



# leadingtogether:

Canada Takes Action on HIV/AIDS (2005-2010)

## ACKNOWLEDGMENTS

*Leading Together: Canada Takes Action on HIV/AIDS, (2005-2010)* was developed collaboratively by a spectrum of stakeholders involved in the Canadian response to HIV/AIDS.

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we know  
what has  
to be  
done.  
now is  
the time  
to act.

## A CALL FOR ACTION

More than 20 years after the first AIDS case was diagnosed, HIV is still with us. Despite progress in both prevention and treatment, HIV continues to cause great harm and loss. A virus that many hoped would be eradicated in the 1980s has now infected and killed millions around the world. Faced with the catastrophic impact of HIV globally and rising rates of infection at home, we in Canada are at a turning point in our fight against HIV.

Do we accept that AIDS will be with us always – a debilitating illness that continues to steal people's health and lives – or do we redouble our efforts to stop the ravages of this preventable disease?

We have chosen to renew our efforts. *Leading Together: Canada Takes Action on HIV/AIDS (2005-2010)* is a hopeful new phase in our collective response to AIDS. It sets out an ambitious coordinated nationwide approach to tackling not just HIV but the underlying health and social issues that contribute to new infections and have devastating effects on people who are infected.

## We know what has to be done. Now is the time to act.

*Together we can: Leadership in a world of AIDS,  
Joint United Nations Programme on HIV/AIDS (UNAIDS),  
June 2001*

This made-in-Canada response to HIV is a call for action.

Over the past 20 years, communities throughout Canada have developed an array of programs and services designed to raise public awareness, prevent the spread of HIV, reduce discrimination, and prolong life for people with HIV/AIDS (PHAs). Hundreds of individuals, organizations and governments across the country are actively involved in the fight against HIV/AIDS, from community-based AIDS organizations and PHAs<sup>1</sup> to physicians and other health professionals, public health units, researchers, human rights activists, advocacy groups, harm reduction services, addictions programs, correctional facilities, organizations that support prisoners, organizations that work with street youth, school boards and health teachers, organizations that work with new immigrants, Aboriginal organizations, housing programs, social service organizations, palliative care programs, and municipal, provincial, territorial and federal governments. For some, HIV is their main focus. For others, it is only a part of what they do.

While there is a great deal of activity throughout the country, it is not always coordinated. This document, which is based on widespread consultation with people across Canada, provides a blueprint for a strategic and coordinated Canadian response to the epidemic. It encourages effective partnerships between jurisdictions, within the health care system and with other sectors beyond health that have an impact on HIV, such as social services, education, housing and justice. It also encourages the meaningful participation of people most affected by HIV.

By acting strategically, working collaboratively and sharing our knowledge, skills and resources, all within a common framework, we will be more effective. By leading together, we will come closer sooner to achieving our common goals. Together, we have the potential to stop HIV.

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<sup>1</sup> For the purposes of this report, the terms "people living with HIV/AIDS," "people with HIV/AIDS" and PHAs will be used interchangeably to represent the full experience of being infected and both living with and dying of HIV/AIDS.

## HOW *LEADING TOGETHER* WAS DEVELOPED

As with all effective HIV approaches in Canada, *Leading Together* has been developed collaboratively. A large number of people have had a hand in determining the actions set out in these pages. Under the leadership of a small steering committee and with the support of Health Canada, broad consultations were held in 2003 to solicit feedback on the document. AIDS service organizations, clinicians and other health care professionals, researchers, national HIV/AIDS organizations and governments at all levels participated in face-to-face meetings. Special emphasis was placed on involving people living with HIV/AIDS and people at risk of HIV/AIDS, including gay men, people who use injection drugs, Aboriginal people, youth, women, people from countries where HIV is endemic and prisoners. A national on-line survey was also used to solicit feedback on the draft. Between 2002 and 2005, the process of revising the document recognized that the strength of *Leading Together* lies in its ongoing use and development.

### 2000: GRAY ROCKS MEETING

- Need for a plan with measurable objectives identified

### 2002: MONTREAL MEETING

- Mobilization on the plan

### 2002: STE-ADÈLE MEETING

- First draft plan developed

### 2003/04

- National, broad consultations

### 2005

- Revisions, publication

## PURPOSE OF *LEADING TOGETHER*

*Leading Together* is a blueprint for Canada's response to HIV/AIDS to 2010.

It lays out the optimal, ideal response to HIV/AIDS in Canada in the third decade of the epidemic. It presents our collective view of what is needed for the future and pushes all those involved in the fight against HIV to seek better ways to respond to the virus. *Leading Together* is a living document that is intended to inspire action on all fronts so that we can all do more and do it better. It challenges us to use our imagination and energy to get ahead of the epidemic.

*Leading Together* captures the principles that drive HIV initiatives throughout the country and builds on strategies that have been used successfully in different parts of Canada and around the world. It reflects the best wisdom, experience and practices of those currently involved in Canada's response to HIV/AIDS.

*Leading Together* responds to calls from throughout Canada for a more strategic and coordinated approach to addressing HIV/AIDS in Canada. It encourages strategic thinking and planning and a sharing of responsibility. It provides an opportunity for increasing our partnerships, aligning our efforts and making more effective use of our collective knowledge, skills and resources.

*Leading Together* challenges governments, organizations and individuals to:

- make strategic decisions about how to use our resources
- identify priorities and actions (i.e., some organizations may have a role to play in all aspects of the document, some may be involved in only one activity and some may select a few priorities that fit within their mandate and resources)
- set out their plans to 2010 and consider how they will contribute to achieving the pan-Canadian targets, desired outcomes, goals and vision described in the document
- use the document to build better working relationships with other organizations that serve the same communities or share common goals
- monitor their initiatives and report on progress
- participate in ongoing efforts to ensure the document continues to reflect the optimal response to HIV in Canada, given that the plan will need to evolve as the epidemic and its response both continue to shift

Governments and organizations across Canada have been calling for a more strategic, coordinated approach to HIV. This document is a guide to help individuals, organizations, communities, provinces, territories and the federal government identify their roles and priorities to 2010. It encourages strategic thinking, research and planning and a sharing of responsibility.

All governments and organizations involved in HIV/AIDS research, policy development, planning or service delivery are already part of a pan-Canadian response: their activities contribute to efforts to achieve common goals. The document will give governments and organizations an opportunity to align their work within a larger plan, to work more closely with other partners and to make more effective use of their collective knowledge, skills and resources.

**In this way, we will lead together.**

Our **VISION** describes a realistic, credible future for all Canadians and, for those who share an uncompromising commitment to achieve this future, it is the drive behind the desire to coordinate our efforts and lead together.

Our **MISSION** articulates the rationale for an “all Canada” HIV/AIDS strategy. It highlights the commitment to a higher-level purpose required to develop an effective, broad, multi-sectoral response to the epidemic.

Our response to HIV is based on key common **VALUES**. These values identify what is important to all stakeholders involved in Canada’s HIV/AIDS response, and they serve as a basis for identifying, assessing and implementing the required strategies.



I

the commitment

**VISION:** The end of the HIV/AIDS epidemic is in sight.

Canada is a leader in the fight against HIV/AIDS at home and around the world. The rights and dignities of people living with or vulnerable to HIV/AIDS are recognized, respected and promoted. People living with and vulnerable to HIV are partners in shaping the policies and programs that affect their lives. They have access to high-quality, effective services that meet their needs, and their health and well-being is enhanced. The racism, discrimination, poverty, and homelessness that fuel the epidemic have been reduced or eliminated.

**MISSION:**

- To champion the needs and rights of people living with HIV/AIDS and people at risk.
- To work collaboratively to build effective responses and lead the fight against HIV/AIDS at home and abroad.
- To act boldly and strategically to stop the HIV/AIDS epidemic.

**VALUES:**

Our response to HIV/AIDS reflects the broader values of Canadian society:

- **Social Justice.** All members of our society should be treated fairly, have their basic needs met, have access to the same services, and have opportunities to participate.
- **Human Rights.** All people, regardless of their sexual orientation, race, culture, gender or risk behaviour, are important, and their human rights – including their economic, social, cultural, civil and political rights – should be recognized, respected and promoted. Not one life is expendable. We recognize the dignity and worth of each person.

- **Diversity.** We recognize, respect and value individual and cultural differences and diversity.
- **Participation and Empowerment.** We support the participation of all, especially people living with HIV and the most disadvantaged. We strive to create an environment that empowers people to make healthy choices.
- **Global Responsibility.** As citizens of a caring and affluent nation, we have a responsibility to contribute our fair share of resources to international efforts to promote health and well-being.
- **Mutual Accountability.** Lives are at stake, and our resources must be used wisely. We are committed to creating an environment in which we hold one another accountable for our collective ability to use our resources effectively to make a substantial, positive difference in people's lives and achieve our goals.

**GOALS**

To the year 2010, we will pursue four main goals. All four goals are intricately linked. The second and third goals are a continuum:

1. Reduce the social inequities, stigma and discrimination that threaten people's health and well-being.
2. Prevent the spread of HIV.
3. Provide timely, safe and effective diagnosis, care, treatment and support for all people living in Canada with HIV/AIDS.
4. Contribute to global efforts to fight the epidemic and find a cure.

At this stage in the HIV/AIDS epidemic in Canada, there are 10 key reasons to step up our collective efforts.



## II

**the current state  
of the epidemic:  
why we need to  
step up our efforts**

## 1. THE EPIDEMIC IS INCREASING

The number of Canadians living with HIV continues to grow. At the end of 2002, an estimated 56,000 people were living with HIV infection<sup>2</sup> (including AIDS), representing an increase of about 12% from 1999. In terms of exposure category, these prevalent infections in 2002 comprised 32,500 men who have sex with men (MSM) (58% of total); 11,000 people who use injection drugs (20% of total); 10,000 heterosexuals (18% of total); 2,200 MSM/people who use injection drugs (4% of total); and 300 attributed to other exposures (<1% of total).

Of the estimated 56,000 prevalent infections in 2002, about 17,000 or 30% were unaware of their HIV infection. These individuals, named the “hidden epidemic,” are particularly important because, until they are diagnosed, they are not able to access support, treatment and prevention services that could help them manage the illness and prolong their lives. A significant number of people in this group are not diagnosed until late in the course of HIV disease, when medications are of little help.

The number of new infections (incident infections) continues at approximately the same rate as three years ago. In Canada, there were an estimated 2,800 to 5,200 new HIV infections in 2002; of these, between 600 and 1,200 were among women, representing 23% of all new infections.

HIV continues to have a disproportionate impact on certain segments of our society. Examining the 2002 estimates by exposure category, MSM continue to represent the greatest number of new infections: 1,000 to 2,000 (40% of the national total of new infections). The proportion of new infections among people who use injection drugs was 30%, and 24% was attributed to the heterosexual exposure category.

The heterosexual exposure category is a diverse group that includes those who have had sexual contact with a person who is either HIV-infected or at increased risk for HIV (such as a person who uses injection drugs or a bisexual male), those who were born in a

country where HIV is endemic, and those who have not identified any risk apart from sexual contact with the opposite sex. It is estimated that in 2002 there were approximately 3,700 to 5,700 prevalent HIV infections and 250 to 450 incident infections among persons who were born in a country where HIV is endemic. These numbers represent approximately 7-10% of total prevalent infections and 6-12% of total incident infections in Canada.

Aboriginal people continue to be overrepresented among HIV infections in Canada. They made up only 3.3% of the general Canadian population in 2001. It was estimated, however, that 5-8% of all prevalent HIV infections and 6-12% of all new HIV infections were among Aboriginal people in 2002.

Although current epidemiological evidence suggests that HIV prevalence is low among youth, data on sexual behaviour and sexually transmitted infections (STIs) clearly indicate that the potential exists for the spread of HIV among young Canadians. Those youth most at risk of HIV infection are those who are street-involved, engaged in the sex trade and/or who inject drugs.

Based on epidemiological evidence, the overall rate of HIV infection in prisons is estimated to be far higher than the rate in the general Canadian population. The need for accessible and innovative prevention and treatment programs for prison inmates is crucial because of the high rate of drug injection, unsafe tattooing and piercing, unprotected sex and other high-risk activities.

## 2. PEOPLE LIVING WITH HIV HAVE INCREASINGLY COMPLEX NEEDS

With the advent of highly active antiretroviral therapy (HAART), people with HIV are living much longer than they did in the 1980s and early 1990s, when the time between diagnosis and death was measured in months. But living for many years with a fatal infectious disease takes an immense toll on people's health, quality of life, finances, independence and self-esteem.

<sup>2</sup> Health Canada. *Estimates of HIV prevalence and incidence in Canada, 2002*. Canada Communicable Disease Report. Vol. 29 No 23. 1 December 2003.

Despite the progress that has been made in treating HIV, many people – particularly those living in small, rural and remote communities, but also many living in large urban centres – continue to have problems accessing care and treatment. This problem is exacerbated by the national shortage of physicians and other health care providers and the increasingly complex care needs of people with HIV.

Although antiretroviral therapies for HIV are effective for many people, they are not benign. In fact, these therapies are associated with a range of serious side effects, such as cancer, heart disease, peripheral neuropathy, lipodystrophy and neurocognitive impairments. The longer people are on HAART, the more likely they are to develop heart, kidney and liver diseases.<sup>3</sup>

A significant proportion of people with HIV also have other illnesses that threaten their health and complicate care. For example, as of December 1999, about 11,194 people living with HIV in Canada – or more than 20% of the total – were co-infected with hepatitis C,<sup>4</sup> and that number has since increased to close to 14,000. According to the Canadian AIDS Treatment Information Exchange (CATIE), the most frequently asked HAART-related questions are about liver failure and how to preserve liver function with HIV/hepatitis C co-infection; about the metabolic changes caused by HAART, particularly to cholesterol, lipid and blood sugar levels; and about lipodystrophy.<sup>5</sup>

Many people living with HIV are also coping with complex issues, such as addiction or mental illness. Between 40% and 60% of people with HIV suffer from depression, which can lead to a weakening of the immune system, faster disease progression, lack of adherence to treatment regimens (which, in turn, can lead to treatment failure and the development of drug-resistant HIV), greater risk of suicide and less ability to maintain safer sex and drug use practices.<sup>6,7,8</sup>

Because of their complex health needs, people living with HIV often face high prescription drug costs as well as costs associated with complementary therapies (e.g., vitamins, massage) that are not covered by government or private health plans. The financial impact of HIV is often exacerbated by the lack of flexible employment opportunities or disability plans that can accommodate the needs of people who will go through periods of ill health when they cannot work. As a result, a growing number of people with HIV in Canada are trapped in poverty and do not have adequate housing.<sup>9</sup>

Many people living with HIV/AIDS also struggle to manage sexual relationships in the context of a life-threatening STI. People with HIV/AIDS have the right to enjoy a healthy active sex life, yet little has been done to help PHAs have a healthy, affirming sexuality, which would also contribute toward lifelong prevention strategies to protect both their partners and themselves (i.e., from re-infection) and help define broader HIV responses.

### 3. TOO MANY PEOPLE WITH HIV ARE NOT RECEIVING, OR ARE RESISTANT TO, TREATMENT; AND TOO MANY ARE DYING

After dropping significantly in the mid-1990s, deaths from HIV/AIDS continue to occur. Some have expressed a fear that deaths may actually have increased recently, pointing, among other things, to the large number of well-known HIV/AIDS activists who have died in recent years (including one member of the steering committee that assisted in the development of this document).

Complex issues related to managing treatments have also emerged. Most people dying now from AIDS were either not treated at all, not treated soon enough or faced challenges in finding the right or most appropriate

<sup>3</sup> Palella Jr FJ, Baker R, Moorman AC, Chmeil J, Wood K, Holmberg SD, and the HOPS Investigators. *Mortality and Morbidity in the HAART Era: Changing Causes of Death and Disease in the HIV Outpatient Study*. Northwestern Univ., Chicago, IL, USA; Cerner Corp., Herndon, VA, USA; and CDC, Atlanta, GA, USA.

<sup>4</sup> Remis R. *Final Report: Estimating the Number of Persons Co-infected with Hepatitis C Virus and Human Immunodeficiency Virus in Canada*. Department of Public Health Sciences, University of Toronto. (March 31, 2001).

<sup>5</sup> Electronic communication from CATIE (June 2004).

<sup>6</sup> Ciesla JA. "Meta-analysis of the relationship between HIV infection and risk for depressive disorders," *Amer J Psychiatry*, 158, 725-30 (2001).

<sup>7</sup> Cohen M et al., "Prevalence of distress in persons with HIV," *Psychosomatics*, 43, 10-5 (2002).

<sup>8</sup> Ickovics JR et al., "Mortality, CD4 cell count decline and depressive symptoms among HIV-seropositive women," *JAMA*, 285, 1466-74 (2001).

<sup>9</sup> AIDS Bureau. *AIDS in Ontario 2002*. Ontario Ministry of Health and Long-Term Care.

medication. Some cannot tolerate the medications or have strains of the virus that are resistant to treatment.<sup>10</sup> Others find it difficult to manage the complex demands of treatment regimens (e.g., the number of pills, when they have to be taken, etc.). In some cases, the complexity makes treatment inaccessible. A study in British Columbia has found that high AIDS death rates persist because of a lack of, or only marginal access to, antiretroviral therapy among certain populations. The study showed that one of every three people who die of AIDS in British Columbia has never been treated with antiretroviral drugs. Aboriginal persons, women, poor people, and people residing in the Downtown Eastside were overrepresented in this group. The researchers concluded that interventions aiming at improving access to antiretrovirals among HIV-infected Aboriginal persons, women, lower-income persons and people who use injection drugs are an urgent priority. They suggested that strategies to improve access and adherence could include better access to illegal-drug treatment programs, directly observed therapy programs, access to medical services without appointment, and on-site pharmacies at medical clinics.<sup>11</sup> Despite major efforts by Canadian prison systems, prisoners with HIV/AIDS also continue to have problems accessing treatment comparable to that available outside prisons. A significant number of prisoners with HIV discontinue antiretroviral treatment while in prison.<sup>12</sup> In addition, CATIE reports an increase in calls about salvage therapy for failing regimens and drug resistance.<sup>13</sup>

The overall prevalence of primary drug resistance was 8.6% in a sample of newly diagnosed individuals who had never received antiretroviral treatment; in this same sample, the prevalence of multi-drug resistance (resistance to more than one class of antiretroviral drugs) was 1.3%. In Canada, primary drug resistance has been observed in

both females and males; across different age groups, ethnicities, and exposure categories; in HIV-1 subtypes A, B, and C infections; and among recent and established HIV infections. This prevalence of primary drug resistance is similar to the rates observed in other countries where highly active antiretroviral treatment is widely used.<sup>14</sup>

These trends also highlight the need for earlier diagnosis, the advent of new treatments and vaccines, less complex treatment regimens, and access to hospice and palliative care.

