Partners in prevention:

*International case studies
of effective health promotion
practice in HIV/AIDS*

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Acknowledgments

Edited and Compiled by:

Anne Malcolm and Gary Dowsett

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Editors

Ms Anne Malcolm
Anne Malcolm Consulting
56 Annesley Street
Leichhardt NSW 2040
Australia

Associate Professor Gary Dowsett
Deputy Director
Centre for the Study of Sexually
Transmissible Diseases
La Trobe University
11–13 Lincoln Square South
Carlton South VIC 3053
Australia

FOREWORD

by Noerine Kaleeba
Community Mobilization Advisor
Department of Policy, Strategy and Research
UNAIDS, Geneva

There is increasing understanding about what works in HIV prevention, but that understanding also comes with the realization that, like all other efforts towards changing human behaviour, HIV prevention programmes may not be effective in influencing behaviour under all circumstances, or for everyone, or forever. What seems to emerge as a consistent feature of HIV prevention programmes that work is the involvement and active participation of community members or community groups.

Community level action, much of it initiated by persons infected with or affected by HIV, has played a major role in the global response to AIDS. In many countries, community response came before official governmental responses and has proved to be essential to many components of a successful national response, most notably raising awareness, assisting with risk assessment, and supporting policy and legal changes,

impact alleviation, advocacy, as well as family and community care and support. Communities, however, are not closed, self-sustaining systems; the ability of a community, no matter how well organized and motivated, is limited. It is not surprising, therefore, that in those countries where there has been successful partnerships between official government and community efforts, HIV prevention programmes have worked to a large extent.

Although we must continue to gather information, test and refine our understanding of what works, UNAIDS believes that the timely sharing of information on what seems to be working well is essential. The publication of the four case studies of Australia, Canada, Thailand and Uganda, which were presented at an official satellite symposium of the XIth International Conference on AIDS in Vancouver in 1996, is one first step by UNAIDS in this direction.

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THE CONTEXTS OF COMMUNITY MOBILIZATION AND HIV/AIDS PREVENTION

by Anne Malcolm and Gary Dowsett

The continuing spread of HIV throughout the world highlights the urgent need to document those approaches that have contributed most in reducing the spread of HIV and in enhancing the capacity of communities to respond effectively. This report records the efforts and experiences of four countries, two developing countries, Uganda and Thailand, and two developed countries, Australia and Canada, in mobilizing their communities to respond to the HIV epidemic in partnership with their governments. Their success in establishing effective prevention programs is attributed to the relationship between communities most affected and the governments, which have sustained these efforts through funding, policy direction and strategic support. The ability to mobilize affected communities and engage government commitment is central to ensuring an effective response to the HIV epidemic.

Community Mobilization

Community mobilization has been defined as community members becoming aware of a problem, sharing the concern and deciding together to take action towards a common solution to derive shared benefits (UNAIDS 1996). This concept has been used widely to promote increased involvement and participation of people within communities to make decisions that will impact on themselves and their environment, and which can often result in catalyzing other people from within and outside of those communities to become involved. It is also a key element of expanding the response to HIV/AIDS where greater emphasis is placed on understanding the societal and individual factors influencing the epidemic, and the development of an enhanced response through the mobilization of human, material and financial resources. Expanding the response calls for social change as a more effective way of reducing risk and vulnerability to HIV (UNAIDS 1996).

Communities are diverse groupings of people with different beliefs and practices. Within these groupings, however, there are common interests and understandings that bring people together and unite them around a common purpose. Broadly, 'community' is defined as a group of people with something in common, whether they live together, come from the same area (village or town), gender or ethnic background. Communities are also people who work together (e.g. sex workers, truck drivers, factory workers), or who share common behaviour such as injecting drug users, or who share a common identity as in gay communities. They may also be a group of people who are connected by the same health concerns related to HIV/AIDS, e.g. people with haemophilia living with HIV/AIDS (UNAIDS 1996).

Community mobilization in response to AIDS is occurring in many countries and has been shown to be an effective way to change attitudes and behaviour within communities, to provide care and treatment to community members, and to design and implement prevention programmes that have a lasting impact. This has occurred where groups or communities have shared specific concerns and come together to take action. These groups may be from differing backgrounds and from a range of geographical areas, but who have a common interest and desire to become

involved in doing something. For example, Positively Women in the United Kingdom, WAMATA in Tanzania, or Gay Men's Health Crisis in New York are organizations that were established through people getting together to do something about HIV/AIDS. Their experiences of community mobilization and lessons learned in their development of prevention programmes highlight some of the key elements of these processes.

First, participation can increase the likelihood of action through community members becoming involved in activities. This involvement may be in the development of ideas, designing an approach, or participation in the implementation of community programmes. Another important aspect of community participation is through action research, a form of research that can lead to change through the interaction of community groups in defining and identifying key areas for behaviour change.

Second, within communities there are already existing resources that can be used to design and develop programmes. These resources are skills, knowledge and information that when utilized within their communities can provide a more relevant and effective response. Resources include local organizations and groups that play a key role in mobilizing change, along with political and religious leaders, and research institutions (Reid 1994).

Third, the involvement of people most affected by HIV/AIDS, including those who are infected, can add significant impetus to change as the community rallies to provide support. Although the stimulus for change, however, may come initially from within an affected community, it can often lead to the development of much wider responses beyond the community, including political and governmental support.

* * *

Community mobilization is presented as a central approach in these four case studies. These studies were initially presented at the symposium HIV Prevention Works, an official satellite symposium of the XI International Conference on AIDS, held in Vancouver, Canada, in July 1996. This symposium was organized by an international steering group supported by the Canadian Public Health Association, Health Canada, the United States Centers for Disease Control and Prevention and National Institutes of Health, and the Joint United Nations Programme on HIV/AIDS. Its purpose was to highlight international practices and models of successful HIV/AIDS prevention programmes and policies, and to share the knowledge and experiences about those programmes and policies. The four country case studies were presented in the session 'Working with Communities' and illustrated how multisectoral approaches involving communities can lead to successful prevention.

At this symposium the key elements of successful prevention efforts were identified as the following (Canadian Public Health Association 1996):

> ***the common theme of this symposium was the importance of breaking through to the political will, without which prevention strategies will only have a limited impact Justice Michael Kirby, Summation Speech***

Create political will

Political leadership and action is clearly needed to set the direction for a national response and initiate the development of policies that provide the overall strategy to manage the epidemic. In many countries a lack of political will has delayed a coherent response to dealing with the epidemic in a number of areas, including at governmental levels. This has often occurred through a lack of recognition of the significance of the potential impact of the epidemic,

through denial of much-needed resources to develop effective programmes to fuelling fear and stigma associated with the disease through a lack of policies that address discriminatory practices.

A number of countries have established a strategic approach at the national level by the funding of specific programmes, the development of national policies, and setting the direction and mechanisms for coordination of a range of government, community and private sector programmes, including biomedical and social research.

The establishment of a high level political response towards HIV/AIDS provides leadership and direction to other sectors of the community and in many situations a commitment to funding specific programmes. Where this leadership has occurred and national policies and programmes have been established, there is a greater level of acceptance and tolerance of people with HIV/AIDS often develops. This leads to a more effective response towards prevention and care programmes targeting marginalized people vulnerable to HIV transmission.

> *It is the responsibility of national governments to work in partnership with other key players, including those living with and affected by HIV/AIDS, to assess the epidemic, to assure a coordinated response, to develop policy and promote global planning, to prevent transmission and to mitigate the impact of HIV/AIDS. Statement supported by participants at Satellite Symposium*

Engage the community
Community leadership and participation are essential elements in building a climate where safer behaviours are the norm.
Dr Lair Guerra de Macedo Rodrigues, Brazil

A key aspect of successful prevention efforts has been the involvement and participation of the communities most affected. Often these communities have initiated a local response to an escalating problem within their community and have developed programmes to educate and support those affected and infected. In many countries, these initiatives provided the initial response to the epidemic and in many situations were successful in preventing many more people becoming infected. These responses are difficult to sustain, however, without broader recognition and funding support. Many of these communities used existing organizations, groups and structures for education and support, and through these created networks and alliances were successful in increasing community awareness and developing a high level of responsiveness to new issues as they arose. In many countries, the initiatives of these communities created the stimulus for broader community involvement and a response to the HIV epidemic at the national level.

Build partnership and trust
The responses to the HIV epidemic that have developed in many countries are made more effective by partnerships created between the players. These partnerships take the form of working closely together through mutual alliances, committees and networks to inform, support and provide a coordinated effort in the delivery of programmes. The key elements in these relationships are communication, trust and willingness to work together. Together, these have created more effective and coherent local and national strategies.

An important partnership is that of community organizations and government. This relationship has enabled governments to be more informed of community issues and concerns, and has ensured the involvement of community groups in the development of relevant policy and decision-mak-

ing. The involvement of community representatives at the highest level has also had the impact of increasing community ownership of policies and decisions, resulting in better prevention and care outcomes.

There is an important partnership between research institutions and community organizations, which, in some countries, has provided the opportunities for greater understanding of the social patterns and behavioural aspects of the epidemic and contributed to the development of more appropriate interventions and better procedures in the clinical setting, e.g. in the trialing of new treatments.

Include people with HIV/AIDS at all stages

In many countries, people living with HIV/AIDS (PLWHA) have been reluctant to become involved because of the fear and stigma associated with HIV/AIDS. Where supportive networks have been established and discriminatory practices have been addressed, PLWHAs have been more likely to come forward to be involved in prevention and care programmes. This involvement increases the visibility of those with the disease within the community and can result in greater level of acceptance and support along with a increased response to prevention activities. A key strategy used in many prevention programmes is to involve PLWHAs in the development of campaigns and health promotion material, which ensures that education is relevant for both those infected and those at risk of infection. Along with their involvement in prevention efforts, PLWHAs are increasingly represented on high level decision-making bodies and are participating in the development of programmes and policies at a range of levels.

The participation of individuals infected with HIV and communities affected by the epidemic is critical to an effec-

tive, humane and ethical response. A key aspect of successful HIV prevention is a non-judgmental approach to individuals and communities most affected by HIV/AIDS. Statements supported by participants at Satellite Symposium

Create an accepting community environment

The development of an environment that is open, accepting and non-discriminatory is essential to enable the community to provide support and ensure that those at risk are able to access prevention and care programmes. Many people with HIV/AIDS are not able to be open about their status and are afraid to seek information, treatment and support because of the negative environment in which they live. Similarly, prevention efforts can be curtailed by an environment of hostility and fear, where people at risk of HIV are not able to acknowledge or discuss their behaviour and level of risk.

Use multisectoral approaches

The HIV epidemic has clearly demonstrated an impact on every sector of every community it has touched. This requires a response that involves every sector and in which each of these sectors can assume a level of responsibility to address particular aspects of the epidemic. The development of networks and alliances within and outside of communities and at the national level can involve these sectors in a coordinated response.

Evaluate what you do

It is clear that determining what works and what needs to be changed is an important part of good prevention programmes. Research and evaluation can assist in developing more relevant strategies in prevention and by demonstrating that prevention works ensure the continuing support of government and communities can be more readily sustained.

▬▬▬ Direct resources to community capacity-building

Community capacity-building is a key element in ensuring the sustainability of prevention efforts. Communities cannot maintain their participation and involvement without adequate resources, including building skills in a range of areas such a programme management, planning and design. This is often a longer-term process, whereby those with skills can transfer these to others in order to ensure that continuity is maintained and that programmes are sustainable for the future.

▬▬▬ Recognize that success is not all-encompassing

Success in one area can contribute to successful responses in other areas; however, new responses are generally required for different areas. The maintenance of success requires sustained efforts, and for many communities working in the epidemic for many years this is becoming a major challenge.

* * *

These are the major elements of successful programmes identified at the Vancouver symposium. Since then, the presenters from Australia, Canada, Thailand and Uganda have rewritten their presentations to clarify their community responses. In essence, these reports focus on what might be considered 'good' prevention practice from their experiences. These country reports focus more critically on the role of the *community* and the *partnerships* that have contributed substantively to their successes. In the following sections, these four country case studies will describe their efforts to mobilize communities and build successful efforts to prevent HIV/AIDS. The studies will address the partnership arrangements between community groups, government and research institutions, and look at how these relationships have developed and how they work in practice.

In particular, these case studies will explore the impact of these partnerships on the ability of community groups to develop new initiatives and expand community efforts. Each country will describe their successes and the lessons learned in order to share their knowledge and experiences with others involved in HIV/AIDS prevention.

Finally, the document draws together the commonalities, key issues and ideas from the different experiences and circumstances within each country in order to reflect on those aspects of the response that have contributed profoundly to the successes in prevention of HIV/AIDS.

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EXPERIENCE FROM AUSTRALIA
by Lou McCallum, Executive Director,
Australian Federation of AIDS Organisations, and Don Baxter,
former Executive Director, AIDS Council of New South Wales Sydney, Australia

OVERVIEW AND CONTEXT

HIV epidemiology
It is estimated that there were 11,080 people living with HIV infection in Australia at the end of 1996. HIV incidence is thought to have peaked in 1994 and a slow but steady decrease in incidence is expected over the next few years. The cumulative number of HIV infections in Australia to the end of 1996 was 16,700, and 95% of these are in men. Incidence of HIV is not evenly distributed geographically across Australia, but concentrated in particular States and cities: 63% of people with HIV reside in New South Wales, 18% in Victoria, and 9% in Queensland-in order, the three largest States. There have been 7,532 people diagnosed with AIDS in Australia since the first case was identified in 1982, and 96% of these were men. Of these, 5,373 have died.

The number of new diagnoses of HIV infection is around 500 cases per year, and there are approximately 200 newly acquired HIV infections each year, i.e. infections definitely acquired only in the previous twelve months. Transmission of HIV in Australia continues to be predomi-nantly linked to sexual contact between men. Over 85% of all HIV transmission in Australia is thought to have occurred this way. Needle-sharing during injecting drug use is the second most common mode of transmission, accounting for approximately five new infections per year (National Centre in HIV Epidemiology and Clinical Research 1997).

Key organizations and players
The response to AIDS in Australia has been characterized by a partnership between government, health providers, researchers and affected communities. The national approach has been guided by successive national HIV/AIDS strategies since 1989, based on a set of principles, policy guidelines and activities developed from 1985 onwards. These strategies have set out basic principles, including the non-partisan political approach to HIV/AIDS, the partnership with non-governmental organizations and the affected communities, and the central role of people with HIV/AIDS in the response.

Australia is divided into six States and two Territories. These States and Territories have responsibility for health service provi-

	Government sector	Non-governmental sector
National level	Commonwealth Government Commonwealth Departments (Health & Family Services, Attorney-General, Social Security, Community Services)	Australian Federation of AIDS Organisations (AFAO) National Association of People With HIV/AIDS (NAPWA) Australian IV League (AIVL) Scarlet Alliance (national sex worker organization) Haemophilia Society
State/Territory level	State and Territory governments Hospitals and health services	State and Territory AIDS Councils, PLWHA organizations, sex worker and injecting drug use (IDU) organizations

sion. The federal government allocates funds to the States and Territory governments for HIV/AIDS initiatives under the strategy. Currently, State and Territory governments are committed under the strategy to match these funds dollar for dollar. The range of government and non-governmental organizations involved in Australia's response are listed in the table below.

The federal government funds the peak NGO body, the Australian Federation of AIDS Organisations (AFAO), and State and Territory governments fund State and Territory NGOs. AFAO's role is to advocate at a national level on behalf of NGOs. The other national peak NGOs which are members of AFAO are: Australian IV League (AIVL), a national organization representing the interests of injecting drug users; National Association of People with HIV/AIDS (NAPWA), the peak PLWHA group; and Scarlet Alliance, a national group representing sex workers.

Each State and Territory has an AIDS Council, which is a community-based NGO responsible for HIV education and care and support activities. AIDS Councils were formed by early 1986 by members of the gay communities in each State and Territory capital city with funding from State and Territory governments. The work of the councils is usually divided between education and prevention activities in the gay community and the care and support of PLWHAs. Gradually, PLWHA, sex worker and injecting drug-users' (IDU) community organizations were set up in most States and Territories. Sex worker and IDU organizations focused on education, prevention and advocacy activities among their particular target groups, and PLWHA organizations generally provided information, support and advocacy for PLWHAs. In some States and Territories, representatives from AIDS Councils, PLWHA, sex worker and IDU organizations were invited to participate in State

AIDS policy advisory committees, which coordinated programme and policy development at State level.

In 1987, State and Territory AIDS Councils joined with the national PLWHA, IDU and sex worker organizations to form AFAO, which would be responsible for advocating on behalf of AIDS community organizations at a national level and for facilitating communication between State and Territory community organizations. Since that time, AFAO has participated in successive national AIDS advisory committees and in the establishment and review of the first, second and third national AIDS strategies. AFAO has developed a strong partnership with the Commonwealth Department of Health and with successive Commonwealth Health Ministers.

**History and structure
of the community-based response**
The first case of AIDS was diagnosed in Sydney in 1982. The gay community in Sydney had recently won a long battle for anti-discrimination law reform and had a range of community organizations and structures which were able to be mobilized to respond to HIV/AIDS. Similar organizations were established by this time in other Australian capital cities. As gay men were being diagnosed with HIV infection or AIDS in Sydney and Melbourne hospitals, volunteers from gay organiations were asked to help with emotional and practical support. Gay men and their friends began forming groups to provide home care and emotional and financial support. Existing gay groups such as the Sisters of Perpetual Indulgence (an Order of gay male nuns) obtained safe sex materials for similar organizations in the United States and modified them for Australia. A newly-formed AIDS charity, the Bobby Goldsmith Foundation, also produced a safe sex pamphlet in 1984-the first Australian material of its kind and funded by the gay community.

A group called the AIDS Action Committee was formed in Sydney and eventually became the AIDS Council of New South Wales (ACON) in 1985. At about this time, the Federal Health Minister, Dr Neal Blewett, travelled to San Francisco and was convinced that a collaboration between government and the affected communities in Australia would be essential to dealing with AIDS. A gay charity and a volunteer care and support organization had already been formed in response to increasing numbers of gay men being diagnosed with AIDS. ACON attracted a small grant direct from the Commonwealth Government and began to produce campaign materials targeted at gay men from 1985 onwards. Eventually, the New South Wales State government took over funding of ACON so that it could produce prevention materials, hold safe sex workshops, advocate for policy development and train volunteers to care for people with AIDS at home.

A similar process was under way in Victoria (the State with the second highest HIV and AIDS prevalence) and a community group called the Victorian AIDS Action Committee had been formed. State and Territory governments soon became convinced that funding gay community NGOs was the most likely way to prevent further spread of HIV. At the same time, the already established Australian Prostitutes Collective began to provide condom campaigns for sex workers and brothels.

There were two key factors which led to success of this community response. The first was the commitment by government to mobilize the affected communities and resource them to provide prevention and care. This was based on the assumption that the communities themselves would produce the most appropriate campaigns and would reach people at risk in a way that government could not. It was also assumed that people from marginalized communities would not present for HIV testing unless their communities supported government initiatives and were supported by government.

The second important factor was the experience that the gay community had developed through the law reform process in establishing and maintaining community organizations. Debate and disagreement flourished in the affected communities, but the experience in working together in community organizations meant that decision-making processes were in place and that progress could be made despite the existence of a wide range of views and perspectives.

Several years later, the Commonwealth Government commissioned the development of a national AIDS policy discussion paper in 1988. This paper was developed following consultation with governments, health workers, researchers and NGOs. The paper established the first ideas about the 'partnership' response to AIDS in Australia and set out a policy and funding framework for its establishment (Commonwealth of Australia 1989, 1993, 1996).

CONCEPT OF PREVENTION

Principles of prevention (guidelines and theories used to develop progammes)

A set of fifteen guiding principles for the design, development and implementation of successful education and prevention programmes emerged over the decade 1984–1994 as community organizations responded to the crisis. These principles, set out below, were developed in the wider context of national government that saw the desirability of political leadership and government commitment early in the epidemic. Its key symbolic message to the affected communities was in effect: 'We want you to survive'. This contrasted starkly at the time with the (then) key message of the US Government to its affected communities: 'We don't care if you die'.

While Australian governments recognised the desirability of most education being conducted by affected communities, they set about removing some of the legal and structural barriers inhibiting prevention efforts. These measures included:

■ decriminalizing homosexual sex;

■ removing barriers to condom accessibility and availability;

■ removing criminal sanctions on carrying injecting drug use equipment;

■ adopting 'harm minimization'—rather than 'zero tolerance'—as the underlying principle of prevention programmes;

■ establishing and defending a large-scale needle/syringe availability programme;

■ enacting legislation guaranteeing confidentiality of HIV test results;

■ enacting other antidiscrimination legislation and conducting associated public education campaigns.

Within this wider context, the affected communities were able to focus on developing, testing and implementing the following fifteen principles for the successful implementation of education and prevention programs.

1. Education designed and delivered by peers is likely to be more effective than education developed and delivered by other 'external' agencies—especially in marginalized communities suspicious of government and its operations.

2. Sustained behaviour change on a wide scale is more achievable through a programmatic focus on influencing social and community norms and beliefs, rather than by a focus on changing individual responses.

3. Education programmes should involve the community in discussion and debate about the range and nature of measures it could take to reduce the impact of the epidemic.

4. HIV-positive people should be involved in all phases of programme design, from initial concept through development to content and delivery.

5. Education should be 'sex positive'.

6. Education should be 'sexuality positive'.

7. Language, images and processes used should be those already existing in the community involved or generated by that community.

8. Language and images used should be direct, explicit, understandable and simple.

9. Campaigns should target high-risk behaviours rather than high-risk groups.

10. Resources and information need to be made available to assist communities coping with change.

11. The objective of information programmes is to provide people from affected communities with sufficient information and support to make their own safe decisions rather than providing a prescriptive set of rules.

12. Education programmes should take great care to share equally the responsibility for preventing new infections between those infected, those not infected, and those unaware of their HIV status.

13. Education programmes should be vigorous, continuous and have the capacity to adapt flexibly to changes in the epidemic and to changes within communities.

14. Education programme design should be supported by an active, reflexive social research programme.

15. These principles need to be endorsed and supported by the political and community leadership.

These principles sit very comfortably within the framework of the Ottawa Charter. Interestingly, however, in Australia their genesis in the mid–1980s arose more from the political and social activism of the gay community and sex worker communities responding to a health crisis rather than a considered and systematic application of the Ottawa Charter principles. In retrospect, it is clear a more rigorous analysis and application of the Ottawa Charter principles could have allowed a more systematic and all-encompassing approach in the early stages of the epidemic.

Specific approaches to prevention
AIDS Councils designed campaigns to encourage a 'safe sex culture' (Dowsett 1990) rather than focus on individual behaviour. The ACON 'Outliving, Outloving, Outlasting' campaign in 1988 is a good example of this approach. This campaign was made up of a series of elements, campaign materials such as posters, T-shirts, caps and brochures, accompanied by community workshops on safe sex, community events, outreach to bars, beaches and discos, the launch of a safe sex hit song to be played in discos and the placement of stories about safe sex in the gay press. All of these elements contributed to the development of a community acceptance of condoms and safe sex.

