Health Canada / Santé Canada

REPORT OF THE FIRST INTERNATIONAL

DIALOGUE ON HIV/AIDS:

POLICY DILEMMAS FACING GOVERNMENTS

Canadian Strategy on HIV/AIDS / La Stratégie canadienne sur le VIH/sida

UNAIDS
The Joint United Nations Programme on HIV/AIDS

Canada

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"It is vital that governments take the lead because only governments can put AIDS at the centre of the national agenda and not just the health agenda. Only governments can make the tough decisions to create more favourable conditions for others to play their role."

Peter Piot, UNAIDS

WHAT EMERGED FROM THE DIALOGUE

Introduction

HIV infection is an unprecedented challenge because it is a complex biological disease, and an even more complex social disease, with an ever-changing face.

Many high-income countries have had success in addressing HIV/AIDS, resulting in a marked decline in overall new infections and AIDS cases. However, the epidemic is spreading among marginalized populations who are the most difficult to reach with prevention, care and treatment programs.

International policy collaboration is a key instrument in addressing the current challenges of HIV/AIDS because it allows us to:

- See the global picture
- Develop a clear vision and focus on priority goals
- Identify the policy issues that must be confronted before developing effective strategies
- Create policy frameworks that can guide program planning and evaluation
- Stimulate innovative policy approaches
- Learn from other countries

On November 8-10, 1999, Health Canada and the Joint United Nations Programme on HIV/AIDS (UNAIDS) co-sponsored the *Dialogue on HIV/AIDS: Policy Dilemmas Facing Governments.* This was the first international event to focus on macro-policy issues related to HIV/AIDS in high-income countries.

Policy experts, representatives from government and non-governmental organizations, and people with HIV/AIDS from Australia, Brazil, Canada, Denmark, India, Mexico, Sweden, Switzerland, Thailand, the United Kingdom, and the United States convened to discuss:

1. What policy issues arise from the determinants and current dynamics of HIV?
2. What policy issues relate to prevention and care for injection drug users in communities and in large-scale interventions?
3. What are the policy issues in caring for the youth population?
4. How do socio-economic policies affect risk for HIV/AIDS and accessibility to care in marginalized populations?

"Because disease is embedded in the social, economic, religious, ethical and legal structures of our society, our objectives for disease control can conflict with societal and religious goals. It's not necessarily a win-win situation on issues such as individual rights versus the common good. Unless we confront the issues, we will not find solutions. This kind of dialogue is an excellent start."

Ian Potter, Canada

In general, the Dialogue confirmed that, despite success in reducing infections in countries represented, the AIDS epidemic is not contained. There are alarming new waves among marginalized populations, including people of colour, women living in poverty, youth, inmates, and especially injection drug users (IDUs). Effective international frameworks to address HIV/AIDS must therefore extend beyond narrow definitions of health to encompass both social and economic policy.

How to tackle entrenched attitudinal barriers stemming from societal discrimination and moral judgements about sexual behaviour remains a primary issue. These issues play a large role in limiting the access of marginalized populations to effective care, treatment and support.

Government leadership at all levels in all sectors is a prerequisite for developing macro-policies that will provide direction and facilitate effective strategies and programs. As well, HIV/AIDS policy decisions require the input of all sectors – the health, educational, political, religious, legal, and social communities, including the community of people with HIV/AIDS.

Major policy decisions and priority directions are complex because HIV/AIDS competes with other health and social problems for human and financial resources. There may also be pressures within dedicated HIV/AIDS resources to having to also focus on comprehensive population strategies versus targeted activities for the most vulnerable populations.

In addition, policies that would facilitate HIV/AIDS health goals may conflict with policies that support other values. This is a critical factor in developing efficient testing and surveillance systems that do not violate the right to privacy, expose people identified as infected to undesirable social consequences, or oppose cultural values. Similarly, policies that support intervening in family life for youth education or care of women may contradict other policies designed to protect family jurisdictions.