#### 4. STIGMA AND DISCRIMINATION CONTINUE TO THREATEN PEOPLE WITH HIV AND COMMUNITIES AT RISK

Although Canadians are less fearful of AIDS than they were in the 1980s and more accepting of people with HIV, stigma and discrimination persist. The stigma associated with HIV continues to make it different from most other diseases. For example, in a recent survey, almost 30% of Canadians said they would not be comfortable working in an office with someone with HIV, and 43% of parents said they would be uncomfortable having their child attend school where one of the students had HIV.<sup>15</sup>

According to a recent report on HIV/AIDS stigma and discrimination, the stigma associated with HIV/AIDS in North America has been profoundly influenced by attitudes toward gay and bisexual men and toward people who use drugs – two groups of people who were highly stigmatized before the HIV epidemic. The report cites a number of studies from North America and Europe that found that a minority of the population are more likely to blame people and less ready to help them if they became infected through homosexual sex or drug use.<sup>16</sup>

<sup>10</sup> Harrigan PR, Hogg RS, Dong WWY, Yip B, Wynhoven B, Woodward J, Brumme CH, Brumme ZL, Mo T, Alexander CS, Montaner JSG. *Predictors of HIV Drug Resistance Mutations in a Large Drug-Naïve Cohort Initiating Triple Antiretroviral Therapy*. BC Centre for Excellence in HIV/AIDS, Department of Medicine, University of British Columbia.

<sup>11</sup> Wood E et al. *Prevalence and correlates of untreated human immunodeficiency virus type 1 infection among persons who have died in the era of modern antiretroviral therapy*. *Journal of Infectious Diseases* 2003; 188: 1164-1170.

<sup>12</sup> Jürgens R. *Canada: Does incarceration result in HIV treatment interruptions?* *Canadian HIV/AIDS Policy & Law Review* 2004; Vol. 9, No 2: 49-50, with reference to T Kerr, A Marshall, J Walsh, A Palepu, MW Tyndall, RS Hogg, J Montaner, E Wood. *Determinants of highly active antiretroviral discontinuation among injection drug users*. *Canadian Journal of Infectious Diseases* 2004; 15 (Suppl A): 86A (abstract 458P).

<sup>13</sup> Electronic communication from CATIE. June 2004.

<sup>14</sup> Public Health Agency of Canada. *HIV-1 Strain and Primary Drug Resistance in Canada: Surveillance Report to March 31, 2004*. Surveillance and Risk Assessment Division, Centre for Infectious Disease Prevention and Control, Public Health Agency of Canada, 2005.

<sup>15</sup> EKOS Research Associates. *HIV/AIDS – An Attitudinal Survey*. March 2003.

<sup>16</sup> de Bruyn T. *A Plan of Action for Canada to Reduce HIV/AIDS-Related Stigma and Discrimination*. Canadian HIV/AIDS Legal Network. 2004.

## elasticity of tolerance

“How comfortable would you be if...?”



EKOS Research Associates Inc.

n=2004; \*half sample HIV/AIDS Awareness Survey, March 2003

Canada does not have comprehensive data on HIV-related discrimination, but we do have some information that gives us some understanding of the extent of the problem.

For example:

- in 1988-89, the B.C. Civil Liberties Association received reports of 83 cases of discrimination against people with HIV (of these, nine related to housing, 32 related to employment, 14 related to access to health services, and 8 related to access to public services). The Association believed these cases represented only a portion of actual incidents.<sup>17</sup>
- in 2000, findings of a needs assessment of people with HIV/AIDS in New Brunswick revealed that of the 50 study participants, 86% feared discrimination because of their HIV status, and 66% *experienced* incidents of HIV-related discrimination (an increase from 33% in 1992). Many experiences of discrimination occurred in public settings (e.g., workplaces and public services).<sup>18</sup>

People with HIV who are part of a specific ethnic or cultural community – such as gay men, Aboriginal people and people from countries where HIV is endemic – often experience stigma and discrimination from within their community. This has implications for both the person with HIV and for the community: the person becomes highly isolated and the community is less able to prevent the spread of HIV or to provide support for those who are ill.<sup>19</sup>

The stigma associated with HIV isolates people who are infected and affects their quality of life. It can make people who are at risk of HIV/AIDS less willing to be tested or to seek treatment.<sup>20</sup> For people who belong to marginalized groups – such as gay men, people who use injection drugs, Aboriginal people, people from countries where HIV is endemic and sex workers – the stigma associated with HIV is compounded by other forms of discrimination, including homophobia, racism, gender inequality and negative attitudes toward drug use and sex workers.

<sup>17</sup> de Bruyn T. *HIV/AIDS and Discrimination: A Discussion Paper*. Canadian HIV/AIDS Legal Network and Canadian AIDS Society. 1998.

<sup>18</sup> Olivier C. *HIV-Related Discrimination Increasing in New Brunswick*. Canadian HIV/AIDS Policy & Law Newsletter. Vol. 5, No 2/3, Summer 2000.

<sup>19</sup> de Bruyn T. *HIV/AIDS and Discrimination: A Discussion Paper*. Canadian HIV/AIDS Legal Network and Canadian AIDS Society. 1998.

<sup>20</sup> Roth K. *Human Rights and the AIDS Crisis: The Debate Over Resources*. Canadian HIV/AIDS Policy & Law Review. 2000; Vol. 5, No 4: 93-98.

Stigma can lead to violations of the human rights of people living with HIV, including unlawful discrimination in housing, employment and health and social services. For example, in a survey of 34 people with HIV in Alberta, almost a third reported being treated unfairly by employers or co-workers as a result of their HIV status. Their jobs were terminated, they were asked to quit or their hours were severely reduced.<sup>21</sup>

Stigma can also lead to infection. For example, the HIV epidemic among Aboriginal people in Canada is compounded by racism, both past and present: forced assimilation, residential schooling and loss of culture have contributed to poverty, unemployment, multigenerational violence and substance abuse, all of which make Aboriginal people – particularly Aboriginal women and two-spirited people – more vulnerable to HIV.

## 5. POVERTY, HOMELESSNESS AND OTHER SOCIAL DETERMINANTS ARE FUELLING THE EPIDEMIC

Although HIV is caused by a virus and exacerbated by stigma, its spread is also fuelled by many factors in our society, including poverty, homelessness, lack of social support, physical and sexual abuse, childhood experiences and lack of education. These social determinants of health can lead to powerlessness in relationships, lack of self-esteem, lack of a sense of community, and other health issues (e.g., addictions or mental health problems) that interfere with people's judgment or ability to protect themselves. A homeless young person who trades sex for a place to stay or a meal may not be able to negotiate safer sex. A woman whose immigration status or financial security is dependent on her partner may be limited in her ability to protect herself. An older gay man who is concerned about his ability to compete in a youth/body-focussed culture may forgo the protection of a condom in order to have sex. Violence against women has a direct impact on their vulnerability. For example, women who are in abusive relationships may be forced to have unprotected sex.

Poverty and other social factors, such as the lack of flexible employment opportunities or adequate disability insurance coverage, also threaten the ability of people living with HIV to maintain their health. As noted earlier, many are unable to afford the high cost of prescription drugs or complementary therapies that are not covered by government or private drug plans. People who are inadequately housed also have difficulty maintaining treatment regimens.

Because social inequities fuel the epidemic, we must fight for social justice. To stop the spread of HIV and to improve care, we must address both the behaviours that put people at risk (e.g., unsafe sex and needle use) and the broader social determinants of health that make it difficult or impossible for people to make healthy choices or maintain their health.

## 6. MISCONCEPTIONS ARE LEADING TO MORE RISK TAKING AND LESS SUPPORT FOR SERVICES

Misconceptions are having a negative effect on our ability to fight the epidemic. For example, young people in 2003 knew less about certain aspects of HIV, such as the risks associated with having more than one sexual partner, than they did in 1989.<sup>22</sup> Even people at high risk have misconceptions: a significant proportion of gay men assume that young gay men are not infected or that they can “tell” when someone has HIV.<sup>23</sup> Based on these assumptions, many are taking more risks and engaging in unsafe sex.

Misconceptions are also affecting public support for HIV/AIDS services. About 81% of Canadians think the treatments now available for HIV are effective, and 17% believe that if people with HIV are treated early the disease can be cured.<sup>24</sup> These assumptions mean that people are less willing to give money to HIV/AIDS programs and services.

<sup>21</sup> AIDS Calgary. Human Rights Project. 2003.

<sup>22</sup> Council of Ministers of Education, Canada. *Canadian Youth, Sexual Health and HIV/AIDS Study: Factors influencing knowledge, attitudes and behaviours*. 2003.

<sup>23</sup> Adams BD, Husbands W et al. *Renewing HIV Prevention for Gay and Bisexual Men. A Research Report on Safer Sex Practices Among High Risk Men and Men in Couples in Toronto*. 2003.

<sup>24</sup> EKOS Research Associates. *HIV/AIDS – An Attitudinal Survey*. March 2003.

## 7. THE GLOBAL EPIDEMIC IS DEVASTATING POORER COUNTRIES AND THREATENING RICHER ONES

HIV is a global problem, and parts of the world are being overwhelmed by the epidemic. According to the *UNAIDS 2004 Report on the global AIDS epidemic*, almost 5 million more people worldwide were newly infected with HIV – the greatest number in any year since the beginning of the epidemic – and 3 million died of AIDS-related illnesses. Over 20 million have died since the first cases of AIDS were identified in 1981. In 2004, 39.4 million people – more than the population of Canada – were living with HIV.<sup>25</sup>

The countries most affected are those with the fewest resources. Over 95% of HIV infections are occurring in poor and/or developing countries. In some countries in sub-Saharan Africa, over 30% of the population is infected, and AIDS threatens to wipe out an entire generation. AIDS is now the leading cause of death in sub-Saharan Africa and the fourth biggest global killer. The virus is also spreading rapidly in other parts of the world, including the Caribbean, India, China and Southeast Asia, and in Eastern Europe and Central Asia, where it is fuelled by injection drug use (IDU).<sup>26</sup> HIV has the potential to devastate emerging economies and destabilize governments. The impact will be felt worldwide.

Because diseases do not respect borders, Canada cannot stop the HIV epidemic at home without helping to stop it worldwide. Canada also has a legal and ethical obligation to contribute to global efforts to stop disease and suffering.

## 8. INCREASED AND SUSTAINABLE FUNDING SOURCES ARE NEEDED TO KEEP PACE WITH THE EPIDEMIC

Funding for HIV/AIDS-specific programs and services comes from many sources: provincial and territorial departments of Health and Social Services, federal departments and agencies (e.g., the Public Health Agency of Canada, Health Canada, Correctional Service

Canada and the Canadian International Development Agency), federal and provincial research funding organizations, municipal governments, foundations and donations. Funding also comes from other government programs and services that serve populations affected by HIV, such as correctional services, addiction programs, STI programs, and programs for Aboriginal people, recent immigrants and youth.

While other health initiatives and diseases rely on private donations to fund programs and services, HIV programs and services have never received a comparable level of philanthropic support. This is in part because HIV infects a relatively small proportion of the population compared to illnesses such as heart disease or cancer. However, other factors also influence the level of private funding for HIV/AIDS. Since the late 1990s, corporate and individual donations to HIV organizations have dropped dramatically – a reflection of both the public misconception that HIV is now a treatable disease and the marginalization of many affected by HIV, such as people who use injection drugs.<sup>27</sup>

Because HIV receives less support from private citizens and companies, there is a stronger imperative for all governments to provide long-term and sustainable funding for HIV initiatives that meet the increase in scope, cost and complexity of the epidemic.

Between 1993 and 2003, HIV/AIDS-related programs and services experienced a 43% increase in demand due to both new infections and people living longer with the disease.<sup>28</sup> As a result, “important prevention efforts were not sustained and new prevention programs were not initiated; new policy was not developed and important research was not conducted; organizations were weakened and had to compete rather than cooperate.”<sup>29</sup> For many organizations – particularly community-based AIDS organizations – this has led to an increase in staff and volunteer burnout and turnover.

Organizations and jurisdictions also report increasing problems attracting and retaining people and expertise, including staff for community-based agencies, volunteers, physicians and researchers. While this growing gap is due

<sup>25,26</sup> UNAIDS. *UNAIDS 2004 Report on the global AIDS epidemic*.

<sup>27</sup> Martin Spigelman Research Associates. *Getting Ahead of the Epidemic: The Federal Government Role in the Canadian Strategy on HIV/AIDS 1998-2008*. 2003.

<sup>28,29</sup> Ibid.

in part to a lack of resources, it is also due to the increasing complexity of HIV/AIDS care (for physicians), the challenge of working with marginalized populations, the misconception that HIV/AIDS is no longer as large a problem as it once was, and the fact that community-based AIDS organizations cannot compete with the private sector and many other organizations in the public sector in terms of salaries.

Securing long-term and sustainable funding for HIV initiatives is also a global issue. Despite the contributions of additional funding by a number of countries to date, global efforts still fall far short of the estimated US\$10 billion a year required to stop the epidemic.<sup>30</sup>

## 9. ACTING NOW WILL SAVE THE HEALTH SYSTEM MILLIONS OF DOLLARS

With the growing number of new infections, the increasing number of people living longer with HIV, and the cost of new therapies, the economic costs associated with AIDS continue to rise. According to an Alberta study, the direct cost of HIV medical care per patient per month increased from about \$655 in 1995 to \$1,036 in 2001, primarily due to HAART. In 1995, antiretroviral drugs accounted for 30%, or \$198, of the cost per patient per month; in 2001, they accounted for 69% or \$775. While the health care system is now spending more on drugs for HIV, because of these drugs it is spending less on in-patient, out-patient and home care.<sup>31</sup>

In Canada, lifetime care and treatment costs have been estimated in 1998 to total about \$160,000 per person with HIV, while the indirect costs associated with lost productivity and premature death may be as high as \$600,000 per person.<sup>32</sup> In addition, treatment costs vary depending on where people live and where they are treated. For example, people living in rural or remote areas who must travel to

receive care often have significantly higher costs. While it is possible to calculate the treatment costs associated with HIV, the personal and social costs of each case of HIV – for the person infected, his or her friends and family, and society – are immeasurable.

Every HIV infection that is prevented avoids approximately three quarters of a million dollars in direct and indirect costs.<sup>33</sup> According to a recent analysis of the costs associated with HIV/AIDS, reducing the number of new infections each year by 50% would save the health care system and society \$1.5 billion over a five-year period. As the report notes, “Because of the enormous economic burden of HIV/AIDS, prevention and management strategies are highly cost effective, and will produce significant long-term direct and indirect cost savings to the Canadian economy.”<sup>34</sup>

## 10. ACTING NOW WILL SAVE LIVES

By acting now and renewing our efforts, we can save and prolong lives.

Other countries that were more aggressive in their response to HIV, such as the United Kingdom and Australia, have had a much smaller epidemic than Canada (1.5 infections per 100,000 people).<sup>35</sup> If we work together to step up prevention, diagnosis, care, treatment and support programs and achieve the targets set out in this document, we can prevent thousands of new infections and save many lives.

With the advent of HAART, people are now living longer with HIV. If we continue to invest in developing new treatments, we have the potential to add more years and more quality to the life of each person who is infected.

By acting now, our society will reap the enormous economic, social and personal benefits of their productivity and creativity.

<sup>30</sup> This is the funding requirement identified by the Global Fund to Fight AIDS, Tuberculosis and Malaria.

<sup>31</sup> Krentz HB, Auld MC, Gill MJ. *The changing direct costs of medical care for patients with HIV/AIDS, 1995–2001*. CMAJ. 2003 July 22; Vol. 169, No 2: 106–110.

<sup>32</sup> Martin Spigelman Research Associates. *Getting Ahead of the Epidemic: The Federal Government Role in the Canadian Strategy on HIV/AIDS 1998–2008*. 2003.

<sup>33</sup> Ibid.

<sup>34</sup> GPI Atlantic. *The Cost of HIV/AIDS in Canada*. June 2001.

<sup>35</sup> www.avert.org. November 19, 2004.

Over the past two decades, Canadians have learned a great deal about how to respond to HIV. We have identified nine critical success factors or ways of working that, when woven together, form a cohesive blueprint for a coordinated and strategic Canadian response to get ahead of the epidemic.



### III

## the blueprint

## 1. COMMITMENT TO SOCIAL JUSTICE AND HUMAN RIGHTS

*“The vulnerable must be given priority ...”*

*Keeping the Promise: Summary of the Declaration of Commitment on HIV/AIDS, Special Session on HIV/AIDS, June 2001*

HIV is more than a health problem. Social factors – such as discrimination in all its forms, poverty, homelessness and abuse – threaten the ability of those who are most vulnerable to protect their health. When social determinants of health are seen from the perspective of a commitment to social justice, they become ethical issues that a caring society has an obligation to address. By combating injustices that contribute to poverty and homelessness, a society can reduce the vulnerability that handicaps many people, particularly women, in their efforts to avoid or manage HIV infection.<sup>36</sup> In the context of health, a commitment to social justice requires us to work collectively for the good of all and address the determinants of health by redressing inequalities and injustices.

### PROGRAMS AND SERVICES BASED ON SOCIAL JUSTICE:

- recognize individual and cultural differences and diversity
- recognize the dignity and worth of each person, and encourage self-esteem
- strive to ensure everyone is treated fairly and has equitable access to services and health outcomes
- meet everyone's basic life needs
- reduce inequities in wealth, income and life chances
- encourage participation by all, including the most disadvantaged.

An effective response to HIV:

- recognizes and addresses the broad determinants of health that make people vulnerable to HIV and to disease progression
- understands those determinants in ethical terms and is committed to addressing the injustices that contribute to them

- is based on human rights and recognizes that protecting people's human rights – including the right to the highest attainable standard of health – is a means of achieving social justice and the goals of this document.

Advocacy is an essential part of a commitment to social justice and to human rights. When the voices of a disadvantaged group are not heard or listened to, others must speak for them and advocate for their civil and political rights (e.g., freedom of expression and association, freedom from torture) and their economic, social and cultural rights (e.g., the right to shelter, food, a safe working environment). All those involved in HIV must champion the rights of people living with HIV and of communities at risk. The determinants of health will be addressed when social justice is achieved, and social justice is achieved when the human rights of every person are fully realized.

## 2. LEADERSHIP AND INNOVATION

*“[P]reventing HIV infection is not only a matter of resources; it is also a matter of political choice, courage and will.”*

*Kenneth Roth, Executive Director, Human Rights Watch, Plenary Presentation, XIII International AIDS Conference, July 2000*

Leadership is a critical part of an effective response to any disease that affects and stigmatizes marginalized people. To tackle the complex underlying causes of HIV, we need leadership at all levels: among people with HIV, in communities at risk, in local communities, among service providers and researchers, in the business community, and within Aboriginal, provincial/territorial and federal governments. We need committed people who are willing to speak out to convince the public and policy makers that HIV deserves focussed, discrete attention. We also need people who are willing to act boldly, to innovate, to fight for unpopular causes, to act against public opinion when necessary, and to find new and better ways to stop the epidemic.

