United Nations
Economic Commission for Africa

African Development Forum 2000

AIDS: the Greatest Leadership Challenge

3- 7 December 2000
Addis Ababa, Ethiopia

Theme Paper

Lessons Africa has learnt in 15 years of responding to HIV/AIDS

ADF-2000 Theme II

Lessons Africa has learnt in 15 years of responding to HIV/AIDS

Working paper

Table of Contents

Executive summary

HIV, the virus that causes AIDS, started spreading in various corners of the globe just over two decades ago. Today, Africa is by far the most severely-affected continent. Africa is home to 70% of the adults and 80% of the children living with HIV in the world, most of whom still have inadequate access to even basic health care. Millions more are still falling prey to the virus every year. Africa has buried three-quarters of the more than 20 million people worldwide who have died of AIDS since the epidemic began. As children lose their parents and teachers, and hospitals, farms and factories their workers, the epidemic has become a full-blown development crisis.

Paradoxically, though, Africa already possesses most of the "tools" – if not all the resources – needed to change the course of the epidemic. As this paper illustrates, communities and countries across the continent have pioneered, developed and tested many successful responses to HIV and AIDS. There is an impressive range of best practice in Africa, proof that the continent is not powerless against the epidemic.

The goal of this paper is to draw out the precious lessons learnt and share them with Africa's leadership at all levels of society. The main lessons have been summarised under just seven headings, as shown below, and each has been illustrated with examples of best practice from countries across Africa.

Readers will note that this report cites a great deal of best practice implemented outside the health sector. There is a good reason for this. AIDS is an epidemic with special features that call for a special response. With no vaccine available against HIV, prevention hinges on informing people, motivating them and empowering them to protect themselves, their partners and their newborn infants. Likewise, though the health sector is the mainstay of health care for those infected, it can do little to alleviate the poverty that afflicts many AIDS-affected households, ease the plight of orphaned children, or safeguard a country's development achievements.

Instead, the response to HIV/AIDS demands strong and creative leadership from all sectors and parts of society as much as increased community ownership of the problem and of its solution. Having analysed the impact of the epidemic, ministries of planning and finance must help ensure financing of crucial interventions for prevention and care –the two reinforce each other -- and devise ways to alleviate the epidemic's toll on households, agriculture, mining and other sectors. Respected community leaders need to encourage people to take the invisible HIV threat seriously and, where necessary, change local attitudes and traditions that make people unnecessarily vulnerable to HIV or to the impact of AIDS. Schools have a responsibility to inform children about HIV before they become sexually active and risk exposure, and teach them the skills they need to navigate safely through life. Religious leaders need to combat the blame and rejection associated with AIDS and encourage a "social contract" between the affected and the as-yet-unaffected. In places where the AIDS stigma is diminished, individuals living with HIV will feel freer to give the epidemic a human face and make their full contribution to combating it.

The "social contract"

With over 24.5 million Africans already infected with HIV, it is important to avoid social division – an "us" versus "them" mentality – and instead encourage a social contract promoting mutual tolerance and shared rights and responsibilities among all persons: those who know they have HIV, those who have tested negative, and the vast majority who do not know their infection status. By "signing on" to such a contract, people can become joint stakeholders in a society of solidarity and sexual precaution that fortifies them against HIV and unnecessary suffering from AIDS.

Examples of best practice:

- In Botswana, President Festus Mogae provides an example of a national leader who has understood and accepted the challenge of building a national response that covers all sides of the social contract.
- In Malawi, South Africa and Zambia, a United Nations Volunteer programme shows how persons living with HIV/AIDS can contribute to national HIV/AIDS responses.
- In Burundi, the National Association for Support of Persons living with HIV/AIDS runs a centre staffed by infected and affected persons which offers prevention activities, voluntary counselling and testing, medical and psycho-social support.
- In Zimbabwe, Chirumhanzu Home-Based Care Project provides prevention and home care activities in a poor rural area, fortifying health system resources with those of families, communities and persons living with HIV/AIDS.
- In South Africa, the Bambisanani programme combines the efforts of government, NGOs and the private sector to provide services to the social, economic and health needs of the infected, affected and vulnerable populations.

Getting the AIDS message out to broad populations – and following up with action

In the absence of a vaccine or cure, preventing unsafe sexual behaviour is still the most cost-effective way of saving lives. In places where denial and ignorance flourish, citizens have little defence against the silent spread of HIV. However, even in countries where the level of basic knowledge is very high among certain populations, significant behavioural change does not always follow. Merely getting the HIV/AIDS message out is not enough: action aimed at reducing stigma, teaching skills and helping people to change behaviour is crucial.

Examples of best practice:

- In Senegal, Muslim and Christian leaders have become advocates for HIV/AIDS prevention and care.
- In Ghana, social marketing of the female condom has gone from pilot project to national programme.
- In Tanzania, traditional healers help dispel incorrect information about AIDS, reach people distrustful of medical systems, and distribute condoms.

Mutual reinforcement of AIDS care and prevention

Care and prevention programmes can be described as the " social contract" in action. Over and above their direct benefits to those infected and AIDS-affected families, these programmes have important spin-offs for the rest of the community. They make the epidemic more visible and hence help uninfected people to take the HIV threat more seriously as well as strengthen efforts in HIV prevention among those infected, affected and the ret of the population.

Examples of best practice:

- Uganda's AIDS Information Centre provides same-day confidential counselling and HIV testing. Counselling and testing helps empower people to access care, if infected, and take steps to protect themselves and/or their partners from infection.
- In Côte d'Ivoire, the Centre for Socio-Medical Assistance (Centre d'Assistance socio-médicale), working in a poor urban setting, has used its prevention awareness work to build support for its clinical and home care activities.
- In Zimbabwe, the Commercial Farmers Union combines peer education and condom distribution with home care for rural populations.
- In Uganda, creative social marketing of a treatment kit for common sexually transmitted infections (STIs) in males simultaneously provides an entry-point for HIV/STI prevention.
- In Uganda, trials of antiretroviral nevirapine have excellent potential for scaling up due to low drug cost and low complexity of treatment.

Something for all, and special measures for those at greater risk

Unprotected sex continues to fuel the HIV epidemic. Therefore, broad prevention campaigns aimed at the general public are still necessary. At the same time, it makes strategic sense to focus strongly on populations at greater risk and geographic areas where rapid HIV spread has become an emergency.

Examples of best practice:

- In Senegal, AIDS education and condom use programming has successfully reduced transmission of HIV among sex workers and their clients.
- In Cote d'Ivoire the Programme for STI/AIDS Care and Prevention among Female Sex Workers and their Partners have drawn the participation of 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.

Making people less vulnerable to HIV infection

An individual or a community's vulnerability to HIV is a measure of their ability to control the risk of infection. Personal factors, factors affecting access to relevant information and services, and societal factors may either mitigate or exacerbate vulnerability. For example, a person who is discriminated against with respect to education or employment on the basis of race, gender, sexual orientation or other characteristics is also more vulnerable to HIV infection. Similarly, a young person who can not access condoms is more vulnerable to HIV than other young people.

In many settings, women – and in particular young women – are especially vulnerable to HIV infection. They may be less able than men to avoid non-consensual or coercive sexual relations.

Rural communities may be vulnerable because of lower levels of literacy and less access to information and services.

Examples of best practice:

- In Kenya, Mathare Youth Sports Association brings life skills and awareness of the HIV risk and prevention to young people before they become sexually active.

- In Ethiopia, the Save Your Generation Association (SYGA) was implemented by a group of young men who wanted to do something about the rising impact of AIDS on young, out-of-school Ethiopians.
- In Tanzania, careful planning for HIV prevention activities among migrant and local labour was carried out before construction began at the hydroelectric project at Kihansi Falls. Programming covered both the estimated 2,000 migrant workers and the 40,000 people already living near the dam site.
- The Society for Women and AIDS in Africa (SWAA) was formed in 1988 to provide a platform for women to address HIV/AIDS and the socio-economic conditions which make them vulnerable to the epidemic. Today it has 28 country branches doing advocacy, prevention and many other activities.
- Tanzania's Female Guardians at Schools programme protects primary school girls against sexual harassment and exploitation, and assists them in dealing with social and reproductive health problems.

Reducing HIV/AIDS impact on people

What should be done when AIDS strikes an individual, family or community? Practices range from palliating painful symptoms of AIDS to outlawing discrimination based on HIV status and improving HIV-affected families' ability to generate income.

Examples of best practice:

- In Uganda, Mildmay Clinic provides specialized palliative care to people living with HIV/AIDS, reducing their suffering and pain, and to die without physical discomfort.
- In Zimbabwe, the Zambezi Valley Organic Cotton Project helps many AIDS-affected agricultural smallholder families (particularly those headed by widows) by equipping them to grow a cash crop while reducing their need for expensive inputs and labour.
- In the capital city of Kenya, the Kariobangi Community-Based Home Care Programme provides a good example of how to serve the children "left behind" by the AIDS epidemic.

Implementing Expanded Reponses

So far the Best Practices we have discussed have dealt with the implementation of specific programmatic and technical approaches to tackling the epidemic. However, ultimately a single comprehensive framework for planning and programming is needed by joining together the building blocks we have discussed.

Experience with such a framework is building up in Africa, and two additional building blocks would include strategic planning on a national level, and support to local responses in the field.

The development of a national strategic plan begins with an analysis of the situation and the response to HIV/AIDS, including risk behaviour and vulnerability factors, and using the resulting data to set priorities and focus initial action. Consensus is required from a wide range of actors including government, civil society, people living with and affected by HIV/AIDS, private sector and supported by the UN Theme Group and donors.

National strategic plans have been completed in 30 countries to date and are close to completion in another 14.

Examples of best practice:

- The process of creating Malawi's National HIV/AIDS Strategic Framework 2000-2004 shows how a broad-based national consensus can be built around a strategic planning process. It informed a wide range of groups and institutions about AIDS as an issue, built a sense of ownership among these groups and institutions and gave political leaders a high-profile document to commit to, with clear goals and principles.
- In Cote d'Ivoire, which is currently experiencing serious political instability, the interaction of Cote d'Ivoire's UN Theme Group on HIV/AIDS and national AIDS officials provides important lessons for coping with such instability and moving the response ahead.
- In Malawi, clear national policy guidelines have shaped the evolution of planning and programming for the country's growing number of orphans. The guidelines are simple and brief, and over the years have provided planning guidance for groups interested in developing orphan care programmes.
- The development of Uganda's 2000-2005 National Strategic Framework for HIV/AIDS Activities illustrates the decisive role that must sometimes be played by national political leadership. President Museveni took personal charge of Uganda's HIV/AIDS planning process after it had lost momentum, and forced it back on track.

Support to local responses to HIV/AIDS is based on the empowerment of communities through the development of local partnerships consisting of social groups, service providers and facilitators. United in these local partnerships, people are gradually building socially acceptable actions that enable them to respond adequately to the epidemic.

Such support can only be based on decentralisation of the overall management of national responses.

The District Response Initiative is now underway in about 15 countries, which represents 50% of countries with national strategic plans.

Examples of best practice:

- In Gaoua: In Burkina Faso the struggle against AIDS involves existing organisations and different administrative sectors. These partners, with the support of Gaoua authorities, have designed a common plan, agreed on shared objectives, and mobilised their own resources.
- In Tanzania, the Kyela District Council has passed a ground-breaking by-law; aimed at addressing local behaviours that increase vulnerability to HIV/AIDS.

Introduction

There are now 16 countries in sub-Saharan Africa where over one-tenth of the population aged 15-49 years of age is estimated to be infected with HIV, the virus that causes AIDS. Since the epidemic began in mid - to late 1970s, over 18 million lives have been claimed worldwide by AIDS. Of these, 15 million have been in Africa. Over 24.5 million Africans (including 1.4 million children) are estimated to be living with HIV and around 4 million Africans are acquiring HIV every year.

For most Africans, however, access to even basic care and prevention services is far from adequate. Nor has the general population been mobilised, through awareness and education campaigns about the epidemic, to "own the issue" and therefore act on it. This is especially tragic given that Africa has – as shown by the variety of best practice in HIV/AIDS responses found in most countries of the continent – most of the tools (if not all the resources) needed to turn the epidemic around.

It was for just this reason – the mounting crisis and the paradoxical existence of the means to solve the crisis – that the International Partnership against AIDS in Africa (IPAA) was created. Its purpose is to help governments, civil society, communities, and national and international organisations, work together more effectively. Only through such concerted action can the inherent strengths of African societies be fully mobilised to curtail the spread of HIV, sharply reduce the human suffering it produces, and reverse its rising human, social, and economic impacts.

A development disaster

AIDS is now deadlier than war itself: in 1998, 200,000 Africans died in war but more than 2 million died of AIDS. In fact, the epidemic has become a full-blown development crisis. Its social and economic consequences are felt widely not only in health but in education, industry, agriculture, transport, human resources and the economy in general.

Because of the insidious ways it destabilises already fragile and complex geopolitical systems, AIDS has become a key issue for human security in sub-Saharan Africa. Recognising this, the United Nations Security Council meeting on 10 January 2000 was devoted to the theme "AIDS in Africa" – the first time that Body had dealt with a development issue.

Yet, the worst impacts of the epidemic on the people and entire economies are still to come. If current trends are maintained, 70% of people currently HIV-positive in sub-Saharan Africa will die of AIDS in the next 10 years.

An international partnership

The International Partnership against AIDS in Africa was created in 1999 in recognition of the fact that national AIDS activities in Africa must be expanded dramatically to make an impact on the epidemic, reduce the human suffering it causes, and halt the reversal of human, social and economic development on the continent.

The Partnership 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 multi-sectoral 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
- mobilise and support communities, non governmental organisations, the private sector and individuals to counteract the negative impact of the HIV/AIDS epidemic in Africa.

Spotlighting success stories

The Best Practice process is crucial in the framework of the Partnership. Best practices include success stories and lessons learned on how and why things work in different situations and contexts. There are indeed many places where effective responses to the virus have been mounted. On a national scale, the biggest success stories to date are those of Senegal and Uganda, but valuable lessons have been learnt in almost all countries in sub-Saharan Africa.

