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**Canada's In-Country
Monitoring and Evaluation Report on the
Implementation of the
UNGASS Declaration of Commitment**

**A project of the
International Council of AIDS Service Organizations
(ICASO)**

**Produced by San Patten, M.Sc.
for AIDS Calgary Awareness Association**

This report is dedicated to Bob Mills
(January 30, 1958 - October 8, 2003)

Bob, a friend, mentor, and advocate to many across Canada, was nominated by the Canadian AIDS Society and chosen by Minister of Health, Honourable Allan Rock as one of two Canadian Civil Society Representatives assigned to the 2001 Canadian Delegation of the United Nations General Assembly Special Session (UNGASS) on HIV/AIDS. Bob sat front and centre at the 'Canada' table in the meetings at the United Nations in New York in June, 2001. Born in Winnipeg, Bob spent 30 years of his life in Edmonton. Bob was diagnosed with HIV in 1989 and lived with AIDS since 1993. He overcame multiple opportunistic infections, along with multiple losses amongst his family and friends. Despite his illness, Bob remained a strong, committed and energized HIV community advocate and activist. For many Canadians, the UNGASS Declaration is brought to life by the image of Bob participating in the UNGASS meetings, and his tireless dedication to domestic and global HIV issues until his last days. One of Bob's final projects was to work with community-based organizations in Alberta to create a document called "Simply Using the UNGASS Declaration of Commitment on HIV/AIDS."

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SECTION 1: EXECUTIVE SUMMARY

Canada's Demographics and Economic Indicators: Although Canada has the smallest population of all G8 nations (32.3 million), it had the second highest rate of population growth among the G8 countries over the last decade, largely due to immigration. Between 2004-05, Canada received approximately 250,000 immigrants. Canada is also one of the leaders in terms of economic expansion, employment and the education level of its workers. Despite Canada's size, it had the third highest gross domestic product per capita in 2004 and the lowest employment rate difference between men and women. However, Canadian society is becoming increasingly polarized between the rich and poor and its economic progress has not put any real dent in child poverty rates. Canada's Aboriginal people are hardest hit by poverty; those living in urban areas are twice as likely to live in poverty as non-Aboriginal people.

Canada's HIV Epidemic: Just under 58,000 HIV diagnoses have been reported to the end of 2004 in Canada, with women comprising over one-quarter of new diagnoses. In terms of exposure category, 45% of new HIV infections in Canada were attributed to men who have sex with men, 30% to heterosexual contact, and 25% to injection drug use. HIV cases in prisons have risen by 18 times since 1989. The provinces with the largest number of HIV prevalent cases are Ontario, Québec and British Columbia.

Canada has a complicated HIV epidemic, comprised mostly of isolated epidemics amongst vulnerable populations such as IDUs, Aboriginal people, MSM, and people from countries where HIV is endemic. The vulnerable populations most severely affected by HIV/AIDS are those which are most adversely affected with respect to the determinants of health (e.g., poverty, poor housing, low education, etc.). There are also distinct differences in access to services (such as harm reduction, research, diagnosis, prevention, care, treatment and support services), with people living in rural areas and in prisons having lower access and more social isolation.

Each of these vulnerable populations requires different strategies from prevention to care, creating a great deal of complexity within HIV/AIDS programming, policy development and service provision. Although AIDS cases are declining in Canada due to the use of antiretroviral therapies, the number of new HIV cases has increased by 20% in the last five years, and Canada must not become complacent.

Canada's Health Care System: Health care is a provincial jurisdiction in Canada but the Canada Health Act mandates that all Canadians have the right to access essential health care services. Although there is officially universal access to health care in Canada, people living with HIV or vulnerable to HIV still experience barriers to accessing health care services and realizing the right to health.

Human Rights and HIV in Canada: There remains in Canada significant legal and policy barriers that adversely affect people at risk of or living with HIV/AIDS, creating and exacerbating situations of stigma and discrimination, leading to covert behaviours, risk of violence and HIV infection. Legal and policy sanctions against drug use, sex work, and needle exchange in prisons create situations in which people become more vulnerable to HIV transmission. As of 2005, no Canadian prison system had yet started a needle exchange program. Other policy issues are problematic from human rights perspectives, such denial of immigration for people living with HIV, opt-out HIV testing policies for pregnant women and mandatory collection of blood for recipients of emergency services.

The Canadian HIV/AIDS Action Plan and Strategy: Canada's HIV/AIDS strategy is not overseen by any one government council or body, but is monitored by several groups: the Ministerial Council on HIV/AIDS, the Federal/Provincial/Territorial Advisory Committee on AIDS, the National

Aboriginal Council on HIV/AIDS, and the Interdepartmental Roundtable of Assistant Deputy Ministers. Canada's HIV/AIDS Action Plan is defined by two documents: the *Federal Initiative to Address HIV/AIDS in Canada: Strengthening Federal Action in the Canadian Response to HIV/AIDS* and *Leading Together: An HIV/AIDS Action Plan for All Canada (2004 – 2008)*. The *Federal Initiative* provides funding to four government departments to implement HIV/AIDS programming: Public Health Agency of Canada, Health Canada, the Canadian Institutes of Health Research and Correctional Service Canada. *Leading Together* was developed by a broad cross-section of organizations and individuals involved in the Canadian response. Canada needs a broad pan-Canadian approach with mutual influence amongst all stakeholders, government departments, and government levels. *Leading Together: An HIV/AIDS Action Plan for All Canada (2004 – 2008)*, is a guiding document that attempts to define actions needed by all stakeholders and levels of government, however, no one body has the responsibility for overseeing and coordinating the entire action plan.

In 2004, the Government of Canada announced that ongoing federal HIV/AIDS funding would increase from \$42.4 million to \$84.4 million. However, it remains unclear how much of this funding will actually end up in the hands of civil society, as opposed to operations and management budgets of the four government departments administering the Federal Initiative funds. Also, the specific allocation of funds for grants and contributions is completely opaque. A significant concern in particular has been the lack of clarity with respect to grants for the national NGOs.

Access to Treatment: The current standard of HIV treatment includes the use of a combination of at least 3 different anti-HIV medications from at least two different classes. Currently there are two major classes of anti-HIV medications available in Canada: reverse transcriptase inhibitors or RT inhibitors (RTIs) and protease inhibitors (PIs). In general, anti-HIV medications are recommended if a person living with HIV has: a T-cell count less than 350, or a viral load greater than 55,000, or any symptoms of HIV disease. Drug coverage formularies through public drug reimbursement plans vary by province as health care is a provincial jurisdiction. There are also 19 federal drug formularies that operate outside of provincial health formularies (e.g., for Veterans, on-reserve Aboriginals or refugees). However, there are significant inconsistencies in access to treatment based on geography and sub-populations through marginalization of certain vulnerable groups. People living with HIV/AIDS in Canada do not always have the information that they need to understand their ARV therapies and their side effects.

Access to Prevention: In theory, all HIV prevention tools (e.g., male and female condoms, lubricants, clean needles, methadone substitution therapy) are available and accessible across Canada, except in prisons where institutional policies prohibit access to clean needles and in some cases condoms. In practice, even outside of prisons, most vulnerable populations (e.g., youth, Aboriginal communities, small rural communities, refugees, trafficked women) have very spotty access to these prevention tools. Prevention initiatives are largely led by community organizations working directly with the vulnerable populations. Most prevention messages in Canada have targeted MSM and gay men, injection drug users and youth, although there are some worrisome findings about the level of knowledge and risk behaviours amongst Canada's youth. Canada is the first country in the world to develop a multi-sector microbicides plan outlining domestic and global contributions, and could serve as a model in the field. A group of government, community and research stakeholders are also working to develop a Canadian HIV Vaccines Plan.

Voluntary Counseling and Testing: Canadians choosing to be tested for the presence of HIV infection may have three different testing options, depending on the province or territory in which testing takes place: Nominal, Non-Nominal, or Anonymous.

Empowerment of Women: *Blueprint for Action on Women and HIV in Canada: Towards 2006* was created by civil society to bring together individuals and organizations addressing the needs of women living with, and affected by, HIV/AIDS in Canada to act as a united voice on policy issues. The coalition will seek to advocate on these issues and influence national, provincial and municipal governments to provide services and funding programs aimed specifically at services for women living with HIV/AIDS and women affected and vulnerable to HIV/AIDS. There have been no specific educational programs initiated by the Government or its partners, focusing on building the capacity of women to reduce HIV transmission.

Human Rights of People Living with HIV: Under the Canadian Human Rights Act people living with HIV/AIDS are protected from HIV-based discrimination in federal jurisdictions because HIV is considered a disability in the context of anti-discrimination law with respect to any employment, goods, services, facilities or accommodation or access thereto or occupancy of any commercial premises or residential accommodation. In all jurisdictions – federal, provincial and territorial – discrimination on the following grounds is prohibited by the jurisdiction’s human rights statute: age, race, ethnicity, colour, religion, sex (including pregnancy), marital status, disability (or “handicap” in some statutes), sexual orientation, and place of origin. While the law in each province and territory prohibits discrimination based on a person’s HIV/AIDS status, there is no explicit reference to HIV/AIDS in the various anti-discrimination statutes. Rather, they refer to “disability” or “handicap.” One issue that is a significant focus in Canada is that people living with HIV face numerous barriers with respect to remaining in employment or returning to employment after taking disability or sick leave. There are many issues faced by people living with episodic disabilities, such as HIV, in Canada. The unpredictability of living with HIV, as with other episodic disabilities, can have a significant impact on income support.

Monitoring and Evaluation: A monitoring plan has not yet been established for Canada’s Action Plan. The *Federal Initiative* states that coordination, planning, evaluation and reporting will be enhanced to optimize both the federal and pan-Canadian responses to the epidemic and the use of resources. The success of *Leading Together* depends on a voluntary nation-wide partnership, the responsibility for steering and monitoring it is to be shared among all the partners.

It should be noted that this report on Canada’s fulfillment of the UNGASS Declaration of Commitment addresses only Canada’s domestic commitments and thus does not reflect Canada’s contributions to global efforts against HIV/AIDS.

SECTION 2: BASELINE STATISTICS

1. Canada's Demographics and Economic Indicators

CANADA'S DEMOGRAPHICS

Canada had the second highest rate of population growth among the G8 countries between 1994 and 2004¹. During that period, the Canadian population grew at a rate approaching 1%, while the rate for the United States was 1.1%. What distinguishes Canada the most was the size of its gains in migratory exchanges. At 0.61%, the Canadian net international migration rate was the highest of any G8 country from 1994 to 2004. Between July 1st 2004 and July 1st 2005, Canada received 244,600 immigrants, 5,500 more than in the previous year. More than half of them (53.2%) chose Ontario as their initial province of residence, but there is significant mobility across Canada.

CANADA'S ECONOMY²

Canada has the smallest population of all G8 nations, but it is one of the leaders in terms of economic expansion, employment and the education level of its workers. Although Canada has managed to control rising labour costs over the past decade and add to its competitive edge, its gains in labour productivity have been substantially below those of France, Japan and the United States.

Despite Canada's size, it had the third highest gross domestic product per capita in 2004, about US \$31,000, third only to the United Kingdom and the United States. Canada led the G8 nations in economic growth between 2000 and 2004, as its output increased at an annual average rate of 3.1%. In contrast, during the early 1990s, it had one of the lowest rates of economic expansion. Canada has also fared well in terms of employment rate growth among the working-age population as well as in the educational attainment of this group.

By 2003, Canada had the third highest employment rate (73.3%) for the core working-age population 25 to 64. It followed only the United Kingdom and Japan. In 1976, Canada was in sixth place. In 2003, the employment rate difference between the sexes, was only 9.7 percentage points, the smallest amongst G8 nations, due to the fact that Canadian women had the highest employment rate of all G8 countries.

Export trade plays a key role in Canada's economy, accounting for one-third of GDP. All G8 members experienced gains in their external trade since 1990. But Canada's export trade more than tripled during the past decade, the biggest increase among all the nations.

Canada's Demographic and Economic Indicators	
Population of Canada ³	32,270,507
Consumer Price Index ⁴ (September 2005)	3.4%
Unemployment rate (October 2005)	6.6%
Gross Domestic Product (2003)	CAD\$38,495 per capita
Average after tax income of families, Canada, 2003	CAD\$59,900

¹ *The Daily* Sept. 28/05, Demographic Statistics, www.statcan.ca

² Statistics Canada: "How Canada compares in the G8" June 2005 online edition of *Perspectives on Labour and Income*, Vol. 6, no. 6 (75-001-XIE)

³ Statistics Canada www.statcan.ca, July 2005

⁴ Statistics Canada www.statcan.ca, October 2005

GROWING DISPARITIES BETWEEN RICH AND POOR⁵

The 2001 Census figures on income indicate that Canadian society is becoming increasingly polarized. The richest 10% of our population has seen its income grow by a 14% while the bottom 10% has seen only a slight increase of less than 1%.

PERSISTENCE OF POVERTY⁶

The income of many working families has actually declined. In the last five years, Canada has not been able to reduce poverty in any meaningful way. Canada's strong economic progress has failed to put any real dent in Canadian child poverty rates – despite the 1989 resolution, unanimously adopted by the House of Commons, to eradicate child poverty by the year 2000.

Percentage of persons in low income (1992 base after-tax income LICO)						
	1996	1998	2000	2001	2002	2003
Persons under 18 years old	18.6	15.5	13.8	12.1	12.2	12.4
In two-parent family	12.4	9.8	9.5	8.2	7.2	7.7
In female lone-parent families	55.8	46.1	40.1	37.4	43.0	40.9
Person 18 to 64 years old	15.7	13.9	12.9	11.7	12.1	12.1
Person 65 and over	9.8	8.6	7.6	6.7	7.6	6.8

POVERTY AMONGST ABORIGINAL PEOPLE⁷

- Over 1.3 million people reported some Aboriginal ancestry in 2001. This was 4.4 % of the total population up from 3.8% in 1996.
- In 2001, those who identified as Aboriginal persons made up 3.3% of the total population, compared with 2.8% in 1996. The Aboriginal population is broken up into North American Indians (2.1% of Canada's total population), Métis (1.0%) and Inuit (0.2%).
- Increasingly, Aboriginal peoples are living off-reserve: only 31% of Aboriginal people lived on reserves and settlements, down from 33% in 1996. In 2001, 49% of the Aboriginal population lived in urban areas, up from 47% in 1996.
- The Aboriginal population is much younger than the Canadian average; the median age of Canada's Aboriginal population was 24.7 years in 2001, compared to 37.7 years for Canada's non-Aboriginal population.
- Aboriginal peoples in urban areas were more than twice as likely to live in poverty as non-Aboriginal people.⁸ On average, 55.6% of Aboriginal people living in Canadian cities were poor in 1995. In some cities, the number of Aboriginals living in poverty is more than three times their proportion of the total population in that city. Several factors can explain this high incidence of poverty among Aboriginal people, including significant barriers in education and employment opportunities.