We can trace the impact of leadership in HIV/AIDS at home and globally. In the early days of HIV in Canada, when homophobia and discrimination made gay men more

<sup>36</sup> Roth K. *Human Rights and the AIDS Crisis: The Debate Over Resources*. Canadian HIV/AIDS Policy & Law Review. Vol. 5, No 4, 2000.

vulnerable to infection, strong leaders in the community, the health care system and government were able to:

- introduce policies to protect gay men's rights and reduce discrimination
- advocate successfully for increased funding for HIV programs and improve care
- challenge Canadian society's reluctance to talk openly about sex and sexuality in care and prevention programs

In other parts of the world, leadership has also played a key role.

### 3. MEANINGFUL PARTICIPATION OF PEOPLE LIVING WITH HIV/COMMUNITIES AT RISK

*The success of our national, regional and global programmes requires the greater involvement of people living with HIV/AIDS. [E]nsuring their full involvement ... will ... stimulate the creation of supportive political, legal and social environments.*

*Article 1, Paris AIDS Summit Declaration  
Greater Involvement of People with AIDS  
(GIPA) Principle, 1994*

The meaningful participation of people living with HIV and of communities at risk is fundamental to reducing the stigma and discrimination associated with HIV, preventing the spread of the virus, improving care, improving living conditions and ending the epidemic. The active, meaningful participation of those most affected by HIV offers a number of distinct benefits. For example:

- it recognizes the rights of people living with HIV to participate in the decisions that affect them
- it gives the health and social service system valuable advice, knowledge and experience, which results in more effective and more cost-effective interventions
- it gives those who become involved better access to social support – one of the determinants of health – and people who have a strong social support network enjoy better health and are more able to influence policies and programs that affect their health

From the beginning of the epidemic in Canada, people living with HIV and communities at risk have been a powerful force in:

- providing leadership
- influencing policy
- planning programs and services
- advocating for research and access to treatments
- delivering peer-led programs

Despite these contributions, the capacity and opportunity of people with HIV/AIDS to participate in and guide HIV programs and services has often been ignored by decision makers and people in authority. Every effort must be made to encourage meaningful participation, particularly by people and groups who have not been actively involved to date and who may lack the needed skills or confidence and need support.

### 4. EARLY INTERVENTION

Services designed to be in place early and to get ahead of the epidemic have the potential to radically change the course of HIV disease in Canada and around the world. For example:

- countries that implemented needle exchange programs early and provided other comprehensive services were able to significantly slow the epidemic among people who use injection drugs
- by offering HIV testing to all women during pregnancy, Canada has almost eliminated mother-to-child transmission and significantly reduced the number of children born with HIV
- the earlier people with HIV are diagnosed, the better chance they have to maintain their health, receive appropriate treatment, potentially prolong their lives, and take steps to prevent HIV transmission wherever possible

Dealing with HIV forces us to be bold and to question how services are provided.

## 5. RESEARCH/EVIDENCE

To get ahead of the epidemic, we need research. Canada's investments in basic science, evaluation and research (epidemiological, clinical, psychosocial, community-based and health services):

- enable us to track and monitor the spread of HIV
  - contribute to worldwide efforts to understand and stop HIV disease
  - help us understand the needs of people living with HIV and of communities at risk
  - lead to stronger care and treatment programs
  - inform policy
  - help us make more effective use of limited resources
- young people need information appropriate to their age and stage of development
  - gay men respond best to initiatives that reflect gay culture
  - women need prevention and treatment services that take into account other issues they may face (e.g., financial dependence, violence, abuse, pregnancy and reproduction issues)
  - people from different ethnocultural and ethnoracial groups need services that are sensitive to their cultural values and beliefs
  - programs and services for First Nations, Métis and Inuit people must “first and foremost, show respect and honour for all Aboriginal beliefs, practices and customs” and reflect the “pride and dignity that Aboriginal heritage demands.”<sup>37</sup>

## 6. A SUSTAINED RESPONSE

Preventing and treating HIV are linked and require comprehensive, long-term programs and services. To be effective:

- prevention information must be delivered many times in many different ways
- prevention programs must be adaptable to new knowledge and changing needs
- prevention programs must be developed for and by people living with HIV/AIDS as part of lifelong disease management
- treatment programs must respond to the needs of people with HIV/AIDS, who are now living 20 years or longer with the disease and need ongoing access to care, treatment and support services that take into account their other health needs as they age

HIV programs and services cannot be short-term, stopgap efforts. They must be both sustainable and sustained.

## 7. CULTURE-, GENDER- AND AGE- APPROPRIATE PROGRAMS AND SERVICES

When dealing with issues like sex, sexual orientation, relationships and substance use, one size does not fit all. For example:

## 8. A COMMITMENT TO MONITORING, EVALUATION AND QUALITY IMPROVEMENT

To stop the epidemic, our programs must be better tomorrow than they are today. We must:

- monitor and evaluate the impact of what we do
- learn from our experiences
- continually refine and improve our services

## 9. SHARED RESPONSIBILITY

Many of the social and economic factors fuelling the epidemic are beyond the scope and control of HIV/AIDS service organizations (e.g., addictions, mental health issues, co-infection with hepatitis C and other STIs) and many are beyond the scope and control of the broader health system. To influence the social determinants of health, we must move to a culture of shared responsibility with other services and systems, such as:

- income programs
- social and housing services
- the justice system
- the education system
- correctional services
- the private sector (e.g., employment)

<sup>37</sup> Canadian Aboriginal AIDS Network. *Strengthening Ties – Strengthening Communities. An Aboriginal Strategy on HIV/AIDS in Canada*. 2003.

## THE HIV BLUEPRINT AT WORK: TWO EXAMPLES

[EXAMPLE 1] **Insite** – Vancouver’s supervised injection facility – is an example of the proposed strategic approach in action. This initiative was driven by social justice: the belief that people who use injection drugs have the same rights as others and that a just and caring society had an obligation to help people who inject drugs reduce the risk of overdose deaths and illnesses, such as HIV and hepatitis C. It was based on a sense of shared responsibility among a number of players and involved leadership; a bold, sustained and persistent approach; and grass-roots action.

In the late 1990s, in the wake of an epidemic of overdose deaths among people who use injection drugs, a small group of community activists – people who use injection drugs, gay men, researchers and a parents’ group – came together to advocate for a legal safe injection site in Vancouver. They saw the site as an effective early intervention that could significantly reduce the harm associated with injecting drugs. Leaders themselves, they inspired others to lead: both the former and current mayor of Vancouver spoke out openly about the need and the city’s responsibility and made services for people who inject drugs an election issue.

The process of advocating for the site was largely led by the people most affected – people who use injection drugs – who spoke out about their needs and helped ensure that the service would be culturally appropriate. The group carefully built an evidence-based case for the safe injection site by researching similar models in other countries, inviting people from other jurisdictions to talk about the experience, conducting studies to demonstrate that the site would be used and using a persuasive legal analysis prepared by the Canadian HIV/AIDS Legal Network. The group also shared responsibility with other sectors highly affected by the problem, including the police, the public health department and health professionals who served the community of people who use injection drugs, and built effective collaboration around a tangible issue. Members devoted significant time and resources to educating the public about the public health and social

benefits of a safe injection site through public fora and the media (members of the group estimate that they were involved in more than 100 media interviews).

After several years of sustained talk, research and advocacy, Insite opened in September 2003 as North America’s first supervised injection site scientific research pilot project. Insite provides a clean, safe environment where users can inject their own drugs under the supervision of clinical staff. Nurses and counsellors provide on-site access and referral to addictions treatment services, primary health care and mental health providers, as well as first aid and wound care. The goal of the research project is to assess whether the safe injection site will reduce the harm associated with IDU (e.g., drug overdoses); reduce the costs associated with serious addiction (e.g., health, social, legal and incarceration costs); improve the health of injection drugs users; and lead to more appropriate use of health and social services by people who use injection drugs.

Ongoing monitoring and evaluation are vital, both because they will help further improve, and hopefully expand, the supervised injection facility and other services for people who use injection drugs in Vancouver and because they will provide data that should assist other communities in their efforts to establish such services.

Insite has been successful in terms of utilization: people who use injection drugs adopted the site much more quickly than expected. It has also been effective in reducing overdose deaths – as of September 2004 (the period for which data are available), no clients of the site had died from an overdose.<sup>38</sup> Clinic staff now oversee approximately 550 injections over an 18-hour period each day. The majority of clients are men. The clinic has also resulted in an improvement in public order: during the first 12 weeks the facility was open, the number of people injecting drugs in public dropped, and the number of discarded syringes decreased by 50%.<sup>39</sup> The more important and valuable evaluation of whether Insite has had an impact on the spread of blood-borne diseases such as HIV and hepatitis C will take many more months.

<sup>38</sup> BC Centre for Excellence. *Evaluation of the Supervised Injection Site. Year One Summary*. September 17, 2004.

<sup>39</sup> Wood E, Kerr T, Small W, Li K, Marsh DC, Montaner JSG, Tyndall MW. *Changes in public order after the opening of a medically supervised safer injecting facility for illicit injection drug users*. CMAJ. Vol. 171, No 7. September 28, 2004.

**[EXAMPLE 2] Changes to the *Patent Act*.**

In August 2003, the World Trade Organization (WTO) decided that under the Agreement on Trade-Related Intellectual Property Rights WTO member countries could manufacture generic drugs under a compulsory licence for export to countries with no or insufficient capacity to manufacture their own generic pharmaceuticals. This ruling opened the door for countries like Canada to help developing countries struggling with the high cost of drugs for HIV/AIDS or other public health problems. For the WTO ruling to have the desired impact, however, individual countries must amend their domestic patent laws to allow generic drug manufacturers to get compulsory licences to produce less expensive medicines for export.

In Canada, the Global Treatment Access Group (GTAG), an affiliation of Canadian civil society organizations committed to health and human rights (e.g., AIDS advocacy groups, humanitarian organizations, development groups, human rights groups, labour unions, student groups, faith organizations), worked to put the issue on the federal government's agenda. Additional support came from Stephen Lewis, UN Special Envoy for HIV/AIDS in Africa, who in a keynote address at the annual general meeting of the Canadian HIV/AIDS Legal Network in September 2003, and again a week later at a conference in Nairobi, Kenya, on AIDS and STIs in Africa, challenged Canada and other wealthy countries to address some of the inequities in AIDS treatment and take action to increase access to cheaper drugs. Then Minister of Industry, Allan Rock, with the support of some Cabinet colleagues, took up the challenge.

But getting the changes implemented required persistence and advocacy. As negotiations proceeded, the civil society organizations were concerned that the proposed changes to the *Patent Act* would be too narrow and restrictive in terms of the drugs or diseases that it might cover, or that the Government would introduce unnecessary and counter-productive provisions. They continually lobbied the Government to ensure that it would live up to international agreements. At one point, concerned that poor legislation was being pushed through too quickly, they advocated

with all parties in the House of Commons to stop the revised bill, arguing that no changes were better than inadequate changes. As a result, the legislation was sent to committee, where some of the major problems were addressed.

The process was a lesson in advocacy and collaboration. The legislative changes involved the work of five different federal departments and agencies – International Trade Canada, Foreign Affairs Canada, Industry Canada, Health Canada and the Canadian International Development Agency – non-governmental organizations and industry, who came together to advise Parliament on the best possible approach. The bill was tabled early in 2004 and enacted by Parliament on May 14, 2004. Although no generic drug companies in Canada have yet come forward to test the new law (as of December 2004), the changes to the *Patent Act* are already having an impact by contributing to the global political momentum to implement the WTO decision.

The same coalition that was successful in advocating for the changes to the *Patent Act* is now encouraging Canadian generic companies to test the Act. They also continue to advocate for other action that would enhance global health, such as increases in Canada's official development assistance, ensuring that Canadian trade policy does not negatively affect access to health care at home or abroad and working to ensure that the review of Canada's foreign policy takes HIV/AIDS and human rights into account.

Government, non-governmental organizations (NGOs) and industry continue to work together to follow through on making use of the Act to provide greater access to affordable medicines for those in need.

With HIV initiatives like these – that are based on social justice and a commitment to human rights, involve people living with HIV, acknowledge a shared responsibility, use leadership and evidence, are culturally appropriate and act early and stay the course – we can get ahead of the epidemic.

Hundreds of people and organizations across the country are involved in HIV programs and services. The main players are those who have a specific HIV/AIDS mandate (e.g., ministries of health, community-based AIDS organizations, health care providers and researchers); however, given the social and economic factors that fuel the epidemic, other government departments, individuals and organizations also play a vital role in our response (e.g., human rights organizations, harm reduction and treatment services for people who use injection drugs, mental health services, housing services, settlement services, schools, programs that serve youth and women, international development organizations). To respond to evolving HIV issues and achieve common goals, all must work together.

## IV



who shares  
responsibility for  
responding to HIV?

## ROLES AND RESPONSIBILITIES

In Canada's response to HIV/AIDS, different actors have different roles:

### 1. People living with HIV or at risk of HIV

- identify the needs that drive services
- help plan culturally appropriate programs and services that meet their needs
- provide leadership and run peer-led programs
- advocate for resources to provide needed services
- play a key role in preventing the spread of HIV
- inform all decisions affecting their lives

In Canada's health care system: the federal government is usually responsible for overall health policy and research; the provinces and territories for planning and managing health services; and individual health organizations for delivering health services. Federal funding for health services is usually given to the provinces and territories, who then decide how best to use it to support their programs and priorities.

Federal government funding for HIV is particularly important because of the stigma and discrimination associated with HIV and because of the need for resources and leadership in this area.

### 2. Local actors

- work with people living with HIV and people at risk to develop and deliver a wide range of services designed to prevent the spread of HIV, provide treatment and care for people with HIV, and address the broader determinants of health and other factors fuelling the epidemic
- undertake research on biomedical, psychosocial and epidemiological aspects of HIV/AIDS
- use new knowledge to develop effective programs and services
- identify emerging trends and issues
- advocate for resources to provide needed services
- work with provincial, territorial and federal partners to develop policies

### 3. Provincial/territorial actors

- monitor the spread of HIV
- develop HIV policies and priorities
- fund health and social programs and services
- monitor the effectiveness of HIV services
- conduct research
- ensure equitable access to provincially/territorially funded services

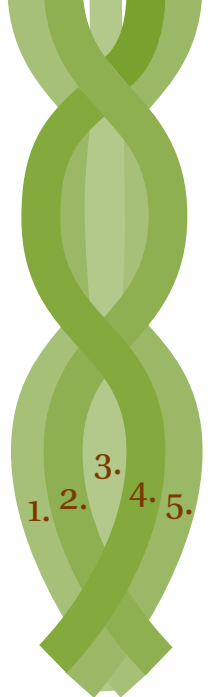
### 4. First Nations, Métis and Inuit communities and governments

- identify the needs of First Nations, Métis and Inuit people, on and off reserve
- develop policies and priorities to meet those needs
- develop culturally appropriate programs and services
- advocate for resources to provide needed services

### 5. National actors

- provide leadership for the Canadian response to HIV/AIDS
- develop policies
- fund research and community-based AIDS prevention initiatives
- work with relevant stakeholders to identify priorities for research in Canada
- conduct research and analysis
- develop resources
- provide education
- advocate for change
- monitor the spread of HIV and disseminate surveillance information
- ensure equitable access to federally funded services
- promote coordination among national, provincial and territorial actors
- negotiate Canada's contribution to the global fight against HIV

Greater collaboration will mean better use of each partner's strengths and resources and, ultimately, better outcomes.

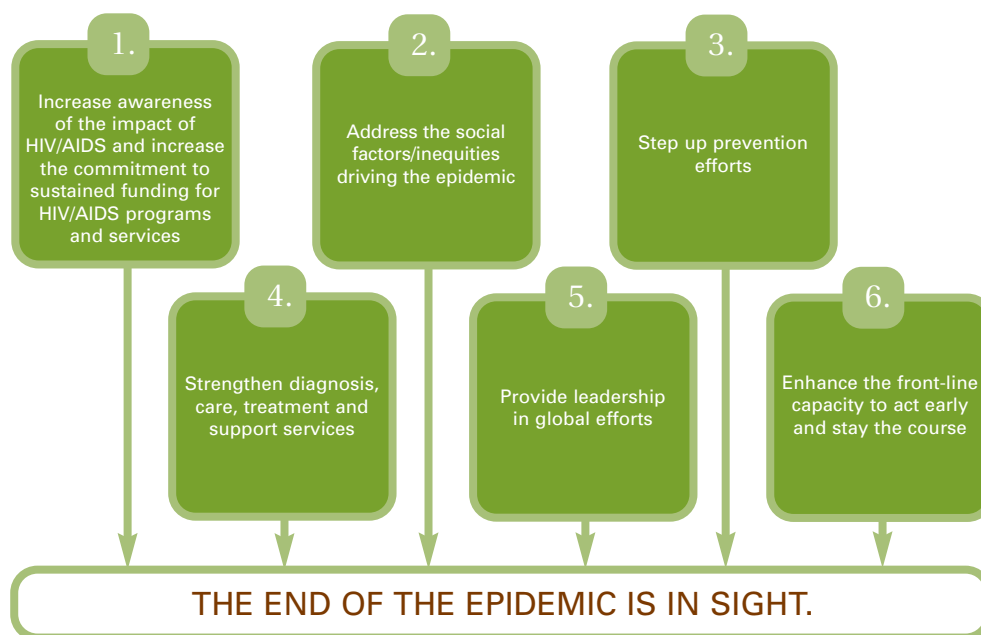


To the year 2010, governments, organizations and individuals involved in the Canadian response to HIV/AIDS should focus their collective efforts on six key strategies in order to get ahead of the epidemic. Each strategy is linked to every other in some way and is not only valuable in itself but is also valuable as part of the whole.

1. Increase awareness of the impact of HIV/AIDS and increase the commitment to sustained funding for HIV/AIDS programs and services
2. Address the social factors/inequities driving the epidemic
3. Step up prevention efforts
4. Strengthen diagnosis, care, treatment and support services
5. Provide leadership in global efforts
6. Enhance the front-line capacity to act early and stay the course

## V

the actions: what we will do between now and 2010



For each of the six strategies, the document sets out:

- the rationale or evidence for the strategy
- desired outcomes
- targets to the year 2010
- a list of recommended actions that jurisdictions and organizations throughout Canada can use and adapt to describe their role in the plan

Some notes on targets:

- In some of the document's areas of action, there currently are little or no baseline data against which to measure progress. In these instances, baseline data will need to be developed so that we can eventually better identify our progress.
- It is important to include targets for each area of action and for each vulnerable population because action is required for all populations.
- The targets identified in the document are included not only to identify and measure progress but also to motivate action. If the document's vision is to be achieved, bold targets are necessary.<sup>40</sup>

## 1. INCREASE AWARENESS OF THE IMPACT OF HIV/AIDS AND INCREASE THE COMMITMENT TO SUSTAINED FUNDING FOR HIV/AIDS PROGRAMS AND SERVICES

### RATIONALE

Despite the lack of high-profile HIV education campaigns over the past 10 years, most Canadians think HIV is a serious health issue (60% consider it very serious and 35% somewhat serious).<sup>41</sup> A survey of Canadian youth in grades 7, 9 and 11 revealed that most students are relatively knowledgeable about HIV, and their level of knowledge increases as they age.<sup>42</sup> These relatively high levels of public/youth awareness are likely due to:

- media coverage of the international epidemic
- sexual health education (School was the main source of information about human sexuality and HIV/AIDS for 51% of males and 41% of females in Grade 9 and for 67% of males and 58% of females in Grade 11)<sup>43</sup>

While members of the public are fairly knowledgeable about HIV, they have some

<sup>40</sup> With respect to setting targets for vulnerable populations, data collection should respect their right to confidentiality and privacy.