Endorsement of, and involvement in, these campaigns by community opinion-makers, commercial venue-owners and community entertainers—in Sydney this usually means drag artistes—is essential to their success. An early—and long-term—success has been the establishment of a volunteer outreach team, the 'Safe Sex Sluts'. These volunteers, usually wearing attention-getting drag, appear at many gay community events and institutions, dispensing safe sex equipment and advice. This team implicitly manifests many of the principles articulated above. The Sluts use gay community iconography to re-affirm the validity of an active sex life and of gay identity. The team reinforces safe sex behaviour in a non-threatening yet persistent and often imaginatively challenging way, and it is able to penetrate a wide range of community events and meeting-places—from large-scale dance parties to smaller events, commercial entertainment venues and sexual meeting places.

Campaigns carried out by AIDS Councils at this time focused less on HIV testing and more on safe sex for all, irrespective of HIV status. These campaigns promoted the use of condoms 'every time' for sex between men. This was a deliberate strategy to present a simple message in order to increase condom use in gay communities. The test became available in early 1985, and testing policies were developed to promote anonymous testing with tight protections on confidentiality. Pre- and post-testing counselling policies were also put in place. Prevention campaigns were then developed in a context of the availability of free anonymous HIV testing and counselling. Gay men presenting for HIV testing were taught skills in negotiating safe sex with partners in HIV counselling sessions. This often involved striking a 'contract' with their existing primary partner for no condom use within the primary relationship but strict condom use outside the relationship. This was accompanied by a discussion of the skills required to disclose to the primary partner if there had been unsafe sex outside the relationship so as not to put him at risk. This system of negotiation was later described as 'negotiated safety' by social researchers (Kippax *et al.* 1993a).

At the same time, sex worker and injecting drug user groups were emerging and designing campaigns and initiatives to target sex workers and users. Sex worker groups used outreach strategies to visit streets and brothels in order to distribute condoms and water-based lubricant and to

talk with sex workers about AIDS and sexual health. IDU groups designed campaigns to reduce needle-sharing and to promote the availability of clean injecting equipment through mobile and fixed-site needle and syringe exchange services. Needle exchanges, which had been established in most States and Territories by 1988, were initially politically sensitive; however, they represented a significant policy shift towards harm minimization and a recognition of the public health risks associated with injecting drug use. At that time, there was a fear that HIV infection, mostly contained within the gay community, would spread to the 'general community' though the 'bridge' of sex workers and injecting drug users. This strengthened the resolve of governments to support sex worker safety and needle and syringe exchange programs.

Relationship with research institutions
An important collaboration between the AIDS Council of New Wales and the School of Behavioural Sciences at Macquarie University, Sydney, developed early in the epidemic. Researchers and community organization activists worked closely together to develop research questions and to design studies that would provide guidance to both community organizations and government for the design of campaigns and programmes. Various steering committees, comprising researchers, community workers and government bureaucrats, were established and provided a forum for discussion of social research needs. Several important studies emerged from this collaboration and continue to provide essential information to guide campaigns and programs. (Much of this research has been summarized in Dowsett 1994.)

The collaborative approach had several distinct advantages. Research questions were developed in response to the changing context of HIV prevention in the affected communities; researchers could gain access to the subjects they needed for their work; governments accepted the community's recommendations for changes to campaigns and programmes as they were backed up by research findings. This collaborative research model requires a high level of cooperation and trust between researchers and communities. It is a relationship of 'managed tension': communities generally want quick answers so that they can respond to changing circumstances, researchers want rigour so that their research results can be trusted; community processes are inclusive and collaborative, the academic environment is highly competitive and has its own pressures, such as the need for peer review. The early collaboration between Macquarie University and ACON was one factor that eventually led to the establishment of a National Centre for HIV Social Research (now the National Centre in HIV Social Research) which has played an important role in Australia's AIDS response. The Commonwealth Government also funded research through its traditional academic research funding mechanisms, with earmarked funds so as to develop research outside that done in the national centres[1], and a number of independent academic researchers have worked in a number of States and Territories on social and behavioural research projects on behaviour change, prevention education, needs assessment and evaluation. The combined efforts of these independent researchers and the national HIV research centres has provided Australia with a very successful and focused research programme as an integral part of the national AIDS strategy. Research collaboration was greatly assisted by the employment of researchers with HIV and researchers from the affected

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[1] There are three national HIV research centres: National Centre in HIV Virology; National Centre in HIV Social Research; and National Centre in HIV Epidemiology and Clinical Research.

communities in many of these research programmes. These people brought an additional perspective to the work of researchers and allowed for the development of strong links between the research and PLWHAs.

COMMUNITY/GOVERNMENT PARTNERSHIP

The development of the partnership

NGOs were originally established from within the metropolitan gay communities in response to the diagnosis of people with AIDS. These small community groups provided the initial volunteer care and support for people with AIDS, raised money to assist people with AIDS, and began to develop information and education materials about AIDS. These NGOs gradually secured funding from government as it became clear that there were significant numbers of people with AIDS in the gay community. Government funds were used by NGOs to develop campaigns and education materials aimed at informing gay men about safe sex. Gradually, governments in the most affected States and Territories established funding programmes to assist NGOs to reach gay communities, injecting drug users and sex workers.

A national AIDS policy discussion paper developed in 1984 proposed the establishment and funding of a partnership response to AIDS, and brought together governments, health workers, researchers and NGOs from the affected communities through the establishment of a National Advisory Committee on AIDS to oversee the national response to public education awareness and community needs. This committee worked in tandem with a medical advisory committee in providing the Commonwealth Government with advice. These two committees were eventually joined together to form the Australian National Council on AIDS (recently renamed the Australian National Council on AIDS and Related Diseases to represent more accurately the breadth of concerns of the third national strategy).

Structure of the partnership

The community/government partnership operates at several levels and its structures are mirrored at these levels. At a national level, the Commonwealth Health Department provides funding to the national AIDS NGO (AFAO) but does not sit on its management committee. AFAO negotiates an annual plan of activities with the Commonwealth and provides an annual report on performance indicators and outcome measures, but AFAO is accountable to its member organizations (the State and Territory AIDS NGOs and national sex worker, IDU and PLWHA NGOs).

The relationship at this level is probably best described as a 'creative tension'. AFAO has autonomy to develop its policies and positions on issues independently and has often publicly expressed its dissatisfaction or disagreement with government policy. AFAO generates its policies and positions by consulting with its member NGOs. In general though, the Commonwealth's AIDS policies and positions are arrived at using a collaborative and consultative process, and there is a general understanding in the partnership that either side will attempt to resolve and policy differences directly before involving the press or community mobilization strategies and/or protests. There is also a generally accepted policy of 'no surprises' in the partnership, i.e. no public criticism of the other partner without warning them beforehand that this public criticism is going to be made. This has led to a high level of trust and cooperation between members of the partnership. It would be unusual for either side to arrive at a policy or position on a controversial AIDS issue without first consulting the members of the partnership and discussing the position

that is proposed. For example, on major issues, such as HIV testing policy or HIV vaccine development policy, the Commonwealth Government has undertaken a consultative process to arrive at a position.

AFAO and NAPWA are represented on key decision-making and consultative bodies such as ANCARD, the principal national advisory committee to the Commonwealth Minister of Health, and its various subcommittees on research, education and clinical trials. AFAO is also represented on the Intergovernmental Committee on AIDS and Related Diseases, the body responsible for communication and coordination between the Commonwealth, State and Territory governments on HIV/AIDS issues.

Campaigns and other materials produced are generally presented to government for approval, although the level of scrutiny varies according to the political context and the level of trust between government and community organizations. At a State and Territory level, AIDS Councils, IDU, PLWHA and sex worker organizations are generally funded by, and work in partnership with, their State or Territory governments, even if the funding originally came from the Commonwealth. Many States and Territories have their own Ministerial AIDS Advisory Committees to advise Health Ministers on policy and programme issues. Community organizations are generally represented on these key decision-making bodies. Policies regarding the approval of campaign materials vary from State to State, but AIDS Councils generally develop comprehensive campaign briefs to inform government of the rationale for particular campaigns. State and Territory community groups also develop strong links with service providers at State level to assist them in providing care and support services.

Although these structures are important, the most important aspect of the partnership has been the commitment by government and community to work together to make the partnership work. Building trust and mutual respect takes time and commitment. Community NGOs and government have different basic aims, different sources of accountability, different processes for decision-making and different constituents. While governments often see NGOs as unpredictable and reckless, and NGOs see government as conservative and fickle, these two sectors have had to learn methods of communication and trust and these have been tested along the way as issues emerged.

Although these two sectors have worked closely together in this partnership it has been important for each to remain separate and autonomous. Community-based NGOs have to maintain their connection with their communities if they are to represent and serve them effectively. They cannot be, and cannot be seen by their constituents to be, too close to government. HIV/AIDS community groups have maintained this separation by ensuring that policies and positions on issues are developed in consultation with affected communities and that people with HIV occupy a central place in their decision-making structures.

Role of community in the partnership
At all levels of the partnership, the community organizations have a key role in bringing the perspective of people with HIV, people at risk and people affected by HIV to the decision- and policy-making setting. Governments decided quite early in the Australian HIV epidemic that access to the affected communities and the trust of these marginalized communities was only going to be achieved by funding and maintaining a relationship with NGOs formed from within those communities. Community NGOs have been responsible for the design and implementation of education campaigns and other initiatives to maintain safe sex behaviour

and safe needle use. These initiatives have included:

- the provision of support groups for people with HIV and people at risk;

- outreach to bars, dance parties and other community events;

- work with sex venues such as brothels, saunas and video clubs;

- provision of information to community social and sport clubs;

- groups for ethnic sub-communities within the gay communities;

- outreach to sites of sex between men such as public toilets, parks, etc.;

- services for subgroups within the community such as deaf gay men.

Community-based NGOs also provide care and support services for PLWHAs and their carers. These services train and support volunteers from within affected communities to provide care at home. This has a spin-off education/prevention effect within communities, as volunteers receive training and support to assist them in maintaining safe behaviour or in dealing with their HIV status. These NGOs also provide essential information to government to assist in policy setting. They advocate on behalf of people with HIV and people at risk to ensure that discrimination and stigma are minimized, health service quality is maximized and access to HIV treatments is ensured.

Community NGOs also play a key role in producing and disseminating information to their communities on risk, HIV transmission, HIV treatments and services. This information is presented in language and formats that are more likely to be understood by and acceptable to affected communities. Publications have included a bimonthly, issues-based magazine (*the National AIDS Bulletin*), a quarterly publication on legal issues *(HIV Legal Link)*,

monthly and bi-monthly treatments information newsletters *(Positive Living* and *HIV Herald)* and community newsletters for sex workers and injecting drug users.

Involvement of PLWHAs

It is often stated that people with HIV have played a central role in the national response to HIV in Australia. Although this is true in the main, creating and maintaining a place for people with HIV in the response has not always been easy, and people with HIV still find that their place is not guaranteed. In the early years of the epidemic, people with HIV were predominantly involved in HIV care and support programs and advocacy for HIV treatments and human rights. Over a period of time, there has been considerable discussion and debate around their inclusion and involvement in the development of HIV prevention campaigns and initiatives, including the use of specific messages relevant to people with HIV and imagery that depicted people living with the virus. These issues were worked out over time; however, they highlighted a tension in community prevention campaigns in Australia between the need to target the gay community and the fear that using images of people with HIV would 'blame the victim' for HIV transmission and place additional stigma and blame on people with HIV. PLWHA groups are now actively involved in the design of prevention campaigns and in the use of HIV positive imagery and messages in prevention campaigns.

People with HIV and the groups that represent them also play a key role in policy and programme development at all levels of the partnership. The involvement of people with HIV relies heavily on the existence of laws and policies that protect their privacy and provide protection against stigma and discrimination. Until these were in place in Australia, it was difficult to maintain the contribution of people with HIV to the response as their partici-

pation required a level of public disclosure of their HIV status. The availability of people with HIV who are prepared to speak publicly about their HIV status has been of particular value. Prevention and care messages delivered by HIV positive people have a particularly strong impact. These people also act as role models for other people with HIV. HIV positive 'speakers bureaux', which train HIV positive people to present information on HIV to schools and community groups, have been successful in reducing stigma and discrimination and in increasing HIV awareness.

MEASURES OF SUCCESS

There are several indicators of success for education/prevention initiatives. At a micro level, campaigns are focus-tested, process-evaluated and their impact on communities is measured. Community NGOs evaluate information and support interventions using client satisfaction, impact evaluation and other measures. Initial behavioural studies of gay men undertaken in 1986 (Kippax et al 1993b) indicate a significant behaviour change had occurred among gay men in New South Wales. Since these, there have been longitudinal studies and 'snapshot' surveys that indicate sustained changes in risk behaviour and assess the impact of the overall prevention program. The Sydney Gay Men and Sexual Health (SMASH) cohort provides ongoing information on patterns of risk-taking among Sydney gay men. This study has been replicated in Melbourne and Brisbane (the two cities with the next largest gay communities after Sydney). In addition, 'snapshot' surveys have been carried out in HIV testing clinics and at gay community events. There have also been two nation-wide anonymous telephone surveys, which have provided information on risk activities among non gay-identified homosexually active men. Studies and surveys of injecting drug use patterns have also been conducted.

The first and the second national HIV/AIDS strategies have been comprehensively and independently evaluated. The evaluation of the second National Strategy was carried out in 1995. The report noted that the reduction in new infections to date among gay men and the maintenance of a low incidence among injecting drug users have been major achievements. However, the evaluation report pointed out that, with current trends, the partnership would not reach its stated target of a reduction in new infections to two per 100,000 people per year. The report urged the partnership to develop new strategies to reduce new infections further. The report also noted the need to design new approaches to deal with the emerging epidemic among Australia's indigenous communities. These communities had not been comprehensively targeted in the first two national strategies.

AT WHAT COST?

Expenditure on prevention programmes
The national AIDS strategies have framed the allocation of specific funding for HIV/AIDS through the public health program. The Commonwealth allocates the majority of this HIV/AIDS funding to the States and Territories using a formula based on prevalence and general population size. Funds are distributed at State and Territory level between government and non-government services. States have, until recently, been required to match the Commonwealth allocation on a 1:1 basis. Some States, such as New South Wales, which has the overwhelming majority of people with HIV, have committed funds well beyond the required 1:1 match. Funding for hospital care is met through Medicare, a national funding agreement between the Commonwealth Government and States and Territories, and pharmaceuticals are funded through a national pharmaceutical funding scheme.

The first national AIDS strategy called upon States and Territories to allocate 50% of AIDS funding to education/prevention and 50% to care and support services. The second national strategy, in recognition of the increasing number of people with HIV requiring care, shifted this proportion to 60% for care and support, and 40% for education and prevention. To some extent, these proportions had little meaning as the definition of education and prevention was not clear and often included provision of HIV testing and sexual health services. Most targeted education and prevention campaigns have been carried out through NGOs and the proportion of NGO funding has remained low.

The first national strategy (1989–1993) allocated approximately AU$8 million per year for four years for education and prevention. This was matched dollar for dollar by the States. Under the first national strategy, approximately 8% (AU$3.5 million per annum) of the education and prevention budget was allocated to State and Territory AIDS Councils for gay men's education. The Commonwealth also kept back some funds for national education campaigns. In the second national strategy (1992/1993–1995/1996) AU$24 million was allocated to States and Territories, which was matched 1:1. The strategy called for a minimum of 40% of the matched funding allocation to be spent on education and prevention programs, with priority given to funding community organizations working with high-risk target groups. The strategy did not specify what proportion of funds as to be allocated to NGOs at State and Territory level.

The third national AIDS strategy (1997/1998–1999/2000) was produced in the broader context of related communicable diseases and sexual health. It allocates a similar annual amount overall but does not specify how the allocation is to be distributed within States and Territories. It identifies gay men and other homosexually active men as the primary target for education and prevention. The strategy is being implemented in an environment of health service reform, which is giving States and Territories increased autonomy in relation to health service provision and increased flexibility for budget allocation and priority setting, but within a much broader definition of public health goals, one that focuses less on specific diseases. This is causing some concern in HIV organizations as States have increased freedom to set public health priorities. There is a fear that the gains made in HIV prevention will be seen as achieved already, and that HIV prevention and education programmes will be scaled down.

LESSONS LEARNED

There have been many lessons learned in the response to HIV/AIDS in Australia, and the most important is that the partnership between governments and communities is a dynamic one that needs nurturing and continued resourcing. This partnership is referred to constantly as the secret of Australia's successful HIV/AIDS response. There is a danger that the partnership sometimes becomes just a collection of sectors, each with different approaches, processes, priorities and contributions, rather than a dynamic relationship between these sectors. The partners need to be able to bring their respective contributions and perspectives without losing their essential identities. Community organizations are sometimes accused by their constituents for appearing to be 'in bed with government' or 'just another arm of bureaucracy'. They are also sometimes accused by government as representing the 'feral' community. It is important for community organizations to maintain their links with the communities they serve. It also important for governments to allow a level of disagreement and debate within the

partnership without feeling that the partnership might threaten their existence.

It has been easy at times to take this partnership for granted, not to respect the individual contributions of its members and to attempt to make the partnership a homogenous entity. An example of the neglect of the needs of the partnership is the occasional misunderstanding of processes of community representation. Government often calls upon community organizations to provide a representative for a decision-making body. It often requires the name of the representative within a few days of the request. It has an expectation that the community organizations will dip into its ranks and pull out a suitably qualified representative. It becomes impatient when the community NGOs say that they have processes for appointing representatives, which involve calling for expressions of interest from affected communities and making a choice from the expressions of interest received. Government often states that it wants a representative who will behave 'reasonably' and not cause problems on the committee, and it sometimes names the person it would prefer. It is important that government understands the processes of the community sector and understands that community NGOs maintain their links with their communities by maintaining transparent and fair decision-making processes. Although this appears a reasonably trivial example, it is an indicator of the level of understanding needed of the difference between government and community, and of the level of autonomy that must be afforded members of the partnership.

Beyond this issue of the relations between the partners, there are a number of basic ideas that underpin good health promotion, learned from the Australian experience:

1. Campaigns are more than just posters and pamphlets. Since the beginning of the Australian AIDS response, NGOs produced campaigns made up of a complex set of elements such as printed resources, merchandizing, strategic community media placements, workshops, seminars, support groups, community outreach and other initiatives. The posters and pamphlets conveyed essential information, but also acted as symbols or reference points for the other elements of the campaigns. There has been a tendency at times to produce campaigns that are constituted only by posters and pamphlets and which lack the other community elements. There is a growing recognition that these streamlined campaigns have less impact than campaigns that include a set of elements aimed at several aspects of community life.

2. Targeting of campaigns is important. Campaigns aimed at members of affected and marginalized communities have often necessarily contained explicit images of sex between men or of injecting drugs. The effectiveness of the use of explicit materials has been clearly demonstrated. These campaigns, howver, are sometimes seen to cause problems if they become available to people outside the main target group, for example, when sexually explicit materials targeting gay men reach school-age young people. These situations can result in political incidents and challenge the stability of the partnership, as governments withdraw their support for a campaign in fear of a political backlash, irrespective of public health needs, and move into damage control. Incidents such as theses damage the working relationship between community NGOs and governments. These can generally be avoided by establishing agreed distribution policies and by community NGOs preparing detailed written briefs for each campaign.

3. Campaigns are best designed and delivered by members of the affected communities targeted. This has been referred to in the principles listed above, but has also been a key lesson learned. The wider the

gap between the campaign developers and the target group the less likely that campaign will produce the required outcomes.

4. Shortcuts in campaign development and implementation reduce the quality of the campaign outcomes. In the haste to get campaigns 'on the streets', it is tempting to take short cuts in design and development or in the implementation of campaigns. The process of the development of a campaign is sometimes as beneficial to the target community as the campaign itself. There is much to be gained from the inclusion, debate and discussion that accompanies campaign development. Campaign issues often change as the campaign unfolds. Focus testing is important, as it is easy to miss the needs of the target community or confuse the message. An evaluation of the process of campaign development is sometimes as important as the evaluation of its impact. There is also little value in developing a wonderful campaign that does not actually reach target communities because of shortcuts in implementation. Communities need to be prepared for their participation in the campaign and given sufficient resources to participate.

5. Peer-based education is likely to be more effective than education developed and delivered by other 'external' agencies, especially in marginalized communities suspicious of government programs.

WHERE TO FROM HERE?

The AIDS response in Australia has developed over thirteen years. There have been many changes in the issues facing people with HIV/AIDS and people at risk, and the partnership has had to remain flexible and strong. The increased success of combination therapies has had a significant effect on the response. There is a temptation to feel that AIDS has been dealt with and no

longer presents a threat. New generations in the affected communities have not had such a close association with HIV/AIDS and may see it as less relevant or not fear it as much. Other issues, such as high rates of sexually transmissible diseases in some communities, and the emergence of an epidemic of hepatitis C, present public health officials and government with new priorities. There is a chance that these priorities will dominate public health policy and funding, and that gains made over the last twelve years in HIV prevention and care might be jeopardized. The rate of new HIV infections in Australia has been stable at approximately five hundred per year for some time. If this rate is to be reduced, governments and communities will have to continue their work and find new ways to assist individuals and communities to avoid HIV transmission.

There are also broader changes in train that affect the relationship between governments and NGOs. The move towards smaller government and to the contracting out of health care services places NGOs in a different role with government. Competition is encouraged between NGO providers. It is possible that the long-standing, co-operative relationship between government and community organizations may be threatened by the emergence of new service providers, one-step removed from government but with no particular community connection. This is particularly a problem in health promotion and community development programmes that rely on connections with communities for their success.

There is also a tendency towards mainstreaming or integration of services and approaches. Although this has some merit at government and health service level, it is difficult to implement at community level. Community NGOs have relied on their success in mobilizing the energy and resources of affected communities. It is not clear that combining communities of peo-

ple with HIV with people affected by hepatitis C (irrespective of possible overlap), for example, would be an effective model. Although there is much to be gained from the sharing of experience and expertise between these communities, combining them at community level may not always produce better health outcomes.

This case study has attempted to summarize the structure and functioning of the partnership response to AIDS in Australia. It has highlighted the lessons learned and the key tensions of the partnership between government and NGOs. The most difficult aspect of the partnership to portray is the nature of the relationships which make up the partnership. This is a partnership which requires continual nurturing, goodwill and commitment. Like all partnerships, it withers if it is taken for granted. The ongoing success of this partnership will be dependent on the desire of all parties to continue to participate, to work together and not to lose sight of each other's essential contribution.

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EXPERIENCE FROM CANADA

by Mr Russell Armstrong, Executive Director, Canadian AIDS Society, and Ms Dina Juras, Programme Consultant, AIDS Community Action Programme, Health Promotion and Programmes Branch, Manitoba/Saskatchewan Region, Health Canada

INTRODUCTION

On an international level, Canada has done comparatively well in its efforts to curb the spread of HIV within its own boarders. This success is largely due to effective collaboration between community-based HIV/AIDS organizations and the federal government of Canada. This article describes how this partnership came to be and how it currently operates. We deal exclusively with the federal government and its relationship to community. There are other levels of government involved in supporting communities affected by HIV/AIDS. There are also other groups and individuals not part of the community-based response working to combat HIV/AIDS. All in their way have contributed to Canada's success. The community/government partnership is but one ingredient necessary for building an effective prevention response.

