has been able to provide annual data on prevalence of HIV and other STDs since 1992. Simple follow-up and evaluation techniques have been in place since 1994 in order to provide programme impact data to funding agencies.

Evaluation Findings

An evaluation carried out in 1999 focused on three main sets of indicators:

1. Coverage of the programme among target groups. Between 1993 and 1995, awareness among sex workers of the Clinique de Confiance's existence grew from 15% to 38%, while the proportion of women who had actually visited it grew from 7% to 21%. By 1997, about half of sex workers knew about it, and some 37% had visited the clinic – an impressive fact given the mobility of many of the women and a high rate of exit and entry into the sex trade. The fact that many more women knew about it than had visited it was partly explained by the difficulty of getting transportation to the clinic, and of arranging education sessions at times that suit women who work all night. Another factor is that of priorities: many of the women recognize the importance of sexual health, but are more concerned with the basic issues of survival – having enough food for themselves and their family, finding and keeping a place to live, and so on. The mobility of the sex worker population

explained the finding that only one-quarter of the women trained as peer educators before 1996 actually participated during 1996 in prevention activities. It was also found that most peer educators had little sense of "ownership" of the programme and took relatively limited roles in its activities.

2. Knowledge and behaviour of participants. The KAP studies over time showed improved knowledge of the modes of HIV transmission and greater use of condoms in the general population, but indicated consistently more knowledge and safer behaviour among women who had had contact with the programme (e.g., self-reporting about condom use with clients, understanding of modes of transmission, etc.).

3. Prevalence levels of HIV and STDs among women coming for their first consultation at the Clinique de Confiance. Prevalence of HIV and some other STDs among sex workers has fallen in Abidjan since 1992. While it is not certain exactly how much of this was due to the PPP and how much to other prevention efforts happening at the same time, and despite some problems of selection bias in the data collection, enough difference can be measured between participant and non-participants to strongly indicate an independent and positive impact of the programme.

As in studies in other parts of the world, PPP and Projet Retro-Ci found that measures of levels of knowledge and behaviour, as well as prevalence of infection, were strongly affected by the proportion of migrants in the population. The reduced proportion of foreign sex workers in Abidjan, which began during the mid-1990s, may have been an important factor in the reduced levels of HIV.

The evaluation also noted the exceptional longevity of the programme (in operation continuously since 1991), due to its ability to find support from and cooperation with a variety of national and international partners.

Lessons Learned

The programme and its various components highlight a variety of useful lessons. The overall lesson appears to be that, when founded on properly collected research data to assess needs and conditions, a community-based IEC strategy can be effective in reducing HIV prevalence and increasing condom use among sex workers.

An extremely important lesson is the value of cooperation between different organizations in order to get the greatest value out of existing resources. The programme allows coordination between local communities, government programmes, NGOs, and international organizations that reflects the strengths of each. Such coordination avoids duplication of effort and provides the best guarantee of sustainability.

Sexually transmitted diseases

In the last decade, sufficient knowledge and expertise have been gathered in the fight against HIV/AIDS and other sexually transmitted diseases (STDs) to enable effective prevention and care interventions to be established. No single strategy will work on its own, and no one nation can work in isolation in the fight against these diseases. A unified approach based on sound principles needs to be implemented globally, regionally, and locally. WHO has estimated that in 1995 around 340 million new cases of curable STDs occurred globally in men and women 15–49 years old. In developing countries, STDs and their complications rank in the top five disease categories for which adults seek health care. In women of childbearing age, disease and death/healthy life lost due to STDs – even excluding HIV – are second only to maternal causes. The scale of the problem is too great to be dealt with in STD centres alone, and steps must be taken to expand and integrate STD management in primary health and other health centres.

STDs continue to spread, and their complications and long-term health effects continue to be a burden on individuals and communities for many reasons. Many cases are asymptomatic, and there is widespread ignorance of STDs' causes, symptoms, cures, and possible consequences. Many people showing symptoms are reluctant to seek health care, and find it difficult to notify their spouse or sex partner(s) of their health status. As well, in many places STD services are unavailable or are unsuitable for many potential clients, and prescribed treatments are often substandard.

However, effective prevention and control of STDs can be achieved using a combination of responses, including a “public health package.” STD service delivery should be expanded to include the following components:

- ◆ promotion of safer sex behaviour
- ◆ condom programming, encompassing a full range of activities from promotion to the planning and management of supplies and distribution
- ◆ promotion of health care-seeking behaviour
- ◆ integration of STD control into primary health care, reproductive health care facilities, private clinics, and other health institutions
- ◆ specific services for populations with high risk behaviours for acquiring and transmitting STD and HIV infections
- ◆ comprehensive case management of STDs
- ◆ prevention and care of congenital syphilis and neonatal conjunctivitis
- ◆ early detection of symptomatic and asymptomatic infections.

West African Project to Combat AIDS: STD control strategies (International)

Starting Year: 1996

Main Topic Area: Sexually transmitted diseases

Other Topic Areas: Community mobilization • Migration • Sex workers and clients

Contact Person:

Robert Beaudry, Project Officer
(Quebec)

Phone: +1 418 657-5525

Fax: +1 418 656-2627

Email: Robert.beaudry@ccisd.org

Web Site: www.ccisd.org

Address:

Centre for International Health
and Development, Inc. (CCISD)

2180, Chemin Sainte-Foy

Sainte-Foy, Quebec,

Canada G1K 7P4

Contact Person:

Pierre Champagne
Regional Representative

Phone: +226-31.35.73

Fax: +226-31.59.45

Email: pierre.champagne@ccisd.bf

Address:

01 B.P. 6643

Ouagadougou, 01

Burkina Faso

Implementers

Working with a variety of African partners in Benin, Burkina Faso, Côte d'Ivoire, Ghana, Guinea, Mali, and Senegal, the project was implemented and managed by the Centre de coopération internationale en santé et développement (CCISD – Centre for International Health and Development) of Sainte-Foy, Quebec. The CCISD has three institutional partners in the project: the Unité de santé internationale de l'Université de Montréal (USI-UdM), the Centre de recherche clinique du Centre Hospitalier Universitaire de Sherbrooke (CRC-CHUS), and the Centre de recherche de l'Hôpital Saint-Sacrement (CRHSS).