Obviously, not all best practices can be applied the same way – or at all – from one country to another. Not only does the stage of the epidemic vary from country to country, but each country has to work within the context of its own administrative structure, institutional capacity, and cultural traditions. Best practices are to be learned from and adapted to specific context rather than copied.

In the following chapters, a variety of best practices are presented. They have been divided into groups that exemplify the following sub-themes:

1. The "social contract"
2. Getting the AIDS message out more effectively, and following up with action
3. Mutual reinforcement of AIDS care and prevention
4. Something for all, and special measures for those at greater risk
5. Making people less vulnerable to HIV infection
6. Reducing HIV/AIDS impact on people

Identifying leadership at all levels

The key priority for the IPAA is to be effective at country level, and to enhance the national response within nationally negotiated partnership plans. While governments will naturally be expected to take a lead role in the overall national response, it is clear that the various institutions and groups that make up civil society within a country (non governmental organisations (NGOs) and community-based organisations (CBOs), religious groups and the private sector) will all have to demonstrate leadership as well.

In order to best serve the intended readership of this paper, the technical aspects of the practices described here have been kept brief, and the leadership component has been highlighted. Readers who would like more detailed information will find references for most of the material cited. The majority of the best practices can be found described at greater length on the UNAIDS web site (http://www.unaids.org).

At the beginning of each chapter, a box shows how the chapter's sub-theme relates to a list of cross-cutting themes developed by the ADF 2000 Technical Advisory Committee to help guide discussions at the Forum.

The accompanying paper "ADF Theme III" moves the focus from the past and present to the present and future.

The social contract

Cross-cutting themes

- importance of top government leadership
- establishing PLHA groups and GIPA
- mobilizing national and international resources
- training and use of local managerial/technical talent
- mobilising local communities

With over 24.5 million people in Africa infected with HIV (most of whom do not know they are infected) and tens of millions affected by the epidemic's impacts, Africans at all levels of society - both those who are HIV-positive and those who have escaped infection thus far - are together in the same storm-tossed boat. Keeping the boat afloat and sailing forward will require everyone doing their part in an atmosphere of social tolerance and solidarity.

The epidemic affects everyone's quality of life in one way or another. But stigma – the shame and blame associated with AIDS - adds an extra layer of suffering to the already difficult lives of those infected with the virus, and the lives of those close to them. Another of its pernicious results is that it hinders HIV-infected individuals from participating in the processes of finding solutions to combat the AIDS epidemic.

If society as a whole does not provide care for those who become infected with HIV, what do people have to gain by testing for their sero status? If people know they are HIV-positive but face rejection if they tell anyone, why should they take measures (such as insisting on condom use) to avoid infecting others when such measures would mark them as possibly infected? If stigma brings active discrimination, endangering positive persons' jobs or access to medical systems, why should they participate publicly in broad prevention efforts – a role in which their voices have proven extraordinarily effective?

This is not to deny that people living with HIV/AIDS have already contributed greatly at all levels of the response. However, their involvement has often been at great personal cost due to stigma, discrimination and what has been termed a "culture of silence" which prevents AIDS being talked about openly and honestly.

Further progress against the epidemic requires a "social contract" that discourages stigma, encourages people to find out if they have HIV, and promotes understanding, solidarity, and sexual prudence among all persons (both infected and not). Only by "signing on" to such a contract can whole populations become joint stakeholders in a society of tolerance and sexual precaution.

A broad range of signatories

Of all the signatories to such a contract, governments have a special responsibility to be willing and active participants. Time and again, experience has shown that effective national responses require political commitment from a country's highest political level. Such commitment leads to high-profile advocacy and helps bring in all the sectors and players, along with the necessary human and financial resources. It is also critical for making hard political choices often involved in adopting intervention methods that really work – such as making sex work safer or bargaining at a national level for better access to care.

Most governments are buying into the HIV/AIDS social contract, increasing their commitment to fight the epidemic, and putting it high on national agendas. The continuous rise of the HIV infection rate in Africa to date and the devastatingly visible impacts of AIDS make an inadequate response untenable today.

Governments cannot be expected to do it all

The social contract is not just top-down, however. The national political structures of a country are not its only sources of social binding and decision-making.

Other levels of government – state or province, district, municipal, village-level – all have roles to play. And those who hold political or administrative posts can act not only in their official capacity but as influential individuals.

Leadership can be exercised in all sectors of society. Religious leaders can speak out to remind the fearful and bigoted that persons living with HIV/AIDS are also God's children, and that all great religions require their adherents to help those who are ill. Businesses can make their hiring practices more inclusive and their working arrangements more friendly and expensive to persons living with HIV/AIDS and their families. And a whole range of NGOs and CBOs and their international partners can continue to help with service delivery, advocacy, and resource mobilization.

GIPA: Solidarity in action

The greater involvement of people living with or affected by HIV/AIDS and representative organisations (known by its acronym, GIPA), is a key feature of the social contract. It also provides a prime example of how the social contract can be made to work if all signatories accept the principle and act to implement it.[1]

The goal of GIPA is to increase the effectiveness of AIDS policy and programming by including those living with the virus - with or without being infected - at all decision-making levels.

This of course brings up a major issue in the African context: few people actually know their HIV status. This is partly because of the lack of voluntary and confidential counselling and testing services generally, and because stigma and ignorance prevent people from getting tested.

[1] See UNAIDS report on the Consultation on the Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA), held in Nairobi, Kenya 28th of February - 1st of March 2000.

Examples of Best Practice

Botswana: Commitment and follow-up from the highest political level

Leadership issues summary

Leadership level: highest national political leadership

Contribution to success: clear, consistent attention to the overall issue; understanding of the necessity of multisectoral response; willingness to invest significant resources; understanding of the care needs of persons living with HIV/AIDS

Botswana's Head of State, President Festus Mogae, provides a strong recent example of a national leader who has understood and accepted the challenge of building a national response to the epidemic that avoids an "us/them" mentality and emphasizes the social contract.

In his capacity as chair of the newly created National AIDS Council (which meets regularly to oversee the national response), President Mogae discusses HIV/AIDS as a national crisis and development priority at all major events. In January 2000, the President publicly chastised Botswana's media organisations, saying they had failed to help remove the stigma attached to HIV/AIDS. His statement emphasised solidarity with HIV-positive people, telling Botswanans that "as long as we still talk derisively about the HIV/AIDS virus and its victims, ... for as long as we talk as if any one of us is immune to infection ... the pandemic will remain the invisible monster that stalks us in the darkness of ignorance and decimates our people".

President Mogae's words of solidarity have been backed by deeds. The country's most recent budget allocated significant national resources to HIV/AIDS: US$ 15 million for implementation of a multisectoral National Operational Plan (putting HIV/AIDS into the planned activities of government ministries and partners in the private sector and among NGOs), US$ 6 million to prevent mother-to-child transmission, US$ 5 million for the newly established National AIDS Coordinating Agency, and US$ 6.8 million for home-based care.

In a situation such as Botswana's, where over one-third of the adult population has HIV and many are already falling ill, the priority and resources assigned to home care is particularly important. Among the essential services provided under Botswana's home-based care effort are home nursing, counselling, and provision of nutritious food for patients. To support the latter, the government has established a "Food basket" for HIV/AIDS patients, which is administered through the Division of Social Welfare.

Malawi, South Africa and Zambia: International GIPA programme bolsters national AIDS responses

Leadership issues summary

Leadership level: persons living with HIV/AIDS working with range of ministries and supported by international agencies

Contribution to success: willingness of national partners to take GIPA seriously

Opportunities: use success of initial placements to extend programme to more countries and sectors

In 1998, the United Nations put the GIPA principle into practice by implementing a pilot programme placing persons living with HIV/AIDS as National United Nations Volunteers (NUNVs). The pilot

project in Malawi currently has 12 NUNVs serving at 11 host institutions, while Zambia has had 21 NUNVs in government, NGOs and the private sector. In South Africa, a "field worker" arrangement was made, placing all volunteers within private sector companies.

Although their job titles vary, their primary function at these institutions is to give HIV/AIDS a human face and voice - and to show that individuals living with HIV/AIDS are not the problem but part of the solution. They do so by:

- sharing their experience of living with HIV/AIDS with staff and management within the host institutions and companies
- carrying out real jobs and responsibilities, rather than "token" jobs that make no difference to the status quo
- establishing PLHA support groups and doing one-on-one HIV/AIDS counselling.

A glance at host institutions gives an indication of the reach of the programme. Host institutions in Malawi have included the Ministry of Agriculture and Irrigation, Agricultural Development and Marketing Corporation, several hospitals and major industrial companies, and a variety of NGOs. Host institutions in Zambia have included the Ministry of Community Development and Social Services, Ministry of Youth, Sport and Child Development, Ministry of Defence, Army, National AIDS Programme, prisons, and a variety of service-providing NGOs and health institutions. As mentioned, all South African volunteers have been placed in private sector businesses.

Burundi: National association of HIV-infected and -affected people runs care and support centre

Leadership issues summary

Leadership level: Persons living with HIV/AIDS, supported by international donor

Contribution to success: courage to go public; determination to follow through with implementation

Opportunities: establish existing facility as a centre of excellence which can increase national capacity

In 1993, a small group of Burundians living with HIV/AIDS publicized their sero- status in a media event that was reported nation-wide. Such an action was risky because it had never been done before, but the overall reaction in Burundi was surprisingly supportive. Shortly after, the group formally established itself under the name "Association Nationale des Séropositifs et Sidéens" (National Association of Persons living with HIV/AIDS, or ANSS) with the aim of dispelling myths about AIDS that were widely held among Burundians. Over time, the group expanded its membership to include those who, though not HIV-positive, are nonetheless affected by the disease (usually family members of HIV-positive persons), those not yet ready to disclose their status, and others who had personal reasons to join.

With the help of a French NGO, ANSS opened a care and support centre called "Turiho", which in the Burundian national language Kirundi means "We are alive." Its main activities are currently prevention activities, promotion of voluntary counselling and testing, and medical care and psycho-social support for individuals living with HIV/AIDS (including home-based care and nutritional support). Staffed by permanent, paid employees in order to ensure high quality and availability of services, the centre is managed by infected and affected people recruited on the basis of their involvement in ANSS's work.

Zimbabwe: Bringing together all the partners at local level

Leadership issues summary

Leadership level(s): local and international health workers, religious authorities, persons living with HIV/AIDS, local health authority

Contribution to success: willingness to go ahead before national health services, have capacity or resources to assist; understanding that home care is most cost-effective way of meeting local needs

Gaps and insufficiencies: so far, traditional leaders have not been recruited to actively help the programme

Opportunities: largely dependent on ability to mobilize more resources

The Chirumhanzu Home-Based Care Project is based in Chirumhanzu District, a farming area in the central Midlands province of Zimbabwe, which has been hit very

hard by the HIV/AIDS epidemic. The project grew out of an initiative in the early 1990s by senior nurses, Dominican Sisters, and expatriate doctors at St. Theresa's Hospital.

The project promotes HIV/AIDS awareness and prevention, both among the general public and among target groups such as sex workers, students, and people being treated for sexually transmitted infections. The project is organisationally separate from the hospital, but collaborates fully with it in referrals and has space in the hospital wing built by the Dominican Sisters. A full-time nurse paid by the hospital works with the project, while the group's full-time coordinator is paid a small honorarium from project funds provided by the NGO SolidarMed. The Ministry of Health nurses provide most materials and drugs used in the home-care service.

The project encourages persons infected or affected by the virus to participate in all aspects of the project. This principle is important not only in itself, but also because it raises the profile of persons living with HIV/AIDS within the community and thus serves to reduce stigmatisation.

Most of the project's volunteer home caregivers are recruited through the district's church parish councils and other local religious organisations. Criteria that guide the councils in their recruitment of these volunteers include compassion and willingness to provide spiritual support and care where needed. There are currently about 30 volunteers in Chirumhanzu. The majority of project members are either HIV-positive or are directly affected in some way by the virus - for example, having had a family member who died of AIDS.

As yet, the project has not been successful in enlisting the active support of local chiefs or village health workers, although the latter give passive support or tacit acceptance, which is essential to the project's work.

South Africa: Bambisanani – an EQUITY Project

Leadership issues summary

Leadership level: Partnerships with the cooperation of several organisations that provide funding and other support

***Contribution to success*:** clear articulation of immediate needs, decentralisation, development of organisational framework, provision of training, understanding the need for multisectoral response

***Opportunities*:** mobilisation of resources, implementation, measurement and evaluation
EQUITY is a USAID-funded project created to support the South African government in providing integrated health care.

'Bambisanani', meaning 'in partnership to help each other', is a multisectoral project involving organisations such as the Employment Bureau of South Africa, the Mineworkers Development Agency and the Planned Parenthood Association of South Africa. Their objective is to enable selected communities in the Eastern Cape 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. Repatriated migrant workers are one particular focus.

Main activities include community capacity building, home-based care, care and support for children in distress and support for groups and income-generating activities.

Getting the AIDS message out to broad populations – and following up with action

Cross-cutting themes

- getting religious and traditional leaders involved
- public education campaigns; fundraising approaches
- importance of top government leadership

Neither citizens nor governments can respond to HIV/AIDS without awareness of the problem - and awareness of the solutions. A country in which denial flourishes is a country whose population is vulnerable to the silent spread of HIV.

Yet getting the message out is not enough. Sometimes, even when the level of basic knowledge is very high among certain populations, people do not alter their risky sexual behaviour – the implicit goal of most awareness campaigns. Reasons for this vary between populations, but often include lack of skills (e.g., knowing that a condom *should* be used is not the same as knowing *how to negotiate its use with a partner*) and poor access to affordable commodities and services.

Correcting ignorance and denial

Simple ignorance or misinformation is an important factor in HIV's spread. For example, rumours recently became widespread in some communities that circumcision acts as a "natural condom" and prevents one from HIV infection. In one study in South Africa, for example, two out of five circumcised men were infected with HIV, compared with three out of five uncircumcised men. Thus, it shows that both circumcised and uncircumcised men can be infected with HIV through unprotected sex.