<sup>41</sup> EKOS Research Associates. *HIV/AIDS – An Attitudinal Survey*. March 2003.

<sup>42</sup> Council of Ministers of Education, Canada. *Canadian Youth, Sexual Health and HIV/AIDS Study: Factors influencing knowledge, attitudes and behaviours*. 2003.

<sup>43</sup> Ibid.

misconceptions that could affect ongoing support for HIV programs. For example, about 81% of Canadians surveyed think the treatments available now are effective, and 17% believe that if people with HIV are treated early the disease can be cured – which is, of course, not true.<sup>44</sup> Youth tend to have these same misconceptions,<sup>45</sup> which are often reinforced by the lack of media coverage of HIV issues and by inaccurate media reports.

To achieve our goals, we must correct these misconceptions and maintain or increase current high levels of awareness of HIV/AIDS among the general public – including young people – and among community and political leaders. We need the support of the general public to ensure ongoing government support as well as private donations for HIV programs and services.

The level of government support can be measured in terms of leadership (e.g., speaking out on HIV issues, convening national fora on HIV/AIDS and funding HIV/AIDS programs and services at home and abroad). Over the past 10 years, Canadian governments have spent less per capita on HIV than other developed countries that have achieved lower rates of HIV infection (e.g., the United Kingdom and Australia). Canadians generally support appropriate government spending on HIV,<sup>46</sup> and there is some political will to provide funding. For example, in June 2003, the Standing Committee on Health recommended an increase to \$100 million in funding for the Canadian Strategy on HIV/AIDS,<sup>47</sup> and the federal government has acted in part on that recommendation.

Despite increases in government funding, HIV programs and services will always have to compete with other health concerns for limited resources. A paper commissioned by the federal Ministerial Council on HIV/AIDS makes a persuasive case for sustained government funding for HIV, and this information should be used to continue to advocate for adequate funding.<sup>48</sup>

It is also important for players at all levels to engage the private sector and increase private donations for HIV/AIDS initiatives. For example, contributions to the British Columbia Persons with AIDS Society dropped 25% in each of the last two years.<sup>49</sup> In their efforts to solicit charitable donations from the private sector, HIV/AIDS organizations are competing with a wide range of health and social causes. To compete effectively, they need clear, sustained and consistent messages about the impact of HIV on society and the benefits of investing in HIV programs and services.

## DESIRED OUTCOMES

### The Canadian public will:

- be aware of the impact of HIV in Canada and the rest of the world
- understand the factors that contribute to the epidemic
- support the need for programs and services to prevent HIV infection and to provide care, treatment and support to those affected by the epidemic
- receive consistent, comprehensive sexual health education, including education about HIV/AIDS, in school
- be knowledgeable about STIs, including HIV, how STIs are spread and how to protect themselves
- stop discrimination against/stigmatization of people with HIV/AIDS

### Political leaders in Canada will:

- be aware of the impact of HIV in Canada and the rest of the world
- understand the factors that contribute to the epidemic
- support a comprehensive approach to stopping the epidemic, including providing adequate sustained funding, recognizing and addressing the impact of social determinants of health and developing supportive laws and policies across departments and branches of government.

<sup>44</sup> EKOS Research Associates. *HIV/AIDS – An Attitudinal Survey*. March 2003.

<sup>45</sup> Council of Ministers of Education, Canada. *Canadian Youth, Sexual Health and HIV/AIDS Study: Factors influencing knowledge, attitudes and behaviours*. 2003.

<sup>46</sup> EKOS Research Associates. *HIV/AIDS – An Attitudinal Survey*. March 2003.

<sup>47</sup> Standing Committee on Health. *Strengthening the Canadian Strategy on HIV/AIDS*. June 2003.

<sup>48</sup> Martin Spigelman Research Associates and The Project Group. *Taking Stock: Assessing the Adequacy of the Government of Canada Investment in the Canadian Strategy on HIV/AIDS*. January 2001.

<sup>49</sup> Vancouver Sun. September 2004.

- speak out in public about HIV/AIDS and Canada's commitment to a stepped-up response

In addition,

- per capita spending on HIV in Canada will be comparable to that of other developed countries that have achieved lower rates of HIV infection (e.g., United Kingdom, Australia)
- the business sector will provide more leadership and support in the fight against HIV
- PHAs will be more visible leading the call for action in Canada and around the world

## TARGETS

### Awareness

- Between 2004 and 2010, public awareness of the impact of HIV in Canada and globally remains at 90% or higher.
- By 2010, the proportion of the Canadian public who have misconceptions about HIV/AIDS drops by 50%.
- Between 2004 and 2010, media coverage of HIV/AIDS issues increases and is accurate and positive.
- By 2010, the proportion of Canadian youth who can accurately answer questions about how HIV is spread and how to prevent transmission will increase by 10% to 15%.
- By 2010, sexual health education – including information about HIV/AIDS – is part of all school health curricula in Canada and is delivered consistently.
- By 2010, the number of times political leaders speak out on HIV/AIDS issues increases significantly.
- The prime minister of Canada opens the 2006 International AIDS Conference in Toronto.

## COMMITMENT TO SUSTAINED FUNDING

- By 2007, all jurisdictions should have adopted a strategic approach or analyzed their position in moving forward with this series of actions.
- Between 2005 and 2010, public support for government funding of HIV programs remains at 90% or higher.

- Federal government funding reaches the level proposed by the House of Commons Standing Committee on Health (\$100 million) as soon as possible.

- By 2008, provincial/territorial governments have increased their budgets and/or have allocated dedicated funds for HIV/AIDS beyond the cost of providing care and treatment (e.g., physician and hospital services).
- By 2010, private donations to HIV/AIDS-related causes have increased significantly.
- By 2010, the business sector provides more financial support and is actively engaged in sponsorships and other HIV/AIDS activities at home and globally.

## ACTIONS

### Awareness

- 1.1 Identify high-profile leaders at all levels – among people living with HIV, communities at risk, local communities and municipal, provincial, territorial and federal governments – who will speak out and raise public awareness of HIV/AIDS and its impact.
- 1.2 Develop ongoing communication strategies and key messages for the public, political leaders and the media about the impact of HIV, the continuing epidemic in Canada and globally and the need for ongoing support and funding.
- 1.3 Ensure that sexual health education, including education on HIV/AIDS, is a mandatory part of all school curricula and is delivered in all schools.
- 1.4 Make more effective, strategic use of the media – nationally, provincially, territorially and locally – to raise awareness and correct misconceptions about HIV/AIDS.
- 1.5 Capitalize on the 2006 International AIDS Conference, being held in Toronto, to increase media coverage and public and political awareness of, and commitment to, stopping the spread of HIV.
- 1.6 Develop the capacity – nationally, provincially, territorially and locally – to respond immediately to any negative or inaccurate information about HIV/AIDS, people living with or vulnerable to HIV and/or factors that affect their health.

## Commitment to sustained funding

- 1.7 Provide adequate sustained funding from the private sector, government and the Canadian public for HIV/AIDS programs and services as well as other initiatives that address the social factors and inequities driving the epidemic.
- 1.8 Continue to track the social and economic cost of HIV/AIDS and develop economic models that can be used to advocate for adequate sustained funding.

## Research/monitoring

- 1.9 Continue to survey the general public and youth in Canada at regular intervals to assess their awareness, level of knowledge and support for HIV/AIDS-related services. Use the findings of this research to refine awareness programs.
- 1.10 Monitor public and private investment in HIV/AIDS-related programs and services and use the findings to advocate for adequate funding.
- 1.11 Reassess how HIV resources are allocated to achieve common goals.

## 2.

### ADDRESS THE SOCIAL FACTORS/INEQUITIES DRIVING THE EPIDEMIC

#### RATIONALE

While the majority of Canadians are aware of how HIV is transmitted, fewer realize the impact of social determinants of health on risk or understand the need for a social justice and human rights approach to HIV. For many communities – gay men, people who use injection drugs, Aboriginal people, and people from countries where HIV is endemic – HIV is only one of a number of pressures that threaten their health. Poverty, homelessness, stigma, addiction, violence, untreated mental health problems, lack of employment opportunities, powerlessness, lack of choice, lack of legal status (i.e., undocumented refugees) and lack of social support create an environment in which HIV and other illnesses flourish and spread.

A community that is more knowledgeable about the link between the determinants of health and HIV is more likely to support social-justice-based programs and services. For example, when people understand the potential benefits of needle- and syringe-exchange programs as not only reducing infections but also strengthening social networks, creating an environment for learning and improving access to other services, they are more likely to agree to have them in their communities.

Public policies in many sectors, including housing, taxation, social services, justice, immigration and income stabilization, can have a direct and immediate impact on people living with HIV and communities at risk. For example, a lack of government investment in affordable housing affects people's ability to find and keep shelter. Policy decisions can either limit or increase access to harm reduction measures, such as the distribution of condoms and clean needles. Policies designed to ensure safety and security for prisoners and staff in correctional institutions sometimes conflict with government obligation to preserve and promote prisoners' health and may limit prisoners' ability to practise safer sex or drug use.

The relationship between Canadian criminal law and sex workers' health and safety, including the risk of HIV infection, is multifaceted. The criminal law reflects and reinforces the stigmatization and marginalization of prostitution and sex workers. The criminal law and its enforcement limit sex workers' life and work choices, thereby placing sex workers in circumstances where they are vulnerable to high levels of violence and exploitation as well as potential exposure to HIV. The preponderance of credible evidence points to the fact that the prostitution-related offences in the Criminal Code both directly and indirectly contribute to sex workers' risk of experiencing violence and other threats to their health and safety.<sup>50</sup>

People who use injection drugs are particularly vulnerable in this regard because of the policies that shape their environment. Existing drug laws in Canada force drug activity underground, causing people who use injection drugs to avoid prevention and harm reduction programs

<sup>50</sup> Betteridge G. *Sex, Work, Rights: Reforming Canadian Criminal Laws on Prostitution*. Montreal. Canadian HIV/AIDS Legal Network. 2005.

that could reduce their risk. When people who use injection drugs are arrested, most end up in prison rather than in treatment, which increases their risk of infection. Recent moves to decriminalize the possession of small amounts of marijuana, to provide alternatives to imprisonment and to expand harm reduction programs for people who use injection drugs are examples of policies that attempt to address root causes and reduce risk.

Problematic policies are not limited to government. Rigid workplace policies in the private sector can prevent someone with HIV from returning to work or working part time and gaining the benefits associated with employment (e.g., social support, being integrated into society, contributing to the economy). The impact of these policies is not limited to people with HIV; they affect many people with long-term, debilitating illnesses.

To reduce the social inequities driving the epidemic, we must deal with stigma, both in the general population and in the communities most affected by HIV. Effective anti-stigma programs will require the meaningful participation of people living with HIV. According to research done on schizophrenia, another highly stigmatized disease, the programs that were most successful in changing public attitudes were those that gave people opportunities for one-to-one contact with people with schizophrenia.<sup>51</sup>

In the 1980s, social support for people with HIV/AIDS within the gay community helped people talk openly about the illness, enhance their health and promote and normalize safer sex practices. In recent years, community-based AIDS organizations report significantly less support for gay men who are newly infected and an increase in stigma within the gay community.<sup>52</sup> HIV is also a highly stigmatized disease in Aboriginal communities and among people from countries where HIV is endemic. These attitudes keep people silent and isolated, and the silence allows the virus to spread.

In June 2001, all the member countries of the United Nations, including Canada, made a commitment to develop national plans to confront stigma and to take other measures to eliminate all forms of discrimination and protect human rights. This document is one step in fulfilling that commitment.

## DESIRED OUTCOMES

- The dignity and worth of each person is recognized.
- Individuals and communities at risk have access to the education, income security, housing, social support and employment opportunities they need to maintain and improve their health and reduce their vulnerability to HIV infection.

## RESOURCES

In 2003, the Canadian HIV/AIDS Legal Network widely circulated for comments and input a draft *A Plan of Action for Canada to Reduce HIV/AIDS-related Stigma and Discrimination*, which sets out the steps that governments, organizations, advocates, individuals and others should take to fulfil their legal obligations:

- participation of people living with HIV/AIDS and vulnerable to HIV
- tackling stigmatizing attitudes
- advocating for rights
- improving services
- strengthening research and evaluation.

The final version of the Plan was released in early 2005.

Theodore de Bruyn, *A Plan of Action for Canada to Reduce HIV/AIDS-related Stigma and Discrimination*, Canadian HIV/AIDS Legal Network, 2004. Available with accompanying booklet in French and English at <http://www.aidslaw.ca/Maincontent/issues/discrimination.htm>.

- People with HIV live longer in better health, free of stigma and discrimination, and have all their basic needs met.
- Communities work together to give people living with HIV and communities at risk access to comprehensive health and social services.
- All jurisdictions have in place supportive policies and laws that promote health and reduce or eliminate the social inequities that fuel the epidemic.

<sup>51</sup> Stuart H. *Stigmatisation : Leçons tirées des programmes visant sa diminution*. Santé mentale au Québec. Vol. 18, No 1:54-72. 2003.

<sup>52</sup> Verbal communication. Ontario AIDS Network. 2003.

## TARGETS

### For individuals

#### By 2010:

- The proportion of people with HIV living in poverty drops.
- The proportion of people living with HIV dependent on food banks drops.
- The proportion of people living with HIV who have affordable, appropriate housing increases.
- The proportion of people living with HIV who report that they have strong social support networks increases.
- The proportion of people living with HIV who report that they have access to flexible employment opportunities that accommodate HIV increases.
- The proportion of people living with HIV who have untreated depression drops.
- The number of reports of incidents of stigma and discrimination in housing, employment, health care settings or other situations drops.
- The proportion of people with HIV who report feeling stigmatized by their illness drops.
- Gay men, Aboriginal people and people from countries where HIV is endemic who are living with HIV receive more support within their own ethnic or cultural communities.
- The proportion of Canadians who are comfortable working with someone who has HIV increases from 70% to 90%.
- The proportion of Canadian parents who are comfortable having their children attend school with a student who has HIV increases from 57% to 80%.

### For organizations and communities

#### By 2010:

- Organizations develop programs to reduce the social inequities driving the epidemic.
- Communities at risk (e.g., people who use injection drugs, Aboriginal people, people from countries where HIV is endemic, people

in correctional facilities) report measurable improvements in their access to appropriate, comprehensive health and social services, including housing, income and health promotion/harm reduction programs.

- Organizations that provide services to people with HIV and communities at risk receive support in reducing HIV-related stigma and discrimination experienced by their communities.
- Communities at risk develop and implement strategies to increase social support for their members living with HIV.

### For governments

#### By 2010:

- Governments have implemented long-term sustained plans to address HIV-related stigma and discrimination.
- HIV/AIDS is on the agenda of intergovernmental discussions about health and well-being, particularly those focussed on inner cities.
- Governments have developed concrete plans to change any policies or laws that hinder efforts to stop the epidemic.
- Governments have taken significant steps to adopt a health and human rights approach (as opposed to a criminal law approach) to drug use.
- Governments create opportunities for greater involvement of PHAs in government decisions, organizations and programs.

## ACTIONS

### Human rights

- 2.1 Pursue collaborative initiatives – locally, provincially, territorially and federally – to raise awareness of the underlying factors that contribute to the epidemic and to develop support for change.
- 2.2 Enforce legislation, policies and other measures designed to protect the rights of people with HIV, and use other measures, including communication and education, to make the public aware of human rights issues.

- 2.3 Fund initiatives that have the potential to reduce social inequities (e.g., domestic violence initiatives, programs designed to reduce physical and sexual abuse, harm reduction programs).
- 2.4 Provide access to legal assistance for people living with HIV and those at risk who are dealing with discrimination or human rights violations.
- 2.5 Create a legal and policy environment that supports the health of people who use injection drugs by reviewing and, if necessary, changing current drug legislation to reflect a human rights approach, reduce the burden on the criminal justice system and ensure that people who use injection drugs have the same access to health services as those who do not use injection drugs.
- 2.6 Create an environment that supports the health of people in correctional facilities by reviewing and, if necessary, changing any policies that have a negative impact on the health of prisoners and their access to HIV-related services that would be available to them in the community.
- 2.7 Create an environment that supports the health of sex workers by reviewing and, if necessary, changing any local, provincial, territorial and federal policies and laws that have a negative impact on the health of sex workers.
- 2.8 Review other laws, policies and practices in the public and private sector, and change any that create barriers to HIV prevention, diagnosis, care, treatment and support.

#### **Income security, housing and employment**

- 2.9 Develop baseline data on the social determinants of health (e.g., the number of people with HIV experiencing problems with poverty, food security, housing, social support, employment, depression, discrimination).
- 2.10 Review and, if necessary, change social assistance policies and practices – and insurance laws, policies and practices – to provide people living with HIV and individuals at risk with greater income security.

- 2.11 Review and, if necessary, change housing policies and practices – municipally, provincially, territorially and federally – to give people living with HIV and communities at risk better access to affordable, appropriate housing.
- 2.12 Review and, if necessary, change employment laws, policies and practices to give all people living with long-term debilitating illnesses greater access to employment opportunities that can accommodate their disability.

#### **Stigma and discrimination**

- 2.13 Implement communication/education initiatives, including age-appropriate education programs for children and youth, designed to fight all types of discrimination (e.g., racism, homophobia, sexism), violence and abuse.
- 2.14 Implement education programs designed to change negative public attitudes toward people who use injection drugs and make people more receptive to harm reduction initiatives in their communities.
- 2.15 Enhance capacity at all levels – federal, provincial, territorial and local – to respond immediately to HIV-related discrimination.
- 2.16 Implement programs to address HIV-related stigma and discrimination that give people opportunities for one-to-one contact with people living with HIV.
- 2.17 Create an environment within the gay community, Aboriginal communities and ethnocultural and ethnoracial communities that affirms members who are living with HIV and their place in the community.

#### **Research/monitoring**

- 2.18 Conduct regular surveys of people living with HIV and communities at risk to assess their access to income, housing, employment and social support, and their experience with stigma and discrimination, with data on vulnerable populations collected in ways that respect their right to confidentiality and privacy.
- 2.19 Develop a better understanding of the relationships between knowledge, personal contact and social distance to inform programs to reduce stigma and discrimination.

### 3. STEP UP PREVENTION PROGRAMS

#### RATIONALE

HIV is first and foremost a preventable disease. Communities most vulnerable to HIV need targeted programs that use culture/gender-sensitive and age-appropriate prevention strategies. They also need access to new prevention tools that will significantly enhance their ability to protect themselves, such as preventive vaccines and microbicides. Stepping up prevention is directly linked with strengthening diagnosis, care, treatment and support. Those currently unaware of their infection will be able to access the services they need and participate in reducing further infections.

