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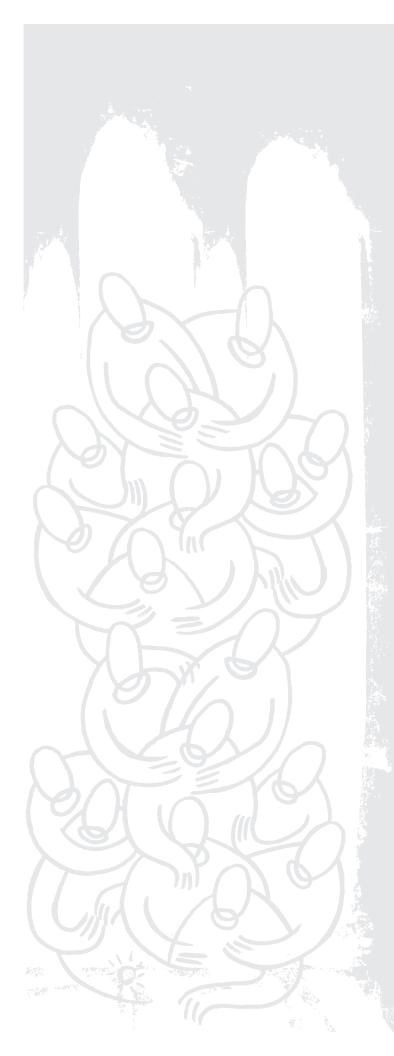
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for Canada to reduce HIV/AIDS-related stigma and discrimination

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CANADIAN RÉSEAU HIV•AIDS JURIDIQUE LEGAL CANADIEN NETWORK VIH•SIDA



Α PLAN OF ACTION for Canada to reduce HIV/AIDS-related stigma and discrimination

prepared by

Theodore de Bruyn for the

Canadian HIV/AIDS Legal Network





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

A Plan of Action for Canada to reduce HIV/AIDS-related stigma and discrimination

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Dedication

To the memory of Bob Mills [30 January 1958 – 8 October 2003]. With gratitude and applause.

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[Ce document est également disponible en français]

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TABLE OF CONTENTS

EXECUTIVE SUMM

A CALL TO ACTION

INTRODUCTION

Part of the Global Ca HIV/AIDS Stigma and Where things stood Time to take stock

About the Plan of Act

How the plan of action The plan of action How to use the plan

SOME IMPORTANT CO

Stigma and stigmatiza

Discrimination Human rights Governments' obl Human rights and International Guid and Human Right Legal protection again The Canadian Cha Human rights legis An intersectional app discrimination

PLAN OF ACTION

PARTICIPATION OF PE HIV/AIDS AND VULNE Participation of peop

HIV/AIDS and vulner Sufficient and stable

ARY	i
N	I
	I
ampaign Against d Discrimination in Canada in 1998	 2 3
ction ion was developed	4 4 5
n of action	7
ONCEPTS	8
ation bligations d HIV/AIDS delines on HIV/AIDS hts inst discrimination in Canada harter of Rights and Freedoms islation proach to stigmatization and	8 9 10 11 12 13 15 15 18 19
	21
EOPLE LIVING WITH ERABLE TO HIV ple living with	22
erable to HIV	22
funding for programs	24

TACKLING STIGMATIZING ATTITUDES	25
Changing Public Attitudes Attitudes in Canada Attitudes in subpopulations The intersection between HIV/AIDS stigma and other forms of stigma and discrimination Information itself is not enough	25 26 27 29 30
Informing Media Coverage The power of media	31
Supporting People Living with HIV/AIDS and People Vulnerable to HIV The effects of stigma Rejecting stigma: people living with HIV/AIDS Rejecting stigma: people vulnerable to HIV	33 34 35 37
ADVOCATING FOR RIGHTS	38
Strengthening Community-Based Education and Advocacy	38
The role of education and advocacy Adequate resources for advocacy	39
Greater Awareness of Human Rights Informing people of their options	44 44
Access to Legal Information and Advice	46
Working with Human Rights Commissions	49
ACCESSING PROGRAMS, SERVICES, ACCOMMODATION, AND EMPLOYMENT	51
Community HIV/AIDS Education and Prevention	51
Health Services Common areas of concern Respect for the choices of people receiving care Confidentiality of health information Access to antiretroviral drugs Concerns of specific populations Prevention and care for Aboriginal people Prevention and care for gay, lesbian, bisexual,	55 58 58 58 58 59 59
and two-spirited people Prevention and care for people of African	60
and Caribbean descent	61
Prevention and care for people who use drugs Prevention and care for prisoners	61 62
Prevention and care for trans people	63
Prevention and care for women	64

Proposed actions to in prevention and care
Housing
Problems with income
Employment HIV testing and confid Accommodation at we making the workplace Workplace policies and
Youth and Education Sexual health Use of alcohol and oth
Immigrants and Refuge Immigration and Refug Concerns about the In Refugee Protection Ac
International Cooperat
STRENGTHENING RESE
Participatory and Inclu
Evaluation of Intervent
SUMMARY OF GOAL
BIBLIOGRAPHY
APPENDICES
Appendix A: Members Committee
Appendix B: Participan to Review the Draft Pl

NOTES

improve HIV

Improve HIV	
L	65
	66
ne support	68
fidentiality work –	70 72
ce work and education	76 77
i other drugs	80 81 86
other drugs gees Jugee Protection Act Immigration and	88 89
Act and Regulations	90
ration	94
ESEARCH AND EVALUATION clusive Research entions	97 97 101
ALS AND ACTIONS	103
	121
	133
rs of the Advisory	133
ants in the Workshop Plan of Action	134

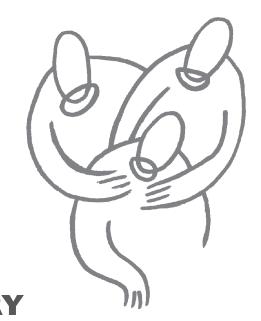
135

EXECUTIVE SUMMARY

CANADA'S COMMITMENT TO TAKE ACTION AGAINST STIGMA AND DISCRIMINATION

There is now worldwide recognition that it is essential to take action on the many forms of stigma and discrimination in the HIV/AIDS epidemic. Taking action on HIV/AIDS-related stigma and discrimination has been the focus of a two-year World AIDS Campaign sponsored by UNAIDS.1 It is also the focus of a two-year campaign of the Global Network of People Living with HIV/AIDS and the International Federation of the Red Cross and Red Crescent.² And it is integral to the commitment that all the countries of the United Nations, including Canada, made at the 2001 General Assembly Special Session on HIV/AIDS.

In 1998 the Canadian AIDS Society and the Canadian HIV/AIDS Legal Network published a comprehensive overview of stigma and discrimination associated with HIV/AIDS in Canada, entitled HIV/AIDS and Discrimination: A Discussion Paper. The overview proposed a framework for action on stigma and discrimination.



i

¹ For more information, see the website of the World AIDS Campaign at www.unaids.org/en/events/world+aids+day+2004/world+aids+day+2003.asp.

² For more information, see the websites of the International Federation of the Red Cross and Red Crescent at and the Global Network of People Living with HIV/AIDS at www.gnpplus.net/advocacy.html.

Today, stigma and discrimination continue to affect people living with HIV/ AIDS and populations associated with the epidemic, particularly those who are socially and economically excluded by our society. It is time to review the situation and see what action needs to be taken now.

A plan of action

This report presents a plan of action for Canada to prevent, reduce, and eliminate stigma and discrimination in the context of the HIV/AIDS epidemic. It was developed through a process of research and consultation with people living with HIV/AIDS, those vulnerable to HIV, community-based organizations, national organizations, and labour organizations.

The plan of action assigns primary responsibility for taking action against stigma and discrimination to those agents (such as governments, service providers, employers) that, according to human rights law, have an obligation to respect, protect, and fulfill the right to freedom from discrimination, as well as other human rights. The plan of action is meant to build on or strengthen action that governments, service providers, employers, national and community-based organizations, people living with HIV/AIDS, and people vulnerable to HIV are already taking against stigma and discrimination.

The plan of action covers five broad areas:

- participation of people living with HIV/AIDS and vulnerable to HIV
- tackling attitudes
- advocating for rights
- accessing programs, services, accommodation, and employment
- strengthening research and evaluation.

The plan of action sets out:

- broad goals
- actions governments and other agents should take to fulfill their obligations
- background information on the topic
- examples of specific problems or issues
- tips on further reading and resources.

How to use the plan of action

If you are an elected official, you can use the plan of action to ensure that your government and its administration are meeting their obligations under human rights law. Are there areas where you need to strengthen the action you are taking to address stigma and discrimination?

If you are a public servant, you can use the plan of action in efforts to ensure that your department, in its policies and programs, is meeting its obligations under human rights law. Are there areas where you need to strengthen the action you are taking to address stigma and discrimination?

If you provide services in public health, health care, education, employment, housing, or other sectors, you can use the plan of action to ensure that you are meeting your obligations under human rights law. Are there areas where you need to strengthen the action you are taking to address stigma and discrimination?

If you provide services in a community organization, you can use the plan of action to ensure that you are meeting your obligations under human rights law. Are there areas where you need to strengthen the action you are taking to address stigma and discrimination?

If you advocate for people living with HIV/AIDS or communities affected by HIV/AIDS, you can use the plan of action to ensure that governments and other organizations are meeting their obligations under human rights law. Are there areas where they need to strengthen the action they are taking to address stigma and discrimination?

If you are a person living with HIV/AIDS or a member of a community particularly affected by HIV/AIDS, or an organization of people living with or a community affected by HIV/AIDS, you can use the plan of action to hold governments and other organizations accountable for their obligations under human rights law. Are there areas where they need to strengthen the action they are taking to address stigma and discrimination?

iii

A CALL TO ACTION

INTRODUCTION

Part of the Global Campaign Against HIV/AIDS Stigma and Discrimination

"Stigma and discrimination are the major obstacles to effective HIV/AIDS prevention and care. Fear of discrimination may prevent people from seeking treatment for AIDS or from acknowledging their HIV status publicly. People with, or suspected of having, HIV may be turned away from health care services, denied housing and employment, shunned by their friends and colleagues, turned down for insurance coverage or refused entry into foreign countries. In some cases, they may be evicted from home by their families, divorced by their spouses, and suffer physical violence or even murder. The stigma attached to HIV/AIDS may extend into the next generation, placing an emotional burden on children who may also be trying to cope with the death of their parents from AIDS."

There is now worldwide recognition that it is essential to take action on the many forms of stigma and discrimination in the HIV/AIDS epidemic. During 2002 and 2003, taking action on HIV/AIDS-related stigma and discrimination has been the focus of a two-year World AIDS Campaign sponsored by UNAIDS.² Since August 2002, the fight against HIV-related stigma and discri-



1

Read more about

The UNAIDS World AIDS Campaign 2002-2003 at www.unaids.org/wac/2002/ index en.html

Global action against HIV/AIDSrelated stigma and discrimination by the Global Network of People Living with HIV/AIDS and the International Federation of the Red Cross and Red Crescent at www.gnpplus.net/advocacy.html and

www.ifrc.org/fr/what/health/ hivaids/antistigma/index.asp

The United Nations Declaration of Commitment on HIV/AIDS at www.unaids.org/UNGASS/ docs/ AIDSDeclaration_en.pdf

The work of the International Council of AIDS Service Organizations on the Declaration of Commitment on HIV/AIDS at www.icaso.org/icaso/icaso.html

mination has also been the subject of a partnership between the Global Network of People Living with HIV/AIDS, UNAIDS, and the International Federation of the Red Cross and Red Crescent Societies.³

In June 2001, all the member countries of the United Nations, including Canada, made a commitment at the General Assembly Special Session on HIV/AIDS to take action on stigma and discrimination. They agreed that by the year 2003 they should

ensure the development and implementation of multisectoral national strategies and financing plans for combating HIV/AIDS that address the epidemic in forthright terms; confront stigma, silence and denial; address gender and age-based dimensions of the epidemic; [and] eliminate discrimination and marginalization.⁴

They also agreed that by 2003 they should

enact, strengthen or enforce, as appropriate, legislation, regulations and other measures to eliminate all forms of discrimination against, and to ensure the full enjoyment of all human rights and fundamental freedoms by, people living with HIV/AIDS and members of vulnerable groups, in particular to ensure their access to, inter alia, education, inheritance, employment, health care, social and health services, prevention, support and treatment, information and legal protection, while respecting their privacy and confidentiality; and develop strategies to combat stigma and social exclusion connected with the epidemic.⁵

Where things stood in Canada in 1998

In 1998 the Canadian AIDS Society and the Canadian HIV/AIDS Legal Network published a comprehensive overview of stigma and discrimination associated with HIV/AIDS in Canada, entitled HIV/AIDS and Discrimination: A Discussion Paper. The overview proposed a framework for action on stigma and discrimination. It called for:6

- community participation in designing, implementing, and evaluating policies and programs;
- staff, protocols, systems, and networks to gather information on stigma and discrimination, analyze information, develop policy, and promote change in policies and practice;
- specialized legal services for people living with HIV/AIDS and populations affected by HIV/AIDS, and a network of lawyers and legal clinics offering such specialized legal services;

- · reviewing and recommending reforms to legislation and law enforcement practices that have an adverse effect on people living with HIV/AIDS and populations affected by HIV/AIDS, to human rights legislation and procedures, and to human rights policies;
- · public education aimed at reducing HIV/AIDS-related stigma and at creating a supportive environment for people living with HIV/AIDS and populations affected by HIV/AIDS;
- · education and training to promote and foster non-stigmatizing and nondiscriminatory attitudes and practices among professionals, particularly those who provide care to people living with HIV/AIDS on an occasional basis:
- · education for children and youth regarding the modes and risks of HIV transmission and the rights of people living with HIV/AIDS and populations affected by HIV/AIDS, both in the schools and through alternative peer-based programs sponsored by social agencies and community organizations;
- initiatives to address HIV/AIDS-related harassment and discrimination in the workplace:
- efforts to increase participation of under-represented populations in research, in identifying research priorities, in designing and implementing research projects, and in the ethical review of research; and
- a plan to monitor and evaluate annually efforts to prevent, redress, and eliminate HIV/AIDS-related discrimination.

Time to take stock

Six years later, in 2004, stigma and discrimination continue to affect people living with HIV/AIDS and populations associated with the epidemic, particularly those who are socially and economically excluded by our society. It is time to review the situation today and see what action needs to be taken now.

This report presents a plan of action for Canada to prevent, reduce, or eliminate stigma and discrimination in the context of the HIV/AIDS epidemic.

