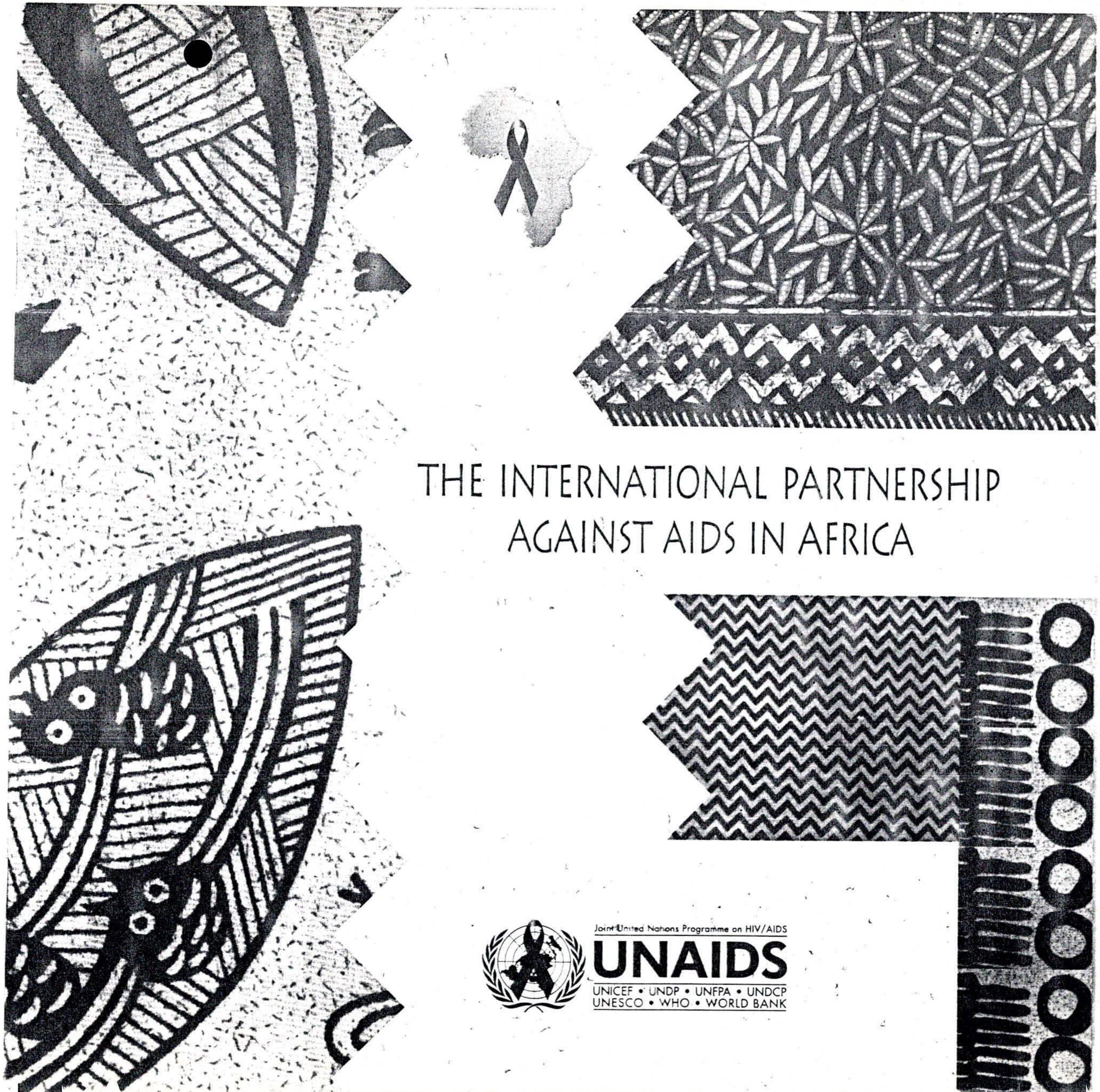

THE INTERNATIONAL PARTNERSHIP AGAINST AIDS IN AFRICA

Joint United Nations Programme on HIV/AIDS
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THE INTERNATIONAL PARTNERSHIP AGAINST AIDS IN AFRICA

Efforts to roll back the AIDS epidemic in Africa simply have not kept pace with the epidemic itself. A bigger, broader effort is needed if the response is to catch up. For many, the answer lies in the International Partnership Against AIDS in Africa. The Partnership is a coalition that works under the leadership of African countries to save and improve many lives. It is made up of African governments, the United Nations, donors, and the private and community sectors.

In international development, never before has such a multisectoral group joined forces to fight a single disease. By providing national leadership, African governments are spearheading broad-based national responses. United Nations organizations are coordinating the global response and providing programme and financial support to country-level efforts. Donor governments are also supporting action at all levels, providing input into substantive development of the Partnership in addition to financial assistance. The private sector is providing expertise and resources to help turn the epidemic around in the business community and beyond. And, finally, the community sector is working to ensure ownership of the Partnership within local civil society and to strengthen regional and country networks.

The Partnership's mission is as ambitious as it is simple: over the next decade, it will help reduce the number of new HIV infections in Africa, promote care for those who suffer from the virus, and mobilize society to halt the advance of AIDS.

AIDS IN AFRICA: DEVELOPMENT IN CRISIS

AIDS is the number one killer in Africa – it kills ten times more people than war.

Over the last two decades real progress has been made in many African countries in health care, education, life expectancy, economic growth and human security. Now, in the hardest hit countries, many of these advances are being reversed because of AIDS. Not just a health problem, AIDS in Africa has become a full-blown development catastrophe.

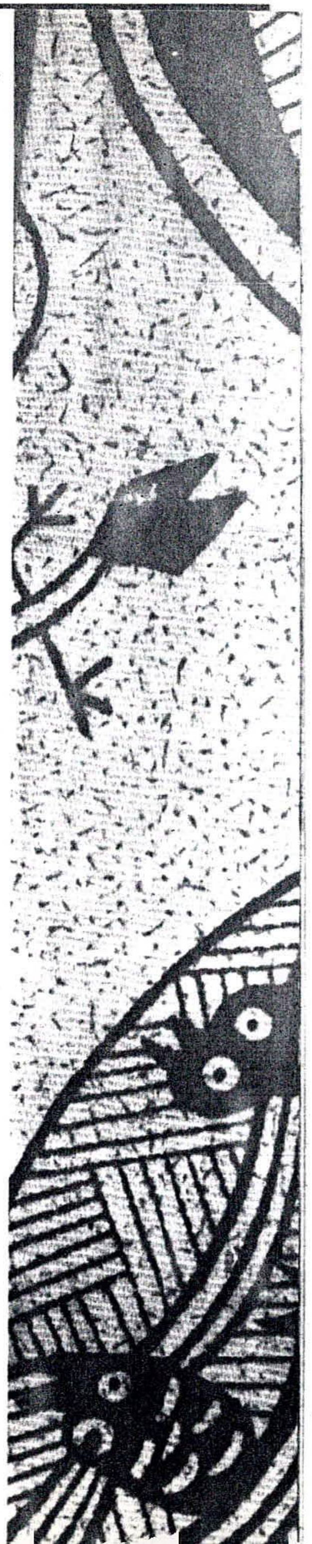
Few expected the AIDS epidemic to be even more devastating than the estimates predicted. In 1991, it was estimated that by the end of the decade, 9 million people would be infected and 5 million would die in sub-Saharan Africa because of AIDS. By the end of the decade, figures were nearly triple those predicted: some 24 million infected, and 13.7 million dead. In 1999 alone, there were around 4 million new infections in sub-Saharan Africa. The speed, spread and scope of the epidemic is unprecedented in modern times.

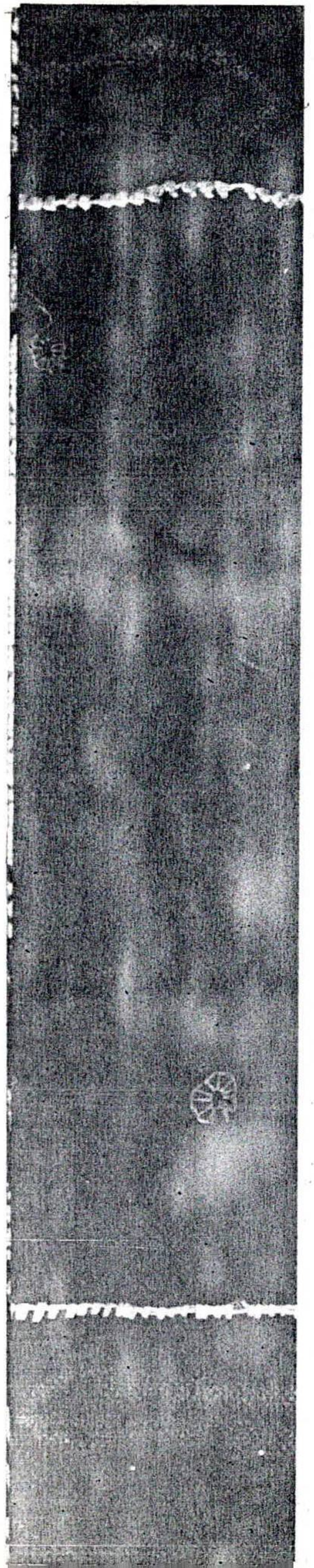
AIDS has become part of everyday life in Africa. It turns young sons and daughters into orphans, kills parents in the prime of life, and saddles grandparents with the dual burden of bringing up babies and trying to make ends meet without help from their own – now deceased – children. By threatening a generation of youthful, productive people, the disease is mortgaging the continent's future.

INTENSIFYING NATIONAL EFFORTS

To move the fight against the epidemic forward, African governments are intensifying their efforts and contributions. But with limited resources, they cannot be expected to turn the tide on their own. The Partnership, through its international outreach and visibility, provides swift and focused assistance – in other words, more resources, more expertise, and more alternatives. Through advocacy and mobilization involving all sectors of society at the highest level, it encourages governments, business and multilateral agencies to increase their resources to fight AIDS, either by reorienting or improving the way they use existing funds, or by seeking new funds if needed. The Partnership provides that extra push, the spark needed to assist countries in moving their programmes forward.

The Partnership's key role is at country level. It supports strategic plans to fight AIDS, and builds upon what already exists and works. By replicating proven successes, the Partnership helps channel isolated actions into coherent, cohesive plans. This capitalizes on individual efforts and avoids duplication, dramatically enhancing the impact of any one action by using it as a foundation for others.





WORKING AT COUNTRY LEVEL

Specific goals promoted by the Partnership include:

- giving young people aged 15-24 the information and skills they need to prevent infection;
- providing HIV-positive pregnant women with access to HIV testing and counselling, and to drugs that can increase their chances of having healthy babies;
- including people living with HIV/AIDS actively in all aspects of social, economic and political life;
- furnishing AIDS orphans with the means to grow up and lead meaningful lives;
- providing HIV-positive people with access to care in accordance with locally established standards;
- ensuring that national and international firms operating in Africa are fully involved in the fight against the epidemic;
- encouraging decentralization of HIV/AIDS programmes and participation of communities;
- promoting an end to stigma and discrimination by social and legal means.

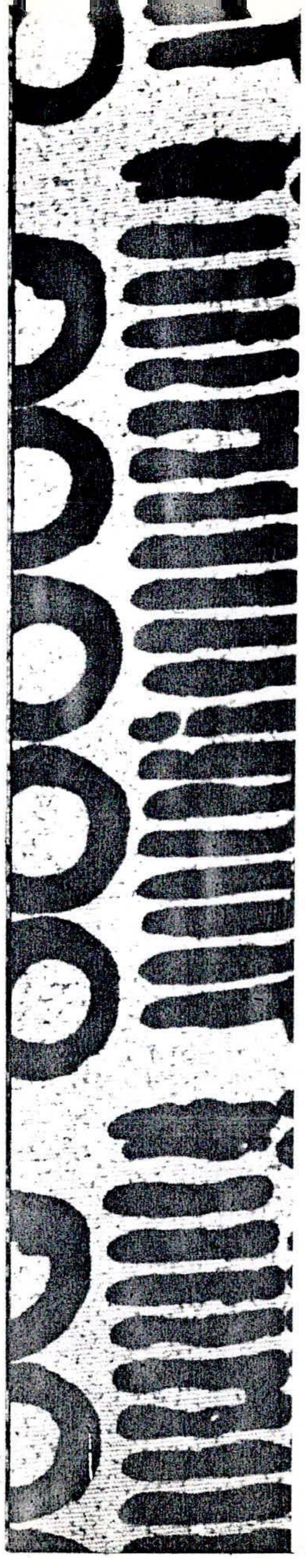
To turn these goals into reality requires not only resources but fundamental changes and intensified efforts within countries. The Partnership seeks to strengthen national responses to AIDS and supports political leaders in continuing to speak out. Most important, society at large must become involved and this is where the Partnership can make a difference.

BREAKING THE SILENCE

The silence and shame surrounding AIDS is slowly changing. Across the continent, African leaders are speaking out publicly about AIDS, giving it a name. Nations are establishing special task forces or technical committees on AIDS at the highest levels of government. Leaders who until recently denied the epidemic's very existence have made dramatic turn-arounds and declared war on it. News of deaths from AIDS touches everyone, including political leaders, some of whom have publicly acknowledged the disease's impact on their own relatives.

AIDS has now been recognized at the highest international political level. It has been discussed at the UN Security Council, the first time that body has ever taken up a health or social issue. It is also at the heart of discussions in major global development conferences, including the World Education Forum in Dakar and recent meetings of the Organization of African Unity.

These combined public acknowledgements have placed AIDS at the centre of the development agenda. Not only is the epidemic the fastest-growing human security issue in Africa, but it also affects every facet of social life.



AFRICA'S ACHIEVEMENTS

At the outset, the Partnership established a joint framework for action. which outlines its priorities and how the partners will work together. Emphasis has shifted to the country level, where AIDS prevention and care is being fast-tracked in a dozen nations. Here are some examples of accelerated action:

- Burkina Faso and Côte d'Ivoire have established a national solidarity fund for HIV/AIDS with a plan for action.
- The Uganda AIDS Commission has announced a five-year national strategy on AIDS.
- In Ethiopia, five-year national AIDS strategic framework and regional plans have been elaborated, and a funding mechanism will be developed soon.
- For the first time in Ghana, AIDS had its own heading in the new budget of early 2000. Also, the country's ministry of education has set up a task-force to tackle the epidemic in all education sectors.
- In Sierra Leone, the National AIDS Control Programme is resuming its role and will receive new international resources.
- South Africa has launched a new initiative, the South African Business Council on HIV/AIDS, to act as a clearing-house for programmes on AIDS in the workplace.

- Delegates from Angola, Mozambique and Namibia have met with counterparts in Brazil and will collaborate in several areas.
- A round-table discussion in Malawi with key partners has yielded unprecedented success in mobilizing new resources.
- Tanzania has integrated AIDS into its major development strategies, including the Enhanced Heavily Indebted Poor Countries (HIPC) initiative and the Social Development Fund.

On the ground, African communities have repeatedly demonstrated they can respond effectively to the epidemic. The international community must support them, and society as a whole should get involved in fighting AIDS.

Here are some examples:

- In Malawi and Zambia, a pilot project places HIV-positive people in jobs where their presence helps bring AIDS out into the open.
- In Kenya, local sports associations promote healthy living and safe sex.
- In Cameroon, Senegal, Uganda and Zambia, religious institutions incorporate information about AIDS prevention into their spiritual teachings.

- In South Africa and Zimbabwe, community groups provide affordable and equitable home-based care to HIV-positive people.

- Across West Africa, a special initiative on migration in 17 countries helps sex workers and their clients become less vulnerable to HIV.

The response to AIDS in Africa has moved to a new level, and commitment to maintaining that momentum has strengthened. For two decades, the world has fought AIDS and these years have yielded a body of knowledge we can now build upon. We know what works and what does not. The Partnership, by bringing different social sectors together and working collectively for the benefit of Africa, will make sure that lack of resources and fragmentation of efforts no longer stand in the way of advances.

Copies may be obtained from the UNAIDS Information Centre or accessed directly on our Web site (see below).

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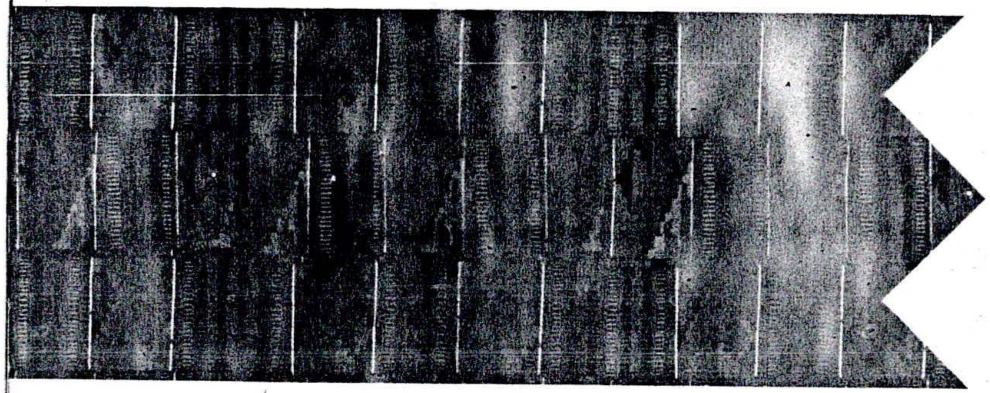

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Enhancing the Greater Involvement of People Living with or affected by HIV/AIDS (GIPA) in sub-Saharan Africa

A UN response: how far have we gone?

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Historical context

By June 2000, the number of people living with HIV worldwide had grown to 34.3 million, according to the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO). Of this total, over two-thirds resided in sub-Saharan Africa—a region with only a tenth of the world's population. Nearly 14 million adults and children have already died of AIDS since the beginning of the epidemic in the late 1970s. Moreover, during 1998, it is estimated that 11 individuals around the world became infected every minute.

The worldwide response of individuals and communities to the epidemic has been encouraging. With courage and compassion, they have mobilized resources to care for and support those affected and to assist others in remaining uninfected. Particularly striking has been the role of people living with HIV and AIDS (PWHA) who, within a short period of time, have given a human face to the grim statistics. (See Box 1 for definitions of terms used in the pilot projects.)

Although only a small percentage of persons living with or affected by HIV/AIDS have come out in the open, declaring their serostatus or the fact that they have been personally affected, those who have done so have been powerful catalysts in the subcontinent. The musician Philly Lutaaya is a good example of an individual who has made an impact and his message of behavioural change and hope reverberates across the continent in his song, Alone and Frightened. At the regional level, the voice of PWHA has been heard during the International Conferences on AIDS and STD in Africa (ICASA), held in 1995 in Kampala, and in 1997 in Abidjan. PWHA can provide important insights into how to address problems, how to strive for positive living and how people can be empowered through the trauma and tragedy of the epidemic.

However, in many sub-Saharan African countries, an environment characterized by high levels of denial, fear, and stigmatization has undermined the involvement of those living with or affected by HIV and AIDS. Even when the political, legal and social environments are conducive, the participation of those living with or affected by HIV and AIDS is seldom reflected in the formulation of national policies and programmes. Although the reasons for this vary from country to country, a certain pattern emerges. First, there is an absence of appropriate mechanisms to ensure that the experiences, perceptions and capacities of those living with or affected by HIV and AIDS are expressed, valued, understood and taken into consideration in the development of policies and programmes. Second, even when an appropriate forum is provided, individuals living with or affected by HIV and AIDS often lack the skills required to engage institutions and governments in policy dialogue. Third, many individuals living with or affected by HIV and AIDS are not in gainful employment, and are therefore too economically weak to engage in any serious discourse. Fourth, even when they are employed, the kinds of institutions they work for are unlikely to generate and initiate policy changes.

These issues were reflected in one of the major outcomes of the Paris AIDS Summit for Heads of State, held on 1 December 1994, where governments from over 50 countries called for increased support for PWHA. Participants resolved that the principle of greater involvement of people living with HIV and AIDS (GIPA) was critical to an appropriate, ethical and effective national response to the epidemic. They agreed to: "Support a greater involvement of people living with HIV/AIDS through an initiative to strengthen the capacity and coordination of networks of people living with HIV/AIDS and community-based organizations."

Box 1: Definitions and concepts as derived from the pilot projects

Individuals living with and affected by HIV/AIDS

The experience of implementing pilot projects in two countries—Zambia and Malawi—suggests that restricting participation to those who are seropositive eliminates critical parties who have experienced HIV and are committed to making a difference. For example, the experience of the many HIV-negative parents who have provided care to their HIV-positive children could facilitate an understanding of how households cope. The experience of the increasing number of discordant couples presents a unique opportunity for people to see that HIV affects ordinary people and, therefore, to encourage the acceptance of the problem within communities. During the recruitment process in Zambia and Malawi, it was also noted that there are many people outside the current networks of people living with HIV/AIDS who are prepared to use their experience without revealing their serostatus. Based on the understanding derived from such examples, an 'individual living with and affected by HIV/AIDS' can be defined as any person who is either HIV+ or has direct personal experience with HIV/AIDS and is committed to sharing their experience with others, to ensure an appropriate national response. An appropriate national response is one that includes policies, strategies and interventions that respect the rights and dignity of persons living with or affected by HIV/AIDS.

Giving HIV a 'human face'

In the mid-1980s, as developing countries engaged in aggressive economic austerity measures, UNICEF raised concern that these economic measures were hurting people in several ways. In their recommendations to the World Bank and International Monetary Fund, they spoke of structural adjustment with a human face. In this context, the human face was meant to reflect the fact that, at the end of the day, these policies must *improve* rather than hinder the welfare of the people. This led to the emergence within the international community of various projects intended to ameliorate the effects of the austere programmes. In the context of HIV, the issue of 'human face' goes beyond welfare to include the experience of those affected—their joys, sorrows, sense of identity and their need to be accepted as part of the community. Giving HIV a human face therefore includes the individuals affected showing the rest of the world that, beyond the grim statistics, are humans—mothers, sons, daughters, nieces, nephews, grandmothers and grandfathers who aspire to living a full life.

Although the GIPA mandate has been generally accepted by all countries, there are still very few successful initiatives under way. Part of the reason for this has been the absence of demonstrated mechanisms for implementing the GIPA mandate. In an effort to address this gap, a collaboration was established among United Nations Volunteers Programme (UNV), United Nations Development Programme (UNDP), The Network of African people living with HIV/AIDS (NAP+) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) to pilot a GIPA initiative in selected African countries.

Why the initiative?

The initiative was deemed necessary for the following reasons: first, to provide the required social setting for dialogue on issues related to HIV/AIDS with those who are affected; second, to allow for the expansion of the national response by involving individuals whose representation has, until now, not been fully recognized (such as parents who are HIV-negative but have nursed an adult child who is HIV-positive, or families wherein one of the partners is HIV-negative); third, to give a human face and voice to the current statistics of HIV/AIDS; fourth, to facilitate the acceptance of the presence of HIV/AIDS in the community; and fifth, to improve the economic status of those living with and affected by HIV/AIDS.

Using a participatory approach to design the project, a consultative process was initiated early in 1995 and preparatory studies were carried out to examine the impact of employing HIV-infected individuals in the insurance sector. The final outcome of this process was a project document entitled, "UNV project to support people living with HIV and AIDS". The project was approved in September 1996 with funding from the Special Voluntary Fund (SVF) and UNDP. Two countries—Malawi and Zambia—were selected to implement a two-year pilot project whose main purpose was to test the use of the national United Nations Volunteer (NUNV) modality as a possible mechanism for enhancing the greater involvement of individuals living with or affected by HIV and AIDS in the national response. The project was launched during the second quarter of 1997 and it is being implemented with technical and financial support from UNAIDS and the UNDP Regional Project on HIV and Development for sub-Saharan Africa, which is based in Pretoria, South-Africa.

The UNV pilot project to support people living with HIV and AIDS

Objectives

The long-term objectives of the project are to deepen understanding of the nature of the HIV epidemic and to strengthen the national capacity to respond effectively, through the involvement of people affected by the epidemic. Specific key objectives include:

- ensuring that the knowledge and expertise of people infected and affected by the epidemic contribute to decision-making at all levels and in all relevant institutions, and that their needs and insights are reflected in policy and programme development;

- strengthening the capacity of networks and organizations of those living with HIV and AIDS for strategic planning and programme management;

- encouraging recognition of the potential role of volunteers and volunteerism in the national response to the HIV epidemic.

Strategic approaches

To achieve these objectives, the project is adopting the following key strategic approaches:

a) Placement of NUNVs in carefully selected local institutions—both public and private—that are involved in HIV and AIDS prevention, care and support activities (see Box 2 for examples).

Box 2: Examples of NUNV placement in Malawi

Heatherwich CHISENDERA

Three times a week, Heterwich shares his experience of living with HIV/AIDS with patients and their escorts at the outpatient waiting room of the 1000-bed Lilongwe Central hospital. He is one of the volunteers placed at the hospital as a counsellor. His primary role is to add value to the HIV/AIDS efforts, activities and programmes of this hospital by giving a human face and a voice to HIV/AIDS for the staff, inpatients, outpatients and caregivers. He normally concludes the sharing of his testimony by saying, "If you have any questions you need to ask, or some issues you want to discuss with me, please come to the counselling room any time." Since his placement, there has been a steady increase in the number of people seeking help and support. The number of clients counselled and tested increased from 36 per month in March 1998, to 87 per month in October 1998. Because of the increasing number of people seeking support, the hospital has now designated every Tuesday as HIV/AIDS clinic day.

Chrissie MILEMBE (RIP)

The impact of Chrissie's testimony can be seen in the reaction of her audience. People were quite attentive as she talked about her life, how she felt and the way people reacted when they learned of her HIV status. "People used to tell me that I am a walking corpse, but let me ask you, 'How would you feel if somebody told you that?'"

Chrissie, a National United Nations Volunteer, had been placed at the Lilongwe AIDS Counselling and Education Centre as a counsellor. She assisted in HIV/AIDS awareness outreach activities and provision of support to HIV-positive clients. She also coordinated the activities of people living with HIV/AIDS in the centre. It was not unusual to find the room completely

> silent following Chrissie's testimony. This silence lasted a few minutes and then there would be countless questions and consequent discussion. Chrissie would say, "You see, AIDS affects you and me, and it's you and me who should do something about it."

b) Capacity-building for NUNVs through training to increase their knowledge and skills base in areas such as policy analysis and development, project development, and project/business management.

c) Capacity-building for representatives of the national network and of organizations or support groups of PWHA through training to increase their knowledge and skills base in areas such as policy analysis and development, project development, and project/business management.

d) Establishment of a micro-grants facility to promote and support community-based initiatives that will arise from the work of the NUNVs, and to develop and strengthen organizations of PWHA and their networks (see Box 3 for an example).

Box 3: Facilitating the establishment of income-generating activities in Zambia

> **Martin CHISULO**
>
> **As a NUNV placed with the Copperbelt Health Education Project (CHEP), Martin has facilitated the establishment of support groups and is helping those that were already in existence but were not progressing well. He is a member of one of the groups. Through him, this group acquired a building that has been renovated with support from the Catholic Church, and a plot of land where members are growing vegetables for their own consumption and for income generation.**

Implementation, monitoring and evaluation processes

To ensure long-term sustainability, emphasis is being placed on ownership by host institutions, the Network of African People Living with HIV and AIDS (NAP+) and government. A key feature of the project is the elaborate process of consultation at every major step of its design, implementation and monitoring. To reflect the consultative process at an institutional level, a governance structure at global and country level has been put in place. These mechanisms are required to ensure the participation of all key stakeholders in the development, implementation and monitoring of the project. The processes defined below highlight how the consultation has taken place on the ground.

Phase 1 – Selecting pilot countries

It was considered important to test the feasibility of using the UNV mechanism to promote GIPA in countries with a mature epidemic and relatively mature response. A preliminary review of documents and discussions resulted in a shortlist of four countries, agreed upon during a joint UNAIDS/UNDP/UNV meeting, which took place in Geneva, 24-25 October 1996. Thereafter, an assessment mission supported by UNAIDS was carried out in the four short-listed countries (26 October-30 November 1996). A combination of key informant interviews and group discussions with potential stakeholders was the *modus operandi* for the assessment mission. Although there was variation between countries, in general the following potential stakeholders were consulted: national support groups and networks of PWHA; National AIDS Control Programmes; AIDS service organizations; nongovernmental organizations (NGOs); UN Theme Groups on HIV and AIDS; and donors. Each of these groups was given the opportunity to participate in the initiative. Two English-speaking countries were selected, based on pre-set criteria. Using the pre-set criteria, the meeting held in Geneva, 5-6 December 1998, agreed that the piloting would be carried out in Malawi and Zambia. With the country selection process completed, two Country Project Coordinators (CPC) were recruited and placed in Lilongwe and Lusaka (see Box 4 for the job description).

Box 4: Job description for Country Project Coordinators

- To manage the day-to-day operation of the project in the country of assignment.
- To assist in the negotiations, selection and placement of the NUNVs in institutions/organizations.
- To support training of the national UNVs (NUNVs)—both formal and on the job—and provision of other forms of support for skills development.
- To work closely with and coordinate all necessary activities among the responsible national bodies/mechanisms, UNDP, UNV, nongovernmental organzations (NGOs), community-based organizations (CBOs), and NAP+.
- To ensure the access of NUNVs to appropriate peer support, counselling and supportive services.
- To provide appropriate guidance and support to the UNVs.
- To assist in developing policies and strategies relating to disclosure, confidentiality, and public profile of the NUNVs.

- To appraise the performance of the NUNVs and provide feedback and of the NUNVs and performance appraisal of the NAP+.
- To administer the small grants component of the project.
- To carry out on-going assessment and refinement of the pilot project and drawing-up/sharing of lessons.
- To work closely with all parties involved in the project formulation, implementation, monitoring and evaluation.

Phase 2 – Launching the project in the two selected countries

In the spirit of consultation, the launching of the pilot initiatives in the two countries involved planning workshops (see Box 5 for the aims and objectives of the workshops).

Box 5: Aims and objectives of the consultative and planning workshops

The workshops were intended to provide an appropriate launch for the project by bringing together a large number of stakeholders in each country, thereby making the process as inclusive as possible. The specific objectives of the workshops were as follows:

(a) to reach consensus and common understanding on the aims and principles of the pilot project;

(b) to identify mechanisms for project implementation, including selection and recruitment criteria of the national UNVs, their placements within institutions such as CBOs, NGOs, and ministries, training needs and methodologies, and support and supervision;

(c) to discuss aspects of project monitoring and evaluation;

(d) to agree on an action plan for the way forward.

The Malawi workshop was held in Lilongwe, 27-29 May 1997, and the Zambia one in Lusaka, 2-4 June 1997. Participants included representatives from support groups and national networks of PWHA, AIDS service organizations, NGOs, NGO umbrella organizations, government ministries and cosponsors of UNAIDS, as well as resource persons from such organizations as the Faces Project from South Africa, the Philly Lutaaya Initiative from Uganda and NAP+. The results of both workshops were similar. A consensus was reached on the purpose and basic principles of the pilot project and on the selection criteria for NUNVs. Mechanisms were identified for implementation, including placement within host institutions and supervision methods. Training needs were also identified, along with potential resources for training in and outside the country. Finally, participants at each workshop came up with a three-month action plan to be carried out by the UNV Project Manager, with the assistance of a Project Advisory Group (PAG).

Phase 3 – Designing a monitoring and evaluation framework

The uniqueness of the design of this pilot initiative was the participatory development of a monitoring and evaluation framework. A technical mission visited both countries and worked with the project's main stakeholders to develop three major elements of the initiative: i) a monitoring and evaluation framework; ii) a process that will enable those involved to identify and meet the training and support needs of the Project; and iii) a decision-making process for the use and monitoring of the project's micro-grants facility.

Using the process facilitation approach as outlined in the UNDP manual, the facilitators worked with key players to achieve the following outcomes:

i) a Monitoring and Evaluation Framework for each country;

ii) Guidelines for the Management and Operations of the Micro-Grants Facility;

iii) a document on Training and Support Strategies, including checklists for follow-up activities.

Phase 4 – Selecting candidates for NUNV posts and identifying future training needs

To facilitate the selection of NUNVS, a joint UNAIDS/UNDP mission was carried out in Malawi, 25–31 January 1998, and in Zambia, 31 January–8 February 1998. This mission was a follow-up to a meeting of the International Technical Advisory Group (ITAG) held in Abidjan, Côte d'Ivoire, 11 December 1997. The terms of reference for the mission are detailed in Box 6. The selection process used a workshop modality to provide 'safe spaces' for potential NUNVs and host institutions to reflect upon their expected roles and responsibilities within the project, to better facilitate their informed decisions about their participation in the project and to define an objective framework for selection of the first group of volunteers to be recruited by the project. Specific objectives of the workshops were for the participants to: i) share their understanding of the project mission and proposed strategy, as well as their roles and responsibilities; ii) express their vision, hopes and fears regarding their roles and the concept of volunteerism; iii) clarify myths and misinformation about the project; iv) discuss and reflect upon the implications of being open about their serostatus (on self, family and community); and v) understand the minimum criteria for selection of the first group of volunteers and define areas where the other candidates could contribute to the project.

Box 6: profile and duties of the NUNVs

Although their job titles vary, their primary function at these institutions is to give HIV/AIDS a human face and voice by sharing their experience of Living with HIV/AIDS, providing peer education or counselling and where possible by initiating discussion/support groups for PLWA. It is expected that the activities of the NUNVs would encourage the development/ enhancement of HIV/AIDS activities, programmes and policies. The volunteers' activities have been categorised into four areas:

i) Sharing of experience with various staff and management within the host institution;

ii) Individual discussions/counselling within the host institutions. These are the one-to-one sessions which Volunteers have at the work place with staff;

iii) Out-reach activities: This refers to Sharing experiences qand performing HIV/AIDS awareness activities outside the host institutions e.g residential quarters, churches and at community events.

iv) Other activities. These activities are not related to sharing experience but are carried out by the NUNVs as in the case of Volunteers with additional responsibilities.

In both countries, the main outcomes were: i) a greater understanding of the project's vision, mission, and proposed strategies, of the roles and responsibilities of each partner, of the concept of 'coming out in the open', and of the selection criteria for NUNVs; ii) a strengthened commitment to the objectives of the project; and iii) the completion of the selection process for NUNVS and host institutions. (See Box 7 for an example of the experience of a host institution with the placement of an NUNV.)

Phase 5 – Capacity building

The fifth phase of the project's implementation involved training for the NUNVs, their counterparts in host institutions and representatives of various support groups and networks of PWHA. Following the Self-reflection and Selection Workshops, the following training needs were identified: a) HIV and development (broader understanding of the epidemic); b) public speaking and media approaches; c) communication skills (including interpersonal skills and team work); d) peer counselling skills; e) writing skills (including reports, project proposals, record keeping); f) micro-project financing (including formulation, monitoring and evaluation); and g) setting up and sustaining support groups.

Box 7: Experience of a host institution with the placement of an NUNV

The Copperbelt Health Education Project (CHEP)

CHEP is an NGO that is involved in the provision of Information, Education and Communication (IEC). Its target audience is the general public and, in particular, the vulnerable groups within society. It provides training to improve services, create a supportive environment, improve counselling services for PWHA and promote appropriate low-risk sexual behaviour.

Before its involvement with the GIPA pilot project, CHEP had both positive and negative experiences while working with PWHA, and the decision to have a PWHA working as an NUNV was informed by these experiences. The first thing CHEP management did was to appoint the new NUNV as Coordinator of PALS programmes, in order to give him greater responsibility and to broaden its own perception of the involvement of PWHA in HIV/AIDS activities.

CHEP was responsible for providing orientation for the NUNV in its ten districts to help him familiarize himself with the province and to understand the problems facing those living with HIV/AIDS. CHEP has helped the NUNV to form five support groups, which have regular meetings, and to participate in Radio Ichengelo—a community station and television. CHEP has also funded three workshops in which the NUNV has been a resource person. Finally, as an organization, CHEP has taken its own initiative to give four support groups an amount of K250,000 (Zambian kwacha) to boost income-generating activities.

In spite of this, CHEP continues to face some challenges in promoting the greater involvement of PWHA in the fight against HIV/AIDS. These are: (a) the failure to provide adequate medical assistance for support group members; and (b) the increasing number of deaths among support group members, which has a negative effect on other members and on the project (e.g. greater contributions expected from the project in terms of funeral arrangements).

In response to this, successful HIV and Development Workshops and a Skills Training Workshop have been held (Zambia, in April and October 1998; Malawi, in September 1998). The Skills Training Workshop included sessions on the basic facts about HIV and AIDS, peer counselling, basic nursing care, nutritional care, advocacy for ethics and human rights, communication skills, group formation, report writing and record keeping, project proposal writing and stress management.

Phase 6 – Translation of the monitoring and evaluation framework into an operational tool for day-to-day management

The framework for monitoring and evaluation which was developed requires further operationalization. Terms of reference have since been developed, especially for the special studies, and both countries are at the stage of implementing the evaluation framework.

Lessons learnt

In order to inculcate a systematic process of learning at global and country level, a joint UNAIDS/UNDP/UNV meeting was held in Bonn, 6-7 April 1998, to go over the experiences gained during the 18 months of the pilot initiative design and implementation.

On the selection of countries

The following were the key lessons that emerged in Phase 1 of the implementation of the pilot initiative in Zambia and Malawi:

(a) Consensus-building around key concepts and operational modalities is critical to the success of the initiative.

(b) It is necessary to establish a shared understanding of HIV and development. The assumption that stakeholders have a working knowledge of the broader developmental dimension of HIV is not valid. During the consultative and planning workshops, some of the stakeholders were not even convinced of the seriousness of the HIV epidemic in their countries. In future, consultative and planning workshops should aim to give all the project's stakeholders the opportunity to reach a shared understanding of the HIV epidemic and its consequences. This would facilitate discussions on selection criteria for the recruitment of NUNVs, and on the roles and responsibilities of host institutions and NUNVs. The use of tools such as the HIV and development workshop before the consultative and planning process would address this problem.

(c) The facilitators should challenge selection criteria proposed during these workshops which may prevent potentially good candidates from being recruited as NUNVs on the basis of, for example, their literacy level or their ability to communicate in the official language (e.g. English). In one country, such criteria have prevented good candidates (especially women) from being selected.

On developing a monitoring and evaluation framework

The monitoring and evaluation frameworks for both countries were derived directly from the project document and are therefore a good reflection of the project's goals and objectives. As indicated above, they were developed with the participation of many stakeholders, but before the selection and placement of the NUNVs. However, the job descriptions of the NUNVs seldom reflect the monitoring and evaluation framework. Moreover, in one country, none of the job descriptions outlined the major function of the volunteer as that of "giving a human face and voice to the HIV and AIDS epidemic."

In addition, the effective use of the monitoring and evaluation framework has been hampered by the fact that in neither country was a baseline assessment conducted at the start of the project. Finally, the framework for each country does not include simple monitoring targets, indicators and tools, which now need to be developed.

On the selection of candidates

The Self-reflection and Selection Workshop, whose main objective was to give an opportunity to candidates to reflect on what it means to talk publicly about their HIV status and their personal experience, was quite stressful for participants. Nonetheless, it was felt that this process was necessary, since future NUNVs would be required to be fully 'open' about their own HIV status, or about how they and their family have been affected by HIV and AIDS.

There had also been an assumption that there would be a strong feeling of 'togetherness' among the members of a particular support group. It was expected that the group would take pride in, and support, the recruitment of one or two of its members and that the NUNVs would be regarded as ambassadors of the group in whatever role they were placed. However, this did not prove to be the case and the problem of competition arose several times.

Methods should be found to minimize the stress induced by the exercise. Possible methods include shortening the selection process, and emphasizing the fact that the recruitment of ten (or more) NUNVs is only one aspect of the strategy/ activities implemented by the project in the country. For those not selected during the first round, the project will provide the following opportunities: i) access to a micro-grants facility (for capacity building, income generating or networking activities initiated by their support group); ii) participation in 'generic' training workshops; and iii) the possibility of being recruited during the second (or third) year.

On the micro-grants facility

The micro-grants facility was established in order to help achieve the project's objectives. In accordance with these objectives, funding made available under the micro-grants facility can be accessed for the purpose of: a) promoting and supporting community-based initiatives that have arisen from the work of the

NUNVs; or b) developing and strengthening PWHA organizations and their networks. Eligible activities may fall into any of the following categories: community group and workplace discussions; capacity-building activities for the volunteers' own support groups; networking; legal assistance; training for members of community-based groups and PWHA organizations (e.g. public speaking, communication skills, skills training, counselling, psychosocial support, home- and community-based care, programme development, monitoring and evaluation, proposal and report writing); income-generating activities (including for survivors); psychosocial support (e.g. counselling, care for support group members and their families).

Although funds were put in place at the beginning of the project, more than 18 months passed before a few proposals submitted by PWHA support groups and NUNVs were finally screened and approved in Zambia. This experience has demonstrated the need for technical input from the project's management team and advisory group. It is felt that skills training on project and proposal writing should have taken place at an earlier stage in the implementation of the project.

On training

The HIV and development workshop proved to be a very powerful tool for bridging the knowledge and attitudinal gaps identified among the various stakeholders of the projects. As already mentioned, however, this workshop should have been conducted much earlier in the consultative process in order to provide an in-depth understanding of the epidemic as a foundation for all subsequent stages of the process. There is also a need to modify some of the content and exercises used in the workshop to improve their tone and make them more user-friendly.

The skills training programme that was organized as a one-week workshop has now been developed into a draft curriculum. This draft will be further refined in the expansion of the project to French-speaking Africa. A week of discussions was held between two of the experts who had conducted the training in both pilot countries. These discussions were aimed at assembling the different components into one draft. It was decided that the curriculum should be packaged in two portions: the workshop portion and the 'on the job' support and supervision of the development of specific skills (e.g. peer counselling, communication and public speaking, report writing, and support group formation). Most of these skills require practice and close supervision if they are to be mastered.

On the concept behind the pilot project

The overall aim of placing volunteers with host institutions is to give a human face and voice to HIV and AIDS. This human face and voice can be demonstrated within the workplace, and through the services offered by the host institution to its target group(s). Importantly, the volunteer must not merely be seen as just an additional employee, but as one who adds value by virtue of his experience of living with or being affected by HIV/AIDS.

However, 18 months after launching the project, it seems that some host institutions, despite all the consultation processes put in place, still consider the volunteers as just an additional pair of hands. Moreover, it has been reported in some instances that some volunteers regard it as a violation of their human rights for the project to expect them to share their personal testimonies in the course of their work.

This is a delicate issue since it is true that no one has the right to require another person to disclose their serostatus if they do not wish to do so. However the requirement to 'be open' was explicitly included in the selection criteria and a very elaborate process was instituted to ensure that those who were selected as volunteers understood that they would need to use their experience as PWHA in doing their work. This creates an awkward situation, resulting in frustration and resentment among those who were not selected among the first round of volunteers and may consider themselves better qualified because of their openness about their HIV status.