OVERVIEW AND CONTEXT

HIV in Canada
The latest information on HIV/AIDS trends in Canada was released by Health Canada's Laboratory Centre for Disease Control in May 1997. As of 15 April 1997, there have been a total of 14,836 cases of AIDS reported in Canada. Of these, 14,677 were adults and 159 were children under the age of 15. When the total number of cases is adjusted for delays in reporting or under-reporting, the number rises to as high as 20,000. As of 31 March 1997, there had been 10,837 reported deaths (Health Canada 1997). AIDS is the leading cause of death for men

between the ages of 25 and 40 in all of Canada's major urban centres.

The largest portion of reported AIDS cases is still among men who have sex with men, although this has been declining. As of 1996, 62.2% of reported cases were among men who have sex with men. Rapid increases in proportions have been seen among women (25% in 1996), those who report injecting drug use (10.3% in 1996) and those who report heterosexual transmission (9.2% in 1996).

Health Canada estimates that there have been between 50,000 to 54,000 people in Canada infected with HIV since the epidemic began. At the end of 1996, there were between 36,000 to 42,000 people living with HIV. As only AIDS cases are reported at the national level and not cases of HIV infection, the extent of HIV infection in Canada can only be estimated. Between 3,000 and 5,000 new HIV infections occur each year in Canada.

Most new HIV infections are occurring among women, injecting drug users and young gay men, although there is significant regional variation in infection patterns. Aboriginal communities and ethno-cultural communities are also affected, although the extent of HIV infection in these communities has been difficult to estimate as information on race and ethnicity is not routinely collected with test results.

Some Facts and Figures About Canada
The current population of Canada is approaching 30 million. Seventy-seven per cent of the population lives in cities; the

remaining 23% lives in rural areas. Canada is made up of ten provinces and two territories, each with its own government. The Canadian Constitution outlines the division of responsibilities between the provincial/territorial and federal governments. Provinces and territories have responsibility for delivery of direct services in health care. Some of this delivery is delegated to the regional or local level. Provinces and the federal government share the financial cost of health services. The federal government transfers health care and social service funds to the provincial level through a transfer payment scheme that has some limited conditions attached to the payments. These conditions ensure a consistent set of approaches in major areas of health and social programmes across all provinces. Federal government support for provincial programmes has declined significantly in recent years due to deficit problems. Canada is undergoing dramatic changes in the organizations of social and health services as a result.

Most of Canada's health care system is publicly funded. Doctors and other health professionals working in hospitals, clinics or in private practice are paid for their services through public monies. Health care facilities receive the most significant portion of their operating funds from government sources. Currently, it is illegal to set up private clinics and charge patients for services that are publicly funded.

To some degree, the community-based HIV/AIDS sector is supported by government funds. However, this level of funding is declining and the community-based sector is relying more and more on charitable contributions from private sources. Individuals in Canada receive income tax credits for contributions to charitable organizations. Community-based AIDS organizations are funded through a mix of government contributions and charitable donations from individuals, private foundations and business.

HISTORY AND STRUCTURE OF THE COMMUNITY-BASED RESPONSE

In the Canadian response to HIV/AIDS, community-based organizations have been at the forefront. These organizations have been remarkably effective at delivering targeted interventions specific to local community dynamics. They have emerged in this role, however, more as a result of troubled undercurrents in Canadian social attitudes, than as a result of supportive health policy decisions early on in the course of the HIV/AIDS epidemic.

Canada recorded its first case of AIDS in 1982. Gay men and haemophiliacs were hardest hit as the HIV epidemic took hold. HIV/AIDS was originally most prominently associated with gay men, and a quick response to the epidemic was frustrated by deeply entrenched public prejudice against gays and lesbians. Although the new epidemic was also affecting other groups in society (early commentators on the epidemic spoke of the four 'H's': homosexuals, haemophiliacs, Haitians, and heroin users), it was widely considered a gay disease and by extension a disease of the socially deviant who fell outside of the sphere of public compassion and responsibility. As a result, gay communities were challenged to respond to HIV/AIDS in the midst of extreme difficulties.

Indeed, HIV/AIDS emerged at a time of antagonism between gay and lesbian communities and public 'authorities'. Gay and lesbian communities, which had been gaining in strength and visibility throughout the decade that preceded HIV/AIDS, gradually provoked significant backlash from police and government in some regions of Canada. A Toronto bath house was raided by police and the national gay and lesbian

news magazine *The Body Politic* was prosecuted for publishing an article on inter-generational relationships. Canadian customs authorities were beginning routine harassment of gay and lesbian booksellers. Magazines imported from abroad appeared in Canada with blank pages or large portions of pages blacked out. Explicit depiction of gay sexuality (whether in newspapers, magazines or novels) was considered degrading. For a time, Canada Customs focused particularly on depictions of anal sex and blacked out or simply banned any materials containing such depictions.

In responding to these multiple challenges, gay communities developed sophisticated skills in advocacy and community mobilization. Gay communities also became accustomed to giving money to support groups fighting the various causes of social oppression. All of this formed a strong base upon which to mobilize quickly and effectively in the face of HIV/AIDS. Despite a complete lack of support from public institutional sources, gay communities across Canada promoted awareness of the emerging epidemic through public information sessions, pamphlets, posters and newsletters. Messages included the latest news about the advancing epidemic, information about safer sex practices and warnings for gay men not to donate blood. In some cases, these were plain, typewritten sheets, photocopied and distributed through bars, saunas and other regular meeting points.

Gradually, as the magnitude of HIV/AIDS grew, government response increased and funding for prevention and support programmes became available. In the nearly decade-and-a-half long struggle with HIV/AIDS in Canada, a vibrant network of community-based organizations has grown to span the country from coast to coast. Most community-based HIV/AIDS organizations are organized under the umbrella of the Canadian AIDS Society (CAS). CAS

is the national coalition of over a hundred such organizations. CAS members are autonomous; the national coalition exercises no authority over their affairs. Members must meet a set of clearly defined criteria in order to belong to CAS and must support community action principles. These membership criteria have helped keep a consistent identity and approach to the ever-expanding community-based sector. The criteria include a requirement for members to demonstrate significant and appropriate representation of people living with HIV/AIDS in all leadership or decision-making roles.

Community-based HIV/AIDS organizations in Canada cross a wide variety of organizational types and designs. Many have evolved from strong gay and lesbian roots and represent a transformation from local gay and lesbian community groups to a full fledged, multi-service HIV/AIDS organization complete with a board of directors, paid staff, a large volunteer pool and a sizable annual budget. These AIDS service organizations offer a range of interventions from support and counselling for people living with HIV/AIDS to education and prevention programmes for individuals and groups at risk of HIV transmission. Within this category, there are organizations with very particular focuses either in the service they provide or in the population they reach. This includes hospices or treatment organizations, for example, or organizations focusing specifically on women, Asian gay men or aboriginal people.

Also included in the Canadian network of community-based HIV/AIDS organizations are the PLWHA organizations. These may be small, relatively informal networks or larger, multi-service agencies. All are governed and often run by PLWHAs. Such organizations have a more specific focus for programmes in that they offer many forms of practical support and assistance

as well as undertake advocacy on social welfare issues directly related to PLWHAs.

CONCEPT OF PREVENTION

The concept of HIV prevention and Canadian approaches to it have evolved over fifteen years of efforts to cope with the impact of the HIV/AIDS epidemic. This development can be seen most clearly in community-based HIV/AIDS prevention interventions and the policies of government funding programmes that support this work. Canada's approach to HIV prevention has been to deliver targeted interventions within communities most at risk of HIV transmission. This approach is founded in the principles of health promotion with a strong emphasis on community development.

Health promotion, as defined by the World Health Organization, is a process of enabling people to increase control over, and to improve, their health. Health, according to the WHO definition, is more than the absence of disease. It includes emotional, physical and social well-being. The community development approach holds that in order for people to gain control over their lives and the circumstances that affect their health, communities must identify their own problems, develop their own solutions and put them into action (WHO 1996).

In 1986, Health Canada formalized this approach into a framework document called *Achieving Health for All* (Epp 1986). This document identified three main health challenges: (1) reducing inequities; (2) increasing prevention; and (3) enhancing coping skills. As a response to these challenges, the framework outlined three health promotion mechanisms: (1) self-care (which encourages healthy choices); (2) mutual aid (people working together in their efforts to deal with their

health concerns); and (3) healthy environments (altering or adapting social, economic or physical surroundings in ways that will preserve and enhance health). The framework also suggested three implementation strategies: (1) fostering public participation (helping people to assert control over the factors that affect their health); (2) strengthening communities and community health services; and (3) coordinating healthy public policy (all policies that have a bearing on health and people's capacity to make healthy choices need to be coordinated and involve other sectors). Within this larger health policy context, community-based HIV/AIDS interventions emerged and were, ultimately, largely supported through funding programmes that attempted to put into practice this language of health promotion and community development. To a significant extent, this policy language helped formalize and make explicit what gay and lesbian communities were learning to do in an intuitive sense as they faced the advancing epidemic.

In the early stages of the epidemic, community-developed pamphlets and posters contained basic information about HIV transmission, including risk reduction or risk avoidance information. The resources were mainly delivered through gay community sources and directed at sexually active gay men. Materials addressed such topics as: condom use; the risks involved in oral sex versus anal sex; the merits of testing; and the debate over whether there was a need to reduce the number of sexual partners versus consistently practising safer sex. Materials also recognized that a variety of contextual factors influenced the experience of HIV and risk. Gay men needed to be motivated to practise safe sex and to maintain a hopeful sense of their own survival in the midst of such adverse forces as an advancing epidemic and broad scapegoating of gay men and their sexual practices as threats to the well-being of society at large. Materials had an encouraging

tone and discussed issues of self-esteem and pride in community.

These early efforts gained momentum as government funding programmes were gradually opened up to support and expand them. Between 1982 and 1989, Health Canada operated the Health Promotion Contribution Programme. Funding under this programme was targeted to various groups, including women, seniors and people with disabilities, to support the general health promotion mechanisms of reducing inequities in health status and strengthening the capacity of people to cope using self-help and mutual aid activities. Community-based HIV/AIDS organizations were also eligible to apply under this programme. Early interventions that were funded included programmes that focused on self-help strategies to cope with the personal impact of the epidemic and those that attempted to raise general awareness about HIV/AIDS in the community at large.

The first National AIDS Strategy and the AIDS Community Action Programme (ACAP) were created in 1989. Within the framework of the Strategy, the ACAP programme focused on ways to increase the prevention effort and formally recognized the value of targeting prevention messages. The first National AIDS Strategy described the approach to prevention in this way:

> *While national programming can be useful for increasing general awareness and promoting positive attitudes, real change in attitudes and behavior is more likely to be brought about through targeted messages, locally designed and delivered. It is important to aim programmes at those areas and people that are at greatest risk... Such programmes must reflect the language, values and practices of those to whom the information is directed, and involve those closest to the community concerned. (Health Canada 1989, p. 41)*

Groups in the population most at risk for HIV infection were identified based on epidemiological data. HIV/AIDS prevention interventions needed to be tailored to the specific social or cultural make-up of these groups and needed to be delivered by a source credible to the group. Broad-based campaigns made specific target groups invisible; or they did not speak directly to the social or cultural context within which HIV risk transpired. What was supported through the programme were interventions that spoke explicitly about sex and HIV risk, for instance, in language and images credible and familiar to the audience these messages were intended to reach.

Alongside targeted, culturally sensitive interventions, the ACAP programme also funded projects designed to reduce barriers that prevented marginalized or socially isolated groups of people from accessing health care. In the context of HIV/AIDS, barriers to access were largely about stigma and lack of knowledge among institutions, policy makers, and public service providers about the issues and concerns of at-risk and/or HIV-infected populations. Interventions dealing with education on AIDS-phobia, homophobia, racism, sexism and poverty were developed and implemented with the support of the ACAP programme to address these barriers (Canadian AIDS Society 1989).

A further aspect of the ACAP programme involved support for activities that integrated messages within contemporary social and health interventions. The programme supported initiatives in cities and provinces where community-based HIV/AIDS organizations worked with public education systems to integrate HIV/AIDS in sexuality education curriculum for schools. It also included situations where community-based HIV/AIDS organizations were contracted by provincial health departments to run province-wide telephone information lines on sexually transmissible diseases.

In 1993, following on from a national consensus conference and a series of federal government-led consultations with community educators and PLWHAs, a more expansive approach to prevention was set out (Health Canada 1992). The most significant shift in emphasis was the increased focus on health promotion for PLWHAs and the creation of supportive social environments as part of expanded prevention programming (Health Canada 1993). A separation between prevention and care was gradually eroded, based on advocacy on the part of PLWHAs to have their needs included in prevention initiatives, and, as well, on a growing understanding of prevention as part a continuum of care and support for both HIV positive and HIV negative members of HIV-affected communities.

Recently, government policies have begun shifting from a health promotion approach to one of population health (Health Canada 1996). Population health explores the interrelationship of multiple determinants of health on individual and population-based health outcomes (Health Canada 1996). This approach is not new to community groups working in the area of HIV/AIDS (Canadian AIDS Society 1996). Addressing the multiple social and environmental factors that determine health has been integrated in prevention approaches for some time. However, understanding the complexity of the interrelationship of multiple determinants of health, and developing strategies that address the impacts of these multiple determinants, have yet to be or are just starting to be incorporated into research agendas, evaluations, and policy and programme planning at both the community and government levels.

COMMUNITY AND GOVERNMENT

As noted above, HIV/AIDS emerged in Canada during a time that saw active hostility between forces identified with government or state and gay and lesbian communities. The roots of community organizing around HIV/AIDS were recently explored through the Commission of Inquiry on the Blood System in Canada. One of the areas for inquiry was how the HIV epidemic emerged in Canada and how the virus subsequently found its way into the blood system. The inquiry examined early community responses throughout Canada's gay and lesbian communities and contrasts these to government indifference or, in some instances, open hostility. Fortunately, the tragedy of AIDS and the challenge of an expanding HIV epidemic have provided the impetus to repair these early fissures and build in their place a strong, collaborative partnership.

The origins of more supportive partnerships in prevention between community and government begins at a particular moment in the history of the epidemic. In Vancouver, 'AIDS Vancouver', one of the first formally constituted community-based HIV/AIDS organizations, approached a regional Health Canada office for financial support to deliver prevention programmes. As noted above, Health Canada, at the time, was well positioned to respond since its policies and general funding programme incorporated principles of health promotion and community development. Funding was provided in gradually increasing amounts to local community organizations to provide targeted prevention programmes in explicit, direct. Public controversy arose occasionally, generally over materials aimed at youth that used direct sexual language, materials depicting safe S/M (sado-masochistic) practices, or materials that appeared to condone illicit activities like injecting drug use.

The formation of the Canadian AIDS Society in 1985 inaugurated a new era in government and community collaboration. CAS began as a national coalition of com-

munity-based HIV/AIDS organizations working at the local level in various regions of the country. In addition to providing a forum for exchange and support amongst these organizations, CAS took on a strong advocacy role at the national level. The result of this advocacy was a strengthened framework for community-based approaches to prevention. CAS lobbied the federal government to recognize the role of community organizations as the most effective delivery mechanism for prevention interventions targeted at those communities most at risk for HIV. CAS also lobbied the government for a national funding programme to support this role.

These lobby efforts were instrumental in the creation of the first National AIDS Strategy in 1989. Central to the Strategy was *partnership*, particularly partnership between government and members of HIV-affected communities. Although this partnership has functioned with relative effectiveness, it is at times highly antagonistic. In 1988, for instance, frustrated by the inaction on the part of the federal government in moving toward the creation of the first National AIDS Strategy, the federal minister of health at the time was burned in effigy by a community-based activist organization outside a national conference on AIDS. The minister was subsequently shifted to another portfolio and replaced by a new, more supportive minister. This event marked a climactic point in the strained relationship between community and government.

In general, the community-based HIV/AIDS movement has shown remarkable skill in analysis and advocacy. Indeed, advocacy has been central to the partnership between community and government, with community providing the analysis to government for the work that needed to be done and spelling out the broader partnerships that were necessary to get the work done. Community-based HIV/AIDS orga-

nizations have also become adept at using the political process to achieve change and progress in government policy. Many of the leaders in advocacy have been PLWHAs, and they have brought an urgency and a focus to advocacy and policy development activities.

Partnership and collaboration between community and government were recently tested again. As part of the federal government's move toward a population health approach, national strategies, including the National AIDS Strategy, were scheduled to conclude and not be renewed. Instead, the government planned to take a more integrated approach and not parcel out its resources to various diseases or issues. For the community-based HIV/AIDS movement, this meant neither a dedicated funding programme for HIV/AIDS nor any visible, high-level commitment on the part of the federal government to continue to deal with HIV/AIDS. In response, the CAS along with many community-based HIV/AIDS activists and PLWHAs led a strong lobbying initiative. Public support for a renewed federal commitment to AIDS was mobilized through media events. CAS member organizations were constantly asked to meet or write to their local member of parliament and to mobilize their own membership to do the same. The result was that during the recent federal election campaign, the federal Liberal Party announced its intention to renew the National AIDS Strategy for another five years at current funding levels. Subsequent to the Liberal's being re-elected to form the government, the commitment has been confirmed and a process has been under way to develop a third National AIDS Strategy in time for World AIDS Day, 1 December 1997.

MEASURES OF SUCCESS

True measures of success in HIV/AIDS prevention work are sometimes elusive.

Demonstrating that a particular intervention results in reduced HIV transmission is difficult. Also, success is due to multiple sectors and partners. In Canada, since HIV/AIDS first emerged in the early 1980s, new cases of HIV infection declined after significant investment in prevention initiatives and as a result of collaboration between government and community-based HIV/AIDS organizations working within communities most at risk HIV infection. The extent of this decline and its relationship to particular interventions are difficult to establish. Indeed, the relationship is further called into question by the troubling fact that new cases of HIV infection have recently begun to increase.

In addition to ongoing epidemiological monitoring, Canada has used other measures to determine success in HIV/AIDS prevention. For instance, large-scale knowledge, attitude and behaviour studies have been conducted to determine the impact of HIV/AIDS prevention efforts within targeted, at-risk communities. The most significant study of this kind was the *Men's Survey*, conducted in 1991 (Myers et al. 1993), and the complementary study *Entre Hommes* (Between Men), conducted at the same time in the province of Quebec (Godin et al. 1993). Both were large-scale surveys administered by gay and lesbian volunteers in community venues. University-based researchers and community-based prevention specialists joined forces to develop and implement a research method that helped strengthen community action on AIDS, while at the same time gathering much needed data on the impact of prevention efforts.

Although the two studies differed somewhat in their recruitment strategies, they both confirmed that a tremendous change had occurred among gay and bisexual men across the country. At the same time, they pointed out that there were small but significant numbers of men who were not being reached by existing interventions. The regional consultation process that followed the survey in 1993 facilitated opportunities for educators to solve problems that had been identified in the research and plan prevention strategies to reach those who were not being reached by existing programmes. A series of recommendations resulted from the consultation and these have continued to guide prevention efforts at the both the local and national level (Canadian AIDS Society 1994).

Another measure of success used in Canada is the programme-based impact questionnaire by the AIDS Community Action Programme (Health Canada 1993). The questionnaire was developed in consultation with community HIV/AIDS organizations and other Health Canada funding programmes. It measures the impact of prevention projects using two health promotion indicators: (1) increasing public participation; and (2) strengthening organizations. First, if we maintain that, in order for people to gain control over their lives and the circumstances that affect their health, they must get involved, then we can measure involvement. If an issue is important to a community, they will name how it affects them, develop the solutions and take action. To measure a project's success at increasing public participation and involvement, the following assessment measures are used:

- people who experience the health or social issue the project addresses are involved in making decisions about the project from planning to evaluation;

- social supports and networks are expanded;

- those involved with the project gain knowledge and skills through their involvement;

- increased collective action results from involvement in the project;

- those involved with the project form a foundation for ongoing social change.

Second, if organizations are a vehicle through which people have a voice in defining their issues, then community organizations must have the capacity to respond and cope with those issues. A project's success in strengthening community organizations is measured according to the following indicators:

- ability to build coalitions and to form partnerships;

- positive visibility, recognition and acceptance within their communities;

- increased knowledge, skills and understanding among group members;

- creation of a foundation to support future activities;

- cooperation with other groups and networks;

- ability to sustain the participation of community;

- an increased sense of the group collective power;

- ability to influence and/or participate in decision-making that affects the community.

Through the administration and assessment of the impact questionnaire results, a consistent method of evaluation has evolved across ACAP-funded projects, including prevention interventions. As well, results have been used to help refine and adjust funding priorities. However, the realities of measurement or making evaluation meaningful to communities has been challenging. More attention needs to be paid to this area. Community organizations often do not see evaluation as a relevant priority in their work. HIV prevention itself is often difficult to evaluate. A recent report by the CAS outlines the challenges facing community-based educators in the area of measuring success (Canadian AIDS Society 1996). In addition, there are complexities involved in creating an appropriate evaluation framework for these preven-

tion interventions. Educators lack evaluation training and often function within a larger context of organizational instability that leaves little time to remedy these problems. As the annual rate of new HIV infections continues to rise in Canada, measuring success and learning from these measurements becomes an urgent priority.

AT WHAT COST?

Estimating Canada's expenditure on prevention in relation to the impact of these prevention interventions on the progress of the epidemic is a complex process. Funds for prevention work come from various levels of government as well as from individuals and business in the private sector. Expanding the impact of funds spent is the non-monetary contribution of the thousands of volunteers working with the community-based HIV/AIDS sector to assist in the delivery of prevention.

Canada's expenditures on prevention are currently being studied. The Canadian Policy Research Network will publish late in 1997 a comprehensive study that details how much has been invested in prevention and where this money has come from. At the national level, under Phase II of the National AIDS Strategy, spending on prevention takes up a significant portion of the overall budget. During Phase II, the overall strategy budget of CAN$42.2 million was allocated each year for the following programme areas:

- CAN$6.2 million on education and prevention initiatives;

- CAN$17.8 million on research and epidemiological monitoring;

- CAN$9.8 million for community development and support to non-governmental organizations;

- CAN$5.4 million for care, treatment and support;

■ CAN$1.5 million for coordination and collaboration.

These figures represent only federal government spending through the National AIDS Strategy. It does not take into account spending by provincial or municipal governments on prevention, or contributions from the private sector. Equally absent is a sense of the countless hours of volunteer labour through community outreach programmes that has contributed immensely to a cost-effective prevention strategy.

One point is worth noting. Of the CAN$42.2 million annual budget of the National AIDS Strategy, only CAN$7.5 million is allocated to the AIDS Community Action Programme. This programme is the major source of support for community action on HIV/AIDS. Given the importance of community action in Canada, it is surprising to see that less than 20% of the national budget on HIV/AIDS supports this sector. This and other questions around the role of community in the delivery of prevention programmes will occupy a significant place in the discussions leading to the development of Phase III of the Strategy.

LESSONS LEARNED

Canada's approach to prevention has been, for the most part, successful. The proof of this is in the shape of the epidemiological curve and in the significant shifts measured amongst men who have sex with men and other communities at risk for HIV infection. Social attitudes toward HIV/AIDS, including people living with the disease, have shifted remarkably during this country's fifteen-year struggle with the disease. Community mobilization partnered with government support has been very effective in developing appropriate programmes and responses. The involvement of PLWHAs has been crucial in the development of an effective community response to the dis-

ease. Consultation, community involvement and transparent processes have helped build successful partnerships. HIV/AIDS work has been a catalyst for larger social policy change.