Key Challenges:

Policy Advocacy

- How to become effective policy advocates and encourage government leadership on critical issues;
- How to balance the people and resources devoted to policy advocacy with those needed for prevention and treatment programs;
- How to involve the most vulnerable, marginalized people in policy advocacy and program design in a way that is meaningful to them;
- How to marshal the evidence that policy advocates require to convince governments and assist them in policy making;
- How to support international collaboration in controlling HIV/AIDS;

Policy Integration

- How to support and integrate social policies with HIV/AIDS policies;
- How to establish comprehensive macro-policies that address priority goals in a national strategy while fostering policy diversity to support regional or community strategies designed for specific populations;

Policies for Balance

- How to balance the need for targeted programs directed toward those at highest risk in epidemic hot spots with the need for general prevention and treatment programs;
- How to balance and coordinate the respective roles and responsibilities of national and local players and of government, professional and community players;
- How to balance the need to accurately track infection and disease with respect for human rights and cultural values regarding privacy, and peoples' realistic fears of discrimination.

Recommended Starting Points:

In some countries, policy leadership begins with direction from a strong, central government. This is Thailand's approach. In other countries, such as Switzerland, a comprehensive approach has emerged within a federation of states.

- Through funding and training, support policy advocacy and human rights activity as part of HIV/AIDS strategies and programs.
- Establish networks of influential community organizations and non-governmental agencies to work towards HIV/AIDS-integrated, comprehensive health care.
- Provide professionals, community members, non-governmental organizations (NGOs), and government policy makers with opportunities to communicate on issues.
- For disease surveillance, consider environmental risk factors and communities as well as cases.
- Collect compelling evidence of successful prevention programs for youth and injection drug users so the information can be used to lobby for improved access to care.
- Equip professionals with the appropriate skills and attitudes to work with injection drug users, high-risk youth, and other marginalized, vulnerable people.
- Increase access to care by bringing culturally sensitive programs to affected people in their own environment, rather than waiting for them to come to the health system.
- Integrate health prevention strategies for youth with broad state and community education programs.
- Demonstrate how HIV among drug users is a health threat to the general population.
- Separate advocacy for harm reduction programs from drug use policy reform.

Inspiring Successes

The Canadian Strategy on HIV/AIDS (CSHA) provides funding and networking opportunities for hundreds of community-based organizations working on all fronts against the epidemic. For example, the Canadian HIV/AIDS Legal Network promotes supportive policy and human rights for people living with the disease.

Despite a strong national policy of criminalizing all drug use and support for drug users, the Brazilian state of Sao Paulo has established harm reduction programs that have reduced high infection rates among injection drug users.

In the face of an economically and socially crippling HIV/AIDS epidemic, Thailand established a coordinated national strategy that has progressed from a health-only focus to one that includes all sectors working toward a healthy social and economic environment.

Switzerland, a high-income country that experienced endemic HIV/AIDS, has based its national strategy on partnership and solidarity and made combating discrimination a priority. Its successful harm reduction program is an example of how to minimize discrimination against injection drug users by decriminalizing activity and providing unprecedented access to care.

Sweden emphasizes HIV/AIDS prevention among youth with an HIV/AIDS program integrated into the school curriculum and sexual transmitted disease education in youth-specific health clinics. Denmark's youth peer-counseling program is another effective approach.

In the United Kingdom, an early (1987) policy shift to support harm reduction accounts for a low rate of HIV infection among injection drug users.

Australia's strategy has been updated to respond to the changing face of the epidemic. It first focused on prevention among homosexually active men and injection drug users. The programs were then framed in the broader context of communicable diseases and sexual health. The current strategy has a supportive legal environment, non-partisan political support, and partnerships with all key sectors.

In India, non-governmental organizations have played a major role in initiating effective interventions, providing care to people living with HIV/AIDS, and defending their human rights. State advisors and decentralized funding strengthen these NGOs.

UNAIDS' advocacy leadership around the globe has helped nations keep HIV/AIDS on government and public agendas. While doing so, UNAIDS has championed equity and framed the epidemic as a medical, public health, social, economic, cultural, and political challenge to be addressed by governments, NGOs, the scientific community, and citizens.

"Some developing countries have incorporated far more supportive social policies than high- income countries."

Peter Piot , UNAIDS

HIV/AIDS DYNAMICS DEFY PREDICTION

New Infection Trends

In Canada almost half of new HIV infections occur in IDUs.

Although racial and ethnic minorities are only one quarter of the American population, they account for half of all AIDS cases.

In Switzerland, over half of newly diagnosed HIV cases resulted from heterosexual contact. In Sweden, slightly more than a third of new cases did.