Community customs and traditional values play their part too: few people are happy to admit that a fatal disease - spread by behaviour branded as "immoral" - could be rampaging through their community or their country. In some countries, denial had a more mercenary motive because AIDS might discourage tourists from visiting their country.

Denial may also have been reinforced by some of the early "scare tactics" used in AIDS awareness campaigns, by declaring that the disease is evidence of (or punishment for) immoral behaviour, and by cultural factors such as taboos against frank discussion of sexual matters.

Fighting stigma and negative attitudes

It is important to reduce stigma about being HIV-positive for a variety of highly practical reasons. In places where stigma is strong, asking a partner to practice safe sex may be seen as an admission that one is HIV-positive, or has doubts about the partner's infection status. In such an ambiance, many people will choose not to use a condom, even if worried about their own or their partner's health.

Another reason to attack stigma is that it makes people reluctant to seek HIV services, including voluntary counselling and testing (VCT). Even where VCT facilities are available, stigma may make people reluctant to consult those services, or prefer not to know their infection status. Improving services must therefore go hand in hand with efforts to diminish fear and rejection of seropositive people, and with the establishment of policies and practices to ensure confidentiality of HIV test results and related information.

Countries have had some success in combating the stigma of AIDS through public campaigns urging solidarity with HIV-affected persons and through public statements by respected leaders. Care providers are learning to manage AIDS services without stigmatizing. At the same time, such campaigns can also empower people living with HIV/AIDS to cope with the disease, "live positively" (which may include continuing to have fulfilling sexual lives with their partners *safely*), and contribute their testimonies to help people change their risky behaviour and prevent transmission of HIV.

Prevention through behaviour change

In the absence of a vaccine or cure, prevention through behaviour change is the most cost-effective way of saving lives. Information, Education and Communication (IEC) programme has been one of the prevention strategies used by national AIDS programmes throughout all the countries in the region. The information and communication contribute to creating awareness, motivation and referral to sources of condoms and services; while the education provides skills and encourages family and peer support. All of these can help promote safer sexual behaviour (including the use of condoms), the seeking of care for sexually transmitted infections and family planning, and positive living. Apart from awareness, IEC programme also provides the information and skills needed to prevent further spread of sexually transmitted infections and HIV.

In general, IEC best practice in recent years has featured:

- replacing "scare tactic" messages with ones promoting hope and pragmatic action
- teaching life skills along with AIDS education
- changing the attitudes of health sector workers to be caring and non-discriminatory against HIV-positive persons
- integration or collaboration with initiatives to increase access to commodities and services.

Examples of Best Practice

Senegal: Muslim and Christian leaders preach tolerance and solidarity

Leadership issues summary

Leadership level(s): highest religious authorities, in cooperation with national AIDS programme; at local level, imams and priests/pastors exercise leadership among their "flocks"

Contribution to success: raised the profile of the epidemic, provided a widespread, highly trusted medium for spreading information

Gaps and insufficiencies: some religious authorities are still unable to support condom promotion

Since almost all Senegalese are active practitioners of Islam or Christianity, religious leaders have an enormously important role in national life. Their support for AIDS prevention activities was vital if the activities were to succeed. And it was clear that religious leaders wanted to be involved in this important area. As early as 1989, a Islamic organisation, Jamra, approached the national AIDS programme to discuss HIV prevention strategies. Although initially rather hostile to condom promotion and some other aspects of AIDS prevention, the group became an important partner in a dialogue between public health officials and religious leaders.

In order to understand the needs of the religious constituency, the government supported a survey of Muslim and Christian leaders. The survey results showed that religious leaders felt they were poorly informed about AIDS, and wanted more information to enable them to give clear guidance to their followers. They also specified what they were prepared to support. For example, they were reluctant to support condom use between unmarried youngsters, but were prepared to support it within marriages.

In response, educational materials were designed to meet the needs of religious leaders. They focused in part on testimonials from people living with AIDS - the human face of the epidemic, often hidden where prevalence remains low.

Training sessions about HIV were organised for Imams and teachers of Arabic, and brochures were produced to help them disseminate information. AIDS became a regular topic in Friday sermons in mosques throughout Senegal, and senior religious figures addressed the issue on television and radio. In March 1995, 260 senior Islamic leaders gathered for a conference on AIDS. The result of the conference was clear support for AIDS prevention efforts. The religious leaders declared that HIV was not a divine retribution for immoral behaviour. They supported the rights of people living with AIDS, including the use of condoms to prevent HIV from spreading within marriage if one partner is infected. And they stated that everyone should have access to full and accurate information about HIV and AIDS.

Among Christians, there was substantial resistance to AIDS prevention at first. And yet Christian organisations are important providers of health services in Senegal, and AIDS clearly threatened to become a major health issue if it were not prevented. Led by a Catholic NGO, SIDA Service, the churches gradually developed a more supportive outlook on prevention. They provided important counselling and psychosocial support, and frequently referred those in need to alternative providers where they could not meet needs, for example for condom provision.

In January 1996 Christian leaders gathered in another conference on AIDS. Every bishop in Senegal was in attendance. Again, the result was a consensus that AIDS prevention was an important national activity.

The moral support for AIDS prevention given by religious leaders allowed secular and health authorities to work productively in providing education and specific HIV prevention services.

Ghana: Social marketing of female condoms

Leadership issues summary

Leadership level(s): national authorities working with international agencies and private sector; prominent woman lending her support to a subject that is difficult to talk about in local culture

Contribution to success: willingness of national leadership and health authorities to adopt innovative approaches to prevention

A programme to market the female condom in Ghana was officially launched on 25 May 2000, with Her Excellency, Nana Konadu Agyeman Rawlings, the First Lady of Ghana presiding over the ceremony.

In her speech, the First Lady emphasised the importance of giving women more control over their own reproductive health and said that "the female condom will give Ghanaian women a greater voice in sexual and contraceptive decision making.... Since the female condom is worn by women themselves, it is found to be empowering and is particularly more popular where men are reluctant to use condoms themselves".

To back up the programme, Ghanaian government announced that it had ordered half a million female condoms from the US-based Female Health Company, which will be marketed at subsidised

prices. Since such marketing must be backed up by knowledgeable support, the Minister of Health stated that more than 3,000 medical and non-medical service providers had been trained to provide the female condom.

The protective device was first tested in Ghana by UNFPA and the Ghana Social Marketing Foundation. National planning was further assisted by the Ministry of Health, UNAIDS, and the Society for Women and AIDS in Africa (SWAA).

Tanzania: Partnership with traditional healers

Leadership issues summary

Leadership level(s): traditional healers and medical staff

Contribution to success: willingness to share experiences and recognize the other groups' strengths and advantages; willingness of medical authorities to tolerate "non-medical" practitioners

In 1989, the increasingly apparent impact of HIV/AIDS resulted in collaboration between traditional healers and medical health workers in the Tanga region of northeastern Tanzania. Meetings between the two groups resulted in a spirit of mutual respect, and permitted them to share experiences on care and prevention of AIDS and other illnesses. The success of the collaboration resulted in the formation of the Tanga AIDS Working Group (TAWG) in 1992.

Since then, TAWG has been collaborating in two districts of Muheza and Pangani with about 60 traditional healers and 60 traditional birth attendants. Training of traditional healers includes basic information about sexually transmitted infections, HIV and AIDS, along with building skills in AIDS counselling and care, condom promotion and community behaviour change. In addition, traditional healers are trained in hygiene and how to sterilise their tools. Field supervision and monitoring follow training as the healers begin adding to their usual activities such tasks as home visits to persons living with HIV/AIDS, promotion of HIV testing and referrals to the biomedical health system. Much of this is done in close cooperation with existing village health projects.

The healers have also worked with doctors and nurses to conduct hundreds of joint educational sessions, both with community groups and with local leaders. Among other results, they have been successful in condom promotion and sales, helping increase "Salama" condom sales by a reported 50%.

Mutual reinforcement of AIDS care and prevention

Cross-cutting themes

- importance of community participation
- mobilising domestic funds (public and private)
- mobilising international resources
- training and use of local managerial/technical talent

Experience in various parts of Africa and the rest of the world confirms that it is vital to provide care and support for people living with HIV/AIDS, not only for the sake of the direct beneficiaries but to also help prevent HIV within the wider community. Treatment and can improve quality of life of those living with HIV/AIDS and thus enable them to participate fully and longer in prevention education in the community. This is an important component of the social contract described in the previous section.

Individuals who know they are infected and receive care can break through the denial about HIV by talking with their friends and neighbours and reducing the discomfort associated with the subject. Care providers who look after HIV-positive people demonstrate to others in the community that there is no reason to fear becoming infected through everyday contact, and thus help dispel misguided beliefs about HIV transmission. Providing diagnosis and treatment for tuberculosis and sexually transmitted infections – diseases that are common among people with HIV – also helps decrease their spread among HIV-negative people.

Care thus has important spin-offs for prevention, in much the same way that prevention measures such as voluntary HIV counselling and testing can result in improved access to care. Recognising these interlocking benefits, development assistance agencies and other financers of AIDS programmes are increasingly seeing care and support for HIV-infected people as a powerful tool for expanding the response to the epidemic. An example is voluntary HIV counselling and testing which helps improve access to care, reduce psychological suffering, and helps a person to recognise their own risk behaviour and decide to change that behaviour.

HIV/AIDS and TB prevention and care

There are many practical ways to care for HIV-positive people. Preventing tuberculosis using a readily available drug called isoniazid can extend the life expectancy of HIV-infected people in countries where TB is common, and it is estimated that good tuberculosis treatment can give HIV-positive people who develop TB up to two additional years of life. From all points of view, dealing with TB among people living with HIV is an excellent and cost-effective way to make measurable progress against AIDS.

The double benefit of STI management

Sexually transmitted infections such as syphilis and chancroid are not only harmful in themselves, but also greatly multiply one's risk of transmitting or acquiring HIV infection. Prompt diagnosis and effective treatment of these infections can thus help reduce biological vulnerability to HIV.

Just as important, health care of this kind provides a widely available entry-point (and in some places, one of the few available entry-points) for preventing both HIV and further episodes of sexually transmitted infection through counselling, condom promotion and IEC messages. Men come more willingly than they would for HIV-specific testing, can be given condoms, and can be encouraged to

participate in both individual and partner counselling. Men can also refer the women with whom they have had sex to the clinic. This can be especially helpful because a woman with a sexually transmitted infection often has no symptoms of illness and may therefore not seek care, even though her untreated infection puts her at high risk for HIV as well as for infertility and other ill-health.

A boost to voluntary counselling and HIV testing

Despite its known benefits, VCT remains a low priority in many places. Governments already hard-pressed to cope with what might seem to be "competing" diseases such as malaria and tuberculosis, sometimes question the relative importance of measures that do not involve vaccines or medicines.

Counselling requires both infrastructure and human capacity, and takes time in order to be done properly. Pre- and post-test counselling, some of it delivered to small groups and some one-on-one, cannot be rushed. As well, the counselling delivered at the time of testing should be reinforced by follow-up sessions in order to really result in behaviour change.

On the demand side, seeking counselling and HIV testing is not an easy step to take for many people. Among low-income groups, many people see little point in getting tested for HIV if treatment is inaccessible. This is changing as access increases to some medications that can only be given to people with known HIV infection. For instance, early treatment with isoniazid and cotrimoxazole prophylaxis can give AIDS patients additional months or years of life. If these preventive regimens are made more widely available in developing countries, they will reinforce demand for wide-scale HIV counselling and testing services.

The introduction of rapid HIV tests is another factor that is making VCT easier and more attractive to clients in developing countries. Pre- and post-test counselling and testing results can be offered during a single visit to a VCT centre or clinic – an important consideration in places where taking time off from work or from child care can be difficult, and transportation can take a long time. The widespread problem of people not returning to get their test results (as frequently happens when tests take up to two weeks to return results) and missing post-test counselling is thus avoided. (Note that centralised laboratories remain essential in many testing programmes, and for purposes such as quality control of services, and surveillance).

Home care and community support

In sub-Saharan Africa, community-based programmes are the only practical way to bring health care to many HIV-infected people and support to many AIDS-affected families. Home care is the field *par excellence* in which civil society has shown both leadership and great creativity. Besides the direct benefits to patients and their families, AIDS care and support programmes have important spin-offs for the rest of the community. They make the epidemic more visible and hence help uninfected people to take the HIV threat more seriously.

People with HIV/AIDS need not only medical care but also support in coping with the unpredictable course of their illness and its impact on themselves and their families. Communities are best placed to identify needy families, vulnerable children and orphans, and develop systems to enumerate and assess the needs of families and children and to determine the extent of problems. The community is also best placed to monitor and maintain contact with children, supervise their activities and prevent child labour and abuse.

Prevention of mother-to-child-transmission

Since the start of the HIV epidemic, it is estimated that 3.8 million children have died of AIDS before their 15th birthday, half a million of them in 1999 alone. Another 1.3 million children are currently living with HIV, and most will die before they reach their teens. The vast majority of these children

were born to HIV-infected mothers: the most vulnerable of all populations, they acquired the virus in the womb, around the time of childbirth, or during breastfeeding.

Over nine-tenths of all children worldwide infected before birth or during infancy in 1999 were born in sub-Saharan Africa. Making HIV counselling and testing services widely available so that infected women can decide whether to take preventive drugs during pregnancy is a measure that could save the lives of hundreds of thousands of children while offering broader benefits as well.

Several countries have recently set up pilot projects which effectively reduce HIV infection among children born, and are actively tackling some of the challenges involved. As well as prevention, ways must be found to provide care and support, not just for the HIV-infected mother and her infant but for the other members of her family. This is largely uncharted territory in developing countries, where it will be necessary to create good referral links from mother and child health centres to other facilities and services in the health system and plan ahead for the increased case-load.

The biggest challenge of all will be to expand coverage beyond the pilot projects to reach all HIV-infected pregnant women and their families. As part of planning ahead for this expansion, health systems will have to rise to the considerable challenge of improving infrastructure, training, motivating and retaining the necessary health staff, and improving distribution systems so that HIV test kits, preventive drugs and infant formula are consistently available to those who need them.