Funding

Overall project funding of CDN\$ 24 million comes from the Canadian International Development Agency (CIDA), but a wide variety of financial backers have been found for specific activities in different countries.

Objectives

The overall goals are to reduce the transmission of HIV through syndromic control of STDs and to ensure effective and sustainable HIV and STD control through:

- reinforcing primary and community health networks
- giving priority to groups likely to adopt high-risk behaviours
- encouraging stakeholders to work on a self-financing basis.

The general objectives are: to help national teams to develop effective and efficient interventions, based on scientifically valid data used in a public health approach; and to set up mechanisms that will ensure permanent availability of essential drugs in the treatment of STDs, in a context of self-financing by users.

Background

The project supports a number of basic health services located in underprivileged urban areas and along migratory routes. Activities centre on personnel training and STD control, particularly by ensuring access to essential drugs, by providing training, and by supporting community organizations. The project operates within the framework of intervention strategies designed at the regional level but does so through interventions implemented and managed at the national level in each of the above-mentioned African countries.

In the field, the project collaborates with the Ministries of Health of the countries involved, the Canadian embassies, and various institutions and NGOs. It coordinates its activities with those of numerous financial backers. A regional office has been set up in Ouagadougou, Burkina Faso. The national teams are connected to each other (and to the rest of the world) through the Internet.

Main Activities

Because of its complexity, this multicountry, multicomponent project is difficult to summarize (for more detail, readers are directed to the implementer's website and project documents). However, for purposes of this booklet, the following activity areas are noted:

1. STD control strategies and essential drugs management

The focus is on technical aspects of STD case management:

- an assessment of STD flowcharts already in use in each country and recommendations to improve them, if necessary
- validation of the choices involved in the flowcharts through a regional study on the etiology of urethritis and genital ulcer cases, and a study limited to two countries on in vitro susceptibility of STD pathogens (*Haemophilus ducreyi* and *Neisseria gonorrhoeae*) to various antimicrobials

- in four countries of the project (Benin, Burkina Faso, Ghana, and Guinea Conakry), a study of the quality of drugs used in treating STDs, in order to provide decision-makers with information that will enable them to better direct their action regarding essential drugs availability. The final report was disseminated in October 1998.

In countries where it has been decided to target sex workers specifically, studies on STD prevalence among sex workers are to be carried out before and after the intervention, this certainly being one of the best guides for estimating orders of medicines and laboratory supplies.

Regarding the management of essential STD drugs, project activities include:

- assessment of management and essential drugs self-financing methods already in use in the intervention units, followed by individual recommendations to improve them
- preparation of management training material where necessary and helping national coordinators to provide training
- for each country, analysis of essential drugs supply mechanisms and networks, tariff structures, and ways to reduce the cost of medicines.

2. Community participation

The community participation regional component ensures the promotion and acceptability of STD control among the populations served by health centres, in particular groups and individuals most exposed to STDs and AIDS. The participation of these high-risk groups in information and education is intended not only to stimulate the demand for STD/AIDS health care services, but also to support the self-development of these populations and encourage decision-making as regards the adoption of preventive measures. Therefore, those organizations must participate in analysing health problems and planning STD/AIDS control activities with health facility officials.

Activities that are supported to achieve this participation include:

- training trainers in the areas of planning, project management, and communication; they, in turn, train national partners, including officials in charge of community support
- supervising officials in charge of community support with regard to the planning of their interventions, and the management, monitoring, and assessment of small initiatives
- developing management tools for small initiatives
- sharing experience and information through meetings, visits, and relevant publications pertaining to the theme
- supporting the implementation of collaboration and consultation mechanisms among relay organizations, beneficiaries, and national and local officials in charge of health facilities
- looking for additional funds to finance small initiatives.

3. Monitoring

The monitoring staff is in charge of assessing the quality of STD case management in more than 487 facilities currently supported by the various country-based components, as well as monitoring the outcome indicators (PIs) selected for the entire project. To carry out the monitoring, a simple baseline surveillance system has been set up that includes a limited number of variables. Data are collected regularly to assess the achievement of planned results, in particular in terms of training and community support.

Several steps remain in terms of integration of national health information systems. First, the various registers and/or files set up in the facilities by the project need to be analysed. These are then to be compared to the same tools in the public facilities under the direct supervision of the national officials. National coordinators (NCs) and an official identified by the health authorities of each country need to confer about the possible harmonization of those instruments and field practices. The goal is for these individuals to agree on the remedial measures to be carried out and/or adaptations to be made in order to enable the national officials of all the intervention countries to effectively adopt the tools and the project's activity monitoring system before the end of the project.

Outcomes

Project reports indicate the following raw measures of outputs, which can be taken to indicate the scope of the project's coverage. As of December 1999, the total cumulative number of patients managed for an STD under the supervision of the project since its beginning was 146,460, of whom 75 per cent were female.

Some 627 health facilities had received support. A total of 1,663 community workers and 3,712 peer educators had received training, while 5,747 health workers had received training and were being supervised on a regular basis. Further, a total of 325 community projects had been completed or were in progress. On the prevention side, an estimated 453,421 persons had been reached by prevention activities associated with the project.

Evaluation Findings

In terms of results related to the objective of improving the quality of STD care and control, the January–September 1998 assessment indicated that the percentage of treatments that complied with national flowcharts had increased in comparison with the first 9 months of activity of the Project (April–December 1997). All the intervention countries have conducted PI6/PI7 surveys at the beginning of Year 2 (except in Ghana, where only one assessment has been made) in order to determine the progress made, since the first assessment, both in terms of the percentages of STD patients managed according to national standards (PI6 indicator) and of STD patients encouraged to use condoms and refer their partners for treatment (PI7 indicator). There has been an increase in scores at the regional level from 8% to 57% for PI6 and from 15% to 49% for PI7 in the supported facilities. Such an increase confirms that health facilities are providing better STD case

management, and the "treatment" aspect is the one for which the project has had the best results.

The percentage of patients who have a complete history has changed little (83% to 89%) and the percentage of patients who have a complete examination has increased moderately (51% to 78%). The percentage of effective treatments has more than doubled, rising from 27% before the intervention to 73% after one year of activities.

As well, the percentages of cases effectively treated are higher if one takes into account those treatments that comply with national flowcharts as well as "prescriptions that do not comply but are considered to be effective": 96% for cases of urethral discharge, 89% for genital ulcers, 81% for cases of vaginal discharge, 73% for lower abdominal pain, and 83% overall at the regional level.