#### Gay men

MSM (including gay and bisexual men) continue to be the group most affected by HIV/AIDS. In 2002, they accounted for 58% of the 56,000 people living with HIV infection and 40% of all new infections (an increase from 38% of new infections in 1999). Over the last few years, there has also been an increase in the number of MSM diagnosed with other STIs, such as syphilis. These trends indicate that gay men are engaging in riskier sexual behaviours.

#### RESOURCES

- Valuing Gay Men's Lives  
[www.times10.org/hiv92001.htm](http://www.times10.org/hiv92001.htm)
- Renewing HIV Prevention for Gay and Bisexual Men  
[www.actoronto.org/website/research.nsf/pages/renewinghivprevention](http://www.actoronto.org/website/research.nsf/pages/renewinghivprevention)
- The Ontario Men's Survey  
[www.mens-survey.ca](http://www.mens-survey.ca)

Findings from two recent studies examining sexual behaviours and attitudes among gay and bisexual men reinforce the need to step up prevention efforts:<sup>53,54</sup>

- A significant proportion of gay men underestimate their risk/are unaware of their HIV status: 27% of HIV-infected men (based on saliva testing) were not aware of their infection.

- More men (25% in one study) are having unprotected sex with casual male partners, and the proportion of gay men engaging in unprotected anal sex, a high-risk activity, has almost doubled in the last decade.
- Many men “trade off” safer sex for a desirable partner, to feel desirable themselves, or when their judgment is clouded by alcohol or drugs.
- Depression makes men more vulnerable to unsafe sex.
- 45% of gay men in one survey reported that they never disclose their HIV status (positive or negative) to casual partners.
- Gay men are making assumptions about their sexual partners' HIV status that could put them at risk. For example, many HIV-negative men assume that a partner who does not initiate condom use is also HIV-negative, while many HIV-positive men assume that partners who are willing to have unprotected sex are positive.
- While most men are practising safer sex and using condoms, a significant proportion report problems with condoms, including erectile difficulties, slippage and breakage.
- Gay men are generally well informed, and effective prevention initiatives should acknowledge and build on this knowledge base.

Among gay and bisexual men, certain groups appear to be at higher risk, including young gay men who tend to assume that HIV is a problem for older gay men or who are vulnerable because of poverty, homelessness or a power differential in their relationships; gay men who are just coming out and may not be as knowledgeable about HIV; men from cultures where there is severe discrimination against gay men; and older gay men who, given the gay-identified culture's focus on physical attractiveness, are willing to take more risks in order to have sexual relationships.<sup>55</sup> According to older gay men who participated in a focus group to develop *Leading Together*, the increasing use of Viagra and increasing sexual expectations are also a factor in unsafe sex.<sup>56</sup>

<sup>53</sup> Adams BD, Husbands W et al. *Renewing HIV Prevention for Gay and Bisexual Men. A Research Report on Safer Sex Practices Among High Risk Men and Men in Couples in Toronto*. 2003.

<sup>54</sup> Myers T, Allman D. et al., Ontario Men's Survey, Toronto: University of Toronto. 2004.

<sup>55</sup> Notes from the Ottawa Focus Group. Consultation on *Leading Together*. January 2004.

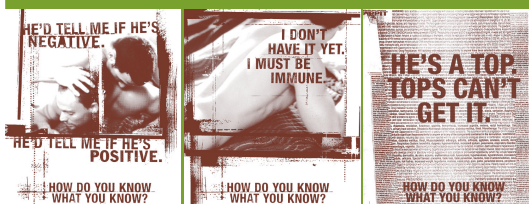
<sup>56</sup> Ibid.

These research findings are being used to develop prevention strategies that engage the gay community in discussions on how to interpret risk messages, negotiate safety and manage relationships.

#### HOW DO YOU KNOW WHAT YOU KNOW? A Prevention Campaign Targeting Gay Men

Community-based AIDS organizations in Vancouver, Calgary, Winnipeg, Toronto, Montréal and Halifax are participating in a prevention campaign that targets gay and bisexual men. Funded by Health Canada and provincial governments, the goal of the campaign is to reduce the incidence of unprotected anal sex in situations where gay men do not know the HIV status of their sexual partner. The campaign challenges gay men to review the strategies they use to assess risk and question the assumptions they make about their sexual partners.

The campaign, originally developed in San Francisco and adapted for use in Canada, is an example of building on other initiatives and pan-Canadian collaboration.



#### People who use injection drugs

Between 75,000 and 125,000 people in Canada inject drugs such as heroin, cocaine or amphetamines.<sup>57</sup> While the majority of people who use injection drugs live in large urban centres, such as Toronto, Vancouver and Montréal, IDU has also been reported in many smaller towns and cities and in rural communities. People who inject drugs are at high risk of health problems associated with their drug use, including overdoses and

infections. When they share needles to inject, they are at extremely high risk of acquiring HIV and hepatitis C. The proportion of people using injection drugs who report sharing needles varies considerably but is exceedingly high in many communities: 76% in Montréal (Bruneau et al. 1997), 69% in Vancouver (Strathdee et al. 1997), 64% in a semi-rural Nova Scotia community (Stratton et al. 1997), 54% in Québec City (Bélanger et al. 1996) and Calgary (Elnitsky and Abernathy 1993), 46% in Toronto (Myers et al. 1995) and 37% in Hamilton-Wentworth (DeVillier and Smyth 1994).<sup>58</sup>

People who inject drugs account for about 20% of people in Canada infected with HIV and for 30% of new infections in 2002. In 2002, between 800 and 1,600 people who inject drugs were newly infected with HIV. This population remains highly vulnerable.

Prevention programs that strive to reduce the harm associated with injecting drugs – such as needle- and syringe-exchange programs, methadone maintenance and other substitution therapy, and safe injection sites – are highly effective in reducing the risk of both HIV and hepatitis C among people who use injection drugs.<sup>59</sup> These harm reduction initiatives are even more effective when they are combined with increased, meaningful involvement of people who use injection drugs, including through support of organizations of people who use injection drugs<sup>60, 61, 62</sup> and other services that meet broader complex health and social needs, such as outreach programs, easy access to non-judgmental primary care, access to stable housing and food, addiction treatment programs and collaboration with the law enforcement and justice system.<sup>63</sup> Given the growing evidence of the link between depression and addiction, better access to mental health services and treatment for depression may also help reduce the risk of HIV, hepatitis C and other harms associated with drug use.<sup>64</sup>

<sup>57</sup> Single E, Rehm J et al. *The relative risks and aetiological fractions of different causes of disease and death attributable to alcohol, tobacco and illicit drug use in Canada*. Canadian Medical Association Journal, 162, 1669-1675. 2000.

<sup>58</sup> Canadian HIV/AIDS Legal Network. *Injection Drug Use and HIV/AIDS: Legal and Ethical Issues*. November 1999.

<sup>59</sup> Public Health Agency of Canada. *Harm Reduction and Injection Drug Use: An international comparative study of contextual factors influencing the development and implementation of relevant policies and programs*. 2001.

<sup>60</sup> Broadhead RS, Heckathorn DD, Altice FL, et al. *Increasing drug users' adherence to HIV treatment: results of a peer-driven intervention feasibility study*. Soc Sci Med. Vol 55 No 2 Pp 235-46. 2002;

<sup>61</sup> Wood E, Kerr T, Spittal PM, et al. *An external evaluation of a peer-run "unsanctioned" syringe exchange program*. J Urban Health. Vol 80 No 3 Pp. 455-64. 2003.

<sup>62</sup> Kerr T, Small W, Pease W, Douglas D, Pierre A, Wood E. *Harm reduction by a "user-run" organization: A case study of the Vancouver Area Network of Drug Users (VANDU)*. International J Drug Policy in press.

<sup>63</sup> Public Health Agency of Canada. *Harm Reduction and Injection Drug Use: an international comparative study of contextual factors influencing the development and implementation of relevant policies and programs*. 2001.

<sup>64</sup> Health Canada. *Best Practices - Concurrent Mental Health and Substance Use Disorders*. 2002.

While some jurisdictions in Canada have been leaders in harm reduction programs for people who use injection drugs, the services currently available do not meet the needs. For example, we do not have enough needle- and syringe-exchange programs, and many of the existing programs are too limited in terms of hours of operation and number of needles distributed to meet needs.<sup>65</sup> Access to methadone maintenance also continues to be limited in many parts of the country. Canada only has one safe injection site, and the rules imposed by the regulator are more stringent than in other countries with safe injection sites, thus limiting access to the site. For example, the rules do not allow one person to inject another, which limits access to this service for, among other people, many women who use injection drugs and rely on their partners to inject them.

Vancouver has taken a leading role in responding to IDU. A draft discussion paper released by the City of Vancouver, "A Framework for Action: A Four-Pillar Approach to Drug Problems in Vancouver," contains an urgent appeal to develop and implement a coordinated, comprehensive framework for action to address the problem of substance misuse in the city of Vancouver. The framework seeks to balance public order and public health and calls for a strong, comprehensive drug strategy that incorporates four pillars: prevention, treatment, enforcement and harm reduction. It is a framework that ensures a continuum of care for those suffering from addiction to substances and support for the communities affected by their drug use.

[www.city.vancouver.bc.ca/ctyclerk/newsreleases2000/NRdraftdrugpaper.htm](http://www.city.vancouver.bc.ca/ctyclerk/newsreleases2000/NRdraftdrugpaper.htm)

Effective prevention programs for people who inject drugs must address the risk of transmission not only through needle sharing but also through sexual activity. The sexual partners of people who inject drugs are at high risk, even if they do not inject. For example, women and youth who inject drugs may be at increased risk because they may be financially dependent and therefore less able to control the conditions that make them vulnerable to infection.

## Aboriginal people

In 2002, it was estimated that approximately 3,000 to 4,000 Aboriginal persons were living with HIV in Canada, representing 5% to 8% of all prevalent HIV infections, compared to the 1999 estimate of about 6% of the total. Note that Aboriginal people make up only about 3% of the country's population.<sup>66</sup> Documented rates of HIV infection are particularly high in western Canada. For example, between 1995 and 1997, Aboriginal people in British Columbia accounted for between 15% and 18% of newly diagnosed infections.<sup>67</sup> Between 1993 and 1998, 26% of Alberta's newly diagnosed HIV cases were in Aboriginal people.<sup>68</sup>

Aboriginal Canadians have also expressed concern about the fact that most jurisdictions do not collect information on the ethnicity of people diagnosed with HIV. In these jurisdictions, therefore, available data are based primarily on information collected among First Nations groups on reserve and do not include Métis, Inuit or Aboriginal people living off-reserve.

Given the lack of consistent data, it is difficult to know the exact extent of the epidemic in this population; high rates of poverty, alcohol and substance use, the long-term impact of discrimination, loss of culture, the legacy of abuse from residential schools, the mobility of this population (on and off reserve) and high rates of incarceration make Aboriginal people highly vulnerable.

Of the estimated 250 to 450 Aboriginal people newly infected with HIV in 2002, the main risk factors for infection were IDU (63%), heterosexual transmission (18%), men having sex with men (12%) and IDU/men having sex with men (7%).<sup>69</sup>

While HIV is a growing issue in many Aboriginal communities, it is only one of a number of health and social problems. Because of this, the focus of the five Aboriginal strategies developed in Canada (Strengthening Ties – Strengthening Communities: An Aboriginal Strategy on

<sup>65</sup> Wood E, Tyndall MW, Spittal P, et al. *Needle exchange and difficulty with needle access during an ongoing HIV epidemic.* International Journal of Drug Policy. Vol.13 No 2. Pp.95-102.2002

<sup>66</sup> Health Canada. *Estimates of HIV prevalence and incidence in Canada, 2002.* Canada Communicable Disease Report. Vol. 29 No 23. 1 December 2003.

<sup>67</sup> BC Aboriginal HIV/AIDS Task Force. *The Red Road: Pathways to Wholeness. An Aboriginal Strategy for HIV and AIDS in BC.*

<sup>68</sup> Alberta Aboriginal HIV Strategy 2001-2004. *Healthy Response to HIV/AIDS.* Health Canada/Alberta Health and Wellness. 2001.

<sup>69</sup> Health Canada. *Estimates of HIV prevalence and incidence in Canada, 2002.* Canada Communicable Disease Report. Vol 29 No 23. 1 December 2003.

HIV/AIDS in Canada, along with strategies for Aboriginal people in British Columbia, Quebec, Alberta and Ontario) is on HIV as part of the larger challenge of building healthy communities.



Within Aboriginal communities, HIV prevention initiatives must target women and two-spirit men as well as the underlying issues of poverty, lack of employment, stigma within the Aboriginal community, substance use and low self-esteem.

Effective approaches will be led by Aboriginal people and grounded in Aboriginal culture, healing and the intertwining of body, mind and spirit. They will also be integrated with other urgent Aboriginal health issues, such as diabetes and the use of tobacco and alcohol, and encourage people to value and take care of themselves.<sup>70</sup> Leadership, innovation and a long-term commitment will be vital. As one of Canada's Aboriginal strategies says, "Tear the ideas apart and identify what doesn't work as well. But don't give up trying ... try again or try something else. HIV has taught us ... that we cannot achieve everything we need alone – we need each other to support and guide, be coaches, listeners and activists, for encouragement, pushing, and pulling as needed."<sup>71</sup>

#### People from countries where HIV is endemic

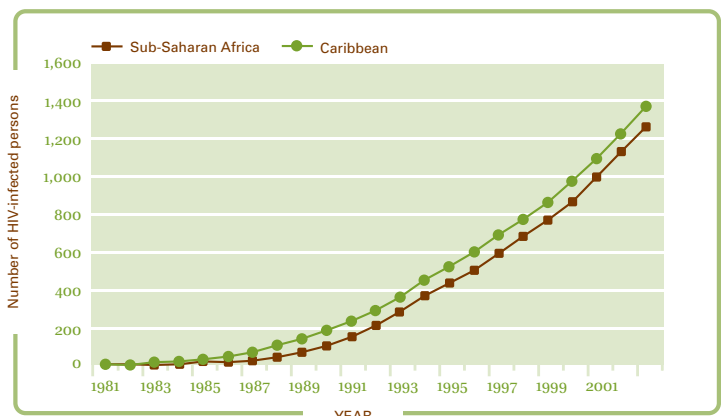
In much of Africa and many countries in the Caribbean, HIV is endemic. But HIV is not just a crisis for people living there – it is also a crisis for people from Africa and the Caribbean who settle in other parts of the world. Over the past 40 years, a growing number of people have immigrated to Canada from Africa and the Caribbean. Most (over 90%) have settled in Ontario and Quebec.

- According to Public Health Agency of Canada data, in 2002, there were 3,700 to 5,700 prevalent HIV infections among people born in a country where HIV is endemic,

which represents 7% to 10% of prevalent infections in Canada.<sup>72</sup>

- Between 1999 and 2004, the proportion of positive HIV test reports attributed to people from a country where HIV is endemic increased from 4.2% to 7.6%.<sup>73</sup>
- The African and Caribbean communities in Ontario account for 2,071 out of 21,453 HIV diagnoses in Ontario. They represented only 6.7% of diagnoses from 1985 to 1998 but 22% of diagnoses in 2001 and 2002. HIV prevalence rates in people from countries where HIV is endemic in Ontario are 50 times higher than in other heterosexual, non-injecting populations in Ontario.<sup>74</sup>

Modeled HIV Prevalence Among Persons Born in Sub-Saharan Africa or the Caribbean. Ontario 1981-2002<sup>75</sup>



- The risk is not limited to new immigrants. In Ontario, 30% to 45% of new infections in African and Caribbean Canadians occur in Canada.
- In this population, the virus is mainly spread through heterosexual contact. Because women are biologically more vulnerable to HIV infection through heterosexual sex than men,<sup>76</sup> African and Caribbean women are at high risk. The majority of HIV-infected babies in Ontario are born to women from countries where HIV is endemic.

<sup>70</sup> Notes from the Vancouver consultation on Leading Together. 2004.

<sup>71</sup> BC Aboriginal HIV/AIDS Task Force. The Red Road: Pathways to Wholeness. An Aboriginal Strategy for HIV and AIDS in BC.

<sup>72</sup> Health Canada. *Estimates of HIV prevalence and incidence in Canada, 2002*. Canada Communicable Disease Report. Vol 29 No 23. 1 December 2003.

<sup>73</sup> Public Health Agency of Canada. *HIV and AIDS in Canada. Surveillance Report to December 31, 2004*. Surveillance and Risk Assessment Division, Centre for Infectious Disease Prevention and Control, Public Health Agency of Canada. 2005.

<sup>74</sup> Remis R. *The epidemiology of HIV infection among persons from HIV-endemic countries in Ontario: Update to 2002*.

<sup>75</sup> Ibid.

<sup>76</sup> Conservative estimates place the risk at two to four times greater for women. Hankins, Catherine. *Sexual transmission of HIV to women in industrialized countries*. World Health Statistics Quarterly. 49(1996). Page 106; Canadian AIDS Society. 1997/98 National AIDS Awareness Campaign: The Changing Face of AIDS. Ottawa: Canadian AIDS Society. 1997. Module 2-4.

- The rapid and growing spread of HIV in African and Caribbean communities in Canada is being fuelled by the stigma associated with HIV, the challenges faced by recent immigrants (e.g., settlement issues, poverty, financial dependence, racism, stigma), cultural attitudes, lack of support from the broader community and lack of comprehensive, coordinated and targeted prevention efforts. We must act now to address the underlying factors and provide services for this community.

### People in correctional facilities

*“By entering prisons, prisoners are condemned to imprisonment for their crimes; they should not be condemned to HIV and AIDS. There is no doubt that governments have a moral and legal responsibility to prevent the spread of HIV among prisoners and prison staff and to care for those infected. They also have a responsibility to prevent the spread of HIV among communities. Prisoners are the community. They come from the community, they return to it. Protection of prisoners is protection of our communities.”<sup>77</sup>*

The proportion of people in Canada’s federal correctional facilities who are known to be living with HIV (2.01%) is significantly higher than in the Canadian population as a whole (0.16%).<sup>78</sup> In 1989, 14 prisoners in Canadian federal

“We owe it to the prisoners, and we owe it to the community, to protect people from infection while they are incarcerated. This requires radical steps before it is too late. The infection of a person who is in the custody of society, because that person does not have access to ready means of self-protection and because society has preferred to turn the other way, is unpala-table.... As a community we must take all proper steps to protect prison officers and prisoners alike. By protecting them we protect society.”

Justice Kirby of the High Court of Australia

prisons were known to have HIV; by 2002, the number was 251 (based on preliminary data).<sup>79</sup> Given that many prisoners may not know they are infected or may not have disclosed their status, the actual number of prisoners infected may actually be much higher. Studies undertaken in provincial prisons have also all shown that HIV seroprevalence rates in prisons are at least 10 times higher than in the general population, ranging from 1 to 8.8%.<sup>80</sup>

Rates of hepatitis C in prison populations are even higher than rates of HIV: in 2002, 3,173 federal prisoners were known to be infected with hepatitis C: 25.2% of male and 33.7% of female prisoners.<sup>81</sup> The high rates of both HIV and hepatitis C in correctional facilities put prisoners who engaged in IDU, unprotected sex and/or tattooing at high risk of infection.