Read more about

The 1998 Discussion Paper on HIV/AIDS and Discrimination at www.aidslaw.ca/Maincontent/ issues/discrimination/discussion papers/DISCtoc.html

About the Plan of Action

How the plan of action was developed

The plan of action was developed through a process of research, advice, and consultation:

- · A review of social scientific literature and of relevant governmental and non-governmental reports was conducted. The review of social literature concentrated on studies published between 1998, when the Discussion Paper was released, and 2003. The review of reports included international and national documents on stigma, discrimination, and issues facing people living with HIV/AIDS or vulnerable to HIV.
- · An advisory committee was brought together to advise on the development of the project. The members of the advisory committee are listed in Appendix A. The committee commented in detail on the first draft of the review of literature and the plan of action.
- Interviews were held with people who provide advocacy or support services to people living with HIV/AIDS in connection with stigma and discrimination.
- Focus groups were held with people living with HIV/AIDS. These meetings were used to gather first-hand information about their experience of stigma and discrimination.
- · Information about the priorities of specific groups of people living with HIV/AIDS or vulnerable to HIV was sought from members of the advisory committee and from organizations working with these groups.
- · A draft plan of action was developed. It was reviewed and revised at a meeting in October 2003. The participants at the meeting included people living with HIV/AIDS, and representatives from national organizations, community organizations, and labour organizations. The list of participants is included in Appendix B.
- A revised plan of action was posted to the website of the Canadian HIV/ AIDS Legal Network (www.aidslaw.ca) in December 2003. Individuals and organizations were invited by email and by regular mail to comment on the plan. Comments were received from 30 organizations and 16 individuals.
- The final plan of action was prepared in light of the comments received.

Although the process used to gather information for, and solicit feedback during, the development of the plan of action was extensive, it was not exhaustive. While the research that contributed to the development of the plan drew on social scientific literature and governmental and non-governmental reports, it did not attempt a systematic critique of that literature based on a unifying theory or method. There was a selection bias in the people and organizations consulted during the development of the plan. Most, if not all, had experience with or concern about HIV/AIDS-related stigma and discrimination. Their perspective may not be that of all people living with HIV/AIDS or vulnerable to HIV. The penultimate draft of the plan was circulated widely in an effort to obtain criticisms and comments from people and organizations across Canada. Nevertheless, the goals and actions set out in the plan may not be shared by all people living with HIV/AIDS, people vulnerable to HIV, or the community-based organizations that serve these groups.

The plan of action

The plan of action assigns primary responsibility for taking action against stigma and discrimination to those agents (such as governments, service providers, employers) that, according to human rights law, have an obligation to respect, protect, and/or fulfill the right to freedom from discrimination, as well as other human rights. The actions are addressed to these agents.

The plan of action is meant to build on or strengthen actions that governments, service providers, employers, national and community-based organizations, people living with HIV/AIDS, and people vulnerable to HIV are already taking against stigma and discrimination. The report provides examples of such actions.

An organization of people living with HIV/AIDS addresses stigma and discrimination:

"British Columbia Persons With AIDS Society already has stigma and discrimination components in many of our existing programs. In fact, the bulk of our work as a society is focussed on reducing stigma and discrimination. Given this fact, we will continue to identify problems, advocate and lobby government, employers and institutions for change when appropriate.... We also look forward to participating in the sharing of best practices.... A national cohesive and collaborative approach to address stigma and discrimination for all people with HIV/AIDS and a clear action plan to do so is urgently needed."

- British Columbia Persons With AIDS Society

The plan of action recognizes that circumstances and needs vary in the diverse communities, provinces, and territories across Canada. The plan of action cannot and does not provide detailed workplans to address every potential circumstance and need. The responsibility for such workplans lies with agents in these jurisdictions.

The plan of action covers five broad areas:

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

The plan of action sets out:

- broad goals
- actions governments and other agents should take to fulfill their obligations
- background information on the topic
- examples of specific problems or issues
- tips on further reading and resources.

A provincial HIV/AIDS strategy addresses stigma and discrimination:

On World AIDS Day 2003 Nova Scotia released its new Strategy on HIV/AIDS (www.gov.ns.ca/health/downloads/HIVAids_summaryreport.pdf). The strategy will address stigma and discrimination by addressing the health, social, political, legal, and economic realities of HIV/AIDS. The community-based strategy was developed through extensive consultation with stakeholders across the province. The strategy sets out detailed recommendations for action under four strategic directions:

- mobilize integrated action on HIV/AIDS
- build a broad research and information sharing strategy
- build a coordinated approach to prevention and harm reduction
- build a coordinated approach to care, treatment, and support service

The recommendations specify ways to:

- reduce stigmatization and discrimination associated with HIV/AIDS;
- · address sexism, racism, and homophobia; and
- remove barriers and inequalities in health services, education, and other public services.

How to use the plan of action

If you are an elected official, you can use the plan of action to ensure that your government and its administration are meeting their obligations under human rights law. Are there areas where you need to strengthen the action you are taking to address stigma and discrimination?

If you are a public servant, you can use the plan of action to ensure that your department, in its policies and programs, is meeting its obligations under human rights law. Are there areas where you need to strengthen the action you are taking to address stigma and discrimination?

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If you advocate for people living with HIV/AIDS or people vulnerable to HIV, you can use the plan of action to ensure that governments and other organizations are meeting their obligations under human rights law. Are there areas where they need to strengthen the action they are taking to address stigma and discrimination?

If you are a person living with HIV/AIDS, affected by HIV/AIDS, or vulnerable to HIV, or an organization of people living with HIV/AIDS, affected by HIV/ AIDS, or vulnerable to HIV, you can use the plan of action to hold governments and other organizations accountable for their obligations under human rights law. Are there areas where they need to strengthen the action they are taking to address stigma and discrimination?

6

7

SOME IMPORTANT CONCEPTS

Stigma and stigmatization

Stigma refers to an unfavorable "mark" placed on a person or a group. The mark is made up of the attitudes, beliefs, and policies directed toward that person or group by others because of a perceived characteristic of the person or group. As it was originally used, the word "stigma" referred to a marking on the body that could be seen, made by a branding iron or pointed instrument.

Stigmatization is a social process of devaluation. People devalue others or themselves because of some characteristic or characteristics they have or appear to have.7 Stigmatization is expressed in fear, avoidance, shame, blame, and judgmentalism.

External stigmatization refers to stigmatization of other people or by other people. For example, people stigmatize people living with HIV/AIDS when they:8

- do not want to share dishes, equipment, or other objects with them;
- do not want to touch them or be close to them;
- do not want to spend time with them;
- pressure them to leave their home;
- pressure them to leave some social setting;
- think it is their own fault for contracting HIV; or
- judge them as being "immoral" or "irresponsible" or "sinful."

Stigmatizing Attitudes in Canada

A recent survey in Canada found that a guarter of the respondents had a low level of comfort in associating with people with HIV/AIDS and that forty percent had only a moderate level of comfort. Almost half of the respondents said that people with HIV/AIDS should not be allowed to serve the public as, for example, dentists or cooks. And while over three-quarters of respondents do not believe that people infected with HIV through sex or drug use have gotten what they deserve, one in ten Canadians still hold this view.

- FKOS Research Associates HIV/AIDS - An Attitudinal Survey

Internal stigmatization – also called "self stigma" or "felt stigma" – refers to ways that people stigmatize themselves. For example, people living with HIV/AIDS may feel that they:10

- are somehow guilty or dirty;
- are a threat to other people's health;
- need to withdraw socially to protect themselves;
- cannot have intimate relations with someone else; or
- must work harder than other people in order to prove themselves.

The stigma associated with HIV/AIDS is complex. It draws on what people think and how they feel about an incurable virus, sickness, and death; about sexual activity and sexually transmitted disease; about homosexuality, sex work, drug use, gender, and ethnicity.

In North America the stigma associated with HIV/AIDS has been profoundly influenced by attitudes toward gay and bisexual men and toward people who use drugs. These two groups of people were highly stigmatized before the HIV epidemic came to North America. Studies in North America and Europe have found that a minority of the population are more likely to blame people for their HIV infection and are less ready to help them if they became infected through homosexual sex or through drug use.¹¹

Discrimination

Discrimination, as defined by the World AIDS Campaign against HIV/AIDSrelated stigma and discrimination, "occurs when a distinction is made against a person that results in his or her being treated unfairly and unjustly on the basis of their belonging, or being perceived to belong, to a particular group."12

This report adopts this broad definition of discrimination. For the purposes of the report, discrimination includes:13

• Actions for which there are legal protections and actions for which there are no legal protections: Certain forms of discrimination are prohibited by international and Canadian human rights law. These laws protect people who belong to certain groups – groups that have historically been discriminated against – from discrimination in various areas of life (see the section below on legal protection against discrimination). But there are areas of life - for example, relations between friends or family members - that are not covered by human rights law.

8

Read more about

Basic information on stigma and discrimination at

www.aidssida.cpha.ca/english/ campgn_e/index.htm

A Conceptual Framework and Basis for Action: HIV/AIDS Stigma and Discrimination, produced by the World AIDS Campaign, at www.unaids.org/publications/ documents/human/WAC

A tool for measuring HIV/AIDS stigma, produced by the POLICY Project in South Africa. at

framework-English.pdf

www.policyproject.com/ Special/ SA_stigma.pdf

- *Direct and indirect discrimination*: Direct discrimination occurs when people are treated differently and negatively because of their association with one of the protected groups. A landlord who harasses a tenant because that person is a person living with HIV/AIDS is engaging in direct discrimination. Indirect discrimination occurs when everyone is treated the same, but the treatment has a negative and differential impact on people associated with a protected group. A doctor who has a policy of prescribing a certain maximum dose of narcotic pain medication, without taking into account the higher level of tolerance for narcotics of a person who has a history of drug use, is engaging in indirect discrimination.
- Actions and failure to act: Discrimination may be the result of an action or a failure to act. Firing an employee because she is HIV-positive is discrimination. An employer is also engaging in discrimination where the employer does not take steps to deal with the harassment an employee faces from her co-workers because she is HIV-positive.
- Unintended effects as well as intentional effects: Discrimination does not have to be intentional or malicious to be illegal. People may discriminate unintentionally or out of good intentions. It is not necessary, under anti-discrimination law in Canada, to prove that the discrimination was intentional or malicious. It is merely necessary to prove that discrimination occurred.
- *Systemic effects of prevailing attitudes*: The prevailing attitudes and practices in a society may exclude or disadvantage particular groups. These attitudes and practices may not be perceived by some to be discriminatory, but nevertheless can have discriminatory effects. Examples would include prevailing attitudes about homosexuality, sex work, or drug use.¹⁴ Stigmatizing attitudes often lead to discrimination against gay men and lesbians, sex workers, or people who use illegal drugs.

Human rights

Human rights are universal rights. In other words, all people have human rights because they are human. These rights derive from the dignity and worth of each human being. They cannot be waived or taken away.

Since the United Nations Charter and the Universal Declaration of Human Rights were put in place in 1948, most of the world's countries have entered into legally binding treaties to protect human rights.¹⁵ The human rights protected by these treaties include the rights to food, housing, adequate income, work, education, participation, privacy, enjoyment of the benefits of scientific progress and its applications, the highest attainable standard of physical and mental health, freedom of association and assembly, freedom of movement, freedom from cruel, inhuman, or degrading treatment, and freedom from discrimination.

Canada has agreed to be bound by these treaties, and reports regularly on its progress with regard to its obligations.¹⁶ Canadian governments have also passed laws that guarantee human rights and laws that protect people from discrimination (see the section below on legal protection against discrimination in Canada).

Governments' obligations

Under international law, governments are *obliged* to respect, protect, and fulfill the human rights guarantees enjoyed by all people.¹⁷

Respecting a human right means that governments cannot violate the right. For example, governments cannot deny prisoners with HIV/AIDS the same quality of medical care that is available in the community.

Protecting a human right means that governments have to prevent others from violating the right, and to provide some form of redress when the right is violated. For example, governments should protect people living with HIV/AIDS from discrimination in their jobs or when they rent an apartment, and should provide ways to challenge discrimination through the courts or human rights commissions.

Fulfilling a human right means that governments have to take steps – pass laws, put in place policies, set up programs, provide funding - to realize the right. For example, governments must enact or strengthen laws and fund programs that promote the equality of women, enact or strengthen laws that prohibit discrimination against gay men, repeal laws and regulations that harm people who inject drugs, and take steps to eradicate poverty among Aboriginal people. There are some human rights that do not depend upon the economic, social, and cultural situation of a country. These are called civil and political rights. Freedom of expression and freedom from torture are two examples of such rights. In contrast, the international community has recognized that a country's obligation to fulfill economic and social rights may depend on the country's economic or other circumstances. In this situation, the country has an obligation to work toward progressive realization of the right, and is obliged to demonstrate that it is making steady progress. In addition, the obligation of wealthier countries to fulfill rights extends beyond their borders. It includes providing technical and financial support to poorer countries.

Read more about

Human rights in Canada, on the website of the Human Rights Program of Heritage Canada, at www.pch.gc.ca/progs/ pdp-hrp/canada/index_e.cfm

Health and human rights, in the World Health Organization's 25 Questions & Answers on Health & Human Rights at

www.who.int/hhr/information/ 25%20Questions%20and%20 Answers%20on%20Health%20 and%20Human%20Rights.pdf

"Human rights and fundamental freedoms are the birthright of all human beings; their protection and promotion is the first responsibility of Governments."

- Vienna Declaration and Programme of Action (1993)¹⁸

Human rights and HIV/AIDS

In the context of the HIV/AIDS epidemic, promotion and protection of human rights and promotion and protection of health are fundamentally linked. At the most basic level, there is a human right to the highest attainable standard of physical and mental health. So, promoting and protecting people's health is human rights "work" and must explicitly include the promotion and protection of human rights, including the right to health. Beyond this, we know that the failure to promote and protect other human rights has made the HIV/AIDS epidemic worse for many populations:

- When people living with HIV/AIDS do not have adequate medical care and treatment, nutrition, shelter, and income, they are more susceptible to poor health, disease, and death.¹⁹
- · Failure to promote and enforce laws and policies prohibiting discrimination against people living with HIV/AIDS has meant that they experience discrimination in housing, employment, health and social services, and other areas of life.20
- The subordination of women and girls which is enforced and perpetuated by domestic violence, sexual coercion, and inability to negotiate safer sex, among other things - has made them vulnerable to HIV infection and prevented them from getting the information, resources, and services that are necessary for their health.²¹
- Hostility toward gay, lesbian, bisexual, trans,²² and two-spirited people²³ has created environments that are silent about their existence, fail to support them in their personal and social development, and deny them the information, resources, and services that are necessary for their health.²⁴
- The subordination of Aboriginal peoples has left a legacy of cultural alienation, political exclusion, dependence, poverty, violence, and substance abuse. These have contributed to high rates of disease, including high rates of HIV infection.25

- · Prisoners depend on the state to give them the resources to prevent infection with HIV and other diseases, to protect their privacy, to protect them from violence, and to provide them with health care. Failure to fulfill these rights has contributed to HIV transmission among prisoners and made the impact of HIV infection worse.²⁶
- · Responses to drug use and sex work put a disproportionate emphasis on controlling these activities through criminal and municipal law. This approach neglects or undermines efforts to prevent disease and promote health among people who use drugs and sex workers, and violates their rights.27

The Declaration of Commitment on HIV/AIDS, which Canada and other United Nations member states unanimously adopted in June 2001, acknowledges that the full realization of human rights is an essential element in all areas of the global response to the epidemic, and sets out some actions to realize those rights.28

International Guidelines on HIV/AIDS and Human Rights

The International Guidelines on HIV/AIDS and Human Rights provide guidance on how human rights should be promoted and protected in the context of the HIV/AIDS epidemic.²⁹ The Guidelines were developed at the Second International Consultation on HIV/AIDS and Human Rights, convened in 1996 by the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS. Although they are not a treaty that binds governments, they set an internationally recognized standard for governments to live up to. The International Guidelines have received the support of the UN Committee on Economic, Social and Cultural Rights³⁰ and the UN Commission on Human Rights.³¹

Guideline 6 was revised at the Third International Consultation on HIV/AIDS and Human Rights in 2002.³² The revised guideline states what governments should do, both nationally and internationally, to ensure access to HIV/AIDS prevention, treatment, care, and support. This includes achieving universal access to HIV antiretroviral and other medicines, diagnostic and other medical technologies, and tools for HIV prevention (eg, condoms, clean syringes microbicides, vaccines, and so on).