The networks of PWHA, both at national and regional level, who are full partners of this pilot initiative, are in the best position to legitimately resolve this dilemma. In the future, appropriate mechanisms should be put in place to give their representatives more influence in the selection process.

UN support to GIPA in South Africa

Context

South Africa has one of the fastest-growing epidemics in the world. Over three million people are currently infected with HIV, yet the epidemic remains almost silent and faceless. The levels of discrimination and social stigma are unacceptably high and people continue to live under a conspiracy of silence. The National AIDS Review of 1997 recommended that greater involvement of PWHA was crucial for effective HIV prevention and management. On the basis of this, the National AIDS Plan identifies GIPA as one of the key components for managing the epidemic in South Africa. The need for capacity building to enable PWHA to fulfil this role efficiently has been identified and training programmes, such as those included in GIPA, are crucial in addressing this.

Project development

Rapid Assessment

In January 1997, the UNAIDS Inter-country Team, together with UNV South Africa, convened a meeting with partners from the Department of Health and the National Association of People Living with HIV/AIDS (NAPWA) to explore the scope of developing a National UNV project similar to the pilot projects in Zambia and Malawi. Following this meeting, it was agreed that, in order to get a better and deeper understanding of the issues around GIPA and to avoid replicating existing efforts, a rapid assessment should be undertaken. Two independent consultants (one a PWHA) participated in the National AIDS Review in July 1997. They also visited and interviewed representatives from a range of public and private sector organizations to assess the need for such a project and inform the design and modality of the project management. As a strategy for expanding the response, the consultants were required to actively explore the role and interest of private sector organizations to participate in such a project.

The rapid assessment confirmed that while some progress has been made in the involvement of PWHA, the epidemic remains largely invisible in South Africa. The environment is not conducive to people disclosing their HIV status because of the fear of rejection. NGOs that do work with PWHA find that their contributions are not sustained because of a high 'burn-out' factor. Workplace HIV/AIDS programmes have not always been effective because people do not see the epidemic as real if they have never seen an infected person.

Planning/consultative meeting

Following the three-month rapid assessment, the UN hosted a one-day planning/consultative meeting. The purpose of the meeting was to flesh out issues pertaining to roles and responsibilities of the project partners, criteria for recruitment and selection of GIPA Field Workers (GFWs), and operational and management issues. The meeting was attended by representatives from government (Department of Health), NGOs (AIDS Consortium, NAPWA, Wolanani, NACOSA), partner organizations (Lifeline, South African National Defence Force (SANDF), Religious AIDS Project) and UNAIDS (WHO, UNDP, United Nations Population Fund, UNV).

Project purpose

Following the planning/consultative meeting, a project document was drafted for funding and approval. The purpose of the project was then defined as being that of: (1) mobilizing the private sector to put in place effective, non-discriminatory HIV/AIDS workplace programmes and policies; and (2) strengthening existing national programmes that involve PWHA.

To fulfil this purpose, the project is placing people living openly and positively with HIV/AIDS in partner organizations to assist with work-based HIV/AIDS policies and programmes.

Project management

Implementation arrangements

A National Project Manager was recruited in March 1998 and a Steering Committee and Advisory Board were established.

Recruitment and selection of GFWs

One of the essential criteria for the GFWs agreed to by the Advisory Board was the need and importance of all candidates to be HIV-positive and willing to be open about their status. Other requirements included having good organizational, verbal and non-verbal communication skills, willingness to be trained, minimum educational qualification of Standard 10 and ability to work as a member of a team. The advertisement for the recruitment of the GFWs was placed in two national newspapers and circulated widely to partners. Following the receipt of approximately 100 application forms, 20 candidates were invited to an intensive two-day Selection Workshop.

The workshop was structured to determine whether the individuals fulfilled the stated requirements, as well as to promote self-growth and personal development. A highly participatory and experiential methodology was selected instead of straight interviews, since a workshop provides more time for assessing applicants' strengths and weaknesses. It also provides a better insight into how applicants handle themselves in different situations. The various activities were selected with the aim of being informative, educational and personally empowering.

At the end of the weekend, a total of 12 candidates were selected as GFWs. In addition to the selection process for GFWs, the workshop was attended by guest participants from Mozambique and Swaziland who used the opportunity to become sensitized to the GIPA principle and to get motivated to kick-start similar processes in their own countries.

Achievements

Placement of GFWs in partner organizations

Since the selection workshop, GFWs have been placed in partner organizations. These include our government partner the Ministry of Health, private organizations (Eskom Electricity Commission, Super Group Pty Ltd, Imperial Transport Holdings, Sowetan Newspaper, Lonrho Platinum Mines and Transnet), and NGOs (Lifeline and A.M.E. Church) (see Box 8 for an example of GFW placement in a partner organization).

Box 8: Example of placement of a GFW in a partner organization

Martin VOFLOO (Eskom South Africa)

Liz THEBE, Manager, AIDS Programme, Eskom, said:

"I have been working with Martin since October 1998. We have held presentations and given talks to more than 700 Eskom employees.

What I have experienced with him is that he does not blame anybody for being HIV-positive except himself, and that is why most people are listening to him and they invite him to come back again. Most of the people have reported seriously considering taking responsibility for their behaviour and health after listening to him. He has an ability to read his audience and is a powerful and straight-to-the-point speaker.

To have Martin as a white person living openly with HIV has made a big impact on many of the people in our company. Most of the whites were thinking of it as a 'black' thing. Some of the whites were surprised to see him, and now they support our AIDS programmes.

Some of the construction camps, where they did not believe that AIDS existed, have changed because of Martin. Most of the blacks were asking, "Why don't you bring a white person who is HIV-positive?" Our training programme has gained credibility and we seem to be reaching more HIV-negative people with prevention messages, as well as HIV-positive ones with messages of hope and health. Thanks to the GIPA Project for bringing Martin to Eskom; it has boosted our AIDS programme and made a tremendous impact so far."

Training and development

In order for the GFWs to perform their duties effectively and professionally, a comprehensive training and development programme has been formulated. The goal is to ensure that, with support and encouragement, each GFW can develop his or her own potential, on a personal and professional level. The GFWs have so far received the following training: basic computer skills; personal empowerment and guidelines to living positively with HIV, modelled on the field of psycho-neuroimmunology; communication and presentation skills; HIV and development; and HIV/AIDS policy and programme development. Further training in counselling and advanced computer skills is planned to follow soon.

GFWs also participate in various HIV/AIDS projects aimed at raising visibility and championing the cause of current issues affecting PWHA in South Africa. They have been involved in the UNDP Human Development Report for South Africa, the Ster Kinekor movie project, Stepping Stones Gender and HIV/AIDS training, UNV workshops, and activities with the South African Broadcasting Cooperation (SABC). GFWs have also assisted with regional workshops organized by UNAIDS to help kick-start GIPA activities in the region.

Media exposure

Many of the GFWs have been interviewed by local and international print and electronic media. Examples of situations where GFWs have spoken publicly about their HIV status include: World AIDS Day press conference with Dr Peter Piot; South African Business Council dinner attended by the then Deputy President, Thabo Mbeki; SABC prime-time slots including the news; and interviews with various newspapers including the *New York Times, Los Angeles Times*, and *The Sunday Independent*. Participation in radio programmes has been extensive, with most national radios having had interviews with GFWs.

Future challenges

The main challenge is to sustain the project by continuing to provide on-going training as well as support for the GFWs in order for them to fulfil their expected roles. This depends largely on availability of resources.

The South African Business Council is currently being established and it is hoped that the links with the GIPA project will go from strength to strength. The training and development programme for 1999 included: on-going skills building; development of a support system for the GFWs; electronic connectivity; an advocacy programme; developing participatory monitoring tools; and extending international opportunities to the GFWs (e.g. the International Conference on AIDS and STD in Africa, ICASA, and the Global Network of People Living with HIV/AIDS and International Community of Women Living with HIV/AIDS (GNP+/ICW+) Conference in Poland.

Lessons learnt

Selection of partner organizations

The rapid assessment process was important as it determined the direction of the project. One of the difficult aspects of the process was the selection of partner organizations. In hindsight, more time should have been devoted to screening the suitability of the organizations identified and interviewed. At least four-out-of-six original organizations have been considered unprepared or unsuitable to host a GFW. The intention of expanding the response was not fully realized and the choice of organizations was very limited in scope. These setbacks have delayed the implementation and the placement process of the GFWs. More effort had to be spent finding new partner organizations—a process that is both very slow and labour-intensive.

Selection of GFWs

A much more intensive reference check is probably necessary to ensure that the selected GFWs have acceptable records with the communities in which they have to serve. This might have to be backed up with preparing the community for the GFW and for talking about HIV/AIDS openly. This should help prevent the sort of unnecessary hostilities experienced in the past.

Motivation of the GFWs

It is important to find strategies that can sustain the interest of the GFWs and provide a certain financial security at the same time. On-going training and support are crucial for the GFWs to continue operating at the energy levels required.

Following a visit of the UNAIDS Executive Director to UNV Headquarters in Bonn in September 1997, and a discussion that took place in New York, in July 1998, with the Director of the UNDP Regional Bureau for Africa, agreement was reached on a number of follow-up actions on future collaborative activities. One of the follow-up actions was the possible expansion of the pilot project to other countries in Africa and to other regions. During the Joint UNAIDS/UNDP/UNV Meeting that took place in Bonn, in April 1998, participants agreed to expand the project, particularly to French-speaking African countries, using a similar approach and building on the lessons learnt.

As a result, a new project was designed to further develop appropriate approaches and mechanisms for enhancing the involvement of individuals living with or affected by HIV and AIDS in the response to the HIV epidemic. The proposal outlines an approach based on two separate but related strategies. The first strategy aims at ensuring, through an appropriate volunteer modality, the meaningful representation of individuals living with or affected by HIV and AIDS in key organizations and institutions engaged in the response to the HIV epidemic at community, district and national levels. The other strategy aims to strengthen the capacity of organizations and networks to participate at all levels in the formulation and implementation of policies and programmes that will create a supportive ethical, legal and social environment for an expanded response to the epidemic.

The NUNV modality, as currently being developed and implemented in Malawi and Zambia, provides an appropriate delivery mechanism for GIPA. Through this expansion, the NUNV modality and any other appropriate volunteer modalities will be further tested—this time in countries that are characterized by a lower HIV prevalence and poorly functioning national organizations and networks of PWHA. These various volunteer modalities will be considered in terms of the following questions: a) As currently developed, can they provide the appropriate space for individuals living with or affected by HIV and AIDS to influence policy and programming in host institutions, and at national level? b) Are these different volunteer modalities an appropriate delivery mechanism for economically empowering individuals living with or affected by HIV and AIDS, and for strengthening their organizations and networks? c) Is the NUNV modality, or any other volunteer modality, a feasible delivery mechanism for promoting GIPA?

Activities to initiate the expansion in two French-speaking countries were started in February-March 1999. UNAIDS and the UNDP HIV and Development Regional Project will be involved in the implementation of this expansion, to an even greater extent than for the pilot phase in Malawi and Zambia.

The formal 'project' approach of placing individuals living with or affected by HIV and AIDS is only one approach to GIPA. The projects currently implemented in Malawi, South Africa and Zambia should provide an opportunity to review different approaches for enhancing GIPA. To that end, a round table discussion was held during the XIth ICASA in Zambia, in September 1999, with the following theme: "Promoting GIPA in sub-Saharan Africa: what does it mean? What are the alternatives? Lessons learnt from Malawi, South Africa and Zambia".

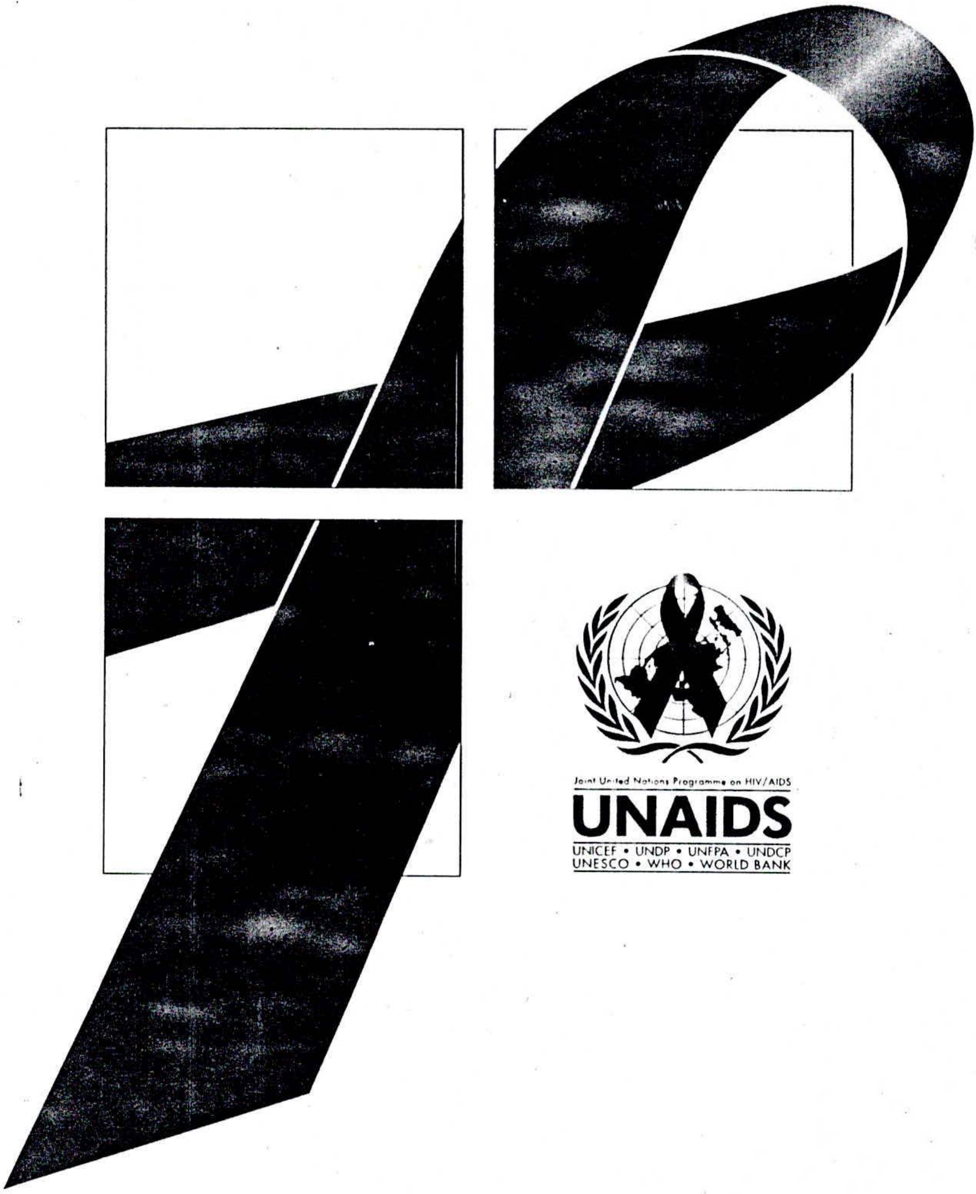
This round table was to create space for the sharing of experiences and lessons learnt from the different approaches to enhancing GIPA, particularly in sub-Saharan Africa. It was also intended to provide a venue for examining the following prioritization issues: a) Given the current trends of the HIV epidemic, should GIPA be considered a key element in the national response to HIV in sub-Saharan Africa? b) Which mechanism is the most appropriate for promoting GIPA, given the different political, economic, cultural and social contexts?

UNAIDS has made the GIPA principles a part of its policy because it has now been demonstrated that GIPA is a key strategy in the response at all levels. A technical consultation on GIPA has taken place and key areas for action have been determined.

Sources: Project document RAF/96/VO1, UNV, Sept. 96; Monitoring & Evaluation Mission Report, UNDP, Oct. 97; Self-reflection and Selection Workshops Trip Report, UNAIDS/UNDP/UNV, Feb. 98; Trip Report on Joint UNAIDS/UNDP/ UNV Meeting, Apr. 98; UNV SVF and SIDA Project Proposals, UNDP, Jun. 98 and Aug. 98; Malawi-Zambia Travel Report, UNAIDS, Sept. 98.

Putting knowledge to work:

Technical Resource Networks for Effective Responses to HIV/AIDS



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KEY MATERIAL

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UNAIDS BEST PRACTICE COLLECTION

Putting Knowledge to Work:

Technical Resource Networks for Effective Responses to HIV/AIDS

UNAIDS
Geneva, Switzerland
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Acronyms and Abbreviations

AF-AIDS	Regional electronic forum on AIDS in Sub-Saharan Africa (English)
CIDA	Canadian International Development Agency
CPAs	Country Programme Advisers (of UNAIDS)
EU	European Union
GLAMS	Latin American Network on Women and AIDS
HIPC	Heavily Indebted Poor Countries
IAEN	International AIDS Economics Network
ICASO	International Council of AIDS Service Organizations
ICTs	UNAIDS' Intercountry Teams
ICT/ESA	UNAIDS Intercountry Team for Eastern and Southern Africa
NGO	Non-governmental Organisation
MTCT	Mother-to-Child Transmission
PLWHAs	Persons Living with HIV/AIDS
RATN	Regional AIDS Training Network
REDPES	Latin American Network on AIDS and Strategic Planning
SAfAIDS	Southern Africa AIDS Information Dissemination Service
SAFCO	Regional electronic forum on AIDS in Sub-Saharan Africa (French)
SEA-AIDS	Regional electronic forum on AIDS in Southeast Asia and the Pacific
SEAL	AIDS and Economics in Latin America Network
SIDALAC	Regional HIV/AIDS Initiative for Latin America and the Caribbean
STI	Sexually Transmitted Infection
TRN	Technical Resource Network
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

Summary

This document provides guidance to practitioners who seek to improve their networking skills for effectiveness in HIV/AIDS programmes and to groups of practitioners who are trying to establish an AIDS technical network in some specific geographical or thematic area of specialization. The complexity and scale of the HIV/AIDS epidemic have spawned a number of programmes aimed at influencing the course of the epidemic. There are wide variations in the scope, technical quality and effectiveness of these programmes. Although relatively successful efforts have been documented in various forms (including collections of 'best practices') the adaptation of these success stories has been slow and patchy. Technical Resource Networks (TRNs) constitute a means of accelerating, in a professional and systematic fashion, the spread of effective responses to HIV/AIDS. They are groups of individuals, communities, institutions or governments that work together towards a shared objective in the fight against AIDS.

Networks assist in building local technical capacity, expanding national and regional advocacy, sharing of information, building peer support and facilitating collective action. By improving knowledge, providing support, developing capacity and sharing approaches proven elsewhere, these networks can both strengthen HIV prevention efforts on the ground and influence policy development at the regional and national levels. UNAIDS supports these efforts though funding and technical collaboration to improve institutional capacity in cooperating countries and subregions.

In the near term, UNAIDS will continue to support networking using the following mutually reinforcing strategies: development of resource materials, expansion of the knowledge base, initiation of new networks on priority themes, as well as improved communications for networking.

1. Introduction

1.1. What is this document about?

This document examines the importance of Technical Resource Networks (TRNs) in the response to HIV/AIDS and defines an agenda for the rapid development of these networks. As the epidemic of HIV/AIDS has grown, so have programmes and projects to combat it. It is striking that there are pockets of excellence in research and programme effectiveness, but that these pockets are outnumbered by less effective efforts that have much to learn from the successful responses. Among the low- and middle-income countries, programmes in Thailand, Senegal and Uganda are often cited as examples of large-scale and successful efforts to curb the spread of HIV. In other places, programmes of limited scale have recorded impressive successes, e.g. peer education, condom promotion and treatment of sexually transmitted infections (STIs) among sex workers in Nairobi. For the most part, however, individuals and groups too often work on common problems in isolation from one another. There is a need to make better use of the knowledge of what works against HIV/AIDS, to increase this knowledge base and to share it more effectively and efficiently. In this context TRNs are becoming increasingly common mechanisms for strengthening and catalyzing national responses to HIV/AIDS.

This document presents an illustrative framework for understanding how networks and networking add value to HIV/AIDS activities. It is the lead volume in a planned series of publications on networks and networking. Subsequent publications will focus on case studies of specific networks and on tools for networking.

Box 1. Key questions to be addressed in this paper

- What are Technical Resource Networks (TRNs)?
- What can TRNs help to achieve?
- How are TRNs initiated and maintained?
- How does UNAIDS support TRNs?
- What are the future roles of TRNs in the response to HIV/AIDS?

1.2. To whom is it addressed?

This document is a guide to effective ***networking*** for individuals and institutions working on programmes to reverse the course of the HIV/AIDS epidemic. It is addressed to programme managers, network facilitators and others interested in expanding the response to HIV/AIDS, including UNAIDS Cosponsors, non-governmental organizations, bilateral organizations and multilateral agencies.

1.3. How is it organized?

Following this introduction, the basic concepts are covered in Chapter 2. These include definitions and a typology of TRNs. Chapter 3 is on the strategic basis for networking. This is followed in Chapter 4 by practical notes on developing and managing networks. In conclusion, Chapter 5 presents an agenda for the rapid development of effective networks against HIV/AIDS.

2. Basic Concepts

2.1. Definitions

Technical Resource Networks are groups of individuals coming from communities, private institutions and governments that work together towards a shared objective: to help achieve specified goals and to improve the performance of programmes supported by network members. Networks can operate at global, regional or national levels. The term 'network' has increasingly been used to describe a range of coalitions and organizations, which work together in the field of HIV/AIDS. These networks can range from specialized 'think tanks' on different aspects of the epidemic to regional support networks, linking together people and programmes with shared challenges.

Box 2. Characteristics of Technical Resource Networks

- Common goals and interests
- Members (individuals, projects, programmes, research institutions)
- Regular communications
- Focus on a specific issue and/or region
- Coordinating mechanism (secretariat, managing committee)
- Common workplan and operational budget

Networking involves making contacts and encouraging reciprocal information exchange, meetings and voluntary collaboration. Networking should encourage and facilitate the autonomy of colleagues rather than reinforcing dependency associations (Starkey, 1997).

2.2. Types of Technical Resource Networks

TRNs exist in various forms and for a number of purposes. For example, a network can cover a particular theme and particular geographic region, such as the newly formed AIDS Strategic Planning Network in Western and Central Africa. Networks may be classified according to geographic scope, thematic focus or membership criteria.

Geographic scope. Networks may be at the global, regional, national or subnational level. In 1999, the UNAIDS Secretariat reviewed a convenience sample of 52 networks being supported by UNAIDS (UNAIDS, 1999). The results showed that 23 networks (44.2%) were at the global level; 25 networks (48.1%) at the regional level; 3 networks (5.8%) at the sub-regional level; and 1 network (1.9%) at the country level.

Thematic networks: These typically address a single subject or group of subjects. They may be among the core disciplines that underpin responses to HIV/AIDS – for example, the International AIDS Economics Network and the Reference Group on Estimates and

Modelling of HIV/AIDS. Others include networks of persons working on the prevention of Mother-to-Child Transmission of HIV and networks on access to pharmaceuticals. Some TRNs focus on developing practical skills and/or building competencies in specific disciplines. Examples include the Africa-based Regional AIDS Training Network and the Asian Harm Reduction Network. Some networks were established primarily to exchange the latest research methods and findings in HIV/AIDS. These networks include the Reference Group on Estimates and Modelling of HIV/AIDS, Monitoring the AIDS Pandemic Network, and HIV Virus Isolation and Characterization Network. Six of the networks sampled by UNAIDS represent inter-agency working groups with varying frequencies of meetings and intensity of activities.

Membership. Some networks are closed while others are open. Closed networks tend to focus on technical subjects of interest to a small number of specialists. An example of a closed network is the Reference Group on Estimates and Modelling of HIV/AIDS. Open networks tend to be less specialized. An example of an open network is SAFCO, an independent public forum on the response to HIV/AIDS in French-speaking Western and Central Africa. Individuals wishing to join SAFCO may do so by accessing the website "http://www.hivnet.ch/fdp/".

2.3. Rationale for networking

Due to the complexity of the HIV/AIDS epidemic and the differing capacities of countries and institutions to respond to it, there are wide variations in the scope, effectiveness and efficiency of responses to HIV/AIDS. Drawing on experiences from around the world, effective approaches, policies, strategies and technologies are identified as 'best practice' by the UNAIDS Secretariat and Cosponsors. The process of best practice goes beyond documentation: practices and lessons learned are promoted and disseminated through the UNAIDS Best Practice Collection, pilot projects, country-level programmes, technical assistance, exchange forums and technical resource networks. TRNs help to improve availability of, and accessibility to, technical know-how. This is needed to help countries and local groups in their response to the HIV epidemic.

Box 3. The rationale for networking

- The overriding rationale for networking is to improve the outcomes of programmes in response to HIV/AIDS, measured in terms of quantifiable reductions in the incidence of HIV, adequate care for persons living with HIV/AIDS and the mitigation of impacts on individuals, households and countries.
- By developing capacity, improving knowledge, providing technical support and sharing approaches and best practices, the networks have both enhanced HIV prevention efforts on the ground and influenced policy development at the regional and national levels.

The acceleration of national-level efforts to expand the response to the HIV/AIDS epidemic has resulted in a substantially increased demand for technical resources – both information and expertise – in a widening array of programme areas. At the same time, effective programme approaches are often specific to cultural, resource and political environments. Individual agencies have made, and continue to make, substantial contributions in specific areas of HIV prevention and care. But it is also increasingly evident that single institutions, whether government departments, UN agencies, non-governmental organizations (NGOs), or groups of people living with HIV/AIDS, do not have the capacity to deal with the multiple determinants of HIV on their own. The need to act simultaneously and synergistically in a number of areas such as targeted interventions, health services, communications, legal reform, education, rural development and the status of women, requires that a range of technical issues must be addressed at the same time. This has further increased the need within countries for access to current technical information and expertise.

Box 4. What influences performance in HIV/AIDS control?

The major factors influencing the level of performance include the following:

- The policy environment, including demonstrated political commitment by government and the commitment of the civil society
- Capacity – technical, managerial and political – to analyse problems and to develop effective strategies for tackling them
- Clarity of objectives in specific and measurable terms
- Information (and knowledge) base
- Use of scientific evidence of what works in the response to HIV/AIDS
- Quality, relevance and timeliness of inputs
- Financial and human resources
- Technology as a tool for exchange of information and knowledge
- Compatibility between interventions and institutions with responsibility for implementing them

Networks can help to strengthen the response to HIV/AIDS by improving the quality of technical support in each of these areas.

3. What Do HIV/AIDS Networks Do?

3.1. Key functions

Networks assist in building local technical capacity, national and regional advocacy, sharing of information, peer support and facilitating collective action. They create influential coalitions among programmes, giving them the critical mass needed to respond to HIV/AIDS at the global, regional and national levels. At the regional level, they help to address cross-border issues that may drive or be the result of the HIV/AIDS epidemic and at the local level, networks can be highly effective for sharing skills, information, resources and peer support.

Box 5. Networks and networking contribute to:

Capacity building
- Acting as a resource on different aspects of response to HIV/AIDS
- Strengthening the ability of local communities and programmes to respond to HIV/AIDS, thus reducing reliance on outside assistance
- Sharing global and regional expertise with partners at the country level

Solidarity and advocacy
- Reducing isolation of members and providing support;
- Strengthening responses in important but poorly addressed areas of HIV/AIDS;

Information sharing
- Promoting the exchange of ideas, insights, experience and skills
- Exchanging and documenting best practices from global, regional and national experience

Funding
- Mobilizing and utilizing financial resources for maximum impact

Most importantly, networks can actually foster the development of new programmes and policies. Thus, they can help to reduce a region's reliance on direct external assistance. This, in turn, builds capacity and enhances the network's functioning. A single network may not perform all the functions outlined in Box 5 however, several TRNs based at the Instituto Nacional de Salud Publica in Cuernavaca, Mexico perform most of these key functions (Box 6).

Box 6. The Instituto Nacional de Salud Publica, Cuernavaca, Mexico.

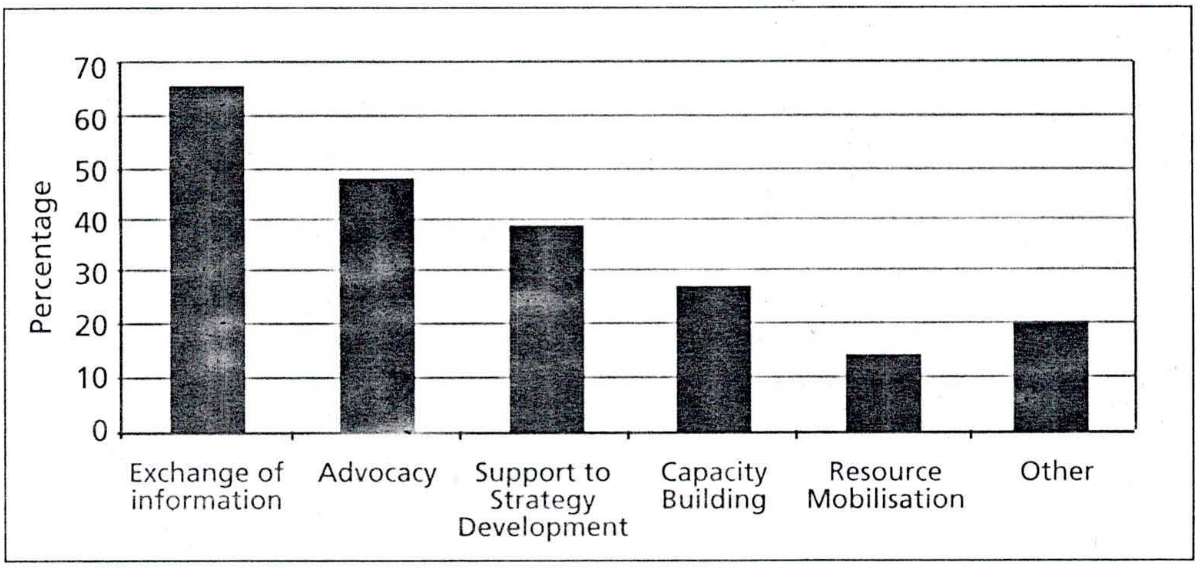
This UNAIDS Collaborating Centre has a wide range of activities in AIDS education and research. In addition, it serves as the headquarters for the following networks:

- ***Latin American Network on Women and AIDS (GLAMS).*** This network promotes research and prevention of HIV infection among women in Latin America through an information exchange network and advocacy. Its activities include development and distribution of a quarterly newsletter; maintenance of a website and an electronic discussion forum; and publications on AIDS and women in Latin America. It receives financial support from the MacArthur Foundation.
- ***AIDS and Economics in Latin America (SEAL).*** This network facilitates communication among researchers working on AIDS and economics in Latin America. It improves access to information on research related to the economic determinants and consequences of AIDS in Latin America. Its activities include maintenance of a website and an electronic discussion forum; technical publications; maintenance of a virtual library of grey literature on AIDS and economics in Latin America; and development of methods for National AIDS Accounts. It collaborates with and/or receives financial support from SIDALAC, UNAIDS and IAEN.
- ***Latin American Network on AIDS and Strategic Planning (REDPES).*** This network aims to: (a) facilitate communication among researchers and policy-makers working on AIDS and strategic planning in Latin America and (b) improve access to information and strengthen capacity for strategic planning on AIDS. Its activities include provision of technical assistance on strategic planning and AIDS; exchange of experiences with other regional networks; maintenance of a website and an electronic discussion forum. It collaborates with and is funded by UNAIDS. REDPES takes the view that strategic plans should be considered as guiding documents that are open to adjustment. Such plans have either been completed or are in draft forms in several countries in the region. In six countries, (Chile, Peru, Colombia, Guatemala, Honduras and Mexico) REDPES has supported the development of "integrated plans" for United Nations agencies in the Thematic Groups that support the national strategic plans.

In the 1999 review of TRNs cited earlier, UNAIDS Secretariat staff members were asked to identify the overall objectives of the networks with which they collaborated. More than one objective was marked where appropriate. Figure 1 presents the percentage of networks with the following objectives: (a) exchange of information, experience, or scientific findings; (b) advocacy; (c) support to strategy development; (d) capacity building through workshops or meetings; (e) resource mobilization; and (f) other.

Figure 1: Objectives of the networks

(Percentage of Total of Networks, n=52)



Source: UNAIDS, 1999

The exchange of information, experience, and scientific findings was the predominant objective of the networks (65.4% or 34 networks) followed by advocacy (48.1% or 25 networks), support to strategy development (38.5% or 20 networks) and capacity building (26.9% or 14 networks). Other objectives (19.2% or 10 networks) included conducting situation analyses and needs assessments, promotion of collaboration/cooperation, and/or identifying research needs.

3.2. TRNs and knowledge management: the practice in 'best practice'

Knowledge management is the systematic dissemination, sharing and adaptation of information and experiences. Knowledge management systems are developed to improve an organisation's effectiveness and efficiency. Much of the initial work on knowledge management was done in the for-profit sector, where efficiency is a major concern: Systems that help to eliminate such waste are attractive to the corporate sector. They are equally attractive to development organizations, particularly for the transfer of internal knowledge and the dissemination of 'best practice'. For development agencies, programme managers and analysts working on HIV/AIDS, the crucial issue is how to use effectively the growing collection of 'best practice' materials. TRNs facilitate this through the dissemination and adaptation of such best practices.

Knowledge management systems seem to work best when the people who generate the knowledge are also those who store it, explain it to others and coach them as they try to apply the knowledge. It has been well documented, however, that typical approaches to knowledge management actually widen the gap between knowing and doing (Box 7).

Box 7. How can typical knowledge management practices make knowing-doing gaps worse?

- Knowledge management efforts mostly emphasize technology and the transfer of codified information.
- Knowledge management tends to treat knowledge as a tangible thing, as a stock or a quantity, and therefore separates the knowledge from its intended use.
- Formal systems cannot easily store or transfer knowledge that is not easily described or codified but is nonetheless essential for doing the work called *tacit* knowledge.
- The people responsible for transferring and implementing knowledge management frequently do not understand the actual work being documented.
- Knowledge management tends to focus on specific practices, while ignoring the importance of philosophy.

Source: Pfeffer J, Sutton R. *The knowing-doing gap: how smart companies turn knowledge into action.* Harvard Business School Press. Cambridge, MA. p22. 2000

The important consideration here is that effective knowledge management *involves sharing know-how* in addition to sharing knowledge. How might TRNs serve as a mechanism for effective management of knowledge? First, we note that in the absence of relevant information and knowledge, organizations (including governments) are less likely to make sound choices. Second, we turn to the social learning theory, which states that individuals learn from others whom they observe, and then imitate by following a similar (but not necessarily identical) behaviour. Such social modelling frequently occurs through diffusion networks. By linking innovators with others who are tackling similar issues, TRNs can perform a catalytic role in the diffusion of innovations for HIV/AIDS control – so-called *diffusion networks* (Rogers, 1999). Diffusion scholars have long recognized that an individual's decision about an innovation may not be an instantaneous act. Rogers (1995) presents a model of the innovation-decision process that is shown below in Box 8. At the same time, similar ideas may develop in different places in response to related problems. TRNs bring together workers in diverse settings, enabling them to share ideas and tools for better performance in the fight against HIV/AIDS.

4. Developing and Managing Networks

4.1. Formation, funding and management

Networks are formed in response to perceived needs. Forming a network usually requires immense commitment and effort from a small group of individuals or agencies. Sustaining a network can be equally challenging as the network's founders struggle to generate the funding, membership, activities and structure to ensure that the network survives and grows. In light of these challenges, the International Council of AIDS Service Organizations (ICASO; www.icaso.org) identified eight key steps to building a network (ICASO, 1997), to which items 9 and 10 have been added in this document (Box 8).

Box 8. Ten steps in building and sustaining a network

1. **Prepare a statement of purpose.** A statement of purpose is a precise and agreed-upon statement of the reason for a network's existence, the values which underline the network and what the members want to achieve.
2. **Define goals and objectives.** A goal is a broad statement that describes the changes that members want to achieve through their actions. Objectives are specific, measurable statements of the desired changes that a network intends to accomplish by a given time.
3. **Create an action plan.** An action plan is a set of steps that are developed to achieve a specific objective. At a minimum an action plan should (a) identify the activities needed to accomplish an objective, (b) identify resources, (c) designate responsibilities to persons in the network, (d) set a timetable for actions and (e) implement, monitor and evaluate.
4. **Establish ground rules.** Early on in the process of networking it is important to address the issue of how members of the network are to interact with one another. ICASO has identified 13 examples of ground rules, of which the following are examples: (a) come to meetings prepared to listen, ponder, debate and question, (b) use your role in the network to build group strength, to facilitate decision making in which everyone can feel comfortable and (c) stay informed about issues related to the work of the network, building your knowledge and understanding of all sides of the issue.
5. **Define a decision-making process.** Decisions can be made in many different ways. Three typical forms of decision making in networks are command, consultative and consensus.
6. **Prepare a communications plan.** This addresses the timely transmission and receipt of information. For formal communications within the network, members may choose combinations of the following: meetings, newsletters, faxes, phone calls, e-mail or web-based discussion. Informal communications among members are less structured, need to be encouraged and never thwarted.
7. **Choose an organization structure.** The key principle is that the structure should help the network to achieve its goals. In practice, it may require the creation of units, including committees or working groups, a coordination unit or secretariat, office staff and a decision-making body.

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8. **Secure resources.** There are three major forms of resources required for networking: money, people and in-kind contributions.
9. **Define responsibilities.** These include responsibilities for making and executing decisions, convening meetings, initiating communications and mobilizing resources.
10. **Develop monitoring and evaluation plan.** A monitoring and evaluation plan is needed to assess progress toward set objectives and to enable corrective action where necessary.

Source: International Council of AIDS Service Organizations. *HIV/AIDS Networking Guide*. 1997, ICASO. Ottawa. pp. 9-17.

4.2. Challenges

Networks face multiple challenges. They include time constraints, limited financial resources, limited technical capacity at the local level, divergent views among funding institutions and technical barriers to the delivery of network services. How well these are resolved will affect the success of the network. Several networks have gone through the formative stages and achieved some of their objectives. They include the Africa-based Regional AIDS Training Network (Box 9) and the Asian Harm Reduction Network (Box 10).

Box 9. The Regional AIDS Training Network (RATN), Nairobi, Kenya.

The Regional AIDS Training Network (RATN) is innovative and adds value to country-level work. RATN includes 13 partner institutions and 9 affiliate institutions in Eastern and Southern Africa, working with WHO, EU, as well as academic and research institutions in Belgium, Canada, Kenya and South Africa.

As part of its benefits to African countries, RATN supports curriculum development, identifies and supports regional training venues, and facilitates communications among institutions, trainers and trainees. As of mid-1999, RATN had served 470 course participants from 17 African countries. Courses include AIDS counselling, management of STI, community care, communications, adult education, policy and planning, research methodology and laboratory management. RATN is gender-sensitive in the content of the course and in the mix of course participants. Former course participants now have a variety of responsibilities for community care and counseling in countries including Kenya, Malawi, Zambia and Zimbabwe.

Expected long-term impacts include: (a) strengthened capacities of regional institutions to function as innovative centres for research and training in STI/HIV; (b) improved skills of STI/AIDS workers in the region; (c) effective exchanges of strategies and information among countries in the region; and (d) improved care, and a decline in the incidence of STI/HIV.

Box 10. The Asian Harm Reduction Network (AHRN)

AHRN is a regional organisation that targets HIV and injecting drug use (IDU). This technical resource network has become an important mechanism for promoting the harm reduction approach in Asia and strengthening HIV prevention among injecting drug users (IDUs).

Among other benefits to countries in the region, the network has proved to be a valuable resource and mechanism for developing and conducting national and multi-country training activities on HIV prevention and harm reduction. These activities have occurred throughout Asia and have targeted policy makers, health workers, law enforcement officials, drug-treatment workers, government and non-government staff and others interested in harm reduction. Training is a useful approach through which AHRN has built capacity at the country level for responses to HIV and IDU.

Some of the lessons in developing and managing AHRN are outlined below.

- Having a funded secretariat, staffed by a full-time coordinator (the executive director), was critical to developing the network, servicing its membership and securing funding for subsequent years.
- Sustaining the network required enormous time, effort and patience from AHRN staff and management.
- Developing AHRN's activities, establishing its secretariat and securing funding required considerable professional expertise.
- Having a broad funding base was important.
- Cross-cultural adaptation of harm reduction strategies was critical to their acceptance.
- Support from local organizations and individuals has been critical to the network's recognition and success.

4.3. Information technology and TRNs

E-mail discussion forums provide opportunities for people to share ideas and information on various topics. Some of these forums are open, such as AF-AIDS and SEA-AIDS, which can be joined by any individual or organization working in the area of HIV/AIDS or interested in the topic (to join, sign up through www.hivnet.ch/fdp/). These forums aim to encourage organizations and individuals to share experiences on HIV/AIDS, learn from the experiences of others or debate issues of a topical nature.

The e-groups set up by the UNAIDS Intercountry Team for Eastern and Southern Africa (ICT/ESA) aim to facilitate the flow of information and to help TRNs share best practices, research and issues emerging from countries (Box 11). 'E-groups' is a web-based application (www.egroups.com) provided free of charge to the user. There are essentially two services related to the e-groups: a group e-mail address and distribution to the group; and a website with various functions that facilitate networking and information sharing among the group.

These functions include:

- *The Document Vault.* Documents of interest can be uploaded and stored in the vault.
- Links to World Wide Web Pages of interest.
- A chat section, which can be used for online meetings, etc.
- A database feature where the contact details of all the members can be stored.
- A calendar feature for arranging meetings.

Box 11. TRNs and the Web: Focus on Eastern and Southern Africa

The UNAIDS Intercountry Team for Eastern and Southern Africa is facilitating the use of information technology by technical resource networks. These networks are:

- ***The UNAIDS E-group.*** This serves as a platform for sharing information among the ICT, the Country Programme Advisers, Junior Professional Officers, Theme Group Chairpersons and the Cosponsors of UNAIDS. This network is used to update members on regional news and to share information on ICT activities at the national level that may benefit others.
- ***The Religious E-group.*** This was developed to support a core group of religious organizations to discuss community mobilization in the context of HIV/AIDS control. The e-group will be taken over by the Norwegian Church AID, which is also exploring the possibility of providing financial assistance to members to cover their connectivity costs. On-going discussions address broadening the core members by inviting other religious bodies to become involved in HIV/AIDS-related issues.
- ***The Debt-for-AIDS E-group.*** The e-group's purpose is to share relevant information and perspectives with key stakeholders working on Debt-for-AIDS activities. Many countries with high HIV prevalence are also heavily indebted to external institutions and governments. Debt service obligations reduce public funds that might otherwise be available for AIDS control programmes. Debt-for-AIDS seeks to alleviate poverty and support development by putting the AIDS control agenda in the key development instruments of these countries, including their Poverty Reduction Strategy Papers, debt relief agreements and Medium-Term Expenditure Frameworks. For countries eligible for debt relief under the Heavily Indebted Poor Countries (HIPC) initiative, Debt-for-AIDS urges that funds from debt relief be tied in part to AIDS control programmes, through short-term actions and medium-term goals. Stakeholders include government representatives, civil society, UN agencies and creditors. This e-group had a membership of 300 persons as of mid-2000.
- ***HIV/AIDS Media E-group.*** This e-group is jointly moderated by UNAIDS and SAfAIDS and aims to provide journalists in the region with updated information on HIV/AIDS.