Finding alternatives to breastfeeding is an important issue, one which is complicated by widespread problems in ensuring the availability of clean water. This illustrates an important multisectoral aspect of the problem, since it brings in questions of infrastructure and poverty.

Finally, it must be remembered that primary prevention is part of the package.

Examples of Best Practice

Uganda: Same-day test results help extend VCT beyond major cities

Leadership issues summary

Leadership level(s): NGOs and international partners, with increasing support from Ministry of Health

Contribution to success: emphasis on using the most up-to-date techniques (if proven cost-effective) to improve service to clients

Gaps and insufficiencies: insufficient coverage of national territory

Opportunities: NGOs and government are cooperating to scale up coverage to all districts

Uganda's AIDS Information Centre (AIC) is a Kampala-based NGO that has provided confidential counselling and HIV testing to over 350,000 clients since 1990. Services are provided by AIC staff at hospitals in 20 of Uganda's 45 districts, and also by mobile AIC units who go to more isolated communities by automobile.

Since January 1997, the AIC has provided same-day VCT services. Previously, clients had to wait two weeks to receive their HIV test results, and 25-30% did not return to get them. Research among its clients confirms that 85% prefer same-day results and 76% are willing to pay more for the rapid service. On average, clients spend two hours at the centre, although the procedure can be completed within 30 minutes. In addition, thousands of HIV-positive and HIV-negative people tested at the Centre have joined the Post Test Club, which not only offers its members health care and other services, but sends them into the community to distribute condoms and spread information about HIV prevention.

Scaling up VCT is the new challenge now being tackled in Uganda. Currently, with financing from USAID, the AIDS Information Centre is working with the Ministry of Health (which is also receiving technical assistance from NORAD) to integrate VCT more consistently into district health services. In addition, financing from the European Union will permit VCT to be provided in Uganda's northern districts, where it is currently not available.

Zimbabwe: Commercial farms combine care with peer education and condom promotion

Leadership issues summary

Leadership level(s): private sector working with community leaders and NGOs

Contribution to success: willingness and need of private sector to invest resources and involve community; willingness of community to provide support to the initiative

Gaps and insufficiencies: lack of national government support and lack of involvement of other potential partners

Opportunities: existing programme and human resources have potential to help scale up prevention and care services beyond the commercial farms to traditional farming sector (this looks less and less likely, owing to national-level obstacles)

The AIDS Control Programme of the Commercial Farmers Union of Zimbabwe has been working since the late 1980s to reduce the incidence of HIV/AIDS and sexually transmitted infections among commercial farmers, farm workers and their families. The project's 30 coordinators and 135 trainers have trained and supervised approximately 10,000 peer educators, and activities have been extended to 3,500 farms in most parts of the country. The programme distributes approximately 1.5 million condoms per quarter.

Zimbabwe's agriculture sector contributes about 20% of the country's gross domestic product. An estimated 2 million people (including children) live in full family situations on commercial farms where basic infrastructure (housing, water, etc.) are provided by the commercial farmers. The Commercial Farmers Union (CFU) is the coordinating body for Zimbabwe's commercial farming sector, which groups 73 farmers' associations within the eight regions of the country.

Trainers of peer educators tend to be middle managers on farms, storekeepers, farm and rural school teachers, police or telephone operators. Peer educators are recruited on the basis of the respect they hold within their communities, and their ability to communicate. Trainers and peer educators are all volunteers. Training materials and curriculum are provided by the Family AIDS Counselling Trust (FACT) in Mutare. Both trainers and peer educators provide home care and counselling, with the trainers monitoring the quality of work provided by the peer educators.

The Union's AIDS Control Programme has a decentralised structure, with central administration comprising only a project manager and two deputy project managers and the CFU's chief accountant and book-keeper. Administrative costs are kept low by maintaining the smallest central organisation possible, and "borrowing" the CFU's own accounting and other services. The coordinators of the project are farmers' wives who volunteer their time and energy to organise training courses, and to distribute HIV/AIDS literature and condoms using their personal cars, farm lorries, and telephones and faxes.

Until recently, the commercial farmers were taking increasing responsibility for providing resources and food for sick farmer workers. Unfortunately, the programme has been seriously disrupted by a wave of social disturbances, and little progress has been made in maintaining, let alone extending, its activities.

Côte d'Ivoire: Care and prevention in a poor urban setting

Leadership issues summary

Leadership level(s): religion-based NGO working with local community and particularly with persons living with HIV/AIDS

Contribution to success: emphasis on involving persons living with HIV/AIDS in running programme; ability of NGO to create links with local health care institutions and other NGOs

The Centre for Socio-Medical Assistance (Centre d'Assistance Socio-Médical - CASM) is an outpatient clinic for people living with HIV/AIDS in Abidjan, that also has a strong prevention component. Many of the people it serves are indigent, have little family financial support, and are severely stigmatised by their family, neighbours and even health officials. The Centre is operated by HOPE Worldwide (an international, faith-based NGO) in collaboration with the Ministry of Health, the National AIDS Programme, and the local teaching hospital.

Along with providing basic treatment, the Centre makes referrals from and to other local care providers, support groups, and a hospice. It employs two counsellors and a psychologist, and has a team of approximately 20 community agents that provide home-based support for persons living with HIV/AIDS from the centre. On average, 25-30 new patients are referred to the CASM every month. Their average age is around 25. The ratio of men to women referred is now 1 to 1 (in the first few years it was almost 4 to 1).

The project's prevention work has sought to include persons living with HIV/AIDS in its programming and execution. In all, prevention programmes have educated over 200,000 people over the past 5 years.

In 1994, CASM helped create the area's first support group for persons living with HIV/AIDS, the *Club des amis* ("Friends' Club"). The *Club des amis* is now a fully fledged association in its own right with over 300 members and has itself helped create three other associations for persons living with HIV/AIDS. Daily, a core of club members supports clinic staff with counselling and support issues, fulfilling their desired role as peer educators and counsellors. Club members are also actively involved in joint AIDS prevention programmes (including participating in the centre's theatre group, whose name, Kazenze, means "staying together").

CASM and the *Club des amis* collaborate on peer education efforts, which have helped increase AIDS awareness at clinic level. For example, peer support groups have aided problem-solving when it comes to psychosocial issues that may inhibit behaviour change. The use of peer counselling has made AIDS education more acceptable to patients who visit the clinic.

Uganda: Innovative social marketing of STI treatment kit for men reinforces HIV prevention

Leadership issues summary

Leadership level(s): national health authorities and private/informal sector

Contribution to success: openness of health authorities to technical innovation, and pragmatism in working with available distribution systems even if these are semi-formal

Gaps and insufficiencies: this is a pilot project, lacks resources to scale up

Social marketing of "Clear Seven," a pre-packaged treatment kit for male urethral discharge syndrome (MuD), has proved a successful strategy for treating sexually transmitted infections and preventing

HIV infection. Besides the kit itself, this pilot programme has taken the innovative tactic of training Uganda's informal "drug shops" to sell the antibiotics without a prescription.

The kit consists of a 7-day "blister pack" of one 500-mg tablet of ciprofloxacin, fourteen 100-mg tablets of doxycline, seven condoms, three partner referral cards, and a multilingual instruction and information leaflet. The kit is packaged in a sealed cardboard box bearing the expiry date and the recommended retail price of US$ 1.35 (this includes a subsidy, since full production cost is US$1.50).

The kit was designed not only to promote MuD treatment compliance (i.e., to ensure people are fully cured by taking the full course of the antibiotics, rather than stopping when the symptoms clear up), but also to support condom use, strengthen partner referral, and also provide health education for risk reduction.

The Clear Seven distribution strategy builds knowingly on existing distribution networks that, despite numerous problems, are widely used by common people. Improving distribution through drug shops is crucial to this strategy. These are small retail outlets that are licensed to sell over-the-counter drugs. Though prohibited by law from selling antibiotics, many will stock and sell them anyway. (Only pharmacies, 90% of which are located in the capital Kampala, are authorised to sell antibiotics.) Drug shops therefore satisfy an unmet demand for health services and serve as the first point of health care for the majority of people with a sexually transmitted infection.

The traditional approach to these drug shops consisted of tightening drug laws and cracking down on offenders. However, realising that the social-economic necessities which contribute to their existence require long-term planning to solve, the Ministry of Health granted permission to utilise these outlets as points of delivery for effective STI drugs. Drug shop attendants were trained in proper diagnosis and management, and were thus prepared to support the Clear Seven initiative.

According to the Ministry, the results of Clear Seven have been encouraging. The cure rate for MuD increased from 46% to 87% in the districts where the pilot project was run, and treatment compliance has increased dramatically. Before the Clear Seven project, under 9% of STI patients followed the national treatment guidelines for MuD.

Uganda: Trials of the antiretroviral nevirapine

Leadership issues summary

Leadership level(s): national and foreign researchers, with support of private sector and approval of national government

Contribution to success: willingness of government to permit trials to go ahead despite some political opposition

Gaps and insufficiencies: still at trial level; will require considerable investment in health infrastructure in order to be scaled up nationally and applied in other countries

Opportunities: excellent potential for scaling up due to low drug cost and low complexity of treatment

The search for more affordable ways of helping HIV-positive women have uninfected babies is a crucial task given the high rates of mother-to-child transmission in Africa. Perhaps the most promising development in this respect was the trial called HIVNET 012, recently undertaken at Mulago Hospital by researchers from Makerere University in Kampala and Johns Hopkins University in Baltimore.

The trial involved giving a single dose of the antiretroviral drug nevirapine to the mother at the onset of labour, followed by a dose to her infant within 72 hours of birth. This was compared with the efficacy of a multi-dose course of zidovudine (ZDV, or AZT) which has till now been regarded as the most cost-effective preventive regimen available to developing countries. After reviewing the results,

a group of experts from WHO, UNICEF, UNFPA and UNAIDS Secretariat agreed that the nevirapine regimen was effective in reducing transmission to infants, while having the additional benefits of being cheap and simple to administer.

The affordability of the nevirapine regimen can be seen in Uganda's calculations of the costs of buying enough of the drug for all HIV-positive pregnant women in the country. In contrast to the cost of supplying zidovudine treatment at US$ 21,450,000 per year, the cost of nevirapine coverage would be US$ 640,000.

Nonetheless, the low price of nevirapine must not blind decision-makers to the fact that effective prevention of infant infections is not simply a matter of finding "the right drug at the right price". Although the drug used is a substantial component of the intervention, many others are independent of the particular drug used. These include the infrastructure of voluntary and confidential HIV testing, many aspects of antenatal and postnatal care of women, psycho-social support to HIV-infected women, the provision of alternatives to breastfeeding, and the follow-up of babies to determine their HIV infection status.

Something for all, and special measures for those at greater risk

Cross-cutting themes

- involvement of private sector
- community and local experiences
- imaginative approaches to fundraising

Unprotected sex continues to fuel the HIV epidemic. Therefore, broad prevention campaigns aimed at the general public are still necessary. At the same time, it makes strategic sense to focus first on specific populations including sex workers, men who frequently visit sex workers, and drug users, as well as geographic areas where rapid HIV spread has become an emergency. These range from categories as large as "young people" and "women" to those as precisely defined as sex workers, migrants and soldiers.

Messages for the general public

A number of options are promoted in prevention campaigns directed at the general public. One message is to abstain altogether from sex – or, for young people who have not yet become sexually active, to postpone the start of their sex life. Another is to engage in sex that involves no penetration. As a further option, people are encouraged to have sex with only one other person – someone who will never have sex with anyone else. Mutual fidelity is protective, of course, only if both partners stick to the rules and were uninfected to begin with. Finally, the consistent and correct use of condoms (either male or female condoms) for every act of sexual intercourse protects both partners from HIV and other sexually transmitted infections.

These are not either/or choices. People may adopt different prevention strategies at different points in their lives, and good prevention campaigns emphasise that many options are available which reinforce each another.

In campaigns directed at "the general public" it must be remembered that half of the population is male, and that men have not only responsibilities but their own factors that make them vulnerable to HIV infection. (This is discussed in more detail in the next chapter, under the heading "Men: also vulnerable, but in different ways.") These campaigns must provide specific and programmatic information on risk behaviours and options for safer behaviours including referral to relevant services to reduce HIV risk.

Reaching sex workers and their clients

In many countries, HIV was first identified in the sex work population. As the epidemic grew, international agencies, governments, and NGOs recognised the need to create interventions to diminish HIV transmission in commercial sexual encounters. Initially, programmes focused mainly on the promotion and distribution of condoms to sex workers, and dissemination of information. Most of these programmes were targeted at the sex worker alone, ignoring the clients. They took inadequate account of the marginalised, illegal status of women that contributed so much to their vulnerability, and of the fact that ultimately it was the male client who had to be convinced to use a male condom.

In the past decade, educational and enabling strategies have been the two main elements used when addressing sex work and STIs and HIV/AIDS. The most successful projects include components of

education, condom provision and empowerment, and target not just the sex workers but the other people who are directly involved, above all the clients, owners and managers of sex establishments, and those who influence commercial sex activity, such as police and law enforcers; health officials; those who can influence perceptions towards sex work; 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 in addition to providing advice, counselling, and information that focus on individual risk behaviours, programmes should pursue objectives such as increasing the sex workers' bargaining power (both individually and collectively) to insist on safer sex.

Examples of Best Practice

Senegal: Preventing transmission of HIV among sex workers and clients

Leadership issues summary

Leadership level(s): national health authorities

Contribution to success: ability to build on an existing, realistic approach to public health problems; understanding of cost-effectiveness of targeted intervention

In Senegal, HIV prevention measures aimed at sex workers were reinforced by measures among the general population from which the sex workers' clients are drawn. Along with risk-reduction (largely through promoting the use of condoms), efforts were also made to reduce vulnerability.