In Brazil, women represent half of AIDS cases, and the majority of all cases has shifted from highly educated people to the illiterate or minimally educated.

In most high-income countries, the rate of infection among homosexual men has declined, though they are often still the largest group infected.

How do the dynamics and determinants of HIV create policy issues?

In the short history of HIV/AIDS, the players and the scenes of action have constantly shifted and expanded. The virus has proved to be a changeable creature, ever ready to mutate.

Due to the complex biological and social nature of the disease, there is simply no way to predict the course of infection based on patterns in the past. Nor can we rely on previously successful strategies to contain infection and alleviate suffering in new, recently infected populations.

The New Wave

The new wave of HIV/AIDS is spreading through socially marginalized groups. The highest incidences of new infection and disease are emerging among women, the poor, people of colour, street youth, injection drug users, and prison inmates.

Five Chances for AIDS

Call her Mary. She has five good chances for HIV infection. She is Aboriginal. She is female. She is young. She lives in an inner city neighbourhood rampant with injection drug users.

If Mary does get infected, chances are she won't use available health care because she doesn't trust the system.

Health Canada

Access to Care

In the current spread of the epidemic among marginalized people, the primary issue is access to care. These are people living on the edge of society: they tend not to use traditional social and health services. Availability of prevention and care is only part of the issue. The other part is the lack of client-provider trust on both sides. The marginalized have little or no trust in a system through which they have often experienced discrimination, and providers have little trust in people they may view as hopeless, irresponsible, or simply desperately needing more than they can provide.

This dynamic is exacerbated in the case of HIV/AIDS because the disease is so closely associated with sexual mores, and infected people also fear rejection by their own communities. For some, the price for seeking a test or treatment could also be exposure as an illegal drug user, a victim of violence, or an undocumented immigrant.

Issues of confidentiality and social alienation also keep socially disadvantaged youth, homosexuals, and lesbian adults from seeking care.

Health Canada

Should HIV testing for pregnant women be mandatory? This is one of many screening issues requiring clear policies.

Should She Be Tested for HIV?

Screening issues raised in the Dialogue are well illustrated by the question of pregnancy testing. Given that transmission from mothers to newborns is a major source of HIV infection and that infected mothers are often unaware they have the virus, should testing for HIV during pregnancy be mandatory? Antiviral therapy given to the mother during pregnancy, labour and delivery, and to the newborn, can reduce HIV transmission from about 25% to 8%, so the potential for prevention is significant.

Policies vary among countries. Advocates concerned for the rights of the individual oppose mandatory testing in favour of routinely offering counseling and testing to all women, though some jurisdictions only offer testing to known high-risk mothers. It is critical that testing programs include informed consent, pre- and post-test counseling, and guarantees of confidentiality.

The policy gap is clear. A policy of universal access to care is critical. In terms of operational policies, the identical programs and community-based approaches that have succeeded with other populations will not necessarily work with marginalized people in this new wave of infection.

The challenges are:

- How can governments at all levels be persuaded to provide equitable care for the marginalized?
- How can the marginalized be reached to provide input into policy and programs and mobilize their energy?
- Given the barriers, what HIV/AIDS programs will meet their needs?

What We Don't Know

In some respects, monitoring HIV and AIDS is like a dog chasing after a car. We never quite catch up to the action. Because the spread of HIV infection is so unpredictable and segments of populations are outside the testing and reporting systems, we can only estimate the current extent of the epidemic and the burden of disease.

However, to predict trends more accurately, monitoring systems need to consider relative risk levels among populations and the socio-economic environments that determine them. It is important to track incidence among social and geographical groups as well as individuals.

The challenge of accurately monitoring HIV/AIDS brings its own issues, primarily the tension between an individual's right to privacy and the common good. HIV/AIDS policy makers have struggled with the questions: Should HIV testing be voluntary or mandatory? Should case contacts be tracked through a unique identifier system or remain anonymous? The very real social stigma of having AIDS complicates such operational policy decisions.

Impact of New Medical Treatments

Antiviral therapies have dramatically reduced the number of AIDS-related deaths in high-income countries. It is not known how this will affect the epidemic in the long term. Clearly, increased survival of infected people increases the prevalence of infection, and there may be more opportunity for spreading infection because of the lag time between HIV and AIDS. Assumptions and perceptions of the effectiveness of these new therapies have resulted in increases in high-risk behaviours and in the potential for increased infections.