Box 12. TRNs and the Web: Focus on the Asia-Pacific Region.

The UNAIDS Asia-Pacific Intercountry Team (APICT) facilitates five electronic networks in support of technical resource networks. These networks are:

- ***The UNAIDS APICT E-group (APICT-net)***: A platform for sharing information among the UN family members in the Asia Pacific Region, specifically Country Programme Advisers, Junior Professional Officers, UNAIDS Theme Group Chairpersons and the UNAIDS Cosponsors. This network is used to update members on news (AIDSFlash) and events from the region, to share information on activities of APICT and the UNAIDS cosponsors. AIDSFlash is a biweekly news service summarizing the HIV/AIDS press from over 20 regional sources. The electronic newsletter is sent to all networks supported by APICT and other interested networks/individuals.
- ***The ASEAN Task Force on AIDS E-Group (ATFOAnet)***: This e-group is jointly moderated by UNAIDS and the AIDS Division of Thailand's Ministry of Public Health. The group provides members of the ASEAN Taskforce on AIDS with a neutral space to discuss issues, identify possible solutions and share experiences and information.
- ***The Asian AIDS Information Network E-group (AAIN)***: This e-group brings together organizations that are sources of HIV/AIDS information to: share relevant information, experiences and resources between collaborating organizations; clearly define respective roles of individual resource centres, and to convey descriptions of services and materials available to clients in the region; reduce duplication efforts in the provision of HIV information and materials; and facilitate the referral of clients to appropriate sources of good-quality information and materials. UNAIDS is currently negotiating with a resource centre based within the region to take over responsibility for the network.
- ***The TB-HIV/AIDS E-Group***: This e-group was established to facilitate the sharing of information, ideas, suggestions and concerns about the growing threat of TB-HIV/AIDS and to explore ways of applying social mobilization to expand the response to this 'deadly duet'.
- ***SEA-AIDS***. Established in 1996, this network pioneered electronic communication in the HIV/AIDS field in Southeast Asia. The email discussion forum brings together around 2400 people and organizations working in and with Asian Nations in response to the epidemic. The forum enables people to discuss current HIV/AIDS issues, share experiences about what does and does not work in responding to the epidemic, as well as sharing news and forthcoming events.

Several lessons have been learnt thus far:

- Where there is a real perceived need to exchange information (i.e. small group of technical experts working on a common area of concern), the e-group system works.
- In some instances, the lack of communication may also be the result of the members themselves not being altogether sure how to use the technology.
- It is time-consuming to set up and maintain the database, links, document vault, etc. The e-group needs to be regularly updated to ensure that the member listing remains current. This is not necessarily the case in small technical e-groups. On the other hand, once this is in place it will be easier to maintain the e-group and keep it going.
- Although there are no cash costs apart from electricity and telephone access, a moderately skilled user is needed to moderate an e-group.
- Being web-based (except for the e-mail function) could present problems in those countries with inadequate telecommunications infrastructure. This is the case in many countries in Southern Africa and therefore accessing the webpage on e-groups, with all the functions and options available, could prove problematic.
- Some people just do not have the time to read through and respond to all the e-mails. Moderated e-mail forums may need to package messages into summaries, in order to present the information concisely and to reduce the time required to read them.

There are similarities among these lessons and those identified by others (Kumaranayake and Watts, 2000).

The Internet, like any information communication technology, is not essential to good information management. A TRN that has defined what information it needs and how information communication technology can be used to meet those needs will be far in advance of one which, in the absence of a thoughtful assessment of its objectives and needs, makes extensive use of computers, e-mail and the Internet. For a more detailed discussion of this, see Powell (1999).

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

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

Produced with environment-friendly materials

Networks assist in building local technical capacity, expanding national and regional advocacy, sharing of information, building peer support and facilitating collective action. Effective networks can strengthen HIV prevention efforts on the ground and influence policy development at regional and national levels. This new title provides practical guidance to those who seek to improve their networking skills. It will also be essential reading for groups of practitioners wishing to establish AIDS technical networks in specific geographical or thematic areas.

Joint United Nations Programme on HIV/AIDS

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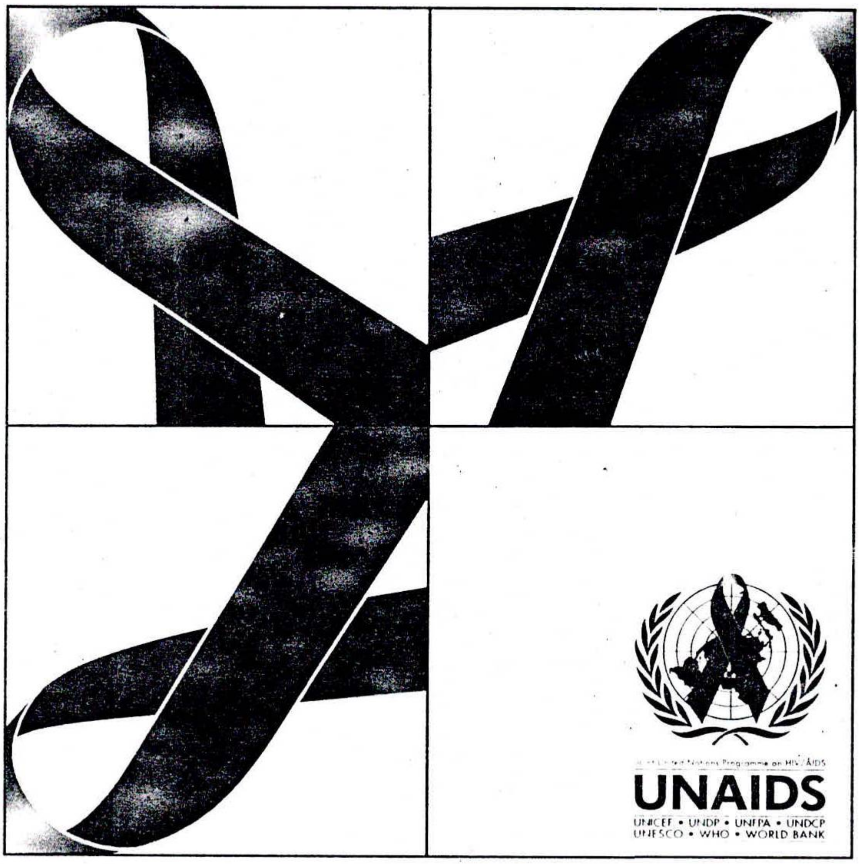

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UNAIDS
Technical update

October 2000

UNAIDS *Best Practice* Collection

At a Glance

Palliative care aims to achieve the best quality of life for patients (and their families) suffering from life-threatening and incurable illness, including HIV/AIDS. Crucial elements are the relief of all pain–physical, psychological, spiritual and social and enabling and supporting caregivers to work through their own emotions and grief.

Palliative care has relieved the intense, broad suffering of people living with HIV/AIDS but the latter brings a number of challenges to its philosophy and practice including:

- The complex disease process with its unpredictable course and wide range of complications, which means that palliative care has to balance acute treatment with the control of chronic symptoms;
- Complex treatments which can overstretch health services;
- The stigmatization and discrimination faced by most people living with HIV/AIDS;
- Complex family issues, such as infection of both partners;
- Role reversal in families, such as young children looking after their parents;
- Burdens on health care workers.

A wide range of palliative care is needed for people living with HIV/AIDS, including:

- Pain relief;
- Treatment of other symptoms such as nausea, weakness and fatigue;
- Psychological support for psychological problems;
- Spiritual support and help with preparation for death;
- Support for families and carers–help with nursing, infection control and psychological support.

To ensure that effective palliative care is provided for all people living with HIV/AIDS, governments must tackle the misconceptions that palliative care is only for people approaching death. They also need to:

- improve the training of health and community workers, and general health education, including tackling stigmatization;
- make good palliative care widely available in hospital, hospices and in the community for people living at home;
- provide access to the necessary drugs;
- provide support for carers, counsellors and health care workers;
- recognize the special needs of children.

UNAIDS *Best Practice* Materials

The Joint United Nations Programme on HIV/AIDS (UNAIDS) publishes materials on subjects of relevance to HIV infection and AIDS, the causes and consequences of the epidemic, and best practices in AIDS prevention, care and support. A *Best Practice* Collection on any one subject typically includes a short publication for journalists and community leaders (Point of View); a technical summary of the issues, challenges and solutions (Technical Update); case studies from around the world (*Best Practice* Case Studies); a set of presentation graphics; and a listing of Key Materials (reports, articles, books, audiovisuals, etc.) on the subject. These documents are updated as necessary.

Technical Updates and Points of View are published in English, French, Russian and Spanish. Single copies of Best Practice materials are available free from UNAIDS Information Centres. To find the closest one, visit the UNAIDS website (http://www.unaids.org), contact UNAIDS by e-mail (unaids@unaids.org), or telephone (+41 22 791 4651), or write to the UNAIDS Information Centre, 20 Avenue Appia, 1211Geneva 27, Switzerland.

AIDS Palliative Care. UNAIDS Technical update. English original, October 2000.
I. UNAIDS II. Series

1. Palliative Care
2. Medical/Nursing Staff
3. Voluntary Workers

UNAIDS, Geneva WC 503

Background

What is palliative care?

Palliative care is a philosophy of care which combines a range of therapies with the aim of achieving the best quality of life for patients (and their families) who are suffering from life-threatening and ultimately incurable illness. Central to this philosophy is the belief that everyone has a right to be treated, and to die, with dignity, and that the relief of pain – physical, emotional, spiritual, and social is a human right and essential to this process.

This philosophy of care developed out of the treatment of patients dying in hospital, usually from cancer. It led to the establishment of the hospice movement, and palliative care is now provided for patients living with many life-threatening diseases, including HIV/AIDS.

Palliative care ideally combines the professionalism of an interdisciplinary team, including the patient and family. It is provided in hospitals, hospices and the community when patients are living at home. This care should be available throughout a patient's illness and during the period of bereavement. An integral part of palliative care is providing the opportunity and support for caregivers to work through their own emotions and grief, which inevitably arise from their work.

Carers work hard to remain sensitive to patients' personal, cultural and religious values, beliefs and practices, and to ensure effective communication with patients, their families and others involved in their care.

Palliative care for people with HIV/AIDS

Experience shows that palliative care can relieve the intense, broad suffering of people living with HIV/AIDS. However, HIV/AIDS has challenged the ideas of palliative care because of its specific dimensions:

- **The complex disease process.** The course of HIV/AIDS is highly variable and unpredictable, with a wide range of potential complications, rates of progression, and survival. Some patients remain free of serious symptoms for a long time; others experience alternating periods of increasing dependency with episodes of acute illness, or suffer frequent non-life threatening complications throughout their infection. So palliative care for HIV/AIDS is – unlike that for other illnesses–a balance between acute treatment and attending to the control of chronic symptoms and conditions. Patients also vary in their emotional response to the infection; this again complicates the planning and delivery of palliative care.

- **Complex treatments.** A wide range of treatments for HIV/AIDS patients is now available. Antiretroviral drugs (ARV) have been shown to be highly effective in controlling the progress of HIV disease, but their high cost means they are not readily available to most patients in developing countries. Patients may experience many treatable opportunistic infections and other symptoms, which puts stress on health delivery systems as well as creating compliance problems when the treatments produce unpleasant side-effects. As HIV/AIDS patients are living longer, they may become more dependent on health care workers, and this can create psychological problems for both patients and carers.

- **Stigmatization and discrimination.** People living with HIV/AIDS face a very specific set of psychosocial problems. Many patients have to live with stigmatization and discrimination, even in high-prevalence countries where HIV affects nearly every member of the population. People are reluctant to be open about their HIV status, thus increasing their feeling of isolation, and carers may be wary of disclosing the positive status of a sick relative. In communities where HIV is less common, people with HIV are often from marginalized or minority groups, such as drug users, men who have sex with men, or sex workers. They may have less well established support networks, and face added discrimination if they are suspected of being seropositive.

- **Complex family issues.** HIV/AIDS has a major effect on families, especially in areas of high prevalence and where most patients are young and economically active. Both partners in a relationship may be infected. Or often the partner of someone with HIV may be unsure if he or she is infected, and thus the illness of one partner raises worries about infection in the other as well as anger with the infected partner. If a child is infected, the mother, and often the father, will usually be infected. Siblings may also be infected. Financial problems increase as the breadwinner becomes ill and children will often not be able to continue, or even start, schooling.

- **Role reversal in families.** HIV care often involves older people looking after their younger, previously productive children, without the financial contribution from those children. This has resulted in harsh economic and social consequences. When people become unwell with HIV disease, and are unable to continue working to support their family, they may return to their parents to be cared for during the last stages of their illness. Old people are being left to care for their grandchildren. In other homes, children have become the main carer for their parents or their sick siblings. Child carers need special emotional and practical support.

- **The burden on health care workers.** Caregivers working with HIV/AIDS patients face causes of stress unique to this condition. So many patients are young and health workers caring for people with late-stage HIV disease face the death of all their patients. Eventually, workers may become withdrawn and fatigued by multiple losses and the complex care needs of patients. In developing countries, these stresses are exacerbated by the lack of resources, in turn creating feelings of hopelessness because workers feel they have so little to offer patients in terms of treatment. In palliative care, the mental health of health care workers is vital if they are to remain empathic and effective in the direction and delivery of care.

The range of care needed for the patient

Treatment of symptoms

PREVALENCE OF SYMPTOMS: Multi-centre French National Study (314 people) [1]

Symptom	Prevalence
Pain	52%
Tiredness	50%
Anxiety	40%
Sleep disturbance	37%
Mouth sore	33%
Sadness	32%
Weight loss	31%
Nausea	28%
Fever	27%
Cough	27%
Depression	24%
Diarrhoea	24%
Skin problem	24%
Pruritus	23%
Respiratory problem	22%
Vomiting	20%

The medical management of people with AIDS is a balance between acute treatment and trying to control symptoms. Most people living with HIV/AIDS suffer from many symptoms, including pain. These symptoms can occur at the same time, can affect one or more body system(s)/function(s) and can lead to other symptoms, including anxiety and depression. As people reach the end of their illness, it may be inappropriate to continue investigations and treatments that will have little long-term benefit and merely add to the distress of the patient. However, some of the HIV associated illnesses and opportunistic infections (OIs) are easy to treat – for example, tuberculosis–and should be treated. Early and accurate diagnosis of OIs is important at any stage of HIV disease. Wherever possible, the person with HIV should decide about his/her treatment and be informed of the options; educating the patient is an essential tenet of palliative care. He/she should be helped to understand the limits of any treatment, and its outcome.

1. Pain

Pain relief is paramount for people living with HIV/AIDS. Pain is what the patient says hurts. It is always subjective, never what others, such as caregivers, think it ought to be. Every patient should be helped to lead as pain-free a life as possible. Health workers should not withhold pain relief because they worry that a

[1] Larue F, Brasseur L, Musseault P, Demeulemeester R, Bonifassi L, Bez G. Pain and symptoms during HIV disease. A French national study. *J Palliative Care* 1994: 10(2):95

patient will become addicted to pain killers. Pain medication should be reviewed frequently and increased when necessary. Pain should be controlled in a way that keeps the patient as alert and active as possible.

Pain relief should begin with a straightforward explanation of the causes of pain. Many pains are best treated with a combination of drug and non-drug measures.

Unlike cancer, pain for AIDS patients is not permanent, but temporary and associated with infections. So if the infections are treated energetically, the pain reduces and less pain control is needed. But there is often more than one source of pain and each needs to be diagnosed and treated.

It is important to remember that emotional pain, the fear of dying, for example, or the pain of guilt, the meaninglessness of life, can be as real and hurt just as much as physiologically inspired pain. The psychological and spiritual suffering of AIDS patients can be unusually severe.

Physical pain can lead to anxiety and/or depression, which in turn can lower a person's pain threshold. If there is a conspiracy of silence in the family concerning the patient's disease, he or she may feel even more isolated and this can lead to more pain and fears about the pain worsening. The problem of uncontrolled pain can create anger from the patient and the family, and anger and/or feelings of inadequacy among carers.

Very anxious or depressed patients may need an appropriate psychotropic drug in addition to analgesia, otherwise the pain may remain intractable. Psychotropic drugs, however, are not analgesics and should not be used instead of analgesics.

A relatively inexpensive yet effective method of pain relief exists for the majority of people with pain. The keys to this method are:

- **"By mouth".** If possible analgesia should be given by mouth.
- **"By the clock".** Analgesics should be given at fixed time intervals. The dose should be titrated against the patient's pain and the next dose should be given before the previous one has fully worn off. In this way, it is possible to relieve pain continuously.
- **"By the ladder".** The sequential use of analgesic drugs is shown in the figure:

The analgesia ladder

Step 1	Step 2	Step 3
Aspirin or paracetamol (simplest and most widely available analgesics)	Codeine or dihydrocodeine With or without non-steroidal anti-inflammatory drugs such as ibuprofen or indomethacin	Morphine With or without co-analgesia; With or without non-steroidal anti-inflammatory drugs. Other strong opioid analgesics include synthetic pethidine and fentanyl
If they do not relieve the pain, move to step 2	*If they do not relieve the pain, move to step 3*	*If pain still uncontrollable, refer to a specialist.*

Adapted from Cancer pain relief, second edition, WHO, 1996 and Douleurs sans frontières, 1998

- **"For the individual".** The choice and dosages of analgesics will vary widely from individual to individual and must be tailored accordingly. Keeping a pain score is useful for adjusting the dose of pain medications.

Recently, pain guidelines have recognized that pain suffered by people with HIV disease is very like that of cancer pain. For this reason, carers should rapidly advance to step 3 medications. When opiate analgesia is given, nausea and constipation commonly occur and it will be necessary to treat these at the same time.

2. Diarrhoea and constipation

Initial management should include the diagnosis and treatment of underlying infection. If no cause can be found and there is no blood in the stools or constant fever, diarrhoea should be treated with oral agents such as loperamide (up to 16 mg per day in divided doses) or codeine (15–60 mg every 4 hours). People with diarrhoea should take plenty of fluids or use oral rehydration solutions to avoid dehydration. If the person has diarrhoea immediately after eating, the initial problem could be lactose intolerance or pancreatic insufficiency. A review of the diet and an attempt to temporarily eliminate milk products or fat may be helpful. A stool with the consistency of thick soup may be caused by the mechanical obstruction by a hard stool or a tumour, and might be treated with an enema rather than something to decrease motility.

Constipation may result from prolonged bed rest, profound cachexia (weakness through considerable weight loss), a poor diet, or opioid use. Treatment includes dietary advice, increased fluid intake and the use of stool softeners and laxatives.

Summary of treatment for oral and oesophageal infections

Gingivitis	oral hygiene metronidazole 400 mg twice daily for 5 days. betadine mouth wash
Oral candidiasis	topical or systemic antifungals (e.g. nystatin oral suspension 2–4 times daily, miconazole oral gel (2–4 times daily) or amphotericin lozenges (10 mg 2-4 times daily)
Oesophageal candidiasis or severe oral candidiasis	systemic antifungals (e.g. ketoconazole 200 mg twice a day for 10–14 days) or fluconazole 200 mg for 3 days
Mouth ulcers	1% gentian violet prednisolone 10 mg daily for 5 days

3. Nausea, vomiting, anorexia and weight loss

Nausea and vomiting can be caused by drug therapy, central nervous system infections or space occupying lesions, gastro-intestinal infections, or blockage of the gastric outlet or proximal duodenum by intra-abdominal tumours (most commonly a lymphoma or Kaposi's sarcoma).

Prochlorperazine (5–10 mg 2–3 times daily) is useful for mild nausea. Metoclopramide (10 mg every 4–8 hours) or ginger is useful for nausea caused by gastro-intestinal disturbance. However, it may cause neurological side effects in people who are cachexic. It should not be used in intestinal obstruction. When nausea is caused by central nervous system disorders, low doses of antidopaminergic drugs such as haloperidol may be useful.

If oral and oesophageal infection is present, antifungal treatment may improve dysphagia (problems with, or painful, swallowing) considerably.

Nutritional support with multivitamin and micronutrient supplementation may be useful, with, if possible, advice from a dietician. Making meals smaller, more appetizing and more frequent may improve dietary intake.

People with advanced HIV infection may have profound weight loss with loss of muscle bulk: the so-called "wasting syndrome". Although dietary advice, antiemetics, appetite stimulants, treatment of diarrhoea, and anabolic steroids may be of some benefit, this usually has a poor prognosis.

4. Cough and shortness of breath

In developing and many middle-income countries, tuberculosis (TB) is commonly associated with HIV infection. As TB can occur at any stage during HIV infection, it should always be actively sought for and treated in people with HIV disease. Any cough that persists for longer than three weeks after treatment with a standard antibiotic should be thoroughly investigated for TB (including by chest X-ray where available because many patients with HIV-associated TB have negative sputum smears). Other causes of cough that should be considered are *Pneumocystis carinii* pneumonia (PCP) and bacterial and fungal pneumonias. Non-infectious causes of cough include pulmonary Kaposi's sarcoma, lymphoma and interstitial pneumonitis.

As well as treating the underlying infections, use should be made of antitussive agents (cough suppressants).

Morphine or codeine can also be used to decrease the sense of breathlessness. People who are very short of breath despite treatment may find breathing easier if they are sitting upright. Physiotherapy is usually helpful to clear secretions and improve air-entry.

Benzodiazepines should be used to relieve the associated anxiety. During a patient's last days of life, scopolamine 0.3–0.6 mg subcutaneously every 4–8 hours or glycopyrrolate 0.1–0.4 mg intramuscularly every 4–6 hours will be useful in reducing the quantity of secretions when the person is too weak to cough.

Oxygen may prolong death rather than improve quality of life, and may not be appropriate.

It is important in such cases to provide support and information for those people at the bedside, particularly if this laboured breathing is perceived as distressing to the patient.

5. Malaise, weakness and fatigue

Fatigue, lack of energy and malaise are common symptoms reported by people with HIV disease. Fatigue is reported as being a distressing symptom by 40-50% of people with advanced HIV disease. There are often many reasons for fatigue, but it may be associated with:

- anaemia
- direct HIV effects on the central nervous and neuromuscular systems
- malnutrition and "wasting" syndrome
- secondary infections and tumours
- adverse effects from drug therapy
- chronic pain
- insomnia
- depression.

Where possible, any underlying problem should be treated. Often no specific cause is found but physiotherapy and rehabilitative exercise may be helpful. Changes in work and household duties may enable people with fatigue to cope better and have an improved quality of life.

6. Fever

Fever is often the sign of secondary infections, and every effort should be made to find and treat the underlying cause. For symptomatic treatment, paracetamol (500-1000 mg every 4-6 hours) or aspirin (600 mg every 4 hours) is usually effective. Paracetamol and aspirin can be alternated every 2 hours if necessary. Ensuring adequate fluid intake is important and sponging the person with a wet towel can also bring some relief.

7. Skin problems

About 90% of people with HIV have skin problems. It is important to recognize the underlying cause, as some of these are treatable with cheap and simple medicines. Successful treatment will improve a person's quality of life because skin problems often cause emotional distress and the avoidance of social interaction. Some people fear stigma or rejection if their lesions are unsightly and may need counselling and reassurance. Scabies is often atypical and should always be considered if significant itching pruritus is present, regardless of the nature of the rash. This will often require at least three courses of treatment as well as antipruritic agents such as antihistamines and/or topical steroids after the treatment is washed off. Opioids may be needed to treat severe itching.

Common skin problems associated with HIV disease

Skin problem	First-line treatment
Bacterial infections (boils, abscesses etc.) violet	Antibiotic treatment (e.g. erythromycin or flucloxacillin) and topical gentian Abscesses should be drained, cleaned and dressed before antibiotic treatment
Fungal infections tinea corporis, folliculitis, candidiasis	Topical antifungals if mild, systemic antifungals in severe cases
Viral infections herpes simplex herpes zoster molluscum contagiosum papillomavirus (warts)	Early herpes zoster can be treated with aciclovir 800 mg 5 times daily (if available) or topical gentian violet and most importantly pain relief. If warts/molluscum are uncomfortable they can be treated with topical podophyllin or a silver nitrate stick.
Scabies	Topical treatment with lindane, benzyl benzoate or permethrin (treat contacts as well).
Pressure sores	Prevent by keeping skin clean and dry and turning a bed-bound person every 2–4 hours. Treat by cleaning with salt solution (should taste no more salty than tears) daily and covering with a clean dressing.
Wounds or ulcers	Clean with salt solution and keep covered with a clean dressing. Infected wounds can be treated with antibiotics: smell and infection can be controlled by metronidazole powder or gel.
Drug-induced eruptions	Supportive care with oral antihistamines and 1% hydrocortisone cream.

8. Brain impairment

HIV associated brain impairment (often called HIV dementia) is an important illness of advanced HIV disease. Up to 15% of people with advanced HIV disease will develop some degree of brain impairment and a further 15–20% may develop some degree of motor or cognitive impairment. HIV associated brain impairment is characterised by abnormalities in motor and cognitive function consisting of psychomotor slowing with behavioural disturbance. Early symptoms include apathy, poor concentration, mood swings and memory disturbance. Later symptoms may include disinhibited behaviour, agitation and poor sleep. Global dementia, paralysis and incontinence can occur in the final stages. It is important to differentiate mild brain impairment from a depressive illness, as the latter is treatable with antidepressants.

Antiretroviral drugs are helpful in treating HIV dementia. Where these are not available, the outlook is poor, as the brain impairment is irreversible and progressive. At the early stages, counselling may be helpful. Environmental clues to improve memory such as family pictures calendars and clocks may be useful. Most importantly, family members and friends should receive support and counselling so that they understand the illness and are aware of the prognosis. Delirium or agitation of late-stage dementia may respond to neuroleptic drugs, such as haloperidol (1–5 mg 6–8 hourly) or chlorpromazine (25–50 mg 6–8 hourly). Low doses should be used initially because of the increased risk of extrapyramidal side effects in people with HIV-related brain impairment. For brain impaired patients who live on their own, day-to-day activities can be a major problem, especially as some people may have few physical symptoms or problems but still need 24-hour supervised care. Hospices or palliative care units, if available, may be required to give medium-term care. If these are not available, regular support and supervision from a home care team is important to support the carer and patient.

Counselling and social support

Psychological problems

People living with HIV/AIDS frequently experience emotional and psychiatric problems. But their quality of life can be considerably improved when health workers, family members and carers understand these problems, and support the patient experiencing them.

Depression is common. If mild and clearly associated with factors in the patient's life, it may be helped by counselling alone. If it does not respond quickly to psychological support, or symptoms are severe, treatment with antidepressant drugs should be started promptly. Tricyclic antidepressants drugs (such as amitriptyline, imipramine or trimipramine) will usually be the first line therapy. In physically ill patients, antidepressant drugs should be started slowly, to minimize side-effects (such as dry mouth, sedation and postural hypotension). Once the depression improves, antidepressants should be continued for a further 4–6 months to avoid relapse. When antidepressants are stopped the dose should be reduced gradually, monitoring for signs of relapse.

People living with HIV/AIDS may consider suicide. This may result from depression or be a rational choice. Such tendencies can usually be helped with emotional support from health care workers, including the reassurance that these feelings of hopelessness are common with any chronic illness and tend to be short-lived. Some people with advanced disease, with severe symptoms, or those who have also watched family and loved ones die from HIV disease, state that they wish to end their lives. Family and spiritual support as well as counselling may be particularly important in these circumstances.

Anxiety is also a common symptom in people with advanced HIV infection, expressed in physical as well as psychological symptoms. Tachycardia, palpitations, shortness of breath and panic attacks may occur. Emotional support and behavioural interventions such as relaxation therapy are the first line of management. Benzodiazipines (such as diazepam 2 mg 6–8 hourly as required) may be helpful for short-term severe anxiety, and beta-blockers (e.g. propranolol 10 mg 4–6 hourly as required) may be used for palpitations.

Forms of psychological support

1. VCT (voluntary counselling and testing)

In many developing countries a diagnosis of HIV infection or AIDS is made by a health care worker when the patient already has advanced HIV infection. If HIV testing is available it should confirm the diagnosis. Whether HIV testing is carried out or not, it is important to share the presumed or confirmed diagnosis with the patient. Carers and families often believe that it is kinder to shield the patient from the diagnosis of HIV infection and that talking about HIV will make him/her more depressed. However, most people with symptomatic HIV infection will have given it much thought and sharing their worries and fears can be of great comfort. They may wish to discuss whether they should disclose their HIV status to other family members and friends, if they have not already done so. Carers can listen, be non-judgmental and offer love and support, especially if the patient feels isolated or fears rejection.

2. *Spiritual support*

Even if they have not been actively involved with a church or religious group, many people find great comfort from priests or other spiritual leaders during chronic illness. Others, however, may feel pressurized into talking about spiritual issues by loved ones, when they would prefer not to. Carers should acknowledge the patient's spiritual needs, or lack of them, and arrange for support and visits from a priest, pastor or other spiritual person, when appropriate.

3. *Preparing for death*

It is often believed that it is not appropriate to talk about the fact that someone is going to die, and that mentioning death will in some way hasten it. However, for those who wish to discuss death, open discussion, ideally from early diagnosis, can help dying persons to feel that their concerns are heard, that their wishes are followed, and that they are not alone. Sometimes it is easier for patients to express their feelings and concerns with a counsellor rather than their family, especially initially. Support groups can provide great comfort and relief; many patients are helped by talking to other people who are terminally ill.

Most people want to know that they will be remembered. Encouraging friends and family to share stories or memories of the individual's life makes the person feel loved and cared for.

People who are nearing death are frequently afraid of dying in great pain. Health workers should be able to reassure patients that pain relief will be carried out up to the point of death. Another great worry is what will happen to patients' dependants after they die. Where possible, plans should be made for dependants and partners. Although it can be distressing to discuss these issues, making plans can reduce anxiety. Making a will can prevent family conflict and ensure that partners and children are not left destitute. This is particularly important where "property grabbing"[1] is common.

Practical issues to be discussed before death

- custody of children
- family support
- making a will
- funeral costs
- future school fees.

Emotional issues to be discussed before death

- resolve old quarrels
- tell patient and family members or friends that they are loved
- share hopes for the future, especially for children who are left behind
- say goodbye to carers and providers.

Support for families and carers

For family members, partners and friends, looking after someone with HIV infection can be very daunting. In high-prevalence areas carers may be looking after several family members who are sick with HIV infection. Carers need technical assistance with nursing and infection control, and emotional support. They need educating in the limits and outcomes of particular treatments, and advice and support so as to avoid burnout.

1. *Nursing*

Nursing people with late-stage HIV can be time consuming and tiring. If the patient is not fully mobile or bed bound he/she will need constant attention, such as:

- turning to prevent bedsores
- helping to the toilet or latrine, or to use a bed pan
- washing and keeping cool by sponging with a damp towel
- if the patient is incontinent of urine or faeces, washing both patient and bedclothes
- preparing food and drinks and helping to feed the patient
- providing company when the patient is feeling lonely, anxious or scared
- helping with drug taking
- cleaning and dressing sores and ulcers.

Many of these nursing tasks will be new to the family or community carer. They will therefore need help and support from a nurse, or knowledgeable health worker, who can explain about drug taking schedules and simple nursing techniques, such as how to dress ulcers. This will

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[1] *"Property grabbing" occurs in some countries in sub-Saharan Africa. It is the practice of relatives of the deceased to seize his/her property at death. This often results in women and orphans being left destitute following a death.*

give them confidence and make them feel less isolated. Written or illustrated material explaining drug taking schedules can be useful as these may be complicated, and some medicines have adverse effects, drug interactions or must be taken with particular foods.

Coping with HIV related brain impairment could be particularly difficult and distressing for friends and relatives, especially when the patient behaves aggressively or without normal inhibitions. Health care workers need to take time to explain what is happening when cognitive and behavioural problems develop, and to support carers in this situation.

2. Infection control

There are many myths about HIV and its transmission. Carers often worry about being infected themselves with HIV by the person they are looking after. Health workers should help carers explore these anxieties and, whilst giving them practical information on how to avoid infection, reassure them that the risk of catching HIV whilst caring for someone is minimal.

Carers should be aware of and understand the following:

- The risk of HIV infection to carers and household contacts is *extremely low*.
- There is no risk from casual household contact such as sharing eating utensils, and gloves do not need to be worn when touching and lifting someone with HIV.
- Gloves, when available, should be worn for cleaning wounds and clearing up blood or body fluids. When gloves are not available, covering the hands with plastic bags is a helpful alternative.
- Spillage of blood, faeces, urine or vomit should be cleaned up using household bleach.
- Cutlery, bed linen, etc. should be washed with normal washing products.

3. Psychological support

When carers, such as partners or children, are uncertain about their own HIV status, health workers can help them address their worries and offer a referral to voluntary counselling and testing (VCT).

Other problems, such as a shift in family dynamics when the elderly parent or young child becomes the carer, can make carers feel isolated. They may be reluctant to talk about these issues for fear of being judged as inadequate. Health workers can try to reassure them that their concerns are normal, or put them in touch with other carers. Sharing their experiences, for example, through support groups, can be very helpful to both parties.

The need to offer counselling to partners and families following the death of a family member or friend is often overlooked, particularly in developing countries. Bereavement counselling can help the bereaved person to discuss and reflect on the changes brought about by loss, to mourn appropriately and to look to the future. Partners and parents of a child who dies may have unresolved fears about HIV infection for themselves, or other family members, and can be helped to come to decisions about HIV testing.

The process of grieving may last many months or even years. However, for some people a single counselling session may be sufficient to clarify their thoughts and feelings, and to reassure them that they are coping as best they can under the circumstances. This is particularly true for people who have other emotional supports, such as family, friends and church or other spiritual support. Other people may need several sessions. Some people never completely come to terms with a loss, particularly that of a child.

In high-prevalence developing countries, grieving may be made worse by multiple losses of friends and relatives through HIV infection. People who have recently suffered multiple losses may be afraid that they are 'going crazy' or losing their mind. Reassurance that such feelings are a normal part of grieving is important. Some traditional beliefs and practices may be helpful, but others, such as "property grabbing" , may add to difficulties.

4. Helping the carers to care

Carers may become exhausted if they have been looking after a sick person for a long time, or if they have had many other friends or family members die recently. If they are tired or distressed, they cannot give their sick relative or friend the care they need. If respite care is available, it may be appropriate for the patient to spend short times there. If this is not available, other family members, friend or volunteers can be encouraged to share the care so that the main carer can get adequate rest. Health workers should reassure carers that they are bound to be tired and give them 'permission' to 'have a break' or take more rest.

Day respite care for children with symptomatic HIV disease may be offered. This not only gives respite to the children, but also to the carers who are often themselves sick or elderly.

Structured home-based care programmes, where available, can provide good support for carers as well as patients. Health workers can share the burden of care, as well as providing treatment, advice and support. They also encourage acceptance of HIV/AIDS patients by communities, and help dispel myths and stigmatization.

Many patients first seek help and support from traditional or complementary medical practitioners. These practitioners may offer symptomatic treatment with herbal or other remedies, or pain relief through therapies such as acupuncture. Patients and carers may also be offered counselling and support. Health workers should discuss treatment and care plans with other practitioners involved in a patient's care, and should ensure that any complementary therapy is useful and not too costly. They can protect patients and carers from exploitation by unscrupulous charlatans.

Challenges:

Perceptions and recognition of palliative care

Palliative care has developed considerably since its early days when most patients treated were terminally ill and approaching death. But still many people living with HIV/AIDS shy away from the notion of palliative care because they link it with death and many of them don't want to admit they are dying. Policy-makers, planners and health workers have to tackle this misconception in order to ensure patients with HIV/AIDS receive palliative care.

Many developing and middle-income countries have limited health resources, including drug budgets, and palliative care, particularly medicines used for symptomatic relief, is not always seen as a priority. Governments must appreciate that for humanitarian reasons alone, palliative care—reducing the pain and suffering of those who are chronically ill or dying—should be a priority.

Although HIV has added enormously to the health care burden in many of the poorest countries, many of the drugs and services which can benefit people with HIV are readily available, listed as WHO/UNAIDS essential drugs, and are cheap. If, however, additional resources are not provided to care for the increasing numbers of people with HIV, and to train carers and health workers, many people will die in pain, isolation and distress, and their carers, including many orphaned children, will be left feeling unsupported and helpless.

In some low-prevalence countries, people living with HIV/AIDS are even more isolated because HIV is perceived as a problem of marginalized groups such as injecting drug users, refugees and men who have sex with men. Health services need to structure health care and support to meet the needs of these particular groups, including tackling their isolation and stigmatization.

There are other sound development reasons for ensuring that people living with HIV/AIDS receive treatment to ensure a decent quality of life. Many people who are ill with HIV are intermittently ill and with access to appropriate medicines they have much to contribute to their families and communities. As people with HIV are often young adults, many have young children who need their parents to be with them for as long as possible.

In order to provide effective palliative care, governments and planners may need to transform health services through improved training, by making care available in a wide range of settings and by ensuring a sustained supply of appropriate drugs and medicines.

Organizing training

Even in settings where HIV is a major health problem, most communication about HIV infection has dealt with HIV transmission and prevention, with little emphasis on how to care for people with HIV. Nor do the majority of health professionals know how to holistically assess and control pain.

Palliative care training should be provided for health care workers in hospitals and in the community, for teachers, religious and community leaders; they in turn can teach community health workers, community volunteers and families caring for people living with HIV/AIDS.

General HIV education in the community can be very beneficial in reducing stigma, by helping to change negative attitudes towards people with HIV and their families, and giving factual information about caring for people living with HIV/AIDS.

Making good palliative care services available

In areas of high HIV prevalence the number of people with symptomatic disease requiring medical and psychological support increases as the epidemic matures. For example, in Zambia, which has a population of about 8.5 million, one in five adults are infected and an estimated 90 000 become unwell with HIV each year. In some hospitals in sub-Saharan Africa, 50–70% of adult medical beds are occupied by people with HIV-related illnesses. This has put an impossible burden on already very over-stretched and under-funded health services. Wards and outpatient clinics become overcrowded and medical staff feel demoralized and impotent as they have little treatment to offer. In response to this crisis, two main approaches have been taken in developing countries. First, alternatives to traditional inpatient and outpatient hospital services were sought. Secondly, there has been a development and expansion of services, including home care services, provided by nongovernmental organizations (NGOs).

1. *Home care*

Many successful models of home care have been developed in different settings. Those that are community-based, rather than developed as outreach from hospitals, tend to be cheaper to run and provide a wider coverage. Using volunteers has not only been successful in keeping costs lower, but has also enabled communities to work together in supporting each other, raising awareness and promoting tolerance and acceptance.

2. *Residential hospice care*

Residential hospices have been set up in many industrialized countries to help care for people with terminal HIV disease. Hospice care is particularly helpful for people who live alone or who have poor symptom control or symptoms that are difficult to manage, such as those associated with severe brain impairment. Hospice care is also useful for providing respite care, when carers need a break or when patients are being stabilized on new drug regimes. In developing countries there are a few examples of hospices, often run by religious groups. In high-HIV-prevalence developing countries, inpatient hospice care is too expensive to provide for the large numbers of people requiring palliative or terminal care.

3. *Day centres*

In some countries day care facilities for people living with HIV/AIDS may be available. These enable patients to remain at home whilst allowing carers time off during the day. Patients can receive palliative care at the day centre, counselling and emotional support, cooked meals, services for their children and, in some cases, schemes for income-generation.

Each of the models of care has advantages and disadvantages and patients may benefit from different care at different stages in their illness.

4. *Access to analgesics and palliative care drugs*

There are often strict legal controls on analgesics such as codeine and other opiates. Because of fears about their misuse, in many countries they can only be prescribed by doctors. In settings where the majority of palliative care is delivered by nursing staff or community carers, and there are few doctors, access to analgesics can be problematic. A balance is needed between increasing access to adequate pain relief for people with HIV and the careful supervision and record keeping of prescription of opiate analgesics.

In some settings cannabis has been found to be helpful in symptom control (particularly for the relief of nausea and improvement of appetite) for people with HIV. However, their use is often restricted by strict legislation. Some PLHA groups argue for these drugs to be made more widely available.

5. *Providing support for carers, counsellors and health care workers*

Health services need to address the specific causes of stress for people who care for HIV/AIDS patients. Support groups for carers enable them to share their particular anxieties and concerns, such as coping with multiple deaths or coming to terms with the person's sexual orientation. Caring for people with HIV at the end of their life is emotionally draining and can be depressing. To avoid burnout adequate support for carers, counsellors and health care workers should be available.

In many cultures, parents find it difficult to discuss painful issues with their children. As a result, children are unprepared for the death of their parents, unable to protect themselves from HIV infection in the future and often unable to trust adults. Children with HIV or whose parents or siblings have HIV disease may need culture and age-specific counselling and their parents or carers need support and guidance in talking to children about sensitive and distressing issues.

6. *The special needs of children with HIV*

Most children with HIV disease in developing countries have little access to medical care, and palliative care or rehabilitation is seldom offered. Assumptions such as 'because the child does not verbalize his or her problems he/she has none', or that 'addressing issues around death and dying will cause more harm than good' are now being challenged. The importance of communicating with children and involving them in decision-making is now being recognised by parents and health workers.

What is currently being done to overcome these challenges?

Examples of current projects initiatives in palliative care.

The Catholic Diocese in Ndola, Zambia

In the late 1980s Zambia developed the new strategy of "home based" care to cope with the increasing number of people with symptomatic HIV disease. This strategy was not confined to medical treatment and nursing care, but took a more comprehensive approach to the needs of individuals, families and communities. However, many of the early projects had limited coverage and were relatively expensive to operate. In 1991 the Catholic Diocese in Ndola, in the Zambian copperbelt, established a comprehensive home care programme for people with HIV disease, which aimed to provide much higher coverage at less expense. The key to its success is the role of the 500 volunteers who offer counselling, social and emotional support, and basic medical and nursing care for people with HIV disease and their families. They also provide links between the local health centres and the community, allowing people with HIV to receive care in their homes rather than as inpatients. HIV education to the communities has helped to change attitudes to PLHA increasing acceptance and tolerance and reducing stigma.