⁵ Census Shows Growing Polarization of Income in Canada, May 16, 2003, <http://www.ccsd.ca/pr/2003/censusincome.htm>

⁶ Family income. *The Daily*, Thursday, May 12, 2005. <http://www.statcan.ca/Daily/English/050512/d050512a.htm>

⁷ Aboriginal Children in Poverty in Urban Communities: Social exclusion and the growing racialization of poverty in Canada, March 19, 2003. <http://www.ccsd.ca/pr/2003/aboriginal.htm>

⁸ Urban Poverty in Canada: A Statistical Profile (CCSD, 2000)

2. Overview of the HIV/AIDS Epidemic in Canada

- In Canada just under 58,000 HIV diagnoses had been reported by the end of 2004. The number of reported new annual HIV infections has risen by 20% in the past five years, and women now comprise over one quarter of new diagnoses. This corresponds to the growing proportion of HIV diagnoses attributable to heterosexual transmission (30% in 2004).⁹
- In Canada, there were an estimated 2,800 to 5,200 new HIV infections in 2002, approximately the same as in 1999.¹⁰
- In terms of exposure category, 45% of new HIV infections in Canada in 2004 were attributed to MSM, 30% to heterosexual contact, and 25% injection drug use. Women comprised 25.7% of new HIV infections in 2004.¹¹
- In 2002, it was estimated that approximately 3,000 to 4,000 Aboriginal persons were living with HIV in Canada. This represents about 5% to 8% of all prevalent HIV infections, compared with the 1999 estimate of about 6% of the total, or 2,500 to 3,000 persons. Aboriginal persons accounted for approximately 250 to 450 of the new HIV infections in Canada in 2002, or 6% to 12% of the total, compared with 9% in 1999.
- HIV/AIDS has a significant impact on Aboriginal women. Females represent nearly half (45.0%) of all positive HIV test reports among Aboriginal peoples, compared with 20.0% of HIV reports among non-Aboriginal peoples.
- At the end of 2002, there were an estimated 7,700 (6,500-9,000) women living with HIV in Canada, (including those living with AIDS), accounting for about 14% of the national total. This represents a 13% increase from the 6,800 estimated in 1999. There were 600 to 1,200 new HIV infections among women in 2003, representing 25.7% of all new infections, a finding similar to that in 1999. In Canada, a total of 1,635 AIDS cases and 7,932 HIV cases have been reported in adult women up to June 30, 2004.¹²
- On the basis of the proportions in positive HIV test reports and reported AIDS cases, 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% to 10% of total prevalent infections and 6% to 12% of total incident infections in Canada.
- As of June 30, 2004, 11.8% (2,293) of all reported AIDS cases have been among persons aged 50 years or older.
- Aboriginal and Black Canadians are overrepresented among reported AIDS cases in Canada, accounting for 14.4% and 20.7% of respective AIDS cases with known ethnicity.
- Published estimates of national HIV prevalence and incidence indicate that 30% or 800-1,600 of the estimated 2,800-5,200 new HIV infections that occurred in Canada in 2002 were among injecting drug users (IDU).
- In Canada's federal prison system (which houses people sentenced to prison terms of two years or more), the number of reported cases of HIV/AIDS rose from 14 in January 1989 to 159 in March 1996 to 251 in 2002 (data for 2002 are preliminary). This means that 2.01 percent of all federal prisoners are *known* to be HIV-positive.¹³ While less than 3% of the national population is Aboriginal, Aboriginal people represent 15% of the federal prisoner population. In the Prairie

⁹ AIDS Epidemic Update, UNAIDS, December 2005. www.unaids.org

¹⁰ Public Health Agency of Canada. *HIV/AIDS Epi Updates, May 2005*, Surveillance and Risk Assessment Division, Centre for Infectious Disease Prevention and Control, Public Health Agency of Canada, 2005

¹¹ AIDS Epidemic Update, UNAIDS, December 2005. www.unaids.org

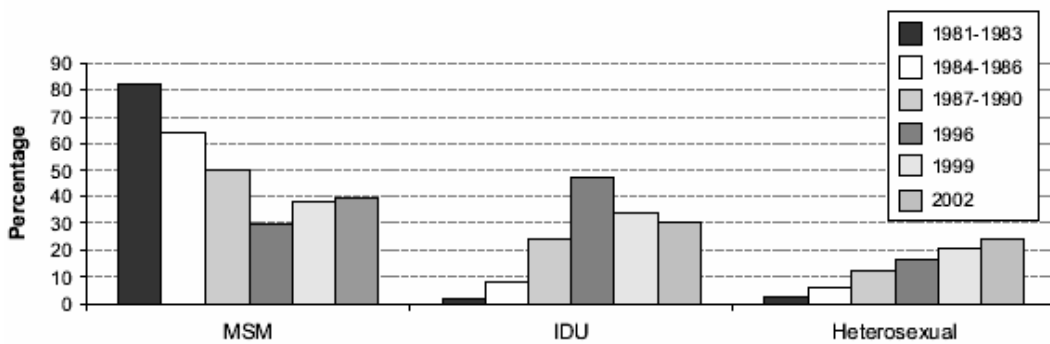
¹² May 2005 Epi Updates at <http://www.phac-aspc.gc.ca/publicat/epiu-aepi/epi-05/index.html>

¹³ Canadian HIV/AIDS Legal Network: 2004/2005 HIV/AIDS and Hepatitis C in Prisons: The Facts. <http://www.aidslaw.ca/Maincontent/issues/prisons/e-info-pa1.htm>

Region of the Correctional Service of Canada (CSC), Aboriginal people account for 64 percent of the prisoner population. A male treaty Indian is 25 times more likely to be incarcerated in provincial jail than a non-Native. A female treaty Indian is 131 times more likely to be incarcerated in provincial jail than a non-Native.

- Persons from countries where HIV is endemic are over-represented in the HIV/AIDS epidemic in Canada. In 2004, Black people in Canada represented approximately 2% of the population and an estimated 12% of the positive HIV tests. Women represented 52% of positive HIV test reports attributed to the HIV-endemic exposure category between 1998 and 2004 and 42% of AIDS cases during the same time period.¹⁴ Across the country, AIDS service organizations are seeing an increasing number of Black people coming for services.

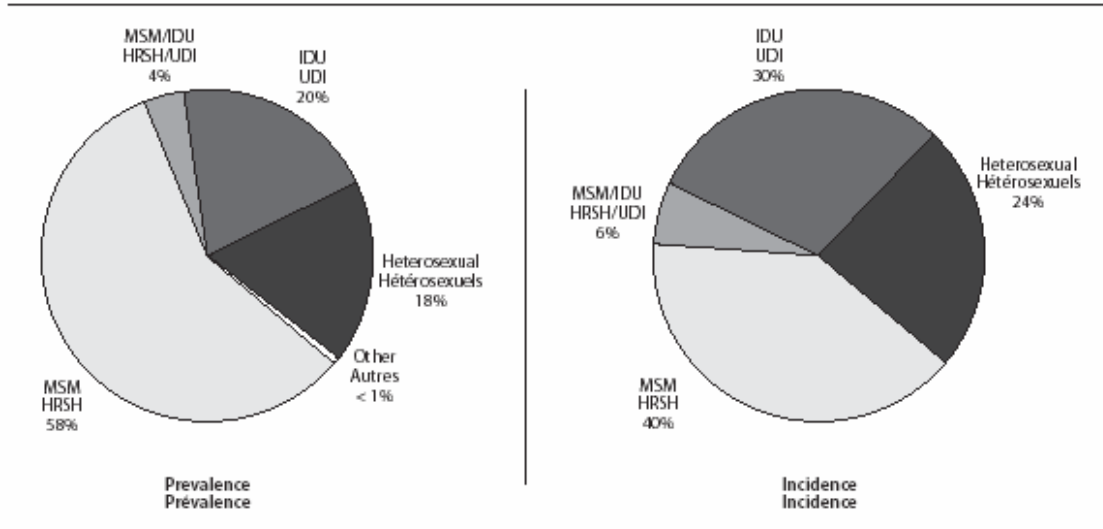
Figure 1. Estimated exposure category distributions (%) among new HIV infections in Canada, by time period



MSM: men who have sex with men; IDU: injecting drug users; Heterosexual: subcategories of heterosexual contact with a person at risk of HIV, origin in a country where HIV is endemic, and heterosexual as the only identified risk. A different method was used prior to 1996.

Figure 1. Prevalent and incident HIV infections in Canada by exposure category, Canada, 2002

Figure 1. Infections et nouvelles infections à VIH, selon la catégorie d'exposition, Canada, 2002



¹⁴ Centre for Infectious Disease Prevention and Control. HIV in Canada Among Persons from Countries where HIV is Endemic (Dec 2005). <http://www.phac-aspc.gc.ca/publicat/epiu-aepi/epi-1205/index.html>

Table 1: Estimates of percentage contribution to the 2002 national incidence and prevalence numbers by P/T and exposure category in Canada for males and females. Data presented in the table are estimated based on information from the 2002 estimates process which also made use of information from HIV and AIDS reporting in Canada.

Province/ Territory	2002 HIV Incidence	2002 HIV Prevalence
Alberta	5.6%	5.6%
Atlantic Region	1.0%	2.3%
British Columbia	20.5%	18.4%
Manitoba, Saskatchewan and Territories ¹	4.4%	4.1%
Ontario	38.9%	38.6%
Quebec	29.6%	31.1%

¹Nunavut started reporting on HIV/AIDS in 2000

3. Reportability of HIV-Positive Tests

As of May 1, 2003, HIV infection became legally notifiable in all provinces and territories¹⁵. Therefore, now both positive HIV test reports and AIDS diagnoses are notifiable in all jurisdictions across Canada. In most testing situations, laboratories and physicians are responsible for reporting HIV infection, but this varies by province or territory. “Nominal/name-based” or “non-nominal/non-identifying” information about an individual who tests positive for HIV infection is forwarded to provincial or territorial public health officials. This includes demographic data, such as the person’s age and gender; risks associated with the transmission of HIV; and laboratory data, such as the date of the person’s first positive HIV test. HIV infection is not legally notifiable at the national level, yet notification to the Centre for Infectious Disease Prevention and Control (CIDPC) is voluntarily undertaken by all provinces and territories. Positive HIV test reports and reported AIDS cases are provided non-nominally to CIDPC.

4. Health Sector Budget Allocation and Spending

Health Expenditure by Use of Funds, by Year, by Source of Finance, by Province/Territory and Canada ¹⁶ 1975-2003 - Current Dollars (\$ millions)									
	Hospitals	Other Institutions	Physicians	Other Professionals	Drugs	Capital	Public Health & Admin	Other Health Spending	Total
2000	30,554.5	9,331.3	12,977.0	11,586.6	15,085.8	3,888.0	6,264.5	8,215.8	97,903.4
2001	32,199.0	10,104.7	13,978.0	12,576.7	16,660.8	4,467.8	7,081.4	9,242.6	106,310.8
2002	34,375.1	10,776.5	15,050.7	13,116.8	18,408.7	4,913.6	7,471.4	9,928.9	114,041.6
2003	36,808.7	11,547.6	16,012.6	13,891.0	20,002.9	5,844.8	8,367.8	10,528.4	123,003.7

Health care is a provincial jurisdiction in Canada and the provinces are responsible for the bulk of their own health care budgets. The Government of Canada contributes approximately one-third of provincial health care spending (amounting to \$25.0 billion in 2004-05) through the Canada Health Transfer, targeted funding for medical equipment (\$500 million) and health reform (\$1.5 billion). The Government of Canada also makes direct contributions to health care and health research, and contributes \$130 million for public health and immunization.

¹⁵ Centre for Infectious Disease Prevention and Control – May 2005 HIV/AIDS Epi Updates, p.11

¹⁶ Canadian Institute for Health Information, www.cihi.ca. Run Date: 05-11-10

Equalization¹⁷ payments can be spent by provinces in any way they wish, but on average, provinces spend about 39% of their program budgets on health care. The Government of Canada's direct spending on health care was estimated at approximately \$5 billion in 2004–05 for First Nations' health, veterans' health, health protection, disease prevention, health information and health-related research. Tax measures such as credits for medical expenses, disability, caregivers and infirm dependants amount to about \$1 billion a year.

It should be noted that Canada's spending on pharmaceuticals is the second highest category of health expenditure, and it has for many years, been the fastest growing category of health care expenditure. This has relevance to access to treatment for PHAs in Canada, since there is increasing pressure to contain costs, and is manifested in greater difficulties getting drugs listed on provincial formularies, for example. At the same time, public health (including health promotion and prevention) is the second lowest level of expenditure, reflecting a low priority on non-critical care and non-clinical sectors of the health care system.

5. Other Relevant Health Statistics

INFANT MORTALITY

The infant mortality rate, that is, deaths in the first year of life, increased in 2002 to 5.4 deaths for every 1,000 live births, up from 5.2 in 2001. The entire increase resulted from female infant mortality.

LIFE EXPECTANCY¹⁸

Life expectancy at birth, 2002 (years)			Life expectancy at age 65, 2002 (years)		
Both sexes	Men	Women	Both sexes	Men	Women
79.7	77.2	82.1	19.1	17.2	20.6

- Men who were born in 2002 could expect to live to the record high age of 77.2, up 0.2 years from 2001. On the other hand, the life expectancy of women at birth remained unchanged at 82.1 years. Life expectancy at birth for both sexes combined reached 79.7 years in 2002 - up 0.1 years from 2001 and entirely a result of the gain among men.
- Between 1979 and 2002, life expectancy for men improved by 5.8 years while that of women improved by 3.3 years.

MATERNAL MORTALITY¹⁹

The reported maternal mortality ratio in Canada has declined from approximately 500 maternal deaths per 100,000 live births in the early 1920s to less than 5 per 100,000 live births in the 1990s, among the lowest reported maternal mortality ratios in the world.

¹⁷ Equalization is a federal transfer program that allows all provinces, regardless of their ability to raise revenue, to provide roughly comparable levels of services at roughly comparable levels of taxation. Currently, eight provinces receive equalization: Newfoundland, Prince Edward Island, Nova Scotia, New Brunswick, Quebec, Manitoba, Saskatchewan and British Columbia

¹⁸ *The Daily*, Sept. 27/04, www.statcan.ca. Life expectancy is calculated from birth and death data that exclude the following: stillbirths; births and deaths of non-residents of Canada and residents of Canada whose province or territory of residence was unknown; and deaths for which the age of the decedent was unknown.

¹⁹ Report on *Maternal Mortality in Canada*, PHAC, www.phac-aspc.gc.ca

SECTION 3: GENERAL OVERVIEW OF THE RESPONSE TO HIV/AIDS IN CANADA (by Government and civil society)

PART 1: Government Response

Civil society is concerned about the lack of political leadership from our elected and non-elected leaders with respect to HIV/AIDS, both domestically and internationally. The Prime Minister rarely speaks publicly about AIDS; the last public announcement from the Prime Minister was in May 2004 regarding Canada's contributions to the World Health Organization's 3 by 5 Initiative and the Global Fund. The Minister of Health and the Minister of State for Public Health speak out about HIV/AIDS only on World AIDS Day, once a year. The Minister of International Cooperation has been the most vocal, but again, only if announcing funding. Our Chief Public Health Officer, appointed in 2004, has yet to say anything in public about HIV/AIDS. Civil society would like to see Canadian leaders speak about HIV/AIDS outside the context of funding announcements, and to see political parties develop platform positions on how they would address HIV/AIDS in Canada and abroad.