The primary policy issue related to new medical treatments is obvious: Who will have access to the expensive but effective treatments and who will pay for them?

"Good thinking about HIV means that prevention and care is integrated at the client level. A good specialized HIV program does not mean a program that only talks about HIV or only cares for HIV disease."

Jeffrey O'Malley, U.K.

The lines between policy and programs are blurred

The many players involved in HIV/AIDS strategies often appear to be on diverging paths with no assurance that they will converge at an agreed upon destination. When policy leadership and infrastructure for collaboration are missing, HIV/AIDS strategies are fragmented at best; at worst, they are paralyzed by contradictory social policies.

Participants in the Dialogue repeatedly stressed the need for strong policy direction at senior levels of government to develop a consensus on priorities and coordinate strategies for diverse populations. Comprehensive programs require national leadership.

Once priorities and major strategies are established, the challenge is to balance programs in three ways: balance activity in the four areas of research (medical and social), surveillance, prevention, and treatment; balance general and focused programs; and balance existing and new programs.

By far the greatest challenge is to integrate HIV/AIDS strategies, policies and programs with broader social ones, a task made more difficult by the present lack of structures to support such coordination.

Recommended Approaches:

- When collecting data, assess the total picture by considering personal, social and economic determinants of risk; by focusing on social units as well as on individual cases; and by relating epidemiology to prevention and care outcomes.
- Establish strong coordinating bodies at the national level and integrated services at more local levels.
- Encourage multi-sector responses to provide a continuum of services in health, education, housing, employment, and family living.
- Fund and incorporate policy advocacy into all HIV/AIDS strategies.
- Develop the capacity for emerging HIV/AIDS populations to participate in policy and program design.

The American AIDS mortality rate dropped 47% between 1996 and 1997, largely due to antiviral therapy.

As many as 1 in 3 cases of HIV may go unreported in Canada.

> "We know what needs to be done. It's a matter of how to garner support to make it happen."
>
> **Mary Beth Levin, UNAIDS**

RESPONDING TO AN URGENT NEED

What HIV/AIDS policy issues relate to injection drug users?

The fastest rate of HIV infection is among injection drug users.

Yet prevention and treatment programs intended for injection drug users are often viewed as the most contentious and are frequently the least available. The overwhelming issue is the gap between what is known to work--such as harm reduction programs--and what governments and the public will support.

The gap exists because the majority of people view drug use as a moral problem rather than a health problem and criminalize drug-related activity. HIV/AIDS harm reduction programs are mistakenly thought to condone and encourage drug use among criminals.

Creating effective HIV/AIDS policies for injection drug users challenges mainstream prejudices deeply embedded in society. However, progress has been made, largely through excellent community projects that demonstrate what can and must be done to achieve healthier and more humane communities. The challenge is to translate these into large scale interventions

Worldwide, IDUs are probably more vulnerable to HIV infection than any other group. It is no accident that in most developed countries the prevalence of HIV/AIDS is almost always proportional to that country's numbers of IDUs.

At the same time, IDUs have the least access to care for two reasons. Socially isolated, and often living with a mental health problem, they seldom seek any kind of health care. In addition, adequate care is not available because many countries have a predominant drug interdiction system that is more likely to imprison drug users than provide health care. In practice, the lack of health services is often due to attitudes – the widely held idea that "immoral junkies" don't deserve care or are beyond help, though evidence shows that drug users can respond to rehabilitation.

Inmates are a striking example of a population with minimal access to care. Though infection rates in prison are many times higher than in the general population, and illicit drug use and sexual activity are prevalent, there are few addiction or HIV/AIDS treatment services, even for those who may have been on harm reduction programs prior to incarceration.

Fortunately, new programs for prison inmates are emerging. Canada is one of the countries that has pioneered screening, needle exchanges and other services for inmates.

The Impossible Made Possible in Brazil

The Brazilian Law of Narcotics makes any assistance programs dealing with drugs a crime, as part of a "war on drugs" policy. Given that opposition, harm reduction programs might seem an impossible goal or a fantasy. Yet advocates in the state of Sao Paulo, led by the Brazilian Harm Reduction Association and the Latin American Harm Reduction Network, have made such programs a reality.