Legal protection against discrimination in Canada

Human rights are protected in Canada by the Canadian Charter of Rights and Freedoms; by federal, provincial, and territorial anti-discrimination legislation (called acts or codes); and by other laws, such as consumer protection laws, environmental laws and, in the area of criminal law, laws that give rights to witnesses, victims, and persons accused of crimes.

The Canadian Charter of Rights and Freedoms

The Charter regulates interactions between the state (federal, provincial, and territorial governments) and the individual in Canada.³³ Section 15(1) of the Charter prohibits governments from discriminating against individuals on the basis of certain characteristics:

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.

The courts have subsequently ruled that section 15(1) also protects against discrimination on the basis of characteristics that are not specifically set out in it, such as sexual orientation.³⁴

Other sections of the Charter also contain important guarantees related to the right to equality. Section 25 protects Aboriginal rights. Section 27 provides that the Charter must be interpreted in a manner consistent with the preservation and enhancement of the multicultural heritage of Canadians. Section 28 specifies that Charter rights are guaranteed equally to male and female persons.

The Charter is part of the Canadian Constitution, which is the highest law in Canada. Under the Constitution, a law that limits a Charter right may be declared invalid. However, the Charter itself allows governments to put some limits on Charter rights. Section 1 of the Charter says that other laws may limit the rights and freedoms in the Charter so long as those laws are reasonable and justified in a free and democratic society. In order to justify a limit on a Charter right under section 1, the government must show that the purpose behind the legislation must be sufficiently important (ie, it must relate to concerns that are pressing and substantial) to override a Charter right. The government must also prove that the distinction drawn by the law being challenged is proportional to the violation of the right. A distinction will be proportional if it is rationally connected to the pressing and substantial purpose of the law and impairs as little as possible the person's Charter right; there must also be proportionality between the "good" the law seeks to establish and the harm caused by the violation of the Charter right.35

Read more about

The International Guidelines on HIV/AIDS and Human Rights at www.unhchr.ch/hiv/ guidelines.htm

An easy-to-read summary of the 1996 Guidelines, produced by the International Council of AIDS Service Organizations, at www.icaso.org

The Rights of Prisoners Living with HIV/AIDS

While prisoners are deprived of the right to liberty and freedom of movement during incarceration, they retain other fundamental human rights, such as the right to health and the right to freedom from cruel, inhuman, or degrading treatment.³⁶ The Corrections and Conditional Release Act states that "offenders retain the rights and privileges of all members of society, except those rights and privileges that are necessarily removed or restricted as a consequence of the sentence."³⁷ Similarly, the Canadian Human Rights Commission has stated that "federally sentenced offenders have a right to treatment that is consistent with the Canadian Human Rights Act [legal protection against discrimination]."³⁸

Prisoners are not explicitly named in section 15(1) of the Canadian Charter of Rights and Freedoms, the equality rights provision, which establishes the minimum standard for the equal protection of groups under human rights legislation in Canada. Prisoners may be protected as a group analogous to those written into section 15(1) of the Charter. But in a recent case in which a prisoner successfully gained the right to vote, four of the nine judges of the Supreme Court of Canada rejected the argument that prisoners are an analogous group for the purposes of section 15 of the Charter.³⁹ The other five judges did not consider the issue.

There is an international consensus that the same standards of health care and health protection that apply in the community should also apply in prisons.⁴⁰ The Correctional Service of Canada (CSC) has a legislative obligation to provide every inmate with essential health care that conforms to professionally accepted standards.⁴¹ This legislative obligation has been interpreted by the CSC to mean that inmates should have access to the same level of health care as is available in the community.⁴²

Providing health care equivalent to that in the community means prisoners are entitled to a number of specific and concrete measures with regard to HIV and hepatitis C (HCV): confidentiality of health information, including health appointments; available and anonymous HIV testing; accommodation in meals and schedules as required by medical treatment; medical treatment and care that meets professionally accepted guidelines and standards; easy access to means to prevent transmission of HIV and HCV, including condoms, dental dams, lubricant, bleach, and sterile syringes; access to the form of drug treatment most appropriate to the individual, including methadone maintenance treatment.

Recent studies have documented the continuing failure of correctional institutions to provide prisoners - both in women's and men's institutions with prevention tools and health care that is equal to that in the community.⁴³ In some institutions prisoners still do not have easy access to condoms, dental dams, lubricants, and bleach, despite official policy that these are to be provided. Harm-reduction measures such as needle exchange, safer tattooing, and information on safer slashing/cutting are not widely available. Many prisoners do not receive pre- and post-test counselling when they go for an HIV test. Many who receive a positive test result may not receive adequate counselling and support after their diagnosis. Some HIV-positive prisoners have had the confidentiality of their HIV status breached through institutional practices. In once case, the Privacy Commissioner of Canada has found that the practice of publicly posting pick-up lists for medical appointments is an invasion of prisoners' right to privacy.⁴⁴ Prisoners with HIV or HCV have difficulties getting medical care. This has been most thoroughly documented among women prisoners, who have problems obtaining blood tests, accessing physicians and specialists, obtaining adequate pain medicine, and accessing medications to relieve the side effects of HIV and HCV drugs.⁴⁵ Prisoners report trouble accessing their HIV antiretroviral medications as prescribed because of security lockdowns, attendance at court, transfers, failure to order or reorder drugs, and other problems.⁴⁶ Treatment interruptions have been shown to result in substandard HIV antiretroviral treatment. There have been several inquests into the deaths of prisoners with AIDS in federal penitentiaries, in which evidence has been heard of inhumane treatment and end-of-life care.⁴⁷

Prisoners have taken legal action against the CSC for failing to provide methadone maintenance treatment, failure to prevent HIV infection, and failure to provide medical care, on both Charter and common law grounds.⁴⁸ And the Canadian Human Rights Commission has recently recommended that the CSC implement a pilot needle exchange program in three or more correctional facilities, at least one of them a women's facility, by June 2004.⁴⁹

Human rights legislation

The federal, provincial, and territorial governments have adopted legislation (human rights acts or codes) prohibiting discrimination on various grounds in relation to: employment; the provision of goods, services, and facilities customarily available to the public; and accommodation. This legislation differs in its application from section 15 of the Charter in that it provides protection against discrimination by individuals in the private sector as well as by governments.⁵⁰

Human rights legislation in Canada does not protect against every experience of discrimination. It provides protection only when:

- the person who experiences differential treatment belongs to a group against which discrimination is prohibited (identified by prohibited grounds of discrimination):
- the treatment occurs in a sphere of activity that is covered by the legislation;
- the treatment falls within the legal definition of discrimination; and
- there are no exclusions in the legislation applying to the treatment.

Prohibited grounds of discrimination typically include race, ancestry, place of origin, colour, ethnic origin, language, citizenship, creed, sex, pregnancy, sexual orientation, age, marital status, family status, mental or physical disability, receipt of public assistance, and record of offences.⁵¹

Spheres of activity covered by human rights legislation typically include notices, signs, symbols, advertisements and messages; goods, services, facilities, and accommodation; leasing of commercial or residential properties; employment; and membership in organizations.

As a result of decisions by courts and tribunals, as well as policy by human rights commissions, all jurisdictions in Canada recognize HIV infection, HIVrelated illness, and AIDS as a "disability" or "handicap" within the meaning of human rights statutes.

The kinds of actions that may be considered discrimination based on disability include having been: 52

· asked to undergo testing for HIV or HIV-related illness (or being asked whether you are HIV-positive or have an HIV-related illness) as a condition of admission to a school, at an employment interview, or an employmentrelated medical examination:

- denied a job, dismissed, or demoted while still able to perform the duties of that job;
- denied special measures of accommodation to ensure full participation in or access to employment;
- denied housing or office accommodation;
- denied service by a provider of services, goods, and facilities, such as a store, restaurant, club, government agency, insurance company, hospital, dentist's office, or physician's office;
- denied permission to attend school;
- · harassed at work by superiors or co-workers; or
- harassed by a landlord, building superintendent, or other tenants.

Similar protections apply to people who are addicted to a legal or illegal substance, perceived to be addicted to a legal or illegal substance, or associate with people who are addicted to a legal or illegal substance.

"We learned that the primary human rights issues facing people living with HIV/AIDS in the Calgary region are also the most basic: discrimination in employment, housing, and accessing health care or dentistry services; inadequate economic supports for nutritious food, safe shelter, and adequate medications; and fear/confusion about disclosure of HIV status. In order to help people overcome these challenges, AIDS Calgary developed a series of fact sheets to educate people about human rights, HIV/AIDS and what to do if they experience discrimination. Our Human Rights Worker also provides information and practical assistance to service providers and people experiencing discrimination."

An intersectional approach to stigmatization and discrimination

When people are stigmatized or experience discrimination and other human rights violations in the context of the HIV/AIDS epidemic, this often occurs not only in relation to HIV/AIDS. It is also in relation to other dimensions of their history, culture, and existence - past and present, collective and individual. The stigma, discrimination, and other human rights violations may relate to their experience as gay, lesbian, bisexual, trans, or two-spirited people; as women; as Aboriginal people; as people on social assistance; as newcomers to Canada; as people who use drugs. It may relate to several of these dimensions at once.

-AIDS Calgary's Equality Project ⁵

One of the criticisms of human rights law, procedures, and decisions in Canada is that they force people to make their multi-layered experiences of inequality and discrimination fit the abstract categories of the law.⁵⁴ Human rights procedures tend to focus on one prohibited ground of discrimination to the exclusion of the entire context of the complainant's experience of discrimination. This may happen even when the complainant cites multiple grounds of discrimination.

"It is increasingly recognized that categories of discrimination may overlap, and that individuals may suffer historical exclusion on the basis of both race and gender, age and physical handicap, or some other combination. The situation of individuals who confront multiple grounds of disadvantage is particularly complex.... Discrimination may be experienced on many grounds, and where this is the case, it is not really meaningful to assert that it is one or the other. It may be more realistic to recognize that both forms of discrimination may be present and intersect."

– Madame Justice L'Heureux-Dubé 55

An intersectional approach to people's experience of stigmatization and discrimination recognizes that the combination of various forms produces a unique experience that is not the same as one form alone.⁵⁶ As a discussion paper published by the Ontario Human Rights Commission argues:

An intersectional or contextualized approach to multiple grounds of discrimination has numerous advantages. It acknowledges the complexity of how people experience discrimination, recognizes that the experience of discrimination may be unique and takes into account the social and historical context of the group. It places the focus on society's response to the individual as a result of the confluence of grounds and does not require the person to slot themselves into rigid compartments or categories. It addresses the fact that discrimination has evolved and tends to no longer be overt, but rather more subtle, multi-layered, systemic, environmental and institutionalized.57

The discussion paper further observes that an intersectional approach "can be a useful strategy to link grounds of discrimination to the social, economic, political and legal environment that contributes to discrimination."58 Conditions such as underemployment or unemployment, poverty, or homelessness can thereby be included in the analysis of discrimination, and human rights protections established in international treaties can be brought into the purview of Canadian human rights statutes. This approach is consistent with the principle, affirmed by the World Conference on Human Rights in 1993, that human rights are indivisible and interdependent and interrelated.59

PLAN OF ACTION

This part of the report contains the plan of action for Canada to prevent, reduce, and eliminate stigma and discrimination in the context of the HIV/AIDS epidemic. It was developed through research and an extensive consultation process with people living with HIV/AIDS, people from communities vulnerable to HIV, community-based organizations, national organizations, and organized labour.

The plan of action is based on goals and actions, organized into five thematic sections:

- participation of people living with HIV/AIDS and vulnerable to HIV
- tackling stigmatizing attitudes
- advocating for rights
- accessing programs, services, accommodation, and employment
- strengthening research and evaluation

With the exception of the section on "participation of people living with HIV/ AIDS and vulnerable to HIV," which contains only one albeit fundamental goal, each section is made up of a number of goals. The plan of action contains 18 goals. Each of the 18 goals is followed by the concrete actions that should be taken to achieve the goal, and assigns responsibility to specific people (for example, government, political leaders, community leaders, human rights commissions, and so on) for taking action.

Each goal and its corresponding action(s) are listed together. Following the list, the rationale behind the goal and action(s) is explained. The rationale is based on the feedback from people who were consulted when the plan of action was being developed. Included are quotes from the people consulted, and examples of actions taken to reduce HIV-related stigma and discrimination. Other evidence of the need for action, based on a review of the existing literature, is also presented.



PARTICIPATION OF PEOPLE LIVING WITH **HIV/AIDS AND VULNERABLE TO HIV**

GOAL I

Participation of people living with HIV/AIDS and vulnerable to HIV in all aspects of the plan of action.

Action 1.1

Governments and other organizations implementing the plan of action take all necessary steps to involve people living with HIV/AIDS and vulnerable to HIV in the design, planning, implementation, and evaluation of their actions.

Action 1.2

Governments provide sufficient and stable funding for long-term communitybased programs to implement actions. This should include funding for advocacy work by or for people living with HIV/AIDS and vulnerable to HIV.

Participation of people living with HIV/AIDS and vulnerable to HIV

"Ultimately, it is the power of community to challenge and 'take charge' that, in many countries, has made the greatest headway against the epidemic."

> - A Conceptual Framework and Basis for Action: HIV/AIDS Stigma and Discrimination 60

When the plan of action was being developed, individuals and organizations stressed that people vulnerable to stigma and discrimination had to be involved in action to address stigma and discrimination. This means that people living with HIV/AIDS or vulnerable to HIV must be involved in the design, planning, implementation, and evaluation of all actions included in the plan of action.