1. Right to Health

In 1946, member countries of the newly established World Health Organization proclaimed in the organization's Constitution that the "highest attainable standard of health" is a "fundamental human right" of every person. The human right to health is similarly recognized in the UN's International Covenant on Economic, Social and Cultural Rights, which was adopted in 1948 and entered into force in 1976; Canada is among the 145 countries that are parties to this treaty. The covenant stipulates that these countries have a legal obligation to take immediate steps towards ensuring the highest attainable standard of health for every person, including actions necessary to prevent, treat and control epidemic and other diseases. Countries such as Canada have pledged to progressively realize this right, both domestically and internationally.²⁰

However, there is no explicit reference to the right to health in either the Canadian Charter of Rights and Freedoms or any other part of the Constitution Act (1982). The Canada Health Act, Section 3 states:

"It is hereby declared that the primary objective of Canadian health care policy is to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers."

Health care is a matter within provincial jurisdiction in Canada, and the Canada Health Act establishes principles by which provinces must abide in order to receive federal funding. One condition is that each jurisdiction must provide public health insurance coverage for "medically necessary" hospital and physician services. The only penalty for provinces' non-compliance is the federal government withholding transfer payments. Some provinces have public health insurance plans that provide full or partial coverage for certain other kinds of health services, but this is not uniform across the country nor is there any legal requirement for such coverage. Consequently, there is no universal public insurance covering costs for such things as prescription medications.

Although there officially is universal access to health care in Canada, people living with HIV or vulnerable to HIV still experience barriers to accessing health care services and realizing the right to health. Many of these barriers are associated with the stigma of HIV status, injection drug use or

²⁰ Global Health is a Human Right! A National Civil Society Summit, 21-22 May 2003, Ottawa, Final Report 30 June 2003

being a gay man. Other barriers are associated with disparate availability of services in rural areas, as compared to urban centres.

2. Laws/Policies Making Certain Professions and/or Behaviors Illegal

ILLICIT DRUG USE²¹

Since the early 1900s, Canada has enacted criminal statutes aimed at the control of particular drugs. The *Opium and Drug Act* of 1911, and later the *Narcotic Control Act* and the *Food and Drugs Act*, governed drug use for 85 years. The *Controlled Drugs and Substances Act* (CDSA) was proclaimed into force in 1997. In general, under the CDSA, the *unauthorized* possession, manufacture, cultivation, trafficking, export and import of substances listed in several Schedules attached to the CDSA are criminal offences. Currently, those Schedules list cannabis, heroin, methadone, cocaine, barbiturates, amphetamine and a large array of other substances as “controlled.” Finally, the CDSA makes it a criminal offence to possess, import, export, or traffic not only the drugs themselves but also “anything that contains or has on it a controlled substance and that is used...in introducing the substance into a human body.” This means that if a syringe or other equipment used for injecting drugs contains residue of a drug, that equipment is technically a “controlled substance” and the person with the syringe could be found guilty of possession. It is within the discretion of local law enforcement jurisdictions to enforce the criminal status of equipment used for ingesting controlled substances, or to prosecute people who have been seen ingesting controlled substances.

SEX WORK²²

Prostitution is not, and never has been, illegal in Canada. However, the majority of activities surrounding prostitution are illegal under the Canadian Criminal Code and sex workers are criminalized even if they work in private (e.g., their homes).

- Under the Criminal Code section 212 regarding procurement, it is illegal for a person to do many of the usual activities associated with pimping, such as living off money made by prostitution, arranging for prostitution to take place, “recruiting” prostitutes, or offering another person’s services as a prostitute. This section can expose sex workers’ personal relationships to possible criminal charges, and also makes it more difficult for sex workers to work together for their own safety.
- According to Criminal Code section 210 regarding bawdy-houses, it is illegal to keep or to be found in a “common bawdy-house, ” a place that is kept or occupied by one or more persons for the purpose of prostitution. It is also illegal to transport or direct any person to a common bawdy-house. This section makes it illegal for a sex worker to work in any private place, be it a brothel, a massage parlour, or their own homes. Even a parking lot or car has been considered a “bawdy-house” by Canadian courts. This law also threatens landlords with criminal charges if they do not take steps such as evicting a sex worker who is convicted of using his or her apartment for their work.
- According to Criminal Code section 213, it is illegal to communicate for the purposes of engaging in prostitution or sexual services, when carried out in public or open to public view. It is illegal to stop or attempt to stop a vehicle, impede the free flow of pedestrian or vehicle traffic, or to stop any person or, in any manner, to communicate or attempt to communicate with that person. Statistics show this section is the one most frequently used to criminalize sex workers, targeting street-based sex workers.

²¹ Canadian HIV/AIDS Legal Network: *The Current Legal Status of Drugs in Canada*, July 2005.

²² Canadian HIV/AIDS Legal Network: *Sex, work, rights: reforming Canadian criminal laws on prostitution*, July 2005.

In 1998, Bill C-15 created law in Canada which prohibits living on the avails of prostitution or engaging in sexual services of a person under the age of 18 (sec. 212(2) and 212(4)). This legislation reflected a change in viewing child prostitutes as victims rather than as offenders. Prior to this, child prostitutes were often charged under the solicitation provision and were treated as offenders. Unfortunately, the new provisions for charging "Johns" and pimps are ineffectual. They require the "John" to be caught in the act and the pimp to be turned in by the prostitute.

Alberta enacted the Protection of Children Involved in Prostitution Act (February 1, 1999). This law allows for the protection of children under 18 years old who are at risk by being involved in prostitution. The law provides protective services such as taking them to a safe house for 72 hours to be assessed and referred for services without bringing charges. Although the legislation has resulted in intervention of child prostitution in Alberta, the enforcement of this law has not resulted in easier prosecution of either the "Johns" or pimps who are sexually abusing these children, and has created difficulties for service providers to deliver outreach programs to youth at risk.

CRIMINALIZATION OF NON-DISCLOSURE OF HIV STATUS²³

A person living with HIV/AIDS may face criminal charges of aggravated assault or aggravated sexual assault (and attempts of either), and other charges such as common nuisance, for engaging in activities that carry a risk of transmitting HIV.²⁴ As confirmed by the 1998 *Cuerrier* decision of the Supreme Court of Canada, people living with HIV have a legal duty to disclose their HIV status before engaging in behaviours that put another person at significant risk of serious bodily harm. The Court clearly stated that risk of HIV infection is risk of a serious bodily harm. An HIV-positive person does not have to infect the other person with HIV to be criminally charged. It is enough that he or she puts the other person at a significant risk of HIV infection without disclosing his or her status. The two most common situations where there is a significant risk of HIV transmission are: (1) unprotected sexual intercourse (anal or vaginal); or (2) sharing injecting equipment (needles and syringes) that contains HIV-infected blood. Practically speaking, this means that people living with HIV must disclose their HIV status before having unprotected intercourse (vaginal or anal) and before sharing injecting equipment (needles and syringes) that contains HIV-infected blood, or face possible criminal penalties.

In the *Cuerrier* case, the Supreme Court suggested that careful use of a condom "may" reduce the risk of HIV transmission to the point where the risk of serious bodily harm is not significant. And as a result, an HIV-positive person who properly uses a condom might not have a legal duty to disclose his or her HIV status before engaging in sexual intercourse. But this was only a suggestion by the Supreme Court, and it not yet confirmed as the law. It is unclear whether or not people living with HIV/AIDS have a legal duty to disclose their HIV status to sexual partners before engaging in activities that pose low risk of HIV transmission [oral sex without a condom; intercourse with a condom]. In *R v Edwards*, a lower court judge indicated that there is no legal duty to disclose HIV status before unprotected oral sex because it is a low risk activity. In the *Williams* case (2003), the Supreme Court of Canada opened up the possibility that a person who is aware of the risk that he or she has contracted HIV may have a legal duty to tell his or her sex partner about this before engaging in unprotected sexual intercourse. The legislation on the obligation to disclose HIV status is evolving and further clarity is needed.

²³ Briefing Note for Community-Based AIDS Organizations: HIV Disclosure & the Criminal Law in Canada: Responding to the Media and the Public. <http://www.aidslaw.ca/Maincontent/issues/criminallaw/BriefingNotes-sept03.doc>

²⁴ Supreme Court of Canada in *Cuerrier* and *Williams* decisions

Community-based AIDS organizations do not have a duty under the criminal law to report to police clients who engage in sex or injecting activities that risk HIV transmission. Therefore, organizations cannot be charged with or convicted of a criminal offence for failing to report a client to police. Criminalization of non-disclosure of HIV status in Canada is increasingly becoming a public issue with new cases emerging regularly. A recent case (October 28, 2005) was highlighted in the Canadian media when the Royal Canadian Mounted Police laid charges against a Saskatchewan Roughrider football player with aggravated sexual assault and disclosed the player's HIV status. AIDS activists in Canada warns against criminal prosecutions to deal with HIV transmission, as criminalizing HIV status only creates an environment of fear and increases stigma and discrimination toward people living with HIV. Canadian epidemiological reports reveal that more than 58,000 Canadians are living with HIV and up to 17,000 Canadians aren't aware of their HIV infection and thus the general guideline promoted by HIV/AIDS educators is that individuals must take responsibility for safer sex.

PRISONERS' RIGHTS TO HIV/AIDS SERVICES²⁵

By its very nature, imprisonment involves the loss of the right to liberty. However, prisoners retain their other rights and privileges "except those necessarily removed or restricted by the fact of their incarceration." In particular, prisoners, as every other person, have "a right to the highest attainable level of physical and mental health": the state's duty with respect to health does not end at the gates of prisons. The 1993 World Health Organization *Guidelines on HIV infection and AIDS in prisons* state, as a general principle, that prisoners have the right to receive health care, including preventive measures, equivalent to that available in the community without discrimination. This is consistent with the *Mission of the Correctional Service of Canada* according to which the provision of a "safe, secure and clean environment that promotes health and well-being" is a "strategic objective."

People who inject drugs prior to entering the prison system are likely to continue injecting in prison and are more likely to share injection equipment, creating a high risk of HIV transmission. Despite the sustained efforts of prison systems to prevent drug use by prisoners — by doing what they can to prevent the entry of drugs into prisons — the reality is that drugs can and do enter. A number of studies have provided evidence of the extent of injection and other drug use in prisons. Sterile injection equipment should be made available in prisons where prisoners inject illegal drugs. In prison systems where distribution has not yet started, pilot projects should be undertaken immediately. Not undertaking pilot needle-distribution projects, in the knowledge that HIV and other infections are being transmitted in prisons, could be seen as condoning the spread of infections among prisoners and ultimately to the general public. As of 2005, no Canadian prison system had started a needle-exchange program. However, a few systems, including the federal prison system, are studying the issue.

In prisons, sexual activity is considered to be a less significant risk factor for HIV and hepatitis C transmission than sharing of injection equipment. Nevertheless, it does occur and puts prisoners at risk of contracting HIV infection. In 1994 as a result of a recommendation by the Expert Committee on AIDS and Prisons, the federal prison system announced that condoms, dental dams, and water-based lubricant would become more easily and discreetly available. However, in some provincial prisons, condoms, dental dams, and lubricant are not available, and in many provincial prisons they are not easily and discreetly available. Some jurisdictions such as Ontario, Alberta, and

²⁵ Canadian HIV/AIDS Legal Network (2004). Prison Needle Exchange: Lessons from a Comprehensive Review of International Evidence and Experience. <http://www.aidslaw.ca/Maincontent/issues/prisons/pnep/toc.htm>.

Nova Scotia, among others, continue their policy of making condoms available only through prison health services.

Also, tattooing is a social activity and involves sharing needles, which makes it risky. In Canada, 45 percent of federal prisoners reported having had a tattoo done in prison. Recently, the federal government has launched a new initiative to open tattoo parlours in federal prisons.

Today, in the federal and in most provincial and territorial systems, prisoners who were already on methadone maintenance treatment (MMT) outside can continue such treatment in prison. However, few systems allow prisoners to initiate MMT while incarcerated. Only the federal system and the BC provincial system have formal methadone initiation programs, while Quebec, Saskatchewan, and Yukon allow MMT initiation under “exceptional circumstances”. MMT is a medically indicated form of treatment that should be available to opiate-dependent people regardless of whether they are outside or inside prison.

There are ongoing systemic and individual problems with access to care for PHAs in prison. However, prisoners report that they sometimes receive care and treatment that is not up to the standard that they received in the community, or even in other prisons they have been in. Other issues include: the increase in the number of sick prisoners; prisons not being equipped to deal with prisoners who require long-term, ongoing care and treatment (including palliative care); and the difficulty of accessing investigational drugs and alternative therapies. Many community-based organizations across Canada – such as the Canadian HIV/AIDS Legal Network, the Prisoners' HIV/AIDS Support Action Network (PASAN), British Columbia Persons with AIDS Society (BCPWA), HIV & AIDS Legal Clinic Ontario (HALCO) – have been working to advocate for HIV-positive prisoners who are not receiving adequate care and treatment.²⁶

OTHER HUMAN RIGHTS ISSUES

There are many other human rights issues in Canada associated with policies and laws concerning those vulnerable to HIV/AIDS, which are too numerous to explain in detail in this report. Generally, there is plenty of room for improvement in Canada with respect to removal of policy and legislative barriers that place individuals at risk of HIV/AIDS, are discriminatory, or create barriers to services that might alleviate their risk of HIV. Other major policy/legal issues not mentioned above are:

- Canada needs more stringent penalties against aggravated assault and domestic violence, better preventive programs and policies, and more accessible reporting structures for victims
- Currently, people living with HIV who want to immigrate to Canada as permanent residents (and are not refugees or exempt family class applicants) are excluded from immigration.²⁷ Canada's immigration policies should be adjusted so that the individual circumstances of each case is taken into account, weighs the costs against the benefits of allowing a particular person to immigrate, and takes humanitarian concerns into account.
- Opt-out HIV testing policies for pregnant women during their prenatal screening in some provinces are compromising informed consent for women being tested without their full awareness. Provincial and territorial governments, in conjunction with health-care

²⁶ PASAN (2003). *Unlocking Our Futures: A National Study on Women, Prisons, HIV, and Hepatitis C*. www.pasan.org/Publications/Unlocking_Our_Futures.pdf; and BCPWA (2001). *Initiative to Monitor Prison AIDS Care and Treatment (IMPACT)*.