Mary Beth Levin

This mother and daughter live in Sao Vincente, a city in Sao Paulo, Brazil. Mother runs a needle exchange program out of her home. She deposits the needles into the box under her arm.

In 1989, 67% of injection drug users in the Brazilian state of Sao Paulo were infected with HIV. Today Sao Paulo is the only Brazilian state with a decrease in the reported cases of HIV/AIDS, in great part due to legalized harm reduction projects.

How did advocates achieve this? They were dedicated, persistent and brave. At one point, staff of projects approved by the National Narcotic Council were threatened with legal action and imprisonment. Activists, public health and legal experts, harm reduction specialists and UNAIDS consultants mobilized to educate and lobby decision makers. Public hearings increased awareness and support.

Advocates argued that HIV/AIDS in Brazil is a major public health threat which – as had been proven in other countries – harm reduction programs could reduce. They were able to convince politicians that programs would not undermine narcotic legislation because they aim to change behaviour, not promote drug use. Activists also pointed out that prevention through harm reduction was cost-effective. Non-government organizations and the media were important allies in the successful campaign.

Paulo Teixeira, member of the Sao Paulo State Legislature who led legislative reform comments:

"I would like to say that authoring and advocating harm reduction legislation was not the most difficult action in this process. I just took the chance created by those who had the courage and insight to get programs started – facing prejudice, repression, and even imprisonment in an effort to defend people's lives."

The success of Sao Paulo harm reduction programs has encouraged legal reform and programs in two other Brazilian states and facilitated a harm reduction strategy in the National Anti Drugs Secretariat.

Now the challenge is to measure the impact of the programs on disease transmission, drug use, and drug-related crimes. Advocates are also working to achieve a federal law for national harm reduction and to expand programs to prison settings.

Large-Scale Interventions

A number of high-income countries have responded to the alarming HIV infection rate among IDUs with harm reduction programs. These are based on the principle that abstinence is a difficult outcome to achieve and probably an unrealistic goal for the majority of IDUs. Highly successful harm reduction programs mounted in the Netherlands, the U.K. and Switzerland have inspired programs in New York, Vancouver, Melbourne and other cities. Typically, harm reduction programs include some combination of needle exchanges, substitute oral drugs, methadone clinics, legal prescribing programs, education, tolerance areas or sites, and an emphasis on decriminalizing activity, with law enforcement focused more on traffickers than users.

Mary Beth Levin

These men participate in a harm reduction program in Sao Vincente, Brazil. The bearded gentleman on the right is the community's outreach worker and an active injection drug user.

"Even in countries where harm reduction is successful at a national level, it invariably started within small communities doing little things like syringe exchange."

Diane Riley, Canada

Governments and communities supporting harm reduction programs have concluded that the spread of HIV is a greater danger to individual and public health than drug misuse. The evidence shows harm reduction programs work to reduce HIV infection, sometimes dramatically. For example, since Australia introduced harm reduction, less than 5% of Australian IDUs have HIV.

Though harm reduction programs work, they are controversial and a small number of participants in the Dialogue opposed them. Those who supported harm reduction measures did not recommend their exclusive use. European centres have shown that harm reduction is most effective as a component of comprehensive strategies that address associated health problems and the environmental conditions that make people vulnerable.

Comprehensive Care Crucial

IDUs have many needs in addition to a need for treatment for HIV/AIDS. They require addiction treatment, and at least half suffer from some form of mental health problem. Tuberculosis and pneumonia are also increasing among the impoverished and malnourished. IDUs who are mothers may most urgently need food, housing, child care and transportation.

Unfortunately, several factors contribute to fragmented policies and services. Pre-existing segmented social systems with separate budgets, contradictions in traditional professional loyalties, and a tendency to medicalize the problem all work against coordination of services.

Integrated Care for Success

In Switzerland, a severely drug-addicted person who has failed other treatment programs has the option of heroin-assisted treatment. Research has shown that the innovative therapy reduces illegal use of drugs and associated criminal activities. It is part of a comprehensive strategy for drug users that includes health care, counseling and social assistance. Swiss facilities and community services for drug addicts more than doubled ove a five year period. For example, Switzerland has more than 100 in-patient facilities, and methadone-maintenance programs are available from special clinics and private doctors.