Lessons Learned

Among the many lessons learned in the course of the project, a main one is that syndromic control of STDs in population groups with high-risk behaviours is feasible within existing primary health care services (i.e., without creating a new service delivery infrastructure) on a drug cost-recovery basis. However, a number of elements are necessary for the success of this approach:

- health-seeking behaviours (notably, where potential clients go for STD services) change substantially from one region to another, so primary assessment of health-seeking behaviours is essential
- community participation activities must be carried out to stimulate the use of STD services, and for information, education, and communication (IEC) to be delivered effectively
- training at the field level of health care workers must be kept very basic, and there should be consistent follow-up by supervisors in order for skills to be maintained
- consistent field-level training and supervision must be matched by advocacy at central (particularly Ministry of Health) agencies if ongoing use of proper algorithms is to be sustained
- the syndromic approach must be part of all health school curricula
- use of generic drugs can and must be adopted throughout the whole of health services
- planning and managerial capacity-building must be built into projects aimed at improving procurement, distribution, and use of essential drugs.

All the country-based teams were made aware of the importance of keeping a common pace and level of quality. Baseline surveillance is currently functional in all countries, albeit to varying degrees according to the age of the supported facilities. Baseline surveillance enables the various national project staffs to monitor over time (with the intervention of the Project) the percentages of STD cases correctly treated and to indirectly assess the

application by trained health care workers of the syndromic approach to STD case management.

Further Reading

CCSID maintains a great deal of information on the West African Project to Combat AIDS on its website at www.ccisd.org. This includes detailed descriptions of activities in each country and contact details for national partners.

United Nations Theme Groups on HIV/AIDS

The ECOSOC resolution establishing UNAIDS called for the setting up of UN Theme Groups as the principal vehicle for carrying out the mandate of the Joint Programme at country level. Under the aegis of the UN's Resident Coordinator stationed in each country, the Theme Groups would “ensure effective and coordinated support by the UN system to the national AIDS programme (i.e. the national response).” At the same time they would “help the UN system integrate more effectively its efforts with national coordination mechanisms” and “whenever possible, facilitate the coordination of other external support to the national programme.”

While core membership consists of representatives of the seven (originally six) UNAIDS cosponsors and other UN system organizations, the resolution specified that Theme Groups on HIV/AIDS could be expanded to include representatives of government and other international organizations, including donor agencies, and that non-governmental organizations representing persons living with HIV/AIDS might also be invited to participate. The ECOSOC resolution thereby recognized the diversity of country situations and allowed a great degree of flexibility, notably concerning the membership of Theme Groups.

The many different effective models of Theme Group operations testify to the variety of settings and contexts within which Theme Groups have evolved or operate. Expanded Theme Groups, rather than those limited to only cosponsors and UN system organizations, are now the rule rather than the exception.*

In the majority of countries, AIDS as a theme is addressed not only by the UN Theme Group. Other mechanisms for doing so include Technical Working Groups (TWGs), consultative policy advisory groups, and working groups on specific HIV/AIDS-related issues or areas such as advocacy, mother-to-child transmission, children and young people, and so on. In many instances the TWGs initially brought together the technical focal points of the UN system agencies to advise the UN TG on the system's programmatic support to the national response. But they have almost invariably expanded to include national and international partners and are often de facto the premier forums

* The term “Theme Group on HIV/AIDS” is often used interchangeably with the term “UN Theme Group.” The latter can refer to any group or groups convened by the UN system, specifically by a designated Chair from the UN system. Such a Theme Group may include a forum for Heads of Agencies or their representatives as well as one that is “expanded” to government and other national and international partners. As such, the UN Theme Group is the expression of UNAIDS in-country. It is a mechanism that is based on the Resident Coordinator system, with the UN Resident Coordinator being responsible for its effective functioning. Its primary function is to ensure a coordinated response by the UN system on HIV/AIDS programmes and policies.

for information exchange and, importantly, for collaborative or joint programming. In contrast, the forum of Heads of Agencies has shown itself to be particularly effective and valuable for policy and advocacy purposes.

Coordination of the national response remains the responsibility of the member state, and there should never be any intention to substitute for, or supplant, that ultimate responsibility. However, the strength of each country's National Programme on HIV/AIDS and its capacity to coordinate the response are critical in determining the way that given UN Theme Groups function. In countries with a strong national coordinating body on HIV/AIDS, there will often already exist an expanded forum for national and international partners, including the UN system. Where national coordinating capacity is weak or if the government so desires, the UN system can continue to play a key role in facilitating regular consultations among internal and external partners. In such cases, the UN Theme Group may assume the responsibility of convening an expanded Theme Group on HIV/AIDS.

Expanded Theme Group (Côte d'Ivoire)

Starting Year: 1995

Main Topic Area: Theme groups – UN system at country level

Other Topic Areas: National strategic planning • NGOs and networks

Contact Person:

Mamadou Diallo

Phone: +225 33 71 54

Fax: +225 33 74 04/ 21 13 67

Email: onusida@africaonline.co.ci

Address:

c/o UNDP Resident Representative

01 B.P. 1747, Abidjan 01

Côte d'Ivoire

Implementers

UNAIDS cosponsors working in Côte d'Ivoire made up the original members of the Theme Group, which has since been joined by many other organizations (see Background).

Funding

UNAIDS cosponsors working in Côte d'Ivoire contribute (see Main Activities) to a common fund administered by the UNDP office.

Objectives

UN Theme Groups on HIV/AIDS have four main functions:

- advocacy for a coordinated, adequately resourced multisectoral response observing high technical, ethical, and strategic standards
- coordination of efforts by cosponsors, other UN agencies, and bilateral and multilateral donors to support the national response
- technical collaboration to support the capacity of governments, communities, and other partners to manage their responses to HIV/AIDS
- policy-creation and promotion of research into new or improved measures against the epidemic.

Background

Côte d'Ivoire's Theme Group was created in December 1995 by the UNAIDS cosponsors, and quickly allied itself with the country's National Programme against AIDS, STDs, and Tuberculosis (PNLS/MST/TUB). Starting in 1997, groups from civil society began to take their place in the Theme Group, particularly NGOs working in the social, development, and health fields, and groups representing people living with or affected by HIV/AIDS.