²⁷ Canadian HIV/AIDS Legal Network (2005): www.aidslaw.ca/Maincontent/issues/Immigration/ImmigrationQ&A2005.pdf

professionals' associations and regulatory bodies, should improve efforts to ensure that all women have access to HIV testing services, and that all pregnant women be routinely offered voluntary HIV testing, with quality pre- and post-test counseling. Doing an HIV test should not be characterized as "routine" for pregnant women in policies, forms, or the education of health care professionals; rather, offering counseling and testing should be routine. Pregnant women should only receive HIV testing with their specific, informed consent.

- There have been some regressive policies such as the Blood Samples Act and the Good Samaritans Bill²⁸. These policies allow mandatory collection of blood from a source individual when a first responder (e.g., police officer, emergency health care worker, etc.) or a victim of crime has come into contact with a bodily substance. There is little indication of the benefit of such a policy, but rather, can encourage a false sense of security because of the window period for HIV seroconversion.

3 Canada's National AIDS Council

Canada does not have a National AIDS Council - i.e., there is no coordinating or governing body connected to the Prime Minister's Office or federal Minister of Health that is responsible for overseeing all HIV/AIDS policies and programs. However, Canada does have several national committees which are proxies for such a council. Canada needs a broad pan-Canadian approach with mutual influence amongst all stakeholders, government departments, and government levels. *Leading Together: An HIV/AIDS Action Plan for All Canada (2004 – 2008)*, is a guiding document that attempts to define actions needed by all stakeholders and levels of government, however, no one body has the responsibility for overseeing and coordinating the entire action plan. Thus, Canada still needs to assemble an overarching coordinating body which would champion, implement and monitor a multi-stakeholder, multi-sectoral, strategic pan-Canadian plan, and address HIV/AIDS and its vulnerabilities from a social determinants of health perspective. The following committees have specific mandates but do not comprise, either alone or together, an inter-ministerial coordinating group at the federal level. While *Leading Together: An HIV/AIDS Action Plan for All Canada (2004 – 2008)* attempts to define the necessary coordination, there is no one committee or government department which has the jurisdiction or authority to take responsibility for and enforce the action plan. Needed are incentives for meeting the actions in the plan, formal mechanisms for linking the provincial and federal governments, accountability structures, and champions in each of the stakeholder groups to take responsibility for the *Leading Together* plan.

MINISTERIAL COUNCIL ON HIV/AIDS

The Ministerial Council on HIV/AIDS (established in 1998) acts as an independent body that advises the Minister of Health on the changing face of the epidemic and on the pan-Canadian implementation of the national HIV/AIDS strategy. The Council promotes alliances and joint efforts; assists in the development of long-term plans for future action on HIV/AIDS; recommends

²⁸The 2001 Bill allows a medical officer of health to make an order requiring the taking of a blood sample from a person if the officer is of the opinion, on reasonable grounds, that the applicant for the order has come into contact with a bodily substance of the person as a result of being a victim of a crime, providing emergency health care services or emergency first aid or performing a function prescribed by regulation. The order will require a legally qualified medical practitioner or other qualified person to take the blood sample and deliver it to an analyst. It will require the analyst to analyse the sample and to make reasonable attempts to deliver a copy of the results to the person from whom the sample was taken and to the person who obtained the order.

actions to reach communities at risk; and works to keep the *Federal Initiative to Address HIV/AIDS in Canada* flexible and responsive to the changing nature of the epidemic. To fulfill this challenging mandate, Council members have been chosen for their experience and collective expertise which spans scientific research knowledge to front-line experience with emerging at-risk groups. Because the Council must be the voice of those infected and affected by HIV/AIDS, five of the fifteen Council members are people living with HIV/AIDS. The Minister of Health meets with the Council at least once a year to receive its advice and recommendations and reports annually to Canadians on the progress of the *Federal Initiative to Address AIDS in Canada*. To encourage collaborative efforts and strong linkages with the provinces and territories, the provincial Co-Chair of the Federal/Provincial/Territorial Advisory Committee on AIDS holds an ex-officio position on the Ministerial Council.

The Ministerial Council is limited in that it reports only to the Minister of Health and does not have jurisdiction across all departments that should play a role in HIV/AIDS issues, although it does advise other federal government departments on matters related to HIV/AIDS. Some civil society representatives also noted that the Ministerial Council lacks transparency and inclusiveness with respect to gathering information and input.

FEDERAL/PROVINCIAL/TERRITORIAL ADVISORY COMMITTEE ON AIDS

Recognizing that HIV cannot be successfully dealt with by any one jurisdiction, the Council of Deputy Ministers of Health (CDMH) has designated the Federal/Provincial/Territorial Advisory Committee on AIDS (F/P/T AIDS) as an "ongoing liaison committee" to ensure ongoing collaboration between governments. F/P/T AIDS has produced in-depth policy and program analyses on emerging HIV/AIDS issues through sharing information and accessing the necessary expertise. The products of these analyses have informed provincial, territorial and federal jurisdictions in policy and program development. Through these activities, F/P/T AIDS significantly influences the development of a pan-Canadian approach to HIV/AIDS. F/P/T AIDS provides policy advice on issues and priority initiatives related to HIV/AIDS in Canada, and promotes timely, effective and efficient intergovernmental and inter-jurisdictional collaboration on issues related to HIV/AIDS in Canada.

NATIONAL ABORIGINAL COUNCIL ON HIV/AIDS

The National Aboriginal Council on HIV/AIDS (NACHA) was formed to create a single council to advise the Public Health Agency of Canada (PHAC) on HIV/AIDS issues that affect all Canada's Aboriginal peoples. NACHA, developed and launched in May 2001 with the strong participation of Aboriginal people, reflects the needs of First Nations, Inuit and Métis. NACHA, as one collective body of Aboriginal expertise, gives advice to PHAC to ensure that the HIV/AIDS-related needs of all Aboriginal peoples in Canada are met. NACHA is composed of 24 members in four distinct groups. There are six members in each group, representing First Nations, Inuit, Métis and the community. The latter comprises community-based AIDS organizations and Aboriginal people living with HIV/AIDS. NACHA members are appointed every two years by individual caucuses at the National Aboriginal Summit on HIV/AIDS.

INTERDEPARTMENTAL ROUNDTABLE OF ASSISTANT DEPUTY MINISTERS

The four government bodies – Public Health Agency of Canada (PHAC), Health Canada (HC), the Canadian Institutes of Health Research (CIHR) and Correctional Service Canada (CSC) - have recently established an Interdepartmental Roundtable of Assistant Deputy Ministers, specific to HIV/AIDS. The Roundtable includes 14 government departments:

- Public Health Agency of Canada

- Health Canada
- Canadian Institutes for Health Research
- Canadian International Development Agency
- Foreign Affairs Canada
- Human Resources and Skills Development
- Industry Canada
- Department of National Defence
- Canadian Heritage
- Citizenship and Immigration Canada
- Correctional Service Canada
- Indian and Northern Affairs Canada and the Office of the Federal Interlocutor
- Department of Justice and Attorney General
- Social Development Canada

4. Canada's Pan-Canadian HIV/AIDS Action Plan

Canada's HIV/AIDS Action Plan is currently defined by two documents:

- *Federal Initiative to Address HIV/AIDS in Canada: Strengthening Federal Action in the Canadian Response to HIV/AIDS.*
- *Leading Together: An HIV/AIDS Action Plan for All Canada (2004 – 2008)*

The *Leading Together Action Plan* is not enshrined in legislation, and thus is not enforceable through the court system. Rather, a vital civil society sector, through champions, partnerships and lobbying efforts, will ensure that the Action Plan is implemented to its fullest extent. The *Federal Initiative* is the latest version of the Canadian HIV/AIDS Strategy. The *Federal Initiative* is not just a health initiative but is the strategy for the federal government across all departments.

While the *Federal Initiative* and *Leading Together* largely address Canada's domestic response to HIV/AIDS, other government departments, including the Department of Foreign Affairs and International Trade and the Canadian International Development Agency, have also developed their own HIV/AIDS strategies, largely reflecting Canada's role with respect to addressing the globally pandemic. It should be noted that this report on Canada's fulfillment of the UNGASS Declaration of Commitment addresses only Canada's domestic commitments and thus does not reflect Canada's contributions to global efforts against HIV/AIDS.

FEDERAL INITIATIVE TO ADDRESS HIV/AIDS IN CANADA

The *Federal Initiative*²⁹ replaces the Canadian Strategy on HIV/AIDS and is an evolution because it addresses HIV/AIDS from across the federal government and not just the Ministry of Health. The *Federal Initiative* builds on the recommendations from the Standing Committee on Health, lessons learned from past federal HIV/AIDS strategies, and consultations with stakeholders, provinces and territories. In May 2004, the Government of Canada announced that ongoing federal HIV/AIDS funding would increase from \$42.2 million to \$84.4 million annually by 2008-2009.

The *Federal Initiative* is meant to contribute to a comprehensive and integrated Government of Canada response towards realizing *Leading Together: An HIV/AIDS Action Plan for All Canada*, which was released in spring 2005.

²⁹ The Federal Initiative can be downloaded in full from:
http://www.phac-aspc.gc.ca/aids-sida/hiv_aids/federal_initiative/initiative/fi/index.html

The *Federal Initiative* provides funding to four government departments to implement HIV/AIDS programming: Public Health Agency of Canada, Health Canada, the Canadian Institutes of Health Research and Correctional Service Canada. Each of these government departments then runs its own programming across all regions of Canada through non-governmental and community-based organizations. There is no formal coordinating body for the *Federal Initiative*.

The goals outlined in the *Federal Initiative* are to be implemented by the Public Health Agency of Canada, Health Canada, the Canadian Institutes of Health Research and Correctional Service Canada as part of their commitment to improve the health of Canadians and contribute to the implementation of *Leading Together*. By working together with other key federal government departments and agencies, provincial and territorial governments, non-governmental organizations and other stakeholders, the national government will strive towards the following goals:

- Goal #1: Prevent the acquisition and transmission of new infections.
- Goal #2: Slow the progression of the disease and improve quality of life.
- Goal #3: Reduce the social and economic impact of HIV/AIDS.
- Goal #4: Contribute to the global effort to reduce the spread of HIV and mitigate the impact of the disease.

The *Federal Initiative to Address HIV/AIDS in Canada* identifies five areas for increased federal action and investment:

- program and policy interventions;
- knowledge development;
- communications and social marketing;
- coordination, planning, evaluation and reporting; and
- global engagement.

LEADING TOGETHER: AN HIV/AIDS ACTION PLAN FOR ALL CANADA

Leading Together is a pan-Canadian multi-stakeholder, multi-sectoral Action Plan, providing an opportunity for all parts of the country and all organizations involved in HIV/AIDS to come together as part of a larger, nation-wide effort. It encourages effective partnerships among jurisdictions as well as within the health care system and with other sectors beyond health that have an impact on HIV/AIDS, such as social services, education, housing and justice. It also encourages the meaningful participation of people with HIV/AIDS. The Action Plan is meant to be implemented by all organizations whose policies and programs affect people living with or are vulnerable to HIV as a guide for their planning and priorities from 2004-2008. Each organization is asked to develop its own plan, setting out its commitment to be part of this all-Canada response to HIV/AIDS and describing the role it will play in our nation-wide effort.

The goals of Canada's *Leading Together Action Plan* are to:

1. Involve people living with and vulnerable to HIV in the programs and services that affect their lives.
2. Influence the broad determinants and underlying causes of HIV.
3. Prevent HIV infection.
4. Ensure every person with HIV/AIDS in Canada has access to timely, safe and effective care, treatment, and support.
5. Provide leadership in global efforts to fight the epidemic and find a cure.

Leading Together outlines the following strategies.

1. Raise public/political awareness of the impact of HIV on society, and of the social factors that contribute to the epidemic

2. Address the social, economic, environmental and health factors that contribute to the epidemic
3. Optimize the voice, involvement and meaningful participation of people living with or vulnerable to HIV
4. Increase capacity to monitor and track HIV, and to develop, share and apply knowledge
5. Re-invigorate primary prevention efforts
6. Provide comprehensive, integrated prevention, diagnosis, support, care and treatment services
7. Strengthen organizations that provide HIV-related services and increase their capacity to meet increasingly complex needs
8. Ensure appropriate, sustainable investment in HIV services
9. Provide leadership in global efforts to combat the epidemic.

Activities will be undertaken in partnership with community organizations, other federal government departments and agencies and other levels of government.

FUNDING FOR THE FEDERAL INITIATIVE

Canada's *Federal Initiative* is supported by a financing plan, although it is neither clear nor transparent. While it has been announced publicly that there will be a scale-up of funding for the *Federal Initiative* between 2004 and 2009, the specific allocation of funds is completely opaque. A significant concern in particular has been the lack of clarity with respect to grants for the national NGOs. Planned federal funding for HIV/AIDS (2003-2004 to 2008-2009) is summarized in the table below:

Fiscal Year	2003-04	2004-05	2005-06	2006-07	2007-08	2008-09 and beyond
\$ Millions	42.2	47.2	55.2	63.2	71.2	84.4

The federal government's per capita health spending on HIV/AIDS in Canada is \$1.46 per person (based on Canada's population of 32,270,507 and \$47.2 million for the *Federal Initiative* in 2004-2005), and provinces/territories contribute variable amounts to HIV/AIDS within their own jurisdictions. Civil society applied a great deal of sustained pressure in order to achieve the funding increase for the Federal Initiative, although the increase in the amount to fund civil society's response is proportionately quite small and is still below what is needed.

The Public Health Agency of Canada (PHAC) was newly created in 2004, and a Chief Public Health Officer newly appointed, with responsibility for the three key functions of the Agency: infectious diseases, emergency preparedness and chronic diseases. The PHAC is part of the public service and will be headed by the Chief Public Health Officer who will report to the Minister of Health. Health Canada will also report to the Minister of Health. Although separate, both will be members of the health portfolio and will work together to improve and protect the health of Canadians. The Agency's infectious disease functions (based out of Winnipeg) include epidemiology, and responses nationally and internationally, in the event of an infectious disease outbreak. The Agency's Ottawa offices will be responsible for working closely with other departments, including Public Safety and Emergency Preparedness Canada, on emergency planning, preparedness and response to national public health emergencies. Ottawa will also coordinate efforts to reduce chronic diseases and injuries. In addition, six National Collaborating Centres for Public Health were created to enhance Canada's response to infectious and chronic diseases, requiring an initial investment of \$15 million dollars over two years to establish them.

One of the criticisms from the civil society HIV/AIDS sector involved is that a significant proportion of the new *Federal Initiative* funding for HIV/AIDS will be allocated to the overhead and administration costs of PHAC and the other government departments administering the *Federal Initiative*. A request has been sent to the Government of Canada for the exact amounts of

Operations and Management funds allocated within the government departments so that civil society can ensure that the amounts are reasonable in relation the funds allocated to actual Grants and Contributions for HIV/AIDS programming and research. Civil society is concerned that the increases in *Federal Initiative* funding for HIV/AIDS will not proportionally benefit national NGOs and community-based organizations due to high administration costs associated with the newly established PHAC, as well as the increasing complexity of the HIV epidemic in Canada.