After public debate and referenda, the Swiss people widely support government policy and programs for prevention, harm reduction, treatment, therapy, research, and training. They see that broad strategy works to reduce addiction and disease. Systematic evaluation of measures and continued research facilitate continued public support.

"You can put the services where the people are if the people don't come to the services."

Carola Marte, U.S.A.

The other key to success is the collaboration among police, public health and social agencies that share a common strategy. The Swiss experience shows that HIV/AIDS programs for drug users are most successful when they are part of a comprehensive program offering counseling and treatment, other health services, and social support.

Key Challenges

- Influencing the public to view drug users as unhealthy people in need of help, rather than as criminals;
- Educating the public and politicians about alternatives to the "war on drugs" approach and gaining support for large-scale harm reduction programs;
- Supporting drug policy research on domestic and international regulation of drugs;
- Finding the right mix of governmental and voluntary efforts;
- Providing integrated health and social services with easy access;
- Developing HIV/AIDS programs that work with this unique population;
- Training interdisciplinary professionals so they acquire the skills and empathy needed to work effectively with drug users.

Recommended Approaches:

- Separate harm reduction strategies from drug policy reform, and do not link reducing harm to the legalizing of drugs.
- Collaborate with the media, drug-user groups, non-governmental organizations and harm reduction networks in achieving policy reform.
- Agree on a common definition of harm reduction.
- Cultivate relationships with law enforcement and justice officials
- Collect supportive evidence from convincing pilot programs and mount new ones.
- Base strategies on pilot programs that have successfully integrated health and social services for IDUs.
- Provide easily accessible services as a point of entry to the continuum of care.
- Help health professionals to better understand drug users.
- Clarify the role of community-based organizations and support it.

"We will never produce the kind of policy changes we need if we don't overcome the stigma and discrimination that make it so hard to reach people. One way of doing that is to involve people who use injection drugs, or used to use them, in our basic structures."

Terje Anderson, U.S.A.

PROTECTING YOUTH

What policy issues affect HIV/AIDS strategies for youth?

UNAIDS estimates that half of global HIV infections occur among young people under 25 years old, so early prevention is critical. In fact, recent American surveys indicate that young people are less knowledgeable about AIDS than they were 10 years ago

UNICEF/Horner

School children in Pang Lao School, Chiang Rai, Northern Thailand, perform a puppet show they have written and directed to communicate the need for AIDS awareness.

"The process was the most valuable output from the meeting. The process was an interesting example of how innovative strategies based upon consensus building and multi-sectorial collaboration can be used to confront policy dilemmas facing governments."

Mandeep Dhaliwal, India

While many young people are vulnerable because of inexperience and a lack of knowledge, some are at risk many times over because they come from impoverished homes or dysfunctional families, the drug culture, or the commercial sex trade, and they lack the self-esteem and life skills to make healthy choices. HIV/AIDS policies and programs must address heterogeneous youth at variable risk and must account for their individual social circumstances and personal resources.

As in other marginalized populations, access to care is a major issue. Sexually active young people frequently do not seek care because the location and hours of health facilities are inconvenient and because staff are perceived to be unfriendly. Confidentiality is a major concern, especially for homosexuals and lesbians who fear family condemnation and the ridicule of peers.

Conflicting Values

While the need for youth HIV/AIDS prevention programs is great, many parents and other adults fear that educating young people about sex and HIV will encourage them to become sexually active early and engage in undesirable behaviour. Actually, research suggests that the reverse is true. If they are well informed, young people are more likely to delay sexual intercourse, and those already sexually active are more likely to protect themselves against disease.

How can effective HIV/AIDS prevention programs be developed for youth in an environment of discomfort or outright opposition from parents and community leaders who see the programs as condoning youth sexual activity and threatening family values of appropriate sexual behavior?

Even when there is support for programs, there are operational policy questions about how and where they should be offered and by whom. Most of the Dialogue participants agreed that HIV/AIDS education should be integrated into general sex and other health education in schools and in the community. Sweden and Brazil have successfully integrated HIV/AIDS education into their school curricula. Street youth and other special groups require non-traditional programs accessible in their environments. Identifying and training people who are non-judgmental and who communicate effectively with young people is another challenge.