This fundamental requirement for action is consistent with commitments on the part of the government of Canada, including:

- The Declaration of Commitment on HIV/AIDS. The declaration states that the "full involvement and participation [of people living with HIV/AIDS] in the design, planning, implementation, and evaluation of programmes is crucial to the development of effective responses to the epidemic" (Article 33).⁶¹
- The Declaration of the Paris AIDS Summit. Canada, along with 41 other national governments, signed this declaration in 1994. Canada agreed to "support a greater involvement of people living with HIV/AIDS through an initiative to strengthen the capacity and coordination of networks of people living with HIV/AIDS and community-based organizations" (Article IV.1).62

This fundamental requirement for action is also consistent with the International Guidelines on HIV/AIDS and Human Rights. Guideline 2, in particular, spells out the obligations of governments in this regard:

States should ensure, through political and financial support, that community consultation occurs in all phases of HIV/AIDS policy design, programme implementation and evaluation and that community organizations are enabled to carry out their activities, including in the fields of ethics, law and human rights, effectively" (Article 24).63

The draft HIV/AIDS Action Plan for All Canada (2004-2008) also affirms the centrality of involving people living with HIV/AIDS or vulnerable to HIV in programs and services. One of the values of the plan is "empowerment":

People living with HIV and populations at risk will have opportunities to participate in a meaningful way in identifying their unique needs and in planning, delivering and evaluating programs and services. Our response will be more effective when the communities most affected are fully engaged in promoting their own health and well-being, and all services are client-centred.64

One of the goals of the plan for the next five years is to:

Involve people living with and vulnerable to HIV in the programs and services that affect their lives.65

And the plan sets out proposed actions to optimize the voice, involvement, and meaningful participation of people living with or vulnerable to HIV.66

"In 1987 I lost my teaching job when my parents found out that I was HIV positive. Since then I have spent my time as an advocate for AIDS issues as well as for Queer rights. Because of my history, much of what I talk about deals with stigma and discrimination, problems in accessing services, systemic discrimination and the pre-existing discrimination facing those groups most affected by HIV/AIDS (men who have sex with men, women, Aboriginals, African Canadians, immigrants and refugees, and those who inject drugs)."

- Eric Smith, gay man living with HIV/AIDS

Sufficient and stable funding for programs

When the plan of action was being developed, representatives from national and community organizations also stressed that sufficient and stable funding is necessary for them to provide the services or programs needed to address stigma and discrimination.

Stigmatizing attitudes and discriminatory behaviour are not changed overnight. Efforts to change them need long-term funding. Short-term funding - particularly funding for individual, discrete projects - makes it very difficult for voluntary organizations to retain staff, maintain programs, and deliver services. For some organizations, the application and reporting requirements for small amounts of funding are so burdensome that they become barriers to obtaining funds.

In addition, restrictions on funding of organizations and programs that focus on advocacy seriously hamper the ability of people living with HIV/AIDS or vulnerable to HIV to advocate for their human rights, including their right to freedom from discrimination.

"AIDS PEI has been working in the area of stigma and discrimination by doing work funded by the AIDS Community Action Program (time-limited projects) dealing with homophobia and promoting harm reduction in PEI. Our long-term plan is to continue this focus primarily to influence public policy. We would need money to assist in the support of on-going work."

- Barbara Gibson, AIDS Prince Edward Island

"Long-term operational funding is required to support the development, implementation, and evaluation of any action plan. The success is hindered by basic expenses such as travel, administration, attendance at conferences and evaluation of services provided."

- British Columbia Persons With AIDS Society

TACKLING STIGMATIZING ATTITUDES

» Changing Public Attitudes

GOAL 2

Greater public support for people living with HIV/AIDS or vulnerable to HIV.

Action 2.1

Political and community leaders make public statements of support for people living with HIV/AIDS or vulnerable to HIV, including:

- the Prime Minister and federal ministers
- provincial premiers and ministers
- municipal representatives
- religious and other community leaders.

Action 2.2

Political and community leaders speak out against intersecting forms of stigma and discrimination affecting people living with HIV/AIDS or vulnerable to HIV, including discrimination against:

- Aboriginal people •
- gay, lesbian, bisexual, and two-spirited people
- ethnic minorities, immigrants, and refugees
- people on low income or on social assistance
- people who use drugs
- sex workers
- trans people. •

Action 2.3

Governments fund national and community organizations to conduct yearround campaigns with strong local community involvement to change negative attitudes toward people living with HIV/AIDS or vulnerable to HIV. These campaigns address, as required by the local situation, intersecting attitudes toward:

- Aboriginal people
- gay, lesbian, bisexual, and two-spirited people
- people from countries where HIV/AIDS is endemic
- people on low income or on social assistance
- people who use drugs
- sex workers
- trans people
- women

Attitudes in Canada

In March 2003, Health Canada sponsored a survey of the knowledge and attitudes of Canadians regarding HIV/AIDS.⁶⁷ The survey, which was conducted by Ekos Research Associates, asked questions about HIV transmission, perceptions of risk, sexual activity, recent HIV tests, sources of information, attitudes toward people living with HIV/AIDS, and support for government involvement in HIV/AIDS.

The findings of the survey with respect to the attitudes of Canadians toward people living with HIV/AIDS were mixed.⁶⁸ Almost 85 percent of respondents said that they could be friends with someone who has HIV/AIDS, and only one in ten believes that people who are infected with HIV through sex or drug use have gotten what they deserve.⁶⁹ But when asked how comfortable they would be with a person with HIV/AIDS in different scenarios, the story is different:

- · About 70 percent of Canadians would be somewhat or very comfortable working in an office where someone developed HIV/AIDS or shopping in a grocery store where they discovered that the owner had HIV/AIDS.⁷⁰
- Only 55 percent of Canadians would be somewhat or very comfortable if their child was attending school where one of the students was known to have HIV/AIDS.71

- About 40 percent of Canadians would be somewhat or very comfortable if a close friend or relative were dating someone with HIV/AIDS.
- Only a little over half of Canadians think that people living with HIV/AIDS should be allowed to serve the public in positions such as dentists or cooks.

Four in ten Canadians know or have known someone with HIV/AIDS.⁷² They are more likely to believe that HIV/AIDS is a serious problem, to rate their knowledge of HIV/AIDS as high, and to be comfortable with HIV/AIDS. They are less likely to distance themselves from the issue. While some people became more cautious and spend less time with a person after they discover that he or she has HIV/AIDS, about as many became more supportive of the person. Those who rate their knowledge as high, and those who actually know more about HIV/AIDS, are less likely to reduce the time they spend with the person.

Attitudes in subpopulations

There are significant variations in these attitudes in certain subpopulations.⁷³ Canadians over the age of 65 and those born outside Canada were less comfortable with the various scenarios in the survey. For all of the scenarios, except the one about a close friend or relative dating someone with HIV/AIDS, comfort levels are higher among people with more education and income. Overall, women are somewhat more likely to demonstrate a high level of comfort than men (38 percent versus 31 percent).

A 2003 survey of attitudes in Québec toward people living with HIV/AIDS found similar variations in subpopulations.⁷⁴ For example, it found that people who are older (aged 50 and over), who were born outside Canada, who have never known someone living with HIV/AIDS, or who are homophobic, are more afraid of people living with HIV/AIDS. They would be uncomfortable in the company of a person living with HIV/AIDS or worried about their health if a co-worker had HIV/AIDS. These subpopulations, along with men and those with less than 14 years of education, would be less willing to befriend or hug a person living with HIV/AIDS, and are more judgmental of people who might have become infected by injecting drugs or through homosexual sex.

Standing up to stigma and violence in 2003⁷

[TRANSLATION] "I've been living in a little village of 1800 people for ten years with my partner and I've been seropositive for 13 years. During all this time, I really tried to cover up my secret but the truth will inevitably come out. The people I live among are surprising because, as generous as they can be in helping you out, they can also destroy you with their words or acts. It's this negative side that made me live through disturbing experiences.

My partner and I were in a bar celebrating the New Year. We met so many people. Everything was going very well until a small group of young people, twentysomethings, started to give me shifty looks. I soon realized that I was the subject of their conversation because, at one point, one of them shouted to me at the top of his lungs: "So how's the guy with AIDS doing?" Needless to say how surprised and even flabbergasted I was. I couldn't let this go unanswered. So I approached them to let them know how annoyed I was. Before I even had the time to register what was happening, the same person who had hurled the abuse at me jumped on top of me while hitting me with such rage and force that I rapidly lost consciousness. When I came to, I noticed that other adults had overpowered my aggressor. My face was bloodied and my jaw was broken....

I had two options. The first was to take him to court. The second was to meet him in order to settle things out of court, to make him understand the wrongs he had inflicted, how extensive they were, and his obligation to make up for them. He chose the latter option....

I would counsel those who will have to live through difficult situations because of HIV to be strong and not to let such events get you down. You have to carry on, face up to things, and defend yourself. Believe me, you'll come out of it a stronger person."

The intersection between HIV/AIDS stigma and other forms of stigma and discrimination

Many studies in North America and Europe have observed an intersection between stigmatization of people living with HIV/AIDS and stigmatization of populations affected by the epidemic, particularly gay men and people who inject drugs.⁷⁶ A minority of the population is more inclined to blame and less ready to help HIV-positive gay men or HIV-positive people who inject drugs.

The Québec survey has confirmed this intersection with regard to homophobia and HIV/AIDS stigma.⁷⁷ While the majority of people in Québec are positive toward gay men, there are higher levels of homophobia in subpopulations, especially among men and among people who were born outside Canada, as well as among people who are older, people with less education, and people who have never known someone living with HIV/AIDS. People who are more negative toward gay men are also more judgmental about people who became infected with HIV through homosexual sex or drug use. They are more afraid to be around someone living with HIV/AIDS and are less likely to befriend them. And they are more likely to think that people living with HIV/AIDS should not be allowed to work in certain jobs.

Qualitative studies of specific populations also observe that different forms of stigma and discrimination intersect with and amplify HIV/AIDS stigma and discrimination. For example, one study notes how stigmatization of homosexuality and drug use contributes to HIV/AIDS stigma in African and Caribbean communities in Canada.⁷⁸ At the same time, the study points out how stereotypes in Canada about African or Caribbean societies, and about the HIV epidemic in those societies, contribute to the stigma experienced by people of African and Caribbean descent living with HIV/AIDS in Canada. Such attitudes add to the challenges of settlement and adjustment in Canada, which are already made difficult by racism and marginalization.

Another study shows how stigmatizing assumptions about sex and drugs intersect with attitudes about and toward women, resulting in discrimination toward women living with HIV/AIDS in many different contexts.⁷⁹ The women in the study reported inappropriate curiosity, belittling questions and attitudes, blaming for being HIV-positive, and denial of service or inferior service in many sectors: the legal system, government offices, businesses, the neighbourhood, and even AIDS service organizations.

Information itself is not enough

Information or knowledge by itself is not enough to overcome stigmatizing attitudes. For example, even people who are relatively well informed about how HIV can be transmitted may continue to fear casual contact with people living with HIV/AIDS.⁸⁰

Efforts to overcome HIV/AIDS stigma often combine information or education with other approaches, such as:

- helping people gain the skills to relate to people living with HIV/AIDS in a relaxed and non-stigmatizing way;
- helping people living with HIV/AIDS cope better with their diagnosis through counselling and support groups; and
- fostering personal contact or communication between the public and people living with HIV/AIDS.⁸¹

A combination of information or education and one or more of these other approaches has been more effective than information or education alone.⁸² Interpersonal communication within social networks appears to be key.⁸³ A recent review of programs to reduce stigmatization of people with schizophrenia in Canada, Australia, and the United Kingdom suggests that local programs that encourage one-to-one contact are more effective in reducing social distance than broad public education campaigns.⁸⁴

A review of interventions to reduce HIV/AIDS stigma, conducted for a project in South Africa, concluded that the following elements were essential:⁸⁵

- information, education, and communications campaigns that are innovative and imaginative;
- interpersonal communication with peers;
- improved access to services; and
- community involvement.

Consequently, the actions set out above must be combined with other actions in this plan of action, specifically peer support, community-based advocacy, and improved delivery of services.

» Informing Media Coverage

GOAL 3

Non-stigmatizing, informed media coverage of HIV/AIDS, people living with HIV/AIDS, and people vulnerable to HIV.

Action 3.1

Governments fund national and community organizations to develop programs, staff, tools, and training to:

- develop media relations
- inform media coverage of issues affecting their populations
- respond to media misrepresentation of issues affecting their populations.

The power of media

While mass media by themselves may have a limited effect in changing individual behaviour, they do contribute to the context within which people think and act.⁸⁶ They therefore have an important role in reducing stigma.

Media coverage around the world has been criticized for reinforcing, rather than countering, stereotypes and prejudices about HIV/AIDS.⁸⁷ Words such as "AIDS victim" or "AIDS sufferer" or pictures of sad or sick people misrepresent those who are living positively with HIV/AIDS. Sensational reports of alleged or actual transmission of HIV reinforce perceptions that people living with HIV/AIDS are irresponsible individuals. Coverage of the HIV/AIDS epidemic may focus on some populations affected by HIV/AIDS to the exclusion of others.

eir populations

"There ARE individuals who are OUT about their HIV status who are NOT afraid to speak up. What is necessary is media coverage not of new medications and side effects, or individuals sick and dying, but interviews with HIV+ individuals who are living!"

- Bradford McIntyre, HIV-positive for 20 years

A review of media coverage of HIV/AIDS suggests that "the most effective journalism integrates the following three elements: The perspectives of people living with HIV/AIDS, the larger cultural, economic and political context which shapes the epidemic and the science of HIV."⁸⁸ In addition, it argues that "the quality of media coverage on AIDS depends not only on the presence of motivated and informed journalists but on the sensitization and commitment of a range of personnel throughout the media hierarchy." Non-governmental organizations and community-based organizations can play an important role in this regard. As the review of media coverage concludes, they "need to develop 'media savvy' and ensure that innovative responses to the epidemic receive adequate media coverage and gain credibility."89

"Media is a powerful tool that can enhance our work and perpetuate inequalities at the same time. The Board of AIDS New Brunswick/SIDA Nouveau-Brunswick is working on a media package for media in New Brunswick that highlights critical issues in the province, including stigma and discrimination, and includes a section on terminology and the power of words." - Haley Flaro, Executive Director

The intersection of stigmas associated with HIV/AIDS requires that work to monitor, inform, and correct media coverage extends to coverage of populations vulnerable to HIV. It includes coverage of, for example, people who use drugs; gay, lesbian, bisexual, trans, and two-spirited people; people of African or Caribbean descent; Aboriginal people; and prisoners.

» Supporting People Living with HIV/AIDS and People Vulnerable to HIV

GOAL 4

Access to peer-based programs tailored to the unique needs of people living with HIV/AIDS and people vulnerable to HIV.

Action 4.1

Governments integrate peer-based programs into their health strategies and programs for people living with HIV/AIDS and those vulnerable to HIV. The terms of reference, principles, and best practices for these strategies and programs must be developed with input from peers living with HIV/AIDS and from communities vulnerable to HIV.

Action 4.2

Governments provide sustained and sufficient funding for peer-based programs for people living with HIV/AIDS. The programs are tailored to their unique circumstances, and address such issues as:

- dealing with diagnosis •
- harm reduction in sexual activity and drug use
- socioeconomic realities of living with HIV/AIDS
- dealing with stigma and discrimination
- relations with intimates, friends, family, and community
- barriers to services
- becoming an advocate.

Action 4.3

Governments provide sustained and sufficient funding for peer-based programs for people vulnerable to HIV. The programs are tailored to their unique circumstances, and address such issues as:

- harm reduction in sexual activity and drug use
- socioeconomic realities that increase vulnerability to HIV infection
- dealing with stigma and discrimination
- relations with intimates, friends, family, and community
- barriers to services
- becoming an advocate.