PART II: Civil society involvement and mobilization

1. The Canadian HIV/AIDS Action Plan

Civil society has been instrumental in the development of Canada's *Federal Initiative*, by lobbying for adequate resources to fuel the *Federal Initiative* and *Leading Together*, and also by lobbying for their meaningful involvement in developing the Action Plan.

PROCESS FOR DEVELOPMENT OF CANADA'S ACTION PLAN

Leading Together: An HIV/AIDS Action Plan for All Canada was developed by a broad cross-section of organizations and individuals involved in the Canadian response. In 1998, when the Canadian Strategy on HIV/AIDS (CSHA) was launched, Health Canada recognized that it could not address HIV/AIDS on its own. To address the epidemic would require many sectors of society to contribute multiple areas of expertise towards the fight. This type of response, stemming from people, communities, governments, researchers and others beyond the realm of the federal government, was dubbed a 'pan-Canadian' response.

Starting in 2000, civil society was involved in a series of consultations and committees to develop the Action Plan. Key experts assisted in identifying strategic directions and specific objectives to answer the question: "What do we need to do to optimize the Canadian Response to HIV/AIDS over the next five years?" The results were used to begin drafting the Strategic Plan. The draft strategic plan then underwent a wide consultation in the Fall of 2003. Two consultation processes were developed. The first was a broad consultation of Canadian participants in the HIV/AIDS response from as many sectors as possible. The second process aimed to consult directly with PHAs and vulnerable populations. The consultation of PHAs and vulnerable populations required particularly innovative mechanisms to allow for the strongest possible voice and input. To assist in guiding the development of that consultation, an advisory group of PHAs, vulnerable Canadians and others was assembled and provided advice and parameters to frame those particular consultations. All of this work culminated in the finalization of a Strategic Plan, announced and launched on World AIDS Day of 2003.

NATIONAL PARTNERS

The *Federal Initiative* to Address HIV/AIDS in Canada facilitates increased engagement by, and improved collaboration among, all levels of government, communities, non-governmental organizations, professional groups, institutions and the private sector. Most of the following national organizations are supported by funding through the *Federal Initiative*

- Canadian Aboriginal AIDS Network
- Canadian AIDS Society
- Canadian AIDS Treatment Information Exchange
- Canadian Association for HIV Research

- Canadian Foundation for AIDS Research
- Canadian HIV/AIDS Information Centre
- Canadian HIV/AIDS Legal Network
- Canadian HIV Trials Network
- Canadian Treatment Action Council
- Canadian Working Group on HIV and Rehabilitation
- Interagency Coalition on AIDS and Development
- International Council of AIDS Service Organizations

COMMUNITY-BASED PARTNERS

The AIDS Community Action Program (ACAP) is one component of the *Federal Initiative to Address HIV/AIDS in Canada*. ACAP is a federal funding program that supports local, regional, and provincial/territorial community-based organizations addressing HIV/AIDS issues across the seven regions of Canada: Atlantic provinces, Quebec, Ontario, Manitoba/Saskatchewan, Alberta, British Columbia, and the Northern Secretariat (Northwest Territories, Nunavut and Yukon).

ACAP programming reflects the principles of community development; health promotion; partnerships and collaboration; population health; and planning and evaluation. These principles are in alignment with the policy direction of the *Federal Initiative*: partnership and engagement; integration and accountability. ACAP funding supports programming in the following areas:

- Prevention Initiatives to prevent HIV in populations known to be vulnerable to HIV
- Health Promotion for People Living with HIV/AIDS to increase the capacity of people living with HIV to manage their condition (services, treatment, support, work, learning), and support for people affected by HIV
- Creating Supportive Environments to reduce social barriers that prevent people living with HIV, those at risk, and those affected from accessing health care and social services. Targeted environments include (but are not limited to): prisons, addiction treatment, professional groups (nurses, educators, pharmacists, physicians, etc.), workplaces, other non-profits, general public
- Strengthening Community Based Organizations to increase the skills and abilities of the people who work at all levels of the community-based HIV movement: board, staff and volunteers.

ACAP resources are available for operational funding (available to AIDS Service Organizations) and for time limited project funding (available to community organizations that deal with HIV/AIDS as part of their wider programming). ACAP plays a key role in influencing the development and implementation of provincial and territorial programs designed to support community-based HIV/AIDS work. Previous evaluation reports of the National AIDS Strategy clearly indicate that continued federal support for ACAP is integral to any success the federal government hopes to have in preventing the spread of HIV and in creating supportive social environments for people living with HIV/AIDS³⁰. ACAP is also an invaluable funding program in furthering multi-sectoral participation in the population health framework.³¹

³⁰ Health Canada. *ACAP Allocations for Regional HIV/AIDS Programming - A discussion paper*. September 1999.

³¹ Susan Dann & Associates. *The PPHB Regional Office Role in HIV/AIDS*. May 2003.

2. Civil Society Awareness and Use of the Declaration of Commitment

To date, Canada has completed two reports on the Declaration of Commitment (2002 and 2003). While the reporting process included civil society input, the use of the input has been less than meaningful. There were significant constraints on civil society input due to a very short turnaround time (5 working days for the 2003 report), making it difficult for civil society to engage in true consultation. It was noted by those who did provide input from civil society in 2003 that very few of their comments were incorporated into Canada's final report. For future consultation processes, civil society representatives recommended longer turnaround time and some method of engaging civil society in dialogue with government, especially regarding the rationale behind decisions to include or not include their suggestions and comments. Civil society representatives also recommended a more transparent process for the periodic review, such as providing the reporting template well in advance for early engagement. Ideally, Canada's report should be a joint report between government (all relevant departments), business/corporations, and civil society.

Civil society for the most part has a basic awareness that the document exists (particularly national NGOs, community-based AIDS organizations, as well as human rights groups and sexual and reproductive health groups), but only a handful have a working knowledge about the document or actively use the document as a tool in planning or guiding their work. Very few know how to operationalize the Declaration into their ongoing programs and service delivery. The Declaration of Commitment most often is used as a reference, particularly for: 1) making advocacy arguments (e.g., letter writing, meetings with policy makers) and referring back to commitments made by the Canadian government; and 2) rationalizing funding proposals, justifying doing the work as important because it is included in the Declaration of Commitment.

Some organizations and coalitions have made efforts to raise awareness about the Declaration of Commitment, such as the Interagency Coalition on AIDS and Development through its International Toolkit, jointly developed with the Canadian AIDS Society, and their guide called "Implementing the UN's Declaration of Commitment on HIV/AIDS - A Guide for Canadian AIDS Service Organizations." The *UNGASS in Alberta* Working Group, comprised of people living with HIV/AIDS and service provider representatives from the Alberta Community Council on HIV, was an ad-hoc group that was formed in 2002 in response to requests for a working tool to bring the Declaration to action. The Working Group developed a document called "UNGASS Made Simple" to discuss how AIDS organizations in Alberta could move the Declaration from a policy document to a working tool. The Alberta Working Group then went on to join with other community-based AIDS organizations in order to operationalize the Declaration of Commitment in Canada, forming the Canadian Community-Based UNGASS Network, which included nine organizations across Canada. However, the Network has not been sustained due to lack of incentives, including lack of implications for community-based resources.

SECTION 4

NATIONAL HIV/AIDS POLICY AND ITS IMPLEMENTATION

PART I: Access to treatment, care and support

1. Components of Anti-Retroviral (ARV) Therapy in Canada³²

In general, anti-HIV medications are recommended if a person living with HIV has:

- A T-cell count less than 350 or
- A viral load greater than 55,000 or
- Any symptoms of HIV disease.

The current standard of HIV treatment includes the use of a combination of at least 3 different anti-HIV medications from at least two different classes. Currently there are two major classes of anti-HIV medications available in Canada:

- reverse transcriptase inhibitors or RT inhibitors (RTIs)
- protease inhibitors (PIs)

The RT inhibitors, or RTIs, are divided into 3 groups based on differences in their chemical structures: nucleoside RT inhibitors (also called "nukes" or NRTIs), non-nucleoside RT inhibitors (also called "non-nukes" or NNRTIs), and nucleotide RT inhibitors (also called NtRTIs). Medications from the class of nukes or NRTIs include:

- AZT (also called zidovudine or Retrovir)
- ddI (also called didanosine or Videx or Videx EC)
- d4T (also called stavudine or Zerit or Zerit XR)
- 3TC (also called lamivudine or Epivir)
- abacavir (also called ABC or Ziagen)
- Combivir (a combination medication of AZT + 3TC)
- Trizivir (a combination medication of AZT, 3TC + abacavir)

Medications from the non-nuke or NNRTI class include:

- nevirapine (also called Viramune)
- delavirdine (also called Rescriptor)
- efavirenz (also called Sustiva)
- tenofovir (also called Viread)

Medications from the class of protease inhibitors include:

- saquinavir (also called Invirase and Fortovase)
- indinavir (also called Crixivan)
- ritonavir (also called Norvir)
- nelfinavir (also called Viracept)
- amprenavir (also called Agenerase)
- Kaletra (lopinavir + ritonavir)

Drug coverage formularies through public drug reimbursement plans vary by province as health care is a provincial jurisdiction. There are also 19 federal drug formularies that operate outside of provincial health formularies (e.g., for Veterans, on-reserve Aboriginals or refugees). Generally,

³² CATIE, Plain and Simple Fact Sheet: Anti-HIV Medications (anti-retroviral therapy). 2003 March 27

while admitted to a hospital, patients will receive drugs free of charge as they are considered medically necessary.

2. Disparities in Access to Treatment

While Canada has the right principles in place to provide access to treatment, the difficulty is putting those principles into practice. There are significant inconsistencies in access to treatment based on geography and sub-populations through marginalization of certain vulnerable groups. The Canada Health Act only requires that public health insurance plans in the provinces/territories cover medically necessary hospital and physician services; this includes those prescription drugs that are supplied to patients while in hospital or sometimes upon discharge from hospital if they are sent home with a supply of medication. Other than that, there is no universal requirement to include coverage for medications in the public health insurance plans. Provinces provide drug coverage for (a) the elderly, and (b) social assistance recipients (including people with disabilities); but even though the province pays the cost, individuals often have to pay the pharmacist's dispensing fee or some small "co-payment". Only some provinces (e.g., British Columbia, Québec) provide a more extensive pharmacare program that isn't just limited to the elderly or recipients of social assistance, but is available to all residents. Finally, there are "catastrophic drug plans" for people (who are not elderly nor on social assistance) who face catastrophically high drug costs. These programs (eg, Ontario's Trillium Drug Program) are income-based – that is, there is a deductible based on the person's annual income; the person pays out of pocket for their medications up to that deductible amount, and the catastrophic drug program covers the remainder of the costs.

Generally, ARVs are covered by provincial health formularies. Some ARV medications are restricted by limited use or can be accessed through exceptions to drug formulary rules, however it requires a lot of paper work and cost for physicians to prove that their patients meet the exceptions. For example, in Ontario with Tenofovir, doctors were asked to provide a genotype test and a full medical history of the patient's file; many doctors find this very daunting and expensive. There are also inconsistencies in the formularies between provincial health jurisdictions; each province re-evaluates their formularies based on recommendations from the national Common Drug Review. In some cases, they disregard the recommendations (e.g., Atavanavir is not on the Manitoba formulary and not on Aboriginal on-reserve formulary).

There are also inequities in access to treatment for specific populations. In urban settings, the ability to access treatment in a confidential way is much greater than in a rural setting. The First Nations and Inuit Health Branch (FNIHB) has its own drug formulary system for on-reserve Aboriginals, however there is no jurisdictional responsibility for ensuring access to treatment for off-reserve Aboriginal people. It is also widely known that women, prisoners, immigrants/refugees and people who use illicit drugs have less access to ARV therapies. There are also rural-urban differences in access to treatment. Rural settings don't get access to as many clinical trials, and women are not enrolled in trials to an equitable degree to their male counterparts.

3. Adequacy of Treatment Information

People living with HIV/AIDS in Canada do not always have the information that they need to understand their ARV therapies and their side effects. Often, they are unable to make informed choices about joining trials; there are often complicated informed consent processes that are not accessible, especially if they don't understand drug resistance and interactions, have low literacy or language abilities. The same problems exist for non-trial drugs; not enough time is spent by doctors to provide treatment information. Treatment options are very complex, with multiple considerations

such as side effects and interactions, resistance – which can be very daunting for an individual without good english literacy and educational background.

One organization working to improve the level of information about HIV treatments is the Canadian AIDS Treatment Information Exchange,³³ a national, non-profit organization that provides treatment information not only for people living with the virus but also for their families, care providers, AIDS Service Organizations and Health Care Intermediaries. It does so through a comprehensive web site, three electronic mailing lists, various print publications and a bilingual, toll-free phone service.

4. Access to Treatment Survey Results

An on-line survey was conducted with people living with HIV across Canada to gather their perspectives on access to HIV treatments. A total of 153 people living with HIV responded to the survey during the three-week survey period. People living with HIV were reached through AIDS service organizations, national HIV/AIDS organizations, and both formal and informal networks. Some organizations facilitated responses from their clients by giving them access to agency computers, or printing out the survey and distributing to those PHAs who did not have access to a computer and then faxing to the author.

Gender	male	female	transgendered
Number of Respondents	113	36	1
Percentage of Respondents	73.9%	23.5%	0.7%

What kind of setting do you live in?			
	city	town or village	rural
Number of Respondents	122	17	8
Percentage of Respondents	79.7%	11.1%	5.2%

Province or Territory	Number of Responses	Percentage of Responses	% of Canada's HIV Prevalence
British Columbia	20	13.1%	18.4%
Alberta	12	7.8%	5.6%
Saskatchewan	3	2.0%	4.1%
Manitoba	2	1.3%	
Ontario	44	28.8%	38.6%
Québec	39	25.5%	31.1%
New Brunswick	2	1.3%	2.3%
Nova Scotia	12	7.8%	
Prince Edward Island	2	1.3%	
Newfoundland and Labrador	8	5.2%	
Yukon Territory	1	0.7%	4.1%
Northwest Territory	1	0.7%	
Nanuvut Territory	2	1.3%	

As indicated in the table above, the response rates from the various regions of the country are reasonably close to the relative prevalence distribution of HIV cases across Canada.

³³ www.catie.ca

The table below indicates the organizations or individuals from whom people living with HIV receive assistance in accessing ARV treatment.

What organizations or individuals have helped you to access the HIV ARV medications that you need?							
	N/A (not taking ARVs)	Family Doctor or GP	HIV Specialist MD	CBOs or ASOs*	Other PHAs	Rehabilitation Professional	Other (please specify)
Number of Respondents	8	57	95	30	18	1	17
Percentage	5.2%	37.3%	62.1%	19.6%	11.8%	0.7%	11.1%

* Community-based organizations or AIDS service organizations

Other organizations or individuals that have helped PHAs to access the ARV medications that they need include:

- *Hospitals or health centres*
- *Provincial health department*
- *Immunologist/Infectious Disease Specialist*
- *Family members*
- *Internet*
- *Private insurance*
- *Immigration lawyer*
- *HIV clinic pharmacist*

As can be seen in the table below, the majority of people living with HIV who responded to the survey felt that they had good access to ARV treatments, information, supports and health care services.