The AIDS Support Organisation (TASO), Uganda

TASO in Uganda was founded in 1987 as a self-help support group, and it is an example of what can be done when people living with HIV/AIDS and their families identify their own needs and spearhead the process of defining the nature of services to meet those needs. TASO began by offering counselling and outpatient clinical care of opportunistic infections to people living with or affected by HIV/AIDS. Soon it became evident that when TASO clients became bed-bound, they were often not receiving good-quality care due to stigma in homes and communities, and the lack of care skills in the homes. TASO started a campaign of AIDS awareness aimed at changing attitudes in communities. At the same time TASO began training and supervision programmes for families and community members in basic home care. People living with or affected by HIV became the driving force of this campaign, sharing their personal experience and advocating "positive living". Family level income-generation activities were started and linked to church and other community-based organizations. TASO also runs training programmes for counsellors, community carers and community-owned resource persons.

The Mildmay Mission Hospital, London, United Kingdom

Mildmay is a Christian foundation and was the first to set up inpatient and day palliative care services in Europe. It is funded mainly through contracts with the National Health Service together with by donations and grants. It is situated in central London and aims to care for people with HIV without regard to race, religion, culture or lifestyle.

People with HIV may be admitted for rehabilitation, respite or terminal care, or for support while changing drug regimens. The use of the hospice has changed since the use of ARVs became routine for people with HIV in the United Kingdom. Many more patients are now seen for rehabilitation or respite care than for terminal care. Associated services include counselling, referral for hospital outpatient care such as gynaecology and dermatology, social support and support for children. Mildmay has a family care unit and a unit for people with brain impairment, with separate day care centres for children and adults. People who use the centre include men who have sex with men, injecting drug users, and people from Africa now living in London. Mildmay has found that close links with churches and religious groups in the community have helped to raise awareness about HIV and enabled people living with HIV/AIDS to obtain ongoing spiritual support once they are back in their homes.

The Mildmay Centre for AIDS palliative care and international study centre, Kampala, Uganda.

The Mildmay Centre in Uganda was developed as a joint project between the Ugandan Ministry of Health (AIDS control programme), the United Kingdom Department for International Development and Mildmay International, who have a contract to manage the centre for ten years. It was opened to patients in 1998.

The Mildmay Centre was designed to provide specialist outpatient palliative care and rehabilitation for people living with HIV/AIDS, and to serve as a demonstration model for cost-effective care in resource-limited settings. It also provides day and residential training programmes in all aspects of HIV care for health workers, volunteers and carers.

The emphasis is on rehabilitation and the promotion of independence wherever possible. It has a patient-focused team with support from:

- Medical and nursing staff
- Physiotherapists
- Occupational therapist
- Nutritionist
- Counsellors
- Spiritual care
- On-site laboratory services
- On-site pharmacy.

At the Mildmay Children's Centre in Kampala, children with HIV have free access to the same range of services as at the adult centre. The services are child-friendly, with therapeutic play and counselling. The aim is to meet not only their physical needs but also their emotional needs as many children seen are severely traumatized. Day respite care for orphans with advanced HIV disease is also provided.

Calmette Hospital, Cambodia

The Calmette hospital and a Phnom-Penh military hospital have implemented an innovative treatment and training programme to fight AIDS in the community through education, and to provide a comprehensive response to the medical and psychosocial care needs of the patients it serves. It is now estimated that 200 000 Cambodians are HIV-positive, of whom 30 000 have progressed to AIDS, with an impact that is also growing on military and police forces. Working with Doctors without Borders, the programme has developed a capacity to provide both care, including inpatient and outpatient services, and training for health care providers. As a result, trained physicians have established a pain clinic and provide pain management in these two hospitals. The current project was based on the premise that a response is required which addresses medical and psychosocial needs simultaneously. Treatment focuses particular attention on pain management and responding to symptoms. Psychological and social supports are provided to infants who are orphans. Another primary objective of the project is to provide education and training for clinicians, pharmacists, and family members. Within communities, families and neighbourhoods receive health education and HIV prevention. The system of care has expanded to include ambulatory and home care for patients living with AIDS and cancer.

Sahara Michael's Care Home, India

Sahara Michael's Care Home, a nongovernmental organization in India, is pioneering a continuum of care that addresses aspects of HIV/AIDS care lacking in the health service, concentrating on areas that include treatment, training, human rights advocacy, and the development of networks and partnerships. The Care Home, a 16-bed facility, evolved in response to changing disease patterns for HIV/AIDS and the need for care giving of a greater intensity and longer periods. The programme has been serving areas of high need, in resource-constrained settings, since 1978. Funded by the Catholic Relief Organisation, the model of care initiated in 1997 for people living with HIV/AIDS is now being utilized by HIV/AIDS communities throughout India.

The model of care includes care giving, counselling, a nutrition programme, cost viable treatment strategies, crisis care, and training for self and family care provided by a team of professionals and non-professionals. The professional team consists of a consulting physician and nurses. The care staff includes 17 men and women who perform a variety of tasks ranging from autoclaving, cooking and driving to hospital visits. In the next year, the team will be developing an outpatient department for HIV-positive people, counselling which embraces issues that go beyond HIV status, and a systematic training programme for the intricacies of HIV/AIDS care.

The Care Home has a spiritual undercurrent to its programmes and a team with a service-like devotion to care giving. This has fostered an acceptance of HIV/AIDS in local communities and encouraged people everywhere to offer materials and support.

The Positive and Living Squad (PALS) and Kara Counselling and Training Trust (KCTT), Zambia

KCTT and the PALS are closely linked Zambian NGOs, working to provide care and support services for people living with HIV/AIDS. The PALS are a group of people living openly with HIV. They organize a wide range of HIV prevention activities, but also have an important role in supporting other people with HIV when they become sick and families when a loved one dies. For people who are unwell with HIV, having support and understanding from someone who is also infected with HIV is often very helpful. It can lessen the feeling of isolation and help families to see that their problems are not unique. During the time of someone's last illness and death the PALS often provide practical and material help, including helping with funeral arrangements and helping make plans for dependants. The PALS also have an important advocacy role and are active in fighting discrimination and promoting the rights of widows and dependants.

Among the activities provided by KCTT is a training programme for home care volunteers. Lay volunteers are taught about basic nursing and listening and counselling skills. KCTT also has a day centre where people with HIV can meet and learn skills from an income generation scheme, counselling services and close links with community based care teams. They also provide TB screening and preventive therapy for people with HIV and family counselling for families affected by HIV.

As palliative and supportive care needs are often overlooked, they must be emphasized in national strategic plans. There is also need for coordination with donors to ensure that palliative care is seen as a priority, and resource mobilization is essential to strengthen these efforts.

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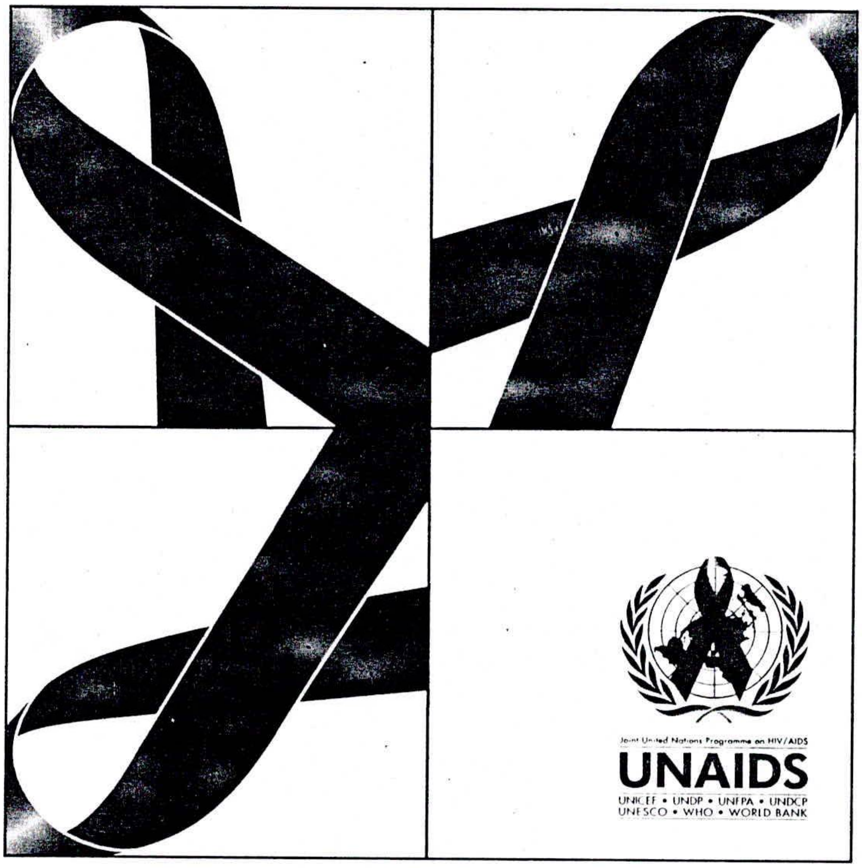
AIDS and men who have sex with men



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UNAIDS
Technical update

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UNAIDS Best Practice Collection

At a Glance

Sex between men exists in most societies. It frequently involves anal sex. Unprotected penetrative anal sex carries a high risk of HIV transmission, especially for the receptive partner.

- **HIV prevention programmes for men who have sex with men (MSM) are hindered by the following:**
  - denial that sexual behaviour between men takes place
  - stigmatization or criminalization of men who engage in sex with other men
  - inadequate or unreliable epidemiological information on HIV transmission through male-to-male sex
  - the difficulty of reaching many of the MSM
  - inadequate or inappropriate health facilities, including sexually transmitted disease (STD) clinics, and lack of awareness or sensitivity among STD clinic staff about the existence of anal, rectal and oral STDs
  - lack of interest among donor agencies in supporting and sustaining prevention programmes among men who engage in same-sex behaviour, and a lack of programmes addressing male sex workers in particular
  - lack of attention in national AIDS programmes to the issue of MSM.
- **Effective responses to these problems include a combination of the following:**
  - commitments by national AIDS programmes and donor agencies to include the issue of MSM in their programmes and funding priorities
  - outreach programmes by volunteers or professional social or health workers
  - peer education among MSM
  - the promotion of high-quality condoms and water-based lubricants, and ensuring their continuing availability
  - safer sex campaigns and skills training, including in the use of condoms, and the promotion of lower-risk sexual practices as alternatives to penetrative sex
  - strengthening organizations of self-identified gay men, enabling them to promote HIV prevention and care programmes
  - promoting mass media campaigns, while ensuring that these are culturally appropriate
  - education among health staff, including within STD clinics, to overcome ignorance and prejudices about MSM
  - efforts to organize health facilities to make them accessible and affordable
  - breaking down social and cultural barriers against the discussion of male-to-male sex
  - reviewing — with the aim of abolishing — laws that criminalize certain sexual acts between consenting adults in private
  - enacting anti-discrimination and protective laws to reduce human rights violations against MSM.

UNAIDS *Best Practice* materials

The Joint United Nations Programme on HIV/AIDS (UNAIDS) publishes materials on subjects of relevance to HIV infection and AIDS, the causes and consequences of the epidemic, and best practices in AIDS prevention, care and support. A *Best Practice* Collection on any one subject typically includes a short publication for journalists and community leaders (Point of View); a technical summary of the issues, challenges and solutions (Technical Update); case studies from around the world (*Best Practice* Case Studies); a set of presentation graphics; and a listing of Key Materials (reports, articles, books, audiovisuals, etc.) on the subject. These documents are updated as necessary.

Technical Updates and Points of View are published in English, French, Russian and Spanish. Single copies of Best Practice materials are available free from UNAIDS Information Centres. To find the closest one, visit the UNAIDS website (http://www.unaids.org), contact UNAIDS by email (unaids@unaids.org) or telephone (+41 22 791 4651), or write to the UNAIDS Information Centre, 20 Avenue Appia, 1211 Geneva 27, Switzerland.

AIDS and men who have sex with men. UNAIDS Technical update. English original, August 1997, first revision May 2000.
I. UNAIDS II. Series
1. Acquired immunodeficiency syndrome - transmission
2. Homosexuality, male
3. Acquired immunodeficiency syndrome - prevention and control
UNAIDS, Geneva WC 503.71

Background

Sex between men occurs in most societies. For cultural reasons, it is often stigmatized by society. The public visibility of male-to-male sex, therefore, varies considerably from one country to another. Sex between men frequently involves anal intercourse, which carries a very high risk of HIV transmission for the receptive partner, and a significant risk, though a lesser one, for the insertive partner. HIV prevention programmes addressing men who have sex with men (MSM) are therefore vitally important. However, they are often seriously neglected – because of the relative invisibility of MSM, stigmatization of male-to-male sex, or ignorance or lack of information.

Identity and behaviour

Sexual identity is different from sexual behaviour. Many men who have sex with other men do not regard themselves as homosexual. In a number of societies, the way such men view their own sexual identity is determined by whether they are the insertive or the receptive partner in anal sex. In these societies, many men who have sex with other men self-identify as completely heterosexual, on the grounds that they take an exclusively insertive role in such activities.

Worldwide, a large percentage of MSM are married or have sex with women as well. This bisexual behaviour is reported to be common in some societies, such as in Latin America (see Schifter J, *et al*, "Bisexual communities and cultures in Costa Rica", and Parker RG, "Bisexuality and HIV/AIDS in Brazil", both in Key Materials: Aggleton P (*ed*), 1996) and in North Africa (see Schmitt A, "Different approaches to male-male sexuality/eroticism from Morocco to Uzbekistan" in Key Materials: Schmitt and Sofer (*eds*), 1992).

A self-awareness among MSM has developed, and now exists to a considerable extent in industrialized countries – though even in these countries there are many men who have sex with other men who do not identify themselves as homosexual or "gay". In some parts of the developing world the number of self-identified gay men has also grown – often through local initiatives – particularly in some Asian and Latin American countries. Along with this self-identification, gay meeting places have sprung up – organized social groups or campaigning groups, and gay bars, discos, gyms and saunas.

Even in places where most MSM are obliged to stay out of public view, some will choose to be visible. These include transvestite men and transsexuals. Because they are often the only visible ones, they frequently become stereotyped as typical of all MSM. In fact, such "transgendered" people usually represent only a very small percentage of all MSM.

Sexual preference

Most same-sex behaviour is conducted out of natural preference. There are also, however, instances of institutions where men are obliged to spend long periods in all-male company, such as in the military, prisons, and male-only educational establishments, and in which male-to-male sex can be common. While such institutional male homosexual behaviour represents only a small part of all male-to-male sex, it can nonetheless be important from the point of view of the AIDS epidemic. Male prisons, for example, have been shown to make a significant contribution to some countries' epidemics – both through drug injecting and male-to-male sex (see UNAIDS Technical Update, *Prisons and AIDS*).

Male-to-male sex, anal intercourse and HIV

Penetrative anal sex frequently occurs in sex between men. If HIV is present in the insertive partner, and if condoms are not used, then anal sex carries an especially high risk of HIV transmission for the receptive partner. The risk to a receptive partner in unprotected anal sex is several times higher than the next most risky category, that of a woman having unprotected vaginal intercourse with an HIV-infected man. The reason for this is that the lining of the rectum is thin and can easily tear – and even only small lesions in the lining are sufficient to allow the virus easy access. Even without lesions, it has been postulated that there might be a lower natural immunity in the cells of the rectal lining to resist HIV than there is, for instance, in the lining of the vagina. There is also a risk of HIV infection from unprotected anal intercourse, though a lesser one, for the insertive partner. (See Detels, R, "The contributions of cohort studies to understanding the natural history of HIV infection", in Nicolosi A (*ed*), *HIV epidemiology: models and methods*, Raven Press, New York, 1994, p.239.)

The presence of other untreated sexually transmitted diseases (STDs) – such as syphilis, gonorrhoea and chlamydia – can further greatly increase the risk of HIV transmission, when HIV is present. STDs located in the anus and rectum can often be asymptomatic.

Oral (oro-penile) sex is also common among MSM. While HIV could be transmitted through such sex if not protected by a condom, the risk is generally considered low. (See Samuel, MC, *et al.* "Factors associated with human immunodeficiency virus seroconversion in homosexual men in three San Francisco cohort studies, 1984-1989". *Journal of Acquired Immune Deficiency Syndromes* 1993 **6**(3):303-12.)

The AIDS epidemic and men who have sex with men

At least 5-10% of all HIV cases worldwide are due to sexual transmission between men, though this figure varies locally very considerably. In North America, Australia, New Zealand and most of Western Europe, UNAIDS believes the figures are closer to 70%.

In most developed countries and some developing ones (such as Indonesia, the Philippines and Mexico), the first detected cases of HIV and AIDS occurred in men who had sex with men. Later, although the *absolute number* of cases of male-to-male transmission in several of these countries often continued to rise, the proportion of such cases decreased while the proportion of cases among heterosexual men and women increased correspondingly. This can hide the scale of the problem for MSM.

Commercial sex between men

In most countries, a certain proportion of sex between men is in some way commercial, though this can cover a wide range of possibilities. Much sex work is highly informal, with the expectation perhaps of a small "present" for services rendered. Some of it is full-time and professional, though proportionally much less so than among female sex workers. Many male sex workers have a wife or regular female partner and would not self-identify as homosexual. Frequently, the clients of male sex workers are married men or behaviourally bisexual.

Male sex workers can often find themselves in a weak bargaining position in their power to insist on condom use. However, reports from some countries, including the Philippines, suggest that the female sex workers there face more difficult conditions, and that the male sex workers have at least some degree of bargaining power. While economic pressure is still an important reason for male sex workers not using condoms, they are usually more able than female sex workers to resist physical coercion, and can often be more selective in choosing clients.

Major social and political upheavals and emergency situations — especially those displacing people and creating refugees — can in certain circumstances act as a catalyst to push significant numbers of young men (as well as women) into prostitution.

Adolescent males

Adolescent men frequently have sex with other males of their age group. They also sometimes have sex with older men — in some cases with men considerably older. This younger-older type of male-to-male relationship is common in certain cultures, where it is frequently within the family (with an uncle, for example). A 'younger-older' male relationship may be more or less consensual, or it may be a violent and abusive one. In either case the younger man is likely to be relatively vulnerable, because of a lack of knowledge about HIV and a lack of negotiating skills — and also because the older partner, simply because he has probably had many more sexual encounters, is more likely to be infected than a partner of the same age..

The Challenges

Denial

Policy-makers and programme managers sometimes deny that male-to-male sex occurs in their part of the world. Denial is an enormous obstacle to efforts at AIDS prevention and care among MSM.

Inadequate epidemiological data

Lack of, or unreliable epidemiological data are an obstacle to HIV prevention work. In some places, risk exposure categories are not properly set up to take account of male-to-male sex.

Lack of knowledge or awareness

In countries where HIV education emphasizes only heterosexual transmission, men may be ignorant of the risks of male-to-male sex, or consider that the risks don't apply to them – and may therefore be less likely to protect themselves.

Lack of appropriate programmes

Many countries lack AIDS programmes for MSM. At the same time, existing programmes may be inappropriate. Educational material that is suitable for people in a self-identified gay bar may be too explicit – and thus counterproductive – for those men who do not self-identify.

Difficulty of reaching many of the men who have sex with men

Many MSM engage in casual, fleeting and anonymous sexual encounters. They may also not think of themselves as having sex with men. The combination of these factors makes them difficult to reach for prevention work.

Male sex workers can be particularly difficult to access, especially where the work is clandestine and where the workers are not organized into establishments.

Difficulties of sustaining "safer sex" practices

Despite the initial successes in many prevention campaigns, in some places — particularly in industrialized countries — MSM have been found in recent years to practise safer sex (including condom use) less regularly than before. Among the reasons for this are: information fatigue; a lack of innovative outreach work; decreased funding for prevention efforts; and uncertainty among HIV-infected men who are receiving antiretroviral treatment about the continued risks — to themselves or their partners — of unsafe or unprotected sex.

Inadequate, inaccessible or inappropriate health facilities

MSM seeking attention on sexual or medical matters, or tests for HIV or other STDs, may find such facilities to be lacking. Alternatively, the facilities may exist, but the men may find access to them difficult – for reasons of negative attitudes on the part of health staff towards same-sex behaviour, lack of discretion or anonymity for clients, inconvenient location or opening hours, or cost.

Stigmatization and criminalization

Societies can be hostile to men who engage in same-sex behaviour, stigmatizing it and treating it as sinful or as criminal – in some places with severe penalties. Men will then often not choose, or have the opportunity, to be honest about the fact that they have had sex with other men. Fearing to be questioned about their sexual behaviour, they will be reluctant to report symptoms of STDs, including HIV. Because of this, all efforts at education on HIV and safer sex, the provision of condoms, and appropriate STD and other medical care, are made extremely difficult.

Hostility on the part of society also hinders effective HIV prevention efforts aimed at adolescents and young men who have sex with other men.

OCCUR

The Japanese organization OCCUR is a good example of a self-identified gay group working to strengthen community-type responses on AIDS among gay men. Since 1986 OCCUR has aimed to create networks among homosexual men and women in Japan, to disseminate accurate knowledge about homosexuality to the general community, and to eliminate social discrimination and prejudice. At the same time it operates safer sex campaigns on a yearly basis and publishes a newsletter for people with HIV and AIDS. In December 1994, one of its leading members, a young man living with HIV, was appointed to join the official Japanese delegation to the Paris AIDS Summit.

The Responses

Condom and lubricant provision

One of the most important and effective responses to the problem of HIV transmission in sex between men through anal sex is to make high-quality male condoms, together with water-based lubricants, available, accessible and affordable to men who are likely to have sex with other men. This can be done effectively through the peer education and outreach programmes described below. In places where there is a gay "scene", condoms and lubricants can be promoted in gay venues. This is particularly important where sex takes place on the premises: several gay bathhouses, including in Hong Kong, Bangkok and Paris, make condoms and lubricants available free to clients.

Instructions on the correct use of condoms should be supplied as part of the packaging of condoms and lubricants, or in the context of skills training.

Peer education and outreach programmes

Peer education uses current members of the affected community. In outreach work, a mixture of trained professionals and volunteers go out to find the MSM, wherever they congregate. The face-to-face methods used in these approaches afford privacy and confidentiality, and enable the person to ask questions. They also enable the educator to train the person. Both approaches – which have been widely used by nongovernmental AIDS service organizations, and others – can be effective for a large range of casual encounters between men.

Both peer education and outreach programmes promote "safer sex" among MSM. Strategies for "safer sex" include switching from anal sex to other forms of sex with much lower risks for HIV/STD transmission, such as oral sex, intercrural sex (between the thighs – without penetration) and mutual masturbation. An important activity of outreach programmes is providing easy access to high-quality condoms and water-based lubricants, and promoting safer sex, knowledge of condom use and negotiating skills. Examples of successful projects include ALCS in Morocco (see Key Materials: Imane, 1995); CAN in Madras, India (see Kashyap N, "Educating Alis and men having sex with men: the Chennai experience", in *AIDS Watch* newsletter, July 1997 **2**(2):2-3, WHO/SEARO, New Delhi); the Lentera project for transvestites in Yogyakarta, Indonesia; Lambda in Chile; the Mpowerment project in Oregon, USA; and Iwag Davao's "Center for Gay Men" on Mindanao island in the Philippines.

It is important that adolescents and young men are educated by their peers on HIV risks and prevention methods. Frequently lacking access to information on sex between men, they are often ignorant of the risks and more vulnerable than others, and will tend to listen to their friends.

Media campaigns

Mass media campaigns on the risks of unprotected sex between men and promoting the use of condoms and water-based lubricants are possible in some settings. In Australia and Switzerland, for instance, media campaigns together with outreach programmes directed at gay men have been shown to have had an impact in changing behaviour. Airing the subject of male-to-male sex in public can also help reduce stigmatization. Campaigns using "small media" such as pamphlets and booklets, which can be distributed discreetly, have been useful in many settings.

Gay community projects

Another approach is to strengthen groups representing self-identified gay men. This applies not only to North America, Europe, Australia and New Zealand, but also to a growing number of large urban areas in other parts of the world, including São Paulo, Mexico City, Bangkok, Hong Kong, Seoul, Taipei, Jakarta, Manila, Kuala Lumpur, Tel Aviv and Cape Town. In Australia, the United States and other Western countries, HIV infection rates among MSM have dropped mainly through the efforts of gay men's organizations themselves. The experience in several developing countries suggests that AIDS has encouraged self-identified gay men to move into community organizing, sometimes with minimal external support.

Parallel with this approach is the possibility of organizing gay bar owners in HIV prevention activities. This happened in Bangkok, where a gay bar owners' association has actively undertaken AIDS education and condom promotion.

Educating the health services

The public health services are one of few (if any) official points of contact where many men who have sexual encounters with men are likely to receive information, counselling, check-ups and treatment. It is important that there should be strong educational programmes among health workers to promote non-discriminatory attitudes towards male-to-male sex, and to have the appropriate counselling, preventive and medical approaches adopted. STD clinic staff should be sensitized to the existence of anally and rectally located STDs. Anonymity is important in encouraging MSM to use these services.

A greater effort by national AIDS programmes and donor agencies

National AIDS programmes should address and incorporate the particular requirements of MSM into the design of their STD/HIV prevention and AIDS care programmes. While some of them do so at present, many still do not. Donor agencies should be given more information on the situation of MSM. They should also make a higher priority of funding the implementation and evaluation of projects with male-to-male sex as one of the main components.

When HIV programmes aimed at MSM are operating, it is vital that they should be maintained. There have been cases, including in developed countries, where programmes had their funds reduced, or even stopped, after the project was declared to have been "successful", or when it was thought that the risk to men engaging in same-sex behaviour had declined.

Greater understanding and an end to denial

All the previous suggested responses have a very much greater probability of success if society adopts a non-discriminatory approach to men having sex with other men – ending the stigmatization and marginalization that exist in many places. More determined efforts must be made to change public perceptions and get rid of denial and prejudices on the subject of MSM. Serious consideration should be given to introducing anti-discrimination and protective laws to reduce human rights violations against MSM, including in the context of HIV/AIDS.

Governments should review, with the aim of repealing laws that criminalize specific sexual acts between consenting adults in private. (According to page 14 of the Second International Consultation on HIV/AIDS and Human Rights held in Geneva in1996, "Criminal law prohibiting sexual acts (including adultery, sodomy, fornication and commercial sexual encounters) between consenting adults in private should be reviewed, with the aim of repeal. In any event, they should not be allowed to impede provision of HIV/AIDS prevention and care services". See *HIV/AIDS and Human Rights: International Guidelines,* available on the UNAIDS website at http://www.unaids.org/publications/documents/human/index.html). Such action will greatly help the provision of HIV/AIDS prevention and care services and reduce the vulnerability of MSM to HIV infection and to the impact of AIDS.

More research towards understanding same-sex behaviour, its prevalence and relation to HIV risk, should also be carried out.

Mass media campaign and NGO projects: the example of Brazil

In the first years of the epidemic in Brazil, from 1983 to 1987, most HIV prevention efforts were aimed at MSM. These included large-scale government-inspired mass media campaigns, and peer education and outreach programmes operated by nongovernmental AIDS service organizations. In São Paulo state – considered representative of Brazil for this purpose – the number of new AIDS cases where infection was through male-to-male sex rose steadily each year, to a maximum of 1464 in 1992. Since that year, the number of new AIDS cases has fallen each year, with 953 reported in 1995. Given the time lag between seroconversion and onset of AIDS, it is possible that HIV incidence had started to fall by 1986 or earlier. This suggests that the combination of early mass media campaigns and NGO work, both aimed specifically at MSM, was effective in Brazil.

Selected Key Materials

Aggleton P (ed). *Bisexualities and AIDS.* London: Taylor and Francis, 1996. Includes chapters on MSM and bisexual behaviour in wide range of countries including Brazil, China, Costa Rica and Mexico.

Aggleton P (ed). *Men selling sex.* London: Taylor and Francis, 1999. Describes male sex work around the world, with many references to HIV/AIDS. Chapters on Brazil, Costa Rica, Dominican Republic, Mexico and Peru; Bangladesh, Philippines, Sri Lanka and Thailand; Morocco; Canada, England, France, Netherlands, USA and Wales.

Altman D. *Power and community.* London: Taylor & Francis, 1994. Analyses practical dilemmas faced by community-based organizations of MSM worldwide, highlighting tensions between AIDS activism and service provision, and between volunteer participation and management control.

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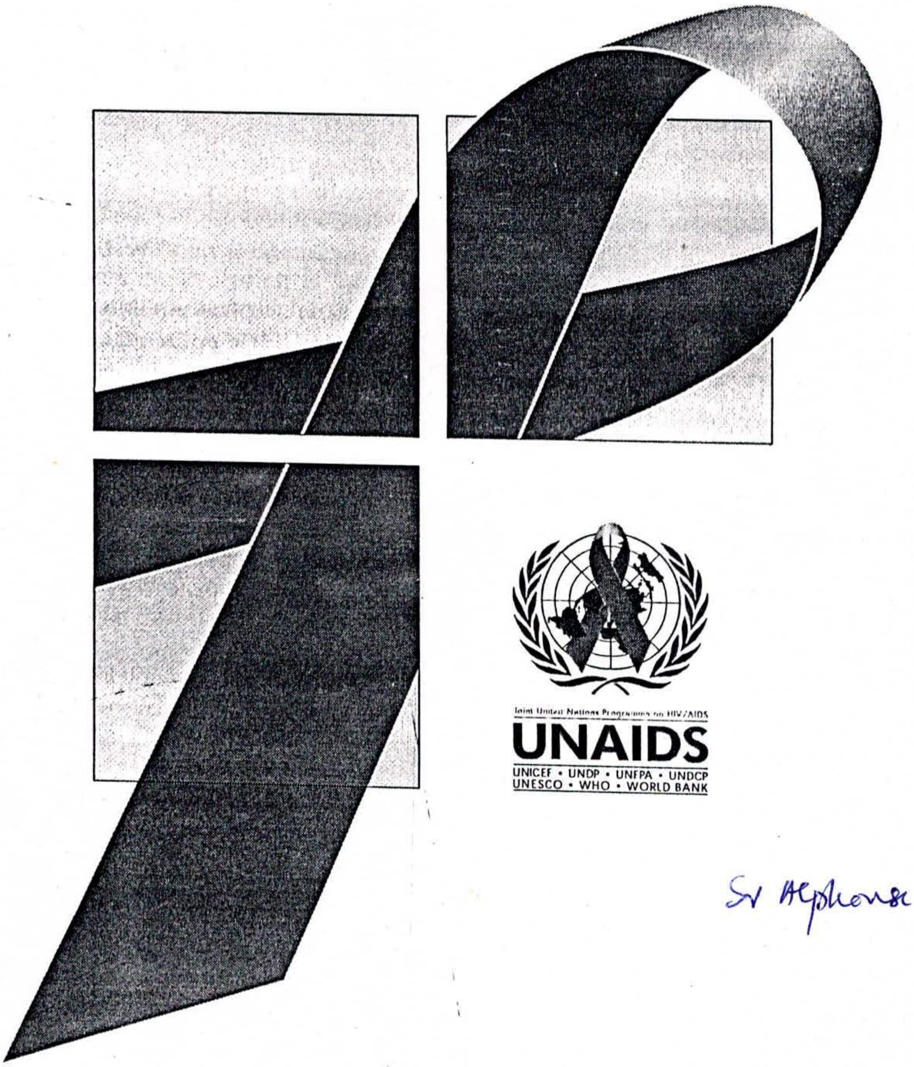
Day 3 — Mani

D15-2K

Sexual behavioural change for HIV:

Where have theories taken us?



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KEY MATERIAL

CHAPTER II

KEY APPROACHES TO BEHAVIOURAL CHANGE FOR HIV

Early in the AIDS epidemic, results of population survey research alerted public health officials of the diversity of sexual behaviours and of the need to act quickly. The first interventions as well as the first applications of theories were propelled by the urgency to do anything to slow the alarming crisis at hand. Through popular public health channels, information was disseminated to populations at risk.

Today, many of the interventions for the prevention of HIV transmission, rather than using one of the behavioural theories in its entirety, have developed programmes based on one or many constructs often depending on the socio-cultural, political, or economic situation and on the stage of the epidemic. Drawing on various models and modifying them to suit the population and context has been critical to implementation of prevention projetcs, especially in international settings, as nearly all theories were developed in the West. These transtheoretical approaches are guided by critical constructs such as risk perception, social norms and sexual communication to form the basis of interventions worldwide.

This section looks principally at the most common approaches used to influence HIV risk reduction. Although these approaches are not consistently or directly derived from behavioural change theories or models, they draw on the multiple constructs mentioned above. The section is split between individual and community-level interventions, where the approach is described and then specific examples of its use are reviewed. See Table 2 for a summary of models and theories tested by research or reviews.

(A) APPROACHES AIMED AT INDIVIDUAL LEVEL BEHAVIOURAL CHANGE

Information, education and communication

Mass and small group education

As information was initially, for many, thought to be the key to behavioural change, HIV prevention programmes began with a focus on increasing awareness about the modes of transmission and prevention (Cohen, 1992). Mass education for HIV prevention can take many forms but is often seen as a key component of a comprehensive AIDS prevention programme (Holtgrave, 1997). Mass media, for example, are directed to the general public and aim at teaching people essential facts, promoting healthy behaviour, quieting anxiety about casual transmission and preventing discrimination.

An analysis of the messages adopted by the information and education programmes of national AIDS control programmes of 38 different countries found that over 90% focused on correcting misperceptions about AIDS. About 80% provided information about personal risk assessment (Cohen, 1992). In many countries, mass education provided the first step to national AIDS control programmes. Many mass education efforts successfully raised AIDS awareness by informing individuals of the risks of HIV infection, and in some cases education-based programmes were sufficient to change high risk behaviours, increase condom sales, and reduce new HIV infections (Kalichman, 1997). The channels that national AIDS control programmes have used for mass education include targeted media, printed media and electronic media (Cohen, 1992).

A review of 49 studies covering 18 countries to identify empirical outcomes or evaluate impact of HIV-related mass-media campaigns in 1996 concluded that most campaigns aiming at "individual-level goals of knowledge, attitude or behavioural changes were generally successful at achieving these goals" (Holtgrave, 1997). However, behavioural endpoints of the projects reviewed were not mentioned. In addition, as the author himself pointed out, a substantial number of the project reports reviewed lacked methodological details; they were reported in conference abstracts. It is therefore difficult to conclude on the relative meaning of the term "successful", particularly in relation to behavioural outcomes.

Small-group AIDS education is taking place all over the world, advancing general knowledge of HIV in numerous communities. Small-group AIDS prevention programmes can be seen as having 3 main components:

- content
- context
- strategies (Kalichman, 1998).

Content includes goals, objectives, and activities. The main content areas in most small-group intervention activities include: basic education about AIDS, sensitization to one's personal risks for HIV, instruction in individual actions that can reduce one's risk and exploring new ways to communication with sex partners. Entire interventions or research questions are built on any one of these content areas.

The second component in small group HIV prevention is the *context*. The different aspects of the intervention should be designed to fit the cultural, gender and developmental issues of participants. For example, one investigator felt concerns of stigma and sexual identity were paramount to African American gay men and dedicated an entire session of this small-group intervention to concentrate on those issues (Kalichman, 1998).

The third component, *strategy*, is the process itself, where emphasis is placed on *how* the interventions are implemented between participants and group leader. Key elements to consider include how to foster trust, build group cohesiveness, encourage motivation and mutual support among participants and between participants and the facilitator (Kalichman, 1998).

Although evaluations of small-group interventions have focused on content and facilitation skills, all three components have been found to be critical to the success of this approach. The literature reports strong evidence for the beneficial effects of small-group HIV prevention from randomized controlled trials of theory-based skills-building programmes (see chapter III for impact of theory based interventions). Several independent reviews of the literature as a whole found that small group HIV risk-reduction interventions result in meaningful changes in HIV risk behaviour (Kalichman, 1998).

One innovative approach targeting hard-to-reach populations in the USA with information and counselling was a multiple session intervention designed to be delivered over the telephone. One reason for this method was to reach populations that do not want to meet a health care provider face-to-face. In an evaluation of the study, the researcher found significant effects of their telephone-based counselling including a decrease in unprotected intercourse from 47% to 26% of the men who completed the programme (Roffman, 1997).

Another study in Uganda looking at gender differences and perception of risk noted that participation in small-group AIDS education was associated with some protective behaviours for women with evidence of a dose response effect. The author suggests that these AIDS education events may also provide a socially sanctioned opportunity for peer group interaction for women (Bunnell, 1996).

Especially in the USA, small-group AIDS prevention efforts have evolved since the beginning of the epidemic from providing basic information in community groups and sensitizing people to personal risk sensitization. Subsequently, interventions began instructing people on condom use skills, eroticizing safer sex, and building safer sex communication skills. Through interventions encompassing these elements, many people have reduced high-risk sexual behaviour, but not everyone is sensitive to small group behavioural interventions. For example, small-group projects targeting heterosexual men for HIV prevention have not shown significant intervention effects. Longer-term behavioural changes require ongoing support and modifications in the larger social environment within which these behaviours take place.

Peer education

Peer education is one approach to small-group HIV prevention usually aimed at individual behaviour. The peer health educator approach recruits leaders in communities at risk to be implementers of the education programme to their peers (Sepulvede, 1992). Selection of peer educators is a key to the success of a programme and often involves:

- acceptance by other members of the group
- being an opinion leader, thus well respected in the group
- willingness to be trained
- committed to the goals of the programme

Many interventions combine peer education with other approaches such as the use of social networks, condom social marketing (Roy, 1998) and outreach (Seema, 1998 & Boontan, 1998) as these approaches can be complementary. Outreach work using peers has resulted in increased participation of targeted community members as well as increased diversity of participants (Broadhead, 1998).

The benefits of working with peers rather than with 'experts' from outside the social network are many depending upon the group at risk. Wingood noted that peer educators may be a more credible source of information for women, may communicate in a more understandable language, and may serve as positive role models (Wingood, 1996). Other studies have suggested that when the group at risk is very different culturally from the majority, peers know the cultural risks and most appropriate and realistic risk-reduction strategies from experience.

The peer educator approach has been used in as diverse populations as: dock workers in Nigeria (Ogundare 1998), Arabian prisoners in Italy (Vacondio, 1998), street youth in Thailand (Boontan, 1998), in-school youth in Armenia (Ter-Hoyakimyan, 1998) secondary school students in Argentina (Bianco, 1998), taxi drivers in Cameroon (Moughutou, 1998), low- and middle-class general population in Zambia (Kathuria, 1998), factory workers in Zimbabwe (Katzenstein, 1998), sex workers in India (Seema, 1998, Roy, 1998), drug users in USA (Broadhead, 1998) and traditional healers in South Africa (Green, 1994), among many, many others.

In these various situations, peer educators performed differing tasks ranging from development and distribution of IEC materials including video clips and pamphlets, as well as condom discussion and distribution to conversations with peers on diverse topics such as empowerment, health and human rights, and basic AIDS information.

Surprisingly, all of the above studies, even though many were not randomly controlled, indicated positive results. But here again, many of these reports were conference abstracts lacking methodological details. Nevertheless, they show the astonishing diversity of populations and contexts with which peer education is being practised throughout the world.

In one study that randomized 40 factories in Zimbabwe into counselling and testing with or without peer education, results reported a 34% lower HIV incidence in peer education than in control group (Katzenstein, 1998). In Zambia, authors noted dramatic declines in syphilis seropositivity in 3 test vs. 3 control sites (by 77%, 47% and 58%) after a 3-year peer education programme that reached 417,000 men and 385,000 women (Kathuria, 1998).

Two studies analysed cost-effectiveness of peer education interventions among IDUs in the USA and factory workers in Zimbabwe. In Zimbabwe costs compared favorably to other HIV prevention programmes (Katzenstein, 1998), and the US researchers found that the peer-driven intervention cost one thirtieth as much as the traditional (external) intervention (Broadhead, 1998).

As any other approach however, peer education has its limits. For example, in Brazil, participants of a target group became health agents and lost their solidarity and support within the group, which is a key element to successful peer education (Leite, 1998). Another example comes from a convenience sample analysis of several peer education programmes across the USA that found a structural tendency for peer education programmes to employ low-income people and treat peer educators as the most marginal sector of the organization's staff (Maskovsky, 1998).

Testing and counselling

In increasing numbers people in industrialized countries are receiving their HIV test results as therapeutic options become available to more people. Research has shown many reasons developing nations should make voluntary testing and counselling (VTC) accessible to their populations (UNAIDS, 1998). Early detection of the virus enables referral for clinical care and psychosocial support. Ethically people have a right to know their serostatus in order to protect themselves and others. And knowing their own serostatus and the options can motivate people to change higher risk behaviours (De Zoysa, 1995). In addition, De Zoysa notes that HIV testing and counselling may have an important social impact through people knowing their serostatus sharing it with others and laying the groundwork for changes in social norms about HIV and AIDS. A positive HIV result has also encouraged some people to give personal testimonies in community fora, a consequence that can have a powerful effect on individual attitudes, behaviours and social norms. In cultural contexts where fertility is highly valued, testing and counselling provides an important behavioural-change alternative to consistent condom use.

The theoretical foundation on which interventions providing testing and counselling are built principally involves the *stages of change* model (De Zoysa, 1995). HIV testing and counselling may promote progression across the continuum of the stages of change. For example, in rural southwestern Uganda, a setting with high HIV prevalence, the majority of respondents in a research study reported that they had already made behavioural changes because of AIDS, but making further changes to protect themselves was contingent on knowing their HIV serostatus (Bunnell, 1996). It has thus been suggested that counselling promotes risk reduction through increasing perception of risk, self-efficacy and personal skills, and through reinforcing social norms or responsibility (De Zoysa, 1995).

In 1991, in an extensive review of 50 testing and counselling studies in Africa, Australia, Europe and North America, Higgins *et al* found substantial risk reduction only among heterosexual couples with one infected partner. In other groups (homosexual men, injecting drug users, women) risk reduction was not significantly associated with counselling and testing (Higgins, 1991).

An updated review of 35 studies conducted by Wolitski et al. in 1997 found similar results to those of Higgins *et al* for some population groups. The clearest evidence for positive behavioural effects of HIV VTC has been heterosexual sero-discordant couples where HIV counselling and testing was a significant motivating factor to risk reduction. Studies of MSM have also indicated significant risk reduction but it was not clearly related to their testing for HIV. Yet a UNAIDS report notes that among a sample of HIV-infected homosexual men in Norway the number of sex partners decreased from an average of 4.3 a year before to 1.6 after counselling and testing (UNAIDS, 1998). In HIV serodiscordant couples a consistent reduction in sexual risk practices followed HIV testing and counselling. Similarly, in most injecting drug users studies, counselling and testing proved to be beneficial in reducing dangerous sexual practices (Wolitski, 1997). Across populations, individuals who learn they are HIV positive have been found to be more likely to change behaviour than those who learn they are HIV negative.