The effects of stigma

Stigma contributes to the isolation of those who are stigmatized. This happens in many ways in the context of the HIV/AIDS epidemic.

- Stigma contributes to silence and denial. Stigma associated with such topics as sex, drugs, and sexual orientation make it difficult for people to talk about HIV/AIDS in many communities.⁹⁰
- Stigma contributes to secrecy. There are many reasons that people living with HIV/AIDS do not disclose their status. They want to spare others from worrying, to protect their children, to keep their jobs, or to develop a friendship. They also want to avoid stigma and discrimination.⁹¹
- Stigma contributes to self-stigma. The sense that people living with HIV/ AIDS have of themselves is influenced by the attitudes and behaviour of those around them. People living with HIV/AIDS can have very negative feelings about themselves, especially when they are first diagnosed.⁹² They may react to themselves as others in their society do, with rejection, denial, disregard, or underrating of themselves.93
- · Stigma contributes to isolation and withdrawal. Studies have found that people living with HIV/AIDS who experience insensitive or blaming remarks from other people are more likely to be withdrawn, isolated, and passive in coping with HIV.⁹⁴ They also have higher levels of depression and anxiety, due in part to the way they cope with their situation.95

· Stigma creates barriers to accessing services. Studies have also found that stigma can prevent people from being tested for HIV or sexually transmitted diseases,⁹⁶ and that stigma can prevent people living with HIV/AIDS from accessing health care.⁹⁷ When HIV/AIDS is highly stigmatized, people living with HIV/AIDS hesitate to access services from AIDS organizations, or take great care in doing so, for fear of disclosure and gossip.⁹⁸ This is also true in situations where it is difficult to remain anonymous or protect confidentiality, as in smaller towns or rural areas.⁹⁹

Understanding and Challenging HIV Stigma: A Toolkit for Action

This toolkit was designed for non-governmental organizations, community groups, and HIV educators (with the input of these groups) to raise awareness and promote actions to challenge HIV stigma and discrimination. Based on research in Ethiopia, Tanzania, and Zambia, the toolkit contains 57 exercises and activities. More than 125 additional exercises are also available as part of the project.

+ For more information, see www.changeproject.org/technical/hivaids/stigma.html

Rejecting stigma: people living with HIV/AIDS

People living with HIV/AIDS can be helped to reject stigma and its consequences for themselves. They can also help other people to reject stigma and its consequences. This can happen in several ways.

- Counselling: People need more than a brief session of information about HIV/AIDS if they are to cope well with the news of their diagnosis. Comprehensive counselling at the time of their HIV test (pre- and post-test) and supportive counselling beyond this time are essential. Without such support, people may cope with their diagnosis by keeping it secret or denying its reality, especially in societies or communities where AIDS is seen as "social and physical death."¹⁰⁰
- Peer support: Participants in the workshop that reviewed a first draft of the

plan of action stressed the importance of community-based peer support for people living with HIV/AIDS or vulnerable to HIV. This was echoed in the launch of an international electronic discussion on self-stigma and HIV/AIDS: "Peer support groups are lifelines for many people newly diagnosed; strengthening the provision of peer support is essential."¹⁰¹

"Our organization has formed a peer group collective of First Nations people living with HIV/AIDS or their affected families. We need guidance and funding for the long term. We recognize our experts in the community are volunteers who deserve support for local awareness raising, education and connecting with others regionally."

- Fairlie Mendoza, Tsewultun Health Center of the Cowichan Tribes

• Treatment: Access to treatment is a necessary condition for eliminating stigma. Access to HIV treatment helps to reduce stigma associated with HIV/AIDS, both for people living with HIV/AIDS and those around them. In countries where there has been little or no access to HIV treatment, the change in attitudes is dramatic once treatment becomes available.¹⁰² The same change has been observed among groups that do not have easy access to HIV treatment in North America, or need support in maintaining HIV treatment.¹⁰³ However, treatment alone cannot eliminate stigma.

"Most of my clients are treatment-naive, thinking of starting treatment in one of our programs. Often I see them in their health care provider's office immediately after they've been given the results of their HIV test. They are tearful, despairing, and they also blame themselves. They often say, "I'm toxic," "I'm poison," "No one will ever love me now," "This will kill my mother/father/family/partner when they find out." ... I'm pleased to say that most clients, by the time they leave our program, are much more optimistic, confident in the knowledge they've gained, and realize they can live relatively normal lives within the confines of their treatment regimens. Although many factors are involved in this change of attitude, I firmly believe the single largest factor is access to treatment."

– Janice Price, Swedish Medical Center, Seattle¹⁰⁴

· Active involvement: Activism, participation in support groups, and volunteering also help people live better with HIV/AIDS. People who are active in these ways are more likely to advocate for themselves, and people who advocate for themselves are more likely to have more effective ways of coping with the issues they face.¹⁰⁵

• Public disclosure: Some people choose to go public about their HIV status in order to fight isolation and stigma. They describe the experience as profoundly liberating and affirming. But they also say that it is not easy, precisely because of the threat of stigma and discrimination.¹⁰⁶ Support from family members and peers, as well as training in public speaking, help them to deal with the reactions they experience when they go public.¹⁰⁷

> "Who better to reach people than those who are living with HIV who are not afraid to talk about the fact that they are living with HIV. People need to see others living with HIV who are out about their status, in order to move away from the fear. . . . Many people world wide are out about their HIV status and many more are voicing they would also like to be able to live without fear and let others know they are living with HIV. Unfortunately, the fear of discrimination still exists today, and this prevents many from feeling safe about revealing their status."

Rejecting stigma: people vulnerable to HIV

Peer support, access to services, appropriate counselling, involvement, and advocacy are also ways to help people who are vulnerable to HIV reject the stigmas to which many of them are subjected. It is beyond the scope of this report to discuss the specific requirements of different populations, and the intersecting stigmas they work to overcome (associated not only with HIV/ AIDS, but also with sexual taboos, homophobia, sexism, racism, phobia of people who use illegal drugs, poverty, incarceration, etc). Examples of action among different populations include:

- a pilot inmate peer health promotion project at Dorchester Penitentiary, New Brunswick;108
- the Canadian Aboriginal AIDS Network's Aboriginal peer health model for federal correctional institutions:¹⁰⁹
- the Safe Spaces project for gay, lesbian, bisexual, and two-spirited youth;¹¹⁰
- the harm-reduction and advocacy work of the Vancouver Area Network of Drug Users;111
- Direction 180, a low-threshold methadone program in Halifax;¹¹²
- · community health centres with an inclusive, feminist, anti-racist, and multilingual approach to health promotion for women, such as Women's Health in Women's Hands, Toronto;¹¹³
- the International Two-spirit Gathering movement.¹¹⁴

- Bradford McIntyre, HIV-positive for 20 years

ADVOCATING FOR RIGHTS

» Strengthening Community-**Based Education and Advocacy**

GOAL 5

Sustained advocacy for the rights of people living with HIV/AIDS or vulnerable to HIV.

Action 5.1

Governments provide long-term operational funding for national and community organizations to:

- advocate for the rights of people living with HIV/AIDS or vulnerable to HIV
- educate others about these rights
- provide training
- build networks
- develop and share resources
- plan and implement joint action.

The role of education and advocacy

National and local community-based organizations have a key role in promoting the human rights of people living with HIV/AIDS and those vulnerable to HIV. They do this by educating their constituents and those who provide services to them, and by advocating for their constituents both as individuals and as a group.

This work may not always be framed as action against discrimination or for human rights. The work may be framed as action to enable people living with HIV/AIDS or vulnerable to HIV get the services they require. Or it may be framed as action to help those who provide services to people living with HIV/AIDS or vulnerable to HIV understand their situation, including:

- the facts about HIV/AIDS;
- the needs of people living with HIV/AIDS or vulnerable to HIV;
- problems that people living with HIV/AIDS or vulnerable to HIV experience in accessing services; and
- how to avoid or resolve these problems.

This work needs to be sustained with adequate resources. It needs to be tailored to the needs of people who at present are not well served. And it can be strengthened by more explicit reference to the right to freedom from discrimination, as well as other human rights.

"Through AIDS Calgary's Equality Project we are already involved in a number of activities that are described in the [draft plan of action on HIV/AIDS-related stigma and discrimination], particularly in the area of human rights education and advocacy. In support of the plan, we could share what we have learned, the research we have done, and the educational tools we have created. In the future, our program would like to focus more on human rights and HIV/AIDS education for health care providers, employers, landlords and lawyers.... In order to continue our work in this area, and to expand it to include the actions proposed in this plan, we would need continued, stable funding to support a full-time human rights worker (we currently have yearly funding)."

Adequate resources for advocacy

In the fall of 2000 the Canadian Strategy on HIV/AIDS (CSHA) began a strategic planning process. Several national meetings were held. Throughout these consultations, national and community organizations stressed the need for adequate resources to deal with the complex needs of people living with HIV/AIDS and people vulnerable to HIV.

The report of the first strategic planning meeting in November 2000 states that has to create a strategy for renewal and development of human resources to deal with the complexity of the HIV/AIDS epidemic."¹¹⁵ It refers explicitly to the need to renew and sustain community-based workers, both those working specifically in HIV/AIDS and those dealing with homelessness, drug use, poverty, or other HIV/AIDS-related issues. The report suggests that organizations working specifically in HIV/AIDS need to assess what their role is and what the role of other community organizations is.¹¹⁶ It also notes that "[i]t is often necessary to overcome systemic 'blindspots' that prevent organizations from recognizing their roles and responsibilities in relation to HIV/AIDS."117 This requires a combination of education and advocacy.

- Jessica Leech, AIDS Calgary

At the second strategic planning meeting in the spring of 2002, participants repeated the need for resources to enable community organizations help people living with HIV/AIDS and people vulnerable to HIV meet their needs. Louise Binder, a woman living with HIV/AIDS and Co-Chair of the Ministerial Council on HIV/AIDS, said:

It is the role of the CSHA to ensure that there is an adequate network (including AIDS service organizations and non-governmental organizations) to help people living with HIV/AIDS deal with these issues and to refer them to appropriate services outside the HIV community. There is not enough money to do even this, especially considering that diverse communities require discrete processes and approaches.¹¹⁸

In the fall of 2003 Health Canada released a draft of *Leading Together: An HIV/ AIDS Action Plan for All Canada (2004-2008)* for comment. It included two strategies that partly address the need for sustained advocacy by and for people living with HIV/AIDS and vulnerable to HIV:¹¹⁹

- Optimize the voice, involvement, and meaningful participation of people living with or vulnerable to HIV.
- Strengthen organizations that provide HIV-related services and increase their capacity to meet increasingly complex needs.

While the descriptions of these strategies propose worthy actions that will help to achieve these goals,¹²⁰ they do not include a clear, unequivocal commitment to *fund* organizations to *advocate* on behalf of people living with HIV/AIDS or vulnerable to HIV. The closest the draft action plan comes to such a commitment is in action 7.2 : "Increase the capacity of organizations to be responsive and sustainable, and to advocate on behalf of individuals and communities at risk."¹²¹

The action plan should state explicitly that advocacy, both individual and collective, is necessary for the realization of the human rights (including the right to health) and well-being of people living with HIV/AIDS or vulnerable to HIV. In fact, advocacy is often the primary way that people who are stigmatized are able to obtain access to care, treatment, and support services that have ignored or excluded them.

"As a highly disenfranchised population, [people living with HIV/AIDS of African and Caribbean descent] are in critical need of advocacy support on a number of issues. There is a critical need for advocacy in relation to immigration, access to HIV information and drug treatment, access to adequate and appropriate housing and access to financial assistance." – HIV Endemic Task Force : Report on Phase Two of Community Consultation¹²²

The action plan should also state explicitly that national and community organizations need long-term operational funding to attract and retain skilled staff, sustain programs and services, build capacity, and plan collaborative action. Advocacy services should qualify for such funding along with other types of services (such as education, prevention, or support services).

Previous consultations have already identified in greater detail the kinds of resources, training, and services that would strengthen the capacity of national and community organizations to advocate on behalf of people living with HIV/AIDS or vulnerable to HIV. For example, in 1999, at the request of Health Canada, the Canadian HIV/AIDS Legal Network conducted a consultation on the need for and feasibility of building the capacity of community-based organizations and lawyers to address legal, ethical, and human rights issues raised by HIV/AIDS. The report put forward a framework for capacity building among community-based organizations and networks (see box).¹²³

The Canadian HIV/AIDS Legal Network and other organizations have taken actions that have helped to build such capacity. It would be timely to review the actions that have been taken, learn from the experience, and plan next steps.

A Framework for Building Capacity for **Advocacy Within Community-Based Organizations and Networks** (Proposed in 2000)¹²⁴

Goal 1: To develop and maintain the capacity to advocate for individuals so that they are able to protect themselves from HIV infection (access to information, materials, and support), are provided with basic human needs (income, shelter, food, health care, medical treatment, supplementary medical benefits, etc), and are protected from unlawful discrimination (in employment, housing, medical care, etc).

- increase the knowledge and awareness of legal, ethical, and human rights issues among staff by providing an annual training institute organized either regionally or nationally.
- support staff in providing advocacy services by developing a resource manual on provincial laws, regulations, and policies, and by providing training in using the manual.
- support staff in sustaining advocacy services by providing training in managing advocacy services (time management, prioritizing services, referring to other services, etc).
- build links between organizations that provide advocacy services, legal services, and/or social services by sponsoring regular interorganization meetings for problem-based networking, exchange, and planning.
- · improve access to legal services for people with HIV/AIDS and populations affected by HIV/AIDS by advocating for funding for HIV/AIDS legal and paralegal services (eg, an HIV/AIDS legal clinic).

Goal 2: To develop and maintain the capacity of organizations individually and collectively to advocate for or bring about change to the policies, laws, and regulations that contribute to the risk of HIV infection in a population, deprive people with HIV/AIDS or people affected by HIV/AIDS of basic human needs, and otherwise discriminate against people with HIV/AIDS or people affected by HIV/AIDS.

- guide collective advocacy by supporting collaborative advocacy planning processes that include needs assessments, information gathering, strategic planning, coordination, networking, and partnering.
- support collective advocacy through exchange of information and expertise (transferring a model from one region to another, engaging expert legal advice, developing a common approach with non-HIV/AIDS organizations, providing HIV/AIDS information and training to other service providers, etc).
- implement collective advocacy by providing tools and training for staff and volunteers (an advocacy manual, summary of key issues, training module for other service providers, etc).

» Greater Awareness of Human Rights

GOAL 6

Greater awareness among people living with HIV/AIDS and vulnerable to HIV of their human rights and of their options when their rights have been violated.

Action 6.1

Governments and human rights commissions fund the development and distribution of easy-to-use tools that explain human rights, violations of human rights, and options for redress to people living with HIV/AIDS or vulnerable to HIV.

Action 6.2

Governments and human rights commissions tailor the above tools and distribution for populations whose legal circumstances are unique, such as:

- Aboriginal people
- immigrants and refugees
- prisoners.