Most prison systems in Canada have taken some steps to protect prisoners (and ultimately the public) by providing education, access to condoms, dental dams and lubricants and by making methadone maintenance treatment available to opioid-dependent prisoners. However, the extent to which these and other prevention measures are available and accessible varies, and generally Canadian systems lag behind some other countries that have implemented comprehensive harm reduction programs, including needle- and syringe-distribution programs.

Comprehensive prevention programs in correctional facilities will reduce the risk to prisoners and, as most prisoners will leave prison and integrate back into society, will also reduce the risk to Canadian society as a whole.

### Women and heterosexual transmission

Over one quarter of the diagnosed and reported HIV infections in 2004 were among women. This is a notable change from the years prior to 1995 when they represented less

<sup>77</sup> United Nations Commission on Human Rights (fifty-second session, item 8 of the agenda). HIV/AIDS in Prisons - Statement by UNAIDS. Geneva, Switzerland, April 1996.

<sup>78</sup> Canadian HIV/AIDS Legal Network. *HIV/AIDS and Hepatitis C in Prisons: The Facts*. 2004. Available on-line at <http://www.aidslaw.ca/Maincontent/issues/prisons/e-info-pa1.htm>

<sup>79</sup> Infectious Diseases Prevention and Control in Canadian Federal Penitentiaries 2000-01. *A Report of the Correctional Service of Canada's Infectious Diseases Surveillance System*. Ottawa. Correctional Service Canada. 2003.

<sup>80</sup> Jürgens R. *HIV/AIDS in Prisons: Final Report*. Montreal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society. 1996. Landry S et al. *Étude de prévalences du VIH et du VHC chez les personnes incarcérées au Québec et pistes pour l'intervention*. Canadian Journal of Infectious Diseases 2004; 15(Suppl A): 50A (abstract 306).

<sup>81</sup> Canadian HIV/AIDS Legal Network. *HIV/AIDS and Hepatitis C in Prisons: The Facts*. 2004. Available on-line at <http://www.aidslaw.ca/Maincontent/issues/prisons/e-info-pa1.htm>

than 10%. The largest rise in this proportion is seen among the 15-29 year age group, where females represented 13.2% of reports in 1985-1994 and 42.2% in 2004.<sup>82</sup> Many of the women are Aboriginal, from a country where HIV is endemic, users of injection drugs or are at risk from sex with a partner who injects drugs or who has had sex with men.

Growing rates of HIV infection in women reflect the fact that women are biologically, economically, socially and culturally more vulnerable to HIV infection than men.<sup>83</sup> Poverty often leads to situations where women trade sex for survival, and economic dependence limits women's ability to leave dangerous relationships or negotiate safer sex with their partners. Domestic violence, sexual violence, abuse and coercion affect women's ability to protect themselves. Women who are in violent relationships or who fear violence cannot negotiate safer sex with their partners.<sup>84</sup> The women who are most at risk may not have the knowledge, resources or power within their relationships to protect themselves from infection. Because women's ability to ensure that their partners use condoms or practise safer sex is often limited, every effort must be made to develop prevention tools that women themselves can control and use to protect their health, such as microbicides and preventive vaccines. Canada must invest adequately in developing prevention strategies for women.

Because women are highly vulnerable to HIV through heterosexual sex, every effort must be made to monitor infections and ensure that prevention and awareness programs are reaching women at risk. Ontario is now working with the Public Health Agency of Canada on a study of the risk factors for all new heterosexual infections in women. The results will be used to guide prevention programs for women and to ensure that initiatives aimed at vulnerable populations (e.g., Aboriginal people, people from countries where HIV is endemic, people who use injection drugs) provide gender-sensitive programs for women.

### At-risk youth

A number of youth in Canada are at high risk of HIV infection, including street-involved youth, transient youth, youth who inject drugs, gay youth and Aboriginal youth. To prevent the spread of HIV among young people, all prevention programs targeting communities at risk should include age-appropriate information and youth-led initiatives for youth. In addition, organizations and agencies serving marginalized or transient youth should be directly involved in delivering HIV prevention/harm reduction messages and skills as part of larger health and social support programs for youth.

### Babies born to women with HIV

Canada has made progress in reducing the number of babies born with HIV. While the number of babies born to women living with HIV has increased from 87 in 1993 to 163 in 2004, during the same time period the percentage of infants confirmed to be HIV-positive born to women living with HIV has decreased from 47% to 2%.<sup>85, 86</sup> The change is primarily due to the development of effective strategies to prevent mother-to-child transmission, including the use of antiretroviral therapy during pregnancy and Caesarean sections. The ability to use these strategies depends on knowing the mother's HIV status. Offering pregnant women HIV testing has proven to be effective in identifying women who are infected and providing appropriate treatment.

Prenatal HIV testing programs are now in place in all provinces and territories in Canada. With infections rising among Aboriginal women, women from countries where HIV is endemic and women who inject drugs, special efforts are required to ensure that these women are provided with access to culturally appropriate information on the benefits of HIV testing during pregnancy and access to voluntary testing and counselling programs. As with all HIV testing, providers are ethically and legally required to ensure

<sup>82</sup> Public Health Agency of Canada. *HIV and AIDS in Canada. Surveillance Report to December 31, 2004*. Surveillance and Risk Assessment Division, Centre for Infectious Disease Prevention and Control, Public Health Agency of Canada. 2005.

<sup>83</sup> Csete J. *Not as simple as ABC: Making real progress on women's rights and AIDS*. Human Rights Watch. July 9, 2004.

<sup>84</sup> *Ibid.*

<sup>85</sup> The process of confirming whether an infant has been infected perinatally takes 15 to 18 months. Approximately 75% of newborns who test positive for HIV are not actually infected but carry their mother's antibodies. Infants who are not truly infected usually lose their maternal antibodies by 15 to 18 months of age, after which time they test negative for HIV antibody. Hoffmaster B. and Schrecker T. An ethical analysis of HIV testing of pregnant women and their newborns. Health Canada. August 1999.

<sup>86</sup> Public Health Agency of Canada. *HIV and AIDS in Canada. Surveillance Report to December 31, 2004*. Surveillance and Risk Assessment Division, Centre for Infectious Disease Prevention and Control, Public Health Agency of Canada. 2005.

that pregnant women give informed consent to be tested. This is best done by asking women whether they want to opt in to testing after providing them with all the relevant information during counselling, rather than by asking them to opt out of testing.<sup>87</sup> More information is required on the long-term impact on children of treatment with antiretroviral therapy.

### People living with HIV

The successful use of HAART means that many people with HIV are living longer in good health, yet little has been done to help people with HIV manage the challenges of living many years with an infectious disease. There have been few PHA-based or PHA-led strategies designed to help people with HIV enjoy full lives while reducing the risk of HIV transmission. To remedy this, more people living with HIV are taking a lead role in prevention programs (e.g., Positive Prevention initiatives in the United Kingdom and the “HIV stops with me” program in San Francisco).

Positive prevention initiatives, which are based on the principles of health promotion, start by actively promoting the physical, mental and sexual health of people living with HIV. By ensuring that PHAs receive appropriate treatment, support in dealing with complex psychosocial issues (e.g., depression, denial, rejection, isolation, grief and loss), and other services that enhance health (e.g., adequate nutrition and housing), these initiatives empower people living with HIV to be actively involved in prevention.

The trend to focus more on positive prevention is driven by:

- the desire of people living with HIV to prevent transmission and protect themselves from re-infection
- the importance of protecting people with HIV from other STIs that could threaten their health
- legal developments indicating that people with HIV may be legally responsible for virus transmission if they have not disclosed their HIV status to their partner

Peer-led prevention programs provide support for people living with HIV in their efforts to practise safer sex and drug use and to protect their own, as well as other people’s, health. They can also help people living with HIV develop strategies to disclose their HIV status where appropriate or, if disclosure is likely to put them at risk of physical harm or discrimination, to protect themselves and their partners without disclosure. PHAs also need strategies to deal with discrimination and stigma following disclosure.

### DESIRED OUTCOMES

- Members of communities most vulnerable to HIV disease have the knowledge, skills, supportive environments to protect themselves from HIV and other STIs.
- A substantial decrease in new HIV infections in Canada.
- All communities at risk have access to targeted, evidence-based, sustained prevention programs.
- Prisoners have access to the same prevention measures available to people in the general community.
- People at risk have access to a wider range of prevention tools, including microbicides and preventive vaccines.
- HIV infections in newborns are further reduced.
- People with HIV are leading positive prevention programs.
- A comprehensive HIV surveillance system provides timely information and reports that provinces and communities can use to anticipate new trends and guide targeted prevention programs.

### TARGETS

#### By 2010:

- The number of new HIV infections each year in Canada drops by 40%.
- The number of new HIV infections each year among gay men drops by 40%.

<sup>87</sup> Stoltz L, Shap L. *HIV Testing and Pregnancy: Medical and Legal Parameters of the Policy Debate*. Ottawa. Health Canada. Available via [www.aidslaw.ca/Maincontent/issues/testing.htm](http://www.aidslaw.ca/Maincontent/issues/testing.htm).

- The number of new HIV infections through IDU drops by 40%.
- The number of new infections among people from countries where HIV is endemic drops by 40%.
- The number of new infections among Aboriginal people drops by 40%.
- The number of new infections in women drops by 40%.
- The number of new HIV infections among youth drops by 40%.
- Rates of other sexually transmitted diseases in communities at risk will remain stable or decrease.
- One hundred percent of pregnant women in Canada are offered voluntary prenatal HIV testing with quality pre- and post-test counselling and respect for the principle of informed consent.
- The proportion of people living with HIV who report that they always practise safer sex increases significantly.
- The proportion of people who use injection drugs who never share needles increases significantly.
- Access to drug treatment, including methadone maintenance treatment, and to harm reduction measures such as needle exchange programs and safe injection sites increases significantly in all jurisdictions in Canada.
- Prisoners in all prison systems have access to the same prevention measures available to people in the general population.
- Canada increases its contribution to global efforts to develop microbicides and preventive HIV vaccines and implements comprehensive HIV vaccine and microbicide plans.
- address the assumptions, risk assessments and trade-offs that affect men's decisions to practise safer sex
- address external and internal homophobia
- address the barriers/problems gay and bisexual men face in using condoms
- provide the education and support that highly vulnerable groups in the gay community (i.e., young gay men, men just coming out, older gay men, immigrant MSM, sex workers) need to protect themselves
- address the role that depression and substance use play in decisions to practise safer sex
- build support for people living with HIV within the gay community.

### 3.3 Implement comprehensive prevention/harm reduction programs that will address the social determinants of health of people who use injection drugs, people infected through IDU and their needle-sharing and sexual partners and that:

- meaningfully involve people who use injection drugs in planning and implementation
- provide effective peer-led outreach to people who use injection drugs
- expand access to existing harm reduction measures (e.g., needle exchanges, methadone programs)
- expand access to new/innovative harm reduction measures (e.g., safe injection sites, prescribed heroin, other drug substitution programs)
- ensure that people who use injection drugs receive appropriate pain management
- expand access to a full range of health and social services, including primary care, housing, food, income security, mental health services and long-term (i.e., 12-month) residential addiction treatment programs
- provide prevention programs specifically targeted to women who use injection drugs and to Aboriginal people who inject drugs.

## ACTIONS

3.1 Step up targeted, peer-led, age/gender/culture-appropriate prevention initiatives for people living with HIV.

3.2 Implement comprehensive prevention programs for gay and bisexual men that:

- are peer-planned and led
- acknowledge the strong HIV knowledge base within the gay community

**3.4** Implement comprehensive, peer-led, culturally appropriate prevention/harm reduction programs that reflect the diversity in Aboriginal communities, address the complex health and social needs of Aboriginal people and communities and that:

- enlist the active support of Aboriginal leaders
- integrate HIV prevention into broader health and wellness programs, including employment and anti-violence programs
- address the high rates of substance use and depression and the lack of self-esteem in Aboriginal communities
- reinforce the Aboriginal view of the inter-relationships among body, mind and spirit
- focus on the unique needs of women and two-spirited men
- increase the number of Aboriginal health care providers and educators, and provide the necessary training
- reduce HIV stigma within the Aboriginal community, and build support for people who are infected.

**3.5** Implement comprehensive, peer-led, culturally appropriate prevention/harm reduction programs that will address the complex health and social needs of people from countries where HIV is endemic and that:

- provide culturally appropriate prevention guidelines and information
- address the issues that contribute to the spread of HIV, including long-term discordant heterosexual partnerships; reproduction, testing, disclosure and partner notification issues; immigration issues; the impact of racism and other discrimination on this population's response to HIV/AIDS; their ability to access HIV information/services; and lack of employment and housing
- target women in these communities and their complex issues (e.g., gender inequality, violence, isolation, the physiological differences in HIV treatment)
- reduce HIV stigma in the community, which isolates people who are infected, and build support for those living with HIV.

**3.6** Implement policies and programs designed to reduce the risk of HIV transmission in all correctional facilities in Canada, and give prisoners access to age-, gender- and culture-appropriate prevention, harm reduction and treatment tools and services, including:

- information and ongoing education
- peer education, counselling and support programs
- condoms, dental dams and water-based lubricants
- bleach for cleaning syringes
- clean needles and syringes
- tattooing equipment
- voluntary HIV testing
- methadone maintenance therapy, for both those on methadone when they enter the facility and those who want to begin treatment while incarcerated
- detoxification and addiction treatment services
- targeted programs for women and Aboriginal people.

**3.7** Implement prevention initiatives that meet the needs of women and support other initiatives designed to enhance women's ability to reduce their risk (e.g., the development of microbicides, anti-violence programs, women's shelters, drug treatment programs for women).

**3.8** Implement prevention initiatives targeted to sex workers.

**3.9** Implement peer-led, age-appropriate prevention initiatives to meet the needs of at-risk youth.

**3.10** Provide and promote voluntary HIV prenatal testing to women and their physicians/midwives, developing special programs to reach Aboriginal women, women from countries where HIV is endemic, and women who use injection drugs.

**3.11** Implement PHA-led positive prevention programs designed to help people living with HIV manage the challenges of living with an infectious disease.

**3.12** Develop plans to support the development of new prevention technologies, including vaccines and microbicides, and to make them available once they are developed.

#### Surveillance/research/monitoring

**3.13** Identify standard, consistent data to be collected on HIV in all jurisdictions, and enhance the capacity of the existing HIV surveillance system to analyze data and provide timely information and reports to guide prevention programs.

**3.14** Conduct targeted epidemiological surveillance studies designed to enhance understanding of the factors that contribute to the spread of HIV in affected communities.

**3.15** Conduct research on effective prevention strategies for communities vulnerable to HIV, and use the findings to inform prevention programs.

**3.16** Monitor the impact of antiretroviral therapy on children born to women with HIV.

**3.17** Develop new prevention technologies beyond vaccines and microbicides.

4.

## STRENGTHEN DIAGNOSIS, CARE, TREATMENT AND SUPPORT SERVICES

### RATIONALE

Although the quality of HIV care and support in Canada is among the best in the developed world, there are still gaps and inconsistencies. Some people – particularly those in rural and remote areas, but also many in marginalized communities in urban centres<sup>88</sup> – still struggle to get the quality care and treatment they need. Strengthening diagnosis, care, treatment and support is directly linked with stepping up prevention efforts.

As the needs of people with HIV become more complex, services must adapt. The main challenges in HIV diagnosis, care, treatment and support in Canada in 2004 are:

- the significant number of people with HIV who are not diagnosed until they are in the later stages of HIV disease and therefore do not have access to appropriate treatment, while managing such complexities such as:
  - demanding treatment regimens that are difficult for people with HIV to maintain
  - the side effects associated with HAART, including cancer, lipodystrophy, heart disease, neurocognitive impairments, liver disease and kidney disease
  - the increase in drug resistance that is associated with lack of adherence to HAART regimens
  - transmission of drug-resistant virus
  - the complex treatment needs of people who are co-infected with HIV and hepatitis C
  - the complex treatment and support needs of people who have addiction or mental health problems
  - the high rate of depression in people living with HIV
  - the changing care needs associated with aging and HIV
  - the unique treatment needs of women with HIV (e.g., managing drug treatments during menopause)
- funding and policy issues, including:
  - the time it takes to approve and license new drugs
  - barriers to having newly approved drugs listed on provincial/territorial formularies
  - lack of access to complementary therapies
- practical and psychosocial issues, including:
  - the need for more assistance with basic needs, such as income, housing, food and disability benefits
  - the lack of employment opportunities that can accommodate people with HIV
  - the challenge of living many years with an infectious, life-threatening illness
  - the impact of stigma and discrimination
  - dealing with relationships and disclosure and the need for effective prevention strategies for people with HIV
  - high rates of depression and the impact on people's health
  - the increase in AIDS-related deaths and the lack of palliative care services for people with HIV

<sup>88</sup> See E Wood et al., supra, note 11

### Increasing access to testing

People who are diagnosed early and offered appropriate treatment and support live longer in better health than those who are not diagnosed until late in the course of HIV disease. They are also better able to prevent the spread of HIV to others. When voluntary HIV testing is accompanied by pre- and post-test counselling – as it always should be – it is both an effective early intervention (i.e., a good way to link people who are infected with care) and an effective prevention strategy (i.e., it gives those who may be engaging in risky behaviours information and support for behaviour change).

All testing should continue to be undertaken only with pre- and post-test counselling and informed consent, and people should opt in rather than opt out of testing. Promoting access to voluntary testing to communities with high rates of HIV infection (i.e., gay men, people who use injection drugs, Aboriginal people and people from countries where HIV is endemic) is a cost-effective way to detect the virus early and link people with HIV to support, information and treatment that can prolong their lives.

### Improving treatment effectiveness

After more than a decade of experience with HAART, clinicians and people living with HIV are identifying problems with treatment failures, drug resistance and side effects and the challenges of treating people who are co-infected with hepatitis C or who have concurrent disorders, such as mental health problems or addictions. Changing and complex care needs highlight the need to continue to develop: new, more effective treatments; strategies to overcome barriers to adherence and reduce drug resistance, such as simpler treatment regimens; vaccines; and a cure. Strategies also need to be developed to address the currently poorer treatment outcomes for women.

### Improving access to treatment

Many Canadians with HIV – such as those in small, rural or remote communities, those in correctional facilities, new immigrants,

Aboriginal persons, women, poor people, people who use injection drugs and sex workers – continue to face inherent barriers to accessing treatment. Some barriers relate to geography and distance, some to culture and language, some to bureaucracy and regulation, others to stigma and discrimination. For example, people who use injection drugs are sometimes denied access to antiretroviral therapy on the assumption that they will not be able to adhere to complex treatment regimens; however, recent research indicates that, with appropriate education and support, people who inject drugs have the same adherence rates as other people with HIV.<sup>89</sup> Prisoners in Canadian provincial/territorial and federal prisons continue to have problems accessing treatment equivalent to that outside. In particular, there is evidence suggesting that a significant number of prisoners discontinue antiretroviral treatment while in prison.<sup>90</sup> Access to medical marijuana remains an issue for PHAs.