More recently a randomized controlled trial in 3 developing countries (Kenya, Tanzania and Trinidad and Tobago) showed that couples receiving counselling and testing reduced unprotected intercourse among their spouses, especially among serodiscordant and seropositive concordant couples (Coates, 1998a). However, results specifically found that VTC produced significant changes in reducing high-risk sexual practices with non-primary partners (Coates, 1998).

In the USA, a randomized controlled trial evaluating HIV post-test prevention counselling was conducted in 5 STD clinics comparing 3 arms: (1) HIV education including 2 sessions with brief HIV/STD messages, (2) HIV prevention counselling, 2 sessions aimed at increasing risk perception, (3) enhanced counselling, 4 sessions based on theoretical constructs of behavioural change; self efficacy and perceived norms, over a 12-month period. They found marked changes in condom use with both main and other partners across arms of the study (Kamb, 1996). After 12 months, there were 19% fewer new STD cases in the brief counselling group, and 22% fewer in the enhanced counselling group, compared with the group that had received only educational messages (Kamb, 1998). These findings support other studies showing benefits of client centered counselling combined with HIV test results.

Other, non-randomized studies in Rwanda, Uganda, Kenya and Zaire reported VTC to be a motivating factor especially for couples to change behaviour (Allen, 1992; Campbell, 1997; Choi, 1994; Alwano-Edyegu, 1996). The AIDS Support Organization (TASO) provides counselling and support services to a variety of clients with AIDS in urban and rural Uganda. In an overall evaluation of TASO, it was noted that 90% of all clients had revealed their HIV status to somebody following TASO services. In contrast, a study in the Gambia showed no effect of individual post-test counselling on condom use among prostitutes who already had high rates of condom use before the intervention (Pickering, 1993).

Wolitski sums up by noting that "*there Is no question that HIV VTC can and does motivate behavioural change in some individuals*", but also that VTC alone does not always lead to changes and does not have the same effect in all populations and in different situations (Wolitski, 1997). As with most other approaches, the stage of the epidemic and surrounding contextual factors will contribute to the outcome of the intervention. In addition, the quality of the counselling provided is a key variable in predicting the impact of the intervention.

Conclusion

After years of experience with HIV prevention and the variety of interventions aimed at individual behavioural change tested in diverse situations, certain characteristics of successful programmes point to key elements of approaches to behavioural change programmes. These elements include: increasing participants ability to communicate effectively about sex; helping participants increase their condom use skills; personalizing risk, achieving participants perception of risk avoidance as an accepted social norm, providing reinforcement and support for sustaining risk reduction. For individual level interventions to be successful, context specific information and skills are critical.

(B) COMMUNITY-LEVEL INTERVENTIONS

Community-level approaches grew out of the realization that, despite the considerable risk reduction through individual-level behavioural change approaches, different approaches were needed as well. Social epidemiology, pointing to differences in prevalence among different social categories within a given risk category in a community suggested intervening along these lines (Friedman, 1997). The programmes in this section encompass the most widely publicized approaches to community level HIV prevention including: interventions based on *social influence* and *social networks*, outreach programmes, school-based programmes, condom promotion and social marketing, community organizing and empowerment and policy level interventions. Each of these types of interventions either try to reduce individual vulnerability to or transmissibility of HIV, change community norms, limit dispersal of high seroprevalence networks or change community organizational structures making them less dangerous (Friedman, 1997). Changing community cultures or community norms provides motivation and reinforcement for individual HIV risk reduction. Many of the following programmes use ideas from the *theory of reasoned action*, the *diffusion of innovations model* and the *theory of social influence* to mobilize peer pressure or to ostracize individuals who continue high-risk practices. Policy level changes such as closing of bathhouses and enforcing condom use in brothels also account for significant impact in community risk practices.

Social influence and social network interventions

Based on the theories of *social influence, diffusion of innovation, reasoned action and social cognitive theory*, these interventions use peers and social networks to disseminate information. Social influence interventions identify key persons in communities who are capable of influencing others. The *social cognitive theory* posits that trusted role models are an important factor in the environment and the environment has a reciprocal relationship both with behaviour and the individual. In the *theory of reasoned action*, perceptions of social norms have a critical influence on behaviour. Social norms created by opinion leaders will ideally have a strong effect on behaviour. *Diffusion of innovation* theory asserts that changing behaviour will more likely happen if the new behaviour is compatible with accepted social norms of a specific social network, is simple to do, and has observable outcomes (Kalichman, 1998). One's social network can be a source of emotional and instrumental support and a reference that establishes social norms.

Research implemented using peer educators to influence social networks in gay communities showed significant self-reported changes in safer sex practices after intervention (Auerbach, 1994). Encouraging results in changing social norms and safer sex behaviour have also been noted in a number of community-level social influence interventions in the USA. One programme implemented among men frequenting gay bars in three Southern cities began by identifying and recruiting opinion leaders. Project staff then trained leaders in risk-reduction, and the final stage involved opinion leaders in disseminating prevention messages to friends and other members of their social networks (Kalichman 1998, Kelly, 1992). In a later study using the same methods, researchers used a randomized experimental design with four test and four control cities and showed a decrease in population-level rates of risk behaviour after one year (Kelly, 1997).

The Mpowerment project was similar to the above studies but focused on young gay men in a midsize urban community in the USA, and included in the intervention package a publicity campaign and small group sessions concentrating on individual behavioural change (Kegeles, 1996). In the test city, there was a 26% reduction in unprotected anal intercourse compared to 3% in the control city. A follow-up study examined the effectiveness of the different programme components (small groups, social events, and outreach) on post-intervention sexual risk-taking. The small groups had a large effect size, but reached substantially fewer men than social events and outreach. Although not as powerful, the social events and outreach were critical to the effectiveness of the programme as sources of recruitment to the small groups and as a means of reaching men not interested in attending small groups. Authors concluded that the effectiveness of programme components were not independent; the synergy created by the whole programme makes the net effect of the intervention activities greater than the sum of its parts (Kegeles, 1998a).

Sikkema et al. tested a comparable approach with women living in urban, low-income housing developments. The intervention included outreach, small groups and community activities to encourage social norms supportive of safer-sex as well as reduction of individual high-risk behaviour (Kalichman, 1998). Women who were identified as opinion leaders participated in a 4-session skills-building intervention centered on HIV prevention knowledge and behaviour. These women recruited other women who participated in the same intervention and the cycle continued until about half the women in the housing development were reached. At the same time, social norm-changing events were being implemented. Results of this randomized controlled trial found that condom use reported by women in the intervention site increased from 29% at baseline to 41% at 3-month follow-up (Kalichman, 1998).

The National AIDS Demonstration Research Projects implemented in more than 60 sites in the USA to evaluate strategies among IDUs, combined research methodologies but focused on the social networks of IDUs as the primary target group. The Indigenous Leader Outreach Intervention Model which combines medical epidemiology and community ethnography guided the project. Former IDUs were employed as outreach workers whose job was to identify and access the social network, document the norms, values and situational factors relating to risk practices. Former IDUs were also responsible for delivering the HIV prevention services. After a four-year intervention, incidence of HIV decreased from 8.4 to 2.4 per 100 person years. Sex risk practices decreased less dramatically than drug risk, but went from 71% to 45% (Wiebel, 1996). The same model was tested among sex workers in Indonesia with encouraging results (Gordon, 1998).

Interpreting these results for social influence interventions indicates that multi-component, individual and community level that combine cognitive-behavioural and norm-changing activities can result in positive changes for MSM and heterosexual women. Despite the fact that all published reports described here were based on interventions in the USA, since they are based on conversations with peers one could assume that they would be ideal for other populations (even non-literate) as well.

Outreach interventions

Outreach interventions are conceptualized in a similar manner to social influence interventions in that they use individuals to pass on information within social networks, however the influential person may or may not be from the targeted community. The outreach worker enters the social system to instigate behavioural change as an individual change agent. Targeted communities are often hard-to-reach groups such as drug users, sex partners of drug users, sex workers as well as isolated rural populations. The aims of outreach have often been harm reduction strategies such as providing condoms to sex workers, but not necessarily addressing sex work itself.

Three large-scale research trials in the USA examined the effects of outreach delivered primarily to injecting drug users. The National AIDS Demonstration Research Projects targeted over 36,000 out-of treatment injecting drug users. Results indicated that sexual practices were much more difficult to change than sharing of drug using equipment. The projects did show reductions in sex risk practices, but less dramatically than for drug risk practices (Wiebel, 1996).

A second initiative entitled the AIDS Evaluation of Street Outreach Projects supported by the CDC was conducted in six US cities, and showed promising outcomes as well as being cost-effective. Again, this project found drug using behaviour easier to change than sexual behaviour. A third outreach project (AIDS Community Demonstration Projects) was implemented in five US cities and had multiple target groups including: IDUs and their partners, MSM, female sex workers, street youth and men who have sex with men but do not identify as gay. The health belief model, social cognitive theory, the theory of reasoned action and the transtheoretical stages of change model guided the outreach intervention. Following formative research, volunteer outreach workers implemented the intervention, by disseminating innovative, carefully designed materials and messages. The evaluation indicated that the communities moved across the continuum of stages of change following the intervention. A dose-response effect was noted according to exposure to the intervention materials (Guenther-Grey, 1996, Kalichman, 1998)

Interventions using outreach as a strategy have been carefully tested in the USA among diverse populations and have shown encouraging results. This approach lends itself as well to hard-to-reach populations and has been used in many parts of the world though randomized controlled trials have not been reported outside the USA.

School-based interventions

By the early 1990s, school-based programmes for HIV education existed in about three quarters of industrialized countries and 60% of developing countries according to a survey of 38 countries (Cohen, 1992). Besides interventions that simply provide basic AIDS information in the classroom, multi-dimensional school-based programmes generally include classroom skills-building sessions, school-wide peer-led activities, and social norm changing programmes. Promotion of condom use was the theme most frequently adopted in programmes for youth in and out of school (Cohen, 1992). An extensive review of school-based interventions revealed that no comprehensive school-based HIV-prevention interventions evaluated showed signs of promoting sexual acting out or hastening the onset of sexual intercourse (UNAIDS, 1997). It was found that effective interventions had a number of characteristics in common:

- accurate information was provided about the risks involved in unprotected sex, enabling informed behavioural decision making
- programmes included skills building sessions enhancing self-efficacy for safer-sex negotiating practices
- components were often based on social cognitive theory including modeling of safer behaviours (Kirby, 1994)
- activities were conducted in small groups or had a minimum of 14 hours of contact
- opportunities for youth to personalize information were provided
- social pressures to engage in sex were addressed with strategies for resisting peer pressure
- reinforced supportive group norms and appropriate individual values for engaging in safer behaviour were emphasized
- extensive training was provided for teachers and/or peers who were to implement the training.

The element distinguishing school-based programmes from other interventions for youth was the supportive structural aspect played by schools and teachers, and the interaction between school, parents, students and community (Peersman, 1998, Kalichman, 1998).

Condom promotion and social marketing

It has now been proven numerous times that correct use of condoms is an effective method of preventing HIV transmission. Yet, countless research studies have identified obstacles to their use in settings throughout the world, including inaccessibility and partner communication among other factors.

Most initial HIV prevention programmes included condom promotion and free distribution as part of a comprehensive HIV prevention package. Free distribution was essentially aimed at introducing condoms where they were not previously available or distributing them to destitute populations at high risk such as sex workers and refugees. Although this approach accomplished its intended outcome of making condoms accessible without delay to large populations, the lack of sustainability and reliability of free condom distribution programmes commanded the introduction of condom social marketing strategies especially aimed at certain populations.

Condom social marketing, which may well be the most developed of public health communication approaches, aims to remove the barriers to condom use by using commercial marketing techniques such as advertising and packaging to make the product accessible, affordable and attractive to all types of people. The theories underlying social marketing programmes derive from many different disciplines including operant conditioning and social cognitive theories as well as economic and marketing principles. Social marketing has been termed a 'strategic planning' approach based on the theoretical 'principal of exchange' which explains that people will only change their behaviour to something less pleasant (like condom use) if they perceive an adequate benefit (Kennedy, personal communication). Social marketing techniques highlight the importance of adapting the campaign to suit the characteristics of the population group being targeted. It dedicates sufficient time to formative research, which necessitates asking the consumer always and often about his or her point of view. Modifying products requires a good understanding of the culture of the target group. Availing condoms at non-traditional outlets such as truck stops, bars, and hotels is integral to social marketing success. Flooding these non-traditional outlets with condoms aims not only to increase availability but also to increase social acceptability (World Bank, 1997).

Results of these programmes have shown dramatic increases in condom sales in countries, such as Côte d'Ivoire, Uganda, and Malaysia where condoms were practically unavailable before social marketing campaigns (World Bank, 1997). After a 3-year peer-led condom promotion programme among sex workers in West Bengal, India, found that condom use rates rose from 3% to 81%, a social marketing campaign was launched. Six months into the project using peer education and community participation, free distribution of condoms had decreased by 50% and the same amount of condoms had been sold (Banerjee, 1998). Social marketing programmes have also been developed in Mexico, Dominican Republic, Canada, Brazil, Vietnam, Pakistan, Zambia, Botswana, Cameroon, South Africa and Haiti for HIV prevention (Holtgrave, 1997, PSI, 1998). Evaluations have shown success in increasing condom use especially among adolescents in Zambia and among married women in small urban areas in Pakistan (PSI, 1998).

Besides condom promotion, social marketing techniques have also been effective for other HIV prevention strategies such as promotion of testing and counselling for adolescents in the USA (Futterman, 1998), and the recruitment of research participants in Puerto Rico (Torres-Burges, 1998).

Community organizing, empowerment and participatory action research

Empowerment approaches are built on the premise that positive public health impact is fostered by recognizing the relationship between social structure and health, and by recognizing that lasting change is a process that initiates from within a community. Empowerment in connection with HIV in the USA has its historical roots in public health and community psychology (Beeker, 1998). From the field of education, Wallerstein defined empowerment as:

> "*Empowerment education, as developed from Paulo Freire's writings, involves people in group efforts to identify their problems, to critically assess social and historical roots of problems, to envision a healthier society, and to develop strategies to overcome obstacles in achieving their goals. Through community participation, people develop new beliefs in their ability to influence their personal and social spheres. An empowering health education effort therefore involves much more than improving self-esteem, self-efficacy or other health behaviours that are independent from environmental or community change; the targets are individual, group and structural change. Empowerment embodies a broad process that encompasses prevention as well as other goals of community connectedness, self-development, improved quality of life, and social justice.*" (Wallerstein, 1988)

Beeker suggests a definition of an empowerment intervention as follows:

> "*A community empowerment intervention seeks to effect community-wide change in health-related behaviours by organizing communities to define their health problems, to identify the determinants of those problems and to engage in effective individual and collective action to change those determinants.*" (Beeker, 1998).

Empowerment approaches assume that health behaviours are not completely under volitional control of individuals, thus are not entirely isolated events, but embedded within social, cultural and economic surroundings.

The impact of society's defined gender roles on protective health behaviour of women highlights the importance of empowerment approaches, especially for HIV-vulnerable women. Beeker describes ideally what the components of an intervention based on community empowerment for women would look like. The intervention would address the cultural environment by recognizing gender roles that define women as subordinate to men; the physical environment by including access to appropriate services and materials such as battered women's shelters and both male and female condoms; the structural environment such as opportunities for women to change their economic status; and the policy/legal environment such as businesses providing paid leave for community service and child care (Beeker, 1998).

Community participation at all levels of implementation is an integral aspect of community empowerment approaches. Interventions include community organizing, and participatory action research (PAR) into their programmes (Israel, 1994, Hiebert, 1998). A strength of PAR resides in the ability of participants in conjunction with committed and creative professionals to adapt methods and content to diverse contexts. The positive outcomes of PAR arise from its collaborative, trust-building capacity, with direct community input that responds to emerging changes in social, political and economic situations (Stevens, 1998). These interventions seek to support communities to be self-determining in their ability to integrate HIV programmes into existing community structures by assessing their own needs and priorities, defining, implementing and evaluating their own work[1].

Empowerment approaches have been used for AIDS risk reduction through numerous different strategies and in countless different settings and contexts. The literature describes empowerment interventions directed at women, young gay men, youth, people with HIV and AIDS as well as many other communities at risk.

A CDC-funded intervention developed for young, pregnant women from low income communities in the USA, randomly assigned women to one of three arms (four sessions AIDS prevention, 4 sessions health promotion, control). The HIV prevention arm focused on enhancing women's skills in negotiating condom use with their partners using role-play and rehearsal, among other methods. Consistent with empowerment ideals, the content included other health matters in addition to HIV prevention and activities were developed to encourage a feeling of 'communal mindedness' in the group. The idea was to promote mutual support in the process

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[1] *See Israel et al., 1994 or IUCN, 1997 for complete definitions and examples of participatory action research.*

of behavioural change. Results indicated that women in the HIV prevention group showed greater changes in intention and practice of safer sexual behaviours than women in other groups (Beeker, 1998). Comments by authors of the report concluded that women in the HIV prevention group gained a sense of perceived control over their lives.

An intervention using PAR among lesbian women highlighted the power of community ownership of the project and its continuity over time that provided a space for engagement and commitment where women focused on community mores, values, and social expectations about sexual relating, drug use and HIV. The feeling of solidarity with peer educators enabled women to reduce risk behaviours (Stevens, 1998).

Empowerment can have far-reaching positive health and welfare benefits. Schuler et al. describes the impact of involving women in credit programmes on contraceptive use. She found that, in Bangladesh, rural credit programmes for women can play an important role in changing fertility norms and accelerating contraceptive use by strengthening women's economic positions and fostering women's empowerment (Schuler, 1994).

Other empowerment interventions for sex workers include a project in Zambia, where women fish traders who often experience sexual exploitation have been supported in forming economic cooperatives as a way of protecting themselves against HIV. A second example is a programme in India where women have been taught how to collectively save sufficient savings to pay bonds binding them to sex work (Aggleton, 1998, Tawil, 1995).

Importantly, Beeker reminds us that empowerment approaches do not strive to substitute for individual psychosocial interventions, but to 'widen the lens to include person-in-environment' approaches. She notes that there is increased commitment to community participation, but that there remains a difficultly surmountable gap between empowerment rhetoric and practice. For that gap to be bridged, one key element is progress in operationalizing new concepts and constructs, and testing hypothesized relationships between, for example, community participation and community capacity to effectively address health issues (Beeker, 1998). Although tools for measurement of single and multi-level (from personal to community level) empowerment have been developed and tested, they have not yet been used on a wide scale (Israel, 1994).

Policy level interventions

Policy level interventions are 'enabling' approaches that attempt to remove structural barriers at a larger level. Many believe that AIDS interventions are moving from solely investigating individual approaches to multi-dimensional models of community mobilization, empowerment and structural policy level interventions (Beeker 1998, Parker 1996).

The earliest and some of the most effective efforts of community level change for HIV have resulted from social action. ACTUP, formed in 1987 in New York, is responsible for many successful policy initiatives for people living with HIV and AIDS as well as advocating for everyone's responsibility to practise safer sex.

Another widely recognized policy level intervention is the 100% Condom Programme in Thailand that mandated condom use in brothels and during other commercial sex encounters. Components of the programme included a requirement that sex workers use condoms with all clients, that condom use be monitored, that brothel owners and managers assist in promoting condom use with uncooperative clients and that there should be sanctions against brothel owners for non-compliance (Aggleton, 1996). The programme showed a dramatic increase in self-reported condom use during commercial sex acts (14% to 90%), a decline in reported STD attendees in government clinics, and a decline of HIV positive army conscripts (Friedman, 1997). Success of the programme has been attributed to the fact that it was based on harm reduction in a population at very high risk. It did not try to eliminate the brothels but attempted to reduce HIV transmission within them, and it used national policy which ensured a broad and lasting effort (Friedman, 1997).

Conclusion

HIV prevention at the community level is an integral component to check further spread of

HIV. By working with communities, in contrast to individuals, one is focusing on changing policy, social structures, social norms and cultural practices that surround individual risk behaviours. Community level changes working at the level of changing subcultures have potential to effect long-term maintenance of changed behaviours, by changing the environment surrounding individuals to support safer behaviours. At the same time, many of these approaches highlight the importance of participatory methods to include and empower individuals. It is important to note that many of the interventions mentioned above may have initially focused on one level (such as policy, or empowering individuals), but as the programmes developed they generally include more target levels including changing local cultures and subcultures (Friedman, 1997). Programmes discussed here have been the most widely publicized approaches to community level HIV prevention yet many more innovative projects exist worldwide.

Finally, development of methods for implementation and evaluation of community-level programmes has not been operationalized on a broad spectrum. Assessing effectiveness of these programmes introduces a number of challenging issues such as measuring community level changes using the community as the level of analysis rather than the individual. Additionally, identifying elements of the intervention to measure, thus defining new community level indicators and obtaining large enough sample sizes to detect significance add new challenges to community level evaluation. This makes design of such programmes and the ability to carry them out possibly more complex than individual-based programmes.

Joint United Nations Programme on HIV/AIDS
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Opening up the HIV/AIDS epidemic

Guidance [illegible]
ethical [illegible]
[illegible]

Executive Summary

Joint United Nations Programme on HIV/AIDS
UNAIDS
UNICEF • UNDP • UNFPA • UNDCP
UNESCO • WHO • WORLD BANK

World Health Organization

This document is an executive summary of
Opening up the HIV/AIDS epidemic :
Guidance on encouraging beneficial disclosure, ethical partner
counselling & appropriate use of HIV case-reporting
(UNAIDS Best Practice Collection, Key Material),
copies of which may be obtained from the UNAIDS Information Centre
(also available in other languages)
or accessed directly on the Web site - see below.

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Executive Summary

Faced with the increasingly devastating impact of HIV/AIDS on individual and community well-being, and on development, life expectancy and childhood mortality, many governments have been reviewing the nature of their response to HIV/AIDS. Some have raised the issue of whether the principles of *confidentiality and informed consent* have hindered efforts to prevent the onward transmission of HIV. Particular concern has been expressed regarding the vulnerability of women to infection by husbands or partners who do not know their status, or refuse to reveal it or refuse to practise safe sex. This has led to calls to adopt policies such as named HIV case-reporting, mandatory disclosure of status and criminalizing the deliberate transmission of HIV.

Recent international consultations on these matters have confirmed that the principles of confidentiality and informed consent are *not* obstacles to effective prevention and care programmes. In fact, if employed appropriately, they are not only valid ethical principles, but are also pragmatic tools by which to best protect both the non-infected and the infected. Rather, it is HIV-related *denial, stigma and discrimination*, and the *secrecy* that results from these, that compose major impediments to an effective response to HIV/AIDS.

Although the epidemic is over 15 years old and although HIV prevalence is very high in many communities, HIV/AIDS continues to be *denied* at the national, social and individual levels; to be highly *stigmatized*: and to cause serious *discrimination* based on HIV/AIDS status. There are many reasons for the stigma, denial, discrimination and secrecy that surround HIV/AIDS, and these will differ from culture to culture. However, in general, it can be pointed out that HIV/AIDS is a condition related to sex, blood, death, disease and behaviour which may be illegal – commercial sex, homosexuality, injecting drugs. The fear and taboos associated with these subjects lead to the denial, stigma and discrimination that surround HIV/AIDS, and breed the secrecy that hinders private and community discussion about the issues and behaviour involved.

Denial causes individuals to refuse to acknowledge that they are threatened by a previously unknown virus which requires them to talk about, and to change, intimate behaviour, possibly for the rest of their lives. Denial also causes communities and nations to refuse to acknowledge the HIV threat, and the fact that its causes and consequences will require them to deal with many difficult and controversial subjects, e.g. the nature of cultural norms governing male and female sexuality, the social and economic status of women, sex work, families separated by migration/work, inequities in health care and education, injecting drug use. Stigma and discrimination, and the fact that for many there is no available treatment, cause individuals to fear getting tested for HIV and to fear disclosing it to health care workers, for care; to families and communities, for support; and to sexual and drug-injecting partners, to prevent onward transmission of HIV.

The prevalence of denial, stigma, discrimination and secre indicate that there is a clear and urgent need to *"open up"* the epidemic. How to achieve this? It is neither feasible nor desirable to force people: to get tested (and retested throughout their lives); to disclose their status; to change their behaviour. This would require the creation of a health "police" state requiring vast amounts of resources for testing and policing. It would also drive further underground the very kinds of behaviour that are already hidden and need to be changed.

However, it is feasible and desirable to *open up* the epidemic in ways that will reduce denial, stigma and discrimination, and will create an environment in which many more people have incentives to access prevention and care services, and are supported to change their behaviour for prevention purposes, to disclose their status to partners and families, and receive care, support and compassion. In this document,[1] the UNAIDS Secretariat and WHO offer guidance concerning how this might best be achieved by policies and programmes that encourage:

- **beneficial disclosure;**
- **ethical partner counselling;**
- **appropriate use of HIV case-reporting.**

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[1] *Opening up the HIV/AIDS epidemic*: Guidance on encouraging beneficial disclosure, ethical partner counselling & appropriate use of HIV case-reporting (UNAIDS Best Practice Collection, Key Material, UNAIDS/WHO, Geneva, November 2000).

As UN system organizations, UNAIDS and WHO are committed to the promotion and protection of human rights, ethical principles and public health. The guidance offered here is based on the firm belief that human rights and ethical principles provide a framework by which the dignity and health of *both* those uninfected and those infected by HIV are safeguarded. Furthermore, adherence to human rights and ethical principles is essential to create an effective public health environment in which the most people are encouraged to, and indeed do, change their behaviour, prevent their own infection or onward transmission, and receive care. Finally, UNAIDS and WHO are also committed to the view that individuals and communities can be, and should be, empowered to deal with the health challenges they face.

In the context of HIV/AIDS, UNAIDS and WHO encourage **beneficial disclosure** of HIV/AIDS status. This is disclosure that is voluntary; respects the autonomy and dignity of the affected individuals; maintains confidentiality as appropriate; leads to beneficial results for the individual, his/her sexual and drug-injecting partners, and family; leads to greater openness in the community about HIV/AIDS; and meets ethical imperatives so as to maximize good for both the uninfected and the infected.

In order to encourage beneficial disclosure, there should be created an environment in which more people are willing and able to get tested for HIV, and are empowered and encouraged to change their behaviour according to the results. This can be done by: establishing more voluntary counselling and testing services; providing incentives to get tested in the form of greater access to community care and support, and examples of positive living; and removing disincentives to testing and disclosure by protecting people from stigma and discrimination.

There already exist a number of community care and support programmes throughout the world that are achieving these results. These should be replicated within and outside governmental programmes. Further, much more can be done by governments to encourage voluntary testing, counselling and beneficial disclosure by implementing public information and media campaigns that promote tolerance and compassion; enacting laws and regulations and implementing legal and social support services that protect against discrimination; supporting community-based organizations engaged in these activities; and involving people living with HIV/AIDS in the formulation and implementation of HIV programmes and policies.

With regard to partner counselling (partner notification), UNAIDS and WHO encourage **ethical partner counselling**. Such partner counselling is based on the informed consent of the source client, and maintains the confidentiality of the source client, where possible. However, it also takes into account the serious possible consequence of not counselling partners – that is, HIV infection.

Because refusal to counsel partners can result in the onward transmission of HIV, HIV counselling and partner counselling programmes should involve strong and professional efforts to encourage, persuade and support HIV-positive persons to notify and counsel partners. In the few cases in which a properly counselled HIV-positive person refuses to counsel partners, the health care provider should be able to counsel partners, without the consent of the source client, after there has been an ethical weighing of the potential harms involved, and appropriate steps have been taken. These steps involve repeated efforts to persuade the source client to counsel partners, informing the source client that partner counselling will occur, keeping his/her name confidential if possible; and ensuring social and legal support for the source client and other relevant parties (spouses, partners, family members) to protect them from any physical abuse, discrimination and stigma which may result from partner counselling.

There is much that governments can do to create conditions to encourage ethical partner counselling. These include setting out policies, laws and guidelines which protect confidentiality and informed consent, and outline clearly the limited circumstances under which partner counselling may take place without consent; training health care workers and counsellors in ethical partner counselling; and increasing social and legal support for those who are involved in partner counselling.

UNAIDS and WHO recommend the **appropriate use of HIV case-reporting.** It has been suggested that HIV case-reporting, including named HIV case-reporting (i.e. the reporting to public health authorities of each individual identified as HIV-positiv could provide accurate information on the spread of HIV, and allow effective actions to prevent further infections and ensure access to care services. However, in resource-poor settings, certain conditions result in the fact that HIV case-reporting does not provide accurate data for surveillance purposes and does not result in better prevention and care. These conditions are: little access to, or use of, HIV tests; a reporting system which suffers from under-reporting, under-diagnosing and insufficient infrastructure to protect confidentiality; little or no access to antiretrovirals; and limited resources which would be better utilized in increasing access to voluntary testing and care and improving prevention activities. In countries where such conditions exist, it is recommended that HIV case-reporting *not* be carried out.

Rather, in assessing the use of HIV case-reporting and other surveillance strategies, countries should refer to the framework of **second-generation HIV surveillance**, where UNAIDS and WHO recommend a combination of both biological and behavioural surveillance tools and suggest that a country choose appropriate surveillance based on its resources and the nature of its epidemic burden and health care response. In gener such surveillance is cost-effective given the financial and human resources available; refines, as well as reinforces, prevention and care efforts; maintains confidentiality; optimizes access to available treatment options, where this is possible; and leads to regular and wide dissemination of information to the population in non-stigmatizing ways that help to open up the epidemic, decrease denial and increase commitment to fight the epidemic. In low-income countries, depending on the state of the epidemic and other factors, it is likely that HIV sentinel surveillance will be the most appropriate form of surveillance to employ.

UNAIDS/WHO

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

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

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CHAPTER II

KEY APPROACHES TO BEHAVIOURAL CHANGE FOR HIV

Early in the AIDS epidemic, results of population survey research alerted public health officials of the diversity of sexual behaviours and of the need to act quickly. The first interventions as well as the first applications of theories were propelled by the urgency to do anything to slow the alarming crisis at hand. Through popular public health channels, information was disseminated to populations at risk.

Today, many of the interventions for the prevention of HIV transmission, rather than using one of the behavioural theories in its entirety, have developed programmes based on one or many constructs often depending on the socio-cultural, political, or economic situation and on the stage of the epidemic. Drawing on various models and modifying them to suit the population and context has been critical to implementation of prevention projetcs, especially in international settings, as nearly all theories were developed in the West. These transtheoretical approaches are guided by critical constructs such as risk perception, social norms and sexual communication to form the basis of interventions worldwide.

This section looks principally at the most common approaches used to influence HIV risk reduction. Although these approaches are not consistently or directly derived from behavioural change theories or models, they draw on the multiple constructs mentioned above. The section is split between individual and community-level interventions, where the approach is described and then specific examples of its use are reviewed. See Table 2 for a summary of models and theories tested by research or reviews.

(A) APPROACHES AIMED AT INDIVIDUAL LEVEL BEHAVIOURAL CHANGE

Information, education and communication

Mass and small group education

As information was initially, for many, thought to be the key to behavioural change, HIV prevention programmes began with a focus on increasing awareness about the modes of transmission and prevention (Cohen, 1992). Mass education for HIV prevention can take many forms but is often seen as a key component of a comprehensive AIDS prevention programme (Holtgrave, 1997). Mass media, for example, are directed to the general public and aim at teaching people essential facts, promoting healthy behaviour, quieting anxiety about casual transmission and preventing discrimination.

An analysis of the messages adopted by the information and education programmes of national AIDS control programmes of 38 different countries found that over 90% focused on correcting misperceptions about AIDS. About 80% provided information about personal risk assessment (Cohen, 1992). In many countries, mass education provided the first step to national AIDS control programmes. Many mass education efforts successfully raised AIDS awareness by informing individuals of the risks of HIV infection, and in some cases education-based programmes were sufficient to change high risk behaviours, increase condom sales, and reduce new HIV infections (Kalichman, 1997). The channels that national AIDS control programmes have used for mass education include targeted media, printed media and electronic media (Cohen, 1992).

A review of 49 studies covering 18 countries to identify empirical outcomes or evaluate impact of HIV-related mass-media campaigns in 1996 concluded that most campaigns aiming at "individual-level goals of knowledge, attitude or behavioural changes were generally successful at achieving these goals" (Holtgrave, 1997). However, behavioural endpoints of the projects reviewed were not mentioned. In addition, as the author himself pointed out, a substantial number of the project reports reviewed lacked methodological details; they were reported in conference abstracts. It is therefore difficult to conclude on the relative meaning of the term "successful", particularly in relation to behavioural outcomes.

Small-group AIDS education is taking place all over the world, advancing general knowledge of HIV in numerous communities. Small-group AIDS prevention programmes can be seen as having 3 main components:

- content
- context
- strategies (Kalichman, 1998).

Content includes goals, objectives, and activities. The main content areas in most small-group intervention activities include: basic education about AIDS, sensitization to one's personal risks for HIV, instruction in individual actions that can reduce one's risk and exploring new ways to communication with sex partners. Entire interventions or research questions are built on any one of these content areas.

The second component in small group HIV prevention is the *context*. The different aspects of the intervention should be designed to fit the cultural, gender and developmental issues of participants. For example, one investigator felt concerns of stigma and sexual identity were paramount to African American gay men and dedicated an entire session of this small-group intervention to concentrate on those issues (Kalichman, 1998).

The third component, *strategy*, is the process itself, where emphasis is placed on *how* the interventions are implemented between participants and group leader. Key elements to consider include how to foster trust, build group cohesiveness, encourage motivation and mutual support among participants and between participants and the facilitator (Kalichman, 1998).

Although evaluations of small-group interventions have focused on content and facilitation skills, all three components have been found to be critical to the success of this approach. The literature reports strong evidence for the beneficial effects of small-group HIV prevention from randomized controlled trials of theory-based skills-building programmes (see chapter III for impact of theory based interventions). Several independent reviews of the literature as a whole found that small group HIV risk-reduction interventions result in meaningful changes in HIV risk behaviour (Kalichman, 1998).

One innovative approach targeting hard-to-reach populations in the USA with information and counselling was a multiple session intervention designed to be delivered over the telephone. One reason for this method was to reach populations that do not want to meet a health care provider face-to-face. In an evaluation of the study, the researcher found significant effects of their telephone-based counselling including a decrease in unprotected intercourse from 47% to 26% of the men who completed the programme (Roffman, 1997).

Another study in Uganda looking at gender differences and perception of risk noted that participation in small-group AIDS education was associated with some protective behaviours for women with evidence of a dose response effect. The author suggests that these AIDS education events may also provide a socially sanctioned opportunity for peer group interaction for women (Bunnell, 1996).

Especially in the USA, small-group AIDS prevention efforts have evolved since the beginning of the epidemic from providing basic information in community groups and sensitizing people to personal risk sensitization. Subsequently, interventions began instructing people on condom use skills, eroticizing safer sex, and building safer sex communication skills. Through interventions encompassing these elements, many people have reduced high-risk sexual behaviour, but not everyone is sensitive to small group behavioural interventions. For example, small-group projects targeting heterosexual men for HIV prevention have not shown significant intervention effects. Longer-term behavioural changes require ongoing support and modifications in the larger social environment within which these behaviours take place.

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HIV/Aids

Community Health Cell

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ARV Access in Jamaica: A dialogue with UNAIDS

By Richard Stern with a Response from Rheeta Batia of UNAIDS

People Living with HIV/AIDS in Jamaica still have no access to anti-retroviral medications, and 6,000 people need treatment now. The situation which was denounced by this author in an article published in January of 2003 (http://www.aguabuena.org/ingles/articules/jamaicabeaches.html) remains unchanged nearly a year and a half later.

An average of 11 people a week die of AIDS in Jamaica, according to official figures but many feel that the actual number could be much higher.

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Jamaica's multi-million dollar Global Fund grant was approved in October of 2003, and could provide treatment for 1,000 people "this year." But the Global Fund contract remains unsigned 7 months after the project received preliminary approval, although the contract will perhaps be signed very soon according to the information provided below.

Even after Global Fund contracts have been signed in other countries, we have been seeing long delays in procurement and distribution of anti-retroviral medications.

Of course, the fact that 1,000 people will receive treatment "this year" does not resolve the situation for the other 5,000 people who need ARV's and can't wait for them. Perhaps 25% of People who have full blown AIDS, die within a year of this diagnosis.

As with many Global Fund projects in the region the speed with which the Jamaican project is being processed does not seem even remotely congruent with the life or death situation faced by the people who might benefit from it. (The Dominican Republic's $40,000,000 Global Fund project was approved in January of 2003, and the contract is still not signed! Up to 5,000 People with AIDS were supposed to have received treatment as a result of this project.)

With the goal of attempting to clarify the role of UNAIDS in relation to the Jamaican context, I spoke with Rheeta Batia

of the UNAIDS Geneva Secretariat for about an hour on May 4th.

The notes from the conversation are provided below, and Reeta's response follows the notes. Reeta has given permission to distribute this dialogue by e-mail.

Its my hope that this brief interchange could be seen as one example of civil society attempting to dialogue with the UN Agencies, as well as PAHO, PANCAP, and CARICOM and others, about issues relating to the urgency of ARV access in the Caribbean region. It is also important that these Agencies be held accountable for commitments that they have made.

(MY OWN NOTES ARE FOLLOWED BY A RESPONSE WRITTEN BY REETA BHATIA)

R. Stern's Notes: Conversation with Reeta Bhatia: Europe/Americas Division, UNAIDS

May 4, 2004

Rita Bhatia was asked to call me by Luiz Loures, UNAIDS Director for the LAC region.

The conversation focused mainly on Jamaica, but also somewhat on other Caribbean countries.

Reeta indicated to me that she is "seconded" from the Canadian government to UNAIDS for a year and will be focusing her attention on the Caribbean region.

1) I had expressed my concern in several letters to Kathleen Cravero and Luiz Loures of UNAIDS regarding the apparent lack of any meaningful input in Jamaica by UNAIDS, and the fact that 6000 people (Reeta's estimate) there need treatment now.

2) We discussed the Global Fund situation there. Reeta informed me that a proposal has been approved which could provide treatment this year for up to 1000 people. But the contract has not been signed yet, as Jamaica was required by the GF to provide a special report related to its capacity for procurement and scale-up. This process has taken several months, but apparently the report is now about to be approved by the Technical Review Panel and the contract for the proposal could be signed with several weeks.

I pointed out to Reeta that even after a proposal is signed it can take up to a year for medications to actually be procured and delivered, situations that are now occurring in both Nicaragua and Peru. I also reminded her that after nearly a year and a half, the Global Fund contract for the Dominican Republic has still not been signed.

In general, I talked about my fears that the Global Fund (GF) process in Jamaica, Belize, Guatemala and other countries approved in the third round could begin to mirror the situation of so many countries approved in the second round, a year and a half ago, who still have not been able to provide any treatment access with GF funds, due mostly to the absurd policies of the Global Fund Board, which are totally incongruent with providing funds rapidly in a situation involving a life or death situation for so many people.

3) Reeta informed me that UNAIDS has diverted some of its resources from other programs and will provide some economic support for JN+, the Jamaican Network of PLWA. I reminded Rita that JN+ needs a lot of technical support and training. I also suggested that it would be very valuable to have a National Encounter of People Living with HIV/AIDS in Jamaica as this has been a useful tool in so many other countries in terms of empowerment and advocacy. Reeta seemed to agree with this idea and said she would bring it up to UN personnel and/or UNAIDS theme group staff.

4) Reeta informed me that Suzette Moses Burton of CRN+ had given a plenary presentation at the All UNAIDS Staff meeting currently being held in Europe (the first ever all UNAIDS staff meeting which is being attended by 200 UNAIDS staff members from around the world) in which she made extensive references to Olive Edwards' letter regarding critical issues in Jamaica. Reeta indicated that this presentation had been very impactful.

Richard Feacham, Director of the Global Fund, also attended the first day of the UNAIDS all staff meeting and staff members expressed various concerns to him related to the Global Fund and ARV scale-up. He also held a private meeting with Peter Piot.

5) Reeta mentioned that the Jamaican legislature was in process of probably passing a law that would favor the use of generic medications. I mentioned that as far as I know, the current generation of ARV's are not patented in Jamaica, but that CIPLA's distributor in Jamaica, LASCO drug, is selling its products at prices that are just under those prices offered by the originator drug companies and not at CIPLA's advertised prices. I also mentioned that the eventual patent investigations required by the Global Fund for procurement take a very long time and should be done as soon as possible rather than waiting for the procurement stage to arrive, thus avoiding another potential

delay.

6) I discussed my impression that it is ironic that while Haiti, one of the world's least developed countries, has been able to provide ARV access for at least several thousand people in spite of its enormous social and economic problems, that its neighbor Jamaica which is a medium level HDI country with a strong tourism industry still does not provide ARV's for anyone.

7) I emphasized my opinion of the importance of the fact that when UNAIDS or other International Agencies and funding sources provide economic support to JN+ or other PLWA groups that the message must be also be given very clearly that this support is <u>unconditional</u> in the sense that these groups know that they are free to advocate for what they feel is best for them and in the form that they feel is best. They should not feel afraid to step on people's toes, meaning decision makers and those who have power.

We discussed advocacy in Canada, where Reeta has worked extensively, but I pointed out my opinion, after many years of working in developing countries, that any amount of money is lot of money for poor people with AIDS in developing countries and that sometime they feel that they must be cautious in order to not "offend" people. (Of course, there are also many exceptions) I feel that UNAIDS, in providing support to the Regional PLWA Networks as well as to NGO's, and for conferences, and scholarships, has not always made this point clear. In fact this point must be stressed and made "pro-actively."

Those who receive support (as well as all other PLWA) must feel free to practice "belligerent advocacy" in their own appropriate cultural context, without any fear that this support will be withdrawn (even it means criticizing UNAIDS itself!)

If this message is not given loud and clear, many groups are hesitant about taking decisive steps. This has, in my opinion, been a problem with the Regional Networks and some large international NGO's financed by UNAIDS, and is certainly a problem with some other Agencies that provide financial support.

8) Reeta is already aware of the TIDES Foundation initiative for the Caribbean which will support grass roots advocacy. A major regional activity related to this initiative is scheduled to take place in August and a steering committee has already been selected.

9) We touched briefly on the situation of other countries in the region such as Belize and Guyana where Reeta is also involved.

10) I mentioned my feeling that the discourse from the UNAIDS Secretariat in Geneva (People such as Reeta, herself as well as Peter Piot, Kathleen Cravero, Michele Sidibe, etc) is often much different from the discourse of the UNAIDS Field Staff. This is also true of other international Agencies, where there is committed leadership at the top, but perhaps the staff on the ground are, in some cases, more identified with local politicians and National AIDS Program Directors, etc and don't want to push them. (Hopefully the "all-staff" meeting that took place in Geneva will help to resolve this problem).