In addition to these success, however, there remain some gaps. These are some of the more significant ones:

■ There is still more work to be done. HIV prevention approaches have not worked for certain communities or are just starting to take hold and it takes sustained support over time to evolve an effective community response. Dramatic rises in new infection rates among women, young gay men, injection drug users, and aboriginal people have recently been observed;

■ Models of community mobilization and intervention that have been successful in gay communities, for example, may not work for populations showing dramatic rises in rates of HIV infection. Rethinking prevention interventions will take time, energy and commitment. Much larger societal factors need to be addressed that are beyond the ability of current partnerships to change: for example, the federal government has recently tightened laws around possession of drugs and drug paraphernalia putting in jeopardy needle-exchange programmes. At the same time, in certain parts of Canada, rates of new infection among injection drug users have recently become the highest in North America;

■ Community-based HIV/AIDS organizations are suffering from fatigue. Constant under-funding and uncertainty about future funding has lead to tension between the need for advocacy to maintain existing levels of support, while at the same time coping with increasing demand for services;

■ Although funding has been provided to support an infrastructure of community-

based HIV/AIDS organizations, community organizations do not participate on a level playing field with government. Financial support should be used to give communities an equal voice in the issues and not to make them solely responsible for these issues;

■ HIV is advancing further into the socially and economically marginalized, therefore coalition-building across a broader spectrum of partners from other social movements needs to be further developed. There have been some very successful outcomes of working together. Recently, governments have positioned diseases and the organizations formed to cope with them as competitors for limited resources. AIDS and breast cancer are the main examples. This has been called a 'competitive misery model' by some. Coalition-building will help strengthen the need for better government investment in community mobilization across all health issues.

WHERE DO WE GO FROM HERE?

As previously noted the HIV epidemic is not over in Canada. In May 1997, new epidemiological data revealed between 3,000 and 5,000 new cases of HIV infection each year. Two years before this, this rate was between 2,500 and 3,000 (Health Canada 1997). Rising rates of HIV infection emphasize the urgent need for longer-term planning and vision. Without adequate government support for programmes and broader ownership of the issues, raising funds to support prevention efforts will supplant the actual work of prevention. Current government funding models are based on short-term project support, which has recently been show to be destabilizing and not conducive to effective prevention programmes. Rising rates of infection have also made improving evaluation more critical. Resources for HIV/AIDS have not significantly increased and are not

likely to do so in the near future. Although the federal government has pledged to renew the National AIDS Strategy for a third five-year phase, it has done so at current levels of funding, despite that fact that there is now a greater number of people living with HIV/AIDS in Canada. Being able to demonstrate the success of prevention programmes will be crucial as government and community alike struggle to use precious programme dollars effectively.

The HIV epidemic is more complex than when it first emerged. Newer populations becoming infected with HIV have complex health and social needs. Ideally, a population-based approach will provide new opportunities for more multisectoral prevention work. As the consultation process for Phase III of the National AIDS Strategy gears up, we face the hopeful possibility of further expanding and reinforcing the effectiveness of prevention work done to-date.

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EXPERIENCE FROM THAILAND

by Dr Wiput Phoolcharoen, Director, AIDS Division,
Department of Centre for Disease Control, Ministry of Public Health, Thailand

INTRODUCTION

Thailand is a tropical country in South-east Asia with a population of sixty million. Over the last two decades, Thailand has been transformed from a subsistence agrarian society into a rapidly industrializing, free-market country. This change has affected not only the labour structure, income distribution and migration patterns, but also disease patterns. Thai society is experiencing a morbidity transition wherein the diseases of affluence are increasing, traditional infections are diminishing, and certain emerging and re-emerging infectious diseases continue to threaten the progress made.

The changes in the economic structure from an agriculture-based to an industry-based economy, with a high concentration of the service sector in the metropolitan area, has brought about large-scale, rural-to-urban migration of labourers who often leave their families behind. Extended families give way to nuclear families, in which often both father and mother have to struggle to earn a living. This is gradually resulting in the breakdown of family ties. This situation has become worse with the influx of Western influence, as well as that of information technology and various forms of non-indigenous entertainment – all of which have affected national and regional culture and traditions.

OVERVIEW AND CONTEXT

HIV/AIDS epidemiology
It is just more than a decade since HIV/-AIDS emerged and spread in Thailand. With the effective HIV surveillance system in Thailand, data are now available to track prevalence, temporal trends and incidence. To date, 850,000 cases of HIV infection have been recorded in the country, although the real figure is estimated to be much higher. The predominant means of HIV transmission has changed over time. In 1984, the first cases of AIDS were recorded among homosexual men. Three years later, the importance of male-to-male sex as a risk factor was quickly overshadowed by the rapid increase in infection among injecting drug users, followed by a parallel increase in seroprevalence among female sex workers. Subsequently, the third wave of infection appeared in clients of sex workers, reflected in an increase of seroprevalence among men attending government sexually transmissible diseases clinics. The fourth wave indicates a spread to the wives and girlfriends of men who visit sex workers, reflected through increasing seropositive rates of women attending antenatal clinics. As a result, the incidence of reported paediatric AIDS cases also increased and can be observed as evidence of the fifth wave of the epidemic.

History and structure of community-based response
Communities in Thailand may be economically poor, but they are culturally rich. The major richness lies in their human resources and the social and cultural values that have been transmitted through generations. 'Community' in Thailand is understood as:

■ geographical community: these are village communities (70,000 in the country) or slums in urban centres (1,000 in Bangkok, 26 in Chiang Mai);

- groups of community-based organizations (CBOs) from many village communities, linked together through networks around particular issues (environment, agriculture, HIV/AIDS, etc.) or according to geographical areas (district, province, region);

- groups of individuals according to their status: monks, teachers, academics, business people, students, sex workers, factory workers, gays, and NGO workers.

- 'communities of needs' or 'communities of life': group of individuals linked by common interests needs, problems, goals and activities, e.g. people with HIV/AIDS groups, associations or clubs.

Thailand is traditionally a patronage society where the government provides a wide range of social services for its people. At present, the governmental system is highly centralized and not necessarily responsive to community involvement. In addition, international development assistance partners are inclined to promote the policies of their respective organizations rather than cater for different priority needs of the people. In rural areas, villagers are being incorporated into health schemes through the establishment of local networks that link village-based volunteers with government or development agencies. Although top-down education programmes have alerted the Thai population to the present and potential threat of HIV/AIDS, this information alone has not resulted in behaviour change. Local participation in community-based projects is crucial to complement national initiatives, both to personalize their relevance and to develop appropriate responses that fit community practices and needs.

Since the first National Economic and Social Development Plan was launched in 1961, Thailand has had a consistent economic growth rate averaging 8 to 9% per year (with 12% in 1989–1990). Despite the high growth rate, the gap between the rich and the poor is widening. Educational and political systems are weak. This is the socio-economic context in which the HIV epidemic emerged and through which it has grown rapidly.

The economic development in the past decades has resulted in new social problems: migration from rural to urban centres (more than 1,000 slums in Bangkok with 1.5 million slum dwellers); disintegration of traditional community and values; deterioration of environment (reduction of forest areas from over 60% in 1961 to about 19% in 1990); prostitution; child labour and child prostitution; drug use; and crime. The urban and industrial society has been extended without appropriate societal and cultural binding, resulting in deterioration of its social structure. Thus, some sections of the urban community have become marginalized and vulnerable.

In many parts of the country, especially the north and the north-east, village communities are deserted, particularly during the dry season. Most young people and adults migrate to urban centres or other regions in search of work. They are to be found in construction sites, in factories, in service enterprises such as restaurants, hotels and tourist sites, in gas stations and garages, in rubber and cash crop plantations, and on fishing boats. About 300,000 Thai workers are to be found in Taiwan, Japan, Brunei, Hong Kong, Singapore and the Middle East. At the same time, there are more than one million migrants from Thailand's neighbouring countries who cross the borders to find work in Thailand.

During the past two decades, the government, realizing the effects of economic development, has placed particular emphasis on rural community development. In most of the 70,000 village communities in the country, there are community-based organizations supported by government and non-governmental organizations (NGOs)

or initiated by the villagers themselves. These include groups for farmers, women, youth, rice banks, medicine banks, cooperative shops, savings groups and handicraft groups. There are also public health village volunteers trained by the Ministry of Public Health as part of the primary health care programme.

For several decades, various NGOs throughout Thailand have made attempts to generate fundamental changes to social and political systems. There are approximately 200 to 300 NGOs that have set up operations in the past fifteen years. Although some may more actively challenge the dominant ideology than others, they frequently undertake activities to correct inappropriate government policy. Health is usually considered within the broad perspective of integrated community development and, at face value, this is very similar to the goals of the government's Primary Health Care programme. NGOs frequently act as coordinating bodies, and it is in this capacity that there is some uniformity in their functioning. Their role of developing links with the hard-to-reach communities, the private sector and the government are imperative to strengthen the foundation of civil society.

Besides many existing community-based organizations in most village communities, there are new community-based organizations being formed to deal with HIV/AIDS problems in the community. Although some models of CBOs were promoted and supported by local government organizations at the beginning of initial response to HIV in 1991, the number has not increased. A small number of village communities have formed extra CBOs to deal with HIV/AIDS. In these situations, they have preferred to include HIV/AIDS as an integral part of community development activities. Many NGOs and scholars who are experienced in community development have adjusted their role to strength-

ening community organization in order to cope with HIV/AIDS related problems. The lesson learned from a decade of working with community has culminated in clearer policies to counteract HIV/AIDS.

The current strategies from the National AIDS Plan for strengthening social support are aimed at two important targets. The first strategy is targeted at community involvement and organizations that encourage a healthy lifestyle as a social norm and foster community action for health. The second strategy targets systems that provide the infrastructure for health care services and related development activities that have an impact on health. Both of these strategies need to be supported and instilled into community awareness.

Role of NGOs
The rapidly increasing number of NGOs has contributed to a multisectoral and holistic approach, and HIV/AIDS has become an integral part of community development programmes. NGOs cooperate well with government organizations at national and local levels. In 1995, the Ministry of Public Health granted about US$200,000 to NGOs involved in HIV/AIDS. In 1996 the budget was increased to US$3.2 million for NGOs and PLWHA groups.

NGOs involved with HIV/AIDS can be roughly grouped according to their target groups. They have an important role in coordinating groups of people with HIV/AIDS groups and are the main players in advocacy and human rights. Initially, NGOs were involved in HIV/AIDS counselling activities and raising public awareness. Their targets were the general public (hot-line telephone counselling, radio programmes), school and college students, commercial sex workers, factory workers, gay communities, poor urban and rural communities, advocacy and human rights. Since 1991, NGOs working in a range of

community development and other programmes have broadened their involvement to include HIV/AIDS. An important part of their work with communities has been to organize seminars and training programmes for representatives from village communities.

With the exception of a few international NGOs, most involved in HIV/AIDS are small. They have only a few staff and volunteers. They usually have no legal status; however, this does not prevent cooperation with government organizations and other agencies, including receiving financial support from government and the business sector. NGOs are also supported partly by international NGOs, bi- and multi-lateral organizations, and partly by the Thai government through the Ministry of Public Health and the business sector.

A good example of this work is the Thai-Australia Northern AIDS Prevention and Care Programme (NAPAC), a bilateral project located in Chiang Mai. Since 1993, NAPAC has been providing financial and technical support to many NGOs, CBOs, PLWHA groups and some projects by local government organizations in Chiang Mai, Chiang Rai and Phayao provinces in the North. NAPAC is a new model of support organization or donor located close to communities instead of being based at the central level with a ministry in Bangkok. It has significantly contributed to the role of 'communities' in HIV/AIDS prevention and care, not only in the Northern region but also for the rest of the country and other countries in this region. NAPAC has encouraged and supported the formation of PLWHA groups and their network in the North. NAPAC also has a resource centre to coordinate and disseminate information to local agencies working at community level. At the same time, it acts as coordinator between local implementing agencies, communities and policy makers at local, national and international levels. NAPAC

has become an important catalyst, facilitating platforms and opportunities for meetings of field workers, local government organizations, NGOs, CBO leaders, academics, researchers, and policy makers.

CONCEPT OF PREVENTION

The concept of HIV/AIDS prevention has rapidly evolved during the last decade. This dynamic response to the epidemic has led to changes in approaches from the individualist and information-driven notions of HIV/AIDS education to more multidimensional models of collective empowerment and community mobilization, as these provide a more effective strategy for the long term.

Over the first decade of the epidemic in Thailand, HIV/AIDS prevention principles were dominated by the notion of 'individual risk', i.e. that specific behaviours which open the way for HIV transmission are linked to individual attitudes and beliefs. After years of deliberation by the academic community and the experience of AIDS activists in the country, this conception of risk was broadened to a more collective social configuration. This paradigm shift was reflected in the National AIDS Plan for the period of 1992–1996, then reformulated in the strategic plan for 1997–2001. This demonstrated the shift from the notion of individual risk to a new understanding of 'social vulnerability'.

Another important issue concerns the scope of implementation of HIV/AIDS programmes. In the first few years of epidemic, government sectors and some NGOs with international financial support played a major role in the HIV prevention programmes. In the early 1990s, the government initiated a national programme with a fiscal budget and provided a leadership role through the National AIDS Plan. A few years later, more partners – the private

sector, community-based organizations and the academic community—participated in this programme, thus expanding the civil response to HIV/AIDS. The nature of the programme changed from a project-based approach to an empowerment approach, which allowed participation with equity.

Another important issue was the concern about PLWHA. In the early days of epidemic, the crucial aim was to prevent the transmission of HIV. Within a decade, it was realized that the HIV epidemic had become endemic, with nearly a million people infected with HIV in the country. Medical and social technology to treat PLWHAs developed rapidly and HIV/AIDS has almost become a manageable chronic illness. Programmes now focus on PLWHAs as an essential human resource to prevent further transmission, rather than as a consequence or reservoir of the epidemic. Collaboration with PLWHAs has been developed, and they are partners in planning and in the implementation of a wide range of prevention programmes from the national plan to community action.

Specific approaches to prevention

■ Information
The HIV sentinel surveillance programme is an information system developed in 1989 to trace the magnitude of the disease in Thailand. Information from this system has enabled social and behavioural research to be developed, and has provided for policy makers with useful data and the public with innovative forms of knowledge. It has been a challenge to change the beliefs of different sectors of the society toward the people with HIV/AIDS and to eliminate discriminatory practices. Collaboration between the media, journalists, NGOs and entertainment leaders has been used to develop public information to mobilize society

around a common objective to fight together against discrimination and stigmatization.

■ Media
In Thailand, television is a primary source of knowledge about HIV/AIDS prevention. Since 1990, warning messages about HIV/AIDS have been aired regularly and repeatedly on television as part of the national strategy to minimize transmission of HIV. The education and prevention messages chosen do more than suggest measures to avoid infection. They have also tended to define the characteristics of people who are signified as threatening agents of infection. In Thailand, sex workers and drug users are portrayed as the 'feared other'. Because sex work is so widespread, the demarcation of sex workers as a high-risk group signals a threat that cannot be easily subjected to conceptual distancing.

■ Condom campaign
The *100 percent Condom Campaign* has contributed significantly to the decrease of HIV transmission among female commercial sex workers and their clients. The programme was invented and developed at the end of 1980s and launched as an innovative national programme in 1991. Under this programme, the government provides condoms and education through existing STD clinics to sex workers and at the same time encourages brothel owners to insist on their clients using condoms. The increasing rate of condom use in commercial sex has been reported as evidence of this successful programme.

■ Multisectoral approach
Educational and service programmes have learnt that they have a limited influence on the reduction of HIV transmission without the involvement of the infected community. By 1995, the approach to HIV/AIDS prevention at the community level gradually became 'holistic', with a focus on strengthening the community and developing a

greater level of self-reliance economically, socially and culturally. Holistic also means multisectoral and integrated community development, an approach represented in the statement 'Only if the community is strong, will we be able to cope with HIV/AIDS'. To reach this level of self-reliance, people need to be involved in their own community development. They have to play a major role in all programmes and projects. To this end, local community initiatives are promoted.

■ Workshops and group interaction

During the recent years, there was a shift from presentations in big seminars and training to small workshops, focus groups, and more interpersonal and interactive methodology, from mass media to more local and cultural media with local community participation, taking cultural diversity into consideration.

■ Community involvement

Community leaders have played a significant part in raising awareness and reducing fear. At the beginning of the social intervention period, stigma was a major problem of HIV/AIDS, and it was foreseen that many Buddhist temples would become hospices and that PLWHAs would die in the temple because they were not accepted by their families and communities. In Chiang Mai, in the north of the country, for example, a hospice run by Phra Phongthep found that most patients were taken to the hospice because relatives had an incorrect understanding of HIV/AIDS. He would spend time talking with relatives, and as a consequence many relatives would take the patient home, while others would stay at the hospice only for one or two days. Today, there are only three hospices in Thailand, two run by Buddhist monks and one by Catholic monks (Franciscans). Most of the monks involved in HIV prevention at community level provide moral support and places to meet in the community, include HIV information

in their sermons, and visit people with HIV/AIDS. Some are trained counsellors in HIV/AIDS.

Another important group at inter-village communities level are traditional healers. Only a small number of the 200,000 traditional healers in Thailand retain their traditional function and virtues. They play an important role in providing medical and psychosocial care to people with AIDS and their families. Their treatment is holistic and includes traditional use of herbs, oil, massage, alternative and complementary therapies. Many of these healers are important resource persons and are well respected and listened to by their communities.

Some new initiatives are being taken by community savings groups. These groups use part of the dividend fund from yearly profits to support families affected by HIV/AIDS. An NGO in the North has been providing matched funds (a long-term loan with an interest rate decided by the community) to these savings groups, with the condition that the profit gained should be used for the welfare of community members. Although this NGO has not directly mentioned that the group should share the profits with affected families, many groups have started to do so. Some savings groups provide members with a small sum for their hospital fees and for funeral or cremation expenses. There are savings groups in the Southern region that pay the hospital bills of members and provide scholarships to children with their self-supported welfare fund created by the savings groups. Although it is only a small amount of money, it is a meaningful act of solidarity of the community towards PLWHAs and their families. Some communities have created other forms of fundraising. One of the most popular ways is the 'Pha-pa' ceremony. It is a traditional Buddhist ceremony whereby people make an offer to the temple in cash or in kind. Many Buddhist monks have given all the offerings to set up

a fund to support people with HIV/AIDS and their families and to support HIV/AIDS activities in the community. These models have been proposed as an alternative and adjunct to government funds and may contribute to the creation of community welfare system and social security that will be important step towards self-reliance of the community.

■ Involvement of PLWHAs

The first group for PLWHAs, the 'Wednesday Friends Group', was coordinated by the Thai Red Cross Society in 1991, followed by the 'Thursday Friends Group' which set up by a branch in Chiang Mai. In 1993, the 'New Life Friends Association' (NLF) was established and this was the first group to be run by PLWHAs. The group now has several hundreds of members and is supported by NAPAC and NGOs. NLF provides counselling services to people with HIV/AIDS and their families. They also visit people with HIV/AIDS and their families in urban and rural communities and are well-recognized resource persons for meetings, seminars, training and conferences at all levels. Association members speak to village communities, to school and college students, and to Rotary and Lion Clubs. The board members identify themselves and tell their stories to the public. To date, twelve life stories of NLF members have been published by NAPAC in a weekly magazine, as a way of raising awareness and to raise funds for people with HIV/AIDS. They are now being republished by the Ministry of Education to be distributed to all schools in the country.

Soon after the formation of the NLF Association, the Widows of Doi-Saket formed their group. These women had lost their husbands to AIDS, and some of these women and their children were infected with HIV. They got together to support one another and their communities. Since many suffered financial hardship and could not continue working, they would meet at the community temple to produce brooms, clothes and other handicrafts to earn some money for their families. The Doi-Saket Widows have become well known to the public since an appearance on national TV. The Widows group has now changed its name to the 'Women's Friendship Group' as most of its members have remarried. They actively participate in the district AIDS programme of Doi-Saket, one of the most successful examples of HIV/AIDS prevention and care programme at community level. Today, there are twenty-six groups representing people with HIV/AIDS in the Chiang Mai province, about thirty groups in the other provinces of the North, and about eighty groups in the whole country. They can be grouped as following :

■ self-organizing groups, such as NLF and Widows group;

■ groups initiated and supported by NGOs;

■ groups initiated and supported by community hospitals;

■ groups initiated and supported by Buddhist monks and temples.

Most of these groups are situated in communities. The NLF and a few other groups are located in towns. They have between 50 to 200 members, and most of these members are full-time or part-time volunteers, providing service to their members, families and communities. They visit families, give counselling and information about basic health care, help solve psychosocial problems, assist and coordinate support with hospitals and local government organizations and NGOs. Some of them have become community 'leaders', not only in HIV/AIDS but also in other matters of community concern.

■ Research institutions

Academics and researchers have participated in HIV prevention and care, not only

through their research activities and contribution to medical and social science, but also through direct involvement in communities in urban and rural areas. They have been resource persons for seminars and training for government organizations, NGOs, CBOs, PLWHA groups, providing information and technical support. Involvement of social researchers commenced in the late 1980s. Many researchers have been catalysts for HIV prevention activities. They have coordinated meetings of government organizations, NGOs, CBOs, PLWHA groups, to assess situations and discuss issues for cooperation among local organizations. They process data and information, especially 'lessons learned', and facilitate forums for the exchange of information.

The Social Research Institute (SRI) at Chiang Mai University has played an important role in facilitating the process of learning for all parties involved in HIV/AIDS. They have developed a number of participatory action-research projects within communities. SRI has also given technical support to the networks of NGOs, groups of PLWHAs, traditional healer groups, CBOs and Buddhist monks activities. SRI also includes HIV/AIDS in their other projects including environmental CBOs and NGOs, advocacy and human rights groups. Some SRI and Faculty of Education researchers are directly involved in the application of Participatory Rural Appraisal (PRA). They are important resource persons for the training of trainers, not only in the Northern region but also in neighbouring countries. Many of them have been working directly with slum communities, construction workers living at the construction sites, and street children. They assist schools with curriculum development in applying PRA and Life Skill training in the schools. The Women's Study Centre at Chiang Mai University also plays an important role in HIV prevention. In addition to organizing meetings, seminars and workshops on women and HIV/AIDS, it conducts and coordinates many participatory action-research projects.

In addition to major universities in Bangkok and three other regions (Chiang Mai, Khon Khaen, and Songkhla), there are thirty-six Rajaphat Institutes (former Teachers Colleges) located mostly in provincial towns all over the country. Many of these are involved in HIV prevention programmes. Since most of the students are from the rural areas, they have great potential to work with communities. Rajaphat Institute, Chiang Rai, is known for their HIV/AIDS prevention programmes in communities and their projects with traditional health care. This Institute is also known for its involvement with farmers' cooperatives, savings groups, and Life Skills training for street children in Chiang Mai. An important role for academics and researchers has been to monitor and evaluate HIV/AIDS prevention and care programmes and projects implemented by government organizations, NGOs, CBOs and PLWHA groups.