In 1998, the Theme Group expanded in order to better reflect the expanded response being carried out in Côte d'Ivoire and to provide better coordination of human, material, and financial resources in that response. The new members of the expanded Theme Group included:

- other UN agencies represented in Abidjan, including the Food and Agriculture Organization, International Labour Office, United Nations Office for Project Services, and United Nations Industrial Development Organization
- bilateral and multilateral partners including the Canadian, Belgian, French, German, and US cooperation missions, and that of the European Union.

Responsibility for chairing the Theme Group revolves among the heads of the cosponsors and lasts six months. Meetings of the core group are held monthly, but may be convoked by the chair as needed. The expanded group meets every two months.

Ongoing financing for the Theme Group is provided by annual membership fees (set at US\$ 5,600 in 1998). This has permitted the hiring of an executive assistant for the Country Programme Adviser, purchase of equipment, and financing of certain partners' participation at international conferences.

Main Activities

The Theme Group is not an executive but a coordinating entity. Major areas of activity include:

1. Support for the National Programme against AIDS, STDs, and Tuberculosis

The executive director of Côte d'Ivoire's PNL/MST/TUB was an early member of the Theme Group, and its technical director attends the meetings of the Theme Group's Technical Working Group (TWG), which is chaired by the UNAIDS Country Programme Adviser. Among other initiatives, the Theme Group and the National Programme are working together on the country's Drug Access Initiative, aimed at improving the provision of HIV-related drugs to persons living with HIV/AIDS.

2. Support to and coordination with other partners

The expanded Theme Group provides a mechanism by which a formal relationship is maintained with important bilateral or multilateral actors in Côte d'Ivoire's AIDS response, and by which the Theme Group can be kept aware of their projects. Examples include:

- the microbicide research project of the Institute of Tropical Medicine, Antwerp, Belgium
- the French government's Solidarity Fund, along with various French-supported research projects, including those on the use of cotrimoxazole against opportunistic infections, use of AZT against mother-to-child transmission, and several social science projects
- USAID's involvement with Projet Retro-Ci's HIV testing and research work (see summary of PPP Project, Côte d'Ivoire).

3. Support to national strategic planning

The Theme Group provided expertise and support in the elaboration of the country's National Strategic Plan on HIV/AIDS, 2000–2004, and was

instrumental in accessing UNAIDS' Strategic Planning and Development Funds to help finalize the plan.

4. Creating a common approach between agencies

The Theme Group in Côte d'Ivoire benefits from the personal attendance of the UN agency heads at the monthly core group meetings. From time to time, the Theme Group sponsors retreats during which the agency chiefs (and sometimes other partners) can work more profoundly on specific issues or activities. This was the case with the country's National Strategic Plan in 1999 and with the country's participation in the International Partnership against AIDS in Africa.

Outcomes

The Côte d'Ivoire Theme Group has been successful in bringing about the following:

- cohesiveness among cosponsors, and effective participation among UN agencies with a part to play in the national response
- strong awareness of HIV/AIDS issues among agency heads
- a close and effective working relationship with the Theme Groups' major national partner, the PNL/MST/TUB, and its executive director
- integration of civil society in the workings of the Theme Group, with benefits to all partners.

In particular, the Theme Group has been able to formulate and adopt an Integrated Work Plan (19 April 2000). The Integrated Work Plan was the result of a strategic planning process financed by UNAIDS. The Technical Working Group (TWG) was chaired by the Country Programme Adviser and attended by the UN agency focal points and the technical director of the PNL/MST/TUB. The TWG met six times, using the PNL/MST/TUB's operational plan for 2000–2001 as a base for analysis in order to identify ways the Theme Group could support the plan, either jointly or according to the specific mandates of each agency. Joint activities were listed, budgets specified, and lead organizations formally designated.

As Côte d'Ivoire is currently directed by a transition government and the traditional international funders have frozen their activities, the plan concentrates on the following:

- vigorous advocacy at both the political (workshops on AIDS and development for political journalists) and institutional level (seminars for government staff and meetings with Ministers) in order to make the subject of AIDS a central issue in electoral campaigns and to set the stage for effective decentralization of action
- reinforcing the capacity of AIDS-related associations and NGOs through training, equipment, and help to coordinate their activities
- reinforcing the institutional capacity of PNL/MST/TUB, through training of personnel, decentralisation of coordination and financing, and creating a database as an important tool for improving administration of activities
- beginning to mobilize the private sector and civil society as a whole in order to make up for internal and external deficits in resources.

Among other features, the plan creates a framework for project proposals in order to help all members (especially those who are not UNAIDS cosponsors) to make proposals for AIDS projects in their sector. The plan specifies that joint evaluations must be done of all interventions, and spells out guidelines for this. These include carrying out midpoint and final evaluations with the participation of representatives from at least two agencies other than the initiator. It also requires that activity reports about each project be given to the Technical Working Group meetings, and that their conclusions be presented to the Theme Group.

Some problems or weaknesses remain to be solved. Lack of clarity in terms of reference have created confusion about membership in the Theme Group and the Technical Working Group; lack of common procedures for disbursement of funds by the various partners (cosponsors as well as civil society partners) has posed difficulties; mechanisms for follow-up or evaluation are as yet in their early stages and need to be strengthened considerably. Also, some member agencies have not entirely accepted or understood the coordinated way of working promoted by the Theme Group, and continue to carry out some activities without reference to the national response or agreed planning mechanisms.

Lessons Learned

The Côte d'Ivoire Theme Group provides a number of important lessons regarding the potential of the UN theme group mechanism in countries facing (as Côte d'Ivoire does) a mature epidemic.

One of the most important is that of establishing close links with the statutory national authorities responsible for AIDS, in this case the Ministry of Health and the National Programme against AIDS, STDs, and Tuberculosis. The links are not just formal but based on real participation at different levels. At the highest level, the executive director of the PNLS/MST/TUB has sat as a member of the Theme Group almost since its beginning. At the working level, PNLS/MST/TUB technical director participates as a member of the Theme Group's Technical Working Group, and is thus kept abreast of all research and intervention activities. The benefits go both ways, for the national authorities have been able to contribute their own considerable knowledge to the Theme Group, and to provide services such as transportation, working space, and logistic support for workshops.