I expressed my disappointment in the work of UNAIDS staff and especially in the response of the UNAIDS theme groups in the Caribbean in the sense that I have not seen them taking a pro-active approach toward the 3 x 5 initiative, recognizing at the same time that I certainly don't know all about what UNAIDS staff are or are not doing in any given region or country. This is just my impression.

****

The following are Reeta Batia's comments after seeing my notes as above:

Regarding the current Jamaican submission to the Global Fund, we understood from the GF Secretariat that the section on procurement of ARVs is the only one pending finalization. This confirmation is dependent upon assessments from the Clinton Foundation and the World Bank on Jamaica's capacity to deliver treatment programs and its subsequent concurrence by the Technical

Review Panel, which is currently meeting in Geneva. A final decision on this component is expected likely this week. In the current proposal, an amount of $2.4 million for two years is earmarked for treatment. The Jamaican government has estimated that around 6,000 individuals are in need treatment and aims to reach this target within five years with 1,000 persons on treatment by the end of 2004.

As we discussed, UNAIDS' ongoing aim is to strengthen support to countries in the region to achieve their HIV/AIDS targets and goals including those related to treatment. In this regard, I stated that one of the key activities where UNAIDS played an instrumental role was in negotiating significant price reductions for ARVs in the Caribbean (in fact, the first negotiations were held in Jamaica). Also as we discussed, to further assist with scaling up HIV/AIDS efforts in the region, UNAIDS is strengthening its presence in the Caribbean including placing a full time UNAIDS Country Coordinator in Jamaica, additional staff for the UNAIDS offices in Haiti and Guyana and in the UNAIDS Inter-Country Team in

Trinidad.

Another point relates to UNAIDS commitment to partnerships with the national and regional community based organizations including those representing people living with HIV/AIDS. Previously for example, UNAIDS has supported AIDS NGOs like the Jamaica AIDS Support and members of JN+ to take part in skills building activities. While I did not make this point specifically, I would like to mention that most recently, UNAIDS assisted CRN+ with the development of their Global Fund proposal.

As stressed, UNAIDS- - at all levels-- is committed to mobilize, empower, and strengthen the capacity of NGOs and PLWHA networks as our ongoing key priority. As promised, we are following up to provide PAF funding to JN+ and to support other NGO capacity building initiatives in the region.

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DIS-2K.

Subject: Notes from the PCB Meeting
Date: Mon, 11 Jun 2001 15:33:34 +0100
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I attach, for your information, my notes and comments from the UNAIDS Programme Coordinating Board Meeting in Geneva 29th May to 1st June, which I attended.

This is not by any means a complete account of the meeting but rather my jottings on points that struck me, one way or another. If anyone wants a copy of any of the documents listed at the end, please let me know.

UNAIDS PCB MEETING NOTES May 2001.doc	**Name:** UNAIDS PCB MEETING NOTES May 2001.doc **Type:** Winword File (application/msword) **Encoding:** base64

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SNIPPETS, OBSERVATIONS, COMMENTS AND CONCERNS ARISING FROM THE UNAIDS PROGRAMME COORDINATING BOARD MEETING,
Geneva, 30th May to 1st June 2001

Agenda Item 1.4: Report of the Executive Director of UNAIDS, Peter Piot
Comments from PCB members in response to the report included:

- The need for UNAIDS to move from the theory of declarations to the sphere of proven practice, and to have mechanisms in place for thorough follow-up.
- Human rights need to be set in the context of HIV and vice versa.
- UNAIDS needs to publicise the gravity of the epidemic in the different continents and to widen the focus of attention away from Africa. AIDS is not an African problem and portraying it as such is extremely dangerous with potentially hugely damaging consequences, both for Africa and for the other continents also seriously impacted.
- The role of faith groups in challenging stigma and discrimination needs to be increased.
- In connection with discussions of mother-to-child transmission it was proposed that ARVs should be made available to women for their own sake and not just because of the risk to the child. Strategies should widen their focus to become concerned with prevention of infection in women and of transmission to their children.
- Countries with low HIV prevalence but high vulnerability need urgent action now.
- Both Dr Piot's report and subsequent interventions made reference to link between debt relief and HIV. UNAIDS are promoting a policy of investing debt relief monies in addressing HIV, in countries most impacted by the virus. *My Concerns: While the report makes some mention of the need to also invest in wider infrasrtutural and other development concerns in order to reduce the impact of HIV, any reference to debt relief in discussions was very narrowly focussed on direct channelling of recouped funds into HIV care and prevention programmes. The direction of the argument was too much one-way re. HIV affecting poverty reduction, with the converse being lost from sight. The World Bank delegate likewise indicated that they would be monitoring countries' Poverty Reduction Strategy Papers for mention of investment in HIV programmes. I think the whole debt relief-HIV debate is "hotting up" and is one that CAFOD needs to engage with, making a more nuanced argument around the* ***reciprocal*** *effects of poverty and HIV vulnerability; that debt relief reduces HIV impact/vulnerability AND that decreasing HIV impact/vulnerability work towards poverty reduction.*

Among the recommendations and conclusions of the PCB on this agenda item were:

- A stress on shifting from small-scale and pilot interventions to programmes covering a much larger number of people and wider areas
- Emphasis o the synergy between prevention and care as complementary strands of a unified response, and on care and support as an indispensable component of effective prevention.
- In acknowledging the need for continuing comprehensive care and support and efforts to fight stigma, the PCB also recognised the role of faith-based groups in areas of care and support. *My concern here is that faith groups are relegated to and contained*

within what is deemed a safe non-contentious area. There was no recognition of the important role faith groups might play in reducing stigma, espousing advocacy and human rights issues and certainly no consideration that faith groups (even in the most enlightened scenarios) had any role at all in prevention strategies.

- Emphasis on prevention as a mainstay of the expanded response to the epidemic (apparently there was much heated discussion in the drafting group on this point, with some of those who are lobbying on access to ARVs objecting to this. As a concession the wording was changed from *the* mainstay to *a* mainstay).
- A strong call for action to make alleviating the economic and social impact of the epidemic a priority over the next two years, especially re. the material and social needs of children orphaned by HIV. How

Agenda Item 1.6 Report by the NGO Representative

The official NGO delegation consisted of two representatives from Africa, two from Asia, one from Latin America and two from North America. Four of these were also people living with HIV and representing local/national networks of people living with the virus. Among the points made in the NGO delegates' report were:

- The need for funding to be delivered quickly and directly to local groups and communities addressing HIV
- The need for specific and targeted support for each of continents/regions impacted by HIV, recognising the different transmission dynamics applying in each region.

Both points were accepted in the recommendations of the PCB although the first was significantly re-worded to read "effective channelling of funds to communities in need".

Agenda Items 2 & 3 UN System Strategic Plan 2001-2005 and UNAIDS Unified Budget and Workplan (UBW) 2002-03

Reports for both were presented by Peter Piot. The UN system strategic plan and UNAIDS Workplan outline the proposals and mechanisms for ensuring HIV/AIDS becomes an integrated and strategic priority for all of the UNAIDS Cosponsors and other UN organisations. Points raised in discussions included:

- The strategic plan and UBW were good and to be commended as an effective way of unifying the various UN actors.
- A number of commentators also noted that the strategic plan was complex, not at all user-friendly, unwieldy and inaccessible for the majority of readers and proposed beneficiaries as well as for those charged with implementing it.
- Concerns were raised around the possibilities of monitoring and evaluation of the plan, and whether sufficient thought had been given to this aspect. There were also concerns that the plan was excessive to staff's capacity, and particularly to an under-resourced UNAIDS capacity to monitor.
- The plan had too many objectives and indicators and this too would make implementation and monitoring difficult.
- The proposal to give preference to investment in HIV prevention in low and medium-level infection countries was questioned and further reflection/debate called for.

The PCB response commended the initiative and endorsed the general contents and direction of the plan. In its more specific recommendations it picked up the various concerns made in the general debate.

Agenda Item 5.1 Special Session on the UN General Assembly on HIV/AIDS (UNGASS)

Dr Piot updated members on this, in the light of the still-ongoing preparatory meetings for UNGASS delegations, being held in New York. Both Dr Piot and the NGO representatives who had come to Geneva from the New York meetings were somewhat pessimistic about how the process was going. Dr Piot reported that most of the Draft Declaration of Commitment (DOC) seemed to have gained acceptance among member delegations. However there were still three significant hurdles, any of which might derail the process:

1. An outright refusal by some delegations to admit any mention of men who have sex with men, injecting drug users, or sex workers among groups vulnerable to HIV. Cultural taboos as well as political and religious prohibitive factors were all at play in this stance.
2. Non HIV-related political issues and issues of human rights e.g. around positions on the Palestinian occupied territories, or an embargo on Cuba, were threatening to take over and halt all discussions of the HIV-related agenda.
3. Discussions/lobbying on intellectual property rights (in connection with access to ARVs) were threatening to overwhelm the wider debate.

Dr Piot noted the varying responses to the UNGASS from governments. Responses from Africa and Caribbean governments have been excellent with almost all of these delegations being headed by the country's president/head of government. Brazil has shown most response from among Latin American countries, with their Prime Minister intending to lead their delegation at the meetings. In Europe only Ireland and Portugal have signalled their wish to have representation at the highest level. The Irish Prime Minister/Taoiseach and Portuguese President have both declared their intentions to head their delegations. As yet, no head of government from Asia has indicated their intention to attend the UNGASS.

Dr Piot commented, in conclusion, that the DOC was in danger of being overtaken by political agendas unrelated to HIV/AIDS.

In response to questions it emerged that there is no limit on the number of people who can be part of a country's delegation, although there are only 6 places allocated per delegation in the plenary sessions. There will also be a number of overflow rooms with video relays of proceedings. The UNGASS official programme will also include a series of round tables, and restrictions on numbers do not apply to these. A number of unofficial side events have also been planned to run in parallel to the official UNGASS.

The PCB encouraged UN member states to work closely with civil society in their own countries in their preparations for UNGASS and to consider including NGOs in their official delegations.

DOCUMENTS HELD IN THE AIDS SECTION

Papers received in Connection with Agenda Items

1. Provisional Agenda for the Programme Coordinating Board meeting
2. Report of the Executive Director of UNAIDS on the last biennium
3. Speech of Dr Piot to the PCB
4. UN System Strategic Plan for HIV/AIDS 2001-2005
5. UNAIDS Unified Budget & Workplan 2002-2003
6. UNAIDS Financial and Budgetary Update 1st January 2000-31st March 2001
7. Report on the follow-up to the UNAIDS Financing Study
8. Progress Report from the Evaluation Supervisory Panel Chair
9. UNGASS: presentation to the PCB Meeting (copy of slides presented).
10. Statement on resources and a global fund for AIDS and health. Dr Piot
11. Report of the Ninth Meeting of the PCB, Geneva May 2000
12. Report of the Third *Ad Hoc* Thematic Meeting of the PCB, Rio de Janeiro, December 2000
13. Summary of the Third Meeting of the Contact Group on Accelerating Access to HIV/AIDS-related care, Geneva, May 2001
14. Draft version of decisions, recommendations and conclusions of the PCB to the agenda items covered in the meeting.

Other Documents:

15. A Human Rights-based Approach to HIV/AIDS. Paper prepared by the UNHCR for informal consultations for UNGASS, 21-25 May 2001
16. List of proposed side events planned to run parallel to the UNGASS meetings in New York in June
17. AIDS, Poverty Reduction and Debt Relief. A Toolkit for mainstreaming HIV/AIDS programmes into Development Instruments. UNAISD Best Practice Collection, March 2001
18. AIDS, Poverty and Debt Relief. UNAIDS newsletters 1-3 (March-May 2001). To subscribe send an e-mail to "poverty-debtrelief@unaids.org"
19. Critical issues Surrounding and International Fund for HIV/AIDS and Other Infectious Diseases. Document circulated by HealthGAP
20. Copy of correspondence between Paul Davis, HealthGAP representative at PCB, and Jeff O'Malley of HIV/AIDS Alliance
21. List of Participants

Guide
to the strategic planning process for a national response *to* HIV/AIDS

Resource mobilization

Situation analysis

Response analysis

Strategic plan formulation

Joint United Nations Programme on HIV/AIDS
UNAIDS
UNICEF • UNDP • UNFPA • UNDCP
UNESCO • WHO • WORLD BANK

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UNAIDS Best Practice Collection
KEY MATERIAL

UNAIDS/00.21E (English original, August 2000)

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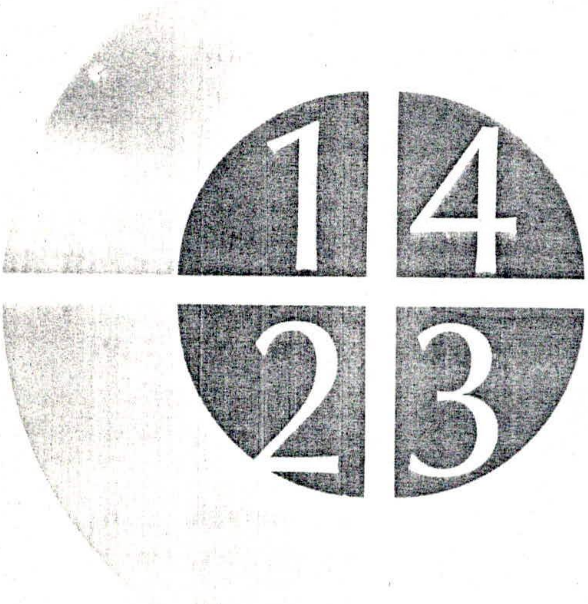
Guide to the strategic planning process for a national response to HIV/AIDS



Resource mobilization

Joint United Nations Programme on HIV/AIDS
UNAIDS
UNICEF • UNDP • UNFPA • UNDCP
UNESCO • WHO • WORLD BANK

Table of contents

module 4: Resource mobilization

Preamble

While the issue of resources in general, and the scope of resource mobilization in particular, is addressed from time to time in the first three modules of the Strategic Planning Guide, a fourth module specifically on resource mobilization is needed to reinforce its various aspects as referred to in modules 1 to 3, and especially to debate and clarify a number of widely held assumptions with regard to resource mobilization.

- Resources, and resource mobilization, are often seen as relating solely to funding; this module defines and clarifies the broader scope of resources.
- Resource mobilization in the context of HIV/AIDS planning is still too often seen as a process or an activity that takes place exclusively after planning; this module highlights that resource mobilization is an integral part of the process of strategic planning.
- Mobilization of resources is also seen as synonymous with securing new or additional resources; this module emphasizes that it is also about making better use of, or maximizing, existing ones.

I. Introduction

The subject of resources, and their availability or non-availability, is – or should be – a major consideration for planners in all areas. Indeed being strategic means, among other things, being realistic not only about the situation one has to address but also about the resources needed to reach one's objectives.

'Resources' is therefore a key theme throughout the strategic planning process (SPP) for national HIV/AIDS programmes. The situation analysis has to deal with the identification of the most important factors that may influence the HIV/AIDS epidemic. These include the status of human, institutional, financial resources that may determine individuals', sectors' or general societal vulnerability to HIV. These resources also determine the scope and effectiveness of national responses (see p. 11 of module 1).

Assessing the resources made available by the key players in the national response to HIV/AIDS is an essential aspect of the response analysis, as is an appraisal of the judicious use that is being or has been made of those resources (see p. 18 of module 2).

The formulation of a strategic plan implies that the availability of adequate resources is taken into account for the implementation of the different strategies in all priority areas; it should also address ways of making better use of existing resources (see pp. 15 and 18 of module 3).

Most importantly, the need to actively involve all key stakeholders in all three phases of the SPP is underlined throughout as a key strategy for mobilizing resources (ref. p. 26 of module 3).

Using this module

The major focus of this module is on 'mobilization of resources' and it should primarily be read or used in conjunction with each of the first three modules. Those who will use it are the situation analysis and/or the response analysis team, and the team responsible for the formulation of the strategic plan.

However there will also from time to time be a need to secure resources after the formulation of the strategic plan, for instance to support the expansion of emerging successful strategies, or to supplement shortfall in funding for a priority strategy or a catalytic project. This module will therefore also deal with relevant approaches, techniques and methods for that purpose.

Following an overview and definition of resources and resource partners, the module:

i. highlights the ways in which resources are effectively mobilized through a strategic planning process;
ii. describes specific approaches to mobilization of 'additional' resources in the course of the implementation of the strategic plan.

II. Defining resources

The term 'resource' is all too often understood to mean only 'funds', especially in the context of resource mobilization. And yet, when for example programme or project failure is attributed to the lack of resources this has often to do as much with human or other resources as with funds. It is therefore useful at the outset to define what is understood by 'resources' and by 'resource partners'.

Resources

"Resources" includes not only money, but also people, goods and services. All types of resource or forms of support can be grouped under one of the following categories:

Human resources

These are the people needed to design, implement and follow up activities and projects.

- They will need to cover a range of appropriate skills and know-how to carry out the diverse specific tasks required.
- They may be paid or voluntary.
- They may be part-time or full-time, on secondment from Ministries and other Government bodies, recruited by international agencies, or employed by national or international NGOs, the private sector, etc.

Financial resources

These may come from a wide variety of sources:

- Government budget (including World Bank credits)
- Grants from international development agencies (IDAs), AIDS Foundations etc.
- NGO budgets
- Private sector.

Goods and services

These include:

- Vehicles and computer equipment
- Office space
- Advertising time or space
- Design and print facilities
- Financial, technical or medical advice
- Training services
- Meeting places and event venues.

These in turn may be provided at reduced cost or be freely donated.

Finally, an important resource that is often overlooked and is best included here is the time that people may contribute voluntarily to various important aspects of HIV/AIDS work from high-level political advocacy to community services.

Resource partners

One can broadly categorize all current and potential "resource partners" at different levels using the following matrix:

	Local/District	Provincial/ Regional	National	International
Government				
NGOs				
Donors/international development agencies				
UN system				
Private sector				
Communities				

Each group presents particular advantages and challenges which can be summarized as follows:

Government

It is critical that there be government ownership and leadership of the national response. A National AIDS Programme with strong government management signifies:

- consistent programme direction and a coherent national response
- potentially substantial resources, including staff, offices, equipment and services
- coordination of external support
- access to the whole spectrum of activities, disciplines and interests in the public sector.

But despite the wide recognition that a multisectoral approach is necessary to tackle HIV/AIDS effectively, in many instances the only significant involvement from the public sector is from the health sector. Further, Government is occasionally plagued by administrative regulations and procedures that can hamper the flow of resources – particularly financial, but also human resources – for example from central to provincial or district levels. Government may also sometimes find it sensitive or difficult to allocate resources to, or be directly associated with, certain HIV prevention activities, such as those targeting behaviours like drug use or commercial sex work that may be outside the law.

NGOs

There are now innumerable AIDS-specific NGOs, national and international, that intervene and provide services across the whole range of prevention and care strategies and activities. They play a vital role and make significant contributions to successful national responses. They present some unique advantages, not least:

- The relevance and responsiveness to community and grassroots needs
- The committed and motivated human resources of the smaller national NGOs
- The ability, unlike the government sector, to work with marginalized populations such as drug users or sex workers.

NGOs are usually also more willing or can afford to take risks, such as allocating resources for untested strategies, or starting up pilot projects in new geographical and thematic areas. As for international NGOs, they also provide links to wide networks and are therefore sources of substantial technical and financial support.

On the other hand, the proliferation of HIV/AIDS-specific NGOs has sometimes taken place at the expense of quality and accountability, with ill-designed or inappropriate projects absorbing scarce resources and failing to have any significant impact. Other areas of concern include:

- Mutual Government/NGO distrust
- Weak management structures
- Specific priorities of some NGOs may not always match those of national programmes.

Donors/international development agencies

In the early years of the HIV/AIDS epidemic, multi- and bilateral development agencies were the major source of resources – especially financial – for national HIV/AIDS programmes. Although the overall financial support to AIDS programmes has declined in recent years, development aid from bilateral donors remains an important, if not the most important, source of financial and human resources, goods and services for many resource-poor countries.

The relationship and dynamics between donors and national governments can in some cases be influenced by the following factors:

- Where support from bilateral donors is channelled to or through NGOs this can aggravate the tensions that may exist between NGOs and Government.
- Particularly when national mechanisms for coordination are not strong, coordination among donors may also be less than optimal.
- Some donors may only be prepared to support specific strategies and seek to influence national programme priorities accordingly.

The UN system

Multilateral support has generally diminished and is now focused more on catalytic action, technical assistance and advocacy, including efforts to leverage additional resources. Concurrently, the establishment of UNAIDS is meant to maximize the resources and ensure greater coherence of the efforts of different UN system agencies in support of country responses.

With the establishment of UNAIDS and the increasing effectiveness of UN Theme Groups on HIV/AIDS in countries, it is anticipated that there will be stronger and better coordination not only of the UN system's support but also that of overall external aid in general.

Through UNAIDS and its cosponsors a number of common goods besides a stronger and more coherent UN system response are becoming increasingly available to all countries, including:

- improved access to and exchange of best practices
- improved access to technical resources (e.g. through technical resource networks)
- better access to goods and services, including condoms and drugs.

Private sector

With growing evidence of the negative impact of the HIV/AIDS epidemic on certain sectors and on productivity, many more members of the private sector are now willing to support prevention programmes which they see as an investment. Of the many partnerships that HIV/AIDS concerns are generating, that between the private and public sectors in countries has unique potential. At the same time it poses a few challenges.

The potential of the private sector resides not just in the financial resources that can be tapped but also in the considerable human resources that it represents and the social leadership that it can provide. Other strengths include:

- its involvement in AIDS prevention may take in both its own workforce and its clients
- specific skills that are very relevant in AIDS prevention, for example in communication
- business-like, professional approaches
- a culture of efficiency, cost-effectiveness and accountability.

On the other hand, the grasp of HIV/AIDS-related issues by the different elements of the private sector is variable and often incomplete. Given these differences and the diverse interests that are represented, coordination and avoiding conflicting messages may be an issue.

Communities

Potentially the greatest resource capacity is to be found within the communities who are or can be mobilized around the issue of HIV/AIDS.

The community or communities here are defined not just in terms of geographical proximity – although this will often be the case – but in the broad, inclusive sense, of groups of people who may be bound by culture, religion, beliefs, practices and, above all, by a common concern with and interest in HIV/AIDS prevention and care. These different types can also be regrouped under the following categories:

- Communities of interest – groups of people with a common purpose, such as health professionals working together on HIV.

- Communities of circumstance – people with different backgrounds altogether but who are brought together by a common event, for example people with haemophilia who have been infected through contaminated blood products.
- Structured communities – people with a common identity or history, and sharing common values or attitudes that unite them and identify them as a distinctive community.

They may be church groups or youth or women's organizations, trade unions, professional associations and sociocultural clubs and, not least, associations of people living with HIV/AIDS. Each of these brings different resources, capacities and preparedness to respond to HIV/AIDS. Notwithstanding these differences, the capacity of such communities, once mobilized around the issue of HIV/AIDS, cannot be over-emphasized.

The strengths of a mobilized community are well summarized in the UNAIDS technical update (see Community Mobilization and AIDS, Technical Update - April 1997). These include:

- awareness of their individual and collective vulnerability to HIV
- motivation to address their vulnerability
- knowledge of the options that they can take to reduce such vulnerability
- the time, skills, and other resources that they are prepared to invest.

III. Resource mobilization through the strategic planning process

The key characteristics and strengths of strategic approaches to HIV/AIDS planning are summarized in the Introduction to the UNAIDS Guides (see pp. 4-5). All of these, directly or indirectly, have resource-related aspects and dimensions. Together, they highlight the fact that resource mobilization is an integral part of strategic planning processes.

The following section analyses further some of the ways in which mobilization of resources de facto takes place through the strategic planning process.

III. 1 Involving key partners in the planning process

The first three modules of the Guide to the SPP (see p. 7 of module 1, p. 25 of module 2, and p. 8 of module 3) all stress that it is critical to ensure the participation of key stakeholders and resource partners at all stages of the SPP. It is imperative that a diversity of skills and expertise be brought together for a thorough situation and response analysis while, for the strategic plan formulation, it is important that as many of the actual and potential partners in the response be involved. These include different Government sectors, community organizations and NGOs, including associations of PWHA, academia and research institutions, the private sector, and international donors.

Such breadth of participation in the situation and response analysis enriches the reflection. Importantly, it also ensures 'ownership' of the process and of the output. By the same token, involvement of the key stakeholders in the strategic plan formulation is a major first step towards mobilizing the financial and human resources of the different partners towards implementation.

Ensuring government leadership

It is increasingly evident that HIV/AIDS will impact on many countries' long-term plans and on their agenda for social and economic development in particular. It is therefore all the more critical that Government, which is responsible for establishing such agendas, assume the leadership of the entire planning process. And it is not just about technical leadership. High-level political leadership is crucial. The viability and sustainability of programmes will depend on the extent to which the response to HIV is built into the national development framework – something which only governments can effect.

Community participation

While materials and funds are undoubtedly required to implement activities, it is even more critical to have motivated and skilled human resources. The participation of the concerned communities at relevant stages of the planning process is as important as government leadership in the planning process. They represent the single most important resource for a country's response. Individually and collectively – be they members of affected populations, associations of PLWA, HIV/AIDS service providers, national or international NGOs, small local organizations, research institutions, epidemiologists or behavioural scientists – they make valuable contributions to the national response, the more so when they are involved in the planning process.

Community participation – challenging though it may be – is the one way to ensure the relevance and realism of strategies and to mobilize the inherent resources of communities.

Involving major international development agencies

Most national programmes to some extent rely upon external support. It is therefore desirable to encourage major donors to participate in a national strategic planning process, especially at the stage of formulation of a strategic plan. As stated in module 3, 'involving all key stakeholders is an early but essential step towards mobilizing resources, human as well as financial' (see p. 8). Such involvement is also to be encouraged since many donors may have specific concerns or priorities that do not always match national priorities.

Their active participation in the national strategic planning process will ensure coherence and maximize the benefits to the country of resource allocation to priority areas. Besides the various 'communities' mentioned above, the 'key stakeholders' at this stage will include not only international donors but also, hopefully, some new or potential resource partners as identified through the situation and response analysis.

As repeatedly stressed in the various modules of the UNAIDS Strategic Planning Guide, people living with HIV/AIDS or directly affected by it are very valuable partners for any HIV/AIDS action. UNAIDS promotes and supports the greater involvement of people living with HIV/AIDS in the response to the epidemic.

III. 2 Maximizing available resources

A widely held assumption concerning resource mobilization is that it is solely about securing additional or new resources. However, within the context of strategic approaches to planning, it is particularly important to emphasize that mobilizing resources is as much about making judicious or better use of available resources as it is about mobilizing additional ones.

The following are key questions in this regard:

- ➢ Is the current response still relevant?
- ➢ Are current responses effective and, in particular, are they cost-effective?
- ➢ Are there opportunities and/or imperatives for reallocation and reprogramming of resources? Where are the priorities now?

➢ Is the current response still relevant?

The first key question is about the relevance of the current response. One of the reasons why it is critical to adopt strategic approaches to HIV/AIDS planning is that we are dealing with situations that are not static. The situations change – sometimes rapidly – over time and place, which means that strategies and activities that are perfectly relevant now may be less so, or even not at all, in the future.

Hence the importance of a situation analysis and then a response analysis which inform the strategic planning team about the relevance of specific strategies and activities at a particular moment in time (see pp. 16-17 of module 2). In all cases, but especially in situations where human and financial resources are scarce and limited, it is a waste if these continue to be channelled to areas where they are no longer relevant or which are of lesser importance than others. Reprogramming these same resources for areas that are now more relevant is as effective a way of mobilizing resources as any.

➢ Are current responses effective? And are they cost-effective?

The second set of questions addresses the issue of whether current strategies and activities, especially in those areas that would have been identified as priority areas through the situation analysis (see pp. 17-18 of module 2), are effective and in particular whether they are cost-effective.

Looking at, and comparing, the effectiveness of specific AIDS prevention and/or impact mitigation interventions or strategies is not straightforward. Issues such as the diversity of epidemiological and social contexts within which interventions take place, the choice and appropriateness of the outcome measures that could be used as proxy indicators of effectiveness, or the complex interaction between the different programmes and strategies that are ongoing at the same time, all complicate attempts at the estimation of effectiveness.

Nonetheless, it is possible and desirable to look critically at some factors that may account for success or failure. These include, among others:

- Adequacy of resources
- Technical soundness
- Cost-effectiveness

Adequacy of resources

Assessing the adequacy of inputs – technical, financial, but also goods and services and, not least, human resources – into specific strategies is part and parcel of a critical analysis of the reasons for their success or failure. It also provides the information required for eventual cost-effectiveness analysis and assists planners and other stakeholders in setting priorities for mobilizing resources for potentially effective strategies that may otherwise get discarded.

The importance of adequate human resources for the success and effectiveness of an activity cannot be stressed enough. While most people will find it easy to attribute failure to lack of material resources, goods or funding, there is often a reluctance to acknowledge that it can be due to lack of specific expertise, inappropriate skills, or even motivation and commitment.

Technical soundness and best practices

As module 2 points out (see p. 18), much has been learnt in the last decade about what can work or does not work in HIV/AIDS prevention and care. Nonetheless there are many instances where programmes are still learning about what might work best in their particular contexts. Many a response analysis will point to the failure of activities due to lack of technical soundness resulting in significant resources being absorbed by ineffective or inefficient activities. Such situations underscore the importance and significance of a strategy of documenting and sharing 'best practices' and lessons learnt as a way of accelerating the 'learning curve' of programmes and minimizing the needless waste of time and resources on less-than-effective interventions.

At all stages of a strategic planning process, but especially the formulation of strategies in priority areas (see pp. 14-15 of module 3), the teams will be able to pinpoint opportunities for national programmes to take advantage of lessons learnt and international best practices.

UNAIDS Best Practice Collection incorporates technical updates, points of view and case studies, as well as key materials, on a wide range of HIV/AIDS topics and issues. In addition to documentation and dissemination of best practice material, UNAIDS is promoting and supporting in countries and between countries 'best practice' processes of learning and reflecting about what works and does not work.

Cost-effectiveness

Cost-effectiveness is a measure of the comparative efficiency of discrete strategies and methods for achieving the same objective (in this case HIV/AIDS prevention and care). As competing programme needs grow or as resources become scarce, cost-effectiveness is an issue that assumes even greater significance and importance. It is the responsibility of strategic planners to advise decision-makers on making best use of scarce resources. In this regard, cost-effectiveness analysis is the tool of choice that enables programme managers and planners to make informed choices about resource allocation. It identifies the relative efficiency of alternative activities by comparing costs and results or outputs.

Focusing on the cost-effectiveness or efficiency of the response involves continuously asking questions such as:

- what are the costs involved in a specific activity or group of activities in the programme?
- what are the returns on that activity, i.e. what are the benefits we get out of it?
- what is the opportunity cost of such an activity? In other words, are we making optimal use of our resources or will we achieve more by spending resources on other activities?

➢ Are there opportunities and/or imperatives for reallocation and reprogramming of resources? Where are the priorities now?

The third set of questions merely underlines the importance of strategic approaches in a context as dynamic as the one of HIV/AIDS. Being strategic means, among others, being relevant to the current situation and realistic about the resources required to implement planned strategies (see Introduction to the SPP Guides, pp. 4-5). Put another way, being strategic is about being responsive to change and about being able to set priorities.

Adapting and responding to change – monitoring and evaluation

The module so far has drawn attention to the critical importance of remaining relevant within the changing contexts of HIV/AIDS epidemics. An iterative process of reflection and analysis is important to allow the various partners in a national response to remain alert to new situations as they evolve, alert to opportunities so as to maximize the benefits of timely reprogramming and resource allocation. Alternatively, it can also be seen as being alert to the obstacles that have to be overcome, and minimizing the losses that may accrue through, for example, the continued channelling of resources to areas that may be less critical now than others or may have ceased to be priorities altogether.

Being strategic is being able to deal with change. This means flexibility on the part of management with, for example, a management structure that combines decentralized decision-making with effective delegation of authority. Above all though, there needs to be a good monitoring and evaluation system. This will serve to provide programme managers and implementers with timely information not just on the status of implementation of programme activities but also, importantly, on the key issues of their effectiveness, efficiency and continued relevance. What is needed for such a system to operate well is a plan that sets out at a minimum:

- Clear objectives, outputs and outcomes
- Realistic targets
- Clear and meaningful indicators.

Setting priorities

Setting priorities is a key and essential feature of strategic planning and, by the same token, one of the many facets of resource allocation and mobilization. At the best of times there are always choices to be made about what must be done and what can realistically be done. This is even more true in resource-constrained settings. The whole strategic planning process is geared to guiding decision-makers in making the choices that will result in the best possible use of valuable human and financial resources.

Too often in the past, planning for HIV/AIDS has resulted in unrealistic plans that have sought to cover all possibilities, plans that did not give due consideration to the relative importance and relevance of specific strategies on the one hand, and to their feasibility, relative effectiveness and affordability on the other.

All the preceding questions – about relevance and cost-effectiveness, about adequacy of resources, about the major determinants of the epidemic and hence the priorities for action, about what is working and is not working, and why – ultimately serve to inform planners and donors about how and where to allocate resources in a way that maximizes the returns on the investment.

III.3 Mobilizing additional resources

The module has stressed the several ways in which mobilization of resources is an integral part – indeed a major outcome – of strategic approaches to planning responses to HIV/AIDS. Specifically it has outlined the extent to which 'mobilization' of resources is effectively taking place through:

- involving all major stakeholders in the strategic planning process;
- identifying the major determinants of the epidemic at a specific time and place;
- setting priorities accordingly;
- ensuring that scarce resources are channelled to the highest priorities and to the most cost-effective strategies and approaches for a determined objective.

The module has also emphasized the importance and relevance of applying and adapting international 'best practices' and the many 'lessons learnt' about HIV/AIDS prevention and care in order to gain valuable time and minimize the losses that would otherwise result from committing resources to less effective or less appropriate strategies.

Notwithstanding these aspects of resource mobilization inherent in strategic planning, it is evident that the dynamics of HIV/AIDS situations and responses are such that there will from time to time be a need for additional resources to address changing situations, to support emerging strategies and allow an expansion of the response.

This section deals with different strategies and methods for securing 'additional' resources and underlines once more that resources include not just funds but also goods and services and human resources. The following are addressed:

a) Identifying and mobilizing new partnerships
b) Developing technical resource networks
c) Fund-raising

a) Identifying and mobilizing new partnerships

Strategic planning is about looking into obstacles to, and opportunities for (see pp. 11-12 of module 1) a stronger and more effective expanded response. In the course of the situation analysis the team will be considering the major determinants and consequences of HIV/AIDS and, hence, the priority areas for action as well as the changes that may be required for moving from the present situation to the desired one. Subsequently it will look both at what stands in the way of changes needed in priority areas and at the factors that can promote such changes.

The team can thus contribute a great deal to mobilizing additional resources not only for the immediate short-term needs but also for those opportunities that may arise in the medium to longer term:

- by identifying opportunities for involving new actors and new resource partnerships to bring these changes about;
- by exploring the different specific reasons which may appeal to these potential new partners to get involved or to commit resources for current strategies and HIV/AIDS programmes;
- by paving the way for mobilizing resources for future interventions and emerging strategies.

Understandably, the focus in terms of mobilization of additional resources will often be on international development agencies. But it is also worth looking beyond the obvious traditional donor governments and agencies. For example, there are now a number of Foundations established by private companies, the entertainment industry or churches, which have resources that can be tapped for specific HIV/AIDS or AIDS-related projects.

While external donors will likely represent a major component, there are equally important 'national' resource partners who could be a significant source of technical and financial resources. The box on page 16 highlights examples of potential new partnerships that may be brought to light in the process of strategic planning, particularly during the course of a situation assessment and analysis.

➢ Developing technical resource networks

As national responses evolve and new strategies emerge, what is increasingly required by countries is technical know-how or expertise. The demand for such expertise in a wide range of programme areas or on specific prevention and care issues is growing as more and more countries seek to pre-empt the epidemic's threat and expand their response to HIV/AIDS. As has already been pointed out (see Technical soundness and best practices, p. 12) the sharing of lessons learnt and experience on best practices can assist countries in shortening the learning curve, thus gaining time and, in the process, saving much-needed resources.

In this regard, identifying and mobilizing new partnerships also encompasses the idea or strategy of development of networks in general and, specifically, of technical resource networks, as a way of broadening a country's or region's resource base and making specific technical expertise more readily accessible to countries.
(UNAIDS and its cosponsors are promoting and supporting the development and strengthening of technical resource networks in a number of key areas at national as well as regional levels.)

➢ Raising funds from donors/IDAs

Involving the development agencies in planning

The Strategic Planning Guides stress the benefits of securing the participation in the planning process of all key stakeholders, including major donors. As with all potential resource partners their participation should ensure 'ownership' of the resulting strategic plan and plan of action and a greater willingness to contribute resources – and particularly funding – for the implementation of activities. Furthermore, it will also make the same donors more receptive to requests for future additional funding, should such funding be required to expand the response or seize opportunities to initiate new projects. Increasingly, too, as national responses have become more multisectoral and multidimensional, donors are seeking some reassurance that new projects or initiatives are more or less guided by a national strategic framework. This is also where consistent high-level advocacy and demonstration of commitment (see also p. 6 – government leadership) can often help to sway the donors.

General/mainstream development nongovernmental organizations and agencies

NGOs or bilateral and multilateral agencies responsible for general development projects may not always be aware of the extent to which the epidemic could impact on the outcome of a particular project, on the intended beneficiaries, or even on the project's workforce. The situation analysis may serve to identify mainstream NGOs or agencies that could be potentially involved, try to answer questions concerning for example a project's 'vulnerability' to HIV (e.g. because of extensive use of migrant labour force), and reinforce the rationale and benefits of integrating HIV/AIDS prevention into the project's activities, for example by including HIV/AIDS awareness programmes in the workforce training package.

The private sector

The impact of the HIV/AIDS epidemic on the private business sector has been growing steadily over the last years, and has become quite visible in some places. Still, many business leaders need to be persuaded that AIDS prevention programmes for their own employees are in their own rational self-interest. In economic terms, such prevention programmes can be marketed as "minimizing costs" or "profit-loss prevention" and protection of valuable fixed investment in "human capital". The advantage of developing new partnerships with private businesses is that they have substantial resources available. At the same time, their workplaces provide excellent opportunities to reach the labour force in large numbers and with high impact.

The situation analysis should briefly describe and prioritize the most relevant sectors of business in terms of HIV prevention in a way that will allow the response analysis team to better focus their investigations into ongoing responses, and the strategic plan formulation team to identify and mobilize or generate partnerships for an expanded response.

The following information may be of interest in that perspective:

- total number of staff
- annual financial turnover
- main sources of income and the particular risk situations related to specific businesses, such as the extensive reliance on migrant labour force, interests in entertainment or tourist industry, etc.
- segmentation of a company's customer base: are vulnerable populations (youth, for example) major parts of that base?

The military

The armed forces represent a discrete and important group, both in terms of risk of HIV infection[1] and of potential resources to change that situation.

Briefly highlighting their vulnerability emphasizes the benefits that may be gained from making the best use of their resources:

- military recruits are often posted far away from their communities and families for relatively long periods
- they are in the age group most sexually active and most inclined to risk taking
- risk taking tends to be part of the military ethos
- they often have more money than local populations

On the other hand, the army disposes of "resources" that may be harnessed for prevention efforts:

- financial (although often not available for *social* services)
- human: educated and skilled staff
- a disciplined and highly organized environment
- a high concentration of easily reachable high-risk behaviour individuals.

This combination of high susceptibility and non-negligible resources means that the armed forces represent a unique opportunity for effective preventive education.

Gathering information on uniformed forces is a sensitive issue in many countries, and the situation analysis team may have difficulties in doing so. The same objective may however be reached in the long run by actively involving a high-ranking officer from the army's social services in the situation analysis team, so that this person himself can organize an appropriate response "in house".

Academic and research institutions

These represent yet another different potential resource in that they house a wealth of scientific data, studies and of course people whose expertise may not have been tapped and who may be helpful in subsequent information gathering and follow-up for comparison with benchmark data.

Once informed and solicited, they represent a major resource among others for epidemiological and behavioural data collection and analysis, and for planning, monitoring and programme evaluation, not to mention the capacity for clinical or operational research or socioeconomic impact studies.

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[1] Comparative studies in several industrialized and developing countries showed that military personnel have a much higher risk of HIV infection than groups of equivalent age and sex in the civilian population.

Packaging proposals

In any event, when it comes to raising funds from prospective donors for programmes or new projects there are a few 'musts' that can help to swing the balance. These include:

- having a strong rationale for a project that drives home its relevance to the situation or to national priorities; in the case of a programme, having a coherent set of priority strategies and activities and an equally sound goal and overall strategy
- having clear and realistic objectives
- spelling out the expected outcome and concrete outputs
- building in a strong monitoring and evaluation component
- having a detailed and realistic budget, including counterpart resources
- paying due attention to ensuring accountability
- addressing the issue of sustainability.

These all add up to the submission of a marketable product, one that can serve to convince potential funders that they are dealing with project management that is focused, transparent, accountable, and backing activities that are seen to contribute to a meaningful response. At the end of the day all donors like to know what the costs are (what are we paying for?) and what the outcome is likely to be (what are we getting for our money?).

Knowing your donors

As critical as the quality and content of the project submission is some knowledge of the specific donor whose support is being sought. In this respect the old saying that you must 'raise friends before raising funds' assumes special significance. International development agencies will always be more likely to entrust resources to known partners and friends with proven track records of delivering what they set out to do and – this may be more important for some donors than others – what donors require in terms, for example, of reporting and evaluation

Indeed, donors are not a uniform group and it is crucial to understand and take into consideration the different and specific factors that motivate donors and dictate their decision to allocate resources or not.

These are some of the questions and issues that may usefully be addressed:

- What are the favourite areas or strategies, if any, of specific agencies?
- Do they have known sensitivities to particular issues or partnerships? For example, are they likely to respond more or less favourably if there is involvement of NGOs or of a UN partner, or if the project takes into account gender issues?
- What mechanisms do they have for allocation of budgets? Who within their administrative structure is likely to provide the most attentive ear?
- What criteria do they have for the selection of projects to be funded?
- Is there an especially 'good' time to submit a proposal? Perhaps towards the end of the agency's fiscal year?

Sustaining interest and commitment of new resource partners

Finally, the focus may too often be on short-term fund-raising and on one-off partnerships with one-time resource benefits. But sustaining the interest and long-term commitment of one's resource partners is an investment strategy of great relevance to HIV/AIDS programmes that are clearly long-term and dynamic. This is particularly true when dealing with international donor agencies and with the private or business sector and suitable attention should be paid to ensuring the durability of partnerships.