COMMUNITY AND GOVERNMENT

The Ministry of Public Health has played a major role in facilitating and coordinating the HIV/AIDS partnership. At provincial level, the governor heads the provincial AIDS committee, with a provincial chief medical officer as secretary, and representatives of other ministries as members. At district level, the head of the district chairs a district AIDS committee, with the district public health officer or director of community hospital as secretary, and district representatives from other ministries as members. Health officers are appointed to provide care at this level and their activities include home visits, facilitating focus groups in primary and secondary schools, colleges and universities, collaborating and

coordinating with other local government organizations, NGOs, CBOs, and PLWHA groups. In every province, an HIV/AIDS Foundation has been established to raise funds to support HIV/AIDS prevention and care programmes. The Ministry of Interior, Ministry of Labour (with its Department of Welfare and Department of Human Resource Development) and Ministry of Education actively participate in the HIV prevention programmes at provincial, district, sub-district and village community levels.

Phayao, a small province in the North, has become a model for all other provinces in the country for HIV/AIDS prevention and care. It has set up a provincial AIDS centre, which provides information, health promotion resources, and coordinates human and financial resources from all ministries, including plans and action programmes. In 1994, the centre trained trainers and a group of resource persons from all ministries in the province to train others at district, sub-district and village community levels. About 650 resource persons have been trained through the PRA method. The aim of this programme is to assist CBOs in all village communities to plan and undertake their own actions. They are supported by seeding funds from the provincial AIDS centre.

At a district level, heads of districts coordinate representatives of other ministries to strengthen communities. There are groups of volunteers consisting of teachers and representatives of ministries, heads of village communities and CBOs, and PLWHAs who facilitate focus group discussions not only to raise awareness of the community, but also to prevent and solve problems related to HIV/AIDS. The communities are given a major role in solving their own problems. The government organizations provide them with facilities, seeding funds and advice. The Ministry of Labour has also established workplace HIV prevention programmes, which includes seminars and training are organized for both owners, human resource managers and workers. Some of the events are organized jointly with NGOs.

Schools curricula include HIV/AIDS education. Although the majority of schools still follow the curriculum developed at the Ministry of Education in Bangkok, there are some schools that have developed their own HIV prevention programmes. Within many schools there are teachers who are actively involved in community activities and where there is close cooperation with communities and NGOs. They have anti-AIDS clubs, in and outside of school activities, organizing youth camps, drama groups playing in schools and in communities.

The Bangkok Metropolitan Administration has its HIV prevention programme in all its districts through community health centres and hospitals. This includes the 'Friends Help Friends' project, curriculum development for schools, and support to NGOs working in slums, with street children, factory workers, sex workers, the gay community, and other specific target groups and areas. Besides counselling, the programme includes home health care and urban community development schemes.

National policy
From 1984 to 1990, HIV/AIDS was perceived to be a newly emerging public health problem. The Ministry of Public Health became a major player in determining national policies and strategies for HIV/AIDS. In 1991, there was a turning point in the Royal Thai Government's AIDS policies, strategies and programmes. The epidemic had spread to all sectors of the society and it became apparent that more concerted efforts and innovative strategies were needed. Hence, the National AIDS Prevention and Control Committee under the chairmanship of the Prime Minister was established. Members

of this committee comprised representatives from the government sector, the private sector, NGOs and academia. In the current National AIDS Prevention and Control Committee there are two members who are representatives of PLWHAs.

It was recognized that a comprehensive multisectoral approach was highly desirable, and efforts were undertaken to involve all government agencies, NGOs, the business sector and the community. As it was seen as a national development issue, the National AIDS Prevention and Control Plan for 1992–1996 was formulated under the coordination of the office of the National Economic and Social Development Board (NESDB), which is the national planning authority. This was to ensure smooth cooperation among the government agencies, NGOs and the private sector in formulating a comprehensive action plan for the medium term. According to this plan, government funding was allocated to meet the initial demands. In 1993, all fourteen ministries submitted funding requests in accordance with the programmes specified in the National AIDS Plan, amounting to US$44 million. The National AIDS Programme's budget was subsequently increased to US$82.3 million in 1996.

In 1995, the national strategic plan was revised and the National AIDS Prevention and Alleviation Plan for 1997–2001 was formulated to address another crucial turning point in HIV/AIDS government policy. The plan shares concepts and features of the National Development Plan, which are holistic, people-centred and participatory. A crucial focus of the strategy is empowering the people to prevent and solve HIV/AIDS problems with their families and communities, and to creating an enabling environment. In the next five years, the plan will provide a management approach to strengthen civil society and to increase the efficiency, flexibility and accountability of the civil services, in order that it can respond to local problems more effectively. In this sense, the national HIV/AIDS plan will be an effective mechanism for enhancing as well as accelerating the development of the whole nation.

MEASURES OF SUCCESS

The indicators to measure the success of interventions to contain the HIV epidemic are:

- **Epidemiological indicators**
HIV epidemiological data have revealed that the rapid upsurge of HIV infection among injecting drug users and sex workers has not been matched by interventions among these groups, e.g. the prevalence of HIV infection among injecting drug users is as high as 46.7%. Government suppression of sex work in 1995 resulted in difficulties in accessing these people, so sex workers were not categorized and the rates of HIV infection among this group appeared low at 16.7% in June 1996. These indicators reflect the failure to stop transmission in these vulnerable populations.

Since 1991, there has been an aggressive approach to HIV public education for the general population. This appears to have resulted in an increased knowledge and behavioural change among some population groups, in particular young men. HIV seroprevalence rates among new military conscripts reflects this behaviour change among young Thai men. Surveys of army conscripts are conducted annually in May and November. The peak of HIV prevalence was about 4% in May 1993 and then declined to 1.9% in November 1996. A behavioural study of the sexual behaviour of army conscripts in the last few years found a decline in visits to sex workers, while those attending brothels were using condoms more often. These changes of

practice were seen to be associated with increased knowledge of HIV/AIDS. Another change has been in rates of infection among antenatal clients. Within this group, HIV had been gradually increasing since 1991; in June 1995, rates of HIV began to decrease from 2.6 % to 2.3 % in December 1995 and to 1.7% in June 1996.

Social indicators
The public in Thailand appears to be 'getting used' to HIV/AIDS. However, the level of acceptance of people with HIV/AIDS varies between urban and rural areas, and among rural village communities from one district to another, one province to another, one region to another. In the three Northern provinces, where HIV prevalence includes about half of the total number of people with HIV/AIDS in the country, and where HIV/AIDS prevention and care programmes have been intensively implemented since 1990 by government organizations, NGOs, CBOs and PLWHA groups, the level of awareness of communities is high compared with neighbouring provinces.

In most communities, PLWHAs live ordinary lives as community members cared for by family members, relatives and friends. This generally is the case for PLWHAs who were 'good' members of the community, particularly women infected by their husbands. There is still discrimination towards those who are considered less worthy of care, and they are often left to care for themselves within their communities. In many rural areas, PLWHAs are often known in their communities. Some choose to reveal themselves, while others are known about. Many of them join PLWHA groups near their home. The level of acceptance of HIV/AIDS among communities is reflected in the number of PLWHA groups and a large number of people within communities becoming volunteers. Forming groups of people with HIV/AIDS does not mean creating separate identities that may isolate people with

HIV/AIDS within communities. It becomes a means to an end. PLWHAs are developing solutions to their own problems, which existing CBOs cannot always address. Through forming a group, they can also assist the community in both prevention and care activities. One major measure of success is that now more and more communities, rural and urban, are supported by government organizations and NGOs in taking a leading role in HIV/AIDS prevention and care. They actively participate in the decision-making, planning and implementation of projects within their community. HIV/AIDS is integrated into general community development programmes and new initiatives are emerging which will lead to greater self-reliance and sustainable community development.

AT WHAT COST?

Government budget
In 1988, the initial funding for the National AIDS Programme was US$ 180,000 million. The budget in the first few years covered the dissemination of educational messages and health care re-orientation to ensure the safety of all health facilities. Under the National AIDS Prevention and Control Committee, the national budget in the financial year 1992 was increased to US$25.5 million and around 50% of this was for education, information and communication. In 1996, the budget increased to US$82.3 million for the National AIDS Prevention and Control Programme. Around 40% of the budget was used to strengthen the medical care and health care for people with AIDS, while prevention efforts were funded through another 40% covering socio-behavioural modification and HIV medical safety. Social welfare activities for the people with HIV/AIDS and their families amounted to 8% of the budget. The rest of the budget is utilized for research and administrative activities.

Community resource mobilization

Resources are provided by the government, local and international NGOs, bi- and multi-lateral organizations; however, the business sector has yet to find its place. It is hoped that tax incentives will encourage further resources from the business sector. Much is still to be done in workplaces and there is an urgent need to involve the community of 'business people'.

As Thailand is becoming a newly industrialized country, there is less and less financial support from international NGOs, bi- and multi-lateral organizations for local NGOs. Prevention and care programmes have to rely more and more on local resources from the government and from the public. It is a challenge for them to create mechanisms to pull resources from various sources within the country to ensure the sustainability of programmes. It is not only the funds, but how to combine fund-raising and awareness-raising in the same activities, and how to include them in the process of learning and in the process of development.

LESSONS LEARNED

For a sustainable HIV/AIDS prevention and care programme, all kinds of communities need to be involved. They must have an active role in decision-making, planning and implementing prevention and care programmes. Government organizations, NGOs and other parties should support their efforts and initiatives. While rural communities seem to be on the right track, much is still to be done as far as urban communities are concerned. There is much to be done to strengthen civil society, especially urban centres, service and industrial sectors. Gender issues need to be addressed and programmes that enable financial support and improve the status of women need to be developed. Additionally, there needs to be contributions from the academics and researchers towards greater understanding of gender issues.

The most important lesson learned is the possibility of working in partnership. Government organizations, NGOs, CBOs, PLWHAs, academics and business people are major partners. Where they have been able to work in partnership, half of the success is already ensured. Partners have to have a common understanding at least of the basic issues, starting with developing human and personal relationships. Not everybody can become partners and work in partnership with others. It is about creating a 'strategic alliance', where it is essential to identify who will be included, how the alliance will be developed, and how partnership arrangements will work in practice.

Many resources exist within communities and much needs to be done to mobilize all possible resources. There is a need for innovative strategies and mechanisms to raise resources. Matching village funds or savings group to create sustainable community welfare systems is one feasible and practical strategy. PRA, Life Skills and focus groups are examples of how to involve communities. Tax reduction for a company's investment in education and welfare measures for people with HIV/AIDS in workplaces is a potential means for more active involvement by the private sector. In each 'community', there is an urgent need to develop appropriate mechanisms to raise the awareness and involvement of its members.

The holistic approach is most appropriate to deal with HIV/AIDS. Only integrated, multisectoral community development can make it possible for communities to cope with this disease. HIV/AIDS has necessitated cooperation of all parties to work together. Even if, one day, there is a vaccine against HIV/AIDS, the better 'vaccine' is family warmth, love and compassion,

values of life, strong community, self-help organization and self-reliance.

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EXPERIENCE FROM UGANDA

by Dr Elizabeth Madraa, Programme Manager, STD/AIDS Control Programme, Ministry of Health, and Major Ruranga-Rubaramira, Assistant Administrator, Coordinator, Ngeni National Guidance and Empowerment Network of PLWHIV/AIDS in Uganda, Joint Clinical Research Centre, Kampala.

INTRODUCTION

Uganda ranks among those countries hardest hit by HIV/AIDS. Despite this, the country is fortunate to have strong political support for the control of the epidemic and a government policy of openness on AIDS. This has prompted a number of intervention strategies such as political involvement, the establishment of the Uganda AIDS Commission and National AIDS Control Programme, encouraging community response and involvement, a multisectoral approach, and fostering research. Various studies have shown that today in Uganda there is a high level of HIV/AIDS awareness, over 80%. There is also encouraging news from population-based KAPB (knowledge, attitude, practice, behaviour) studies carried out in various districts in the country, which show a change in sexual behaviour particularly among the youth.

OVERVIEW AND CONTEXT

HIV/AIDS Epidemiology

It is estimated that there are 1.6 million people with HIV are living in Uganda, which represents 8% of the total population and around 15% of all sexually active men and women (UNAIDS 1997). The reported cases of AIDS at March 1996 was 48,312 (Uganda Ministry of Health 1996), although it is suggested that the number of AIDS cases is more likely to be around 500,000. Surveillance data also show that there are much larger numbers of young women with AIDS than young men and there is a concentration of cases of AIDS in the city areas, especially around the capital, Kampala, in southern/central rural areas, and in the war-torn district of Gulu in the North (Uganda Ministry of Health 1996).

Some information about Uganda

Uganda is one of the countries of East Africa, bordered by Sudan in the north, Kenya in the east, Tanzania in the south, Rwanda in the south-west and Zaire in the west. In 1996, Uganda had a population of about 21.3 million people with four main ethnic groups (Bantu, Luo, Nilo-hamites, and Nilotics) and over twenty tribes. The cultures are as diverse as are the tribes. The majority of Ugandans are Christians (Catholic, Church of Uganda, Orthodox, and Seventh Day Adventists), with Moslems forming the minority. There are strong cultural ties among the tribes of Uganda giving rise to tight but open inter-tribal communities. Politicians have used this in the past as a divisive element, giving rise to a number of civil wars and tribal stress. The civil wars have directly affected the economic status of the country, resulting in high poverty levels in some war-torn zones. This has hampered the delivery of social services like health.

Uganda is a developing country with a gross domestic product (GDP) per capita income of about US$160, 40% of which is non-monetary. Ninety-one percent of Ugandans live in the rural areas, with the majority involved in subsistence farming. There is a clear difference between the urban rich and the rural poor, with the literacy level low in rural areas. About 49% of the people have access to basic health services. Although Uganda has gone through much political turmoil over the past ten years, the country has been through a period of recovery that has improved the infra-

structure and social services. The country recently accomplished the election of the first democratically elected President.

**History and structure of
the community-based response**
The first AIDS cases in Uganda were recognised in 1982 in Rakai district, situated in the south-western part of Uganda. Although AIDS was recognised at this time, there was a 'silence' about the disease until 1986, when President Kaguta Yoweri Museveni came to power. This long period of silence coupled with the political turmoil could have contributed to the rapid spread of AIDS in the country. Soon after gaining power, President Museveni recognized, acknowledged, and was open about the existence of AIDS in the country. He immediately requested a donor's conference, which was held in Kampala, and this led to the establishment of the National AIDS Control Programme (NACP) within the Ministry of Health with support from WHO's Global Programme on AIDS (GPA). One of the largest AIDS prevention campaigns ever mounted in Africa soon followed. This campaign dealt almost exclusively with prevention of transmission and advised people to 'love carefully' and 'love faithfully', giving little regard to the fact that there were already people being diagnosed with HIV and AIDS. The impact of this campaign enhanced fears of contagion among the population and resulted in discrimination and stigmatization of people with HIV/AIDS. As a result, families failed to care for their loved ones and many health care workers expressed prejudice in using scarce resources to care for AIDS patients who were 'going to die anyway'.

In some areas, community groups began to spring up where there was a gap in services. For example, the Christian church spearheaded AIDS care services in Uganda, led simultaneously by religious sisters at Kitovu and Nsambya Hospitals. These two hospitals, Kitovu in a rural area and Nsambya in an urban area are situated where the HIV epicentre was first located. Government efforts to care for AIDS patients were spearheaded by a physician, Dr. Katabira, responding in 1987 to the increasing numbers of AIDS patients he was seeing by setting up the first AIDS referral clinic at Mulago government hospital. It was also in early 1987 that Christopher Kaleeba, who had been diagnosed with AIDS while studying in England the previous year, died at Mulago hospital. Prior to his death, he and his family had experienced stigma and rejection, which had led them to seek support and to want to share their agony with other families with similar experiences. They formed a support group named TASO (The AIDS Support Organization) and began to advocate for care and support, not only for AIDS patients, but also for persons and families living with HIV, by example and practical demonstration of what could be done. This triggered a powerful care and support movement under the slogan 'living positively and dying with dignity'.

AIDS service organizations (ASOs), covering activities ranging from awareness promotion, counselling and testing, legal advice, and care and support of infected and affected persons, sprang up with moral support and technical guidance provided by the government through the NACP. This trend has continued, allowing Uganda to demonstrate a unique partnership which has been the foundation of the current strides made in the national HIV/AIDS response. There exists today in most urban areas in Uganda a comprehensive approach to respond to the HIV epidemic, with both government and community groups involved in providing a range of programmes. These ASOs or NGOs include:

- women's groups: Uganda Women Foundation Fund, Slums AIDS Project, Uganda Women's Effort to Save Orphans;

- religious groups: World Vision, Islamic Medical Association of Uganda, Baptist Student Ministry, Uganda Catholic Secretariat, Protestant Medical Bureau, Church Human Services Association (Church of Uganda);

- youth groups: Uganda Youth Network on AIDS, Uganda Youth Development Link, Uganda Youth Anti-AIDS Association;

- other organizations: TASO, AIDS Information Centre, AIDS Care Education and Training, Uganda Red Cross, Federation of Uganda Employers.

The majority of these groups and organizations are providing information, education, care and support of infected and affected persons as well as counsellor training. Government and mission hospitals provide hospital care, and there many families and community groups which are providing much needed home care for people with AIDS.

The stage for the Ugandan community response to HIV/AIDS may have been set well before the onset of the HIV epidemic. The people of Uganda have had well-established community structures: one belonged to a family and the family belonged to a clan and the clan belonged to a tribe. Another example is the unity within a given village. It was easy for a neighbour to be assimilated into a family to which he or she did not necessarily belong even as a clan member. These structures had well-established cultural norms, which made it easy for the community to respond promptly to any threats, whether these were natural disasters, wars or epidemics. The onset of the HIV epidemic was seen as a threat to the existence of the community. Initially, communities turned to supernatural powers, and when they saw no immediate response they turned to the government. Once activated, the government responded immediately to the community

concern. The Ministry of Health was charged with the responsibility of handling the epidemic by developing intervention strategies, and its medical services were responsible for the treatment of AIDS-related complications. They were also charged with the responsibility of ensuring that there was screened and safe blood for transfusions.

CONCEPT OF PREVENTION

The first health promotion campaign started with a cultural signal of the beating of the drum on radio and television to warn people of the HIV/AIDS danger. Due to similar cultural influences, most of the original messages were threatening and embedded in fear. The initial response was the responsibility of the NACP, which was charged with mobilization of resources, developing intervention strategies and surveillance of the epidemic. These included the development and production of posters, pamphlets, booklets and use of mass media.

The epidemic of HIV became increasingly difficult to monitor, and the Ministry set up a surveillance system specifically to monitor HIV/AIDS trends in the country. Although the district hospitals were charged with passive surveillance, the district health educators were responsible for the implementation of health promotion interventions. Drama, songs, films, and even the churches and mosques were used to pass on HIV/AIDS messages. Both these government and cultural institutions made it easy for the messages to get to the communities. This was primarily through the political structures of local counsellors who through their administrative systems assisted in setting up strategies at the local level. Alongside the government response to the epidemic, the community started a number of intervention strategies to complement government efforts.

The approach to prevention has changed over time as new ways of imparting information and education have been developed based more on positive messages. Early in the epidemic, the NACP invited a prominent Ugandan pop musician with HIV/AIDS, Philly Bongoley Lutaaya, who was living in Sweden, to return home to Uganda to help with the prevention response. Increasingly, PLWHAs have become involved as educators within their communities, and this approach has helped to reduce stigma and community fear as well as build community awareness of HIV and strategies for behaviour change. Prevention and care are to a large extent integrated at the community level, where community groups and organizations are providing both education to those at risk of HIV and support to those most affected.

There are currently two main strategies for health promotion in Uganda. These are promotion of safer sex behaviours and the prevention and treatment of sexually transmissible diseases (STDs). Strategies to promote behaviour change include condom marketing and distribution, radio and TV advertising, peer education, and use of PLWHAs as educators. There is also an increasing focus on prevention and treatment of STDs as part of a broader approach to HIV/AIDS health promotion, and the STD Control Programme has now merged with NACP at the national level, allowing for a more strategic approach to management of sexual health.

■ **Multisectoral approach**
The use of a multisectoral approach and community involvement has enabled the government to undertake a greater range of prevention strategies. With the increasing prevalence and growing numbers of people with HIV/AIDS and deaths from AIDS, and the potential socio-economic impact of the epidemic, the government was convinced that this was a problem that could not be handled by Ministry of Health alone. As a result, a range of sectors, government ministries, NGOs, both local and international, CBOs, religious organizations and other bodies came together in a multisectoral setting to consolidate care and prevention interventions. With this approach, individuals at the grassroots level have had greater access to care, counselling, education services and prevention information, and this has enabled many more people to access information on factors that predispose them to the risk of HIV infection. These factors include the cultural barriers to behaviour change and risk situations, such as uncontrolled alcohol consumption, multiple sexual partners, and unsafe sexual practices.

■ **Community involvement**
The success of Ugandan prevention efforts would not have occurred without the intensive participation and involvement of the community leaders. After an initial sensitisation and training, community leaders were involved in the mobilization and dissemination of health promotion activities. Community groups have also used innovative means in music, dance and drama to bridge the knowledge gap, and to appeal to people's emotions and change their attitudes. Local talented artists have produced plays in local languages to appeal to different audiences.

■ **Involvement of PLWHAs**
The willingness of PLWHAs to participate in the prevention interventions contributed to the positive coping mechanisms for those who are infected and silent. It also empowered individuals, especially young people, to take personal responsibility for remaining uninfected. This willingness also contributed to the high level of acceptance PLWHAs and the establishment of the Legal and Ethics Network. This network helped to respond to discriminatory practices that threatened the rights of PLWHAs in workplaces and within their communities. PLWHAs have also formed their own

networks to respond to care and prevention intervention.

A prominent example of a PLWHA organization is the Philly Lutaaya project. This initiative is named after the musician Philly Bongole Lutaaya who, after being diagnosed with AIDS, spent the last year of his life leading a campaign to give AIDS a human face. In this initiative, young men and women living with HIV volunteer to be trained in communication skills and then offer testimony of their experiences in order to mobilize communities to change risky sexual behaviour and reflect on their attitudes towards PLWHAs in their own communities. They also carry the 'Living Positively' banner from village to village, through music, drama and face-to-face discussions. This has proved to be a crucial tool in a country where a large percentage of rural people cannot read or write. It has also given AIDS a human face in Uganda.

COMMUNITY AND GOVERNMENT

As important aspect of the Ugandan response has been the collaboration between a broad range of community, government and donor agencies in the struggle against HIV/AIDS. The openness of the government has created a conducive environment for interested agencies and organizations working in HIV/AIDS activities to work together. Included here are a large number of international donor agencies that have contributed financially and offer technical assistance to the Ugandan government and community organizations. The government policy to adopt a multisectoral approach in the management of HIV epidemic has led to the following:

■ acceptance of sharing responsibilities in the HIV/AIDS prevention intervention and care programmes;

■ the decentralisation of implementation programmes, and the integration of HIV/AIDS services into existing structures;

■ establishment of a national coordinating body, the Uganda AIDS Commission, for all HIV/AIDS programmes in different ministries, NGOs, CBOs, etc.;

■ resource mobilization at local, national and international levels.

The Ugandan AIDS Commission was established in 1992 to coordinate national policy and provide advice to a range of other organizations, including the NACP. The Commission comprises twelve members from a cross-section of government departments, including the Ministry of Health, NGOs and religious organizations. As part of the structure of the Commission, a broad-based Advisory Committee and a number of technical committees have been established. These committees focus on speciality areas such as prevention and control, care and support, policy and ethics, research and development, and traditional practices. The Advisory Committee includes representatives from NACP, PLWHA groups and UNAIDS.