### Strengthening support services

People with HIV are a highly diverse group, socio-economically and culturally. While some are working and managing their illness, a growing number are struggling to meet basic needs and to live a full life in the midst of a long-term, life-threatening illness. They need a wide range of culturally appropriate support services that can assist with practical as well as psychosocial needs – housing and food as well as social support and prevention strategies. Many of the services that people with HIV need are beyond the traditional mandate of care and support programs. To meet these needs, services must adapt.

### Providing quality end-of-life care

With the advent of HAART in the 1990s, many of the buddy and hospice programs developed for people living with HIV in the 1980s have been closed down or reduced. With the number of people being diagnosed in late stages of the disease, the increase in drug resistance, more people failing on HAART, and the sometimes life-threatening side effects of treatment, more people are once again dying from HIV/AIDS and need access to compassionate hospice palliative care.

<sup>89</sup> Canadian AIDS Treatment Information Exchange. *Anti-HIV Agents: Teaching Adherence to Substance Users*. Treatment Update 127. May 23, 2002; Canadian HIV/AIDS Legal Network. *Injection Drug Use and HIV/AIDS. Legal and Ethical Issues*, 1999.

<sup>90</sup> Palepu A, Tyndall MW, Li K, Yip B, Hogg RS, O'Shaughnessy MV, Montaner J, Schechter M. *Access and sustainability of antiretroviral therapy among injection drug users in Vancouver*. Canadian Journal of Infectious Diseases 2001; Suppl B:32B; Altice FL, Mostashari F, Friedland GH. *Trust and acceptance of and adherence to antiretroviral therapy*. Journal of Acquired Immune Deficiency Syndromes 2001; 28(1): 47-58; Kerr T, Marshall A, Walsh J, Palepu A, Tyndall MW, Hogg RS, Montaner J, Wood E. *Determinants of highly active antiretroviral discontinuation among injection drug users*. Canadian Journal of Infectious Diseases 2004; 15 (Suppl A): 86A (abstract 458P).

## DESIRED OUTCOMES

- All people in Canada with HIV have access to a full continuum of appropriate health services, from diagnosis to palliative care.
- All people in Canada with HIV live longer in better health.
- Treatments for HIV are more effective, with fewer side effects.
- All people in Canada have access to high-quality rehabilitation programs and services.
- All people in Canada with HIV have access to culturally appropriate support services and enjoy a better quality of life.
- All people in Canada with HIV have access to treatment information to make informed decisions about available treatments.

## TARGETS

### By 2010:

- Testing rates in communities at risk increase without compromising informed consent, counselling and confidentiality.
- The number of people with HIV diagnosed in late stages of the illness is reduced.
- Over 95% of people living with HIV report that they have appropriate, timely access to primary care and specialist services.
- Everyone living with HIV has urgent access to the appropriate antiretroviral therapy with additional support.
- The rate of adverse events associated with HAART in Canada is reduced.
- Clinical outcomes for people co-infected with HIV and hepatitis C improve.
- The average time it takes to approve a new drug or therapy in Canada drops significantly.
- All people living with HIV have access to pharmacare programs that cover the majority of their medication costs.
- The average life span of a person living with HIV diagnosed in his or her thirties is at least 60 years.
- People with HIV report fewer problems accessing affordable housing, food and other basic needs.

- All people living with HIV have access to end-of-life care that allows them to die with dignity, free of pain, surrounded by their loved ones in a setting of their choice.

## ACTIONS

- 4.1 Identify the barriers to HIV testing in communities at risk and develop culture/ gender-sensitive and age-appropriate strategies to promote voluntary confidential/ anonymous HIV testing (including pre- and post-test counselling) in each community.
- 4.2 Take steps to improve the quality and effectiveness of HIV/AIDS therapies, including:
  - speeding up the new drug review process to give people living with HIV/AIDS faster access to promising therapies
  - ensuring that all people living with HIV/AIDS have access to clinical trials, regardless of where they live or are being treated
  - implementing a national pharmacare program as recommended in the report of the Commission on the Future of Health Care in Canada<sup>91</sup>
  - providing equitable access to microbicides and vaccines when and as they are developed
  - developing and maintaining up-to-date national HIV treatment standards that will ensure greater consistency in HIV care
  - promoting and funding rehabilitation programs and services for people living with HIV
  - addressing side effects of treatment with rehabilitation programs and services.
- 4.3 Increase access to evidence-based complementary and alternative therapies by:
  - funding research on complementary and alternative therapies in the treatment of HIV
  - developing cost recovery models for people living with HIV for those treatments found to have positive impacts

<sup>91</sup> Commission on the Future of Health Care in Canada. Building on Values; The Future of Health Care in Canada. Health Canada. 2002.

- ensuring the safety of these products
- assessing any potential interactions with HIV therapies
- educating health care providers about the potential benefits of these therapies
- providing easy access to information on complementary and alternative therapies that are safe and effective.

**4.4** Develop and implement treatment programs designed to advance/improve care for people co-infected with HIV and hepatitis C.

**4.5** Develop comprehensive diagnosis, care, treatment and support programs that meet the unique needs of communities affected by HIV, including:

- ensuring that people who use injection drugs, other people in marginalized communities and prisoners have the same access to the best available HIV treatment and pain management as other people living with HIV/AIDS
- improving access to existing harm reduction measures for people living with HIV (e.g., needle exchanges, methadone programs)
- ensuring that people with HIV who inject drugs have the opportunity to maintain or begin medications (e.g., antiretroviral therapy, methadone) when incarcerated and when they make the transition back to the community
- improving services for people living with HIV who have mental health issues, including depression
- educating rehabilitation professionals on HIV and their role in diagnosis, care, treatment and support
- addressing the housing, income, employment and other social needs of people living with HIV
- addressing the psychosocial issues associated with a long-term, life-threatening illness
- ensuring people living with HIV have access to good end-of-life care, including

home care, respite care, compassionate leave, pharmacare, access to non-prescribed therapies and access to hospice palliative care professionals 24 hours a day, 7 days a week.

## Research and monitoring

**4.6** Conduct post-marketing surveillance (i.e., monitor and assess the long-term impact [benefits and risks]) of approved drugs and their potential toxicities by:

- bringing together people with HIV, drug manufacturers, clinicians and regulators to establish a system for drug safety monitoring
- developing electronic networks to support the rapid exchange of drug safety and adverse event information
- requiring pharmaceutical companies to develop plans for post-marketing surveillance as part of drug development.

**4.7** Conduct research into key urgent aspects of HIV diagnosis, care, treatment and support, including:

- strategies to ensure that all people with HIV are diagnosed and receive the best available treatment
- drug resistance and treatment strategies to reduce it
- factors that affect adherence and strategies to improve adherence
- new antiretroviral therapies and regimens
- effective treatments for people who are co-infected with HIV and hepatitis C
- complementary therapies
- organ damage
- child pediatrics
- prevalence of HIV-related impairments, activity limitations and participation restrictions
- the role of rehabilitation in improved health
- HIV vaccines and microbicides
- population-specific treatment needs (e.g., women, older people)

## 5.

## PROVIDE LEADERSHIP IN GLOBAL EFFORTS

## RATIONALE

Large parts of the world are being overwhelmed by HIV/AIDS. As noted earlier, this disease has the potential to devastate emerging and established economies and destabilize governments, and the impact will be felt worldwide.

The countries most affected are those with the fewest resources. Over 95% of HIV infections are occurring in the developing world, where factors such as poverty, stigma, gender inequality and other forms of discrimination and disempowerment are driving the epidemic. The situation is complicated by the fact that the epidemic itself exacerbates poverty, costing already poor countries people and resources. In these countries, the high rates of death from AIDS-related causes are due largely to lack of access to antiretroviral therapy and other medicines, care and treatment, the costs of which are beyond the reach of many developing countries faced with high debt burdens.

Canada has always played an active role in international aid and development. We have a moral obligation to address the inequities that exist between developed and developing nations and to contribute our knowledge and expertise to fighting the global epidemic. As a State Party to the International Covenant on Economic, Social and Cultural Rights, Canada is obliged to “take steps, individually and through international assistance and cooperation, especially economic and technical, to the maximum of its available resources, with a view to achieving ... the rights recognized in the present Covenant by all appropriate means ...”

As part of its obligations, Canada has:

- endorsed the 10-year action plan in the UNGASS Declaration of Commitment on HIV/AIDS, through which countries agreed to work together to achieve significant targets in prevention, care, treatment and support; human rights; and research and development

In the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) Declaration of Commitment on HIV/AIDS, 189 countries around the world agreed to work together to:

- secure more resources to fight HIV/AIDS
- ensure that a wide range of prevention programs are available in all countries
- ensure young people (ages 15 to 24) have access to information, education and services to reduce their vulnerability to HIV
- reduce the rate of infections in young people
- reduce the number of infants born with HIV
- strengthen anti-discrimination and human rights protections for people with HIV and vulnerable groups
- strengthen participatory programs to protect the health of those most affected by HIV
- empower women to reduce their vulnerability
- develop national strategies to strengthen health care systems and address access to HIV drugs

- endorsed the United Nations Millennium Development Goal to halt and begin to reverse the spread of HIV/AIDS by 2015
- supported the Global Fund to Fight AIDS, Tuberculosis and Malaria
- supported the WHO's and UNAIDS' 3 by 5 Initiative to help developing countries develop the systems to provide antiretroviral therapy to 3 million people with HIV/AIDS by the end of 2005
- supported global efforts to develop a preventive vaccine for HIV/AIDS, as well as microbicides
- implemented the World Trade Organization decision that permits countries to use compulsory licensing to produce and export less expensive generic drugs to countries in need

At the XV International AIDS Conference in Bangkok in 2004, UNAIDS estimated that US\$12 billion would be needed by 2005 and US\$20 billion by 2007 to fund effective prevention, care, treatment and support programs in low- and middle-income countries. In 2003, the resources available from private, national and international sources totalled only US\$4.7 billion. Funding for HIV/AIDS programming must more than double over the next two years to meet the anticipated needs in developing countries. Canada's contribution to HIV/AIDS has not kept pace with the scope of the emergency.

The Global Fund is a cost-efficient and effective mechanism to make additional resources available to fund country-led projects addressing AIDS, tuberculosis and malaria. Canada's contribution of \$US50 million per year is well below our fair share of the global cost to fight these diseases. As a high-income country, Canada should be contributing an equitable amount in proportion to our Gross National Product (GNP). According to the House of Commons Standing Committee on Foreign Affairs, the federal government should triple its contribution to the Global Fund.<sup>92</sup>

Since the mid-1980s, Canada's contribution to development assistance has fallen dramatically and now represents only 0.25% of our GNP. This falls far short of the agreed-upon target set over three decades ago and reiterated in the UNGASS Declaration of Commitment on HIV/AIDS of 0.7% of GNP; and it also falls short of Canada's commitment at the G8 Summit in Kananaskis, Alberta, in 2002 to increase its official development assistance by 8%. When Canada does increase its official development assistance for HIV/AIDS, this must be new funding as opposed to money shifted from other important development projects.

Over the past few years, Canada's aid programs have focussed on helping developing countries take the lead in setting their own priorities and in ensuring better coordination with other donors, closer working relationships with the private sector and greater coherence in policies that affect our developing country partners.

While most of the responsibility for our global efforts rests with the federal government, other organizations and individuals can and should play key roles. For example, a number of Canadian civil society organizations have come together to form the GTAG, share information and develop joint efforts to influence Canada's international contribution. At a 2003 summit (*Global Health is a Human Right*) sponsored by GTAG, a wide range of Canadian organizations came together to develop a common platform that proposes concrete actions organizations can advocate for on human rights; gender and health; public health systems; access to medicines; trade and investment; financial policies; research; and corporate social responsibility.<sup>93</sup>

At the individual level, Canadians are working in developing countries around the world, helping them increase their capacity to fight the epidemic, provide care, evaluate programs and monitor the spread of disease.

It is important to build links between our global and domestic responses. Canada's researchers, policy makers, community activists and others have much to contribute to – and much to learn from – international experience.

## DESIRED OUTCOMES

- Canadians are aware of the seriousness of the global HIV/AIDS epidemic and support Canadian efforts to help.
- Canada is a recognized leader in global efforts to stop HIV/AIDS.
- Canada fulfils its international commitments and is more effectively engaged in the global response.
- Canada pursues a consistent, cohesive policy in all its international relationships, which reflects the social justice, human rights and gender equality values that drive this document.

## TARGETS

### By 2010:

- Over 90% of Canadians are aware of the global HIV/AIDS epidemic and its impact.
- Over 90% of Canadians believe that Canada should provide sustained, ongoing financial support to fight HIV/AIDS beyond our borders.

<sup>92</sup> House of Commons Standing Committee on Foreign Affairs. *HIV/AIDS and the Humanitarian Catastrophe in Sub-Saharan Africa*. Canada, 2003.

<sup>93</sup> Global Treatment Access Group. *Global Health is a Human Right! A Civil Society Common Platform for Action on HIV/AIDS and Global Health*. May 2003.

Canada is providing strategic leadership internationally by:

- chairing the governing body of the UNAIDS from 2004 to 2005
- assuming a seat on the board of the Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria
- making a major contribution to the WHO's and UNAIDS' 3 by 5 Initiative
- hosting the XVI International AIDS conference in Toronto in 2006

- Canada makes an equitable contribution to the Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria, in proportion to its share of the global economy, as measured by GNP.
- Canada further increases its contribution to the 3 by 5 Initiative to increase access to antiretroviral treatments.
- Canada's contribution to development assistance increases from 0.25% to 0.7% of GNP.
- Official development assistance for HIV/AIDS is increased significantly and represents new funding, rather than being taken from existing development budgets and projects.
- All new and renewed international trade and investment agreements support HIV prevention, care and treatment.
- The Government of Canada has developed a single, cohesive strategy/plan to respond to the global epidemic.
- Canada makes a strategic and relevant contribution to global HIV/AIDS policy, within both multilateral fora and bilateral dialogues.
- Canada makes an increased, strategic contribution to support global efforts to eliminate HIV/AIDS-related discrimination and to respect, protect and fulfil human rights in the context of HIV/AIDS.
- Canada is at the forefront of global efforts to promote gender equality and sexual and reproductive health rights.
- Canada makes an increased, strategic contribution to global research efforts to develop treatments, technologies, vaccines, microbicides and prevention strategies.

- Canada increases its research capacity to undertake culturally appropriate research to strengthen prevention and care in developing countries.

## ACTIONS

### Awareness

**5.1** Increase and maintain public awareness of the global HIV epidemic and Canada's responsibility to respond by developing a long-term communications strategy that:

- communicates tested and consistent messages about the global epidemic
- makes more effective use of World AIDS Day activities to draw attention to the global epidemic
- uses mass media campaigns and press releases to sustain public interest throughout the year
- engages high-profile Canadians to champion global efforts
- engages local, provincial, territorial and national leaders/spokespeople, including youth leaders, union representatives and representatives of faith-based organizations, and ensures that they have the support/resources to fulfil their role
- actively promotes the XVI International AIDS Conference in Toronto in 2006.

### International commitments

**5.2** Fulfil Canada's international commitments by:

- making an equitable contribution to the Global Fund to Fight AIDS, Tuberculosis and Malaria in proportion to our share of the global economy, as measured by GNP
- working toward an official development assistance target of 0.7% of GNP as soon as possible
- further increasing our contribution to the 3 by 5 Initiative to increase access to antiretroviral treatments
- involving the private sector and civil society more broadly in the global response
- supporting, strengthening and empowering organizations/networks working in developing countries to address the HIV epidemic

- reporting on our international commitments.

**5.3** Establish coherent, consistent policies among federal departments and agencies – including but not limited to Health Canada, Foreign Affairs Canada, International Trade Canada, Industry Canada, Citizenship and Immigration Canada, Justice Canada, National Defence, Correctional Service Canada, Canadian Institutes of Health Research, Canadian International Development Agency and the Public Health Agency of Canada – that reflect the social justice values of *Leading Together*, and develop a single Government of Canada plan to respond to the global epidemic.

**5.4** Make strategic use of Canadian expertise in global efforts to respond to the epidemic, guided by the priorities of the countries we are trying to help.

**5.5** Support efforts to ensure the sustainability of the global response to HIV/AIDS.

#### Human rights

**5.6** Integrate human rights, including the right to the highest attainable standard of physical and mental health and the human rights of women, into Canada's international relationships by:

- strengthening and enforcing human rights agreements
- supporting the work of the UN Special Rapporteur on the right to health and the follow-up work stemming from it, along with other mechanisms that contribute to realizing the right to health, the International Labour Organization standards on workers and health, and the International Guidelines on HIV/AIDS and Human Rights, and other international guidelines on health and human rights
- supporting global efforts to eliminate HIV/AIDS-related discrimination and to respect, protect and fulfil the human rights of people living with HIV/AIDS and of individuals and groups vulnerable to discrimination and marginalization
- supporting global efforts to reduce gender-based discrimination and promote gender equality

- supporting efforts to promote and protect sexual and reproductive health and rights and to effectively integrate such efforts with HIV/AIDS

- supporting HIV prevention options that can be controlled by women (e.g., microbicides)

- considering implications for access to HIV prevention, care and treatment when renewing existing and/or developing new trade and investment agreements

- complying with international guidelines for conducting health research

- ensuring that Canadian companies and organizations operating abroad have policies on HIV/AIDS in the workplace that meet or exceed the standard of the International Labour Organization.

#### Research and expertise

**5.7** Participate in global research efforts to develop HIV/AIDS treatments, technologies, vaccines, microbicides and prevention strategies and to identify effective ways to provide care within existing health systems.

## 6.

### ENHANCE THE FRONT-LINE CAPACITY TO ACT EARLY AND STAY THE COURSE

#### RATIONALE

*Leading Together* is an ambitious plan. To meet our targets and achieve our goals, Canada must have the people, knowledge, skills, resources and structures to raise awareness; address the social factors driving the epidemic; step up prevention efforts; strengthen diagnosis, care, treatment and support; and provide global leadership. We must have the front-line capacity to act early – to respond quickly to urgent needs and to stay the course – in order to develop long-term sustainable programs that will stop the epidemic.

Canada already has an extensive network of dedicated people and organizations involved in advocacy, policy development, prevention, care, treatment, support and research. Over the next five years, we will be strategic in our efforts to enhance these front-line services. Our

goal is to build and support a service system that can respond quickly to the changing and emerging needs of people living with HIV/AIDS and communities at risk, at home and globally. We must continually reassess our programs and structures to ensure that they are meeting needs and making effective use of knowledge and skills. For example, are the needs of people living with HIV/AIDS best met by HIV-specific programs or by more integrated programs that address a range of needs, such as HIV and hepatitis C or HIV and substance abuse problems? Are there more effective ways to plan and fund community-based programs? Are there better models for developing, sharing and integrating knowledge, coordinating services and responding to emerging issues?