The following are a few useful hints:

- involve them in the planning and development of programmes or projects
- tailor the design of projects to the donors' and sector's interests and mandate (this is especially applicable to the private sector)
- review progress regularly together with resource partners
- recognize and mark a partnership's achievements from time to time.

Conclusion

This fourth module draws attention to the broad scope of resources and of resource mobilization. It highlights in particular the different ways in which mobilization of resources effectively takes place through the strategic planning process as outlined in the first three modules.

With HIV/AIDS continuing to present an ever-growing challenge both in terms of prevention and of impact mitigation measures, resources will continue to be at a premium. In the resource-constrained settings within which national programmes are operating, additional or new resources will always be required and beneficial. However, it is also important to underscore the significance of making judicial use of existing resources. This is what this module does through emphasizing the resource mobilization aspects of the strategic planning process.

Further reading

- UNAIDS. Guides to the strategic planning process for a national response to HIV/AIDS, UNAIDS Best Practice Collection. Geneva, 1998.
- World Bank. Confronting AIDS – Public Priorities in a Global Epidemic. New York, OUP, 1997.
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- Guinness L, Watts C, Mills A. Technical Brief on Cost-Effectiveness of HIV/AIDS Prevention Strategies. Background Paper for UNAIDS, 1997.
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Joint United Nations Programme on HIV/AIDS

UNAIDS

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

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

Guide to the strategic planning process for a national response to HIV/AIDS

This guide, comprising four modules plus an introduction, is intended for use by country programmes, either at a national or decentralized level, other agencies and organizations such as international nongovernmental organizations and donor agencies.

Introduction

Strategic planning, as developed in the present guide, defines not only the strategic framework of the national response, i.e. its fundamental principles, broad strategies, and institutional framework, but also the intermediate steps that need to be taken in order to change the current situation into one that represents the objectives to be reached.

Module 1. Situation analysis

A situation analysis looks specifically at situations that may be relevant to HIV, the factors that favour or impede its spread, and the factors that favour or impede achieving the best possible quality of life for those living with HIV and for their families.

Module 2. Response analysis

In analysing the response, countries look at all the relevant initiatives in a priority area, not just those that are part of the official national programme. Community-organized activities and those organized by private companies, academic organizations, and nongovernmental organizations all contribute to the national response.

Module 3. Strategic plan formulation

The formulation of a strategic planning process deals with the question of what should be done about the HIV situation in the country in the future. The plan includes not only a strategic framework but the more detailed strategies necessary to change the current situation and the successive intermediate steps needed to reach the stated objectives.

Module 4. Resource mobilization

The resource mobilization module is a useful guide to find out how to acquire the resources needed to carry out work on HIV/AIDS. It focuses on the necessary steps to assess what resources are currently available (and how those resources are being used) and how additional resources (and resource partners) can be identified and accessed.

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Ethical considerations in HIV preventive vaccine research

Joint United Nations Programme on HIV/AIDS
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Produced with environment friendly materials

In some jurisdictions, individuals who are below the age of consent are authorized to receive, without the consent or awareness of their parents or guardians, such medical services as abortion, contraception, treatment for drug or alcohol abuse, treatment of sexually transmitted diseases, etc. In some of these jurisdictions, such minors are also authorized to consent to serve as participants in research in the same categories without the agreement or the awareness of their parents or guardians provided the research presents no more than "minimal risk". However, such authorization does not justify the enrolment of minors as participants in vaccine trials without the consent of their parents or guardians.

In some jurisdictions, some individuals who are below the general age of consent are regarded as "emancipated" or "mature" minors and are authorized to consent without the agreement or even the awareness of their parents or guardians. These may include those who are married, parents, pregnant or living independently. When authorized by national legislation, minors in these categories may consent to participation in vaccine trials without the permission of their parents or guardians.

Ethical considerations in HIV preventive vaccine research

UNAIDS guidance document

May 2000

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sexual activity, lack of access to HIV prevention education and means, and engagement in injecting drug use.

Therefore, vaccine development programmes should consider the needs of children for an effective HIV vaccine; should explore the legal, ethical and health considerations relevant to their participation in vaccine research; and should enrol children in clinical trials designed to establish safety, immunogencity, and efficacy for their age groups, once they can be so enrolled in terms of meeting the health needs and ethical considerations relevant to their situation. Those designing vaccine development programmes that might include children should do so in consultation with groups dedicated to the protection and promotion of the rights and welfare of children, both at international and national levels.

Unless exceptions are authorized by national legislation in the host country, consent to participate in an HIV vaccine trial must be secured from the parent or guardian of a child who is a minor before the enrolment of the child as a participant in a vaccine trial. The consent of one parent is generally sufficient, unless national law requires the consent of both. Every effort should be made to obtain consent to participate in the trial also from the child according to the evolving capacities of the child.

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[4] As defined by the Convention on the Rights of the Child, Article 1 : "... a child means every human being below the age of eighteen years unless, under the law applicable to the child, majority is attained earlier."

themselves and for their fetus or child. As with all research participants, steps should be taken to ensure that pregnant or breast-feeding women who are enrolled in vaccine trials are capable of giving informed consent, as indicated in ***Guidance Points 12*** and ***13***. Furthermore, in order for (pregnant) women to be able to make an informed choice for their fetus/breast-fed infant, they should be duly informed about any potential for teratogenesis and other risks to the fetus, and/or the breast-fed infant. If there are risks related to breast-feeding, they should be informed of the availability of nutritional substitutes and other supportive services.

Children[4], including infants and adolescents, should be eligible for enrolment in HIV preventive vaccine trials, both as a matter of equity and as a function of the fact that in many communities throughout the world children are at high risk of HIV infection. Infants born to HIV-infected mothers are at risk of becoming infected during birth and during the post-partum period through breast-feeding. Many adolescents are also at high risk of infection due to

Guidance Point 18 : Children

As children should be recipients of future HIV preventive vaccines, children should be included in clinical trials in order to verify safety, immunogenicity, and efficacy from their standpoint. Efforts should be taken to design vaccine development programmes that address the particular ethical and legal considerations relevant for children, and safeguard their rights and welfare during participation.

Introduction

As we enter the third decade of the AIDS pandemic, there still remains no effective HIV preventive vaccine. As the numbers of those infected by HIV and dying from AIDS increase dramatically, the need for such a vaccine becomes ever more urgent. Several HIV candidate vaccines are at various stages of development. However, the successful development of effective HIV preventive vaccines is likely to require that many different candidate vaccines be studied simultaneously in different populations around the world. This in turn will require a large international cooperative effort drawing on partners from various health sectors, intergovernmental organizations, government, research institutions, industry, and affected populations. It will also require that these partners be able and willing to address the difficult ethical concerns that arise during the development of HIV vaccines.

In an effort to elucidate these ethical concerns, and to create forums where they could be discussed in full by those presently involved in, or considering, HIV vaccine development activities, the UNAIDS Secretariat convened meetings in Geneva (twice), Brazil, Thailand, Uganda and Washington during 1997-1999. These meetings included lawyers, activists, social scientists, ethicists, vaccine scientists, epidemiologists, representatives of NGOs, people living with HIV/AIDS, and people working in health policy. In the regional meetings, efforts were made to include people from a number of countries from that particular region. The entire process involved people from a total of

33 countries.[1] The goals were to : (1) identify and discuss ethical elements specific to development of HIV preventive vaccines; (2) reach consensus when possible, and elucidate different positions, when not; (3) progress in ability to address these matters during pending or proposed HIV vaccine research.

In the present document, UNAIDS seeks to offer guidance emanating from this process. This document does not purport to capture the extensive discussion, debate, consensus, and disagreement which occurred at these meetings. Rather it highlights, from UNAIDS' perspective, some of the critical elements that must be considered in HIV vaccine development activities. Where these are adequately addressed, in UNAIDS' view, by other existing texts, there is no attempt to duplicate or replace these texts, which should be consulted extensively throughout HIV vaccine development activities. Such texts include : the Nuremberg Code (1947); the Declaration of Helsinki, first adopted by the World Medical Association in 1964 and subsequently amended in 1975, 1983, 1989 and 1996; the Belmont Report - Ethical Principles and Guidelines for the Protection of Human Subjects of Research, issued in 1979 by the US National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research; the International Ethical Guidelines for Biomedical Research Involving Human Subjects, issued by the Council for International Organizations of Medical

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[1] For a full description of the process and participants, see "Final Report, UNAIDS-Sponsored Regional Workshops to discuss Ethical Issues in Preventive HIV Vaccine Trials", available from UNAIDS. See also Guenter, Esparza, and Macklin: Ethical considerations in international HIV vaccine trials: summary of a consultative process conducted by the Joint United Nations Programme on HIV/AIDS (UNAIDS. Journal of Medical Ethics (February 2000), vol. 26, No. 1: 37-43.

Guidance Point 17 : Women

As women, including those who are potentially pregnant, pregnant, or breast-feeding, should be recipients of future HIV preventive vaccines, women should be included in clinical trials in order to verify safety, immunogenicity, and efficacy from their standpoint. During such research, women should receive adequate information to make informed choices about risks to themselves, as well as to their fetus or breast-fed infant, where applicable.

Women, including pregnant women, potentially pregnant women and breast-feeding women, should be eligible for enrolment in HIV preventive vaccine trials, both as a matter of equity and because in many communities throughout the world women are at high risk of HIV infection. Therefore, the safety, immunogenicity, and efficacy of candidate vaccines should be established for women, and for their fetus and breast-fed child, where applicable. In these situations, the clinical trials should be designed with the intent of establishing the effects of the candidate vaccine on the health of the woman and the fetus and/or breast-fed infant, where applicable.

Although the enrolment of pregnant, potentially pregnant, or breast-feeding women complicates the analysis of risks and benefits, because both the woman and the fetus or infant could be benefited or harmed, such women should be viewed as autonomous decision-makers, capable of making an informed choice for

- Those participating in the planning of vaccine development programmes should seek to provide a comprehensive care and treatment package based, at a minimum, on standards of care developed by the community, but also taking into account the additional resources and higher standards brought by the sponsor into the research setting.
- Sponsors should contribute to the building up of both the research capacity and the health care delivery capacity of the community where the research is to be carried out, in such a way that they become integrated into the infrastructure of the community.

Such a care and treatment package should include, but not be limited to, some or all of the following items, depending on the type of research, the setting, and the consensus reached by all interested parties before the trials begin:

- counselling
- preventive methods and means
- treatment for other STIs
- tuberculosis prevention and treatment
- prevention/treatment of opportunistic infections
- nutrition
- palliative care, including pain control and spiritual care
- referral to social and community support
- family planning
- home-based care
- antiretroviral therapy

Sciences (CIOMS) in 1993 (and developed in close cooperation with WHO); the World Health Organization's Good Clinical Practice (WHO GCP) Guideline (1995); and the International Conference on Harmonisation's Good Clinical Practice (ICH GCP) Guideline (1996).

It is hoped that this document will be of use to potential research participants, investigators, community members, government representatives, pharmaceutical companies, and ethical and scientific review committees involved in HIV preventive vaccine development. It suggests standards, as well as processes for arriving at standards, and can be used as a frame of reference from which to conduct further discussion at the international, national, and local levels.

Context

The HIV/AIDS pandemic is characterized by unique biological, social and geographical factors that, among other things, affect the balance of risks and benefits for individuals and communities who participate in HIV vaccine development activities. These factors may require that additional efforts are made to address the needs of participating individuals and communities, including their urgent need for a HIV vaccine, their need to have their rights protected and their welfare promoted in the context of HIV vaccine development activities, and their need to be able to be full and equal participants . These factors include the following :

- The global burden of disease and death related to HIV is increasing at a rate unmatched by any other pathogen. For many countries, it is already the leading cause of death. Currently available treatments are inadequate because they do not lead to cure, but at best slow the progression of disease. The most effective treatment for slowing HIV-related disease progression, antiretroviral medication, is complicated to administer, requires close medical monitoring, is extremely costly, and can cause significant adverse effects. Because of this, antiretroviral medication is not readily available to the vast majority of people affected by HIV/AIDS. These are people living in developing countries and in marginalized communities in

if sponsors fill this role

- governments' desire to be able to attract research into their countries in order to address the critical need of their populations for an HIV preventive vaccine
- the right and responsibility of sovereign nations and communities to determine for themselves the balance of risks and benefits they are willing to accept.

In the light of these competing concerns, it is recommended that:

- A consensus on the standard/level of care and treatment, its duration, and who will bear the costs should be reached prior to a decision to host HIV vaccine development.
- This consensus should emerge from an extensive dialogue involving the above-mentioned competing concerns among sponsors, and representatives from the potential host country and communities from which potential trial participants would be drawn, e.g. government officials, national scientific and ethical communities, affected populations, relevant NGOs, local religious and community leaders.
- Such a consensus should aim for achieving, as closely as possible, the ideal of provision of the best proven therapy for trial participants, in the light of relevant conditions and concerns.
- Sponsors should seek, at a minimum, to ensure access to a level of care and treatment that approaches the best proven care and treatment that are attainable in the potential host country.

care and treatment, post-exposure prophylaxis and antiretroviral therapy, according to the best scientific evidence for effectiveness available at the time of the trial; and should last at least for the duration for the trial, and longer, if so negotiated

- at a level decided upon by the host country, e.g. it might include immunological monitoring, physician visits, prevention and treatment of opportunistic infections, and palliative care, but not necessarily antiretroviral therapy; and should be made reasonably available for the lifetime of the participants
- at a level consistent with that available in the host country; there is no imperative to provide a level of care consistent with that in the sponsoring country, or with the highest available in the world.

Competing considerations that have led to disagreement about the standard of care and treatment include:

- the need to achieve equity in care and treatment for all participants in HIV vaccine trials globally; in particular, to achieve equity between potential participants from sponsor countries and host countries
- an ethical obligation of sponsors to provide care and treatment according to their resources
- concern that a high level of care and treatment will constitute undue incentives and inducements for countries and communities to participate
- concern that governments might abdicate on their responsibility to provide care and treatment

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developed countries. There is therefore an ethical imperative to seek, as urgently as possible, a globally effective and accessible vaccine, to complement other prevention strategies. Furthermore, this ethical imperative demands that HIV preventive vaccines be developed to address the situation of those people and populations most vulnerable to infection.

- Genetically distinct subtypes of HIV have been described, and different HIV subtypes are predominant in different regions and countries. Yet the relevance of these subtypes to potential vaccine-induced protection is not clearly understood. Thus, it is not known whether a vaccine targeted at one subtype will protect against infection from another subtype; and it is likely that a vaccine directed at a particular subtype will need to be tested in a population in which that subtype is prevalent. Therefore, developing a vaccine that is effective in the populations with the greatest incidence of HIV is likely to require experimental vaccines be tested in those populations, even though these populations may for a variety of reasons be relatively vulnerable to exploitation and harm in the context of HIV vaccine development. Additional efforts may need to be made to overcome this vulnerability.
- Some candidate vaccines may be conceived and manufactured in laboratories of one country (sponsor country or countries), usually in the developed world, and tested in human populations in another country (host country or countries), often in the developing world.

[The term 'sponsor' has usually referred to the individual or institution who either owns the candidate vaccine or provides the material resources necessary to carry out the vaccine development programme. Traditionally, the sponsor has been thought of as a single corporate entity, such as a pharmaceutical company. In modern vaccine development programmes there are commonly multiple sponsors including one or more corporations, one or more national governments and one or more international agencies.] The potential imbalance of such a situation demands particular attention to factors that will address the differing perspectives, interests and capacities of sponsors and hosts with the goal of encouraging the urgent development of effective vaccines, in ethically acceptable manners, and their early distribution to populations most in need. In this regard, potential host countries and communities should be encouraged and given the capacity to make decisions for themselves regarding their participation in HIV vaccine development, based on their own health and human development priorities, in a context of equal collaboration with sponsors.

- HIV/AIDS is a condition that is both highly feared and stigmatized. This is in large part because it is associated with blood, death, sex, and activities which are often not legally sanctioned, such as commercial sex, men having sex with men, and substance abuse. These are issues which are difficult to address openly - at a societal and individual level. As a result, people affected by HIV/AIDS can experience stigma, discrimination,

Sponsors need to ensure care and treatment for participants who become HIV-infected during the course of the trial. At present, there is no universal consensus regarding the level of care and treatment that should be provided. This was evidenced at the UNAIDS-sponsored regional workshops to discuss ethical issues in preventive HIV vaccine trials at which the following three different conclusions were reached. Care and treatment for those who become infected should be provided:

- at the level of that offered in the sponsor country, and should include preventive risk behaviour counselling, general HIV

Guidance Point 16 : Care and treatment

Care and treatment for HIV/AIDS and its associated complications should be provided to participants in HIV preventive vaccine trials, with the ideal being to provide the best proven therapy, and the minimum to provide the highest level of care attainable in the host country in light of the circumstances listed below. A comprehensive care package should be agreed upon through a host/community/sponsor dialogue which reaches consensus prior to initiation of a trial, taking into consideration the following :

- ***level of care and treatment available in the sponsor country***
- ***highest level of care available in the host country***
- ***highest level of treatment available in the host country, including the availability of antiretroviral therapy outside the research context in the host country***
- ***availability of infrastructure to provide care and treatment in the context of research***
- ***potential duration and sustainability of care and treatment for the trial participant.***

partnership. Consideration should be given to the expansion of the responsibilities of the clinical trial monitor to include adherence to the informed consent and counselling process, and/or the appointment of an independent counselling monitor, as suggested in ***Guidance Point 13***. The appropriateness of such plans should be determined by the scientific and ethical review committees that are responsible for providing prior and continuing review of the trial. This recommendation supplements the usual guidelines for the monitoring of vaccine trials for safety and compliance with scientific and ethical standards and regulatory requirements.

and even violence; and governments and communities continue to deny the existence and prevalence of HIV/AIDS. Furthermore, vulnerability to HIV infection and to the impact of AIDS is greater where people are marginalized due to their social, economic and legal status. These factors increase the risk of social and psychological harm for people participating in HIV vaccine research. Additional efforts must be made to address these increased risks, and to ensure that the risks participants take are justified by the benefits they receive by virtue of their participation in the research. A key means by which to protect participants and the communities from which they come is to ensure that the community in which the research is carried out is meaningfully involved in the design, implementation, and distribution of results of vaccine research, including the involvement of representatives from marginalized communities from which participants are drawn, where possible and appropriate.

The provision of counselling to reduce risk should be monitored to ensure quality and to minimize the potential conflict of interest between the risk-reduction goals and the vaccine trial's scientific goals. As new methods of prevention are discovered and validated, these must be added to the preventive methods being offered to trial participants.

Guidance Point 15 : Monitoring informed consent and interventions

A plan for monitoring the initial and continuing adequacy of the informed consent process and risk-reduction interventions, including counselling and access to prevention methods, should be agreed upon before the trial commences.

The value of informed consent depends primarily on the ongoing quality of the process by which it is conducted, and not solely on the structure and content of the informed consent document. The informed consent process should be designed to empower participants to allow them to make appropriate decisions. Similarly, there are many ways in which risk reduction (counselling and access to means of prevention) can be conducted, with some methods being more effective than others in conveying the relevant information and in reducing risk behaviour.

A method for monitoring the adequacy of these processes should be designed and agreed upon by the community-host-government-investigator-sponsor

Guidance Point 14 :
Risk-reduction interventions

Appropriate risk-reduction counselling and access to prevention methods should be provided to all vaccine trial participants, with new methods being added as they are discovered and validated.

Reducing the risk of HIV infection throughout the trial among participants is an essential ethical component of HIV preventive vaccine trials. All trial participants should receive comprehensive counselling concerning methods of decreasing the risk of transmission of HIV. This should include the basic principles of safe sexual practice and safe use of injection equipment, as well as education concerning general health and treatment of sexually transmitted infections (STIs). Investigators should provide trial participants appropriate access to condoms, sterile injecting equipment (where legal) and treatment for other STIs. All trial participants should also be counselled prior to enrolling in a clinical trial regarding the potential benefits and risks of post-exposure prophylaxis with antiretroviral medication, and how it can be accessed in the community.

The technique and frequency of counselling should be agreed upon by the community-host government-investigator-sponsor partnership, and should be based upon reliable information about the prevailing social and behavioural characteristics of the study population. Consideration should be given to providing counselling through an agency or organisation that is independent of the investigators in order to prevent any real or perceived conflict of interest. Local capacity should be developed to employ such means in a culturally suitable and sustainable fashion, guided by the best scientific data.

Suggested guidance

Guidance Point 1:
HIV vaccines development

Given the severity of the HIV/AIDS pandemic in human, public health, social, and economic terms, sufficient capacity and incentives should be developed to foster the early and ethical development of effective vaccines, both from the point of view of countries where HIV vaccine trials may be held, and from the point of view of sponsors of HIV vaccine trials. Donor countries and relevant international organizations should join with these stakeholders to promote such vaccine development.

Given the global nature of the epidemic, the devastation being wreaked in some countries by it, the fact that vaccine(s) may be the best long-term solution by which to control the epidemic, especially in developing countries, and the potentially universal benefits of effective HIV vaccines, there is an ethical imperative for global support to the effort to develop these vaccines. This effort will require intense international collaboration and coordination over time, including among countries with scientific expertise and resources, and among countries where candidate vaccines could be tested but whose infrastructure, resource base, and scientific and ethical capacities could be insufficient at present. Though HIV vaccines should benefit all those in need, it is imperative that they benefit the populations at greatest risk of infection. Thus, HIV vaccine development should ensure that the vaccines are appropriate for use among such populations, among which it will be necessary to conduct trials; and, when developed, they should be made available and affordable to such populations.

Because HIV vaccine development activities take time, are complex, and require infrastructure, resources and international collaboration,

- potential sponsor countries and host countries should immediately include HIV vaccine development in their regional and national AIDS prevention and control plans.
- potential host countries should assess how they can and should participate in HIV vaccine development activities either nationally or on a regional basis, including identifying resources, establishing partnerships, conducting national information campaigns, strengthening their scientific and ethical sectors, and including a vaccine research component to complement other prevention interventions.
- potential donors and international agencies should make early and sustained commitments to allocate sufficient funds to make a vaccine a reality, including funds to strengthen ethical and scientific capacity in countries where multiple trials will have to be conducted and to purchase and distribute future vaccines.
- potential sponsors should establish partnerships

- Persons who engage in illegal or socially stigmatized activities are vulnerable to undue influence and threats presented by possible breaches of confidentiality and action by legal forces. Such persons include sex workers, intravenous drug users, and men who have sex with men.
- Persons who are impoverished or dependent on welfare programmes are vulnerable to being unduly influenced by offers of what others may consider modest material or health inducements.
- Women living in cultures where their autonomy as individuals is not sufficiently recognized are vulnerable to influence and coercion from male partners, family, or community members.

Steps that might be taken to ensure that ongoing free and informed consent is given by participants from these groups include :

- appointment of an independent ombudsperson and/or group to monitor these issues
- expansion of the responsibilities of the clinical trial monitor to include adherence to the informed consent and counselling process, or appointment of an independent counselling monitor
- training of the counsellors on these issues, and
- group counselling and/or interaction with local NGOs representing the groups from which such participants are drawn.

and how it can be accessed, if they become infected with HIV during the course of the trial (see ***Guidance Point 16***).

Guidance Point 13 : Informed consent - special measures

Special measures should be taken to protect persons who are, or may be, limited in their ability to provide informed consent due to their social or legal status.

There are several categories of persons who are legally competent to consent to participate in a trial, and who have sufficient cognitive capacity to consent, but who may have limitations in their freedom to make independent choices. Those who plan, review, and conduct vaccine trials should be alert to the problems presented by the involvement of such persons, and either exclude such persons, if their vulnerability cannot be addressed, or take appropriate steps to ensure meaningful and independent ongoing informed consent, respect their rights, foster their well-being, and protect them from harm. The following are individuals or groups who should be given extra consideration with regard to their ability to provide informed consent in HIV preventive vaccine trials:

- Persons who are junior or subordinate members of hierarchical structures may be vulnerable to undue influence or coercion in that they may fear retaliation if they refuse cooperation with authorities. Such persons include members of the armed forces, students, government employees, prisoners, and refugees.

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with potential host countries, and begin discussions regarding community consultations, strengthening necessary scientific and ethical components, and eventual plans for equitable distribution of the benefits of research.

Guidance Point 2 : Vaccine availability

Any HIV preventive vaccine demonstrated to be safe and effective, as well as other knowledge and benefits resulting from HIV vaccine research, should be made available as soon as possible to all participants in the trials in which it was tested, as well as to other populations at high risk of HIV infection. Plans should be developed at the initial stages of HIV vaccine development to ensure such availability.

Although making a safe and effective vaccine reasonably available to the population where it was tested is a basic ethical requirement, some have argued that it could be a disincentive for industry to conduct studies in countries with large populations, or that it could constitute an undue inducement for a resource-poor country or community to "cooperate". Given the severity of the epidemic, it is imperative that sufficient incentives exist, both through financial rewards in the marketplace and through public subsidies, to foster development of effective vaccines while also ensuring that vaccines are produced and distributed in a fashion that actually makes them available to the populations at greatest risk.

As health and research communities build HIV preventive vaccine research programmes, attention needs to be given immediately to how a successful vaccine, and other benefits resulting from the research, will be made readily and affordably available to the communities and countries where such a vaccine is tested, as well as to other communities and countries at high risk for HIV infection. This process of discussion and negotiation should start as soon as possible and should be carried on through the course of the research.

At a minimum, the parties directly concerned should begin this discussion before the trials commence. This discussion should include representatives from relevant stakeholders in the host country, such as representatives from the executive branch, health ministry, local health authorities, and relevant scientific and ethical groups. It should also include representatives from the communities from which participants are drawn, people living with HIV/AIDS, and NGOs representing affected communities. The discussions should include decisions regarding payments, royalties, subsidies, technology and intellectual property, as well as distribution costs, channels and modalities, including vaccination strategies, target populations, and number of doses.

Furthermore, the discussion concerning availability and distribution of an effective HIV vaccine should engage international organizations, donor governments and bilateral agencies, representatives from wider affected communities, international and regional NGOs and the private sector. These should not only consider financial assistance regarding making vaccines available, but should also help to build the capacity of host governments and communities to negotiate for and implement distribution plans.

prospective participant must be informed, using appropriate language and technique, of the following specific details:

- Prospective participants of phase II and III trials of HIV preventive vaccines should be informed that they have been chosen as prospective participants because they are at relatively high risk of HIV infection.
- Prospective participants for phase I, II and III trials should be informed that they will receive counselling and access to the means of risk reduction (in particular, male and female condoms, and clean injecting equipment, where legal) concerning how to reduce their risk of infection; and that in spite of these risk reduction efforts, some of the participants may become infected, particularly in the case of phase III trials where large numbers of participants at high risk are participating.
- They should be informed that it is not known whether the experimental vaccine will prevent HIV infection or disease, and further, that some of the participants will receive a placebo instead of the candidate HIV vaccine, when such is the case.
- They should be informed of the specific risks for physical harm, as well as for psychological and social harm, and of the types of treatment and compensation that are available for harm, and of services to which they may be referred should harm occur.
- All prospective participants of phase I, II or III trials should be informed of the nature and duration of care and treatment that is available,

post-test counselling, should also be given for any repeated tests for HIV status. Throughout all stages of the trial and consent process, there should be assurance by the investigator that the information is understood before consent is given.

In some communities, it is customary to require the authorization of a third party, such as a community elder, in order for investigators to enter the community to invite individual members to participate in research. Other situations which make individual informed consent difficult include those in which an individual requires approval of another person or group in order to make decisions, where there is coercion, and where there is a cultural tradition of sharing risks and responsibilities, e.g. in some cultures where men hold the prerogative in marital relationships, where there is parental control of women, and/or where there are strong influences by community and/or religion or hierarchy (see ***Guidance Point 13***). Such authorization or influence must not be used as a substitute for individual informed consent. Nor should trials be conducted where truly individual and free consent cannot be obtained. Authorization by a third party in place of individual informed consent is permissible only in the case of some minors who have not attained the legal age of consent to participate in a trial. In cases where it is proposed that minors will be enrolled as research participants, specific and full justification for their enrolment must be given, and their own consent must be obtained in light of their evolving capacities (see ***Guidance Point 18***).

In addition to the standard content of informed consent, prior to participation in an HIV vaccine trial, each

Guidance Point 3 : Capacity building

Strategies should be implemented to build capacity in host countries and communities so that they can practise meaningful self-determination in vaccine development, can ensure the scientific and ethical conduct of vaccine development, and can function as equal partners with sponsors and others in a collaborative process.

Potential host countries and communities have the right, and the responsibility, to take decisions regarding the nature of their participation in HIV vaccine research. Yet disparities in economic wealth, scientific experience, and technical capacity among countries and communities can lead to undue influence over and possible exploitation of host countries and communities. The development of an HIV vaccine will require international cooperative research, which should transcend, in an ethical manner, such disparities. Real or perceived disparities should be resolved in a way that ensures equality in decision-making and action. The desired relationship is one of collaboration among equals. Factors that may increase vulnerability to exploitation of host countries and communities may include, but are not limited to, the following:

- level of the proposed community's economic capacity, such as is reflected in the Human Development Index of the UNDP
- community/cultural experience with, and/or understanding of, scientific research

- local political awareness of the importance and process of vaccine research
- local infrastructure, personnel, and technical capacity for providing HIV health care and treatment options
- ability of individuals in the community to provide informed consent, including the effect of class. gender, and other social factors on the potential for freely given consent
- level of experience and capacity for conducting ethical and scientific review, and
- local infrastructure, personnel, and technical capacity for conducting the proposed research.

Strategies to overcome these disparities could involve:

- scientific exchange, and knowledge and skills transfer between sponsor countries and institutions, and host countries and communities
- capacity-building programmes in the science and ethics of vaccine development by relevant scientific institutions and international organizations
- support to development of national and local ethical review capacity (see ***Guidance Point 6***)
- support to affected communities and communities from which participants are drawn regarding information, education, and capacity and consensus-building on vaccine development, and
- early involvement of affected communities in the design and implementation of vaccine development plans and protocols (see ***Guidance Point 5***).

'contagion', 'placebo', 'double blind', and other concepts involved in the scientific design of the research.

HIV preventive vaccine trials require informed consent at a number of stages. The first stage consists of screening candidates for eligibility for participation in the trial, which will involve, among other things, an assessment of the individual's risk-taking behaviour and a test for HIV status. Informed consent should be obtained during this screening process after the candidate has received all material information regarding the screening procedures, as well as an outline of the vaccine trial in which he will be invited to enrol, if found eligible. Fully informed consent should also be given for the test for HIV status, which should also be accompanied by pre-and post-test counselling, and referral to clinical and social support services, if found positive.

The second stage at which informed consent is required occurs once a person is judged eligible for enrolment. That individual should then be given full information concerning the nature and length of participation in the trial, including the risks and benefits posed by participation, so that s/he is able to give informed consent to participate.

Once enrolled, efforts should then be made throughout the trial to obtain assurance that the participation continues to be on a basis of free consent and understanding of what is happening. Informed consent, with pre- and

In an effort to address the concern of lack of benefit to those randomly placed in a placebo control arm, apart from the benefits described in **Guidance Point 10**, it is recommended that the provision to these persons of another vaccine, such as for hepatitis B or tetanus, be considered. The appropriateness of such a step should be analysed in terms of the scientific requirements of the trial, the health needs of the population of participants, and the balance of benefits and risks to the active versus control arms of the trial.

Guidance Point 12 : Informed consent

Independent and informed consent based on complete, accurate, and appropriately conveyed and understood information should be obtained from each individual while being screened for eligibility for participation in an HIV preventive vaccine trial, and before s/he is actually enrolled in the trial. Efforts should be taken to ensure throughout the trial that participants continue to understand and to participate freely as the trial progresses. Informed consent, with pre- and post-test counselling, should also be obtained for any testing for HIV status conducted before, during, and after the research.

A process of consultation between community representatives, researchers, sponsor(s) and regulatory bodies should be used to design an effective informed consent strategy and process. Issues such as illiteracy, language and cultural barriers, and diminished personal autonomy should be addressed in this consultative process. In some communities, special efforts may be required to achieve adequate understanding of 'cause and effect',

Guidance Point 4 : Research protocols and study populations

In order to conduct HIV vaccine research in an ethically acceptable manner, the research protocol should be scientifically appropriate, and the desired outcome of the proposed research should potentially benefit the population from which research participants are drawn.

In order to be ethical, clinical trials of vaccines should be based on scientifically valid research protocols, and the scientific questions posed should be rigorously formulated in a research protocol that is capable of providing reliable responses. Valid scientific questions relevant to HIV vaccine development are those that seek:

- to gain scientific information on the safety, immunogenicity (ability to induce immune responses against HIV) and efficacy (degree of protection) of candidate vaccines
- to determine immunological correlates or surrogates in order to identify the protective mechanisms and how they can be elicited
- to compare different candidate vaccines; and
- to test whether vaccines effective in one population are effective in other populations.

Furthermore, the selection of the research population should be based on the fact that its characteristics are relevant to the scientific issues raised; and the results of the research will potentially benefit the selected population. In this sense, the research protocol should:

- justify the selection of the research population from a scientific point of view
- outline how the risks undertaken by the participants of that population are balanced by the potential benefits to that population
- address particular needs of the proposed research population
- demonstrate how the candidate vaccine being tested is expected to be beneficial to the population in which testing occurs, and
- establish safeguards for the protection of research participants from potential harm arising from the research.

These general principles will be further elaborated below.

A vaccine with proven efficacy in preventing infection or disease from HIV does not currently exist. Therefore, the use of a placebo control arm is ethically acceptable in appropriately designed protocols.

Guidance Point 11 : Control group

As long as there is no known effective HIV preventive vaccine, a placebo control arm should be considered ethically acceptable in a phase III HIV preventive vaccine trial. However, where it is ethically and scientifically acceptable, consideration should be given to the use in the control arm of a vaccine to prevent a relevant condition apart from HIV.

Participants in the control arm of a future phase III HIV preventive vaccine trial should receive an HIV vaccine known to be safe and effective when such is available, unless there are compelling scientific reasons which justify the use of a placebo. Compelling scientific reasons to use a placebo rather than a known effective HIV vaccine in the research population include the following :

- The effective HIV vaccine is not believed to be effective against the virus that is prevalent in the research population.
- There are convincing reasons to believe that the biological conditions that prevailed during the initial trial demonstrating efficacy were so different from the conditions in the proposed research population that the results of the initial trial cannot be directly applied to the research population under consideration.

Guidance Point 10 : Benefits

The research protocol should outline the benefits that persons participating in HIV preventive vaccine trials should experience as a result of their participation. Care should be taken so that these are not presented in a way that unduly influences freedom of choice in participation.

Some of the activities related to the conduct of HIV vaccine trials should benefit those who participate. At a minimum, participants should :

- have regular and supportive contact with health care workers and counsellors throughout the course of the trial
- receive comprehensive information regarding HIV transmission and how it can be prevented
- receive access to HIV prevention methods, including male and female condoms, and clean injecting equipment, where legal
- have access to a pre-agreed care and treatment package for HIV/AIDS if they become HIV-infected while enrolled in the trial (see ***Guidance Point 16***)
- receive compensation for time, travel and inconvenience for participation in the trials, and
- if the vaccine is effective, develop protective immunity to HIV.

Guidance Point 5 : Community participation

To ensure the ethical and scientific quality of proposed research, its relevance to the affected community, and its acceptance by the affected community, community representatives should be involved in an early and sustained manner in the design, development, implementation, and distribution of results of HIV vaccine research.

Involvement of community representatives should not be seen as a single encounter, nor as one-directional. The orientation of community involvement should be one of partnership - towards mutual education and consensus-building regarding all aspects of the vaccine development programme. There should be established a continuing forum for communication and problem-solving on all aspects of the vaccine development programme from phase I through phase III and beyond, to the distribution of a safe, effective, licensed vaccine. All participating parties should define the nature of this ongoing relationship. It should include appropriate representation of the community on committees charged with the review, approval, and monitoring of the HIV vaccine research. Like investigators and sponsors, communities should assume appropriate responsibility for assuring the successful completion of the trial and of the programme.

Appropriate community representatives should be determined through a process of broad consultation. Members of the community who may contribute to a vaccine development process include representatives of the research population eligible to serve as research participants, other members of the community who would be among the intended beneficiaries of the developed vaccine, relevant nongovernmental organizations, persons living with HIV/AIDS, community leaders, public health officials, and those who provide health care and other services to people living with and affected by HIV.

Participation of the community in the planning and implementation of a vaccine development strategy can provide the following benefits:

- information regarding the health beliefs and understanding of the study population
- input into the design of the protocol
- input into an appropriate informed consent process
- insight into the design of risk reduction interventions
- effective methods for disseminating information about the trial and its outcomes
- information to the community-at-large on the proposed research
- trust between the community and researchers
- equity in choice of participants
- equity in decisions regarding level of standard of care and treatment and its duration, and
- equity in plans for applying results and vaccine distribution.

With regard to psychosocial risks, participation in a complicated, lengthy trial involving intensely intimate matters, involving repeated HIV testing, and involving exposure to culturally different scientific and medical concepts may cause anxiety, stress, depression, as well as stress between partners in a relationship. Participation, if it becomes publicly known, may also cause stigma and discrimination against the participant if s/he is perceived to be HIV-infected. Finally, some people may develop a positive HIV test after receiving a candidate HIV vaccine, even though they are not truly infected with HIV, i.e. a 'false positive' HIV test. This may result in the same negative social consequences that exist for those actually HIV-infected. The protocol should describe these, as well as ensure that the research occurs in communities where confidentiality can be maintained and where participants will have access to, and can be referred to, ongoing psychosocial services, including counselling, social support groups, and legal support. Consideration should also be given to setting up an ombudsperson who can intervene with outside parties, if necessary and requested, on behalf of participants, as well as to providing documentation to participants that they can use to show that their "false positive" is due to their participation in research.[3]

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[3] When a vaccine is tested, laboratory techniques should be available to differentiate HIV-positivity due to vaccination from that due to actual HIV infection.

- A person who has received a candidate vaccine and is then exposed to HIV may have a greater risk of developing established infection, or of progressing more rapidly once infected, than if the vaccine had not been administered. This potential harm has not been observed in trials thus far.
- An HIV vaccine may require that several injections be given over months or years, resulting in pain, occasional skin reactions, and possibly other biological adverse events, such as fever and malaise.
- Injuries may be sustained due to research-related activities during the course of the trial.

The potential for adverse reactions to the candidate vaccine, as well as possible injuries related to HIV vaccine research, should be described, as far as possible, in the research protocol and fully explained in the informed consent process. Both the protocol and the consent process should also describe the nature of medical treatment to be provided for injuries, as well as compensation for harm incurred due to research-related activities, including the process by which it is decided whether an injury will be compensated. HIV infection acquired during participation in an HIV preventive vaccine trial should not be considered an injury subject to compensation unless it is directly attributable to the vaccine itself, or to direct contamination through research-related activities. In addition to compensation for biological/medical injuries, appropriate consideration should be given to compensation for social or economic harms, e.g. job loss as a result of testing positive following vaccine administration.

Guidance Point 6 : Scientific and ethical review

HIV preventive vaccine trials should only be carried out in countries and communities that have the capacity to conduct appropriate independent and competent scientific and ethical review.

Proposed HIV vaccine research protocols should be reviewed by scientific and ethical review committees that are located in, and include membership from, the country and community where the research is proposed to take place. This process ensures that the proposed research is analysed from the scientific and ethical viewpoints by individuals who are familiar with the conditions prevailing in the potential research population.

Some countries do not currently have the capacity to conduct independent, competent and meaningful scientific and ethical review. If the country's capacity for scientific and ethical review is inadequate, the sponsor should be responsible for ensuring that adequate structures are developed in the host country for scientific and ethical review prior to the start of the research. Care should be taken to minimize the potential for conflicts of interest, while providing assistance in capacity-building for scientific and ethical review. Capacity-building for scientific and ethical review may also be developed in collaboration with international agencies, organizations within the host country, and other relevant parties.

Guidance Point 7 : Vulnerable populations

Where relevant, the research protocol should describe the social contexts of a proposed research population (country or community) that create conditions for possible exploitation or increased vulnerability among potential research participants, as well as the steps that will be taken to overcome these and protect the dignity, safety, and welfare of the participants.

Some countries or communities, often described as "developing", have been perceived as inappropriate participants for some phases of clinical research, due to a real or perceived increased level of vulnerability to exploitation or harm. The usefulness of the "developing/developed" terminology for assessing risk of harm and exploitation, however, is limited. It refers primarily to economic considerations, which are not the only relevant factors in HIV vaccine research. It also establishes two fixed categories, whereas in reality, countries and communities are distributed along a spectrum, characterized by a variety of different factors that affect risk. It is more useful to identify the *particular* aspects of a social context that create conditions for exploitation or increased vulnerability for the pool of participants that has been selected. These aspects should be described in the protocol, as should the measures that will be taken to overcome them. In some potential research populations (countries or communities), conditions affecting potential vulnerability or exploitation may be so severe that ensuring adequate safeguards is not possible. In such populations, HIV preventive vaccine research should not be conducted.

Guidance Point 9 : Potential harms

The nature, magnitude, and probability of all potential harms resulting from participation in an HIV preventive vaccine trial should be specified in the research protocol as fully as can be reasonably done, as well as the modalities by which to address these, including provision for the highest level of care to participants who experience adverse reactions to the vaccine, compensation for injury related to the research, and referral to psychosocial and legal support, as necessary.

Participation in HIV preventive vaccine research may involve physiological, psychological and social risks. With regard to the physiological risks, the purpose of an HIV preventive vaccine is to induce an immunological response in the human body to counteract the HIV virus if it enters the body, or to prevent it from entering at all. Vaccines currently being considered for human trials are not capable of causing infection, i.e. they do not include replicating HIV.[2] Several candidate HIV vaccines have been tested in laboratories, and some have been tested in human subjects. Not all of these candidate vaccines are the same, and not all candidate vaccines carry the same risks for harm. Thus far, however, significant adverse biological effects have not been observed. Nevertheless, some of the more likely physiological risks of participating in vaccine research include the following:

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[2] Some of the most effective viral vaccines are based on live-attenuated viruses and some investigators have proposed a similar approach for HIV vaccines. Any decision regarding testing a live-attenuated HIV vaccine in humans would have to be carefully assessed in view of the significant safety concerns associated with such a vaccine approach.

their residents will be adequately protected from harm or exploitation, and that the vaccine development programme is necessary for and responsive to the health needs and priorities in their country; and

- all other conditions for ethical justification as set forth in this document are satisfied.

In cases in which it is decided to carry out phase I or phase II trials first in a country other than the sponsor country, due consideration should be given to conducting them simultaneously in the country of the sponsor, where this is practical and ethical. Also, when the host country or community is not familiar with conducting biomedical research in human subjects, phase I/II trials that have been performed in the country of the sponsor should ordinarily be repeated in the community in which the phase III trials are to be conducted.