A highly practical lesson can be learned from the Theme Group's financing arrangements, which, by levying membership fees, ensure its ongoing sustainability. This also provides an excellent indicator of the level of "ownership" and sense of commitment felt by the member agencies.

The problems the Theme Group has experienced with members' terms of reference and with the members' various disbursement procedures underline the importance of high administrative standards in all the workings of the Theme Group. Administrative arrangements don't just happen naturally; they need to be planned and implemented with care if the Theme Group is to achieve its full potential. Members must therefore be fully familiar with the *Guide pratique* (procedures guide) created by the group for exactly this purpose.

Other important lessons include:

- the motivation and personal participation of the agency chiefs are essential to the success of Theme Groups
- nomination of focal points must be formal, and must be followed by regular and active participation in the Technical Work Group
- involving the other UN agencies in addition to the cosponsors is a useful practice and one that increases the dynamism of the Theme Group
- funding of strategic planning and/or acceleration of programmes serves to increase the Theme Group's credibility.

World of work: employers and workers

With the rising prevalence of HIV/AIDS, employers are increasingly concerned about the impact of the disease on their organizations. At the same time, workers' representative organizations are deeply disturbed by the epidemic's impact on their members. These concerns are well founded. At the broadest level, businesses are dependent on the strength and vitality of the economies in which they operate. HIV/AIDS raises the costs of doing business, reduces productivity, and lowers overall demand for goods and services. It therefore makes sense to invest in prevention, care, and support programmes to stem declining business productivity and profitability.

The world of work faces enormous challenges in responding to AIDS. For the most part, business managers want to do the right thing for their employees, but when it comes to AIDS they often feel they don't know how, or are afraid it will be too expensive. Businesses may be reluctant to set up workplace HIV/AIDS programmes because they feel they lack the resources, do not have adequate in-house knowledge, or consider the matter too sensitive. They may also lack links with the wider community and thus miss out on ways in which community and other outside groups could help them in dealing with HIV/AIDS issues – and vice versa. Many companies setting up workplace programmes do so without clear policies on how to deal with HIV/AIDS. Even when companies do have policies, these are often unconnected to national HIV/AIDS policies, or else are limited in scope or short-term in nature. Educational programmes, for instance, often consist of single-session courses, with poor and unsustainable results.

Effective workplace programmes can be set up by a company at a fraction of the current, rising financial cost of AIDS to the business. Companies should not wait for the government or health sector to take action for them. In a growing number of countries, including Brazil, South Africa, Thailand, and the United States, companies have formed business coalitions to pool resources and help each other to respond better to the crises in their workplaces and communities.

Workplace HIV/AIDS programmes are most effective when their planning and monitoring processes involve representatives from a wide range of sectors. Thus, there should be included representatives from the workforce, from management, from the company's health clinic (if there is one), as well as a representative concerned with human rights issues and representatives from the wider community, including non-governmental organizations, especially if the company does not have an in-house clinic or support service.

While mandatory HIV testing is strongly discouraged, employers may choose to offer voluntary, informed, and confidential testing and counselling for employees and their partners as part of the employee education programme.

The recommended components of a workplace AIDS programme are:

- ◆ an equitable set of policies that are communicated to all staff and are properly implemented
- ◆ ongoing formal and informal education for all staff on HIV/AIDS
- ◆ availability of condoms
- ◆ diagnosis, treatment, and management of sexually transmitted diseases, for employees and their sex partners
- ◆ HIV/AIDS voluntary testing, counselling, care, and support services for employees and their families.

The effectiveness and sustainability of workplace HIV/AIDS programmes are enhanced if they are periodically monitored, re-evaluated, and updated. As well, workplace programmes should be constantly evolving. Knowledge of employee culture – and of such factors as the incidence of STDs, violence (including rape), and drug and alcohol use among employees and in their community – is essential for making programmes as relevant and effective as possible.

Commercial Farmers' Union AIDS Control Programme (Zimbabwe)

Starting Year: 1986

Main Topic Area: World of work: employers and workers

Other Topic Areas: Sexually transmitted diseases • Male condoms • Community mobilization • Agricultural/ Rural Development • Local responses to HIV/AIDS

Contact Person:

Kerry Kay

Project Manager

Phone: +263-4-309800

Fax: +263-4-309874

Email: kerrykay@cfu.co.zw

Web Site:

www.samara.co.zw/cfu/commodity/aids.html

Address:

Agriculture House

Marlborough Drive

Marlborough

Box WGT390, Westgate

Harare, Zimbabwe

Implementers

The Commercial Farmers' Union (CFU) is the coordinating body for Zimbabwe's commercial farming sector, which groups 73 farmers' associations within the 8 regions of the country.

Funding

Overall programme funding is currently provided by the Royal Netherlands Government. Earlier funding was provided by USAID through Family Health International and AIDSTECH. Other contributions in cash, kind, or technical support have been provided by the Family AIDS Caring Trust, the International Tobacco Growers Association/Zimbabwe Tobacco Association, National AIDS Coordination Programme, UNICEF, and the Zimbabwe National Planning Council.

Objectives

The main programme goal is to reduce the incidence of HIV/AIDS and STDs among commercial farmers, farm workers, and their families through the reduction of high-risk sexual behaviour. Specific objectives are to:

- increase the knowledge of HIV/AIDS among the target population
 - increase the target population's perception of the risk of acquiring HIV/AIDS
 - reduce the incidence of sexually transmitted diseases through early symptom recognition and promotion of early treatment-seeking behaviour
-

- ensure condom availability and accessibility and promote condom use
- enhance parent/teacher-to-child communication
- implement community and home-based care for the terminally ill
- train volunteers in bereavement, marriage, and youth counselling.

Background

Zimbabwe's agricultural sector contributes about 20 per cent of the country's gross domestic product. An estimated two million people (including children) live in full family situations on commercial farms where basic infrastructure (housing, water, and so on) are provided by the commercial farmers.

The CFU AIDS Control Programme began in 1986, following the earliest reporting of AIDS in the country, with a pilot project on the farm of the late Peter Fraser-Mackenzie in Mutorashanga. The project was extended to Mashonaland, where five farmers' wives volunteered to work as coordinators for what were then mostly condom distribution campaigns. In 1995 the CFU received funding from Family Health International and expanded activities to include communication interventions for behavioural change and extensive peer education. Since then, the programme has expanded beyond the commercial farming sector to communal, resettlement, and small-scale farming areas, to HIV/AIDS education in schools in connection with the Ministry of Education and UNICEF, and also to training rural police and people working in rural agri-business.