PHAs' Level of Agreement on the Following Statements:	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A
People living with HIV in my community can easily access antiretroviral (ARV) therapy.	31.4%	35.3%	5.2%	8.5%	3.3%	0.7%
It is easy for me to access antiretroviral therapy when I want it.	41.8%	27.5%	5.2%	3.9%	2.6%	2.6%
I feel well-informed about the HIV treatment options available to me.	36.6%	30.7%	7.2%	7.2%	2.0%	0.7%
I have access to adequate health care for my HIV-related treatment needs.	28.8%	34.6%	5.9%	9.2%	3.3%	1.3%
I have access to adequate HIV-related care/support in my community.	22.9%	30.1%	12.4%	11.1%	5.9%	0.7%
I have access to a wide range of health care services (e.g., complementary or alternative therapies).	14.4%	26.8%	14.4%	15.0%	11.1%	2.0%
I can get support if I need help with following my prescribed drug regimen.	21.6%	32.0%	13.7%	5.2%	5.2%	5.9%
I feel that my health status is adequately monitored during ARV therapy.	26.8%	36.6%	11.1%	3.9%	0.7%	4.6%

The respondents were asked: Where do you usually get information that you need about ARV therapy? (they were able to select more than one source of information)

	from other PHAs	from my doctor	from other health professionals	from ASOs or CBOs	from workshops or other training sessions	from the internet	brochures, pamphlets or information sheets	books or articles
Number of Respondents	76	101	37	88 *	59	83	62	40
Percentage	49.7%	66.0%	24.2%	57.5%	38.6%	54.2%	40.5%	26.1%

* specific AIDS service organizations or community-based organizations mentioned were the Canadian AIDS Treatment Information Exchange (3), CPAVIH (2) and Comit, Lipo-Action!

Other sources of HIV treatment information included:

- *I work in the HIV/AIDS field*
- *I attend many HIV/AIDS conferences*
- *Pharmaceutical companies*
- *medical journals*
- *videos*

As indicated in the table below, most of the respondents rarely to never experienced barriers with respect to accessing ARV medications. The barrier that was cited by the most respondents was the concern regarding development of resistance to the ARV drugs.

How often do you face the following types of barriers with respect to ARV medications?	Always	Usually	Sometimes	Rarely	Never
Access: The drugs I need aren't available	3.3%	5.9%	9.8%	19.0%	40.5%
Prices: I can't afford the drugs I need	6.5%	7.2%	7.8%	17.0%	38.6%
Information: I have difficulty understanding the drugs and their effects	1.3%	5.2%	17.6%	32.0%	20.9%
Care: I have difficulty finding a competent health care provider to provide HIV-related treatment and care.	0.7%	5.9%	13.1%	20.9%	37.9%
Adherence: I have difficulty adhering to my drug regimen as prescribed.	0.0%	7.2%	19.6%	25.5%	26.1%
Resistance: I have concerns about developing resistance to some types of drugs.	17.0%	12.4%	25.5%	13.7%	9.8%

Out of 153 respondents, 100 (65.4%) of were currently taking antiretroviral therapies. A complete listing of the drugs and their combinations is not included here, but can be accessed through AIDS Calgary upon request.

Of the 53 (34.6%) of respondents who were not currently taking ARVs, their reasons were as follows:

- *Good CD4 counts, ARVs not yet needed (13)*
- *I am supposed to be taking medications, but have stopped on my own (2)*
- *Structured Treatment Interruption or “drug holiday” on physician’s advice (6)*
- *Stopped taking ARVs because of side effects (e.g., high cholesterol)*
- *I lived for 2 months in housing that provided no privacy for taking medication*
- *Not able to afford the up-front costs of buying medications and waiting for reimbursement (2)*
- *On methadone maintenance therapy*

Many of the respondents were undergoing treatment for opportunistic infections (such as thrush, pneumonia, shingles, cytomegalovirus, peripheral neuropathy, and psoriasis). With respect to Sexually Transmitted Infections, respondents indicated that they were receiving treatment for herpes, genital warts, gonorrhoea and yeast infections. Respondents also indicated that they were receiving treatment for chronic diseases such as Hepatitis B and C, depression (very commonly listed by respondents), diabetes, hypertriglyceridemia, cancer, irritable bowel syndrome, heart disease, asthma, sinusitis, arthritis, heart disease, bipolar disorder, addiction, fibromyalgia and chronic fatigue syndrome, osteoporosis, hypertension, lipodystrophy, and many others. A complete listing of the other conditions for which respondents are being treated can be obtained from AIDS Calgary upon request.

Finally, respondents were asked to provide any other comments about access to treatment in Canada. Many individuals noted that the side effect of lipodystrophy (a disturbance in the way that they body produces, uses and distributes fat as a side effect of the use of protease inhibitor drugs) as a major concern for people using ARV treatments in Canada. Lipodystrophy places people living with HIV under the additional burden of poor body image, social isolation, depression and greater opportunities for stigma and discrimination on the basis of visible physical characteristics such as “buffalo hump” or wasting in the face. Many PHAs called for the government to provide coverage of expenses associated with repairing the effects of lipodystrophy (e.g., facial implants or plastic surgery):

“I wish the government would provide financial assistance for treating lipodystrophy. We should be treating the expenses of repairing side effects from the treatments, not as aesthetic expenses, but as essential for the wellbeing of the person when s/he is disfigured or deformed by these drugs.”

Other concerns were:

- *Limited access to care and support services for refugees*
- *Need for better information for patients and health professionals, and more research, regarding side effects of ARVs (especially lipodystrophy), risks of drug resistance, drug interactions and treatment alternatives (such as complementary therapies and nutritional supplements)*
- *Need for a more efficient drug monitoring process and post-approval rapid access to the new compounds for treating HIV*
- *Need for better treatment access and support for Aboriginal peoples and other marginalized populations, reducing disparities between urban/rural settings*
- *Shortage of HIV or infectious disease specialists as well as difficulty finding family practitioners who are knowledgeable about HIV/AIDS, requiring many PHAs to travel great distances at their own expense to access specialized care and treatment. Furthermore, some respondents noted that they have experienced stigma and discrimination from health care professionals and the health care system.*
- *Disparities in access to clinical trials outside large urban centres, and the need for greater access to experimental treatments*
- *More support needed in Canada long term survivors and AIDS-related bereavement*

- *More support for PHAs experiencing poverty, social isolation, poor body image, poor life and job skills*
- *Lack of universal coverage of ARV medications and complementary therapies outside private/employer drug plans or government support programs for the disabled/impooverished. For those who do have health plan coverage of their medications, the deductible payments or up-front payments can still be too expensive for many PHAs.*
- *The barriers of stigma and discrimination have yet to be reduced in any significant way*
- *Need for increased resources for community-based AIDS service organizations*
- *Need for more culturally-appropriate, and language-specific, care and support (e.g., for Aboriginal people and other ethnocultural minorities)*
- *More treatment, research and services specific to women living with HIV/AIDS*
- *People living with HIV need better access to, and understanding of the benefits of, rehabilitation and complementary therapies, both for treatment of HIV itself, but also for improved quality of life and amelioration of drug side effects*

Several respondents noted that they feel very fortunate to live in Canada and have access to ARV treatments. Some of the comments include:

“We in Canada are very luck in that we have access to HIV drugs. We also have a good standard of living and access to health care for even the poorest of us”.

“I really feel that Canada is one of the better countries to reside in when it comes to living with HIV/AIDS. I come from a third world country and I therefore find the health care providers here very professional. I cannot believe that my HIV medication bottles say a total of about \$2000 and I don't pay a cent of it. I'm very amazed”

“It is a privilege to live in Canada; as an HIV positive man I have access to treatment, medical care and support to address my health concerns. I am well aware that the favorable conditions that have allowed me to survive this condition are not the realities for the rest of the world.”

PART II: Prevention

1. Availability of Prevention Tools and Programs

In theory, all HIV prevention tools (e.g., male and female condoms, lubricants, clean needles, methadone substitution therapy) are available and accessible across Canada, except in prisons where institutional policies prohibit access to clean needles and in some cases condoms. In practice, even outside of prisons, most vulnerable populations (e.g., youth, Aboriginal communities, small rural communities, refugees, trafficked women and sex trade workers) have very spotty access to these prevention tools. For over a decade, it has been recommended that Canadian prison systems move ahead with implementing needle exchange programs in prisons.³⁴ In 2006, Correctional Services Canada is to receive advice from the Public Health Agency of Canada regarding how best to pilot needle exchange programs in one or more federal prisons.

Provision of these prevention tools and programs varies according to province and between health regions, especially for female condoms, needles, methadone and bleach. For some small communities, even where these prevention tools are accessible, individuals may be reluctant to access them from health centres or stores due to lack of privacy. Refugees, immigrants and trafficked women may not be able to get prevention tools and programs due to language barriers or lack of availability. Vancouver (British Columbia) is piloting Canada's first official safe injection facility and thorough evaluation is being conducted in order to assess the impacts of the program on drug use, overdose, infection, and crime rates.

2. Delivery of HIV Prevention Education Programs

Generally, HIV prevention education programs are developed and delivered by community-based organizations. Some prevention education is provided by schools, although not in a standardized way across all of Canada. Governments indirectly deliver prevention education by funding community-based prevention programs in schools, public health clinics, testing clinics, and STI clinics. Prevention education is most commonly targeted to youth post-puberty and there is much less emphasis on educating youth *before* they are likely to become sexually active.

3. Main Prevention Messages

With the exception of World AIDS Day campaigns led by the Global AIDS Campaign, there are no standardized prevention messages in Canada. Any information, education or communication initiatives on prevention are local or regional, sporadic, and time-constrained (mostly around AIDS Awareness Week and World AIDS Day – e.g., the Assumptions Campaign and Condom Country Campaign). The curriculum in schools varies by province and school board with respect to condoms and needle use messages. Communities generally develop and deliver their own targeted messages, due to restraints from school boards and the need to deliver population-specific messages. Most community-based prevention messages are based on sex-positive and harm reduction approaches, as opposed to abstinence-based models, recognizing that most people are sexually active and/or use drugs, while also providing them with information and prevention messages that will assist them to protect their health.

³⁴ Canadian HIV/AIDS Legal Network: *Prison Needle Exchange: Lessons from a Comprehensive Review of International Evidence and Experience* (2004).

4. Targeting Vulnerable Populations

There are a limited number of First Nations, Métis and Inuit prevention messages and programs being offered to Aboriginal youth³⁵. Of the messages that are available, a pan-Aboriginal approach is sometimes being taken that is often ineffective. In particular, Inuit youth are being lost in this approach. Aboriginal youth under the age of 15 and injection drug users are the groups most in need of HIV prevention messages but they are among the least likely to be receiving them. Prevention education must begin before youth become sexually active, and it must address injection drug use.

There are now efforts underway by the African and Caribbean Council on HIV/AIDS in Ontario to develop a National HIV/AIDS Strategy for Black Canadian, African and Caribbean Communities. Generally speaking, targeted prevention programs are well-designed and well-targeted but grossly under-resourced (due to one-time project funding). Prevention initiatives are largely led by community organizations working directly with the vulnerable populations. Most prevention messages in Canada have targeted MSM and gay men, injection drug users and youth. Limited messages have been targeted to women, migrants and mobile populations, very few prevention initiatives have been implemented for prisoners and transgendered people, and none have been targeted to sex workers.

5. HIV Prevention Needs Amongst Youth

The Canadian Youth, Sexual Health and HIV/AIDS Study, administered by the Council of Ministers of Education, Canada, in collaboration with the Canadian Strategy on HIV/AIDS of Health Canada, produced some worrisome findings about the level of knowledge and risk behaviours amongst Canada's youth.³⁶ Some students, for example, had the misconception that there is a vaccine available to prevent HIV/AIDS, and approximately 66% of Grade 7 students and 50% of Grade 9 students did not know that there is no cure for HIV/AIDS.

HIV/AIDS education in Canada's public education sector is hugely inconsistent. In some provinces and territories, HIV/AIDS education begins early in elementary school and includes information about HIV/AIDS-related stigma and discrimination, while in others, HIV/AIDS is only first mentioned in grade 8 learning outcomes and includes limited information. The Canadian AIDS Society CAS undertook an examination of the state of public school-based AIDS education, and developed a position statement and background, as well as educational resources³⁷.

6. Microbicides

The Canadian Microbicides Action Plan Steering Committee, coordinated by the Canadian AIDS Society, is working to develop a multi-sector Action Plan. During two successful Canadian Microbicides Symposia, representatives from various sectors (government, industry, community, research) jointly identified the need for a multi-sectoral Action Plan to articulate domestic and global contributions from Canada. A Steering Committee is undertaking the development of this Action Plan, which will position microbicides strategically within broader Canadian and international HIV/AIDS platforms, including *Leading Together*, the *Federal Initiative*, CIDA's HIV/AIDS Strategic Directions paper, and the Canadian HIV Vaccines Plan, also currently under development. A

³⁵ Canadian Aboriginal AIDS Network: HIV Prevention Messages for Canadian Aboriginal Youth, March 2004. http://www.caan.ca/english/grfx/resources/publications/youth_prevent.pdf

³⁶ The Canadian Youth, Sexual Health and HIV/AIDS Study. 2002. <http://www.cmec.ca/publications/aids/>

³⁷ The Status of HIV/AIDS Education in Canada's Public Education Sector. Canadian AIDS Society's Position Statement on The Status of HIV/AIDS Education in Canada's Public Education Sector. <http://www.cdnaids.ca/web/position.nsf/cl/cas-pp-0296>

Canadian Microbicides Action Plan would complement Canada's recent contribution to international microbicides research and development efforts, thus contributing to comprehensive, pan-Canadian, multi-sectoral, domestic and global responses. Canada is the first country in the world to develop a multi-sector microbicides plan outlining domestic and global contributions, and could serve as a model in the field.

Canada is well positioned to develop such an Action Plan, given the strong community-based response to microbicides, a strong HIV research basis, the existence of cross-departmental and cross-sector mechanisms for collaboration, and domestic and international commitments made to accelerate microbicides development and delivery. We would enhance our domestic response across sectors, contribute to global efforts in the field, and create and build on opportunities to support similar work in other AIDS-affected regions of the world.

7. HIV Vaccines

A group of government, community and research stakeholders are also working to develop a Canadian HIV Vaccines Plan. In June 2003, Health Canada convened the *Ottawa Roundtable on HIV Vaccines: Towards a Canadian HIV Vaccines Plan* to lay the foundation for a Canadian plan for the development and equitable distribution of HIV vaccines. The round table was able to reach a consensus on the components of a Canadian HIV Vaccines Plan. Organizations engaged in developing the plan have so far included:

- Health Canada (and now the Public Health Agency of Canada) Centre for Infectious Disease Prevention and Control and Division of Immunology and Respiratory Infections,
- Health Canada International Affairs Directorate, ?
- Canadian International Development Agency, ?
- Canadian Institutes of Health Research, ?
- the Federal Provincial Territorial Committee on HIV/AIDS, ?
- Canadian HIV/AIDS Legal Network, ?
- Canadian AIDS Society, ?
- International AIDS Vaccine Initiative, ?
- CANVAC, ?
- BC Centre for Excellence in HIV/AIDS, and the ?
- Canadian HIV Trials Network. ?