Action 6.3

Governments and human rights commissions fund training for communitybased workers to use the above tools with people living with HIV/AIDS or vulnerable to HIV, and to support them in making decisions when their rights have been violated.

Informing people of their options

Governments and other sectors (such as employers, landlords, health-care providers, social service providers) have specific obligations under human rights law. Failure to meet the needs of, or provide services to, people living with HIV/AIDS or people vulnerable to HIV should not be seen only in terms of needs and services. It should also be seen in terms of rights and obligations. In practice, the priority for individuals who experience discrimination in some service may be, first of all, to obtain the service elsewhere. They may, for example, want to rent an apartment somewhere else or find a different health-care provider. The wishes and priorities of individuals in these circumstances should be respected. But at the same time they should have information about their rights and about how they can challenge or redress discrimination, in case they choose to do this. Sometimes, just having this information helps to restore a person's sense of dignity and worth after an experience of discrimination.¹²⁵

Some community organizations have developed tools to make people more aware of their rights and of ways to protect their rights. AIDS Calgary's Equality Project is one example.¹²⁶ With funding from the Alberta Human Rights, Citizenship and Multiculturalism Education Fund, the project has employed a part-time human rights worker. The first step of the project was to gather information through a survey and focus groups on discrimination experienced by people living with HIV/AIDS in Alberta.¹²⁷ The next step was to develop fact sheets to inform people about their human rights and about what they can do when they experience discrimination. These fact sheets are used to educate or assist service providers as well as service users. Future work in the project will focus on building better links with human rights or legal services, and educating perpetrators of discrimination and other human rights violations about their obligations.

Certain populations will need legal information that is specific to their situation. For example, Aboriginal people should be aware that the Canadian Human Rights Act, by virtue of section 67, cannot be relied upon to challenge any provision of the Indian Act.¹²⁸ Legislation to repeal section 67 was introduced into Parliament, but was never passed. It was not re-introduced in the third session of the 37th Parliament. Similarly, people seeking to enter or remain in Canada as immigrants or refugees should be informed of the protections that are available to them under the Canadian Charter of Rights and Freedoms, and any limitations to those protections.¹²⁹

Pivot Legal Society's Rights Cards¹³⁰

Pivot Legal Society's mandate is to advance the interests and improve the lives of marginalized persons through the use of law reform, legal education, and strategic legal action. In July 2002, Pivot launched its Rights Card campaign to address lack of knowledge on the part of residents of the Downtown Eastside of Vancouver about their Charter rights. The wallet-sized Rights Cards provide people with a plain-language summary of their legal rights during arrest. They are available in English, French, Spanish, and Chinese.

- + To order cards, see
- www.pivotlegal.org/pdfs/RightsCards-orderform.pdf

» Access to Legal Information and Advice

GOAL 7

Access to legal assistance for people living with HIV/AIDS or vulnerable to HIV who choose to seek redress against discrimination or other human rights violations.

Action 7.1

Governments fund the development, maintenance, and distribution of resources to support community workers and lawyers in addressing legal issues, including discrimination and other human rights violations, faced by people living with HIV/AIDS or vulnerable to HIV.

Action 7.2

Governments fund the development and implementation of a plan to strengthen relations and referrals between community organizations and lawyers in private practice.

Action 7.3

National and community organizations working on HIV/AIDS collaborate with other organizations to advocate for an adequately funded legal aid system, with sufficient dedicated resources for civil and administrative law.

When faced with discrimination, people living with HIV/AIDS or vulnerable to HIV may choose to file a human rights complaint, a grievance with an employer or professional association, or some other legal action. At that point they may need legal information or legal advice. With appropriate training and resources, community workers can provide legal information. But there will be cases when they will need to refer to a lawyer for legal advice.

In 1998, when the Canadian Strategy on HIV/AIDS (CSHA) was established, the Canadian HIV/AIDS Legal Network led a national planning exercise to guide the new component on legal, ethical, and human rights issues under the CSHA. The report on that exercise found that the lack of legal services was an area of concern.131

Subsequent consultations confirmed these observations about lack of funding for legal services and lack of referral between community organizations and local lawyers.¹³² A framework for capacity building among lawyers was proposed,133 similar to the framework for capacity building within communitybased organizations and networks, above.

Again, the Canadian HIV/AIDS Legal Network and other organizations have taken action to build such capacity. And again, it would be timely to review the actions that have been taken, learn from the experience, and plan next steps. There continues to be a need for community organizations to be able to refer people who experience violations of their rights to lawyers in the community who are knowledgeable about and experienced in issues facing people living with HIV/AIDS or vulnerable to HIV.

"Positive change: Advocacy for People with HIV disease and AIDS"

In February 1999, the British Columbia Persons With AIDS Society (BCPWA) published Positive change: Advocacy for People with HIV disease and AIDS. Funding for the project was provided by the Law Foundation of British Columbia. The manual is intended to be a resource for individuals or organizations working on behalf of people living with HIV/AIDS. It provides legal information only, not legal advice. A referral section listing some of the free and low-cost legal resources available has been included for those who need legal advice.

+ For more information, see

www.bcpwa.org/advocacy.php under "Advocacy Publications."

"HIV & the Law Advocates Manual"

HALCO, the HIV & AIDS Legal Clinic (Ontario), is producing a manual for advocates on HIV and the law. It is designed for use by HIV-positive people, their families and friends, their caregivers, legal clinics across the province, health providers, social service agencies, and HIV/AIDS organizations. Some sections of the manual are specific to Ontario law, but other sections are about laws that apply throughout Canada. The manual, which will be completed in 2004, provides a useful model that can be adapted in other provinces. It includes chapters on:

- Powers of Attorney and Living Wills .
- Immigration and HIV •
- Prisons and HIV
- Human Rights
- Employment
- Insurance
- Landlords and Tenants
- + For more information, see www.halco.org

"Understanding the Law: A Guide for Women in Nova Scotia"

Understanding the Law: A Guide for Women in Nova Scotia was prepared by the Nova Scotia Association of Women and the Law (NSAWL). Its purpose is to provide women of all ages and from all walks of life with information about the laws that affect them....The fourth edition of Understanding the Law: A Guide for Women in Nova Scotia is the most comprehensive yet. It includes new information reflecting recent developments in the law pertaining to common law and same-sex couples, particularly the introduction of registered domestic partnerships in 2001. This edition was also expanded to include information on collaborative family law, international adoptions, victim impact statements, suing sexual assault perpetrators, and the Domestic Violence Intervention Act.... "[The] Guide provides general information only. Changes in the law can occur rapidly and the information in this Guide will go out of date. If you have a specific legal problem you should talk to a lawyer, your local legal aid office, or one of the agencies or organizations listed in the Resources section of this Guide," 134

+ The Guide is available at www.nawl.ca/affil/NSAWL-utl.pdf

» Working with Human Rights Commissions

GOAL 8

Widespread awareness of the rights of people living with HIV/AIDS or vulnerable to HIV, and timely redress for violations of rights.

Action 8.1

Human rights commissions collaborate with national and community organizations working with people living with HIV/AIDS or vulnerable to HIV to:

- raise awareness among staff of the commissions about issues faced by people living with HIV/AIDS or vulnerable to HIV
- develop educational and advocacy resources for use in the community ٠
- identify and remove barriers to people seeking redress.

Action 8.2

Aboriginal organizations advocate for the repeal of section 67 of the Canadian Human Rights Act and identify culturally appropriate ways to promote human rights in Aboriginal communities.

Human rights commissions, and the procedures they have established, are the main avenue of redress for human rights violations in Canada. The system is far from perfect, as various reports and studies have noted.¹³⁵ It is beyond the scope of this report to discuss the problems in detail. But they include:¹³⁶

- barriers to marginalized populations in accessing the commissions and making complaints;
- delays and backlogs in processing complaints;
- inadequacies in information provided to people making complaints;
- inadequacies in the investigation of complaints;

- lack of direct access to adjudication (in most jurisdictions the commission screens complaints and determines which go forward for adjudication);
- failure to recognize discrimination arising out of multiple, intersecting aspects of a person's identity;
- failure to address systemic forms of discrimination;
- perceived or real conflicts between the commission's functions (investigation, conciliation, adjudication, education); and
- growth in number of complaints received without equivalent growth in funding for the commissions.

Human rights commissions have developed policies or educational material specifically with regard to HIV/AIDS,¹³⁷ alcohol or drug testing,¹³⁸ sexual orientation,¹³⁹ gender identity,¹⁴⁰ and source of income,¹⁴¹ among other prohibited grounds of discrimination. Yet many of the people consulted for this project who have experience or expertise in dealing with human rights commissions indicated that staff of human rights commissions are not fully aware of the difficulties faced by people living with HIV/AIDS or vulnerable to HIV. Two suggestions were offered:

- · human rights commissions would benefit from hearing from communitybased advocacy and human rights workers about the realities of people living with HIV/AIDS or vulnerable to HIV; and
- community-based advocacy and human rights workers, if funded, could help human rights commissions fulfill their mandate of proactively preventing human rights violations by educating employers, service providers, and others to whom human rights legislation applies, about their obligations.

ACCESSING PROGRAMS, SERVICES, ACCOMMODATION, AND EMPLOYMENT

» Community HIV/AIDS Education and Prevention

GOAL 9

Targeted, culturally specific HIV/AIDS education and prevention programs for populations vulnerable to HIV, commensurate with rates of HIV prevalence and incidence in those populations.

Action 9.1

Governments ensure that funding levels and allocations for targeted, culturally specific HIV/AIDS education and prevention programs are commensurate with rates of HIV prevalence and incidence.

Action 9.2

Governments require that the design and delivery of HIV/AIDS education and prevention programs are tailored to the culture, needs, and points of access for the population to be reached.

Action 9.3

Community organizations delivering HIV/AIDS education and prevention programs are accountable for their effectiveness in meeting the needs of specific vulnerable populations.

Action 9.4

Governments provide sustained funding for self-governing organizations and networks of people vulnerable to HIV, in order to increase their involvement in designing, planning, implementing, and evaluating HIV/AIDS education and prevention programs.

Populations vulnerable to HIV in Canada come from many different cultures and social settings. They have different and specific needs with regard to HIV/AIDS education and prevention, as well as, more broadly, health promotion. The means, language, locations, and partners needed to effectively reach a particular population will likely be specific to that population. Effective HIV/AIDS education and prevention programs must take into account the dynamics and impacts of stigma and discrimination within populations. Stigma and discrimination against people living with HIV/AIDS and those perceived to be at risk of HIV are an obstacle to HIV prevention. So long as people associate HIV/AIDS with groups of "others", they will not see themselves at risk of HIV and will not be receptive to education and prevention messages. Conversely, HIV-related stigma and discrimination may lead people who know that they are at heightened risk of HIV infection to avoid HIV/AIDS education and prevention programs for fear of being (further) stigmatized. Specific, culturally sensitive, targeted HIV/AIDS education and prevention programs are needed to overcome the barriers created by stigma and discrimination.

"Many prevention initiatives and strategies – for example, distributing condoms, outreach nursing and care, needle exchanges, safe injection sites and special prison-based programs – have proven their effectiveness either in Canada or elsewhere. To be effective, however, these programs must be adapted to the specific needs and cultural diversity of the populations to whom they are targeted.... Furthermore, prevention efforts must be based upon sound evidence rather than on stigma or perception."

- Five-Year Review of the Canadian Strategy on HIV/AIDS 1998-2003 142

"Sex Now, a survey of 1900 gay men in British Columbia, found that only a quarter of those surveyed had visited an AIDS organization in the past year. HIV-positive men were far more likely to participate in AIDS organizations than HIV-negative men (59 percent versus 21 percent). The authors suggest that, while HIV-positive men may be reached through AIDS organizations, there is "a strong need to break out of habitual patterns with health promotion and STD prevention activities to reach the majority of gay men where they are, on their own cultural ground."

- Sex Now by the Numbers 143

Funding and programs for HIV/AIDS education and prevention are not keeping pace with continuing and emerging needs. Gay and bisexual men have seen a decline in efforts to maintain or increase HIV prevention programming commensurate with the prevalence of HIV in the population.¹⁴⁴ People who use drugs have had to fight to obtain harm-reduction measures of proven effectiveness, such as safe injection facilities.¹⁴⁵ Other vulnerable populations, such as people of African and Caribbean descent¹⁴⁶ or trans people,¹⁴⁷ have struggled to obtain the prevention services they require.

"The difficulty for [people of African and Caribbean descent] is that mainstream health and [AIDS service organizations] cannot always address needs and concerns in a culturally appropriate manner, while going for help in their own communities is fraught with fear of gossip and ostracism." - HIV Endemic Task Force ¹⁴⁸

Systemic failure to fund, allocate, and target HIV education and prevention programming in a manner commensurate with ongoing and emerging incidence of HIV infection has resulted in competition for funding among organizations, and allocations that are perceived to be or in fact are discriminatory.

"We've known since a national 1991 survey that Vancouver's gay men were more likely to practice unprotected anal sex than were men elsewhere in Canada. Yet, less than 0.1 percent of the \$11-million provincial AIDS program was being applied to gay men's prevention by the year 2001. And by that year, federal government was funding only a program for Asian men's outreach – since suspended – and one gay men's outreach worker in Victoria. This is insanity!"

- Xtra! West 149

Populations whose needs are currently unmet, and the steps to be taken to meet them, will vary according to the local situation. But several things need to happen to change systemic barriers to meeting the needs of different vulnerable populations adequately and appropriately:

- · Funding levels and allocations for HIV/AIDS education and prevention programs for specific vulnerable populations must be commensurate with the rates of HIV prevalence and incidence in those populations.
- Design and delivery of HIV/AIDS education and prevention programs for a vulnerable population must be targeted and appropriate to the culture, needs, and points of access of that population. This will require multiple programs delivered in multiple venues by multiple agencies.
- · Organizations delivering HIV/AIDS education and prevention programs must be accountable for their effectiveness in meeting the needs of specific vulnerable populations. The draft HIV/AIDS Action Plan for All Canada has proposed a series of actions to this end.¹⁵⁰
- · Vulnerable populations must, through self-governing organizations or equivalent means, be involved in determining whether local HIV/AIDS education and prevention programs are meeting their needs. The draft HIV/AIDS Action Plan for All Canada has proposed a series of actions to achieve this.151

» Health Services

GOAL 10

Education, training, systems, and practices in client-centred health care that explicitly address intersecting forms of discrimination toward populations affected by HIV/AIDS:

- Aboriginal people •
- gay, lesbian, bisexual, and two-spirited people ٠
- ethnic minorities, immigrants, and refugees
- people who use drugs
- prisoners

٠

- sex workers
- trans people
- women.

Action 10.1

Educational institutions training health-care providers (eg, medical schools, nursing schools, community colleges) include curriculum on the right to nondiscrimination in health care and on attitudes, practices, and systems that meet the specific needs of the above populations.

Action 10.2

Professional associations (physicians, nurses, pharmacists, home-care workers, etc) provide continuing education on the right to non-discrimination in health care and on attitudes, practices, and systems that meet the specific needs of the above populations.