The project has a decentralized structure, with central administration comprising only a project manager and two deputy project managers and the CFU's chief accountant and book-keeper. The coordinators of the project are farmers' wives who volunteer to do HIV/AIDS activities. The coordinators have varying backgrounds, including nursing, police work, occupational therapy, and counselling. There are no formal qualifications except the commitment to volunteer time and energy to organize training courses, and to distribute HIV/AIDS literature and condoms using personal cars, farm lorries, and telephones and faxes.

Main Activities

The guiding strategy behind the programme is behaviour-change communication through peer education. The main activities under the responsibility of the coordinators (who themselves receive training and have formal meetings and follow-up) are:

1. Training of peer trainers

Trainers are selected from farming community members. Selection criteria included respect within the community and sufficient education to read and understand HIV/AIDS materials (including good ability to read and write English) and pass them on to their peers. Peer educators tend to be middle managers on farms, storekeepers, farm and rural school teachers, police, telephone operators, and so on. Training materials and curriculum are provided by the Family AIDS Counselling Trust (FACT) in Mutare, and courses cover all basic information on HIV/AIDS and STDs, counselling and communications skills, condom negotiation, reporting techniques, home-

based care, spiritual aspects, and so forth. Trainers are taught by CFU coordinators, experienced trainers, and invited experts.

Trainers conduct follow-up visits for peer educators and report to coordinators. All are volunteers who use their bicycles in their monitoring and supervisory role. Some of the bicycles were donated by USAID and the Dutch government, and some farmers associations.

2. Peer education

Individuals chosen to be peer educators are respected men and women selected by their coworkers, or people who volunteered. Already credible as knowledgeable individuals and role models, they receive training from the coordinators and trainers in groups of 15 comprising both men and women. Some of the training facilities, food, transportation, and firewood are contributed by the farmers. Peer education activities include: giving condom demonstrations, distributing information materials, performing educational dramas, conducting informal group discussions about HIV/AIDS, showing videos, providing individual counselling, teaching home-based care, and referring people to care facilities. An important activity is providing compassionate support to people living with HIV/AIDS. Most of the work is done during lunch breaks, after work, and over weekends. Follow-up and supervision of peer educators is carried out by coordinators and peer trainers at contact points including churches, farm compounds, streets, and drinking places. Peer educators are not paid, but receive certificates, badges, and occasionally T-shirts. A major motivation is provided in biannual follow-up/refresher courses, which include social activities, good food, and the chance to share experiences.

3. Home-based care and counselling

Trainers and peer educators provide these services whenever possible, and increasingly the commercial farmers take the responsibility of providing resources and food for sick farm workers.

4. Distribution of condoms

Condoms are provided free by the Zimbabwe National Family Planning Council (courtesy of the British government), and it is the responsibility of each farmer to ensure that condoms are available on their farms. To increase accessibility to condoms (and so that people don't have to request them directly from their employers), many outlets on farms have been established such as farm stores, garages, post offices, butchers, and meeting halls.

5. Advocacy

Though careful to position itself as complementary to the government's HIV/AIDS efforts, the CFU carries out advocacy to influence government policy or legislation related to health care, drug distribution, orphan support, and other HIV-AIDS related issues. As well, the CFU maintains strong

networks with other NGOs and AIDS service organizations, and attends both national and international workshops, meetings, and conferences when relevant to its activities and objectives.

Outcomes

The project's 30 coordinators and 135 trainers have trained and supervised approximately 10,000 peer educators. Activities have been extended to 3,500 farms in most parts of the country. The programme distributes approximately 1.5 million condoms per quarter.

The programme has produced an educational video called *Jamie*, the testimonial of a farmer's son succumbing to AIDS. Two others are in production, in English (*Listening and Learning from Youth*) and Shona.

Evaluation Findings

A KABP (knowledge, attitudes, behaviours, practices) study was carried out in 1997, and an end-of-funding evaluation in 1998. The evaluations both showed high HIV/AIDS knowledge of between 80 and 84 per cent for adults and youth. Almost all respondents had heard about HIV/AIDS. Condom distribution was good on most farms, though on some the farmer was not always able to ensure a constant supply. Focus group discussions found that condom use by women was much lower than that of men, owing to the stigma of promiscuousness that attached itself to women who provide condoms. Despite the behaviour change activities of the programme, the practice of non-regular sex partners was still a problem for both male and female farm workers. Reasons included the context of seasonal inflow of workers, a harsh economic climate and high unemployment rate (highly conducive to women providing "survival sex"), and certain social factors connected to ethnicity and religion.

A lack of baseline data hampers more in-depth evaluation of programme impact on behaviour or disease incidence.

Lessons Learned

The organization of a programme by commercial farmers has proved an effective access point for HIV/AIDS interventions for the two million people living and working in the sector. In particular, the programme benefits strongly from the sector's existing infrastructure (communications, transportation, organization, and so forth). The CFU notes that its success has brought an unfortunate by-product: other organizations and individuals attempting to implement their own AIDS-related activities on commercial farms, while ignoring to a large extent the desperate needs of the even greater rural population.

Other lessons learned include:

- The decentralization of the programme appears to have contributed to its ability to cover so many of the commercial farms in the country. Administrative costs are kept low by maintaining the smallest central organization possible, and "borrowing" the CFU's own accounting and other services.

Zimbabwe

- The fact that the programme is based on voluntarism has proved a benefit in that instability of funding does not affect the work carried out on the "front lines." At the same time, coordinators are mindful of the dangers of burn-out, and the importance meetings, training follow-up, and social events for volunteer motivation.
- Better methods must be found to increase women's empowerment and self-esteem, since the traditional norm of men making most sexual decisions (particularly whether or not to use a condom) remains pervasive.
- The openness encouraged by the programme's design for group discussions and information distribution appears to have had spinoff benefits both within and outside the target population. These are noted in the greater cohesiveness of different groups of people within farming communities, increasing numbers of volunteers for the programme from communal farming areas (i.e., external to the commercial farms), and greater grassroots political awareness.

Further Reading

See web pages at www.samara.co.zw/cfu/commodity/aids.html.