In many countries, prostitution was ignored until the advent of AIDS, when it became clear that sex workers were very vulnerable to HIV infection and could in turn quickly pass the virus on to large numbers of other people. In Senegal, however, services for sex workers' have existed since the profession was legalised in 1969. Registered sex workers have since then been required to have regular health checks, and are treated for curable sexually transmitted infections if necessary. This system of registration provided a framework within which to approach sex workers with educational and health campaigns.

Once the threat of an HIV epidemic became clear, decision-makers in Senegal immediately understood that sex workers were at extremely high risk both of contracting HIV and of passing it on to their clients. Preventive interventions focusing on the promotion of condom use with clients were immediately put in place, and treatment of sexually transmitted infections moved up the list of health priorities. Many sex workers began to join support groups to safeguard their health in the face of AIDS. Over 30 such groups were established.

Prevention efforts were also made to reach populations that may be regular suppliers or consumers of casual sex, whether or not in exchange for money. These include mobile populations such as migrant workers and transport workers. Locations where casual sex may take place, such as weekly markets, are also becoming targets for more active prevention efforts.

Before the HIV epidemic, condom use in Senegal was extremely low, less than one per cent. And indeed, it remains low as a method of contraception or between spouses. However, in casual sexual relationships - exactly those targeted by the AIDS prevention campaign - condom use has risen dramatically. In a 1997 population survey in Dakar, more than two-thirds of men and close to half of women who had had casual sex in the past 12 months used a condom with their last such partner.

Information and condom promotion targeted at sex workers seems to have been even more effective. In a 1998 study of prostitutes, 99% reported that they had used a condom with their most recent new

client, and 97% with their most recent regular client. In the capital, Dakar, the HIV prevalence rate among sex workers appears to have remained stable at around 17% since 1993.

Côte d'Ivoire: Programme for care and prevention among female sex workers and their partners

Leadership issues summary

Leadership level(s): NGO working with government health authority and external donors

Contribution to success: willingness to empower sex workers, despite their semi-legal status; seeking cooperation from members of the sex workers' milieu as well as the women themselves

Since its start in 1991, the Programme for STI/AIDS care and prevention among female sex workers and their partners (PPP, in French "Programme de Prévention et de Prise en Charge des MST/SIDA chez les Femmes et leurs Partenaires") has targeted 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.

The sex trade in Côte d'Ivoire has an ambiguous status, being illegal, tolerated by the legal authorities, and widely used by men from all sectors of society. A large proportion of the women are migrants from other countries, a factor which increases their vulnerability.

PPP has taken a pragmatic approach, starting with research on the target populations. In 1993/94, the National AIDS Programme became PPP's institutional "home" within the country's health system, overseeing its administrative and financial management. It has since been extended to four other cities: Bouaké, Daloa,

Korhogo and San-Pédro. Staff includes health educators, sociologists, and government social workers, along with peer educators recruited from among the sex workers.

A major focus has been community mobilisation and education. Activities include educating and involving all interested parties in prevention work, from the local government authorities to the 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 are held in places where sex workers live or work. The meetings' curriculum includes information about HIV and other sexually transmitted infections (STI), prevention methods, testing, and STI services.

Peer education is carried out through recruitment of sex workers who perform outreach to other prostitutes 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 operated by a project with similar objects, Projet Retro-Ci. 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.

Making people less vulnerable to HIV infection

Cross-cutting themes

- public education campaigns
- mobilising domestic funds (public and private)
- mobilising international resources
- training and use of local managerial/technical talent

An individual or a community's vulnerability to HIV is a measure of their ability to control the risk of infection. Personal factors, factors affecting access to relevant information and services, and societal factors including social, economic, political and cultural situations may either mitigate or exacerbate vulnerability. For example, a person who is discriminated against with respect to education or employment on the basis of race, gender, sexual orientation or other characteristics is also more vulnerable to HIV infection. Similarly, a young person who can not access condoms is more vulnerable to HIV than other young people.

In many settings, women – and in particular young women – are especially vulnerable to HIV infection. They may be less able than men to avoid non-consensual or coercive sexual relations.

Rural communities may be vulnerable because of lower levels of literacy and less access to information and services.

Many factors and forces exist that restrict people's autonomy and leave them particularly exposed to HIV infection, or vulnerable to needless suffering once they are infected. Intolerance of racial, religious or sexual minorities; discrimination against people with known or suspected HIV infection; lower status of women; abuse of power by older or wealthier individuals; scarcity of HIV counselling and testing facilities and of condoms; lack of care and support for those infected or affected; poverty or trafficking that leads to prostitution; domestic violence and rape; military conflict and labour migration which split up families – the list is a long one and varies from place to place.

Recognition of the factors that fuel the HIV epidemic is key to the development of programmes for reducing vulnerability in the civil, political, economic, social and cultural arenas. Properly designed, these can reinforce the more traditional prevention approaches aimed at persuading individuals to change their risk-taking behaviour.

Social policy is essential

To be effective, therefore, personal risk-reduction programmes must be designed and implemented in synergy with other programmes, which, in the short and long term, increase the capacity and autonomy of those people particularly vulnerable to HIV infection. Social policy, with a clear statement of vision and values, is essential to provide a conceptual framework for vulnerability reduction. For example, the chronic and acute poverty of urban households that leads to their eventual breakdown and the move of children out of school and to the street (where they become highly vulnerable to HIV infection) is not an issue that can be easily addressed at a household or community level alone. Similarly, problems such as gender imbalance and the inability of women to negotiate when, how and with whom they have sex is the type of broad social policy issue that must be tackled if such programmes are to be successful.

Addressing the societal forces that determine vulnerability to HIV requires engagement at the policy level and political will and resources. Effective social policy reform is a long-term agenda, but even small-scale and incremental steps can send important messages about political commitment to

reducing the vulnerability of individuals and communities to HIV. (For an example of broad social policy creation, see Malawi's policy on orphan care in the accompanying paper.)

Fortifying young people

As programme planners turn their attention to different parts of the population, they must remember not only those who are currently exposed to risk but those who will face exposure in the future. Individual risk and vulnerability change over people's life cycle, and this change is especially marked as children mature into adolescence and adulthood. Many young people can go in and out of commercial sex during their youth period.

Among the various measures tried to date, the teaching of life skills has proved one of the most important for young people. The skills enable them to manage situations of risk for HIV/AIDS infection and prevention of many other health problems. Such skills include: how to respond to demands for sexual intercourse and offers of alcohol and drugs, how to take responsible decisions about difficult options, how to negotiate and apply risk reduction techniques, how to refuse unprotected sex when sexually active, and how to seek peer support and seek care including health services and counselling.

An important priority in the African context, given the large numbers of children who are not in school, is to find ways to teach these skills in the settings where out-of-school young people spend their time. (See next chapter for a discussion of the special vulnerability of girls and young women in the general population.)

The vulnerability of women and girls

Women of all ages are more likely than men to become infected with HIV during unprotected vaginal intercourse. Compounding their biological vulnerability, women often have a lower status in society at large and in sexual relationships in particular.

In the sub-Sahara African context, a number of culturally specific, gender-based practices (varying widely from country to country and within different cultural groups) can increase HIV transmission. These include widow inheritance and certain circumstances related to polygamy. (While absolute fidelity will protect a polygamous household from AIDS, infidelity in just one spouse can lead to all members becoming infected). Lower emphasis on educating girls and women's pervasive financial dependence on a husband or partner mean that they may endanger their primary relationship if they voice suspicions about male infidelity or ask for condom use. In addition, women entrepreneurs such as market vendors with little capital, unable to count on protection from the legal system, are especially vulnerable to sexual coercion in return for services or even the right to operate their business.

This gender vulnerability, again, is particularly acute for young girls, where the interplay of biological, cultural and economic factors makes young girls particularly exposed to the sexual transmission of HIV. While both girls and boys engage in consensual sex, girls are more likely than boys to be uninformed about HIV, including their own biological vulnerability to infection if they start having sex at a young age. Girls are also far more likely than boys to be coerced or raped, or to be enticed into sex by someone older, stronger or richer.

While there are many cultural and economic reasons for cross-generational sex, the fear of HIV seems to be prompting some men to seek out partners they believe are less likely to be infected – young girls. There is a double deadly irony here. Men who are fearful of acquiring HIV may be infected themselves without knowing it. Moreover, given the very high infection rates now being seen in girls, it is unwise to expect young partners to be free of HIV.

Whether sexual initiation is consensual or coerced, it may occur at a very early age in particularly marginalised communities. In a survey of 1600 children and adolescents in four poor areas of the

Zambian capital, Lusaka, over a quarter of children aged 10 said they had already had sex, and the figure rose to 60% among 14-year-olds. In South Africa, 10% of respondents in a study in six provinces said they had started having sex at age 11 or younger.

Men: also vulnerable, but in different ways

While women's vulnerability to HIV is increasingly well known, it is less often recognised that cultural beliefs and expectations also heighten men's vulnerability. Except in a handful of countries, men have a lower life expectancy at birth and higher death rates during adulthood than women. Many of the health problems that men face could be prevented or even cured with early medical intervention or a change in lifestyle. Yet men are less likely to seek health care than women, and are much more likely to engage in behaviours - such as drinking, using illegal substances or driving recklessly - that put their health at risk.

Some circumstances place men at particularly high risk of contracting HIV. Men who migrate for work and live away from their wives and families may pay for sex and use substances, including alcohol, as a way to cope with the stress and loneliness of living away from home. Men living or working in all-male settings, such as the military, may be strongly influenced by a culture that reinforces risk-taking behaviour. In addition to these specific risk settings, poverty and unemployment may increase men's sexual risk-taking as a way of compensating for their perceived loss of manhood. Research in some rural areas of Kenya and Tanzania finds that when men become unemployed and hence lose their status as providers, they are more likely to have sex with sex workers or other partners to feel "more like men".

In addition to men's prevention needs, far greater attention must be given to the needs of the millions of men now living with HIV, including helping them to avoid infecting others. On a continent where AIDS is causing illness and death on a vast scale, men must also be encouraged and helped to play a much greater part in caring for orphans and sick family members. Finally, even though the results may take years to materialise, it is important to challenge harmful concepts of masculinity, including the way adult men look on risk and sexuality and how boys are socialized to become men.

All this does not mean an end to prevention programmes for women and girls. Rather, the aim is to complement these by measures that more directly involve men.

In the year 2000, the theme of the World AIDS Campaign is "Men Make a Difference". By focusing on the male role in the epidemic, the Campaign aims to involve boys and men more fully in the effort against AIDS and to bring about a much-needed focus on them in national responses to the epidemic. In 2000, the Campaign has three broad goals. The first is to raise awareness of the relationship between men's behaviour and HIV. The second is to encourage men and adolescent boys to make a strong commitment to preventing the spread of HIV and caring for those affected. And the third goal is to promote programmes that respond to the needs of both men and women.

Migration and AIDS

In East and Southern Africa, various studies have shown a much higher HIV prevalence in people with a record of international mobility or migration (this is probably also true for internal migrants, but so far there is little data on this question). In West Africa, studies carried out in health care centres confirm the correlation between international mobility and vulnerability to HIV. For instance, research in the main health care facility for HIV-infected patients in Senegal shows that 70% of them have a migration background in Central and West Africa.

As used by UNAIDS, the term "migrants" includes people who move from one place to another permanently or temporarily, voluntarily or involuntarily. Some may be refugees or displaced persons. Other people cross borders for a wide variety of professional reasons. Whatever the circumstances, it must be remembered that *being a migrant, in and of itself, is not a risk factor for HIV and sexually*

transmitted infections; it is the activities undertaken and the situations encountered during the migration process that are the risk factors.

Migration issues are particularly important in the African context owing to the continent's large numbers of migrant labourers (particularly for the agricultural and mining industries) and those who are displaced by violent conflict (see below). Both male and female migrants frequently occupy vulnerable positions in the receiving society, with few rights in the place where they are living, and little access to social and health care services. Many may see their families only once a year, and are highly likely to form local relationships, visit sex workers or seek casual sex in places where alcohol is consumed. In such circumstances, the risk of HIV and other sexually transmitted infections is very high – a risk which then travels back to the spouses and sex partners of migrant workers when they return home.

Few national AIDS plans deal with migration in ways that take into account its importance to the international epidemic. This could be because of an "us" versus "them" mentality by national authorities, legal requirements to spend national resources only on citizens, or the political temptation to ignore illegal or undocumented immigrants. In fact migrant and ethnic minority populations, and also those who are internally displaced, all too often become 'invisible', and are easily forgotten.

War and AIDS

Armed conflict also causes mass displacement on the continent, particularly in chronic "hot spots" such as the Great Lakes region, the Horn of Africa, and the southern Sahara. Besides "official refugees" (as defined in the relevant UN Convention) there are also millions of internally displaced persons. The vulnerability of the latter may be even greater than that of refugees since, lacking official status, they are frequently ignored in public health planning and therefore have little or no access to services. Many are concentrated in conflict zones where relief organisations (including those providing health services) are frequently refused access on the grounds that the relief workers' safety cannot be guaranteed.

Such populations often fall between the cracks of international AIDS programmes as well. Since they move from place to place they become the responsibility of no one – yet the fact is that they interact with local populations, and can both affect and be affected by a wide cross-section of society.

Marginalized groups: forgotten or wilfully ignored

Groups who live on the margins of society exist in every country, although they differ from place to place. What marginalised groups have in common is an increased vulnerability to HIV, whether the individuals concerned are illegal immigrants, drug users, sex workers or men who have sex with men.

Those who engage in stigmatised behaviour are less likely to be cared about or even acknowledged by society's decision-makers, who do not want to spend their political or financial capital on AIDS programmes for them. Even where AIDS prevention and care services for them exist, individuals whose practices are against the law – or whose presence in the country is illegal – may be reluctant to risk exposure by participating in them and taking self-protective action against HIV.

Examples of Best Practice

Kenya: Life skills to fortify young people against HIV

Leadership issues summary

Leadership level(s): young people, community leaders, private sector (both national and international)

Contribution to success: understanding that leadership can be exercised by young people if properly supported and organised

Opportunities: could be used as a model for other countries

In Kenya, Mathare Youth Sports Association (MYSA) brings life skills and awareness of the HIV risk to young people before they become sexually active.