The partnership between government and community was formalized early in the epidemic when Noerine Kaleeba, one of the founders of TASO, was appointed to the first National AIDS Control committee. This committee comprised representatives from the major religious communities in the country. Increasingly, PLWHAs began to be represented on all major committees as they became more visible and involved in the response. PLWHAs are also represented on the Uganda AIDS Commission and are appointed by the President. They are also represented on all major policy and strategy committees, such as the law, ethics and HIV.

Research involvement
As has already been mentioned, the community response to HIV in Uganda was triggered by the need for compassionate care, and, as the epidemic grew, community response became more and more orient-

ed toward care and support. It is not surprising, therefore, that research efforts in the country have been influenced by this need felt by the community. Research projects whose agenda had not been planned to include care and support components have had to revise these agendas after realizing that care was a very appropriate entry point into communities who were having to bear an increasing burden of care.

Numerous research projects have been carried out ranging from behavioural KAPB studies, behavioural intervention studies, and clinical trials. There have been, for example, two notable research projects situated in rural southwest Uganda: a Medical Research Council project in Kyamuliibwa, Masaka district; and a Columbia University collaborative study in the Rakai district. These have demonstrated positive collaboration between government and external researchers, and have been instrumental in boosting the research capacity of the Uganda Virus Research Centre through staff training and support, infrastructure development and providing laboratory services to the National AIDS Control Programme, mission hospitals and other NGOs.

The initiation of these two research projects involved extensive community consultations using the popular system of governance known as 'local resistance committees'. Researchers working on these projects live in the communities where the research is conducted. Over the years, research findings from these projects have been used to structure community prevention services. For example, in response to findings and community requests, two projects are providing STD care and counselling as well as home care for AIDS patients.

Community-oriented intervention studies like the recently concluded mass treatment of STDs and the ongoing comparison study between treatment of STDs and health

education alone have cemented the researcher-community relationship. These studies were set up as community-based surveillance studies periodically (every six months) to monitor the epidemic in the community. Observations from these studies have been crucial in substantiating the NACP sentinel surveillance data that shows a fall in HIV prevalence. These projects have also shown a fall in incidence rates among specific age groups, in particular young people.

MEASURES OF SUCCESS

The political commitment of the Government of Uganda, combined with the efforts of the donor agencies, bilateral and multi-lateral, international and local NGOs, CBOs, PLWHAs, and religious organizations in the struggle against HIV/AIDS in the last decade has contributed to the following successes.

■ The HIV/AIDS awareness level is above 80%. This has been recorded by several surveys carried out within the country, recording a positive response to preventive strategies such as condom use, and the acceptability of and demand for condoms. In all peripheral health units, there is a demand for sterile and/or disposable syringes and needles. In the communities, the Traditional Birth Attendants demand protective hand gloves for delivery. Traditional surgeons for circumcision use sterile or one knife for each candidate instead of the old tradition of one knife for many candidates.

■ There is an increased demand for voluntary testing and testing facilities. More and more couples are being screened before marriage. Also a high demand for condoms is reported at testing sites.

■ The increased targeting of youth groups has contributed to the decline in HIV incidence among the age groups of 13–19 and 19–24 years.

- Increased counselling services have increased coping mechanisms and the adoption of preventive measures among the PLWHAs.

- Formation of independent networks of PLWHAs has led to increased self-esteem, a sense of belonging, shared confidentiality and breaking of the stigma associated with HIV/AIDS.

- Uganda stands out as the country in the 'south' with the highest number of open PLWHAs, almost similar to the gay community in the 'north'.

- Collaboration between government, NGOs, CBOs and religious organizations has led to capacity-building, channelling of resources and funds from government to NGOs for implementation of HIV/AIDS interventions, development of mid-term plans, support and supervision, technical assistance, training and monitoring, and evaluation.

- This has led to the formation of spontaneous self-help groups—NGOs, CBOs and AIDS service organizations—which has meant better coverage of services and prevention information to the grassroots throughout the country.

- Government has developed a strategy of joint action with international donor agencies, e.g. the Uganda/UNDP programme on HIV/AIDS prevention and poverty reduction, the World Bank District Health Service Project/Sexually Transmitted Infection Project, and the MILDMAY International in the field of holistic care and support for the terminally ill.

- Requests led the government to establish a palliative care centre for the terminally ill with stress on PLWHAs.

Epidemiological evidence
The STD/AIDS Control Programme in the Ministry of Health has been estimating the HIV prevalence rates using antenatal sentinel populations since 1989. Recent studies have shown declining prevalence rates among women attending antenatal clinics in some sentinel sites. Other studies carried out by Mulago Hospital among pregnant mothers and by the AIDS Information Centre among people who come for voluntary HIV testing and counselling have also shown declining HIV prevalence rates. Through this surveillance system, declining HIV trends in the urban sentinel sites have been observed. Collaborative evidence from a cohort study in Kyamulibawa-Masaka has also shown declining HIV incidence among young adult men and women living in the rural areas in Masaka district.

These observations prompted the carrying out of population KAPB surveys in five districts in the country to ascertain the probable explanation for the decline. The following interesting issues came out from these surveys:

- A high proportion of respondents (68%) reported change in behaviour in the last five years in response to HIV/AIDS. The reported changes were 'sticking to one partner', faithfulness, abstinence, and condom use.

- There was a reported increase in overall condom use. In the capital city Kampala, for example, the increase was from 7% in 1989 to 24% in 1995. This observation was more pronounced among the age group 15–19 years, where the rate among females has more than trebled.

- There is high condom use with non-regular partners. In Kampala, this was 64.2% among the males.

- There has been a significant delay in the age at first sexual intercourse. A smaller proportion of the 15–19 years age group report sexual intercourse compared with 1989.

AT WHAT COST?

Funding for HIV/AIDS programmes in Uganda amounted to US$700,000 in 1995/96. This amount will exceed US$1.1 million in 1996/97. There is substantial funding provided for the national Sexually Transmitted Infections project for the period 1994 through to 2000. This is in addition to the funding for HIV/AIDS activities. In terms of opportunity costs, resources in the health sector to fund to HIV/AIDS prevention activities may be viewed as a diversion of funds and resources from the economic sector. Further cost analysis, however, could focus on whether the improvement in the knowledge and behaviour change among the communities has been the result of prevention measures or the control measures resulting in the provision and improvement of the existing health care delivery services systems. External funds have also greatly enhanced Uganda's support of HIV/AIDS prevention activities since 1986. There have been various and unconsolidated levels of support and it is difficult to determine a definite cumulative cost of HIV/AIDS prevention programmes.

LESSONS LEARNED

In the achievement of the successes mentioned above, Uganda has learnt several lessons. The key lesson was that effective HIV prevention cannot be managed by one sector. HIV/AIDS is not only a health problem and, therefore, the intervention cannot be based only on public health approaches. The large numbers of PLWHAs, orphans and widows have had a significant socio-economic impact and, as a consequence, the social impact of the HIV epidemic on the government, social services and the labour force could not be ignored. The country, therefore, had to change strategies and adopt a multisectoral approach to prevention of HIV/AIDS.

Another lesson learned was that without the active participation and involvement of the community, personal responsibility for HIV prevention could not be achieved. The involvement of the community leaders in any intervention is crucial, because they already belong to and lead an existing community, and this enables them to play a catalyst role in mobilization and sensitization. Prevention without care of PLWHAs is 'like pouring water in a basket'. It was necessary to take care of and involve PLWHAs at all levels as one of the key preventive measures. It takes two people to transmit the virus: one who is infected and another who is not.

In the implementation of the prevention interventions, there are areas that are lacking: (1) health promotion messages focused on the uninfected and the infected were not targeted adequately; and (2) lack of basic treatment and care services for PLWHAs. There is also an apparent gap in intervention between: (1) urban and rural, e.g. media coverage is wider in the urban areas than in rural areas, and AIDS service organizations tend to prefer areas of high infrastructure, usually urban areas, and, as a result, condom acceptability, accessibility and use is higher in the urban areas than in the rural; and (2) female and male accessibility to intervention messages, e.g. in both urban and rural areas, the males tend to be better informed than the females. These areas will need to be addressed in future programmes within Uganda.

WHERE TO FROM HERE?

There are a number of areas to focus on in the future, which will assist the government and communities to continue to respond effectively. These are:

■ the current STD/HIV/AIDS surveillance system needs to be broadened and

strengthened through adequate financial and technical support to ensure its sustainability;

■ PLWHAs must be empowered to manage their own organizations and provide support to infected and affected families;

■ health promotion interventions should continue with specific emphasis on rural areas and on targeting youth, women and other vulnerable groups, and condoms and other HIV-related services need to be provided to rural communities;

■ the community requires more testing centres, counselling and social support services, and the government will need support from local and international donor agencies to meet this demand;

■ there is need for regional cooperation to address issues regarding policies, intervention strategies, research, resource mobilization and equitable allocation of resources to HIV/AIDS prevention;

■ asic medical and nutritional care for PLWHA needs be made available and accessible.

CONCLUSION

Uganda has a substantial epidemic where one in ten adults may be infected with HIV. There is still a long way to go to meet the needs of people and communities affected by this epidemic. In the last decade the basis of good prevention programmes has been established; however, there are some key areas on which a focus needs to be maintained.

First, government ownership of the issue of HIV/AIDS and political commitment to resource mobilization and facilitation in intervention programmes has been crucial in the development of HIV/AIDS prevention intervention strategies. In addition, the collaboration between multilateral, bilateral donor agencies and NGOs in supporting HIV/AIDS initiatives has been a vital part of Uganda's effort to curtail the epidemic. These partnership arrangements need to be maintained if Uganda is sustain its high level of community awareness of HIV and achieve a continuing decline in its HIV incidence rates. Second, community involvement at all levels is a key element in making prevention work, as is the development of strong networks between PLWHAs and HIV/AIDS intervention programmes. These need to be established and strengthened to enable the effort to continue. Finally, it has been demonstrated that a strong and effective surveillance system is an important prevention factor in monitoring trends and evaluating interventions, as well as identifying the successes. These systems need to be adequately resourced and have sufficient expertise to ensure that programmes can be developed and modified on the basis of accurate and up-to-date information.

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PREVENTION IN PRACTICE:
SUMMATION OF GUIDING PRINCIPLES
by Anne Malcolm and Gary Dowsett

HIV prevention programmes delivered through community organizations in partnership with government are demonstrating their effectiveness in reducing the transmission of HIV and in increasing support and awareness of HIV among communities. Although the approaches differ between countries, it is clear from the case studies presented here that there are a number of common elements crucial to developing and sustaining successful prevention programmes. These are:

- political will and government support;

- community mobilization and involvement;

- alliances and networks between community agencies, government and private sectors;

- community capacity-building;

- involvement of PLWHAs;

- development of safe and supportive environments;

- multisectoral approaches;

- involvement of researchers and evaluation of programmes.

Community organizations comprise a range of differing entities and their capacity to function effectively in the context of HIV/AIDS prevention depends on their mandate and representativeness within the community in which they work. Community organizations are essentially community-based organizations (CBOs) that work closely with communities, employ people from within these communities, and may or may not be managed by people from these communities. Non-governmental organizations (NGOs) are orga-

nizations independent from government and are often involved in grassroots activities. Other terms such as AIDS service organizations (ASOs) are used to describe those organizations not part of government services.

The distinction between CBOs, NGOs and ASOs is not clear, and these terms are used interchangeably. NGOs working in HIV/AIDS cover a broad range of organizations. These include organizations formed through interest groups and by people most affected by the epidemic such as TASO in Uganda initiated by PLWHAs, EMPOWER in Thailand established by sex workers, and AIDS Councils in Australia set up by gay communities. NGOs may also be large international development organizations such as the Red Cross, Oxfam, or the Salvation Army, which often operate independently of the communities in which they work, but fund organizations that work closely with communities.

Many community-based HIV/AIDS organizations were established through concerns within their communities and because of a lack of any other initiatives to address emerging epidemics. These often operate as 'self-help' organizations to alleviate social problems through action within their communities. These organizations tend to involve members in activities that reflect the needs of their specific communities, and in the case of HIV/AIDS these have often functioned with volunteers from affected groups within the community. For these reasons, many HIV/AIDS CBOs are characterized by cultures of commitment, volunteerism and advocacy, where there is an emphasis on involvement

and participation of those most affected in decision-making and a focus on human rights and advocacy for vulnerable and marginalized groups (Altman 1994).

In many countries, HIV/AIDS CBOs have grown significantly in scope and responsibility, not only within their communities, but also in their capacity to influence at a broader level. As a result of the epidemic, many CBOs are now much larger organizations, with substantial funding and resources, and they provide a broader range of programmes than was originally intended. For some groups, this has meant moving further away from the communities within which they were initially established; for others, this has meant developing new ways to maintain participation and involvement of their constituents. The increasing influence of these organizations at a broader level may be due partly to the networks that have been established between organizations, which strengthen their sphere of influence, but it is also due to the significance of their intervention programmes within the communities in which they work, which have become models for other communities.

CONCEPT OF PREVENTION

HIV/AIDS health promotion has evolved through a number of stages since the beginning of the epidemic. The initial stage was characterized by programmes focused on individual risk and responsibility through provision of information, awareness-raising, campaigns and, sometimes, fearful messages. As the epidemic progressed, it was clear that the efforts to maintain behaviour change were paramount, and health promotion messages needed to focus on sustaining safe behaviour. Greater understanding of the cultural and social dimensions of behaviour were crucial to developing more sophisticated responses aimed at facilitating community support

for changed behaviour. After more than a decade, the epidemic in many countries has resulted in a sense of complacency as people grow tired and despairing of an end to the epidemic, and messages are having less and less impact on behaviour. Younger generations may think that, for them, HIV/AIDS is less relevant. Also, in countries where new treatments are having a significant impact on the health of PLWHAs, AIDS is less likely to be the outcome of an HIV infection, and uninfected persons may fear infection less than they once did. This multiplication of responses to the extending but ever-changing epidemic has been termed the 'post-AIDS epidemic', not because the epidemic is over but to acknowledge that there are multiple perceptions and divergent experiences of the epidemic, and new initiatives are needed to rekindle the sense of immediacy among those who have been living within the epidemic for many years (Dowsett, 1996). This diversifying epidemic makes the problem of prevention education and health promotion for PLWHAs a process that is becoming more complex and more diverse.

In many countries, the focus of HIV/AIDS health promotion has broadened to include sexual health and reproductive health, and, as described in the Canadian report, a shift from a health promotion approach to population health. Broadening the approach which includes the recognition of the multiple social and environmental factors that impact on health outcomes is an important shift in furthering the response. This is also termed an 'holistic' approach, where HIV is seen as part of comprehensive primary health care that takes account of the social and environmental factors impacting on general health. This has been the focus of community building and development, key strategies used in many countries.

In this, community organizations have had a primary role in initiating responses that best meet the needs of their communities

and begin to change structures that may improve health outcomes of their populations. Redressing poverty and increasing education programmes are good examples of structural approaches to improving health outcomes. An example of such an approach is the income generation scheme, which in many developing countries has been used to provide alternative options for women whose only opportunity for income has been through sex work. These schemes are improving the status of women and developing a more secure future for families, as well as reducing poverty.

Prevention strategies
It is clear that the strategies used in HIV/AIDS health promotion have also evolved over the past decade in many countries. The notion of 'individual risk' and 'risk groups' has been replaced by collective responsibility and a greater understanding of the impact of social and cultural contexts in which people live and how these environments influence beliefs and behaviour. The focus for health promotion has consequently shifted from the individual to the community, and strategies such as the development of 'enabling environments' and peer education are providing more support for sustained behaviour change. These strategies also work to strengthen communities and facilitate their development and sustainability.

The need to create health-promoting environments has long been a goal of public health; however, it was the Ottawa Charter for Health Promotion in 1986 that finally established a comprehensive approach for public health action. This approach acknowledged the social and environmental factors that influence individual behaviours, and included the strategies for health promotion programmes: build healthy public policy; create supportive environments; strengthen community action; develop personal skills; and re-orient

health services. These strategies are being applied through many of the programmes described in this report and, together, they have created significant changes in people's behaviour.

Four key models used in HIV/AIDS health promotion programmes have been described. These are: (1) the information-giving model; (2) the self-empowerment model; (3) the community-oriented model; and (4) the social transformatory model (Aggleton, 1993). These approaches are not necessarily mutually exclusive, but differ in terms of the processes they use and their outcomes. Information-giving and self-empowerment models are most commonly used in HIV/AIDS work; however, with the need for broader community involvement and social change, community-oriented and social transformatory approaches are more often being utilized.

The shifting emphasis in the use of these models is in keeping with the re-focusing of health promotion from individual to collective responsibility, described in the Canadian and Thai reports, highlights the need to consider health promotion programmes within a continuum where particular approaches may be used depending on the outcomes desired. For example, within a community-oriented approach, there may also be the need to provide information and self-empowerment through written material and counselling. Similarly, campaigns and pamphlets may complement social transformatory approaches.

The methods used by CBOs to educate and inform vary widely. These range from the provision of written and visual information through pamphlets, posters, campaigns, videos, films and drama groups, to personal contact such as public speaking, counselling, direct outreach and group support. Campaigns and social marketing are essentially top-down approaches that have been used in HIV/AIDS education

with varying success. The '100% condom campaign' is an example of such an approach. This campaign was conceived by Thailand's national AIDS programme and was successful in raising awareness and enforcing behaviour change through the cooperation of a number of sectors within the country. Other similar top-down approaches have been used by national governments and are often without sustained success, in that they may raise awareness, and sometime fear, but may do little to change how people behave in the longer term. It is clear that the cooperation and participation of communities in such campaigns can help to ensure that educational messages are embedded in daily practice and clearly understood. Other educational approaches, however, need to accompany social marketing campaigns, as was demonstrated in the Thai condom campaign. Here, brothels and community groups actively supported the campaign through the provision of condoms and information on HIV/AIDS.

Peer-based education is an approach commonly used within communities to develop personal skills and the capacity of these communities to make behaviour changes. The development of organizations of sex workers, injecting drug users, young gay men, and women who have lost their husbands are examples of how people can come together to develop innovative ways of working with their own communities to prevent further transmission of HIV. Some of these innovative strategies have included the use of drama. For example, in Vanuatu, in the Pacific, a small group called 'Wan Smolbag' invites people from the community to develop educational plays based on HIV and other health issues, which they then perform in their communities. Similar drama initiatives include the 'White Line Dance Troupe' in Thailand, which performs in gay bars; and MAPS, an audio-drama programme aimed at rural people in northern Thailand. The development of

visual material such as comics has also been a successful strategy used in a number of communities. Here, stories are developed by particular groups within communities and are depicted through images and language appropriate for those people. This has been an effective way of reaching hard-to-reach groups.

The use of peers as outreach workers has been a widely used strategy to ensure that messages are appropriately communicated and the needs of the target group are better understood. Furthermore, this approach operates from the principle that there is an equal relationship between peers, which can facilitate greater learning and awareness, as well as support for ongoing behaviour change. Peer education is often instituted within a community development approach, which can assist to build the capacity of communities to respond and begin to change community norms through increasing the skills and knowledge of individuals. Examples of this approach include the use of peers to target sex worker in bars, outreach workers to reach men who frequent public places for male-to-male sex, and PLWHAs to provide information and support to other infected people. These activities not only provide information to peer groups, but people from these groups may in turn become involved in acting as educators within their own networks. The use of these strategies has been shown to increase awareness among those whose behaviour places them at risk of infection and to facilitate the development of a culture within communities which supports safe practices.

There has been an increasing focus within health promotion programmes on PLWHAs, not only as recipients of, and participants in, education programmes, but also in their involvement in the design and implementation of interventions targeting both HIV-positive and HIV-negative people. Peer-education strategies, such as the

use of HIV-positive speakers and support groups for positive people facilitated by peers, have been successful in promoting awareness and understanding of risks associated with HIV/AIDS as well as increasing self-esteem and well-being of those involved.

Approaches to the provision of prevention and care services have been integrated in many countries at the community level. For communities with a high prevalence of HIV and AIDS, messages to prevent further transmission of the virus are an essential part of support to people already infected. In these communities, contact with people with HIV/AIDS may be more frequent, and this can be a powerful strategy to prevent further infection. It is also the case that in many communities resources are limited, and the use of prevention and care programmes to provide an integrated service is a cost-effective option.

Strategies to develop supportive environments are becoming essential components of many health promotion programmes, including the need to ensure the provision of basic health and social services. Legislative changes, such as decriminalizing prostitution and homosexuality, are examples of law reform that promote greater acceptability and openness towards people who may be isolated and hidden within communities. Similarly, the development of policy and frameworks, such as harm minimization, provide a supportive approach to those whose behaviour places them at risk of HIV. For example, needle exchange programmes based on a non-judgmental approach towards drug users have been used successfully in many countries to reduce transmission of HIV through changing people's practices of sharing contaminated injecting equipment. Other policies and legislation to reduce stigma and discrimination have helped to increase access for those most vulnerable to much-needed information and services.

THE ROLE OF PLWHAS

PLWHAs have a crucial role in health promotion programmes. Their contribution as educators through public speaking, counselling, peer support and information, and as advocates and policy makers has resulted in greater acceptability and visibility of those infected within communities. Increasingly, PLWHAs are part of government decision-making bodies. Their inclusion is seen as essential for good policy decisions and to ensure that government decisions are properly informed and cognizant of the needs of those most affected.

A common strategy has been the utilization of PLWHAs as public speakers. This can have a profound impact on others' behaviour, as meeting a person infected with HIV provides a reality to what is often perceived as an abstract or distant issue. The role of positive people as educators is illustrated in the comment that the spread of HIV is affected by 'whether conditions exist for people to tell their stories of being infected, and their stories of changing their behaviour to prevent themselves from being infected' (Reid, 1992: 30). Prevention strategies are recognizing the need to target people already infected rather than focus only on those uninfected. The inclusion of PLWHAs in community efforts to prevent further transmission of HIV has been a feature of successful responses to the epidemic, and prevention strategies are recognizing the need to target people already infected rather than focus only on those uninfected.

The formation of PLWHA groups has been an important feature of prevention responses. These groups were initially established to provide mutual support, but have come to represent the interests of people with HIV/AIDS, and in many situations to act as advocates for better services and policies as well as establishing direct services for their members. They have also

contributed to raising public awareness within their communities. TASO in Uganda and New Life Friends Association in Thailand are examples of PLWHA organizations which provide a range of prevention, care and support services to their communities. Other organizations like National Association of People with HIV/AIDS (NAPWA) in Australia have a strong advocacy role and wield considerable influence at the national level through their involvement in policy and in the development of education strategies.

POLITICAL WILL

Government commitment to fighting the epidemic has seen the establishment of national control programmes in most countries around the world. Although many governments were initially slow to respond and set up national programmes, they now have accepted the responsibility to provide policies, education campaigns, health and social services, as well playing a central role in coordination and the provision of technical support to those working in the field. Political will to act through defining national strategy and a coordinated response has been shown to be crucial for the development of effective prevention. The establishment of national AIDS councils or control programmes with an advisory and/or strategic function in many countries, and often chaired by senior government officials, reflects this willingness to act to prevent what is seen as a serious public health issue.

Increasingly governments are seeking to work closely with community organizations and are providing funding to enable these groups to continue to work directly with their communities. Partnerships between communities, governments and people most affected by the epidemic have resulted in a greater understanding of the needs of these communities and the specif-

ic approaches required to have an impact on people's behaviour. Whether these approaches are locally based or have a national focus, they need to be developed within the context of this partnership relationship, ensuring that education messages are relevant, understood by those who provide funding, and supported by those at whom they are targeted.