Annex 1: Making a proposal for the Summary Booklet

UNAIDS welcomes proposals for inclusion in the Summary Booklet of Best Practices. Sample forms are shown on the following pages. These should be sent to the UNAIDS Country Programme Adviser or UN Theme Group in the country concerned (see Annex 2), or to the UNAIDS Secretariat in Geneva:

UNAIDS Best Practice Coordinator
Department of Policy, Strategy and Research
20 Avenue Appia
1211 Geneva
Switzerland.

Electronic documents can be e-mailed to summaryreply@unaids.org

Best Practice Submission Form (page 1 of 3)

Please mark the topic areas that the proposed practice fits into:

<input type="checkbox"/> Access to care and support	<input type="checkbox"/> Access to drugs
<input type="checkbox"/> Agricultural/Rural development	<input type="checkbox"/> AIDS in crisis situation
<input type="checkbox"/> Antiretroviral therapy	<input type="checkbox"/> Blood safety
<input type="checkbox"/> Children	<input type="checkbox"/> Communications programming
<input type="checkbox"/> Community mobilization	<input type="checkbox"/> Cost-effectiveness analysis
<input type="checkbox"/> Counselling and voluntary counselling and testing	<input type="checkbox"/> Determinants of the epidemic
<input type="checkbox"/> Education (outside school-settings)	<input type="checkbox"/> Estimates and projections (epidemiology)
<input type="checkbox"/> Female condoms	<input type="checkbox"/> Gender and HIV/AIDS
<input type="checkbox"/> Greater involvement of people living with or affected by HIV/AIDS	<input type="checkbox"/> Health system personnel and training
<input type="checkbox"/> Home care	<input type="checkbox"/> HIV diagnostic tests
<input type="checkbox"/> HIV testing	<input type="checkbox"/> Human rights, ethics, and law
<input type="checkbox"/> Impact on agriculture and rural households	<input type="checkbox"/> Impact on countries' development and economies
<input type="checkbox"/> Impact on children and families	<input type="checkbox"/> Indigenous peoples
<input type="checkbox"/> Injecting drug use	<input type="checkbox"/> Local response: urban and rural communities
<input type="checkbox"/> Male condoms	<input type="checkbox"/> Men who have sex with men
<input type="checkbox"/> Microbicides	<input type="checkbox"/> Mobile populations: displaced people, migrants, refugees, mobile workers
<input type="checkbox"/> Mother-to-child transmission	<input type="checkbox"/> National strategic planning and management
<input type="checkbox"/> NGOs and networks	<input type="checkbox"/> Older people
<input type="checkbox"/> Opportunistic infections	<input type="checkbox"/> Paediatric AIDS
<input type="checkbox"/> Palliative care	<input type="checkbox"/> Prisons
<input type="checkbox"/> Religion	<input type="checkbox"/> Reproductive health

<input type="checkbox"/> Resource mobilization	<input type="checkbox"/> Sectoral impact (development)
<input type="checkbox"/> Schools	<input type="checkbox"/> Sex workers and clients
<input type="checkbox"/> Sexually transmitted diseases	<input type="checkbox"/> Surveillance and reporting (epidemiology)
<input type="checkbox"/> Theme Groups – UN system action at country level	<input type="checkbox"/> Tuberculosis and HIV/AIDS
<input type="checkbox"/> Uniformed services	<input type="checkbox"/> Vaccines
<input type="checkbox"/> Virology, immunology, and laboratory practices	<input type="checkbox"/> World of work
<input type="checkbox"/> Young people	<input type="checkbox"/>

Best Practice Submission Form (Page 3 of 3)

Name	<i>Name of project, policy, law, or strategy</i>
Country	<i>Country where the practice is or was carried out</i>
Topic area	<i>Which of the 50 topic areas on the previous page apply to this practice? (Include up to 4.)</i>
Year	<i>When did it start, finish, or plan to finish?</i>
Contact person	<i>Name Title</i>
Contact information	<i>Mailing address Phone, fax, e-mail, website, etc.</i>
Implementers	<i>Who carried it out? If it was a partnership, who were the partners? Were people living with HIV/AIDS or their representative groups involved?</i>
Funding	<i>Who provided the funding and other resources?</i>
Objectives	<i>What was supposed to change or be accomplished as a result of the practice?</i>
Background	<i>What historical, medical, social, or other background can help readers understand the need for the practice, or the context in which it was carried out?</i>
Main activities	<i>What are the main things the practice does to accomplish its objectives? How is the work organized, and who does what? Is there an order in which activities are carried out?</i>
Outcomes	<i>What were the practical outcomes, including the measurable results or outputs of the practice? For example, numbers of condoms distributed, numbers of people trained, etc.</i>
Evaluation	<i>Was an evaluation done? If so, describe methodology used and results.</i>
Lessons learned	<i>What are the most important lessons that a reader should take from this practice? What are the keys to its success? What problems or obstacles were encountered, and how were they – or could they be – overcome?</i>

Please attach extra pages if you wish to give more information. Include with your submission any documents that will help us to understand the practice (e.g., evaluation reports, project documentation, academic articles, or newspaper clippings).

Annex 2: Theme Groups and Country Programme Advisers in sub-Saharan Africa

Please submit your proposed Best Practice to the UN Theme Group on HIV/AIDS or the UNAIDS Country Programme Adviser in your country (you may at the same time wish to send a copy to the Best Practice Coordinator at the UNAIDS Secretariat in Geneva).