Mathare is the largest slum area in the Kenyan capital, Nairobi. MYSA began in 1987, when a football league was formed with the dual purpose of carrying out environmental clean-ups and organising sporting activities. By 1998, it was Africa's largest football organisation (410 boys' teams and 170 girls' teams). The original aim was to promote social responsibility and leadership both on and off the field. Since then, it has taken on the mission of fighting the HIV epidemic by promoting healthy living, teamwork, and involvement in community-improvement activities.

MYSA has been training its footballers to be peer educators about HIV since 1994, and is estimated to have reached some 20,000 young people between 1994 and 1997. Members of the senior squad, who are well-known and respected, and therefore have influence with their peers, were the first to be trained. The adolescents stress abstinence from sex; but for those who are sexually active, they emphasize the importance of using condoms and staying faithful to one partner.

MYSA peer educators talk about the problems of boy-girl relations, particularly the problems that arise when boys base their self-esteem on sexual conquests, and girls base theirs on having boyfriends. Peer educators aim to provide information and improve communication skills, with the goal of changing values and attitudes and strengthen peer support, all of which help reduce vulnerability to HIV risk behaviour..

The leagues are run by local committees of team coaches and captains. There is strong support from the private sector. Funding comes from a number of private-sector sponsors, including Orbitsports (supplies sporting equipment), Norsk Hydro (sponsors MYSA's professional football team), Coopers & Lybrand (audits the club's annual accounts gratis), Norwegian Agency for Development (NORAD), the Ford Foundation, and the Population Council.

Ethiopia: Save Your Generation Association targets out-of-school young people

Leadership issues summary

Leadership level(s): young people, community in cooperation with international agency

Contribution to success: willingness of young organisers to reach out to traditional leaders; emphasis on understanding the perceptions of the target group

Gaps and insufficiencies: insufficient funding to extend coverage

In Ethiopia, the Save Your Generation Association (SYGA) was implemented by a group of young men who wanted to do something about the rising impact of AIDS on young Ethiopians. Its main

objective is to change the health behaviours, including the sexual behaviour, of out-of-school young people in Ethiopia through peer education. The project's various activities include producing and distributing educational materials, training peer counsellors and educators, and promoting condoms.

Early on, the project recognised that achieving behaviour change among young people would require support from the wider community. SYGA therefore pursues meetings with established community groups (Edir members) to discuss the vulnerable conditions and HIV risks facing young people and what can be done about them.

Both community leaders and young people themselves agree that one of the most pressing needs of out-of-school young people is a source of income. If this need is not met, the prospects for successfully changing behaviours are extremely poor, and so SYGA works hard to create income-generation opportunities for its clients.

Tanzania: Advanced planning for AIDS prevention among migrant and local labour at a hydroelectric project

Leadership issues summary

Leadership level(s): national electric authority; international private sector and international donors; national and local authorities

Contribution to success: emphasis on learning from previous experience and thinking hard about vulnerability; willingness to invest resources in prevention and care

Opportunities: extend this model to other major infrastructure projects in sub-Saharan Africa

Planning for a five-year hydroelectric project for the Kihansi Falls in south-central Tanzania established that preventing HIV and other sexually transmitted infections was a priority both for the estimated 2,000 workers (mostly young men) expected to migrate to the area and for the 40,000 people already living near the dam site.

The national power company, TANESCO, working with its Scandinavian partners and local government authorities, benefited from lessons learned from an earlier project in the early 1990s. A public health project called MUAJAKI (taken from the Swahili name meaning "Kinhansi Participatory Public Health Project") was created early in the project cycle. It placed HIV/AIDS among several negative health consequences expected from the project, including a rise in malaria, alcohol and substance abuse, and industrial and motor vehicle accidents.

Activities began in 1996. These included: collection of baseline health data; information, education and communication campaigns; social marketing of condoms; new sexually transmitted infection (STI) clinics; monitoring; and support to people living with HIV. All MUAJAKI activities were integrated with the health care system of the local district, bolstering it with 10 health professionals, more support staff, and additional funding from the hydro project funders. Condom sales to date are far above the Tanzanian average, and the number of infections diagnosed in the STI clinics has been dropping.

Though final evaluation is not complete, MUAJAKI already shows the benefits of two important approaches to preventing HIV transmission in the workforce at major construction projects: (a) anticipating their social and public health impacts; and (b) integrating local health authorities in the planning and implementation of activities to mitigate such impacts.

International: Advocacy for AIDS responses that benefit women

Leadership issues summary

Leadership level: civil society as represented by women's groups

Contribution to success: determination to increase understanding of the gender component in HIV/AIDS epidemic

Gaps and insufficiencies: projects are all small-scale, with insufficient resources to scale up

The Society for Women and AIDS in Africa (SWAA) was formed in 1988 to provide a platform for women to address HIV/AIDS and the socio-economic conditions which make them vulnerable to the epidemic. The initial focus of SWAA was to bring to the fore the impact of AIDS on women in Africa, mobilise women at country level to carry out relevant activities, and develop a regional network of SWAA branches for inter-country exchange and collaboration.

After its first three years, SWAA recognised the need (i) to work with national programmes to promote action in respect of women and AIDS, (ii) to work with adolescents, especially girls, to develop risk-reduction skills and (iii) to broaden its network to include women living with HIV/AIDS as well as community-based women's groups not yet working on the epidemic to enable them to incorporate HIV/AIDS into their activities. Since then, SWAA's regional mobilisation initiative has resulted in the formation of 28 country branches. In Senegal, for instance, SWAA has achieved a high profile, particularly in its work among women working in factories and in its promotion of the female condom. As yet, however, no projects have been scaled up to a national level.

The spontaneous response of women to the epidemic has been encouraging, as is the high level of their commitment. A broader perspective on women and AIDS issues and interventions has ensured that women (besides female sex workers, who have been the focus of many prevention programmes) received greater attention than was the case. The involvement of adolescents has been rewarding, resulting in the formation of SWAA youth wings in some countries.

Tanzania: Female guardians at schools

Leadership issues summary

Leadership level(s): local educational authorities, working with students

Contribution to success: realistic understanding and willingness to openly talk about vulnerability of young girls; willingness to encourage leadership among community members

In Mwanza, primary schools work on an AIDS-competent environment by training so-called guardians. The main goal of the guardian programme is to create a more protective environment for primary-school girls, to prevent sexual harassment and exploitation, and to assist the girls in dealing with social and reproductive health problems encountered during their schooling period. The school Board, based on specified criteria, selects a guardian who is offered special training.

The programme is successful: pupils have been empowered to report culprits. The District Education Officer indicated that cases of sexual abuse of schoolgirls by teachers and of pregnancy among schoolgirls have gone down considerably. The school programme has now been accepted by the national government for replication nation-wide.

Reducing HIV/AIDS' impact on people

Cross-cutting themes

- Improved approaches for capacity building and brokering technical support
- mobilising domestic funds (public and private)
- mobilising international resources
- training and use of local managerial/technical talent

What must be done when AIDS strikes an individual, family or community? Practices range from palliating painful symptoms of AIDS to outlawing discrimination based on HIV status, and improving HIV-affected families' ability to generate income.

Before looking at ways of reducing the impacts of the epidemic, it must be understood just what these impacts are. As with most aspects of AIDS, its impacts are complex and multi-faceted.

Impact on individuals' health and quality of life

In public health, a focus on budgets and systems sometimes takes away attention from the human toll exacted by AIDS. The importance of palliative care – particularly reducing pain and discomfort – should be central to AIDS care programming. As their immune system becomes compromised, people living with HIV may suffer over a long period from a variety of opportunistic infections or cancers, experience multiple symptoms, and face a myriad of psychosocial issues. Moreover, the course of the disease is unpredictable: declining health may alternate with periods of physical and emotional stability, resulting in chronic uncertainty about what tomorrow will bring. Major symptoms include:

- pain, often increasing in severity as disease progresses
- diarrhoea and constipation
- fever, nausea, vomiting, anorexia and weight loss
- cough and shortness of breath
- fainting, weakness and tiredness.

Most people with advanced HIV infection require pain control at some point. While treatment of the underlying condition is important, pain relief is a priority: no one should have to suffer uncontrolled pain. In low-resource settings, however, pain management often receives inadequate attention. In the African context, the scarcity of doctors creates an obstacle in cases where, by law, only doctors can prescribe morphine and other narcotic painkillers. Uganda has tackled this obstacle by changing its legislation so that nurse-practitioners have this authority as well as doctors. It is also important to educate health workers to understand that they should not withhold strong medications such as narcotic painkillers for fear that the patient will become addicted. Overall, a balance has to be struck between ensuring adequate pain relief and careful supervision and record-keeping of narcotic painkillers.

The impact on families

The few surveys of the impact of having a family member with AIDS show that households suffer a dramatic decrease in income. Decreased income inevitably means fewer purchases and diminishing savings. Tragically, the prospect of new AIDS drugs becoming available in Africa adds a new danger to family stability, since the cost of these drugs (if unsubsidised) can quickly drive people into debt, force them to sacrifice their children's education, or sell off their farm equipment or animals and even their homes. When family members in urban areas fall ill, they often return to their villages to be cared for by their families, thus adding to the call on scarce resources and increasing the probability that a spouse or others in the rural community will be infected.

Families make great sacrifices to provide treatment, relief and comfort for a sick breadwinner. A common strategy in AIDS-affected households is to send one or more children away to extended family members to ensure that they are fed and cared for. Such extended family structures have been able to absorb some of the stress of increasing numbers of orphans, particularly in Africa. However, urbanisation and migration for labour, often across borders, are destroying those structures.

A distressing development resulting from the epidemic in Africa is the rising number of families headed by young children or very old persons, who not only have to do the myriad tasks needed to run a household but also have to care for the sick adults. While progammes can and must be created to support such families, the difficulties must not be underestimated. It is extremely difficult for children to understand and apply important aspects of home care such as improving hygiene, while the physical demands of housework and care tasks (for example, lifting bed-bound patients) may be extremely hard on both children and aged people. Care demands at home often force children to leave school, or severely affect their ability to study.

The rising tide of orphans

Before AIDS, about 2% of all children in developing countries were orphans. By 1997, the proportion of children with one or both parents dead had skyrocketed to 7% in many African countries and in some cases reached an astounding 11%. In African countries that have had long, severe epidemics, AIDS is generating orphans so quickly that family structures can no longer cope. Traditional safety nets are unravelling as more young adults die of this disease. Families and communities can barely fend for themselves, let alone take care of orphans. Typically, half of all people with HIV become infected before they turn 25, acquiring AIDS and dying by the time they turn 35, leaving behind a generation of children to be raised by their grandparents or left on their own in child-headed households.

Wherever they turn, children who have lost a mother or both parents to AIDS face a future even more difficult than that of other orphans. According to a report published jointly in 1999 by UNICEF and the UNAIDS Secretariat, AIDS orphans are at greater risk of malnutrition, illness, abuse and sexual exploitation than children orphaned by other causes. They must grapple with the stigma and discrimination so often associated with AIDS, which can even deprive them of basic social services and education. By the time one or both parents have died, household assets and property are often already sold off to pay for medical costs – leaving the children totally destitute. Sometimes the orphaned children only find out that they have nothing when new owners of their parents' property come to take possession.

When discussing programming for AIDS orphans in Africa, the special context of African cultures must be taken into account. In some ways the very phrase "programmes for AIDS orphans" is problematic because of the highly inclusive nature of childrearing in much of Africa. Families from all levels of society – even, and sometimes <u>especially</u> the very poorest families - may take in orphans and treat them as they do their biological children. Therefore, programmes which provide special services to orphans (school clothes and books, food, free education etc.) are likely to be disruptive if

the other children in the same family need those things but are not provided with them. Such exclusivity can offend the sharing principle so important to Africans, and may serve to exacerbate stigma directed at orphans.

The impact on societies

It is now clear that the population structures of badly affected countries will be radically altered by HIV. Many HIV-infected women die or become infertile long before the end of their reproductive years, which means that fewer babies are being born; and up to a third of the infants born to HIV-positive mothers will acquire and succumb to the infection. But the most dramatic change in the population comes around 10 or 15 years after the age at which people first become sexually active, when those infected with HIV early in their sexual lives begin to die off. The populations of women above their early 20s and men above their early 30s shrink radically. Only those who have not been infected can survive to older ages (though there are many other factors in Africa that keep life expectancy lower there than in other parts of the world).

What this means for society is hard to predict, since the world has never before experienced death rates of this magnitude among young adults of both sexes across all social strata. But there is one certainty: a small number of young adults – the group that has traditionally provided care for both children and the elderly – will have to support large numbers of young and old people. Many of these young adults will themselves be debilitated by AIDS and may even require care from their children or elderly parents rather than providing it.

Even without analysing the data on death rates, countries with severe long-standing HIV epidemics know from the massive increase in funerals that deaths are on the rise. The data show the same rising trend. Recent analyses of household-based data for countries with high HIV prevalence rates show clear increases in both adult and child mortality rates, which often appear after many years of a steady decline in death rates. The subsequent upturn has been attributed to AIDS.

The impact on economies

AIDS can affect economies in a variety of ways, from the micro- to the macro-economic. There is growing evidence that as HIV prevalence rates rise, both total national income and incomes per capita fall significantly. African countries where less than 5% of the adult population is infected will experience only a modest impact on GDP growth rate, but as the HIV prevalence rate rises to 20% or more (as it has in a number of countries in Southern Africa), GDP growth may decline by up to 2% a year.

All the major sectors of the economy are beginning to feel the negative effects of the HIV epidemic in Africa. For example, labour-intensive businesses will be severely affected by AIDS, and some companies report that profits are already reduced by 15% because of higher absenteeism, health care costs, death benefits, and retraining.