Action 10.3

Governments take steps to remedy deficiencies in prevention, support, care, and treatment programs that effectively discriminate against the above populations, such as:

- lack of support to gay, lesbian, bisexual, two-spirited, and trans people ٠ in the coming-out process or the process of gender identity
- lack of access to harm-reduction tools in prisons ٠
- ٠ lack of access to harm-reduction tools in the community
- lack of access to different models of drug treatment, including low-٠ threshold programs, in the community
- barriers to accessing HIV antiretroviral drugs in the community
- interruption of HIV antiretroviral drugs in prisons.

Experience of health care and health-care providers varies among people living with HIV/AIDS and those vulnerable to HIV. Some express profound appreciation for the care they receive from some providers.¹⁵² Others experience discrimination in health care, and this experience often has a lot to do with their social location. The perception and experience of health care for people who have only basic education, who are poor, who are members of visible minorities (such as Aboriginal, African, or Caribbean people), who are living partly on the street, who are using or have used drugs, who are or have been sex workers, and/or who are or have been in prison, is quite different than for those who are white, highly educated, and/or hold or have held professional employment.¹⁵³

Sometimes people experience direct discrimination. For example, some individual health-care providers refuse to provide care or they make stigmatizing remarks when they provide care.¹⁵⁴ Sometimes people experience indirect discrimination. For example, studies have found that several populations people who use drugs, Aboriginal people, women, people with low incomes do not have equal access to HIV antiretroviral drugs and appropriate support in staying on the drugs (see below). Some populations experience systemic discrimination. For example, attitudes toward gay, lesbian, bisexual, and trans people or people who use drugs result in a failure of the health system and of health-care providers to acknowledge and respond to their health needs (see below). All these forms of discrimination compromise or violate people's right to health and health care (see box).

What is Meant by "The Right to Health"?

The United Nations Committee on Economic, Social and Cultural Rights has set out four criteria by which to evaluate the right to health:¹⁵⁵

(a) Availability. Functioning public health and health-care facilities, goods and services, as well as programmes, have to be available in sufficient quantity.

(b) Accessibility. Health facilities, goods and services have to be accessible to everyone without discrimination, within the jurisdiction of the State party. Accessibility has four overlapping dimensions:

- Non-discrimination;
- Physical accessibility;
- Economic accessibility (affordability);
- Information accessibility.

(c) Acceptability. All health facilities, goods and services must be respectful of medical ethics and culturally appropriate, sensitive to gender and life-cycle requirements, as well as being designed to respect confidentiality and improve the health status of those concerned.

(d) Quality. Health facilities, goods and services must be scientifically and medically appropriate and of good quality.

Non-discrimination in relation to health and health care can be summarized as proscribing "any discrimination in access to health care and the underlying determinants of health, as well as to means and entitlements for their procurement, on the grounds of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status (including HIV/AIDS), sexual orientation, civil, political, social or other status, which has the intention or effect of nullifying or impairing the equal enjoyment or exercise of the right to health." 156

Common areas of concern

Respect for the choices of people receiving care

People living with HIV/AIDS put a lot of work into their health care. They work at finding doctors, building relationships with doctors, challenging them at times, monitoring their symptoms, making decisions about treatment, getting medications, fitting treatment into their lives, dealing with side effects, and reflecting on their choices, their health, and their sense of self.¹⁵⁷ People living with HIV/AIDS express frustration with physicians who do not recognize their particular needs or circumstances and do not respect their choices when making decisions about care, particularly about stopping and starting antiretroviral therapies. They are more satisfied with their health care when their physicians hear and give priority to their experiences and priorities.¹⁵⁸

Confidentiality of health information

People living with HIV/AIDS continue to report that the confidentiality of their health information is breached in health-care settings, particularly in hospitals. A survey of 34 people living with HIV/AIDS in Alberta found that one-quarter had problems in controlling who knew their HIV status in the hospital.¹⁵⁹

"The hospital system is very bad. They do things they shouldn't be doing. They destroyed my whole life. The nurse told my neighbour that my husband died of AIDS when I told her not to. The nurse told the neighbour because she said she needs to know in order to protect her family [from HIV]."

– Woman of African descent living with HIV¹⁶⁰

Access to antiretroviral drugs

Recent studies in Vancouver indicate that certain populations are not receiving or being maintained on antiretroviral treatment. One study found that people living with HIV/AIDS who lived in poorer neighbourhoods and had a history of injection drug use were significantly less likely to be offered triple (as opposed to double) antiretroviral therapy, and were more likely to die earlier as a consequence.¹⁶¹ A second study found that, among 1239 people who died of HIV between 1995 and 2001, those who never received antiretroviral treatment

(32.8 percent) were more likely to be Aboriginal, female, or below the lowincome cutoff of \$14,147, and that those who received antiretroviral treatment but discontinued it sometime later (after three months) were more likely to be female or have lower income.¹⁶² The authors suggest that improved access to treatment for illegal drug use, directly observed therapy programs, access to medical services without appointments, and onsite pharmacists at medical clinics, may improve access and adherence to antiretroviral drugs.¹⁶³

Concerns of specific populations

Prevention and care for Aboriginal people

In small centres, the stigma of HIV and fear of disclosure can prevent Aboriginal people from being tested for HIV or accessing HIV care.¹⁶⁴ In larger centres, Aboriginal people may be deterred from seeking HIV care for reasons that, indirectly if not directly, relate to discrimination and racism.¹⁶⁵ These may include personal histories of poverty, low education, physical and sexual abuse, drug use, poor housing, and imprisonment that are the legacy of residential schools, forced assimilation, and cultural disruption. In addition, Aboriginal people must often migrate to cities to obtain care, where unfamiliarity with health systems and failure to accommodate Aboriginal traditions into the delivery of health care can deter people from accessing those systems. Not accessing health-care services can have severe consequences: HIV-positive Aboriginal people have been found to become sicker earlier, die sooner, receive antiretroviral therapy less often, experience more hospital admissions, and receive less palliative care than non-Aboriginal people.¹⁶⁶

> "When I first found out I was HIV positive, I was five months along going into six. I was having a lot of problems.... Back at home, my doctor was quite ignorant of HIV. The way I found out was very bad because he was so overwhelmed by the results that he didn't know how to tell me. He left his door wide open and he was practically shouting at me and waving the piece of paper ... he stood across the other side of the room and talked to me. The whole time he had his rubber gloves on."

- Aboriginal woman living with HIV/AIDS¹⁶⁷

Prevention and care for gay, lesbian, bisexual, and two-spirited people

There are many ways in which heterosexism and homophobia result in inadequate health care for gay, lesbian, bisexual, and two-spirited people. Health-care providers rarely ask about sexual orientation, but rather assume heterosexuality. Many are unaware of the unique health-care issues of gay, lesbian, bisexual, and two-spirited people, and have little understanding of the coming-out process. When they are aware of the sexual orientation of gay, lesbian, bisexual, and two-spirited people, many health-care providers demonstrate negative attitudes and behaviours (embarrassment, anxiety, pity, disgust, revulsion, hostility, rejection, condescension) and discomfort. Anticipating such reactions, gay, lesbian, bisexual, and two-spirited people delay or decline seeking health care. They fear ridicule, abuse, prejudice, discrimination, disclosure of sexual orientation to friends and family, or other negative responses, if they disclose their status. Many assume that they must hide or camouflage their sexual orientation in order to receive adequate and equitable health care. This prevents gay, lesbian, bisexual, and two-spirited people from discussing issues and receiving services that are specific to their sexual orientation, the coming-out process, sexual safety, and HIV prevention.

"If the results of Sex Now suggest one general direction for change it is this: strengthen the availability of up-to-date information about factors affecting gay men's sexual health. While we did not deal with awareness of current information directly in Sex Now, we certainly uncovered critical gaps when we discussed our findings with various groups prior to publication. Information that HIV infections were on the increase locally was at best inconsistently held even among health care providers. There was little awareness of increases in other cities such as Amsterdam, Berlin or San Francisco where many gay men travel. Few were aware that there had been recent syphilis outbreaks among gay men in many of these same cities."

- Sex Now by the Numbers ¹⁶⁹

Prevention and care for people of African and Caribbean descent¹⁷

People of African and Caribbean descent experience barriers similar to those of Aboriginal people. Some people view "Western" health care, treatment, and health-care providers with suspicion because of a longstanding history of racism as well as ongoing mistreatment and discrimination.¹⁷¹ Among people of African and Caribbean descent, many who access health services find that family doctors, home-care nurses, pharmacists, and other health-care providers

do not have a basic and adequate understanding of HIV and the issues it raises.¹⁷² Individuals have experienced breaches of confidentiality, derogatory remarks, and lack of respect and courtesy.¹⁷³ African and Caribbean women living with HIV find that health-care providers either ignore their complaints and suggestions, downplay their concerns, talk over their heads, or treat them as uneducated, ignorant, or little children.¹⁷⁴ They find that they lack cultural sensitivity in providing health care.¹⁷⁵

> "Home care said they would call Children's Aid because my kids would go to school and give it to other kids and that the other children living at home would also get it. So I called the social worker at the hospital and she explained to the home care worker about the virus. After this, the homecare worker said I need help from Children's Aid to help with the kids. I said I don't need any help, I have raised my kids all this time."

Prevention and care for people who use drugs¹⁷⁷

People who use drugs report that they experience derogatory remarks, namecalling, and demeaning treatment from health-care providers. They find that they have to wait far longer than other people for medical attention in emergency departments, and that they receive insufficient care and medication for pain. Treatment programs for drug use may impose conditions that are insurmountable barriers for some people who use drugs, including abstinence from all drugs or penalties for failing to make scheduled appointments. Participants feel that such programs treat them like children, whereas more flexible programs give them a sense of responsibility.¹⁷⁸ According to a number of people consulted during the development of the plan of action, some shelters or residential treatment centres for people who use drugs have imposed unnecessary and stigmatizing requirements on those who are HIV-positive (eg, requiring them to use gloves while preparing food), and may wrongfully disclose their status in the process. Finally, the HIV care of people with a history of drug use can be substandard. As noted above, they have not been well received by some health-care providers, they have not been offered antiretroviral therapy, and they have encountered barriers when accessing and adhering to antiretroviral drugs.¹⁷⁹

- HIV-positive woman of African descent ¹⁷⁶

"Some of the worst discrimination you get in emerg. Being a junkie I do overdose. Once they find out you are HIV-positive, I find their attitude changes. You don't get the same quality of health care."

- person living with HIV who uses drugs

"We go to hospitals and see doctors for a reason.... We put our trust in them, and the last thing I see when I walk into a hospital is trust."

- woman with a history of drug use ¹⁸⁰

"I wouldn't last in that ... program. It's too structured, there are too many rules, and you have to stop everything [give up all drugs] all at once." "You are given some rope [at Direction 180], given some responsibility to decide what to do. This one is working ... the effort comes from me." "The staff can tell when something is wrong. They are sincere, they care, they are helpful, they've been there."

– people using Direction 180, a low-threshold methadone maintenance program in Halifax¹⁸¹

Prevention and care for prisoners¹⁸²

Recent studies have documented the continuing failure of correctional institutions to provide prisoners - both in women's and men's institutions - with prevention tools and health care that is equal to that in the community. Prisoners do not have easy access to condoms, dental dams, lubricants, and bleach. Harmreduction measures such as needle exchange, safer tattooing options, and information on safer slashing/cutting are not available. Many prisoners do not receive pre- and post-test counselling when they go for an HIV test. Those who receive a positive test result feel that they do not receive adequate counselling and support after their diagnosis. The confidentiality of their HIV status has been breached through institutional practices. (The Privacy Commissioner of Canada has found that the practice of publicly posting pick-up lists for medical appointments is an invasion of prisoners' right to privacy.) Prisoners with HIV or HCV have difficulties getting medical care. This has been most thoroughly documented among women prisoners, who have problems obtaining blood tests, accessing physicians and specialists, obtaining adequate pain medicine, and accessing medications to relieve the side effects of HIV and HCV drugs. Treatment interruptions have been shown to result in substandard HIV antiretroviral treatment. Prisoners report trouble accessing their HIV antiretroviral medications as prescribed because of security lockdowns, attendance at court, transfers, failure to order or reorder drugs, and other problems. There have been several inquests into inhumane deaths of prisoners with AIDS in federal penitentiaries.

"In prison, I fought tooth and nail for virtually anything and everything that was available outside. Achieving quality of life in prison is a lot more challenging. You don't have the same access to general standard of care. It was very difficult to get a proper diet or things that help with side effects. Most often, you can't even get additional food so you can take your meds properly, the way they're prescribed. Plus, there's no access to adequate vitamins or supplements."

Prevention and care for trans people¹⁸⁴

There are numerous threats to health among trans people, many of which result from the stigma and discrimination against them in society. These include: lack of family and social support, low self-esteem, depression and anxiety, suicidal thoughts and behaviours, self-harm, substance use, eating disorders, isolation, unsafe sexual practices stemming from low self-esteem, sexual exploitation, violence, homelessness, and under- or unemployment. The health system often adds to, rather than helps to remedy, these threats. Prejudice against trans people in society and among health-care providers prevent them from accessing primary health care, let alone disclosing their gender identity. Physicians have been known to refuse trans people as patients. The health system may not cover the costs of hormonal and surgical interventions, or ongoing follow-up care to these interventions. For low-income, homeless, and streetinvolved trans people, consistent self-care and medical care is difficult, including HIV-related care. They encounter the same problems as other homeless and street-involved populations, in addition to the difficulties of finding a physician who is supportive of trans people and knowledgeable about issues unique to HIV-positive trans people.

- Michael Linhart 183

HIV prevention and care for women¹⁸⁵

Women living with HIV/AIDS, and those vulnerable to HIV, report numerous ways in which the health system, health services, and health-care providers discriminate indirectly, if not directly. Pregnant women, women of colour, and street-involved women are targeted for HIV testing. Women who are perceived to fall outside these categories are less likely to be offered an HIV test, and have been denied an HIV test or stigmatized when they request it. The first point at which HIV is often raised with women is during pregnancy, and not in routine health consultations. A number of studies show that health-care providers are not consistently offering pregnant women HIV testing, obtaining their consent for the test, or providing appropriate pre- and post-test counselling.¹⁸⁶ Healthcare providers who are not experienced with HIV disease in women are unlikely to be able to recognize symptoms of HIV in women. They may also be unaware of and insensitive toward the health-care needs, including risk of HIV infection, of lesbian women and trans women. Some women lack access to HIV antiretroviral drugs and are not supported in taking the drugs.¹⁸⁷ For women with children, the fragmentation of services for adults and children, geographical distances between services, and lack of adequate child-care facilities make it difficult for them to access health care for themselves and their children.188

Proposed actions to improve HIV prevention and care

The draft HIV/AIDS Action Plan for All Canada (2004-2008) proposes several actions that, if implemented, would address some of the above problems. They include actions to:189

- develop culturally appropriate, linguistically accessible, comprehensive, and integrated prevention, support, care, and treatment strategies to address the complex health, social, and community needs of specific populations (gay men, injection drug users, Aboriginal people, people from countries where HIV is endemic, prisoners, women at risk);
- · reinforce and promote the principles of appropriate HIV testing with all individuals and organizations that provide HIV testing (ie, voluntary, confidential, mandatory pre- and post-test counselling, informed consent);
- identify and remove any barriers to testing, particularly among populations at risk (eg, lack of culturally appropriate testing services);
- · develop culturally appropriate and linguistically accessible programs to promote HIV testing among gay men, injection drug users, Aboriginal people, people from countries where HIV is endemic, prisoners, and women:
- ensure all health and social service professionals receive some education about HIV and its management during their training and have access to continuing education in HIV treatment;
- · develop strategies to eliminate discrimination on the part of health-care professionals against people with HIV, particularly injection drug users and prisoners, and ensure they receive treatment services that meet or exceed professionally accepted standards;
- collaborate with the addiction treatment system to develop comprehensive addiction management programs that will meet the needs of people living with HIV who are drug dependent, as well as those at risk of HIV;
- · develop links/networks with organizations that have the responsibility/ expertise to help meet the unique needs of people living with HIV and communities at risk.