MULTISECTORAL RESPONSE

It is clear that the development of a multisectoral response is a key feature of successful prevention efforts. The collaboration of government departments, community organizations, PLWHA groups and sectors such as international donors, private industry and media has been shown to be an effective way of mounting a broad approach to managing the epidemic and initiating effective strategies. These broad coalitions are often effective in commanding a level of authority at a high levels of government, primarily due to the credibility and strength they derive from the affiliation of a diverse range of community groups. Examples of this kind of coalition with significant influence at a national level are the Malaysian AIDS Council, which coordinates 32 NGOs, the Australian Federation of AIDS Organisations (AFAO), which acts as a peak body for NGOs at the national level in Australia, and the Canadian AIDS Society in Canada. There are also many examples of the creation of alliances and networks within communities; however, while these are important to coordinate and conduct programmes at a local level, they are rarely able to exert influence outside of their communities towards government policy or national direction.

In the current global economic climate, funding for HIV/AIDS programmes is under threat as governments look to cut back spending and have other priorities for funding. It is also the case that internation-

al donors are looking to reduce or reprioritise funding arrangements. This is evident where donor organizations are shifting funds away from countries that have more stable epidemics toward countries with emerging and rapidly developing epidemics. Many community organizations rely on government and donor funding and are having to consider other ways to raise monies to continue to sustain their programmes and services. Fund-raising and the use of volunteers have been part of how many HIV/AIDS community organizations operate; however, these efforts are proving difficult to sustain in areas where resources are limited and where communities have been devastated by the epidemic. Developing new partnerships such as those with private sector organizations may provide an opportunity to continue prevention efforts; however, these would still need to be developed within broad national strategies and through a coordinated response.

ROLE OF RESEARCH AND EVALUATION

Partnerships between research institutions and community organizations has been a feature of many successful prevention efforts. These partnerships have primarily occurred between social researchers and community-based services, and functioned as a way to inform prevention efforts and assist those working in communities to apply a greater theoretical understanding to their work. These partnerships also provide the opportunity for social research to view more critically their approaches and to refine and develop new methods of inquiry.

Research conducted with affected communities in conjunction with community-based services has played an essential role in informing the development of appropriate strategies for the prevention of HIV. An approach commonly used in a number of countries is participatory action research, where small-scale projects are set up within communities and research is undertaken by community members. These projects derive their strength from the learning processes that occur between those involved, through the development of ideas and practices, and in the evaluation and critical reflection of these practices. This approach has worked to benefit many prevention programmes through the processes established to gather new information, and in the development of skills for community workers. It also provides a cost-effective way of evaluating and refining interventions.

HIV prevention research is an integral part of the national priorities, and funding for research is an important component of the government response to the HIV epidemic in many countries. Research institutions are playing an important role in the development of national policy through their participation on national committees and through their contribution to practical and theoretical understanding of key issues relating to effective prevention. Research evaluation of the effectiveness of prevention efforts has also been used to inform policy and the development of strategies at a local and national level. An example of this is described in the Canadian report, where measures have been developed to assess the impact of prevention programmes through community participation and strengthening the capacities of community organizations. The indicators developed assess organizations' capacity to develop mechanisms for increased participation and involvement in project planning and evaluation, through to developing coalitions and building alliances with other agencies.

FUTURE CHALLENGES

It is clear from the case studies that these countries are not dealing with a single epidemic, that there are a variety of epidemics occurring, which requires a range of

responses. These have presented differing challenges for communities and governments. Responses to newly emerging epidemics are requiring different prevention approaches than those used at a similar stage of epidemics in other countries. For example, in Thailand, responses to manage a relatively new epidemic have been derived primarily from adapting existing structures and approaches within communities, rather that looking to other countries for solutions. In these new epidemics we see the growing energy and commitment of communities in crisis and the development of partnerships and alliances between government and community groups. At the same time, however, countries like Thailand are also experiencing rapid economic development, which presents new challenges in relation to social dislocation and changes to traditional patterns. This significant social and economic change is testing the capacity of these countries to maintain an effective response to the epidemic.

Countries with mature epidemics, where patterns of infection are relatively stable, such as Canada and Australia, are beginning to consolidate practice and more critically analyze their efforts in order to address future strategies. These countries are also experiencing a growing sense of complacency, as rates of new infections fall and people begin to re-assess their level of risk of HIV infection. In this environment, there is also the risk that governments will begin to minimize their commitment to maintaining a specialized focus on HIV/AIDS and change the partnership arrangements that have been the keystone of a successful response.

This is evident in both Canada and Australia, where a broader public health or population health approach is being applied to achieve better health outcomes for population groups at risk, through coordination and collaboration of public health programmes. However, population-based health objectives may in some cases rely less on the involvement of communities than HIV/AIDS has done to date. Within the population approach, funding for specifically targeted programmes for HIV/AIDS must compete with other public health programmes for priority. This may inevitably lead to a diminished focus on HIV/AIDS as other priorities are put forward.

Similarly changes in political leadership can impact on effective responses. In Uganda, for example, the election of President Musevani placed responsibility for managing the response to the epidemic at the highest level. This commitment has been demonstrated in other countries, however, it is equally likely that a change in political leadership can result in a reduction of commitment to maintaining HIV/AIDS prevention efforts.

What can we do for the future?
Without a vaccine or affordable treatments in the majority of HIV-affected countries, prevention remains the most effective way of reducing the burden of HIV/AIDS. It is vitally important therefore, that we maintain the effort to find approaches that work, foster the development of new initiatives and provide sufficient resources to optimize their implementation. In the development of good practice in HIV prevention, we must remain vigilant, reassessing and restructuring our approaches, knowledge and learning.

Second, it is important for governments to maintain a focus on HIV/AIDS. Letting this slip to become a lower priority reduces the capacity of communities to maintain an effective response, and signals to those whose behaviour places them at risk of infection that HIV is no longer a serious issue. Governments also need to maintain leadership in this area not only in the development of national strategies to con-

tain the epidemic, but also in developing sound public policy to reduce the impact of HIV/AIDS within communities.

Third, we need to strengthen the networks and alliances between community groups and other government organizations. These alliances can assist with building the capacity of communities to mobilize and act to gain resources and influence. The establishment of broader networks also promotes learning across communities and provides for a more effective coordinated response.

Finally, we need to look at how we can integrate our responses to ensure the longer-term effectiveness of our efforts. The integration of prevention with care and support programmes as well as with research, advocacy and policy adds significant value to any community response. HIV/AIDS prevention works where an integrated approach can provide a broader framework through which effective interventions can be developed.

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Aggleton, P. 1993, 'Promoting whose health? Models of health promotion and education about HIV disease', *Advances in Medical Sociology,* vol 3, pp. 185–200.

Altman, D. 1994, *Power and Community: Organizational and Cultural Responses to AIDS,* London, Taylor and Francis.

Dowsett, G.W. 1996, 'Living 'post-AIDS'', *National AIDS Bulletin,* vol 10, no. 2, pp. 18–23.

Reid, E. 1992, 'The global spread of AIDS', *National AIDS Bulletin,* vol 6, no. 7, p 30.

This list of resources includes reports of interventions, research, and policy relating to HIV/AIDS health promotion. It is intended as additional material that might assist people with further information about aspects of HIV/AIDS prevention in practice. Each reference is followed by a short annotation that outlines the content and strengths of the resource.

RESOURCES LIST

compiled by Elizabeth Morrow, Anne Malcolm and Gary Dowsett

Aggleton, Peter 1993, 'Promoting whose health? Models of health promotion and education about HIV disease', *Advances in Medical Sociology,* vol. 3, pp. 185–200.

> Describes four influential models used in HIV/AIDS work: information-giving; self-empowerment; community-oriented; and social transformation models. Illustrations are provided to highlight their respective strengths and limitations. Concludes that few approaches can produce determinable outcomes, posing major challenges for those working to prevent new cases of HIV infection and to support those already affected.

Altman, Dennis 1994, *Power and Community: Organizational and Cultural Responses to AIDS,* Taylor and Francis, London.

> The central challenge facing the community movement is how to strengthen its political effectiveness without compromising its base in grassroots participation and control. Of concern are: emerging tensions within community-based organizations between activism and service provision; altruism and self-help; volunteer participation; and management control. The author argues that direct community sector involvement in the policy making process represents the best strategy for ensuring that national AIDS policies are responsive to those most affected by the epidemic.

Altman, Dennis 1995 'Communities, governments and AIDS: making partnerships work', in *AIDS: Safety, Sexuality and Risk,* (eds) Peter Aggleton, Peter Davies and Graham Hart, Taylor and Francis, London.

> Looks at the question of meaningful partnerships between government and communities. While partnership implies common goals, it also relies on mutual respect and adequate resources. Argues that while governments may have the necessary resources they often lack the will to act effectively, unlike communities of people who share a common sense of purpose and oppression. Altman examines the notion of meaningful partnership as played out in various countries and suggests ways of harnessing the resources of both groups to make partnerships work.

Alvarez, R.O. 1995, 'National strategy document on HIV/AIDS launched', *MARHIA,* vol. 8, no. 4, p. 1.

> The 25–page National HIV/AIDS Strategy document was developed to 'serve as a framework for both individual and community responses to the challenge of HIV infection and AIDS. It seeks to provide the appropriate context necessary for both independent as well as coordinated responses'. The strategy presents nine major principles useful for developing and carrying out HIV/AIDS programmes. Copies are available from the STD/AIDS Unit of the Philippines Department of Health. It is suggested that the document be widely discussed so that the strategy may be used to aid in the development and evaluation of programmes on HIV/AIDS.

Anon 1993, 'Schools against AIDS project—for the future of our teenagers', *South African Medical Journal,* vol. 83, no. 10, p. xxvii.

> In South Africa HIV infection is spreading fastest among teenagers. The Schools Against AIDS Project is designed to give teenagers a voice to discuss their sexuality and to encourage the design and implementation of practical, sustainable and appropriate prevention programmes. It has achieved much in encouraging cooperation between NGOs and education departments. The intention is to bring about a partnership in which the needs of

young people and their school communities come foremost.

Asthana, Sheena and Oostvogels, Robert 1996, 'Community participation in HIV prevention: problems and prospects for community-based strategies among female sex workers in Madras', *Social Science and Medicine,* vol. 43, no. 2, pp. 133–148.

Examines the role that community participation can play in HIV/AIDS prevention and care efforts, focusing on prospects for participation among sex workers in Madras, India. Although a brief review of recent public policies and legislation relating to HIV/AIDS reveals increasing support for the idea of strengthening community action for HIV/AIDS prevention, analysis of a pilot project established by the Tamil Nadu state government and WHO in 1993 indicates that the sex trade is not conducive to collective action. After identifying factors which have hindered community-based strategies, several changes are suggested.

Awusabo, Asare K. 1995, 'HIV/AIDS education and counselling: experiences from Ghana', *Health Transition Review,* vol. 5, Suppl, pp. 229–236.

This paper describes some of the approaches adopted in three settings in Ghana to provide community education and counselling for communities, patients, and their relatives on HIV/AIDS infection. HIV/AIDS education, counselling and intervention strategies are presented, which constitute major innovations in public health education and counselling in Ghana. However, all of the projects depend on external assistance, which has serious implications for project continuity and sustainability.

Ball, A. 1996, 'Averting a global epidemic', *Addiction*, vol. 91, no. 8, pp. 1095–98.

By 1995, intravenous drug use had been documented in 118 countries, with 78 of these countries also reporting HIV infection in the drug-injecting population. To address this problem the dual epidemic of drug-injecting and HIV infection must be conceptualized as a public health problem rather than a law enforcement issue. Through community-based outreach strategies such as peer education, links must be established between the health services and marginalized drug users. Although interventions including: syringe distribution and exchange; education on syringe cleaning; and methadone and opium substitution have been effective in some situations, programmes must be feasible for and acceptable to the target population. Strategies should be designed on the basis of an understanding of the characteristics of the target population and its risk behaviours the dynamics of drug availability and use, the context of drug use, and existing resources.

Berer, Marge (ed.) with Ray, Sunanda 1993, *Women and HIV/AIDS: An International Resource Book. Information, Action and Resources on Women and HIV/AIDS, Reproductive Health and Sexual Relationships,* Pandora Press, London.

HIV/AIDS was finally granted international acknowledgment as a major women's issue in the late 1980s. There remain, however, inadequate links between HIV/AIDS work and the broader women's health movement. This edited anthology represents current knowledge and experience of HIV/AIDS from a women-centred perspective and emerged from collaboration among activists in developed and developing countries. Summaries of factual information on the salient medical and social issues are intermingled with: descriptions of HIV/AIDS prevention campaigns; personal histories of women living with HIV/AIDS; examples of grass-roots, women-centred organizing; and reproductions of graphics used in mass media campaigns.

Caceres, C. 1993, 'Methodologies to evaluate HIV/AIDS programmes', *AIDS Health Promotion Exchange,* no. 4, pp. 11–12.

A summary is provided of methodologies to evaluate HIV/AIDS programmes through qualitative and quantitative assessment. Evaluations of HIV/AIDS programmes can take the form of process of output evaluations, outcome evaluations, or impact evaluations.

Other newer forms of evaluation include: formative evaluation, which refers to needs and situation assessments before programme evaluation; and summative evaluation, which entails assessment after implementation or an accomplishments or cost benefit review. Qualitative assessments are based on field data and loosely constructed assumptions in order to create theoretical frameworks. The relevance of qualitative methods becomes obvious in situations where changes in perceived norms amongst adolescents is desired. Survey questions inadequately measure norms and other structural barriers to practicing preventative behaviour. Participant observation provides a friendly atmosphere for obtaining sincere responses and more detailed accounts. Another situation where qualitative methods are useful is one in which information is sought on meaningful behaviour, motivations leading to particular behaviours or the degree of satisfaction with an intervention.

Care, Lesotho 1995, 'Lesotho's footballers join the fight against AIDS', *AIDS Analysis Africa,* vol. 5, no. 6, p.7.

Traditionally, Lesotho's HIV/AIDS programme was undertaken by church organizations and medical personnel. In 1994 an innovative strategy called Footballers Against AIDS was introduced. CARE Lesotho enlisted footballers to speak to youth, fans and the general community about AIDS. League matches have been designated as HIV/AIDS awareness matches and an educational football theme comic has been developed. Many players have changed their sexual behaviour as a result of their participation in the programme. Expansion of this programme using athletes from other sports is planned and CARE offices in other countries are exploring the possibility of adopting this idea.

Chalkley, M., Fowler, D. and Young, F. 1994, Innovation, tolerance and pragmatism: three essential tools in developing a partnership approach, Paper presented to the Tenth International Conference on AIDS, Yokohama, Japan, 7–12 Aug, (Abstract no. 440D).

Australia's education and prevention campaigns have been widely regarded as successful to date. They are distinguished by a pragmatic and innovative approach to partnerships between Federal, State and Territory governments and with organizations of communities infected with and affected by HIV/AIDS. There has been a substantial decrease in the number of HIV infections in Australia since 1987, with a plateauing of infections more recently. Nevertheless, governments must be constantly vigilant and able to assess programmes that were once successful but are no longer appropriate, and replace them with new ones.

Connolly, M. 1992, 'Street Kids International: Karate Kids—reaching the unreached', *AIDS Education and Prevention,* Fall, Suppl, pp. 92–93.

The Karate Kids cartoon is part of a cross-cultural health education programme devised by WHOs Global Programme on AIDS, the AIDS Unit of International Planned Parenthood Federation, and a variety of international health education, communication specialists, street youth and educators. Called the Survivors Project, it aims to inform the 100 million poor, working, street children and teenagers who do not attend school about HIV/AIDS and to bolster their self-esteem. The project includes a cartoon, comic book and teaching book to generate discussion about HIV/AIDS, STDs, and sexual exploitation of children and teenagers by adults. Educators who have been trained in and are willing to discuss health, sexuality and AIDS and are either in poor, community-based outreach projects or are street educators are most effective in using the material.

Coghlan, A. 1995, 'Participatory evaluation methods for community-based AIDS programmes: lessons from Uganda', *Proceedings from the 3rd HIV/AIDS Prevention Conference,* Washington D.C., USAID, (Abstract no. 80).

Recent research has found advantage in involving programme target populations in all stages of an evaluation. The author explores how participatory evaluation meth-

ods could be used to help Ugandan communities fight HIV/AIDS. The study looks at the work of the Rakai AIDS Information Network (RAIN), a non-governmental organization which provides integrated HIV/AIDS prevention programmes within a community-based health care framework. The participatory evaluation methods are described in sections on the evaluation design workshops: a sampling exercise and escorting interviewers; the evaluation presentation and feedback session; and community action plans with follow-up assessments. It is possible that participating in the evaluation made community members more determined to work toward the prevention of AIDS.

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Davis, M., Dowsett, G., Connell, B., Ariss, R., Carrigan, T. and Chapple, M. (eds) 1993, *Class, Homosexuality and AIDS Prevention: Resource Material for use in HIV/AIDS Education,* National Centre for HIV Social Research, School of Behavioural Sciences, Macquarie University, Sydney.

The CHAP project was based on in-depth interviews and meetings with working-class gay men. Designed to be used by workers in the HIV/AIDS field, these resources aim to raise awareness of social and cultural issues for gay working-class men in HIV/AIDS educators, and to provide the basis of discussion of the education needs of gay working-class men. Topics covered include: the idea of the working class; gay working-class men; aspects of community life; sexuality and the practice of safe sex; HIV/AIDS education/knowledge; visual images and language; and developing HIV/AIDS education strategies for working-class gay men.

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de Bruyn, M and van der Hoeven, F. 1994, 'Primary health care and AIDS: African experience', *AIDS Bulletin,* vol. 3, no. 1, , pp. 6–7.

The authors discuss the rationale for integrating HIV/AIDS efforts into primary health care (PHC) programmes, including: models of prevention and care; the hospital-centred model; the AIDS service organization model; obstacles to PHC-based home care; and participa-

tory action research. The latter is important because communities tend to function as implementors rather than designers and evaluators of interventions. By integrating HIV/AIDS prevention and care into PHC programmes, community ownership of activities could be stimulated. It is stressed that such integrated programmes must still be economically viable, sustainable, and of satisfactory or better quality. PHC programmes, NGOs and community members need to decide together how best to divide tasks, how to share responsibilities and how to coordinate their work.

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de Gagne, D. 1994, 'People living with HIV/AIDS: promoting health through partnership', *AIDS Health Promotion Exchange,* vol. 3, pp. 1–3.

People living with HIV/AIDS (PHIV) in developing countries face many problems including: isolation; discrimination; abuse; and loss of fundamental human rights. In 1992, PHIV in Rwanda formed themselves into a self-help group called Mirror of Health. They received support from health care workers, community groups and the government, and much of the relief PHIV feel as a result of this was reflected in their general sense of well-being. Many PHIV spoke about living with the disease to ensure that others do not become infected. Others worked with a District HIV Prevention and Care Team and enhanced the knowledge and perceptions of the people attending the educational sessions. The authors conclude that PHIV are not part of the problem, but part of the solution.

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Elkins, D.B., Kuyyakanond, T., Maticka, Tyndale, E., Rujkorakarn, D., and Elkins, M. 1996, 'Multisectoral strategy for AIDS prevention at community level', *World Health Forum,* vol. 17, no. 1, pp 70–74.

Multisectoral AIDS prevention strategy (MAPS) entails use of integrated government and non-governmental AIDS-related services to conduct community-defined initiatives. MAPS was implemented at the community level in four northeastern provinces in Thailand (where a very developed infrastructure for health, education and social welfare

exists), using an audio-drama. It revolved around the needs of married women in relation to HIV/AIDS prevention and addressed how men and rural people in general are involved. Stages of the programme were: a pre-drama subdistrict meeting; a week of drama in the communities; a post-drama community meeting to discuss a community HIV/AIDS strategy; and a post-drama subdistrict meeting to present and consolidate the strategy and implementation of the strategy.

Foster, G. 1990, 'Raising AIDS awareness through community mobilization', *Tropical Doctor,* vol. 20, no. 2, pp. 68–70.

Community-based HIV/AIDS education, counselling and information services are an essential alternative in developing nations where HIV/AIDS support and prevention programmes are poorly developed, and AIDS awareness is hindered by illiteracy and lack of access for large numbers of people to education. The Family AIDS Caring Trust (FACT) is a community-based organization staffed by volunteers. After training, they organize their own programmes and financing, including counselling doctors to refer patients with HIV/AIDS to them, producing HIV/AIDS education and awareness literature, and meeting with the community to inform them of HIV/AIDS prevention.

Franzkowiak, Peter and Wenzel, Eberhard 1994, 'AIDS health promotion for youth. conceptual framework and practical implications', *Health Promotion International,* vol. 9, no. 2, pp. 119–135.

Presents a conceptual framework and detailed guidelines for the planning, implementation and evaluation of HIV/AIDS health promotion for youth. The framework focuses on basic principles of health promotion, and refers to the living conditions and lifestyles of youth relevant for the development of gender roles and sexual behaviour. Community organization plays a crucial role for HIV/AIDS health promotion for youth. Only comprehensive approaches taking account of social and cultural conditions present an adequate arena for successful HIV/AIDS health promotion.

French Guiana, Aides-Guyane 1992, Designing prevention programme of basic information for a specific ethnic group: tribalized and urbanized Bush Negroes in French Guyana, Unpublished paper prepared for Agence Francaise de Lutte contre le SIDA France, Office de la Recherche Scientifique et Technique Outre-Mer (ORSTOM), Département de la Santé.

An HIV/AIDS awareness and prevention programme was targeted for the 20,000 Bush Negroes (Maroons) in four tribal groups living in French Guiana. This population is characterized by distrust of the West and by geographical dispersal and diversity of social settings. By 1990, 10 Maroons had died of AIDS acquired through blood transfusions or from prostitutes. The high mobility and the cultural and linguistic isolation of the group adds to the risk. In order to develop an appropriate communication strategy, in-depth ethnographic studies of traditional health care systems were consulted, and a three-month study of current attitudes, beliefs, and practices were carried out. Using the results of this study, a communication and prevention programme was developed involving: a video; a slide show; trained Maroon commentators; and a musical theme. Evaluation revealed that it was enthusiastically received and achieved a successful break-through in the acceptance of HIV/AIDS as a new disease. However, changes in sexual behaviour will be hard to achieve until respondents are disabused of the notion that greater care in partner selection is appropriate preventative behaviour.

Freudenberg, N., Eng, E., Flay., B., Parcel., G., Rogers, T. and Wallerstein, N. 1995, 'Strengthening individual and community capacity to prevent disease and promote health: in search of relevant theories and principles', *Health Education Quarterly,* vol. 22, no. 3, pp. 290–306.

The authors contend that the social psychology underpinning much of the theory on HIV/AIDS prevention is limited, as it can only explain the causes of health problems and not suggest useful principles of practice. The lat-

ter is mainly derived from practitioners. The authors suggest that by looking at the links between theoretical models and practical experience informing health education, it may be possible to develop more coherent and effective interventions.

Gray, J. 1995, 'Operating needle exchange programmes in the hills of Thailand', *AIDS Care,* vol. 7, no. 4, pp. 489–99.