Some factors to be considered are those listed in ***Guidance Point 3*** which influence the disparity in real or perceived power as between sponsors and host countries, as well as the factors listed below that can also increase the nature and level of risk of harm to participants:

- governmental, institutional or social stigmatization or discrimination on the basis of HIV status
- inadequate ability to protect HIV-related human rights, and to prevent HIV-related discrimination and stigma, including those arising from participation in an HIV vaccine trial
- social and legal marginalization of groups from which participants might be drawn, e.g. women, injecting drug users, men having sex with men, sex workers
- limited availability, accessibility and sustainability of health care and treatment options
- limited ability of individuals or groups in the community to understand the research process
- limited ability of individuals to understand the informed consent process
- limited ability of individuals to be able to give freely their informed consent in the light of prevailing class, gender, and other social and legal factors, and
- lack of meaningful national/local scientific and ethical review.

Initial stages in a vaccine development programme entail research in laboratories and among animals. The transition from this pre-clinical phase to a phase I clinical trial, in which testing involves the administration of the candidate vaccine to human subjects to assess safety and immunogenicity, is a time when risks may not be yet well defined. Furthermore, specific infrastructures are often required in order to ensure the safety and care of the research participants at these stages. For these reasons, the first administration of a candidate HIV vaccine in humans should generally be conducted in less vulnerable research populations, usually in the country of the sponsor.

Guidance Point 8 : Clinical trial phases

As phases I, II, and III in the clinical development of a preventive vaccine all have their own particular scientific requirements and specific ethical challenges, the choice of study populations for each trial phase should be justified in advance in scientific and ethical terms in all cases, regardless of where the study population is found. Generally, early clinical phases of HIV vaccine research should be conducted in communities that are less vulnerable to harm or exploitation, usually within the sponsor country. However, countries may choose, for valid scientific and public health reasons, to conduct any phase within their populations, if they are able to ensure sufficient scientific infrastructure and sufficient ethical safeguards.

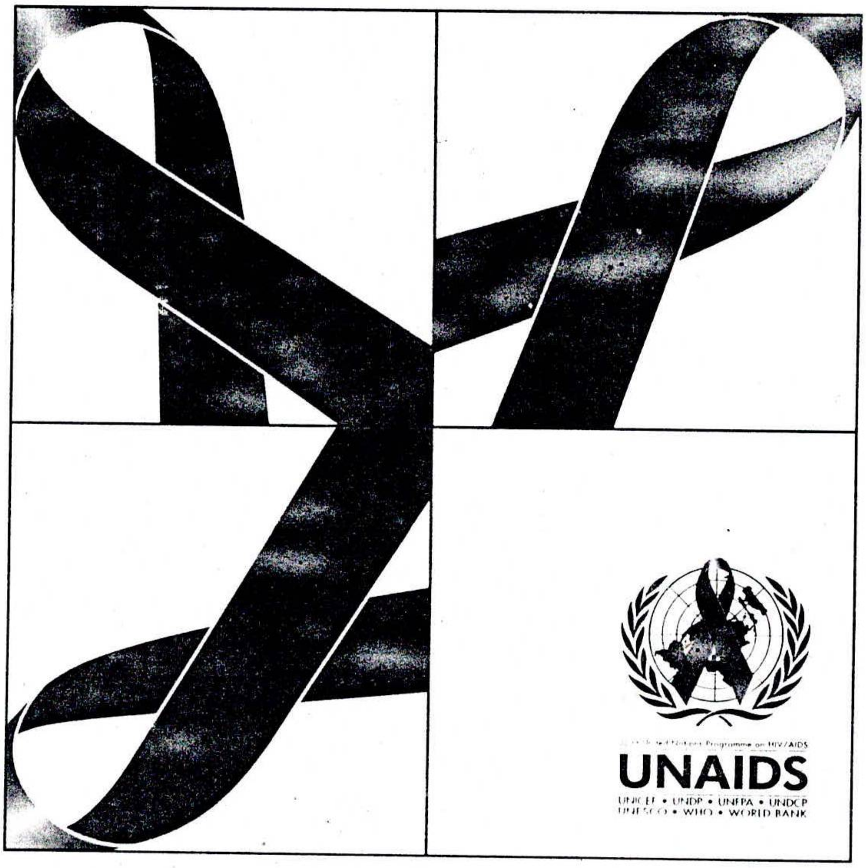
There may be situations, however, where developing countries choose to conduct phases I/II and/or III (large-scale trials to assess efficacy) among their populations that are relatively vulnerable to risk and exploitation. For instance, this

could occur where an experimental HIV vaccine is directed primarily towards a viral strain that does not exist in the sponsor country but does exist in the potential host country. Conducting phase I/II trials in the country where the strain exists may be the only way to determine whether safety and immunogenicity are acceptable in that particular population, prior to conducting a phase III trial. A country may also decide that, due to the high level of HIV risk to its population and the gravity of HIV/AIDS already in country, it is willing to test a vaccine concept that is not being tested in another country. Such a decision may result in obvious benefits to the country in question if an effective vaccine is found. It may also provide an important capacity-building experience, if phase I or phase II trials are conducted in a host country prior to a phase III trial being initiated there.

Establishing a vaccine development programme that entails the conduct of some, most, or all of its clinical trial components in a country or community that is relatively vulnerable to harm or exploitation is ethically justified if :

- the vaccine is anticipated to be effective against a strain of HIV that is an important public health problem in the country
- the country and the community either have, or with assistance can develop or be provided with, adequate scientific and ethical capability and administrative and health infrastructure for the successful conduct of the proposed research
- community members, policy makers, ethicists and investigators in the country have determined that

Voluntary Counselling and Testing (VCT)



UNAIDS
Technical update

May 2000

UNAIDS Best Practice Collection

At a Glance

HIV voluntary counselling and testing (VCT) has been shown to have a role in both HIV prevention and, for people with HIV infection, as an entry point to care. VCT provides people with an opportunity to learn and accept their HIV serostatus in a confidential environment with counselling and referral for ongoing emotional support and medical care. People who have been tested seropositive can benefit from earlier appropriate medical care and interventions to treat and/or prevent HIV-associated illnesses. Pregnant women who are aware of their seropositive status can prevent transmission to their infants. Knowledge of HIV serostatus can also help people to make decisions to protect themselves and their sexual partners from infection. A recent study has indicated that VCT may be a relatively cost-effective intervention in preventing HIV transmission.

There are several challenges related to the establishment and expansion of VCT services:

- **Limited access to VCT.** Many of the countries most severely affected by HIV are also among the poorest countries. Establishing VCT services is often not seen as a priority because of cost, lack of laboratory and medical infrastructure and lack of trained staff. This has resulted in VCT being unavailable to most people in high-prevalence countries. It is important to document the benefits of VCT in order to promote and expand access to it.
- **Improving the effectiveness of VCT.** Innovative ways can be developed to reduce the costs of VCT by using cheaper and more efficient HIV testing methods and strategies. Improving Information, Education and Communication (IEC) to advocate the benefits of VCT and raising community awareness may lessen the time required for pre-test counselling. Integrating VCT into other health and social services may also improve access and effectiveness and reduce cost. Social financing of VCT services has also been shown to be an effective approach in some settings.
- **Overcoming barriers to testing.** In some countries where VCT services have been established there has also been a reluctance of people to attend for testing. This may be because of denial and of the stigma and discrimination that people who test seropositive may face, and the lack of perceived benefits of testing. To overcome the barriers to establishing VCT services it is important to demonstrate its effectiveness and to challenge stigma and discrimination so that people are no longer reluctant to be tested. The role of VCT as a part of comprehensive health care, with links to and from other essential health care services (such as tuberculosis services and antenatal care), must be acknowledged. The structure of VCT services should be flexible and reflect an understanding of the needs of the communities they serve. Services should be easily accessible and closely linked with community organizations that can provide care and support resources beyond those offered by VCT services alone.
- **Publicizing the benefits of VCT.** Until recently, there was a paucity of data indicating that VCT may be important in changing sexual behaviour and a cost effective intervention in reducing HIV transmission. However, there are now studies available showing that VCT is a cost-effective intervention in preventing HIV transmission and that VCT gives seropositive people earlier access to medical care, preventive therapies and the opportunity to prevent mother-to-child transmission of HIV.
- **Understanding the needs of specific client groups.** VCT services should be developed to provide services for vulnerable or hard-to-reach groups. Community participation and involvement of people living with HIV is essential if these services are to be acceptable and relevant.

UNAIDS Best Practice materials

The Joint United Nations Programme on HIV/AIDS (UNAIDS) publishes materials on subjects of relevance to HIV infection and AIDS, the causes and consequences of the epidemic, and best practices in AIDS prevention, care and support. A *Best Practice* Collection on any one subject typically includes a short publication for journalists and community leaders (Point of View); a technical summary of the issues, challenges and solutions (Technical Update); case studies from around the world (*Best Practice* Case Studies); a set of presentation graphics; and a listing of Key Materials (reports, articles, books, audiovisuals, etc.) on the subject. These documents are updated as necessary.

Technical Updates and Points of View are published in English, French, Russian and Spanish. Single copies of Best Practice materials are available free from UNAIDS Information Centres. To find the closest one, visit the UNAIDS website (http://www.unaids.org), contact UNAIDS by email (unaids@unaids.org) or telephone (+41 22 791 4651), or write to the UNAIDS Information Centre, 20 Avenue Appia, 1211Geneva 27, Switzerland.

Voluntary Counselling and Testing (VCT). UNAIDS Technical update.
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1. Voluntary workers
2. Counselling
3. AIDS serodiagnosis

UNAIDS, Geneva WC 503.6

Background

What is VCT?

Voluntary HIV counselling and testing (VCT) is the process by which an individual undergoes counselling enabling him or her to make an informed choice about being tested for HIV. This decision must be entirely the choice of the individual and he or she must be assured that the process will be confidential.

UNAIDS policy statement on VCT[1]

VCT has a vital role to play within a comprehensive range of measures for HIV/AIDS prevention and support, and should be encouraged. The potential benefits of testing and counselling for the individual include improved health status through good nutritional advice and earlier access to care and treatment/prevention for HIV-related illness; emotional support; better ability to cope with HIV-related anxiety; awareness of safer options for reproduction and infant feeding; and motivation to initiate or maintain safer sexual and drug-related behaviours. Other benefits include safer blood donation.

UNAIDS therefore encourages countries to establish national policies along the following lines:

- Make good-quality, voluntary and confidential HIV testing and counselling available and accessible
- Ensure informed consent and confidentiality in clinical care, research, the donation of blood, blood products or organs, and other situations where an individual's identity will be linked to his or her HIV test results.
- Strengthen quality assurance and safeguards on potential abuse before licensing commercial HIV home collection and home self-tests.
- Encourage community involvement in sentinel surveillance and epidemiological surveys.
- Discourage mandatory testing.

Elements of VCT HIV counselling

HIV counselling has been defined as "a confidential dialogue between a person and a care provider aimed at enabling the person to cope with stress and make personal decisions related to HIV/AIDS. The counselling process includes an evaluation of personal risk of HIV transmission and facilitation of preventive behaviour."[2] The objectives of HIV counselling are the prevention of HIV transmission and the emotional support of those who wish to consider HIV testing, both to help them make a decision about whether or not to be tested, and to provide support and facilitated decision-making following testing. With the consent of the client, counselling can be extended to spouses and/ or other sexual partners and other supportive family members or trusted friends where appropriate. Counsellors may come from a variety of backgrounds including health care workers, social workers, lay volunteers, people living with HIV, members of the community such as a teachers, village elders, or religious workers/leaders.

HIV counselling can be carried out anywhere that provides an environment that ensures confidentiality and allows for private discussion of sexual matters and personal worries. Counselling must be flexible and focused on the individual client's specific needs and situation.

In some settings HIV counselling is available without testing. This may help promote changes in sexual risk behaviour. In one rural area, community-based counselling significantly increased rates of condom use among adults.[3]

Voluntary testing

HIV testing may have far-reaching implications and consequences for the person being tested. Although there are important benefits to knowing one's HIV status, HIV is, in many communities, a stigmatizing condition, and this can lead to negative outcomes for some people following testing. Stigma may actively prevent people accessing care, gaining support, and preventing onward transmission. That is why UNAIDS stipulates testing should be voluntary, and VCT should take place in collaboration with stigma-reducing activities.

Confidentiality

Many people are afraid to seek HIV services because they fear stigma and discrimination from their families and community. VCT services should therefore always preserve individuals' needs for confidentiality. Trust between the counsellor and client enhances adherence to care, and discussion of HIV prevention. In circumstances where people who test seropositive may face discrimination, violence and abuse it is important that confidentiality be guaranteed. In some circumstances the person

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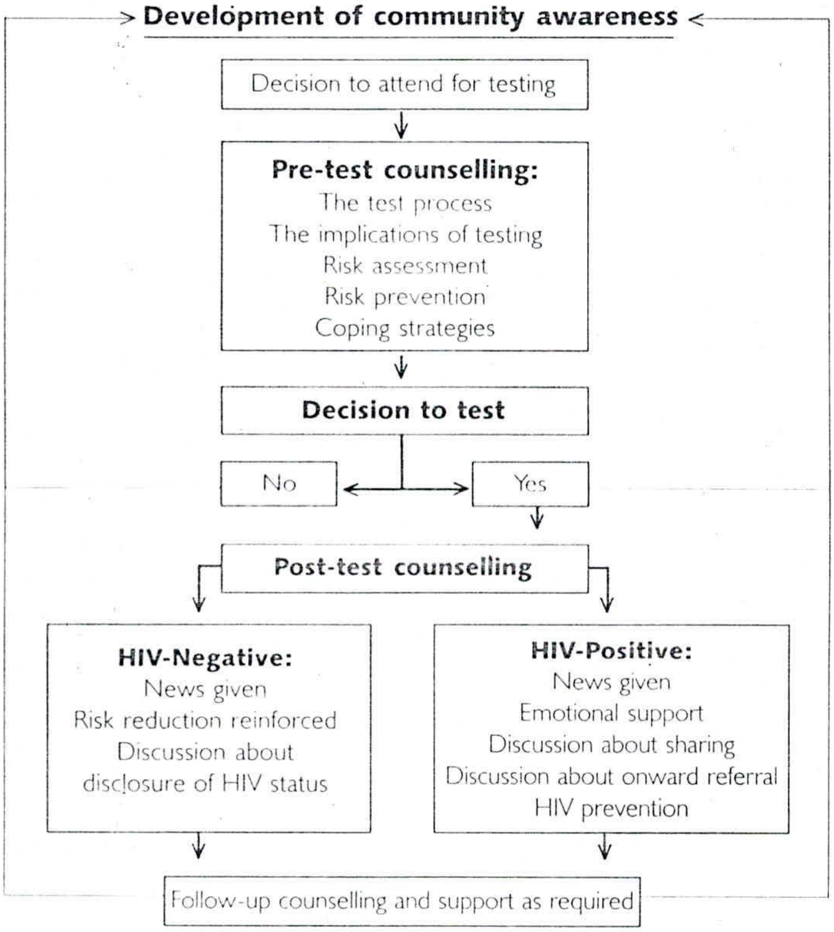
[1] *UNAIDS.* Policy statement on HIV testing and counselling. *Geneva, UNAIDS, 1997 (see for full statement).*

[2] *WHO.* Counselling for HIV/AIDS: A key to caring. For policy makers, planners and implementers of counselling activities. *Geneva, World Health Organization/GPA, 1994.*

[3] *Mugula F et al.* A community-based counselling service as a potential outlet for condom distribution. *Abstract WeD834, 9th International Conference of AIDS and STD in Africa. Kampala, Uganda, 1995.*

requesting VCT will ask for a partner, relative or friend to be present. This shared confidentiality is appropriate and often very beneficial.

Figure 1: Pre-test and Post-test Counselling



The counselling process

The VCT process consists of pre-test, post-test and follow-up counselling. HIV counselling can be adapted to the needs of the client/s and can be for individuals, couples, families and children and should be adapted to the needs and capacities of the settings in which it is to be delivered. The content and approach may vary considerably for men and women and with various groups, such as counselling for young people, men who have sex with men (MSM), injecting drug users (IDUs) or sex workers. Content and approaches may also reflect the context of the intervention, e.g. counselling associated with specific interventions such as tuberculosis preventive therapy (TBPT) and interventions to prevent mother-to-child transmission of HIV (MTCT).

Establishing good rapport and showing respect and understanding will make problem-solving easier in difficult circumstances. The manner in which news of HIV serostatus is given is very important in facilitating adjustment to news of HIV infection.

Counselling as part of VCT ideally involves at least two sessions (pre-test counselling and post-test counselling). More sessions can be offered before or after the test, or during the time the client is waiting for test results.

Pre-test counselling

HIV counselling should be offered before taking an HIV test. Ideally the counsellor prepares the client for the test by explaining what an HIV test is, as well as by correcting myths and misinformation about HIV/AIDS. The counsellor may also discuss the client's personal risk profile, including discussions of sexuality, relationships, possible sex and/or drug-related behaviour that increase risk of infection, and HIV prevention methods. The counsellor discusses the implications of knowing one's serostatus, and ways to cope with that new information. Some of the information about HIV and VCT can be provided to groups. This has been used to reduce costs and can be backed up by providing written material. It is important, however, that everyone requesting VCT has access to individual counselling before being tested.

People who do not want pre-test counselling should not be prevented from taking a voluntary HIV test (for example people who have had VCT may request testing but not wish to have further pre-test counselling). However, informed consent from the person being tested is usually a minimum ethical requirement before an HIV test.

Post-test counselling

Post-test counselling should always be offered. The main goal of this counselling session is to help clients understand their test results and initiate adaptation to their seropositive or negative status.

When the test is seropositive, the counsellor tells the client the result clearly and sensitively, providing emotional support and discussing how he/she will cope. During this session the counsellor must ensure that the person has immediate emotional support from a partner, relative or friend. When the client is ready, the counsellor may offer information on referral services that may help clients accept their HIV status and adopt a positive outlook. Sharing a seropositive result with a partner or trusted family member or friend is often beneficial and some clients may wish someone to be with them and participate in the counselling. Prevention of HIV transmission to uninfected or untested sexual partner/s must also be discussed. Sharing one's HIV status with a sexual partner is important to enable the use of safer sex practices, and should be encouraged. However, it may not always be possible, especially for women who face abuse or abandonment if known to be seropositive.

Counselling is also important when the test result is negative. While the client is likely to feel relief, the counsellor must emphasize several points. Counsellors need to discuss changes in behaviour that can help the client stay HIV-negative, such as safer sex practices including condom use and other methods of risk reduction. The counsellor must also motivate the client to adopt and sustain new, safer practices and provide encouragement for these behaviour changes. This may mean referring the client to ongoing counselling, support groups or specialized care services.

During the "window period" (approximately 4-6 weeks immediately after a person is infected), antibodies to HIV are not always detectable. Thus, a negative result received during this time may not mean the client is definitely uninfected, and the client should consider taking the test again in 1-3 months.

Counselling, care, and support after VCT

VCT services should offer the opportunity for continued counselling to people whether they are seropositive or seronegative. For seropositive people, counselling should be available as an integral part of ongoing care and support services. Counselling, care, and support should also be offered to people who may not be infected, but whom HIV affects, such as the family and friends of those living with HIV.[4]

HIV testing

The diagnosis of HIV has traditionally been made by detecting antibodies against HIV. There has been a rapid evolution in diagnostic technology since the first HIV antibody tests became commercially available in 1985. Today a wide range of different HIV antibody tests are available, including ELISA tests based on different principles, and many newer simple and rapid HIV tests.[5] Most tests detect antibodies to HIV in serum or plasma, but tests are also available that use whole blood, dried bloodspots, saliva and urine.[6]

VCT as an entry point to prevention and care

VCT is an important entry-point to both HIV prevention and HIV-related care. People who test seropositive can have early access to a wide range of services including medical care, ongoing emotional support and social support. People who test seronegative can have counselling, guidance and support to help them remain negative.

Entry point to medical care

Health care services may refer people, particularly those with symptomatic disease, to VCT, to aid with further management. Collaboration and cross-referral can ensure that people with HIV receive appropriate medical care, including home care and supportive and palliative care. There are benefits of other health care services, such as tuberculosis services, working in close collaboration with VCT services. People attending VCT can be screened for clinical TB and treated appropriately, or offered TBPT if TB screening is negative, and TB services can refer people to VCT. This may be particularly important in countries where dual infection is common, with up to 70% of people with TB also having HIV infection, and TB being a major cause of morbidity and mortality in people with HIV.[7] Prevention or early treatment of TB in people with HIV can be a cheap and effective intervention.

Entry point for preventing mother-to-child transmission of HIV infection (PMTCT) interventions

Increasing numbers of countries are now offering interventions to PMTCT. VCT is offered within the antenatal setting or close links are formed with VCT services. It is important that women receiving VCT in this setting have adequate time to discuss their

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[4] WHO. Source Book for HIV/AIDS Counselling Training. *Geneva, WHO/GPA, 1994.*

[5] WHO. *The importance of simple and rapid tests in HIV diagnostics: WHO recommendations,* Weekly Epidemiological Record *73 (42):321-328, October 1998.*

[6] *UNAIDS.* HIV testing methods: UNAIDS Technical Update. *Geneva, UNAIDS, November 1997.*

[7] *Elliott A et al. The impact of HIV on tuberculosis in Zambia: a cross sectional study.* British Medical Journal, *1990, 301: 412-415.*

own needs and not just those concerned with PMTCT, and that there are links with services which can provide ongoing support and care for women with HIV.

When counselling women in the antenatal setting for PMTCT interventions, special consideration should be given to:

- counselling about infant feeding options
- counselling about all available PMTCT options
- family planning counselling
- for seropositive women, referral for ongoing medical and emotional support
- for negative women, counselling about prevention of HIV infection during pregnancy and breast-feeding
- counselling on the advantages and disadvantages of disclosure, particularly to her partner
- involving the partner in counselling and decision-making

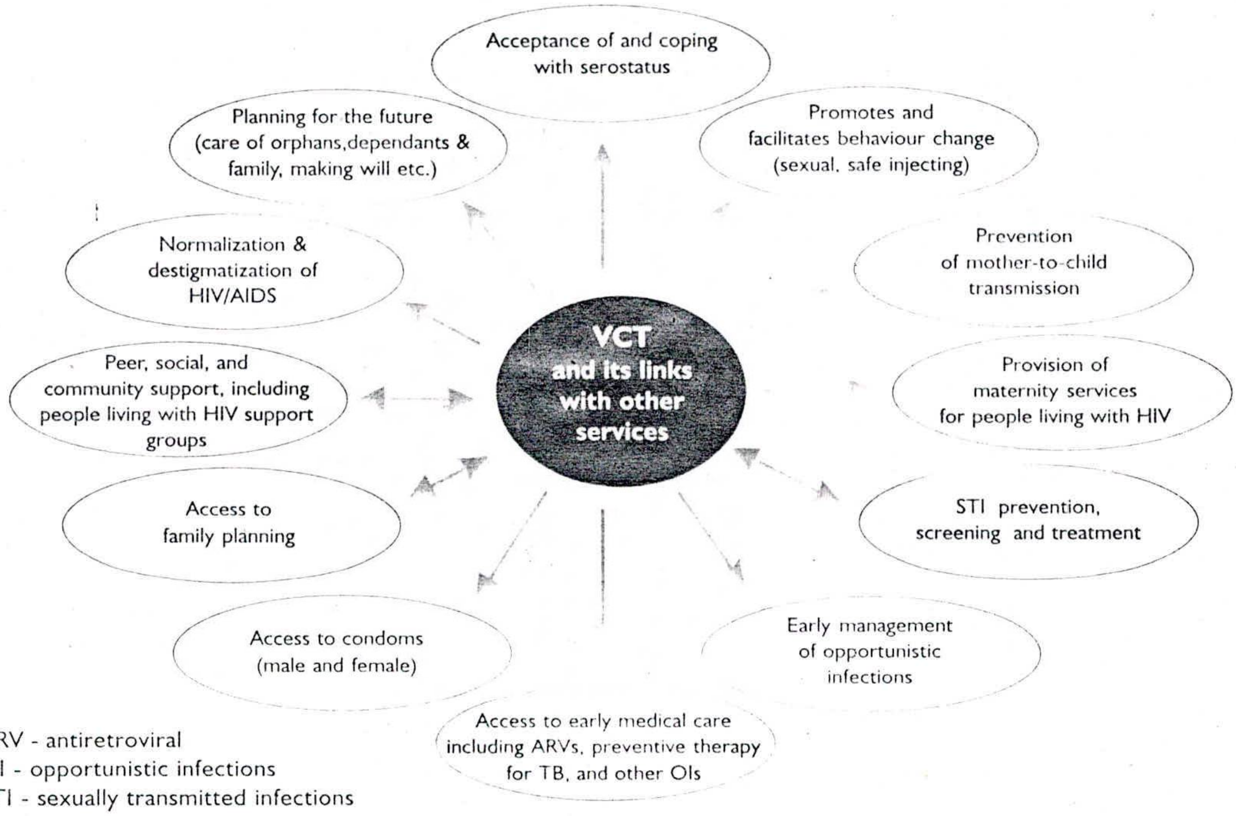
Entry point for ongoing emotional and spiritual care

Although the immediate emotional needs of people following VCT may be met by the counselling service some people will require longer-term support and care. Counsellors will need to be aware of all services available for people following testing. These may include spiritual services, traditional medical practitioners and support groups for people living with HIV.

Entry point for social support

One of the benefits of VCT is that it can help people with HIV to make plans for their future and the future of their dependants. HIV counsellors should be knowledgeable about legal and social services available to help people with these decisions. Material and financial support is sometimes requested, and counsellors need to be aware of any available services, although these are often limited in developing countries.

Figure 2: VCT as an entry point for prevention and care



ARV - antiretroviral
OI - opportunistic infections
STI - sexually transmitted infections

Limited access to VCT

VCT has not been seen as a priority in HIV care and prevention programmes in many developing countries and has therefore often not been widely available. Reasons for this include:

- complexity of the intervention
- the relatively high costs of its various components
- the lack of evidence of its effectiveness in reducing HIV transmission
- the lack of evidence of its cost-effectiveness as measured by number of cases of HIV averted

It is sometimes difficult to measure the impact of counselling on behaviour change. It is understandable that VCT will often not have an easily measurable effect, because of the complexity of sexual behaviour and relationships, and factors which affect these, such as gender inequalities, and lack of empowerment of women in many high-prevalence settings. In countries where resources are very limited VCT services may, therefore, not obtain priority in government planning, and counselling may not receive the official approval, resources, and support it needs to be implemented effectively. Decision-makers may also question the benefit of providing counselling and testing services in places where clinical care options are limited.

Improving effectiveness of VCT

Even where VCT is considered important, its widespread implementation is often limited by lack of funding, infrastructure, trained and designated staff, clear policies on staffing and service sustainability. Counsellors often have other roles within a health care system – such as nursing or social work – which reduce the time available for counselling as a part of HIV testing. Without adequate staffing levels and policies guaranteeing counselling as a priority, pre-test and post-test counselling are often not delivered at all, or are done so hurriedly that clients are not given the time and attention they need.

Inadequate preparation of the settings in which VCT services are offered may also be a problem. This may result in insufficient privacy during counselling sessions, inconvenient opening times or difficult physical access. Clients may feel intimidated by reception staff or have fears regarding the confidentiality of their test results.

Burnout – emotional exhaustion that results when a counsellor has reached his or her limit to deal with HIV and its related emotional stress – may result in rapid turnover of counsellors. This is especially true in high-prevalence areas, where the "breaking of bad news" may occur several times a day. Effective VCT services must find ways to ensure ongoing support and supervision of counsellors and help them to cope with burnout and remain motivated.

Overcoming barriers to VCT

Although VCT is becoming increasingly available in developing and middle-income countries, there is still great reluctance for many people to be tested. There are several possible contributing factors that must be addressed if VCT is to have an important role in HIV prevention and care:

Stigma HIV is highly stigmatized in many countries and people with HIV may experience social rejection and discrimination.[8] In low-prevalence countries, or places where HIV is seen as a problem of marginalized groups, rejection by families or communities may be a common reaction. This fear of rejection or stigma is a common reason for declining testing.

Gender inequalities The need for protection and support of vulnerable women who test seropositive must be considered when developing VCT services. In Zambia, women said that it was thought to be shameful to have HIV and if they were known to be seropositive, they worried that they would suffer discrimination. Studies from Kenya have also shown that women may be particularly vulnerable following VCT and in some cases have lost their homes and children or have been beaten or abused by their husbands/partners if their status became known.[9]

Discrimination In some countries people with HIV are subject to discrimination at work or in education. Unless legislation is in place to prevent this some people will be reluctant to undergo VCT.

Publicizing benefits of VCT

Even in areas where VCT services are available, uptake of services is often poor. A common barrier to VCT is the lack of perceived benefit.[10] If VCT is linked with medical care, and effort is made

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[8] *Karim Q., Karim S., Soldan K., Zondi M.* (1995) Reducing the stigma of HIV infection among South African sex workers: socioeconomic and gender barriers. American Journal of Public Health 85 *(11): 1521-5*

[9] *Temmerman M et al. The right not to know HIV-test results.* Lancet, *1994, 345:696-697.*

[10] *Baggaley R, et al.* Barriers to HIV counselling and testing (VCT) in Chawama, *1995, Lusaka, Zambia, 9th International* Conference on *AIDS and STDs in Africa, December 1995.*

to improve medical services for people with HIV, this will help to reduce this barrier to testing. Offering interventions to prevent MTCT can also be recognized as a major benefit of VCT.

Understanding the needs of specific client groups

The HIV epidemic does not affect all sectors of society equally, or in the same way within countries or cities. Some groups are particularly vulnerable to HIV for a variety of reasons including age, profession or specific risk behaviours. For example in the former Soviet Union HIV is largely a problem among IDUs and the HIV prevalence in the general population is low. It may therefore be appropriate to provide specific resources for VCT for IDUs rather than provide a comprehensive service for the general population. VCT services which are acceptable to one group – for example, to men who purchase the services of commercial sex workers – may not be acceptable for other groups, such as the sex workers themselves. Rapid assessment techniques for analysing potential client needs in a given area may exist, and are relatively inexpensive and simple to carry out. However, there may not be adequate and locally available management expertise for creating effective services in response to the findings of an assessment.

Expanding access to VCT

For VCT services to be promoted and developed it is important to document their usefulness in:

Reducing HIV transmission

Improving access to medical and social care

Facilitating MTCT interventions

Improving coping for people with HIV

Several studies have demonstrated that VCT can prevent HIV transmission among serodiscordant couples. There have also been some studies showing significant behaviour change in individuals following VCT. A recent multi-site study conducted in Kenya, United Republic of Tanzania and Trinidad has provided data on the role of VCT in HIV prevention and its cost-effectiveness compared with other HIV prevention interventions.[11] This study demonstrated that VCT significantly reduced sexual risk behaviour – specifically, unprotected sex with non-primary partners, with commercial sex workers, and among couples who have been tested and counselled together. Furthermore VCT did not increase the occurrence of negative effects such as stigmatization or disintegration of relationships. The study also showed that VCT could be cost-effective in terms of the cost per HIV infection averted. The cost per client for VCT was $29 in the United Republic of Tanzania and $27 in Kenya, and was more cost-effective when targeted to HIV-positive persons, couples, and women.

There are several examples where VCT has been shown to help people access appropriate medical and social services.[12] In industrialized countries VCT enables people to access antiretrovirals (ARVs) earlier and therefore decrease HIV-associated morbidity. In developing countries PLHA can have access to TBPT and targeted health care.

If pregnant women are to have access to interventions to prevent MTCT it is important that they know and understand their HIV status. VCT associated with MTCT interventions has been shown to be acceptable in some settings.[13] However, barriers to VCT services in antenatal clinics exist where associated ongoing care and support are not available for pregnant women.

Reducing the costs of VCT

The cost of HIV testing has been reduced significantly over the past decade, as cheaper testing methods are manufactured. Simple/rapid testing enables testing to be carried out without laboratory facilities and equipment or highly trained personnel. These factors could enable HIV testing to be made more widely available and can be suitable for rural areas and sites outside capital cities.

Innovative approaches can be devised to help make the counselling component of VCT less labour-intensive. Group education prior to pre-test counselling can shorten the length of time required for one-to-one counselling, and hence reduce costs. Sometimes counselling can be carried out by trained volunteers or lay people and this may also reduce costs. However, if volunteers or lay counsellors are employed adequate training, supervision and support must be ensured, otherwise counsellors may leave and burnout

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[11] *Sweat ML et al. Cost-effectiveness of voluntary HIV-1 counselling and testing in reducing sexual transmission of HIV in Nairobi, Kenya and Dar Es Salaam, Tanzania: the voluntary HIV-1 counselling and testing efficacy study. Lancet, 2000, July.*

[12] WHO. TASO Uganda, the inside story: Participatory evaluation of HIV/AIDS counselling, medical and social services, 1993-1994. *Geneva, WHO/Global Programme on AIDS, 1995.*

[13] *Bhat G et al.* Same day HIV voluntary counselling and testing improves overall acceptability among prenatal women in Zambia, 1998. *Abstract no. 33283, XII international Conference on HIV/AIDS, Geneva, Switzerland.*

will be common.

Integrating VCT services into other existing health and social services may also help to reduce costs and make services available to a wider range of people.

Cost sharing has been used in some countries to help provide a more sustainable service. In Uganda, where the AIDS information centre provides VCT, clients are expected to pay a share of the costs. One day a week is set aside for free testing, to enable people who are unable to pay to still have access to VCT. When this was introduced it did not lead to a decline in testing.

Social marketing of VCT has also been proposed as a way of increasing access to sustainable VCT services and has been successfully implemented in Zimbabwe.

Challenging stigma and improving education and awareness

In countries where stigma and discrimination have been challenged with political and financial commitment, VCT has been an important component of the process. However, in many communities HIV remains a stigmatizing problem and VCT is not recognized as being an important part of HIV prevention and care. Societal attitude towards HIV can have a strong impact on individual choices, and if people known to have HIV face discrimination and stigma, VCT is unlikely to be a popular intervention. Stigma and discrimination must be challenged by government and in communities.

Greater involvement of people living with HIV/AIDS in developing and promoting VCT and providing education and awareness about its benefits can be important in providing a more relevant service.

Legislation to protect the rights of people living with HIV in employment and education and to prevent discrimination, need to be in place if people are to feel comfortable and secure about seeking VCT. Mandatory testing should also be discouraged.

Although there are public health benefits of partner notification, making this a compulsory component of VCT has not been shown to be helpful, and may lead to discrimination of the infected partner.

Promotion of the benefits of VCT

The benefits of VCT are often not widely known and understood. Promotion of the advantages of VCT should be an integral part of HIV education programmes and included in IEC materials.

VCT without associated support and care services has been shown to be unpopular in many settings. An explicit policy of care and support for people following VCT should be developed in conjunction with VCT.

If VCT services are to be effective, some important considerations include:

- The location and opening hours of the service should reflect the needs of the particular community. VCT has been carried out in STI clinics, hospital outpatient departments and hospital wards, but also in centres specially dedicated to HIV counselling.[14] VCT services for sex workers, as well as condom supplies, are sometimes offered in the vicinity of nightclubs, and operate at night.[15]
- Counselling sessions need to be monitored to ensure that they are of high quality and that informed consent is always sought and counselling offered before a client takes an HIV test.
- Counselling should be integrated into other services, including STI, antenatal and family planning clinics. Community-based counselling services should be initiated and expanded.
- A referral system should be developed in consultation with NGOs, community-based organizations, hospital directors and other service managers, as well as with networks of people living with HIV and AIDS. Regular meetings among service providers should be held to review and improve the referral system.
- Counsellors need adequate training and ongoing support and supervision to ensure that they give good-quality counselling and can cope with their stresses and avoid burnout. Development of tools for monitoring the quality and content of counselling and counsellor needs would be useful.

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14 *Sittitrai W and Williams G.* Candles of Hope: The AIDS Programme of the Thai Red Cross Society, London, *TALC (Strategies for Hope No. 9), 1994.*

15 *Laga M., et al. Condom promotion, sexually transmitted disease treatment and declining incidence of HIV-1 infection in female Zairian sex workers Lancet, 1994, 344(8917):246-8.*

If VCT services are to be effective, some important considerations include: (con't.)

- Innovative ways of scaling up VCT services and making them more accessible and available should be explored. Interventions to prevent MTCT have provided an important impetus to make VCT more widely available for women and their partners. Pre-test group information can reduce the costs and staff needed for VCT, but individual or couple counselling should also be available.
- New testing methods such as simple/rapid testing will make VCT more available, especially in rural areas and where laboratory facilities do not exist. Quality control, basic training and supply systems need to be organized to ensure that these services are delivered safely and appropriately.
- Home testing and self-testing are likely to be more commonly used. This will provide greater access to VCT for people who are reluctant to attend formal VCT services. However, it is important that adequate information about and provision of follow-up support services are available.
- Linkages to crisis support, follow-up counselling and care for those testing seropositive, and strategies to enable people who test seronegative to stay negative, should be developed.

Development of VCT for specific groups

When VCT services are being developed consideration should be given to the different needs of the people attending and the communities for which the VCT services are designed.

VCT for prevention of mother-to-child transmission

Counselling and testing can benefit women who are or who want to become pregnant. Ideally, women should have access to VCT before they become pregnant so that they can make informed decisions about pregnancy and family planning. For women who test seropositive, counselling can help them decide whether or not to have children, and help explore family planning options. For women who are already pregnant and who test seropositive, counsellors can help them make decisions about terminating their pregnancy if abortion is a safe, legal and acceptable option. For women who choose to continue with their pregnancy, counsellors can discuss the use of interventions, such as short-course zidovudine (ZDV, also known as AZT), to reduce the risk of transmitting HIV to the unborn child, if this is available. Infant feeding choices can also be discussed.[16] Where possible, and when the woman agrees, partners should be involved in counselling sessions in which decisions about their present and future children are being discussed and made.

Counselling services for women should not be confined to those associated with MTCT interventions. Services should reflect the multiple roles and responsibilities of women and embrace a comprehensive approach to meet the health needs of seropositive women.

VCT for couples

Counselling and testing can be provided to couples who wish to attend sessions together before and after testing. This has been shown to be a successful approach in some countries.[17,18] During pre-test counselling couples can discuss what they propose to do depending on their test results and thus help prepare the couple for their results. Post-test counselling helps the couple understand their HIV test results. If a couple has serodiscordant test results this can pose difficult challenges in the relationship. Counselling can help the couple overcome feelings of anger or resentment (which in some cases can lead to violence, particularly against women). Counselling is important to help couples accept safer sex practices to prevent transmission to the uninfected partner.

Couple counselling for HIV can also be provided as part of pre-marital counselling, and can continue after the testing is completed.

VCT for children

In many countries, HIV increasingly affects children. Children may themselves be

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[16] UNAIDS. Mother-to-child transmission of HIV/AIDS: UNAIDS Technical Update. Geneva, UNAIDS, October 1998.

[17] Allen S et al. Confidential HIV testing and condom promotion in Africa. JAMA, 1992, 8:3338-3343.

[18] Allen S, Serufilira A, Gruber V Pregnancy and contraceptive use among urban Rwandan women after HIV counselling and testing. American Journal of Public Health, 1993, 83:705-10.

infected, or they may be part of a family in which one or both of the parents are either infected or have died of AIDS.

When children have clinical signs suggestive of possible HIV infection, VCT can provide a confirmatory diagnosis. The counselling sessions may include both the parents and the child. HIV-positive children have special counselling needs such as understanding and coping with their own illness, dealing with discrimination by other children or adults, and coping with the illness and deaths of other HIV-infected family members. HIV-negative children who are affected by HIV through the illness of a parent or sibling also have special counselling needs, such as coping with the emotional trauma of seeing their loved ones ill or dying and dealing with social stigma related to HIV. Older children may need counselling related to developmental issues (such as sexuality and the avoidance of risk behaviours) or coping with and healing from childhood sexual abuse that has put them at risk for HIV infection. In all cases, counselling provided to children should use age-appropriate educational and counselling methods.

VCT for young people

Teenagers are often particularly vulnerable to HIV infection. For VCT services to be effective for young people they must take into account the emotional and social contexts of young people's lives, such as the strong influence of peer pressure (e.g. to take drugs or alcohol) and development of sexual and social identities. They must also be "user-friendly", offered in non-threatening, safe, easily accessible environments. Counselling should be age-appropriate, using examples of situations that are familiar and relevant to youth, and language that is non-technical and easily understood.

Anonymous VCT services may be preferable for some young people. However, different countries and cultures may have their own legal requirements and social expectations that prevent young people from accessing VCT services without parental consent or notification. Although VCT services must always take into account any relevant laws regarding the rights and autonomy of minors and the responsibilities of parents for their children, they must also remember that the dignity and confidentiality of the young persons must be protected and respected.

VCT for injecting drug users

Services targeting injecting drug users (IDUs) must take into account several factors. Injecting drug use is a practice that is illegal and socially stigmatized in many cultures. Because many drug users have experienced social stigma and unpleasant encounters with the law, they may distrust or fear government-based or hospital-based social services. VCT services that are part of such institutions may, therefore, be unlikely to attract drug-using clients. Examples of more successful VCT programmes for drug users are those coordinated with existing HIV prevention and social service outreach programmes that go to the places that drug users frequent. Often, the outreach workers are former drug users themselves, so they can understand the drug culture's particular social norms and values. Also, because they have already established trust with the drug using community, counselling and prevention messages delivered by such outreach workers are often perceived as being more credible. Such outreach workers, when trained as HIV counsellors, can explain HIV testing and the importance of knowing one's status in terms with which the drug users are familiar and which they can accept.

While HIV counsellors should discuss risk reduction with their clients at both pre- and post-test, they should also understand that IDUs may not be willing or able to change certain behaviours, such as their drug use or having unprotected sex. In these cases, HIV counsellors should discuss safer methods of practising these behaviours – such as not sharing needles or sterilizing needles and syringes before sharing – in order to prevent the clients from becoming infected or spreading their HIV infection to others.

Counselling for sex workers

VCT for commercial sex workers need to be sensitive to the problems of stigma and illegality associated with commercial sex in many societies. Sex work is usually the client's livelihood and thus stopping some or all risk behaviours may reduce the sex worker's ability to earn a living. Furthermore, sex workers may be under considerable pressure to perform especially risky activities (e.g. sex without a condom), either through financial inducement or coercion by a pimp or client. Counsellors must understand these issues, and help the sex worker find ways to work around or reduce the obstacles they face when trying to reduce their risk. In some cases, counsellors may want to work closely with community organizations that empower and support sex workers' desire to keep themselves healthy and safe.

Selected Key Materials

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