"The strategy is to involve the young people in the AIDS campaign. We encourage young people to form groups in the school or in the village to become aware of the dangers of drugs and to swear for themselves and to try to convince others not to become involved in drugs."

Apichart Nirapathpongporn, Thailand

Whose Rights?

Youth access to HIV/AIDS prevention and health care programs is an issue of human rights. The question is: Whose rights? There is the right of the public to be protected from endemic infections through prevention programs for the common good. There is the right of children or youth to healthy, safe lives, and to confidentiality. There is the right of parents to have jurisdiction over their children's upbringing without undue interference from the state. These rights are often competing and are certainly open to interpretation.

Dialogue participants affirmed the policy stance advocated by UNAIDS, which unequivocally supports the fundamental right of children and young people to information and other resources to protect themselves from infection. These include access to appropriate education about sex, sexuality, drugs, and relationships; tools for prevention, such as condoms and clean needles and syringes; and youth-friendly services.

Youth Leading the Way

Around the world, young people have shown that they are one of the strongest forces for change in the fight against HIV/AIDS. When youthful energy, creativity, enthusiasm and compassion are harnessed, young people become very influential educators for other young people, and sometimes for adults as well. Young educators in Thailand and Denmark can take a good share of the credit for prevention programs that work.

UNICEF/Horner

Thai school girls in the city of Chiang Rai draw lines on a poster to connect groups at risk for HIV/AIDS. Some older youth in Thailand have become impressive leaders in AIDS education for their communities.

Recommended Approaches:

- Address the needs of youth in the context of their families, peer culture and community environment.
- Educate adults and identify who is likely to facilitate acceptance of youth educational programs.
- Involve youth in program planning, and avoid information-driven, top-down programs.
- Provide confidential testing and prevention tools, such as condoms and clean syringes and needles.
- Create policies that will help protect youth from coercive sex.

THE PROBLEM BEHIND THE PROBLEM

How can supportive social policies reduce HIV/AIDS risk in the most vulnerable populations?

The best predictor of AIDS prevalence is the social and economic health of a country, city, community, or family.

Marginalized populations are the most vulnerable to HIV infection because their opportunities to make positive life choices are significantly determined by social circumstances --economic and social class, race, gender, country of origin, and peer culture. As indicated in previous sections of this report, the social policy connection is a reality – and therein lies the most challenging policy dilemma.

How can an effective social policy response be mounted when those who need the policy changes have no social and economic power?

UNAIDS/Noorani

An awareness outreach worker distributes pamphlets on HIV/AIDS to sex workers in a brothel in Phayao, northern Thailand.

"If we focus attention on the 'other', we'll never turn our attention to the structures that in fact produce the problems we're talking about. In a sense, we keep sliding past the problem, not addressing the issue because we are always focusing on the supposedly vulnerable."

Susan Kippax, Australia

The Issues

A comprehensive HIV/AIDS strategy requires integration with education, legal, economic, social, and other health systems but the structure to support integration does not exist, and competition among sectors for resources discourages cooperation.

Though it is critical to address HIV/AIDS and social policy connections, the complexity of social ills and injustices makes it very difficult to identify priorities for action.

In gathering evidence to lobby for policy change, it is difficult to distinguish individual social behavioural factors from environmental components.

In high-income countries, predominating prejudices against the disadvantaged, fears about their impact on society, and stigmas about their inability to change are the biggest barriers to advancing social and HIV/AIDS policies.

Human rights issues also have a direct impact on HIV/AIDS-affected people in many ways. For example, access to HIV/AIDS prevention and care is not a universal human right.

Recommended Approaches:

- Gather appropriate evidence to demonstrate the relationship between social policy, human rights and effective HIV/AIDS strategies.
- Support a measure of social policy advocacy within HIV/AIDS strategies.
- Devote resources to communicating with other sectors and mounting collaborative programs.
- Work from the top down with political and bureaucratic leaders and from the bottom up through communities.

Whichever Way Works

Initiatives for effective HIV/AIDS policy can come from the top down or the bottom up. In Canada and the U.S.A, the homosexual community, along with other grass-roots supporters of human rights, has been extraordinarily effective in stimulating policy reform, provision for health care, and maintenance of legal and ethical rights. Apart from any political leverage, advocates have appealed to justice and compassion.