Injecting drug use is increasing markedly among the ethnically distinct Hilltribe people of northern Thailand. This paper reports on the establishment of needle exchanges in three remote Hilltribe villages. Through a series of meetings in the villages various means available to prevent the transmission of HIV/AIDS in an injecting drug use context were discussed. The villagers themselves have assumed responsibility for much of the needle exchange operation. The sharing of needles by injecting drug users changed significantly with the introduction of the exchanges. Reluctance on the part of local government officials to participate in the programme created difficulties in maintaining needle supply, which led to some resumption of sharing. The success of the needle exchange programmes is dependent upon cooperation from various government agencies and NGOs, as well as the local communities.

Harris, C. 1994, 'Closing the gaps in health education', *IDRC Reports,* vol. 22, no. 1, p. 14.

The University Partnerships in Essential Health Research Project aims to encourage new models of community participation in health education and research. Some models include: creating projects that emerge from true partnerships between communities; universities and governments; and research ideas stemming from community interaction. Ways of achieving this include teaching leadership and partnership skills to medical students so they are able to listen to communities and establish links between professional and regional groups, including essential health research on the curriculum. The universities, communities and governments must all accept

the need and significance of working together to have a complementary relationship.

HIV/AIDS and International Development Network of Australia year? *Community Action on HIV, a Resource Manual for HIV Prevention and Care,*

Of particular interest is Chapter 5 titled, 'Answering the questions: HIV prevention and case strategies'. This chapter looks at peer education, mass media, methods of condom distribution in Zaire and Thailand, and more.Copies can be obtained from:
HIV/AIDS and International Development Network of Australia
c/o Australian Council For Overseas Aid
Private Mail Bag 3
Deakin ACT 2600 AUSTRALIA

Kelly, J.A., St Laurence, J.S., Stevenson, L.X. et al. 1992, 'Community AIDS/HIV risk reduction: the effects of endorsements by popular people in three cities', *American Journal of Public Health,* vol. 82, pp. 1483–1489.

Presents a study that introduced the intervention method of training popular people to serve as behavioural change endorsers to their peers sequentially across three different cities. Article includes method and results, in particular the effects of intervention on community population behaviour.

Kilimwiko, L. 1991, 'Condoms hitch lift with truckers' *WorldAIDS,* no. 17, September, p. 9.

Research has shown that men are more receptive to safe sex messages given in a work setting, and that those at risk, like truck drivers, are unlikely to attend rallies or listen to radio messages. In order to educate them, gas pump attendants and prostitutes in Dar Es Salaam and other road stops in central Tanzania are offering condoms to truck drivers. The peer educators are trained in HIV/AIDS prevention and are paid a monthly wage. However, it is difficult both to sustain the distribution outside a medical setting and to monitor and support peer educators spread out across the country.

Kippax, S., Crawford, J., Connell, B., Dowsett, G., Watson, L., Rodden, P., Baxter, D. and Berg, R.

1992, 'The importance of gay community in the prevention of HIV transmission: a study of Australian men who have sex with men', in *AIDS: Rights, Risk and Reason,* (eds) Peter Aggleton, Peter Davies and Graham Hart, Falmer Press, London.

In the context of HIV/AIDS, gay subcultures have played and continue to play an active educative role. In Australia, gay communities developed some of the most successful initiatives in Australian HIV/AIDS education. This study attempts to capture and quantify aspects of gay community and to isolate the impact of gay community attachment on behaviour change. Findings include: that urban gay men who identify with a gay community are more likely to change their sexual behaviour than semi-rural gay men not attached to a gay community; that health campaigns should continue to be informed by gay communities; finally, that health campaigns need to be more explicit about risks if they are to reach all men who have sex with men.

Lenneiye, N., Canlas., Malunga, L., Nsungu, M. and Tengende, M. 1991, *World Vision Relief and Development, Inc. Final Evaluation Report, HIV/AIDS Prevention in Africa Program, Marondera District, Zimbabwe. Beginning Date: October 1, 1989. Ending Date: September 30, 1991,* World Vision Relief and Development, Monrovia, California.

Sixty-two focus groups undertaken in the Marondera District, Zimbabwe, were conducted to evaluate the HIV/AIDS Prevention in Africa Programme (HAPA). The focus groups indicated a need to find more effective strategies to communicate the seriousness of AIDS. A main gap between goals and achieving them was that HAPA neither tested nor reviewed the relevance, appropriateness, and the effectiveness of the initial goals. The purpose of the planning workshop was to review and reset goals and indicators, but the workshop yielded more general recommendations instead. If HAPA were to be continued, a protocol delineating rules and obligations of the partners (including the integration of HAPA into the Ministry of Health planning structures and systems) should be prepared and a condition of HAPAs existence. The distribution of planning responsibilities between MOH and World Vision Zimbabwe also needs to be specified.

Magezi, M.G. 1991, 'Against a sea of troubles: AIDS control in Uganda', *World Health Forum,* vol. 12, no. 3, pp. 302–306.

Looks at the work of The AIDS Support Organization (TASO) in overcoming obstacles to HIV/AIDS prevention caused by social, economic and cultural factors in Uganda. Their programme includes: training on HIV/AIDS awareness; community mobilization in the form of counselling by community members; medical services; educational materials; and promotion of income generating efforts. One of the biggest obstacles to prevention programmes is the promotion of condom use. In order to surmount the problem of the financial cost of condom use and the moral taboos connected to it, TASO has provided information on condoms and has targeted traditional healers and tribal and religious leaders to help in this effort.

Moodie, R. and Aboagye-Kwarteng, T. 1993, 'Confronting the HIV epidemic in Asia and the Pacific: developing successful strategies to minimize the spread of HIV infection', *AIDS,* vol. 7, no. 12, pp. 1543–51.

In Asia, modes of HIV transmission vary from country to country and include injecting drug users, sex workers and their clients, commercial blood donors, haemophiliacs, and homosexuals. Social, cultural and health factors also affect transmission. Governments must create an environment for behaviour-change through financial, political and legislative measures. Community organizations also play a role in prevention. Successful behaviour change of individuals is based on: redefinition of peer norms; understanding the danger and vulnerability to infection; and building confidence to change behaviour. Successful programmes require placing priority on HIV issues on the political agenda, negotiation and consensus-building skills, and competent programme management.

Ngugi, E. and Plummer, F. 1991, 'Prostitutes teaching prostitutes in Nairobi', in *AIDS Prevention Through Health Promotion: Facing Sensitive Issues,* comps. World Health Organization and Royal Tropical Institute, Geneva, Switzerland.

> In Nairobi, Kenya, in 1987–1988, a multidisciplinary team was dispatched to improve the health of prostitutes. The initial contacts, the evolving programme, the educational methods and the results are presented. The ten best questions and answers generated among 250 women completing the questionnaire on how to teach others to prevent the spread of HIV/AIDS are also included. The authors conclude that the success of the programme was due to the women being responsible for the programme. This success was reinforced by taking services to the people and mobilizing the community. Easy availability of condoms was also important.

O'Dell, V. and Nkowane, B. 1990, 'Community-based management of AIDS', in *The Handbook for AIDS Prevention in Africa,* (eds) Peter Lamptey, Peter Piot and Robert Gringle, Family Health International, Durham, North Carolina.

> In Africa, primary health care (PHC) continues to provide accessible essential health care to communities and community education on persistent health problems. This handbook looks at the services performed by PHC community health workers, including: informing patients about what HIV/AIDS is; how it is transmitted and how to prevent it; counselling for people with HIV/AIDS and their families; and care for people with HIV/AIDS, the latter preferably in their homes. This manual also provides a table of how to treat symptoms of HIV-related illnesses.

O'Malley, J., Vinh, Kim Nguyen and Lee, S. 1996, 'Non-governmental organizations', in *AIDS in the World II: Global Dimensions, Social Roots and Responses,* (eds) Jonathan M. Mann and Daniel J.M. Tarantola, Oxford University Press, New York.

> Looks at the types of non-governmental organizations (NGOs) which have arisen in response to the AIDS crisis. Areas covered includes: range, roles, and achievements of NGOs; needs, capacities and priorities of service delivery organizations; activism and response to other social problems such as gay rights and equality; and relations between NGOs and governments. This chapter also looks at how funding agencies support established NGOs in AIDS prevention, but does not suggest that they broaden their scope. Author argues that the complementary nature of AIDS-specific and non AIDS-specific NGOs should be recognized and supported, as the most effective and sustained response to HIV/AIDS will continue to arise from the affected communities.

Parker, Richard, Quemmel, Renato, Guimares, Katia, Mota, Murilo and Terto Jnr, Veriano 1995, 'AIDS prevention and gay community mobilization in Brazil', *Development,* vol. 2, June, pp. 49–53.

> Article examines HIV/AIDS prevention activities in Brazil during the last decade. It is argued that where sexual communities are absent or less apparent, possibilities exist for community prevention programmes. Objectives, cultural interventions, outreach activities and collaborations with commercial establishments and public health centres, workshops, counselling and condom distribution, as well as systematic evaluation are described.

Parker, R.G. 1996, 'Empowerment, community mobilization and social change in the face of HIV/AIDS', *AIDS,* vol. 10, Suppl. 3, December, pp. 27–31.

> During the early to mid–1990s, thinking about HIV/AIDS changed. Critical thinking about the social, cultural, economic and political etiology of the disease expanded from issues of individual risk to those of social vulnerability. Dominant theories and models have been revised to encompass mulit-dimensional models of collective empowerment and community mobilization as effective prevention strategies. The struggle to control HIV/AIDS is now being viewed as part of the struggle to achieve far-reaching social justice and social change to

address the underlying issues which contribute to the spread of the disease.

Peterson, C. and Szterenfeld, C. 1992, 'Organizing a project with community-based health agents recruited from prostitutes in Rio de Janeiro', *Public Health,* vol. 106, no. 3, pp. 217–223.

In 1988, the Brazilian Ministry of Health asked the Prostitution and Civil Rights Programme to join the Ministry in producing STD/AIDS prevention materials. In 1991, recruiting began of prostitutes and transvestites for its Health Education Project. After informal training, 17 community-based health agents went into their communities to inform people of their health agent role, distributed free condoms and HIV/AIDS education material. The agents complete weekly reports on the distribution of material and are now mapping the sex trade to target health care and other resources in each area. Involvement of sex workers in all phases contributes to the success of the project, while further research is needed to determine whether the project is reducing risk of HIV transmission.

Power, R., Dale, A. and Jones, S. 1991, 'Towards a process evaluation model for community-based initiatives aimed at preventing the spread of HIV amongst injecting drug users', *AIDS Care,* vol. 3, no. 2, pp. 123–135.

Describes an action research model designed to monitor and assist development of community-oriented HIV/AIDS intervention services. Its short- and long-term applications are illustrated by a study of a multidisciplinary community drug team in London, England. Ways in which the model benefits researchers and service providers are described, and the value of action-research methodology in assessing HIV/AIDS prevention is stressed.

Preston-Whyte, E.M. 1995, ''Bring us the female condom': HIV intervention, gender and political empowerment in two South African communities', *Health Transition Review,* vol. 5, suppl, pp. 209–22.

HIV/AIDS is spreading rapidly in South Africa and women are at greater risk than men of contracting HIV infection. In this context, some Black African women are demanding the female condom. The author argues that this demand, not shared by all Black South African women, reflects the women's relative level of domestic and gender empowerment, as well as their high degree of political mobilization. The call for the availability of the female condom was also a challenge to the research community to rethink its position in research and to acknowledge the implications of committing to a participatory model of community-based intervention research.

Reid, Elizabeth 1993, 'Inter-country consultation', *AIDS Health Promotion Exchange,* no. 4, pp. 9–10.

In December, 1991, the UN Development Programme (UNDP) organized the African Informal Consultation on Behaviour Change as it relates to the HIV pandemic. Participants from community-based organizations strongly endorsed the possibility for individuals and communities to change their attitudes and behaviours in response to HIV/AIDS, and stressed the importance of evaluation and documenting these changes and sharing lessons learned. The groups concluded that: research in the field of HIV should be action-oriented and participatory; and that new research methods and ways of presenting data were called for. Participants in the 2nd consultation held in the ASIA/Pacific region in November 1992 also stressed the importance of developing community-based monitoring, evaluation, and programme development methodologies. The UNDP responded by launching a number of initiatives to explore ways in which communities may be helped to document ongoing changes, assess their impact and efficacy, and share them with others. New approaches to evaluation are also being explored based upon processes of assessment ad redesign already occurring in the communities.

Reid, Elizabeth (ed) 1995, *HIV and AIDS: The Global Connection,* Kumarian Press, Connecticut.

The series of papers introduced by the author call for a move away from use of the language

of crisis and catastrophe which has entered the discussion of HIV/AIDS. Empowered by their seropositive status, HIV-infected people have begun to talk to each other, to speak out, to form groups and organizations, and to go beyond the personal, emotional and professional boundaries in which they would otherwise constrain themselves. Therefore, despite the seriousness of the epidemic, considerable hope prevails wherever people care for one another. A language needs to be developed which emphasizes hope rather than hopelessness. The various forms of mutual support are discussed.

Remkes, T. 1991, 'Fighting AIDS in Southern Africa', *International Nursing Review*, vol. 38, no. 1, pp. 9–10.

An $11 million project to combat HIV/AIDS in southern Africa will focus on developing HIV/AIDS training and education, with the existing primary healthcare system re-oriented so that more information is given to the neglected area of sexual health. The belief is that by decentralising HIV/AIDS education projects, non-governmental organizations will be encouraged to participate. The project uses the assistance of local people such as traditional healers, healthcare professionals, civil servants, community workers and women's leaders, to support small, community-based projects in slowing the HIV epidemic.

Rhodes, Tim 1994, 'Outreach, community change and community empowerment: contradictions for public health and health promotion', in *AIDS: Foundations for the Future,* (eds) Peter Aggleton, Peter Davies and Graham Hart, Taylor and Francis, London.

In Britain, the HIV epidemic has encouraged a rapid revision in the policy approaches to drug treatment and prevention, characterized by the emergence of pragmatism. This shift has encouraged the development of what have come to be viewed as innovative styles of service delivery, characterized by friendly communication philosophies, the implementation of a nationwide network of syringe exchange schemes and a greater focus on outreach work. The article looks at the potentials and limitations of outreach, exploring the possible contradictions between community health approaches and public health perspectives, with regard to the facilitation of empowerment over health and health choices among drug injectors and their peers.

Schopper, D., Doussantousse, S., Idro, W.J. and Homsy, J. 1994, 'Country Watch. Uganda', *AIDS Health Promotion Exchange,* no. 2, pp. 9–10.

Looks at an HIV/AIDS prevention programme initiated by Medecins sans Frontieres in 1991, in the Moyo district of Uganda. This programme aimed at gradually transferring responsibility for prevention to the local people through training of AIDS control advisers (ACA). Informational pamphlets were developed along with an action plan for a village-based information campaign, followed by the insertion of eight women and 22 men into a two-week training course on prevention measures and communication. The ACAs were evaluated monthly both qualitatively and quantitatively with and overall evaluation conducted in January 1992. Community collaboration was excellent, although condoms were distributed only to adults and older teenagers in response to local cries that condom distribution encouraged immorality. ACAs continued to distribute condoms to a wide range of people.

Seguin, A. and Rancourt, C. 1996, 'The theatre: an effective tool for health promotion', *World Health Forum*, vol. 17, no. 1, pp. 64–69.

'Forum theatre' is a dramatic piece composed of sketches that depict situations requiring change. Actors and actresses first enact the situation, then a facilitator helps the audience explore new solutions through improvisation, the goal being to produce a variety of options. One of the forum theatre projects involved educating women in urban Quebec about HIV/AIDS prevention so that they could develop a positive attitude towards safe sex, strengthen their capacity for self-assertion and communication and become more informed about safe sex.

Shaw, Nancy Stoller 1988, 'Preventing AIDS among women: the role of community organizing', *Socialist Review,* vol. 18, no. 4, pp. 76–92.

An investigation of the potential of community organizing as a strategy to reduce transmission of HIV in the US. Neighbourhood organizing, direct action, community health projects and national intervention models are reviewed. Examples of community-based HIV/AIDS prevention projects are compared to the models and assessed in terms of community development and effectiveness. It is concluded that effective community organizing has reduced HIV transmission.

Singer, M. 1996, 'The evolution of AIDS work in a Puerto Rican community organization', *Human Organization,* vol. 55, no. 1, pp. 67–75.

This paper describes the evolution of HIV/AIDS prevention education work at the Hispanic Health Council, a community-based health research, service and advocacy organization. The development of community-based AIDS programmes has attracted the interest of public health researchers because they recognise that to be effective HIV/AIDS prevention must be sensitive to the cultures of targeted populations.

Staugaard, F. 1991, 'Role of traditional health workers in prevention and control of AIDS in Africa', *Tropical Doctor,* vol. 21, no. 1, pp. 22–24.

Many indigenous concepts on the cause and transmission of HIV/AIDS are compatible with modern scientific concepts, although expressed in different terms and conceptual frameworks. In their role as informal community leaders and guardians of social norms, healers and midwives can channel educational messages and act as change agents.

Tanasugarn, C. and Wienrawee, P. 1994, 'Community mobilization for AIDS prevention in Bangkok', *AIDSCAPTIONS,* vol. 1, no. 2, pp. 10–15.

Bangkok has a population of 8 million people with an increasing rate of HIV seroprevalence. The AIDS Control and Prevention (AIDSCAP) Project, contracted with the Faculty of Public Health at Mahidol University to work with the Bangkok Metropolitan Administration to apply community mobilization methods to HIV/AIDS prevention. This article covers: social networks and community mobilization; conducting a community network diagnosis; converting the information into action; strengthening networks; and what lessons have been learnt. According to the authors, community mobilization allows one to define and work with such a large urban population through social networks, ensuring that relevant prevention messages will apply to all populations at risk.

Tankoano, F. 1994, 'Applying research to AIDS programmes in villages. Burkina Faso project learns from community survey', *Sante Salud,* Winter, p. 7.

Since 1992, PLAN and the local Ministry of Health have been conducting an HIV/AIDS prevention programme in the province. After conducting an initial baseline survey to assess knowledge, attitudes and practices about the disease, a programme was implemented based on what had been discovered. As illiteracy rates were quite high, 'Village Communicators' were trained in appropriate information, education and communication techniques regarding AIDS prevention. They then organized and conducted two-weekly sessions. A team of health personnel, artists and a traditional music group also conducted collective sessions to promote condom use and address problems relating to AIDS (polygamy, remarrying of spouses of AIDS victims, availability of testing during prenuptial visits). Village leaders, traditional healers and PLAN and Ministry of Health staff promoted condom use at community sessions, and a community-based system, managed by village communities for the sale and distribution of condoms, has been established.

Tanzania Red Cross Society 1995, 'Policy and practice. Supportive environments', *AIDS Action,* no. 29, Jun–Aug, p. 3.

Efforts can be made to prevent and control HIV/AIDS both countrywide and at the local, community level. While changes at the national level require great political commitment and resources, it can also be difficult to change community policy and norms on sex behaviour since such behaviour and norms are rarely the subject of open public discussion. Participatory research and community discussion can, however, help people to acknowledge relevant issues and look for solutions. The process may span several years and require the involvement of key decision makers. Health or education team staff often begin by raising the issue with community leaders, allowing people to explore the problems and decide upon appropriate strategies. People then often decide to select a few individuals to be trained as community counsellors who act as advisers and link the community with the health service.

United Nations Development Programme HIV and Development Programme. 1993 *HIV and Development in Africa,* UNDP, New York.

Looks at the need for a process of national and community mobilization within a supportive legal, human rights and policy framework. Examines how the relationships between social, economic, cultural variables and the spread of HIV must be considered in the design of HIV/AIDS prevention programmes. New social contracts and partnerships—between men and women, the infected and those not yet directly infected, and communities and governments – based on mutual respect and supported by laws, policies and budgetary priorities must be fostered.

van Reyk, Paul 1994, *Preventive Education and Behaviour Changing HIV and AIDS,* National Centre in HIV Social Research, Macquarie University, Sydney.

This paper sets out to consider what evidence there is that preventive education programmes targeted at gay and other homosexually active men have reduced the likelihood of the transmission of HIV. Looking at evidence from several countries, including Australia, the author

concludes that: educative information has resulted in significant reductions in practices which facilitate transmission; in many cases a supportive collective environment has been utilised or established to disseminate the information; change in sexual behaviour occurs when the population is well informed; and that attachment to gay communities and the various forms of socio-cultural support that accompanies it are crucial for the exposure to and familiarity with safe sex culture.

Visrutaratna, S., Lindan, C.P., Sirhorachai, A. and Mandel, J.S. 1995, ''Superstar' and 'model brothel': developing and evaluating a condom promotion programme for sex establishments in Chiang Mai, Thailand', *AIDS,* vol. 9, Suppl. 1, July, pp. 69–75.

A year-long intervention targeting sex workers, brothel owners and clients, promoted cooperation between these groups and the public health office and established free condom supply for sex establishments. The 'model brothel' component encouraged all brothel owners in Chiang Mai to insist on mandatory use of condoms. Concludes that involving sex workers as peer educators and enlisting the support of owners and operators can result in improved condom use over time.

Williams, E. 1993, 'How to improve prevention: empower African women', *Network,* vol. 13, no. 4, p. 8.

In 1988 the Society of Women and AIDS in Africa (SWAA) organized to address the special needs, constraints and vulnerabilities of women in relation to HIV/AIDS. SWAA has directed attention to the major HIV/AIDS risk factors for women and the barriers to prevention and control, ensuring that women-centred prevention and control strategies are incorporated into national AIDS programmes, fostering the development of AIDS programmes for women at national level and promoting the rights of women affected and infected by HIV/AIDS. To best make progress towards the goals of SWAA, AIDS programme managers, opinion, policy leaders and private health care providers must be sensitized to and educated on the issues at stake for women.

Wolfers, Ivan 1992, *AIDS and Primary Health Care: The Role of Non-Governmental Organizations,* VU University Press, Amsterdam.

Wolfers describes the consequences of the HIV/AIDS epidemic for the developing world. In particular he looks at aspects of concern for primary health care workers such as the situation where HIV/AIDS is the problem of a minority. In this case, how can the whole community be mobilized? The book also looks at the various types of NGOs active in the field of HIV/AIDS. A disctinction is made between NGOs among people who are directly involved with the problem (HIV organizations) and those involved for humanitarian reasons. Each NGO group has different tasks, with different potentials and problems, underpinned by different policies, all of which are explored in the book. The author takes the view that NGOs play a crucial role in motivating total populations by forming the right coalitions between interest groups.

World Health Organization, South-East Region, 1991, *NGO's Role and Involvement in the Prevention and Control of AIDS,* Report of a Regional Workshop, October 30 – November 1, no. 2, Feb. 19., SEA/AIDS/22.

This regional workshop aimed to: exchange information; inform non-governmental organizations (NGOs) on the epidemiology and control of HIV/AIDS; share the experience of NGOs; identify the involvement of NGOs in HIV/AIDS control programmes; and understand the impact of discriminatory measures. Topics for discussion included: the global HIV/AIDS situation and control; the role of NGOs in control; the legal, ethical and human rights issues in HIV/AIDS prevention and control; and the involvement of NGOs in prevention and control of AIDS. Argues that NGOs need to mobilize other NGOs in HIV/AIDS prevention. Also that governments should include NGOs on national AIDS committees, particularly those which are community-oriented and not politically affiliated, and those which work with women and marginalized groups.