In December 2003, a second round table meeting was held to develop an outline for the Plan and discuss next steps, and to establish a small Canadian HIV Vaccines Plan Steering Committee. In 2004, posters were presented at Canadian Association for HIV Research Conference and the International AIDS Conference in Bangkok, describing the goals and components of the plan.

In 2005, the Steering Committee developed a roadmap document, called "Imagining a World Without AIDS: Roadmap for a Canadian HIV Vaccines Plan" for broader consultation. The goal was to engage a larger group of stakeholders and use the roadmap to develop a comprehensive Canadian HIV Vaccines Plan. This document is the result of a collaborative process, involving researchers, government and the community, and sets out some elements of a Canadian HIV Vaccines Plan, as well as the issues that a comprehensive plan should address. Approximately 25 of Canada experts were consulted in various components of the Plan, next steps are being developed for further articulating the Plan and putting the Plan into action.

Part III: Voluntary Counseling and Testing

1. Types of HIV Testing in Canada

Canadians choosing to be tested for the presence of HIV infection may have three different testing options, depending on the province or territory in which testing takes place: Nominal, Non-Nominal, or Anonymous.

1. Nominal/name-based HIV Testing - May be carried out at numerous locations, including clinics, mobile health care providers, and the offices of health care providers. The person ordering the test knows the identity of the person being tested for HIV and the test is ordered using the name of the person being tested, along with other patient information such as age, gender, city of residence, name of diagnosing health care provider, country of birth, HIV-related risk factors; and laboratory data. The amount of information collected varies according to the province/territory. If the test result is positive, the person ordering the test is obligated by law to notify public health officials and the test result is recorded in the health care record of the person being tested.

2. Non-Nominal/Non-Identifying HIV Testing - Similar to nominal/name-based testing with one exception: the HIV test is ordered using a code or the initials of the person being tested (not including the full or partial name).

3. Anonymous Testing - Usually available at specialized clinics, organized and supported by public health departments, and by some health care providers. The person ordering the HIV test does not know the identity of the person being tested for HIV and the test is carried out using a code. Only the person being tested for HIV knows their unique, non-identifying code. Information such as age, gender, HIV-related risk factors and the ethnicity of the person being tested for HIV may be collected during anonymous testing, depending on the province or territory in which the test is ordered or on the test site. Test results are not recorded on the health care record of the person being tested. Only the person being tested may subsequently decide to give his or her name and include the HIV test result in the medical record. Unfortunately, anonymous HIV testing is only available in British Columbia, Alberta, Saskatchewan, Ontario, Quebec, New Brunswick, Nova Scotia, and Newfoundland (by request only).

2. HIV Testing of Immigrants

As of January 2002, all people applying to immigrate to Canada as “permanent residents” (including refugees and sponsored family class applicants) must have an HIV test as part of the immigration medical exam³⁸. In practice, only people living with HIV who fit into certain categories can successfully immigrate on a permanent basis. Unless otherwise exempt, all applicants for permanent residence have to establish that they will not pose an excessive demand on health or social services. Canada generally only excludes people with HIV if they can be expected to place an “excessive demand” on publicly funded health and social services. Unless they are very ill, short-term visitors who are living with HIV/AIDS are not expected to place excessive demands on publicly funded health or social services and are generally allowed to come into Canada.

3. HIV Testing in Aboriginal Communities

A major barrier to HIV testing for on-reserve Aboriginal peoples is the lack of confidentiality around HIV testing and disclosure. Often, community health centres on reserves are run by friends or family members of community members, thus compromising the perception of confidentiality and privacy for people seeking an HIV test.

³⁸ Canadian HIV/AIDS Legal Network (2005).
www.aidslaw.ca/Maincontent/issues/Immigration/ImmigrationQ&A2005.pdf

Part IV: Empowerment of Women

1. Blueprint for Action on Women and HIV/AIDS Coalition

Recently, the Public Health Agency of Canada has been working with the coalition called “Blueprint for Action on Women and HIV/AIDS” in order to discuss the draft Framework on Population Specific Approaches for the *Federal Initiative* and to identify priority actions/issues for consideration for women in each of the priority vulnerable populations listed in the *Federal Initiative Blueprint for Action on Women and HIV in Canada: Towards 2006* (referred to as *The Coalition*) was created by civil society to bring together individuals and organizations addressing the needs of women living with, and affected by, HIV/AIDS in Canada to act as a united voice on policy issues. The coalition seeks to advocate on these issues and influence national, provincial and municipal governments to provide services and funding programs aimed specifically at services for women living with HIV/AIDS and women affected and vulnerable to HIV/AIDS.

The aim of the coalition is to develop a set of demands addressed to governments, the pharmaceutical industry and other stakeholders addressing all aspects of HIV/AIDS including prevention, care, treatment and support, research and policy initiatives that would stop the alarming infection rate and lack of gender-based treatment information and research. The Blueprint has defined a group of demands with one overarching demand: All demands must have adequate and sustained resources, including financial and human resources; must be culturally and linguistically appropriate and must include women with HIV as an integral part of the solution making and decision making process.

These demands were presented on World AIDS Day 2005 and included the following themes³⁹:

- Legal, Ethical and Human Rights
- Research
- Stigma and Discrimination
- Diagnosis and Treatment
- Prevention and Education
- Care and Support

The Blueprint Coalition will also be developing a report card to evaluate how well key stakeholders are doing in meeting these demands. This will be presented at the International AIDS Conference to be held in Toronto in August, 2006. The Coalition will also act to ensure that international women’s issues will be an integral part of the International AIDS Conference being hosted in Canada in 2006, including highlighting Canada’s response to women’s issues both domestically and globally.

2. Women’s Access to Medical Care and Treatment for HIV/AIDS

Further work needs to be done by appropriate stakeholders, including governments, healthcare institutions, healthcare providers and HIV-positive women, to develop responsive models for health care and support delivery that acknowledge and affirm the multiple roles that women play and the importance of including these in care and support plans. With respect to women’s care, treatment and support issues, the Blueprint Coalition makes the following recommendations:⁴⁰

- Ensure that informed choice and option of treatments (e.g., complementary and alternative medicine) be available and specific to women

³⁹ The full text of the Blueprint for Action on Women and HIV/AIDS can be requested from the Canadian AIDS Society: www.cdnaids.ca

⁴⁰ *Blueprint for Action on Women and HIV/AIDS in Canada: Towards 2006*, April 1-2 2005 Meeting, Minutes

- Ensure that there is a systemic post-approval surveillance system on drugs for women (and their treatment). This does not currently exist.
- Investigate and research how stigma and discrimination are barriers for getting and receiving support and care. The collected data should be segregated by sex and age.
- Gather and provide gender specific treatment information to: (a) ensure that treatment options are just as good for women as men, and that women are treated as women (not just mothers), and (b) provide health care professions with gender-specific information
- Across the country, establish standards of care, improve access to treatment (add treatment to formularies quickly)
- Coordination of treatment information across Canada

3. Female Condoms

Some public health units and community-based organizations distribute female condoms, but there is no government program to supply them. Female condoms are generally available for purchase at supermarkets and drugstores, and distributed free of charge or for a reduced price at some STI clinics, public health centers, or Family Planning Clinics. However, accessibility for women varies depending on their level of awareness of how to use female condoms, the limited number of stores that carry them, and their high cost relative to male condoms.

Information is available about how to use female condoms, their effectiveness, cost, and advantages/disadvantages compared to other protective measures. Information is available online through the following websites: PHAC, Canadian Health Network, Health Canada, SexualityandU (sexualityandu.ca), and local NGOs. Information is also available through fact sheets or brochures available in local NGOs.

4. Women's Barriers to HIV Treatment⁴¹

Women tend to receive HIV-positive test results later in the course of the disease (often finding out during pregnancy) because many doctors, and women, still believe women are at low risk of contracting HIV. Women therefore are discouraged from receiving early detection and treatment, receiving both can maintain health over a longer period of time.

Discrimination against women and failure by the medical community to understand the disease in women also prevent women from receiving effective treatment. Many HIV-positive women feel intimidated by doctors and may not ask as many questions as their HIV-positive male counterparts.

Pharmaceutical companies and the medical community must remove barriers preventing women from joining drug studies. Governments must remove the social and economic barriers preventing women from gaining access to treatment. Women need greater social and economic support if they are to receive effective treatment.

Poverty is another barrier to treatment because anti-HIV drugs are very expensive, and although the majority of costs are often covered by provincial plans, deductibles, co-payments and dispensing fees may prove prohibitive for people on low-income. Women earn less than men; many women work part time, and are often excluded from health plans; many mothers place the financial needs of their children and families above their own. Complementary and alternative therapies are typically not covered by provincial health plans, placing such therapies out of reach for many women.

⁴¹ Canadian AIDS Society. www.cdnaids.ca

Clinical Trials: despite increasing rates of HIV among women, they are woefully under-represented in clinical trials, which require a substantial time commitment, and may result in unpaid time away from work. Pharmaceutical companies and hospitals do not provide child-care services or compensatory money, making it difficult for women to participate in studies. Taking time off work may raise disclosure issues, as some women may not want to disclose their HIV status to employers. Women are often excluded from drug trials because of their biological potential for pregnancy. Many women lack support in the home, which can hinder their ability to participate in studies.

Barriers to drug adherence: as with barriers to treatment, social and economic factors prevent HIV-positive women from keeping to a drug regimen. However, women are faced with an additional burden: as traditional family caregivers, they give much of their time and energy taking care of others. Skipping medications, or taking drugs later than recommended, can reduce the overall level of health in HIV-positive women. Women need a family-centred approach to care and treatment.

5. Availability of Information about Women and HIV/AIDS

Government has undertaken some measures in the form of statistics, surveillance, epidemiology to enable and empower women to better understand and articulate their health needs, in an effort to combat HIV/AIDS. For example, information resources produced by the federal government include: HIV/AIDS Epi Update, May 2005, HIV and AIDS Among Women in Canada⁴² or the Women's Health Surveillance Report: Women and HIV.⁴³

However, measures such as programs, support etc. have been undertaken primarily by community-based organizations such as:

- Voices of Positive Women
- Positive Women's Network
- CRISS: Centre of Resources, Interventions, and Services in Sexual Health
- Canadian Federation for Sexual Health

Limited resources are available online specifically regarding women and HIV/AIDS. Most websites contain separate information on women and HIV/AIDS but general information lacks details on issues surrounding women and HIV/AIDS. There have been no specific educational programs initiated by the Government or its partners, focusing on building the capacity of women to reduce HIV transmission.

6. Protocol for Emergency Services in Rape or Sexual Abuse Cases

The protocol for emergency services in the case of rape or sexual assault varies for each health and law enforcement jurisdiction. Two examples of protocols in Canada:

Vancouver⁴⁴

Post-exposure prophylaxis (PEP) is available for survivors of sexual assault in Vancouver. However, PEP is not always being appropriately prescribed in the British Columbia program; 50% of those receiving treatment did not qualify for PEP according to the guidelines. They conclude that "greater effort is needed to support health care providers in their assessment of HIV risk in order that they appropriately prescribe these potent medications".

⁴² http://www.phac-aspc.gc.ca/publicat/epiu-aepi/epi_update_may_04/5_e.html

⁴³ http://www.phac-aspc.gc.ca/publicat/whsr-ssf/pdf/WHSR_Chap_26_e.pdf

⁴⁴ *Prophylaxis Following Nonoccupation Exposure to HIV*, HIV InSite Knowledge Base Chapter, February 2004, Michelle Roland

Niagara Health System⁴⁵

Four options for treatment after sexual assault are provided to women, within three days of the assault occurring. Clients may choose any or all of the following:

- pregnancy prevention (Morning After Pill)
- prophylactic treatment of sexually transmitted infections
- HIV post exposure prophylaxis
- follow up with social worker for trauma counseling

7. Specific Prevention and Diagnosis Services for Women

Diagnosis is one important part of the continuum of services to address HIV/AIDS, along with prevention, care, treatment and support. There is a need for more anonymous testing sites and population-specific testing sites, particularly for women. Physicians need better training on how to recognize and respond to signs and symptoms that women are in abusive relationships. Partner notification and disclosure in the context of violence against women is not well-addressed in Canada.

⁴⁵ www.niagarahealth.on.ca

Part V: Protecting the Human Rights Of PHAS And Vulnerable Groups

1. HIV as a Human Rights Issue

While Canada has enacted human rights legislation, and interpreted it in a way that it includes people living with HIV/AIDS under the umbrella of physical disability, enforcement of this legislation remains inadequate. In most cases, it is up to the individual who experiences discrimination to 1) know their rights, 2) recognize that they have been discriminated against, 3) have knowledge of the complaints mechanisms available for redress, and 4) be willing/able to lodge a complaint. These mechanisms for enforcement present many barriers for people living with HIV/AIDS and vulnerable populations. In order to access their basic rights, people must first have access to basic human rights information, rights-based education, and knowledgeable service providers to advocate and support self-advocacy. Given the nature of HIV/AIDS related stigma and the corresponding need for confidentiality, national and community-based AIDS service organizations have a key role to play in eliminating discrimination by bridging the enforcement gap through supporting such education and advocacy. The role of education and advocacy is not just the promotion of human rights, but also an integral part of ensuring the adequate enforcement of human rights legislation (particularly for vulnerable populations who might not otherwise have access to the information and resources they need).

2. Legal Protection from Discrimination⁴⁶

Section 15(1) of the Canadian Charter of Rights and Freedoms⁴⁷, which applies to all laws and other actions by governments in Canada, states:

“Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.”

Under the Canadian Human Rights Act people living with HIV/AIDS are protected from HIV-based discrimination in federal jurisdictions because HIV is considered a disability with respect to any employment, goods, services, facilities or accommodation or access thereto or occupancy of any commercial premises or residential accommodation. While the law in each province and territory prohibits discrimination based on a person’s HIV/AIDS status, there is no explicit reference to HIV/AIDS in the various anti-discrimination statutes. Rather, they refer more generally to “disability” or “handicap.” Various human rights commissions have adopted policies stating their interpretation of these terms to include HIV and AIDS, and numerous court and tribunal decisions have confirmed that protections against discrimination based on real or perceived disability include protections against discrimination based on real or perceived HIV-positive status or AIDS diagnosis.

Discrimination on the basis of sexual orientation is also prohibited in all jurisdictions of Canada. Gender-based discrimination is prohibited, as with HIV status or sexual orientation. However, only one jurisdiction in Canada (the Northwest Territories) has explicit protection on the basis of gender identity. Discrimination on the basis of race or ethnicity is prohibited. Discrimination on the basis of age is prohibited for those between the ages of 18 and 65 (youth and the elderly are not generally covered). Discrimination on the basis of injecting drug use is not prohibited under anti-discrimination legislation in any jurisdiction. However, in the employment context, some courts and

⁴⁶ R. Elliott & J. Gold. Protection against discrimination based on HIV/AIDS status in Canada: the legal framework. *HIV/AIDS Policy & Law Review* 2005; 10(1): 20-31.