Thailand demonstrates the effectiveness of policy leadership from the top – the Prime Minister is chair of the National AIDS Prevention Committee and he delegates work to every ministry and sector in the country. The Thai government recognized that its AIDS epidemic threatened the entire socio-economic structure of the country, and it has diminished that threat with concerted action.

"We are being given an opportunity to use HIV as a vehicle to implement broad-scale socio-economic policy changes, and discuss the fact that these changes are necessary in reducing HIV risk not only among marginalized populations, but also among our general populations."

Marsha Martin, U.S.A

A POLICY CHECK LIST FOR NATIONAL HIV/AIDS STRATEGIES

- Where possible, are HIV/AIDS policies integrated into national social policies?
- Do national policies provide sufficient direction and coordination for a comprehensive strategic program and freedom for effectively targeted regional initiatives?
- Are policies based on epidemiology of risk, on evidence of best practices, and on human rights imperatives?
- Do monitoring systems account for the social determinants of risk?
- Do intermediate policies and operational program policies serve national policy goals to avoid fragmentation?
- Are programs and projects evaluated for their contribution to national policy goals?
- Do testing and tracking systems respect privacy rights and cultural values?
- Do policies have the support of senior politicians and senior managers?
- Are strategies, programs, and projects provided with resources for training in and supporting policy reform and human rights advocacy?
- Are prevention and treatment programs evaluated for their long-term contribution to building relationships and educating against discrimination?
- Is there adequate opportunity for consultation among people in research, epidemiology, prevention, and treatment initiatives?
- Are vulnerable populations that are directly affected by the disease consulted when making policy and planning programs?
- Are the results of programs and strategies communicated effectively to national policy makers?
- Do national domestic HIV/AIDS policies promote international collaboration?
- Are principles and values behind policies transparent and debated openly among politicians, professionals, affected communities, and the public?

"We convinced the Government that if we didn't do anything our country is going to be faced with a tragedy. We have taken strong action. We have educated people with a good prevention program and this is one of the reasons HIV has recently declined in our country."

Apichart Nirapathpongporn, Thailand

CONTINUING THE DIALOGUE

"The discussion reconfirmed the importance of our 1987 policy shift to support harm reduction for injection drug users. It has had a major impact on the low level of HIV among our IDUs."

Nick Partridge, U.K.

Next Steps

The Dialogue revealed how wide the horizon of HIV/AIDS policy has to be, extending beyond health to social, educational and economic issues. It also underscored the importance of consultative and collaborative processes: HIV/AIDS policy needs the input and support of affected communities, professional associations, government agencies, politicians, religious leaders, and others. Above all, the Dialogue enabled countries to learn from one another about the problems they face and the approaches they are taking.

Issues that require further discussion include the following:

- What level of HIV infection might be considered "acceptable" and on what terms?
- How will the introduction of an HIV vaccine affect education and prevention efforts?
- Can we find a common language and common objectives for both efforts to reduce the harms of injection drug use and efforts to prevent the use of drugs?
- How can HIV/AIDS policies and practices in high-income countries support effective HIV/AIDS policies and practices in low-income countries?
- What would be required to develop an international network of policy-makers on HIV/AIDS?

It is essential to sustain and deepen what was begun in Montebello. There will be several occasions for doing so in the year 2000, including a possible session during the 13th International Conference on AIDS in Durban, South Africa and a second Dialogue on HIV/AIDS hosted by Sweden.

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"Now I have a network to contact for all kinds of strategic thinking."

Kristina Ramstedt, Sweden

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Dialogue Papers

All papers are available in a portable document format (.pdf) from the Canadian Strategy on HIV/AIDS' web site at www.aidsida.com

The Dynamics and Determinants of HIV in High-Income Countries
Roy Anderson, Geoff Garnett and Polly Weiss

HIV-AIDS Policy Issues Related to Care, Treatment and Support of IDU Communities
Carola Marte and Jose M. Gatell

HIV/AIDS Policy Issues Related to Large-Scale Targeted Interventions for Injection Drug Users
Diane Riley and Luis Paulo Teixeira Ferreira with Dominique Hausser

HIV/AIDS Policy Issues Relating to Youth
Peter Aggleton and Cathy Campbell