Some companies in Africa have already felt the impact of HIV. Managers at one sugar estate in Kenya said they could count the cost of HIV infection in a number of ways: absenteeism (8,000 days of labour lost due to sickness between 1995 and 1997 alone), lower productivity (a 50% drop in the ratio of processed sugar recovered from raw cane between 1993 and 1997) and higher overtime costs for workers obliged to work longer hours to fill in for sick colleagues. Direct cash costs related to HIV infection have risen dramatically in this same company: spending on funerals rose fivefold between 1989 and 1997, while health costs rocketed up by more than 10-fold over the same period, reaching KSh 19.4 million (US$ 325,000) in 1997. It is believed this is largely attributable to HIV/AIDS.

Agriculture is one of the most important sectors in most sub-Saharan countries, particularly when measured by the percentage of people dependent on it for their living. AIDS can be devastating to farming families. As an infected farmer becomes increasingly ill, he and the family members looking

after him may spend less and less time working on his family's crops. The family begins to lose income from unmarketed or incompletely tended cash crops, has to buy food that it would normally grow for itself, and may even have to sell off farm equipment or household goods to survive. (This can be particularly important where efforts to modernise agricultural production are constrained by reduced incomes of farming families who are unable to buy the required inputs such as machinery, fertilisers, pesticides or additional labour.) The vicious circle is compounded by the high costs of health care. And when the most debilitating phases of AIDS coincide with key farming periods such as sowing or clearing, the time spent nursing a sick person and lost to farm labour is sorely missed.

Altogether, the effects on production can be serious. In West Africa, many cases have been reported of reduced cultivation of cash crops or food products. These include market gardening in the provinces of Sanguié and Boulkiemdé in Burkina Faso and cotton, coffee and cocoa plantations in parts of Côte d'Ivoire. A recent study in Namibia by FAO concluded that the impact on livestock is considerable, with a heavy gender bias: households headed by women and children generally lose their cattle, thus jeopardising the food security of the surviving members.

Examples of Best Practice

Uganda: Specialised palliative care reduces suffering, improves quality of life

Leadership issues summary

Leadership level(s): international NGO with support of national health authority and funding from international donor

Contribution to success: willingness of government to support innovative approaches from "outside"

Gaps and insufficiencies: quality care is expensive and need is rising; requires consistent source of funding but national resources are scarce

Opportunities: high potential for extending capacity building in this often-neglected aspect of care beyond local area to national and international level

The Mildmay Centre opened just outside of Kampala in 1998. It provides comprehensive outpatient palliative care, and rehabilitative services, for men, women, adolescents and children living with HIV/AIDS. In palliative care, the relief of pain and other distressing symptoms can help prolong life, which in turn benefits the immediate community both socially and economically. Palliative care is also intended to facilitate a comfortable death with both peace and dignity.

Rather than becoming a patient's primary carer, Mildmay is a specialist referral centre which aims to support existing services, and to assist in patients' rehabilitation. The major problems of referred patients were persistent or recurring pain (47.02%), cough (39.45%), and skin problems (38.37%). Therapies or treatment prescribed by the doctors included medication (especially cotrimoxozole prophylaxis, particularly for children), counselling, spiritual support/counselling, physiotherapy, aromatherapy, nutritional advice, and occupational therapy.

Staff include doctors, nurses, nursing assistants, counsellors (including those skilled in working with children), a physiotherapist, occupational therapist, aroma therapist, nutritional advisor, as well as pastoral care workers, laboratory personnel, pharmacy staff, and a volunteer workforce to accompany patients around the Centre. The majority of referrals (90%) are from within and around the Kampala and Entebbe area.

While many patients pay at least part of the costs of the services they receive, Mildmay has a Hardship Fund to help pay for the care and treatment of all children and adolescents, and for some

adults. Many patients are children suffering from chronic disabling conditions, whose families and communities have great difficulty in doing anything to reduce their suffering.

In order to ensure capacity building in AIDS palliative care, the Mildmay Centre has been carrying out extensive educational programmes throughout the region. This is one of its most important roles, and one that benefits the response at a national level.

Mildmay is an expensive institution to run owing to the very high quality of care it provides and its excellent facilities. While it is clear that such quality and facilities cannot be provided everywhere in Uganda, the clinic has an important value as the country's "centre of excellence" for AIDS palliation. Its existence contributes to improving standards in the country, and in the region.

Zimbabwe: Organic Cotton Project helps AIDS-affected smallholder farming families

Leadership issues summary

Leadership level(s): international NGO with support of national health authority and funding from international donor

Contribution to success: willingness of government to support innovative approaches from "outside"

Gaps and insufficiencies: requires consistent source of funding but national resources are scarce

Opportunities: high potential for extending capacity building in this often-neglected aspect of impact alleviation beyond local area to national and international level

The Zambezi Valley Organic Cotton Project offers a number of benefits to farming families whose productive capacity has been undermined by AIDS.

Productivity and incomes among Zimbabwe's traditional smallholder farmers are some 10% lower than in the country's commercial farming system. Most cultivation is done by family members, using hand hoes and animal-drawn ploughs. At the same time, high HIV prevalence is striking the farming population hard. AIDS widows in particular suffer the effects of increased poverty, reduced availability of labour and lack of experience in managing the crop cycle. Many are left to look after six or more children.

At the request of about 40 women farmers (including widows) who could not afford to buy pesticides, Zimbabwe's first organic cotton project was set up in Zambezi Valley in 1995. With support from the NGO African Farmers' Organic Research and Training (AFFOREST), the project has grown considerably, successfully selling organic cotton and several other organic crops both locally and for export.

Many AIDS widows have joined the project, benefiting from the low input costs and lower labour requirement than traditional cotton cultivation. They receive training and support from AFFOREST-supported Farmer Field Schools, many of whose trainers are women. The curriculum includes a component on AIDS prevention and women's vulnerability, and the schools do social marketing of condoms.

An analysis during the 1997-98 season indicated that while conventional farmers spend more than 15 hours per week on pesticide-related activities (purchasing, carting of water for dilution, spraying), organic farmers spend 1-2 hours per week scouting for pests and predators. As well as saving on pesticide costs, the women avoid cash outlays for hired labour.

Kenya: Strengthening orphans for their future lives

Leadership issues summary

Leadership level(s): religious and community leaders working with local health authorities, and supported by international donors

Contribution to success: recognition that rising numbers of orphans will overwhelm traditional African child-rearing capacity, so new ways must be found to look after these children

Gaps and insufficiencies: insufficient resources

Working at grassroots level, the Kariobangi Community Based Home Care Programme is a good example of how to serve the children "left behind" by the epidemic. The problem is a huge one. In 1997 there were an estimated 416,000 orphans in Kenya, of whom 66,000 were HIV-positive. By comparison with pre-epidemic figures, the total number of orphans in 1990 was estimated to be 25,000.

The programme operates in the Korogocho slums in Nairobi, where formal employment opportunities are scarce and most homes are headed by women alone. A 1997 survey conducted in Korogocho showed 32% of the population was infected with HIV. Child-headed households are becoming increasingly common.

The Programme provides basic medicines and organises home care, both through the training of AIDS-affected family members and through voluntary Community Health Workers. In 1998, some 68 voluntary health workers cared for 1,880 people living with AIDS. They are supported by a team of five nurses, a social worker, and two counsellors, a social worker (who visits the mothers with AIDS and helps them plan for the future of their children), and a pastoral worker.

There is a strong emphasis on children in the project. As the AIDS epidemic expands it becomes more difficult to find family members to care for orphans. With this in mind, Kariobangi runs a Child Crisis Centre where children can stay temporarily when a mother is too sick to cope, or when a mother dies suddenly. The Crisis Centre is also a safe haven where children who are caring for sick parents come to learn, and where they can always get advice, moral support, and emotional support.

Children with HIV are given medical care under the programme. For children who are healthy, but who will in future be orphaned, there is a Children's Programme that prepares them for life without parents. They also 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 which it is hoped will help them in the future.

Implementing expanded responses

National strategic planning

A single, powerful national AIDS plan involving a wide range of actors – government, civil society, people infected with and affected by HIV, the private sector and (where appropriate) donors — is a highly valuable starting point of a strong strategic response to the epidemic. The development of a country strategy begins with an analysis of the national HIV/AIDS situation, risk behaviours and vulnerability factors, with the resulting data serving to set priorities and focus initial action. It is essential to find out where people in the country are already infected, where they are most vulnerable, and why.

Effective strategy development then involves drawing on evidence-based methods of HIV/AIDS prevention, care and impact alleviation – "best practices"- recognising that some of these may be culturally sensitive (for example, accessible and confidential reproductive health services for adolescent girls) or require hard political choices (for example, needle exchange for injecting drug users). At the same time attention needs to be given to ensuring that the relevant services and commodities such as STI services or condoms are affordable and available.

Formulating a national strategic plan will also involve learning from those programmes which have successfully, though usually on a small scale, dealt with different aspects of the epidemic. The Plan should work towards incorporating or adapting elements from these best practice programmes and implementing scaled up versions of them, to eventually provide national coverage of, say, voluntary counselling and testing, or 100% condom use. Governments can effectively adopt policy changes and programme approaches that have "passed the test" at the local level.

These programmes' staffs and volunteers have much to offer a national response. They can use their experiences and insights to train others so that the original programmes can be scaled up.

However, the process is not easy and requires patience and tolerance. Participation and consensus is essential, as opinions differ and it is important to listen to as many different points of view as possible and to take them into consideration during the planning process. While many countries have national strategic plans, they have often failed to act as a platform around which all actors have been willing and able to programme their resources. Impact on the epidemic is compromised by fragmentation. Different actors pursue different agendas in isolation from each other. Instead of working within nationally negotiated and agreed strategic agendas, actors – whether government or non government, UN or private sector – have tended to address HIV/AIDS as an area for designing and implementing multiple, often small-scale projects, with their own objectives, management, monitoring and evaluation systems.

The strategic plan must be implementable, given a country's constraints. There must be earmarking of funds specifically for HIV/AIDS, and they should include financial resources for action at community level.

It must be possible to move from planning to effective strategic management. This involves a strong monitoring process, feedback to decision makers, holding key players accountable for activities which they are responsible for.

Examples of Best Practice

Malawi: Consensus-building for the National HIV/AIDS Strategic Framework 2000-2004

Leadership issues summary

Leadership level(s): highest political level, with assistance from international agencies

Contribution to success: commitment to inclusiveness, ability to seek out participation from most sectors

Gaps and insufficiencies: financial and scheduling aspects have not been fully addressed, which may delay implementation or decrease its effectiveness

Malawi's experience shows how a broad-based national consensus can be built around a strategic planning process. The approach of using extensive workshops and community consultations proved effective as a means of gaining information about local situations. It also had the added benefits of informing a wide range of groups and institutions about AIDS as an issue, building a sense of ownership among these groups and institutions, capacity building, and giving the country's political leadership a high-profile document to commit to, with clear goals and principles.

Although the government has since 1985 undertaken a variety of HIV/AIDS activities, infection rates have not yet begun to slow down. Officials and donors have recognized that behaviour change is limited and a culture of silence is still a major factor. This has been compounded by weak institutional capacity to provide policy and technical leadership in such areas as surveillance, counselling, home-based care, civic education, and control of sexually transmitted infections.

Starting in 1998, Malawi created its Strategic Framework and Agenda for Action 2000-2005 with technical assistance from UNDP, UNICEF and UNAIDS. The process used was the Strategic Framework approach adapted from UNDP's HIV and Capacity Building Initiative, which emphasizes social mobilization and consensus building methods to create institutional involvement at the plan preparation stage. The Ministry of Health led the way by creating a Strategic Planning unit to manage the 18-month process, which proceeded as follows:

- Situation Analysis and Response Analysis (February-September, 1998) to estimate the current impact of the disease and document what the country was doing about it

- Strategic Plan Formulation (October 1998-April 1999) to decide what major actions had to be taken in response to prevaling conditions and estimated resource levels

- Consensus Building Phase (May-August 1999) to ensure that all significant partners (both existing and potential) in the response understood the plan and agreed with it.

These Situation Analysis and Response Analysis activities were conducted together through "issues workshops" aimed at gaining community input. This permitted an inventory of existing community actions against AIDS to be made. The resulting report was organised on thematic areas and provided a broad analysis of the existing strengths and opportunities in the national response. A total of 57 religious institutions, NGOs, and public and private organisations were involved in the process

The cost of the 18-month planning process was an estimated 1 million USD. A Resource Mobilisation round table (workshop) was held in March, 2000, during which partners pledged US$121 million.

The resulting Strategic Framework contains goals for nine major components of the response, guiding principles, broad objectives for each component, a budget estimate based on international partner pledges for the period, and strategic actions for each component. The nine components provide guidelines for districts or sectors rather than inflexible directives, with implementing agencies

expected to prioritise actions based on their own capacities. With the Framework as a broad guide, the next step was to write a detailed National Agenda For Action defining specific activities and listing implementing agencies or partners.

The process has not been perfect. An initial review of the Strategic Framework and Agenda for Action noted that no provision for a reprogramming cycle was made in order to plan for the period 2004-2008, and implementation arrangements are unclear and complex. There are as yet no mechanisms to define multisectoral action.

Nonetheless, Malawi has clearly moved ahead by putting together its first comprehensive plan on mitigating the impact of the epidemic, and on breaking the silence surrounding HIV/AIDS. With a view to maintaining momentum and ensure follow up, a Cabinet Committee on HIV/AIDS Prevention and Care, chaired by the country's Vice-President, was set up to guide policy formulation and implementation, speed up enactment of legislation on HIV/AIDS issues and ensure HIV/AIDS attains priority in all arms of government.

Cote d'Ivoire: Maintaining AIDS programming consistency despite national instability

Leadership issues summary

Leadership level(s): UN system working national health authority and other partners

Contribution to success: commitment to keep developing the national HIV/AIDS response despite uncertain political situation

In countries facing an uncertain political situation, wide consensus is hard to build, donors are notably reluctant to commit funding, and government priorities may change rapidly and often, making planning difficult. The interaction of Cote d'Ivoire's UN Theme Group on HIV/AIDS and its officials responsible for the national HIV/AIDS response provides a number of important lessons for coping with such circumstances and moving the response ahead.