⁴⁷ Canadian Human Rights Act: <http://www.efc.ca/pages/law/canada/canada.H-6.head.html>

tribunals have considered drug addiction/dependence to constitute a disability (or “handicap”, depending on the wording of the applicable statute) under law and therefore there is a duty to accommodate that disability, short of “undue hardship.”

There is also no protection for sex workers against discrimination based on their involvement in sex work. If an individual is convicted of using a place for prostitution, the owner or landlord of that space must be notified and can face criminal charges and conviction if they do not take steps – such as evicting the sex worker from his or her apartment – and the sex worker is subsequently convicted again.

Anti-discrimination legislation needs improvement in terms of protecting youth, transgendered people, drug users and sex trade workers. According to an environmental scan conducted by the AIDS Calgary Equality Project, there is a dearth of information on HIV-related discrimination in Canada. It is unknown how frequently HIV-based discrimination occurs, in what contexts, the responses to HIV-based discrimination, and how individuals seek effective redress.⁴⁸ Human Rights Commissions are charged with providing redress for discrimination, and some have a fast-track process or special guidelines for HIV-based complaints. However, there are concerns about delays and hurdles in getting Commissions to adequately respond to HIV-related complaints, largely due to resource constraints. Canada needs some additional research to gain a more thorough assessment of the extent of discrimination – in employment, housing, harassment, health care settings – on the basis of HIV status. Human Rights Commissions would be able to provide information about the number of complaints filed, which is generally believed to be a small proportion of actual incidents of discrimination.

3. HIV/AIDS in the Workplace

As the nature and impact of HIV/AIDS have shifted in recent years, many people living with HIV in Canada are living longer, but also with impairments, activity limitations and participation restrictions. Many community-based AIDS organizations in Canada are initiating work to address workplace issues for people living with HIV, such as the Canadian AIDS Society, COCQ-sida, British Columbia Persons with AIDS Society, AIDS Committee of Toronto, the British Columbia Coalition of People With Disabilities, the Interagency Coalition on AIDS and Development (ICAD), AIDS Calgary, and the Canadian Working Group on HIV and Rehabilitation (CWGHR). People living with HIV face numerous barriers with respect to remaining in employment or returning to employment after taking disability or sick leave. There are many issues faced by people living with episodic disabilities, such as HIV, in Canada. Two priority issues identified by the participants of the Episodic Disabilities Network are income security and labour force participation. The unpredictability of living with HIV, as with other episodic disabilities, can have a significant impact on income support.

ICAD is working to apply a rights-based approach to policy development and the practical considerations for implementing employee rights and employer obligations in the workplace. ICAD is developing training materials and workshops for both employers and employees regarding human rights and employment related legislation in Canada and how this relates specifically to HIV/AIDS as well as other life threatening, chronic and/or episodic disabilities. CWGHR is leading the "Labour Force Participation and Social Inclusion for People Living with HIV and Other Episodic Disabilities" project. This project is building on a network of episodic disability groups to identify and analyse policies, programs and practices of public and private disability income support and workplace issues to determine strengths, gaps and barriers. This knowledge will then be transferred

⁴⁸ Canadian HIV/AIDS Legal Network (1998). *HIV/AIDS and Discrimination: A Discussion Paper*

to policymakers, employers, human resource professionals, labour representatives, insurance providers and other relevant stakeholders. Finally, the project will facilitate labour force participation by testing and evaluating new models for flexible employment and income support to accommodate people with episodic disabilities.

SECTION 5: MONITORING AND EVALUATION

MONITORING CANADA'S ACTION PLAN

Each organization which receives funding from the *Federal Initiative* must submit funding proposals and progress reports to the government department administering the funding. Additionally, there are departmental workplans within each government department, with funded evaluation components in each department, and regular reports are provided to the Ministerial Council regarding the status of *Federal Initiative* spending.

A monitoring plan has not yet been established for Canada's Action Plan. The *Federal Initiative* states that coordination, planning, evaluation and reporting will be enhanced to optimize both the federal and pan-Canadian responses to the epidemic and the use of resources. The focus will be on supporting the implementation of *Leading Together* and the development of issue-specific plans (for example, vaccines, population-specific approaches) and an evaluation strategy for the *Federal Initiative*. Integral to this will be mechanisms that enhance the engagement of people living with and vulnerable to HIV/AIDS. The following activities were outlines for coordination, planning, evaluation and monitoring of the *Federal Initiative*

- A body will be established to coordinate and align the work of departments and agencies participating in the *Federal Initiative*.
- A multi-jurisdictional and multisectoral model will be developed to support the implementation of *Leading Together*.
- National and regional plans consistent with *Leading Together* will be developed and implemented.
- A performance measurement and evaluation strategy will be developed and implemented. Progress toward the goals of the *Federal Initiative* will be monitored on an ongoing basis.
- An annual report will be published each year on World AIDS Day as a key component of the performance measurement strategy.

The success of *Leading Together* depends on a voluntary nation-wide partnership, the responsibility for steering and monitoring it is to be shared among all the partners. The process for monitoring will likely involve five stages:

1. Commitment. Identifying the partners who should be part of the collective plan, and receiving from them a commitment to participate.
2. Roles and Responsibilities. Encouraging each partner to define its roles and responsibilities in implementing the Action Plan, based on its mission, skills and resources (i.e., what can each organization bring to our collective effort?)
3. Operational Plans. Asking each partner to identify the steps it will take over the next five years to implement the Action Plan, and reviewing all the operational plans against the Action Plan to identify any gaps (i.e., are there any outcomes or actions in the Action Plan that are not addressed by at least one partner?).
4. Monitoring Progress. Identifying the measures we will use to assess our progress and the information that partners will provide to support monitoring.
5. Steering the Plan. Using the monitoring information to develop progress reports, share effective strategies, and identify the need for new outcomes or actions, or to make changes in the Action Plan to respond to changing needs and knowledge.

SECTION 6

CONCLUSIONS, RECOMMENDATIONS AND LESSONS LEARNED

CONCLUSIONS

Overall, Canada's strong economic position has not been adequately reflected in the reduction of poverty, isolation, marginalization and overall vulnerability of many populations. Canada has not made enough progress with respect to addressing the determinants of health that make individuals vulnerable to HIV, addiction, and violence. People living with HIV in Canada still face significant levels of stigma and discrimination, and people who are vulnerable to HIV face policy and systems barriers that put them at greater risk of HIV. Canada's HIV rates continue to rise both amongst isolated vulnerable populations such as injection drug users and men who have sex with men, but also through heterosexual contact and increasingly amongst women. Aboriginals continue to be disproportionately affected by HIV, and HIV amongst people from countries where HIV is endemic is the fastest increasing risk category. A significant proportion of youth in Canada are complacent about HIV, and a significant proportion have erroneous understandings such as there being a cure for HIV.

Although people living with HIV in Canada officially have access to universal health care and fairly complete coverage of antiretroviral treatments, the realities in practice can be very sub-optimal for people who live in rural-remote areas, don't have private/employer health benefits, or for Aboriginals and refugees. The side effects of protease inhibitors such as lipodystrophy have created a new layer of stigma and discrimination amongst people living with HIV and health care systems need to provide the treatments that alleviate those side effects so that people living with HIV not only live longer but also with high quality of life. A major human rights issue for people living with HIV in Canada is adequate supports through policies and programs that facilitate return to work or continuation of employment.

Civil society and government generally work well together to address HIV/AIDS from a multi-sectoral, multi-stakeholder perspective, and Canada's newest incarnation of a national HIV/AIDS strategy, the *Federal Initiative*, brings new hope that HIV will be addressed from across the federal government and not just the Ministry of Health. However, Canada still needs to assemble an overarching coordinating body which would champion, implement and monitor a multi-stakeholder, multi-sectoral, strategic pan-Canadian plan, and address HIV/AIDS and its vulnerabilities from a social determinants of health perspective. Needed are incentives for meeting the actions in the *Leading Together* plan, formal mechanisms for linking the provincial and federal governments, accountability structures, and champions in each of the stakeholder groups to take responsibility for the action plan. Civil society would also like to see national leaders (the Prime Minister, the Minister of Health, the Minister of State for Public Health, and others) speak about HIV/AIDS to the public to help raise awareness and reduce stigma, in speeches outside funding announcements or beyond once a year on World AIDS Day.

RECOMMENDATIONS

Policies: Leadership is needed across all levels of government in Canada to create, implement and strongly enforce laws that prohibit human rights violations against people living with HIV and vulnerable populations (such as women, Aboriginal people, people who inject drugs, prisoners, gay men, sex trade workers, refugees, and others). In particular, anti-discrimination legislation needs improvement in terms of protecting youth, transgendered people, drug users, prisoners and sex trade workers. Additional leadership is needed from the private sector to develop, implement and

sustain policies prohibiting discrimination against HIV+ employees in the workplace, or those who have HIV+ family members, with strong enforcement provisions; to provide ongoing HIV/AIDS awareness campaigns for their employees.

There should also be immediate decriminalization of sex workers by the federal government; virtually every activity related to prostitution is criminalized. Also, Canada needs stronger enforcement of laws, policies and practices that prohibit violence against women and their families. Law enforcement agencies charged with enforcing them must do so rigorously. Archaic policies against illicit drug use and sex work must be modified in order to reduce the harms of violence, disease, criminality, stigma and discrimination faced by people who use drugs or who engage in sex work.

Aboriginal Issues: There is an urgent need for leadership and immediate action from all levels of government in Canada to redress the impacts of colonization and racism that are fueling the HIV epidemic for Aboriginal people in Canada. There should be public acknowledgement by all levels of government in Canada of the direct causal relationship between colonization, stigma and discrimination and Aboriginal people's (particularly women's) susceptibility to HIV/AIDS. Governments must redress this historical legacy by providing resources to Aboriginal peoples, including First Nations, Inuit and Métis, to develop appropriate solutions. The Canadian government should provide full support for Aboriginal peoples to develop culturally and linguistically appropriate prevention and education strategies and programs for First Nations, Metis and Inuit peoples across Canada.

Research: Canada needs a comprehensive research strategy on HIV/AIDS that specifically addresses cultural groups and life experiences impacted by HIV, including questions regarding prevention, diagnosis, care, treatment and support. This agenda must be developed by relevant stakeholders including researchers, research funders, men and women living with HIV, institutions doing research and research coordinating bodies. All HIV/AIDS research should be community-based, i.e., include meaningful involvement of women and men from all cultural backgrounds and life experiences to ensure ownership and direction by research participants. Canada must dedicate more resources to the development of women-initiated forms of HIV/AIDS prevention, particularly microbicides, including a dissemination plan which will allow affordable, free and unlimited access to these methods. Canada's research efforts on vaccines and microbicides must be coordinated through strategic and cooperative plans that bring together all stakeholders in one common agenda.

HIV Prevention: A number of studies have provided evidence of the extent of injection and other drug use in prisons. Sterile injection equipment should be made available in prisons where prisoners inject illegal drugs. Pilot projects for needle exchange programs in prisons should be undertaken immediately. Canada's education system at all levels and across all educational institutions must mandate inclusion of age-appropriate HIV/AIDS education as a subject of school curricula. Prevention initiatives must target those younger than 15 years old. Limited messages have been targeted to women, sex workers, migrants and mobile populations, and very few prevention initiatives have been implemented for prisoners and transgendered and bisexual people. More Aboriginal, youth-specific services and prevention programs need to be developed and maintained. Rural areas, isolated areas and on-reserve need special attention. More targeted prevention messages that recognize the unique cultures of First Nations, Métis and Inuit youth need to be developed and maintained.

HIV Testing: There is a need for further development and accessibility of culturally and linguistically relevant testing sites with services provided by health-care providers trained in HIV testing protocol, including comprehensive pre- and post-test counselling, voluntary testing and informed consent. Canada's health care system must implement and enforce policies and practices that prohibit

mandatory testing of all women, including pregnant women, or testing without full informed consent. Health care providers should have to complete compulsory education about women and HIV/AIDS as part of their professional training.

Empowerment of Women: The Government of Canada has not developed a strategy specifically to protect and to provide opportunities for empowering women in the context of the AIDS epidemic, although “women at risk” are one of the vulnerable groups named in the *Federal Initiative*. It should be noted that no specific mention of sex trade workers as a vulnerable population is made in the *Federal Initiative*. No strategies specific to empowering women are mentioned in the *Federal Initiative* or *Leading Together*. Rather, women are mentioned in a general context along with others groups of people vulnerable to HIV/AIDS.

Access to Treatment: Particular attention must be paid by all stakeholders, including governments, pharmaceutical companies, people with HIV/AIDS, and health care providers, to redress the imbalance with respect to access to treatment. Women need a family-centred approach to care and treatment. All health care providers need to ensure that informed choice and option of treatments (e.g., complementary and alternative medicine) are available to people living with HIV. Generally, Canada lacks population-specific strategies that provide confidential, culturally and linguistically relevant HIV/AIDS treatment and treatment information for different groups of people living with HIV/AIDS. There is also inadequate population-specific research on treatment beyond Caucasian men. The Public Health Agency of Canada is currently working on developing population-specific strategies and funding envelopes across all programming areas.

Canada’s health care systems also need to develop more integrated team models of health care delivery with respect to HIV/AIDS, giving more responsibility to pharmacists, nurse practitioners, rehabilitation professionals and home care providers, taking some responsibilities out of the hands of doctors whose main responsibilities should be diagnosis and treatment.

Finally, there is an overall shortage in Canada of infectious disease physicians and other health care providers who specialize in HIV or who are willing to treat people living with HIV. It is very difficult, for example, for people living with HIV to find a dentist who will treat them.

LESSONS LEARNED

Canada has a very complex HIV epidemic; its subpopulations of vulnerable groups most affected by HIV essentially comprise several sub-epidemics, each requiring their own strategies to prevention, diagnosis, care, treatment and support. The authors found it difficult to fully elaborate on these specific vulnerable groups and their associated strategies through this civil society report template.

While the report covers in a reasonable amount of detail domestic status of our country in meeting the Commitments of the UNGASS Declaration, the report template is missing a whole other set of responsibilities, especially for developed countries, of ensuring that the DoC is implemented globally. The report template does not allow space for Canada to assess its leadership in developing countries with respect to resources, policies, research, technical support, and partnerships.

For future consultation processes, civil society representatives recommended longer turnaround time in order to engage civil society more meaningfully, and some formal method of engaging civil society in dialogue with government, especially regarding the rationale behind their different perspectives on the adequacy of HIV/AIDS programs and policies in Canada. Canadian civil society values the opportunity to provide its own assessment of Canada’s fulfillment of the UNGASS Declaration of Commitment, separate from government, as a means of ensuring that its strong voice stands out on its own.