#### INNOVATIVE FUNDING MODELS SUPPORT FRONT-LINE SERVICES

In Alberta, governments that fund community-based AIDS services have come together to develop the Alberta Community HIV Fund (ACHF). A collaborative initiative of the Alberta Community Council on HIV (local government), Alberta Health and Wellness (provincial government) and the Public Health Agency of Canada (federal government), the ACHF works with PHAs and the HIV community to identify the programs they need and gives community organizations one-window access to a total of \$3,012,687 in funding each year.

The ACHF has simplified the process agencies must go through to apply for funding. It also provides longer-term (three-year) operational funding for programs and staff. This funding model demonstrates the governments' shared long-term commitment to help HIV prevention, care and support "stay the course." Organizations can also apply to ACHF for time-limited funding to help them "act early" to address unmet and emerging needs and priorities. In 2004-2005, 16 AIDS service organizations received three-year operational funding.

In larger communities that have a significant population of people who inject drugs, for example, HIV-related services for people who inject drugs may be more effective when integrated with other harm reduction and treatment services, including outreach services,

needle and syringe exchange programs, methadone maintenance therapy, addiction treatment services, hepatitis C treatment, case management, primary care and housing services. There is also a growing trend toward providing medical services for populations affected by HIV (e.g., gay men, Aboriginal people, people from countries where HIV is endemic) in a setting that can also provide cultural support, client advocacy, counselling, prevention and social support services (i.e., one-stop shopping for clients), particularly in larger centres that have a critical mass of people in a given population or community affected by HIV.

We must also provide the support and knowledge that front-line organizations need to strengthen their services, develop innovative models of care and support and develop linkages that will help meet the needs of people with HIV and communities at risk. This document focuses primarily on the following front-line services: peer-led initiatives, community-based AIDS organizations, health professionals, researchers and non-HIV-specific front-line services.

#### Peer-led initiatives

From the beginning of the epidemic, people living with and vulnerable to HIV have played a vital role in establishing community-based programs and services, shaping provincial, territorial and federal policies and advocating for research and treatments. The International Guidelines on HIV and Human Rights established by UNAIDS and the Office of the United Nations High Commissioner for Human Rights ask all countries to "ensure through political and financial support that community consultation occurs in all phases of HIV/AIDS policy, design, program implementation and evaluation." This guideline is consistent with the federal government's policy on citizen engagement. It is also consistent with many provincial, territorial and local policies and practices.

While gay men have a long history of organizing to provide both social support and political leadership, the same is not true of all other communities at risk of HIV – although some recent efforts by drugs users to organize and advocate for harm reduction measures, such as needle exchange programs and a safe

injection site, have been very successful (a number of studies show that peer-led or assisted interventions are more effective than health care provider interventions in populations of people who inject drugs).<sup>94</sup>

More must be done to give people living with HIV/AIDS a strong voice in the programs and services that affect their lives. At the same time, the system must be careful not to expect more of people living with HIV/AIDS than it does of people with other life-threatening illnesses. It must also provide accommodations that take into account HIV-related disability and the side effects of medications.

### Community-based AIDS organizations

*“Non-governmental organizations are often thought to be more flexible and responsive to changing conditions, and thus more able to act quickly. Yet governments routinely impose on these agencies the same requirements, and sometimes methods, that make their own line operations less effective. More troubling is that government sometimes imposes accountability standards that it will not apply to itself. The result is often a non-government agency that is less effective than it could be. ...*

*If we believe that a non-governmental agency ... offers substantial advantage over direct government operations, we must resist the tendency to impose restrictions that remove that advantage.”<sup>95</sup>*

Since the first days of the epidemic, community-based AIDS organizations have been leaders in advocacy, policy development, community development, empowerment and service. They play a key role in our collective response to HIV. Over the past 20 years, most organizations have seen the number of people they serve increase significantly – thanks to HAART, more people are living longer with HIV in Canada than ever before – and their needs become more complex. However, funding has not kept pace; most organizations now operate with fewer resources than they had in the early 1990s. As a result, community-based AIDS organizations face a number of urgent pressures, including:

- **the need to work with other services and agencies**, such as mental health services, addiction treatment and harm reduction services, housing programs, income programs, food banks, legal services and others, to help clients meet their basic needs and address social justice and human rights issues.
- **greater dependence on short-term project funding and fund-raised dollars**, which limits the ability of organizations to provide long-term, sustainable services. For example, community-based AIDS organizations in Ontario report that about 55% of their funding is now from sources that are not stable or secure.<sup>96</sup> The situation is compounded by the lack of funding for other health and social services required by people with HIV/AIDS and communities at risk, such as social assistance, mental health services, addiction treatment, methadone services and vocational counselling. According to a recent report from the Canadian Council on Social Development<sup>97</sup>, “[t]he capacity of the nonprofit and voluntary sector to fulfil its important role in Canadian society is being undermined and eroded by new funding strategies,” including a marked shift away from a core funding model, an unwillingness to fund administrative costs, shorter and more unpredictable funding periods and increased reporting requirements. As a result of the change in funding, “much organizational time is now devoted to chasing short-term sources of funding, often at the expense of the organizations’ mission and core activities.” Most HIV organizations have seen a drop in fund-raised dollars due to donor fatigue and more competition.
- **cutbacks in services**. In a survey of AIDS service organizations in Ontario, at least 50% reported that they have either cut back or eliminated some services, including prevention programming, education programming, “buddy” programs, employment services, transportation services, food banks and financial support/services. A significant proportion (25% to 50%) also reported cutbacks in counselling programs,

<sup>94</sup> Grund JP, Blanken P, Adriaans NF, Kaplan CD, Barendregt C, Meeuwse M. *Reaching the unreached: targeting hidden IDU populations with clean needles via known user groups*. J Psychoactive Drugs. vol 24 no 1 Pp.41-7. 1992.

<sup>95</sup> Skirrow J. *Lessons from Krever? A Personal Perspective*. Canadian HIV/AIDS Policy & Law Newsletter 1999; Vol. 4, No 2/3. Available via [www.aidslaw.ca](http://www.aidslaw.ca).

<sup>96</sup> Ontario AIDS Network. *Stemming the Tide: The Case for More Investment in Community-based HIV/AIDS Prevention and Support Services*. January 2004.

<sup>97</sup> Scott K. *Funding Matters: The Impact of Canada's New Funding Regime on Nonprofit and Voluntary Organizations. Summary Report*. Canadian Council on Social Development in collaboration with the Coalition of National Voluntary Organizations. 2003.

community development, community awareness, community outreach, special events, the production/provision of safer sex materials and other resources, and emergency services. All organizations reported that they are no longer able to adequately meet client needs in any of their key roles.<sup>98</sup>

- **high levels of staff burnout and turnover**, due to low salary levels compared to other health and social service agencies, limited opportunities for advancement, increasingly complex client needs, the uncertainty associated with working on short-term contracts, lack of benefits and organizational instability. High staff turnover rates result in lack of continuity of care, lower-quality services, higher recruitment and training costs, and fewer resources for front-line services.
- **problems recruiting volunteers**, due in part to competition with other health and social service organizations for a diminishing pool of volunteers, as well as the public perception that HIV is not as important an issue as it once was. Some organizations are also having difficulty matching volunteers to tasks for clients who have increasing and ongoing needs.
- **an increase in administrative workloads** to account to funders for the effective use of funds.
- **less ability to advocate** for clients and for systemic change because of the challenges in developing advocacy skills, the lack of funding for advocacy efforts, and concern that funders may not renew short-term funding if organizations advocate.
- **the need for faster access to information, research findings and skills** that can be used to enhance programs and services.

To enhance our HIV prevention and support programs, these issues must be addressed.

### Health professionals

Canada has a shortage of health professionals willing to work with people with HIV. Most HIV care is provided by a small number of infectious disease specialists and some primary care physicians, many of whom are

located in large urban centres. We also lack health professionals who can provide culturally appropriate and linguistically accessible services for some communities, such as Aboriginal people or people from countries where HIV is endemic.

The lack of health professionals in this field is exacerbated by the overall shortage of physicians and nurses (Romanow 2002) and by the fact that a significant proportion of those who have been providing care since the beginning of the epidemic are now nearing retirement age.

Because of the complexity of HIV care, it is difficult for professionals who see only a small number of clients to remain current. This situation is particularly troublesome for professionals working in smaller communities, where they do not have easy access to specialists who can provide information and advice.

To enhance our front-line capacity to provide HIV care and treatment, we must address the issues that keep health professionals from this field, including:

- discomfort working with the marginalized populations most affected by HIV
- lack of education in HIV care
- lack of confidence in their ability to manage the complex care that people with HIV/AIDS need
- lack of access to expert advice and support
- reimbursement systems that do not acknowledge the time required to provide complex HIV care

### Researchers

As part of the UNGASS Declaration of Commitment on HIV/AIDS, Canada agreed to:

- increase and accelerate research on HIV vaccines and increase research to improve prevention, care, treatment, women-controlled methods of prevention, microbicides and the means to prevent mother-to-child transmission

<sup>98</sup> Ontario AIDS Network. *Stemming the Tide: The Case for More Investment in Community-based HIV/AIDS Prevention and Support Services*. January 2004.

- develop approaches to monitoring treatment efficacy, toxicity, side effects, drug interactions, resistance and the impact of treatment on HIV transmission and risky behaviour
- strengthen the process of cooperation and transferring research findings and best practices to those who can use them

Over the past 20 years, Canada has developed a group of highly skilled researchers who have made major contributions to global efforts to understand and stop HIV with a relatively small research investment. Canadian research contributions include the discovery of 3TC; the creation of the Canadian HIV Trials Network and its work, including establishing the efficacy of protease inhibitors in antiretroviral combinations; the generation of knowledge of HIV immunology among sex workers in Africa; major work on drug resistance; contributions to international vaccine research; studies to identify the behavioural factors that contribute to the spread of HIV in different populations; and research on harm reduction initiatives for people who use injection drugs. Canadian researchers are actively involved in basic, clinical, epidemiological and psychosocial/behavioural research in HIV, and in surveillance, monitoring and evaluation. Canada has also established a strong foundation in community-based research, which directly involves people living with HIV and community-based organizations in identifying research questions, conducting research and using research findings to improve services. Through the Canadian Association for HIV Research, Canadian HIV researchers work together to organize and coordinate their research efforts.

To enhance our research capacity, we must address a number of challenges, including:

- **Canada's role in global research efforts.** As only one partner in international HIV research efforts, Canada must identify specific roles that will make the best use of our research skills/resources and avoid duplication.

- **the urgent need to attract new researchers to HIV.** Canada must continue to develop, mentor and support HIV researchers.
- **the need for support for community-based research.** This field is in its infancy and needs time and resources to achieve its potential.
- **the lack of funding for HIV research.** Currently, Canada lags behind many other countries in its spending on HIV-related research. For example, while Canada spends about \$1.3 million annually on vaccine research, the United States allocates US\$400 million (approximately C\$485 million) and France €8 million (approximately C\$12.7 million).<sup>99, 100</sup>
- **the gap between research and practice.** Research findings must be used more effectively to improve programs and services.
- **the pressing need to develop safer, more effective treatments,** and the challenge posed by the collision of two major epidemics: HIV and hepatitis C (see section 4).
- **sustainability challenges.** Researchers burn out or otherwise leave the field. More support and security is needed for this demanding work.

#### **Other agencies that share responsibility for serving people with HIV**

The front line is not limited to HIV-specific services. People living with HIV/AIDS and communities at risk use many other health and social services, including mental health services, addiction and harm reduction services, housing programs, food banks, shelters, women's programs, youth services, settlement services, legal services, home care services, palliative care programs, rehabilitation programs and services and others. To enhance the ability of these agencies to share responsibility for meeting the needs of people living with HIV/AIDS and communities at risk, and to create a true system of services, we must address the following issues:

<sup>99</sup> Standing Committee on Health, Strengthening the Canadian Strategy on HIV/AIDS. Canada. 2003.

<sup>100</sup> Canadian dollar amounts estimated as of January 2005.

- the need for non-HIV-specific agencies to have better information about HIV and the needs of individuals and communities affected
- any discomfort these agencies may feel in working with people and communities affected by HIV
- the need for these agencies to receive appropriate levels of funding to fulfil shared roles

### DESIRED OUTCOMES

- All organizations and individuals serving people with HIV/AIDS and communities at risk have the skills, knowledge, resources and capacity to respond to changing and emerging needs.
- People living with HIV/AIDS and communities at risk have a stronger voice in the programs and services that affect their lives and are leaders in Canada's response to HIV/AIDS.
- Community-based AIDS organizations are leaders in developing innovative models of service that address the root causes of HIV infection and other illnesses, in identifying PHA needs from diagnosis to end of life and in developing services to meet those needs.
- The capacity of community-based AIDS organizations to address social justice and human rights issues and to undertake both individual and systemic advocacy has increased significantly.
- Canada has an adequate number of health professionals who are knowledgeable about HIV and willing to provide care.
- Canadian researchers continue to make significant and measurable contributions to the world's knowledge of HIV and to efforts to treat and stop the disease.
- Other agencies that provide services for people with HIV/AIDS and communities at risk have the knowledge and skills to be part of an effective service system.

### TARGETS

#### By 2010:

#### Peer-led initiatives

- Effective, adequately resourced peer-led organizations are in place locally, provincially/territorially and nationally.
- All organizations funded to provide HIV-related services have policies to ensure the meaningful participation of people with HIV/AIDS and communities at risk.
- People living with HIV/AIDS are represented on all groups that advise governments and non-governmental organizations and that plan and deliver HIV programs and services.
- People living with HIV/AIDS and members of communities at risk play a lead role in designing and delivering their services.

#### Community-based AIDS organizations

- Community-based AIDS organizations have the knowledge, skills, resources and capacity to respond to the complex health and social needs of people living with HIV/AIDS and of communities at risk.
- Community-based AIDS organizations are leaders in addressing social justice and legal, ethical and human rights issues and in developing working relationships with other health and social services that reflect their shared responsibility for the health and well-being of people living with HIV/AIDS and of populations at risk.
- Community-based AIDS organizations are able to attract and retain highly skilled and highly motivated staff.
- Community-based AIDS organizations and peer-led organizations across Canada have the resources they need to advocate on behalf of individuals and for systemic changes that will benefit populations at risk.

### Health professionals

- The number of health professionals providing care for people with HIV/AIDS increases.
- The proportion of health professionals who receive education about HIV as part of their initial and continuing training increases.
- Primary care providers have easy access to support and advice from specialists.

### Researchers

- Canada has a comprehensive, targeted HIV research plan.
- New researchers are attracted to, and remain in, the field and make measurable contributions.
- Canada increases its contribution to global efforts to improve HIV/AIDS treatments and develop microbicides and HIV vaccines.
- Research findings have a direct and measurable impact on practice.
- Canada provides a dynamic and supportive environment for HIV researchers across all disciplines.

### Other service providers

- Staff working in other agencies report greater understanding of the issues facing people living with HIV/AIDS and populations at risk.
- Staff working in other agencies report greater comfort and confidence in providing services to people living with HIV and populations at risk.
- People living with HIV report greater satisfaction with the services they receive from other agencies.

## ACTIONS

### General

- 6.1** Develop funding models that will enhance the front-line capacity to act early and stay the course by decreasing reliance on short-term project funding and enabling longer-term planning and action.

- 6.2** Involve people with HIV/AIDS and communities at risk in identifying priorities, planning and delivering of all HIV programs and services (e.g., diagnosis, care, treatment, support, research) and in advising governments and other decision makers.

- 6.3** Provide both volunteer and employment opportunities for people living with HIV and members of populations at risk.

### Peer-led initiatives

- 6.4** Provide support to self-governing organizations and advocacy groups for people living with HIV/AIDS across Canada.

- 6.5** Provide support to self-governing organizations and advocacy groups for communities at risk.

- 6.6** Provide capacity-building programs to help people living with HIV/AIDS and communities at risk develop the skills to play a lead role in planning, delivering and evaluating HIV-related research and services.

### Community-based AIDS organizations

- 6.7** Increase the capacity of community-based AIDS organizations and peer-led organizations to address social justice and human rights issues and to advocate for individuals and communities.

- 6.8** Develop effective working relationships among AIDS organizations and other agencies that share responsibility for serving people with HIV/AIDS and populations at risk.

- 6.9** Implement and evaluate innovative organizational models that have the potential to meet the complex health and social needs of communities at risk and people living with HIV/AIDS from diagnosis to end of life.

- 6.10** Implement strategies to attract, train and retain skilled staff and volunteers.

## Health professionals

- 6.11 Ensure that all health and social service professionals receive some education about HIV and its management during their training and have access to continuing education in HIV treatment.
- 6.12 Develop education, support, mentorship and other programs to overcome the barriers to attracting and retaining the appropriate number/mix of health professionals in HIV diagnosis, care, treatment and support.
- 6.13 Explore the potential to use technology to link primary care providers, particularly those in small communities, with infectious disease specialists.
- 6.14 Develop shared-care models that will explore the potential for a team approach (e.g., nurse practitioners, primary care physicians, specialists, physiotherapists, occupational therapists, speech/language pathologists, vocational counsellors, counsellors, nutritionists, community-based services) to meet complex client needs and reduce the pressure on sole practitioners.

## Research

- 6.15 Develop an HIV research action plan for Canada that will:
  - identify Canada's strategic research priorities to 2010, based on the needs of people living with HIV/AIDS and communities at risk
  - define, based on our comparative research strengths, how we will fulfil our UNGASS commitments and strategically increase Canada's contribution to international research efforts to develop new treatments, HIV vaccines and microbicides
  - encourage collaboration among researchers to achieve common goals
  - identify strategies to attract and mentor young researchers
  - identify strategies to ensure that research findings are shared and that new knowledge is incorporated into practice

- enhance our capacity to evaluate interventions in terms of their effectiveness in increasing the health and well-being of people living with HIV or in stemming the epidemic
- provide funding at levels that will optimize output
- maintain researchers in Canada and working in the field.

## Other agencies

- 6.16 Provide the education and support non-HIV-specific agencies/service providers need to fulfil their role.
- 6.17 Develop models of care that make effective use of the knowledge, skills and resources of other agencies/service providers.

“For there to be any hope of success in the fight against HIV/AIDS, the world must join together in a great global alliance.”

Kofi Annan, Declaration of Commitment on HIV/AIDS, UNGASS, June 2001

## VI

# conclusion

In June 2001, the United Nations challenged all countries around the world to work together to fight HIV. Canada is one of over 100 countries who adopted the UNGASS Declaration of Commitment on HIV/AIDS. As part of that commitment, we promised to strengthen our HIV programs at home and to contribute to worldwide efforts to combat HIV.

*Leading Together* is a key step in fulfilling that promise. It describes a bold vision of where we want to be as a nation in the fight against HIV for the next five years. It sets out a hopeful, comprehensive approach to HIV, one that focuses on the underlying health and social issues that put people at risk of HIV and other health problems. It challenges all those in Canada involved in HIV to work together to develop a more effective, coordinated response that will stop the virus and save lives.

*Leading together, we can make the third decade of HIV/AIDS the last decade.*