Perhaps the most important lesson is the value of establishing close links between the Theme Group and the statutory national authorities responsible for AIDS. The links with Cote d'Ivoire's Ministry of Health and the National Programme Against AIDS, STIs and Tuberculosis (PNLS/MST/TUB) are not just formal but based on real participation at different levels. At the highest level, the Executive Director of 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.

The Theme Group in Cote 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.

In particular, the Theme Group has been able to formulate and adopt an Integrated Work Plan for the cosponor agencies (April 19, 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 PNLS/MST/TUB. The TWG met six times, using the PNLS/MST/Tub's operational plan for 2000-2001 as a base for analysis in order to identify ways the Theme Group could support in a joint fashion, and/or according to the specific mandates of each agency. Joint activities were listed, budgets specified and lead organisations formally designated.

As Côte d'Ivoire is currently directed by a transition government and the traditional international funders have frozen their activities, the Theme group provided a mechanism by which a formal relationship is maintained with important bilateral or multilateral actors in Cote d'Ivoire 's AIDS response, and close touch kept with 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 the antiretroviral ZDV against mother-to-child transmission, and several social science projects; USAID 's involvement with Projet Retro-Ci 's HIV testing and research work.

Malawi: National policy guides evolution of planning and programming for orphans

Leadership issues summary

Leadership level(s): national government working with UN system and a variety of national partners

Contribution to success: creation of clear policy guidelines which made sense for the country's specific conditions and political/administrative commitment to applying them guidelines consistently over time

In Malawi the problem of caring for AIDS orphans is already felt and is expected to worsen. Malawi's HIV infection rates are among the highest in the world standing at 13.0% of the population. With such high infection rates, the problem of orphans is a significant national priority, and efforts have therefore been made to systematically address the problem.

In 1991, the Government of Malawi with the assistance of UNICEF organised a National Consultation on Children Orphaned by AIDS to plan in which a large number of children would be orphaned by AIDS. This gathering realised that they were dealing with a complex problem that requires careful planning. The Consultation produced a 12-point "Policy guidelines for the Care of Orphans in Malawi and the Coordination of Assistance", to guide the development of a national Programme based on building capacities for orphan-care especially at the community and at national level. The Guidelines are simple and brief, and over the years have often been used by the Government as programme development guidance for groups interested in developing orphan care programmes.

The consultation also created a National Task Force on Orphans (NOCTF) to ensure that the policy is implemented. It includes national and district government representatives from the Ministry of Women Youth and Community Services; the Ministry of Health and Population through the National Aids Control Programme (NACP); key NGOs and Community Based Organisations (CBOs); major religious bodies in Malawi, and UNICEF.

In Malawi there are many stakeholders in orphan care necessitating proper and effective coordination, without which chaos could result. The first task was to lay down clear guidelines as to how the various issues would be handled i.e. who was responsible for what at all levels. In Malawi's case it was decided that there were already existing structures such as AIDS Committees, which would integrate, orphan-care rather than create new ones. These structures have been utilised ever since. Emphasis has been placed in building their capacity so that they can act independently and be self-reliant. This has been done through training and orientations, supporting networking and information sharing. Multisectoral approaches have also been given much emphasis.

Large numbers of orphans may be intimidating and lead to a programme that addresses only the immediate or survival needs of individual orphans such as shelter, homes, food and clothing and advocacy. In the early years, the Malawi Programme was unintentionally caught in this trap, where much attention was focused on these material and physical needs of orphans.

As the Malawi programme has grown it has increasingly began to recognise and address all the rights of children to survival, development, protection and participation. The integration of all rights has not

come about deliberately but per-force of circumstances for example older orphans increasingly participate in orphan - committees in various capacities. Experience in Malawi shows that orphans are vulnerable to having their rights violated even by their own guardians, the community at large and the State. Therefore deliberate steps should be taken to ensure that orphans are protected in any way possible. The frequently violated rights include the right to be heard in situations which affect their lives e.g. in adoption cases, custody, the right to inherit property from their deceased parents, right to education and health care in certain circumstances.

The need for cost effectiveness has been a major influence in the development of approaches in the Malawi orphans' programme. The current Orphan-care National Programme was estimated to require K20.0 million USD30 m) for the three years from 1996-1998, to meet the costs of capacity building at all levels, including that of the Ministry, NGOs, CBOs and village orphan committees, monitoring and assessment of the orphans, advocacy, policy and legal review. Experience has shown that funding from Government is lower than planned and erratic in the middle of economic restructuring. The Programme has relied heavily on donor funding as a result with Government providing support in kind, mainly manpower. Because of these constraints against a background of high demand for services, it is necessary to seek interventions that have a high impact at lowest costs.

The resultant approach therefore has been to target affected communities or those that show initiative, rather than individual orphans as this is an effective way of reaching the large numbers of needy orphans., The Programme has adopted the policy that the day to day responsibility for providing for children including orphans is that of the family or community, and should remain so. The Programme is therefore to strengthen this not substitute it. Targeting whole communities has the advantage of reduced per-capita costs, and therefore reaching more children.

Uganda: Keeping a strategic planning process on track

Leadership issues summary

Leadership level(s): highest national political office

Contribution to success: decisive action at a time when the process had slowed down and was becoming irrelevant

The development of Uganda's 2000-2005 National Strategic Framework for HIV/AIDS Activities is one example of the decisive role that can be played by national political leadership. The previous Framework (1998-2002) having been created but not implemented, President Museveni took personal charge of the planning process, which resulted in government-wide implementation of Uganda's 2000-2005 National Strategic Framework.

The process to develop the 1998-2002 Framework started in 1996, and was planned as a two-year process of extensive consultations among stakeholders. A core group of representatives from eleven key organisations (called CG 11) involved in HIV/AIDS activities in Uganda undertook the task of drafting this framework. These were Uganda AIDS Commission, Ministry of Health, Ministry of Local Government, Ministry of Finance, Planning and Economic Development (MFPED), UNAIDS, UNFPA, the Islamic Medical Association of Uganda, The AIDS Support Organization (TASO), Joint Clinical Research Center, Medical Research Council, and Networks and Associations of PHAs. The CG 11 was later expanded to include a representative from UNICEF) and Uganda Youth network on AIDS and STIs. Situational information was obtained from a range of commissioned studies. Finally, the drafting exercise was achieved through a series of meetings of the CG 11 and its thematic sub committees.

The draft framework was refined during the two workshops in 1997 that involved major partners in the area of HIV/AIDS in Uganda.

After that, the process lost momentum. Among other problems, many Ministries had not fully understood or accepted their role in a multisectoral approach, and were not prepared to make new

resources available for it. By 1999, the Framework had still not been adopted government-wide and, due to changing economic conditions and the development of the epidemic, was fast becoming obsolete.

At this point, the President intervened, emphasising his personal interest in this matter of national importance and insisting that the process be finished quickly. The Permanent Secretaries (heads of civil service) in all Ministries met to re-define their overall roles in the response, and the planning work was updated between September 1999 and March 2000. During that time, the Ministry of Health lent its AIDS expertise to other Ministries more actively than during the previous process, and this (plus the weight of the President's interest) made a considerable difference. A three-day consensus meeting was all that was finally needed for the Framework to be updated and adopted.

It is not the purpose of this paper to go into the details of the Framework, but in the context of our discussion of public administration and governance it is worth noting some structural innovation in the Framework, which should help the efficiency of the response. This is the creation by statute of a new National AIDS Commission and supporting Secretariat.

Responsible for overall coordination of all AIDS activities in Uganda, and for periodic evaluation and monitoring of the national program, the Commission is composed of a chairman not belonging to any government ministry and a maximum of seven members who are men and women of integrity and influence and, with knowledge and experience in HIV/AIDS. These will include one PHA, youth and at least one woman. Appointment of Commissioners and Director General for the Secretariat will be done by the President through an transparent political procedure including approval of suitable candidates by cabinet. Among other duties, the Commission will institutionalise a national joint planning team (NJPT) for the purpose of over seeing the national HIV/AIDS programme, specify data needs for evaluation, convene quarterly meetings of the NJPT for purposes of planning and harmonising plans and reports, and effectively monitoring and evaluating the national program.

Support to Local Responses to HIV/AIDS

Support to local responses to HIV/AIDS is based on the empowerment of communities through the development of local partnerships consisting of social groups, service providers and facilitators. United in these local partnerships, people are gradually building socially acceptable actions that enable them to respond adequately to the epidemic.

Such support can only be based on decentralisation of the overall management of national responses.

The District Response Initiative is now underway in about 15 countries, which represents 50% of countries with national strategic plans.

Examples of Best Practice

Gaoua: Consensus building of all actors

Leadership issues summary

Leadership level: governmental and non-governmental organisations, communities, NGOs, religious authorities

Contribution to success: Agreement on a common plan, shared objectives and priorities, mobilisation of own resources

Opportunities: Expanding local responses on a national and international level

Since 1987, the country has set up large scale HIV prevention activities. The country has been exploring, since 1998, different new approaches to become more effective in responding to HIV/AIDS. Those are currently being formulated in the 2001-2003 National Strategic Plan that is in the process of being developed, and will be finalised by the year 2000. It involves the Health Sector and non-health public sectors, as well as the voluntary and private for profit sectors, who take the necessary time and attempt to define the best solutions to the problems and realities of the country, in contrast to quick fix solutions imposed from the outside. Several Ministries, in addition to the MoH, are presently directly involved in the planning of activities: Economy and Finances, Social Action and Family, Secondary Education, Higher Education and Scientific Research, and Communication and Culture.

Presently the intensification of the national response lies in four domains:

- institutional strengthening (still heavily centralised health system and limited managerial capacity of NACP),
- financial sustainability (increase the financial support for new strategies and the national and district levels, and finding mechanisms for effective transfer of funds to Districts),
- HIV drugs procurement policies and strategies and kits and materials for safe blood transmission,
- Necessary changes in law (for example in more effective channelling of funds).

Tanzania: A ground-breaking by-law

Leadership issues summary

Leadership level: District Council, village governments, ward and village leaders

Contribution to success: Remedial measures to change behaviours

Opportunities: Decrease of vulnerability and risk

Socio-cultural factors that increase vulnerability to HIV/AIDS are being addressed by a number of district responses. Kyela District Council has passed a ground-breaking by-laws aimed at addressing local behaviours that increase vulnerability to HIV/AIDS. Following training sessions, Ward/Village leaders were challenged to identify cultural practices that increase vulnerability to HIV/AIDS and to propose remedial measures. This was done but later on it was decided by the District Council that all cultural practices that hamper development and not only those that increase vulnerability to HIV/AIDS, should be addressed. Village governments in Mbeya, Kagera and Mwanza have also adopted by-laws to fight HIV/AIDS. These by-laws usually discourage or sanction contexts that enhance sexual intercourse outside a monogamous marriage. The contexts identified vary by villages but include: widow inheritance, traditional ceremonies and festivities involving weddings, harvests and initiation ceremonies; alcohol consumption, collecting firewood by women late in evenings, men bathing near women in rivers or at the lake and the new disco culture. But risk factors associated with initiation rites at puberty do not seem to have been addressed anywhere. For example, initiation ceremonies for girls at menarche, which moulds them as subservient subjects for satisfying the sexual needs of their husbands, have not been addressed by the by-laws or other measures.

Bibliography

Challenges facing women's AIDS NGOs: the experience of SWAA. International Conference on AIDS. 1996 July 7-12; 11 (1) 390 (abstract no. TU.D.2736).

FAO and UNAIDS Joint Publication, UNAIDS Best Practice Collection. Sustainable Agricultural/Rural Development and Vulnerability to the AIDS Epidemic.

Orientation Global Network, AFP "Ghana turns to female condom to combat spread of HIV virus", 28 August 2000.

PR Newswire, "Female Condom 'Dream Come True for Ghanaians' First Lady of Ghana Supports Launch", 1 June 2000.

UNAIDS. Report of the Technical Consultation on Greater Involvement of People Living with or affected by HIV/AIDS (GIPA), June, 2000.

UNAIDS. Key Material, UNAIDS Best Practice Collection. Enhancing the Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA) in sub-Saharan Africa. A UN response: how far have we gone? October, 2000.

UNAIDS. Case Study, UNAIDS Best Practice Collection. Comfort and Hope: Six case studies on mobilizing family and community care for and by people with HIV/AIDS, June 1999.

UNAIDS. Key Material, UNAIDS Best Practice Collection. Acting early to prevent AIDS: The case of Senegal, June 1999.

UNAIDS. Key Material, UNAIDS Best Practice Collection. Collaboration with traditional healers in HIV/AIDS prevention and care in sub-Saharan Africa. A literature review. September, 2000

UNAIDS. Key Material, UNAIDS Best Practice Collection. Summary Booklet of Best Practices, Issue 1, June 1999.

UNAIDS. Key Material, UNAIDS Best Practice Collection. Summary Booklet of Best Practices in Africa, Issue 2 of the Summary Booklet series, September 2000.

UNAIDS. World AIDS Campaign. Men and AIDS – a gendered approach, 2000 World AIDS Campaign, March 2000.

UNAIDS. L'Equipe Interpays de l'ONUSIDA, L'Initiative Ouest Africaine, Resultats de Recherche-Action Projet "Migration et SIDA" Burkina Faso, Côte d'Ivoire, Mali, Niger, Sénégal. 2000.

UNAIDS. Presentation at OAU Health Ministers Meeting on AIDS, Ouagadougou, Burkina Faso, by Robert Hecht. Poverty, Debt, and AIDS – Mainstreaming the Epidemic and Mobilizing Additional Resources for the Response. May 2000.

UNAIDS. Presentation at 13th International AIDS Conference, UNAIDS Local Responses Satellite, by Jean-Louis Lamboray. Going to Scale with Local Partnerships on HIV/AIDS. July 2000

UNAIDS. Report on the global HIV/AIDS epidemic. June 2000

UNAIDS and WHO. Report on the global HIV/AIDS epidemic. June 1999

UN Foundation, UN Wire, "HIV/AIDS II: Botswana President Blasts Media Inaction", 21 April 2000, quote from Mmegi, Gabarone *Reporter*.