Angola
Rui Gama Vaz President, Groupe
Thematique des Nations Unies sur le
VIH/SIDA
C.P 3243 Luanda
Tel: (244) 2 33 42 38 (A.M. only)
Tel: (244) 2 39 04 85 (P.M.. only)
Fax: (244) 2 33 23 14
E-mail: sida@ebonet.net

Congo (Democratic Republic of)
Charles Misangu
National Programme Adviser
UNAIDS
c/o UNDP
B.P. 7248
KIN 1 Kinshasa
Tel: (243) 880 0840
Fax: (243) 88

Botswana
Rosalind Saint-Victor
UNAIDS Country Programme Adviser
c/o UNDP
Barclays House, 2nd floor, P.O. Box 54
Khama Crescent, Gaborone
Botswana
Tel: 267 352 121
Fax: 267 353 093
E-mail: rosalind.saint@undp.org

Côte d'Ivoire
Mamoudou Diallo
Country Programme Adviser
UNAIDS
c/o UNDP
01 B.P. 1747
Abidjan 01
Tel direct: (225) 20 32 51 51
Tel: (225) 20 33 71 52 - 54
Fax: (225) 20 33 71 53 / 21 13 67
E-mail: onusida@africaonline.co.ci

Burkina Faso
(Mali and Niger)
Kourouma, Kékoura
InterCountry Programme Adviser
c/o UNDP
01 BP 575
Ouagadougou 01
Tel: (226) 30 67 62/64
Fax: (226) 31 04 70 / 31 05 81
E-mail: kekoura.kourouma@undp.org

Eritrea
Rachel Odede
UNAIDS Focal Point
UNICEF
P.O. Box 2004
Andenet Street, No 5
Asmara
Tel: (291) 1 15 11 16
Fax: (291) 1 15 13 50
E-mail: rodede@unicef.org

Cameroun
Emmanuel Gnaoré
UNAIDS Country Programme Adviser
c/o PNUD
Rue Giscard d'Estaing B.P. 836, Yaounde
Cameroun
Tel: (237) 22 57 63 / 22 99 30
Mobile: (237) 22 99 90/ 22 31 82
Fax: (237) 22 63 89 / 23 16 53
E-mail: e.menze-monie@unesco.org

Ethiopia
Claire Mulanga Kabeya
Economic Commission for Africa
P.O. Box 3001
Addis Ababa
Tel: (251) 1 51 65 13
Fax: (251) 1 51 37 98
E-mail: cmulanga@hotmail.com

Ghana
Cynthia Eledu
Country Programme Adviser
UNAIDS
c/o UNDP
P.O. Box M. 1423 Accra
Tel/Fax: (233) 21 23 82 56
E-mail: eledu@ighmail.com

Kenya
Warren Naamara
Country Programme Adviser
UNAIDS
c/o UNDP
Room 119 Block Q, UN Gigiri Complex
Nairobi
Tel direct: (254) 2 62 43 89
Tel Secretariat: (254) 2 42 43 91
Fax: (254) 2 62 43 90
E-mail: warren.naamara@undpken.org

Madagascar (Comoros, Mauritius,
Seychelles)
UNAIDS Office
c/o OMS
B.P. 362
Antananarivo 101
Tel: (261) 2022 64669
Fax: (261) 2022 64677 / 29913
E-mail: onusida@bow.dts.mg

Malawi
Angela Trenton-Mbonde
Country Programme Adviser
c/o UNDP Resident Representative
P.O. Box 30135
Lilongwe 3
Tel: (265) 78 26 03
Fax: (265) 783 992
E-mail: atrenton-unaidsmz@malawi.net

Mali (see Burkina Faso)

Mozambique
Maria Tallarico
Country Programme Adviser
UNAIDS
P.O. Box 4595
Av des Presidentes 33
Maputo
Tel: (258) 1 49 23 45 / 49 17 75
Fax: (258) 1 49 23 45
E-mail: unaidsmz@virconn.com

Namibia
Mulunesh Tennagashaw
Country Programme Adviser
c/o UNDP
Private Bag 13329
Windhoek

Tel: (264) 61204 6219
Fax: (264) 61 204 6203
E-mail: muluresh.terragashaw@undp.org

Niger (see Burkina Faso)

Nigeria
Brigitte Imperial
Country Programme Adviser, a.i.
UNAIDS
c/o UNDP
P.O. Box 2075
11 Oyinkan Abayomi Drive
Ikoyo, Lagos
Tel: (234) 9 413 4226
Fax: (234) 9 413 5673
E-mail: bimperial@uncef.org

Rwanda
Ivan Hermans
Country Programme Adviser
UNAIDS
c/o UNDP
P.O. Box 445
Avenue de l'Armée
Kigali
Tel: (250) 510 623
Fax: (250) 76 263
E-mail: ivan.hermans@un.rw

Sudan
Abdalla Ismail Mohamed
Country Programme Adviser
UNAIDS
c/o UNDP
UN Compound, Juba
P.O. Box 913
Khartoum
Tel: (249) 11 77 31 21/23/25/28
Fax: (249) 11 78 37 64
E-mail: abdalla.ismail@unpd.org

Swaziland
Bernadette Olow-Freers
Country Programme Adviser
UNAIDS
c/o WHO
P.O. Box 903 Mbabane
Swaziland
Tel: (268) 404 8559 (268) 404 2928
Fax: (268) 404 9931
E-mail: bolowo-freers@realnet.co.sz

Tanzania
Evaristo Marowa
Country Programme Adviser, a.i.
UNAIDS
c/o WHO
Luthuli Road
P.O. Box 9292

Dar-es-Salaam
Tel: (255) 51 13 03 50
Fax: (255) 51 13 96 54
E-mail: tnazania-unaid@twiga.com

Togo
Yamina Chakkar
Intercountry Programme Adviser
c/o WHO
B.P. 1504
Lome
Togo
Tel: (228) 22 46 52 / 21 33 60 / 21 41 58
Fax: (228) 21 78 32
E-mail: ychakkar@rdd.tg

Uganda
Jantine Jarobi
Country Programme Adviser
UNAIDS
c/o WHO
P.O. Box 24578
Kampala
Tel: (256) 41 34 01 12/4/5
Fax: (256) 41 34 01 13
E-mail: jarobi@infocom.co.ug

Zambia
Kenneth Ofosu-Barko
Country Programme Adviser
UNAIDS
c/o 4th UN Building
P.O. Box 31966
Alick Nkhata Road
10101 Lusaka
Tel: (260) 1 255 364
Fax: (260) 1 25 1214
E-mail: kofosu-barko@unicef.zm

Zimbabwe
George Tembo
Country Programme Adviser
UNAIDS Office
c/o UNDP
P.O. Box 4775
Harare
Tel: (263) 4 79 26 81
Fax direct: (263) 4 250 691
E-mail: gtembo@id.co.zw

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Joint United Nations Programme on HIV/AIDS (UNAIDS)
UNAIDS - 20 avenue Appia - 1211 Geneva 27 - Switzerland
Telephone: (+41 22) 791 46 51 - Fax: (+41 22) 791 41 87
E-mail: unaids@unaids.org - Internet: <http://www.unaids.org>