Read more about barriers to health care among

People who use drugs: Injection Drug Use and HIV/AIDS: Legal and Ethical Issues, available at

www.aidslaw.ca/Maincontent/ issues/druglaws/e-idu/graphics/ e-idu.pdf

Gay and bisexual men: Access to Care: Exploring the Health and Well-Being of Gay, Lesbian, Bisexual, And Two-spirit People in Canada 190

Prisoners: Unlocking Our Futures: A National Study on Women, Prisons, HIV and Hepatitis ¹⁹¹

Prisoners: Action on HIV/AIDS in Prisons: Too Little, Too Late: A Report Card ¹⁹²

GOAL II

Access to affordable, adequate, and accessible housing for people living with HIV/AIDS.

Action 11.1

Governments increase the supply of subsidized housing and establish procedures to facilitate access to subsidized housing for people living with HIV/AIDS and vulnerable to HIV.

See also actions in the section "Advocating for Rights."

People living with HIV/AIDS continue to experience direct discrimination in housing related to their HIV status. A survey among 34 people living with HIV/AIDS in Alberta in 2002 found that 15 percent had problems finding a place to live due to their HIV status and that six percent were harassed or evicted by their landlord or landlady due to their HIV status.¹⁹³

"I also know of people that were harassed by their landlords due to their [HIV] status ... people were dealing with their HIV status and were worried about being booted on the street because they didn't know their legal rights, their human rights. They were terrified that their landlord was going to boot them on to the streets."

- person living with HIV/AIDS 194

In addition, people living with HIV/AIDS encounter barriers to housing that are related to the level and source of their income. Many people living with HIV/ AIDS are poor and depend on social assistance for their income. Some experience direct discrimination from rental housing owners. Others cannot find housing because of a lack of affordable or subsidized housing. The Alberta survey found that 59 percent of people living with HIV/AIDS who were on social assistance did not have access to safe housing.¹⁹⁵ Advocacy workers in several regions report that many of the people living with HIV/AIDS whom they assist are living in very unhealthy housing.¹⁹⁶ This has been amply documented as well among populations vulnerable to HIV. Many people who use drugs, especially those who use cocaine,¹⁹⁷ do not have stable housing; they are homeless, living in single-room-occupancy hotels, or living temporarily with friends or relatives.¹⁹⁸

"We went looking around for a place to stay and [we] were rejected a place to stay because we don't have a job, but yet, we have assured income, both [of us]."

"Well, there again, you don't say Hi, I'm [so and so], I'm broke, I make no money, I'm on assistance, I have HIV ... please rent me a room!"

When people living with HIV/AIDS are the victims of discrimination in housing, or are unable to obtain adequate housing because of their low income, they may be forced to live in unstable, substandard housing. Some people end up homeless. The detrimental impact of unstable and substandard housing, and homelessness, on people living with HIV can be extreme. Stable housing is a key factor to maintaining good health. When people living with HIV/AIDS live in stable housing, it is much easier to take care of their health and well-being, from adhering to antiretroviral therapy, to getting proper nutrition, to accessing home health-care service. Homelessness can greatly increase the risk of disease and death.

Homelessness: A Predictor of Death

A recently published study has found that homeless women in Toronto between the ages of 18 and 44 were 10 times more likely to die than women in the general population.²⁰¹ The study followed 1981 women who used homeless shelters in 1995. The rate of mortality of homeless women in this age group was similar to the rate of mortality among homeless men in the same age group.²⁰² The authors comment: "Given that HIV/AIDS and drug overdose are the most common causes of death in these women, programs to prevent and treat HIV infection and to improve access to treatment for drug addiction are essential. Mental health issues must also be addressed, given the high prevalence of depression among homeless women and their high risk of suicide." ²⁰³

People living with HIV/AIDS need affordable housing that is clean, safe, quiet, accessible to people with disabilities, and close to health services and other services.²⁰⁴ In addition, certain populations vulnerable to HIV, such as people living with addictions and/or mental illness, have specific housing needs, such as housing providers that accept ongoing substance use while seeking to minimize harms to the user.²⁰⁵

- person living with HIV/AIDS 199

- person living with HIV/AIDS 200

"With some hotels you can't cook in your room.... Like the place I live right now I have to go down 4 flights, lug everything out of my room down 4 flights! By the time you get [to the kitchen] you're too tired to cook! But then you have to lug everything back up. And you have to stand there and watch your food like a hawk ... most rooms downtown don't have a fridge as far as I know."

- woman living with HIV/AIDS 206

Problems with income support²⁰⁷

Many people living with HIV/AIDS rely on Employment Insurance, Canada Pension Plan disability benefits, private insurance disability benefits, and provincial/territorial and municipal social assistance programs for their income.

People on public disability pensions or social assistance often feel stigmatized by the philosophy and the politics surrounding the programs. The need for social assistance is often portrayed as a failing on the part of the recipient rather than an obligation on the part of society. This notion has been reinforced by largely unsubstantiated claims of "welfare fraud" as well as by the shift from "welfare" to "workfare." It is also reflected in the low level of benefits provided under long-term disability or social assistance. These benefits can be significantly below the local cost of living.²⁰⁸

*"I get \$756, or something like that, per month and my rent is \$725 for a two bedroom apartment. Imagine, you know, having to provide for your children [on that]!"*²⁰⁹

"This study clearly demonstrates that maximum BC Employment and Assistance benefit rates remain too low to sustain anyone requiring income support ... income assistance meets only 44% of the costs incurred by a single adult, 48% of a childless couple's expenses, 60% of the minimum expenses for a single parent with a three year old, and 59% of the living costs of a single parent with a teenager and a couple with two children."²¹⁰

In addition to the philosophy of the programs, there are the challenges of the paperwork required to obtain, stay on, or return to these programs. For people who are not accustomed to the forms and procedures, the process can be daunting. Lack of coordination between the three main public programs – federal Employment Insurance, the federal Canada Pension Plan disability benefits, and provincial/territorial long-term disability and social assistance programs – adds to the difficulties. Consequently, organizations run by people living with HIV/AIDS have established support or advocacy workers to assist people with all the procedures.

Then there are unique problems faced by people with a lifelong disability who are able to work intermittently (sometimes called an episodic disability). This includes people living with HIV/AIDS, as well as people with other disabilities, such as multiple sclerosis, arthritis, diabetes, addictions, or mental illness.²¹¹ People living with HIV/AIDS report high levels of impairment (bodily symptoms such as pain or fatigue), activity limitations (ability to carry out tasks such as household chores or getting groceries), and participation restrictions (ability to work or study).²¹² There may be periods when people living with HIV/AIDS are able to work, but there may also be periods when they are unable to work. Because of inflexibility in disability programs, people living with HIV/AIDS who are on disability benefits may be reluctant to return to work for fear that, if they are unable to work in future, they may not be able to get back on disability benefits easily.²¹³ This is also a disincentive to starting vocational training while on disability, since participation in such training can be interpreted as being able to work.

In addition, in some jurisdictions people living with HIV/AIDS have had to fight for supplementary disability benefits related to their health care, such as telephone and transportation allowances (which they need to communicate with health-care providers and travel to health-care appointments) and nutritional supplements (which they need to maintain their health). In British Columbia, for example, the previous NDP government agreed to provide a supplementary benefit for nutritional supplements to all social assistance recipients with HIV after the British Columbia Persons With HIV/AIDS Society applied for it in over 450 individual cases, winning each case on appeal.²¹⁴ But the success was short-lived; the current Liberal government has eliminated the benefit entirely.

Finally, private insurance companies can legally disqualify applicants for disability insurance, life insurance, and mortgage insurance on the grounds of a pre-existing condition, provided there are reasonable grounds for the exclusion. Given the dramatic increase in life expectancy for most people living with HIV/AIDS since 1995-1996 (when highly active antiretroviral therapy was introduced in Canada),²¹⁵ it is essential that exclusion criteria used by the insurance industry are based on current actuarial data. For example, a Swiss study has found that people living with HIV/AIDS who are not co-infected with hepatitis C and who are being successfully treated for HIV have a short-term mortality rate that is as low or lower than people who have been successfully treated for cancer – a group that is able to obtain life insurance.²¹⁶

In February 2003 the Canadian AIDS Society and the Canadian Working Group on HIV and Rehabilitation submitted a brief on these issues to the Parliamentary Sub-Committee on the Status of Persons with Disabilities.²¹⁷ In 2004 the Canadian HIV/AIDS Legal Network will publish the final version of a report on these issues. For more information, visit the websites of the Canadian Working Group on HIV and Rehabilitation at www.hivandrehab.ca and the Canadian HIV/AIDS Legal Network at www.aidslaw.ca.

» **Employment**

GOAL 12

Renewed efforts by governments, employers, and unions to promote and enforce laws and policies protecting the rights of people living with HIV/AIDS and those vulnerable to HIV in the workplace.

Action 12.1

HIV/AIDS organizations, employers, and unions collaborate to promote the employability and employment of people living with HIV/AIDS.

Action 12.2

Human rights commissions collaborate with employers, unions, and HIV/AIDS organizations to provide detailed and easy-to-understand information about the rights of people living with HIV/AIDS and people vulnerable to HIV in the workplace.

Action 12.3

Employers and unions review and update their policies on HIV/AIDS in the workplace, and renew their educational activities on HIV/AIDS in the workplace. These activities should include education about the rights of people living with HIV/AIDS as employees, co-workers, or recipients of services.

Because of improvements in treatments, people living with HIV/AIDS may continue to work or may be able to return to work. However, many fear stigma and discrimination in the workplace.

In 1997 and 1998 the Canadian AIDS Society conducted a national survey of over 1400 people living with HIV/AIDS.²¹⁸ Thirty-eight percent of respondents were working and 20 percent were looking for work. Of those who were working, 54 percent had not revealed their HIV status. When asked why they did not reveal their HIV status, the majority identified negative attitudes or fears from an employer or co-workers (56 percent) and discrimination from an employer or co-workers (45 percent). Of those who were looking for work, 57 percent said they would not reveal their HIV status.²¹⁹

There is evidence from smaller studies that people living with HIV/AIDS have reason to be concerned. The 2002 survey in Alberta found that, among 34 people living with HIV/AIDS, 29 percent had been treated unfairly by their employer or co-workers.²²⁰ A story that one person shared with the project shows how discrimination in employment can be subtle and how people in temporary jobs are particularly vulnerable:

It's just like when the employer found out [your HIV status], he'd send you on time off and then say sorry, we don't have any work right now, don't bother coming back right now. They don't say, "You have HIV, we don't want you there." Nobody is that silly. Even the last job I was on, they knew I was taking all kinds of pills, and as far as I disclosed to them it was diabetes, but they probably didn't want some pill popper [working for them].... I think the fact that you're taking all those pills makes them wonder.... I'm sure as far as direct discrimination there really isn't anything there. I ask for a record of employment and they say shortage of work, but they hired two new guys.²²¹

Québec Reorients AIDS-in-the-Workplace Program

A new AIDS-in-the-Workplace program being implemented in Québec emphasizes the rights of workers living with HIV/AIDS. The program tackles issues such as confidentiality of HIV status, access to insurance benefits, discrimination, and the need for employers to take reasonable measures to accommodate the disabilities of workers. The program is run by COCQ-sida with funding from the Québec Ministry of Health and Social Services.²²²

HIV testing and confidentiality

According to human rights law in Canada, it is illegal for employers to inquire about the HIV status of prospective employees, or to require that they have an HIV test, unless being HIV-negative is a legally justified requirement of the job, referred to in law as a "bona fide occupational requirement." There are very few jobs for which this is necessary. In 1996 the Canadian Human Rights Commission adopted a policy stating that "it will not accept being free from HIV/AIDS as a bona fide occupational requirement or a bona fide justification unless it can be proven that such a requirement is essential to the safe, efficient and reliable performance of the essential functions of a job or is a justified requirement for receiving programs or services." 223 (A "bona fide occupational requirement" is a quality that is necessary to perform a job; a bona fide justification is a quality necessary to receive a program or service.) The Commission also states that "[a]ny decision made by an organization relying on health and safety considerations to exclude a person must be based on an individual assessment supported by authoritative and up-to-date medical and scientific information." 224

Despite this long-standing policy, there have been a number of high-profile cases recently of organizations requiring prospective employees to have an HIV test.²²⁵ In January 2004 the Grand Séminaire de Montréal, a Roman Catholic seminary, announced that as of September 2004 all applicants for the priest-hood would be required to undergo HIV testing.²²⁶ There was considerable reaction to the policy. The Canadian HIV/AIDS Legal Network wrote the Archbishop of Montréal about the illegality of the policy. Together with COCQ-sida, the Legal Network asked the Québec Human Rights Commission to launch an investigation into testing candidates for the priesthood. The Commission agreed to consider the request. However, on 16 February 2004 the Archdiocese of Montréal issued a statement saying that it had rescinded its plan to require that applicants to the Grand Séminaire undergo HIV testing.²²⁷

At about the same time it was reported that the Montréal Police Force would require new recruits to be tested for HIV as of 1 March 2004, and that candidates who tested positive for HIV would not be hired.²²⁸ Initially, a member of the city's executive committee responsible for public security cited "public security" as one of the reasons for the policy. "A police person is called into emergency situations where there is obviously injuries, open lesions," he said.²²⁹ A few days later, the executive committee member provided the following explanation for the policy: "We want to protect the employee and the public – it's a public health issue. We're looking at a 30-year proposal here; we want to bring people into the force and work right to retirement."²³⁰ In response, the Legal Network, COCQ-sida, and AIDS Community Care Montréal pointed out that the only appropriate and effective way to protect public health is to use routine precautions in police work.²³¹

Workplace education, routine precautions, post-exposure procedures, and voluntary testing - not mandatory testing - should be the standard practice in occupations where there is a risk of exposure to potentially infectious bodily fluids.²³² This standard was questioned by some in the aftermath of the disclosure by Ste-Justine Children's Hospital in Montréal that an HIV-positive surgeon had practised at the hospital.²³³ The hospital recommended that all 2614 patients upon whom the physician had performed surgery be tested for HIV infection.²³⁴ The surgeon had informed her immediate supervisor in 1991 that she was HIV-positive, and a committee was formed to determine "what kind of medical work [the surgeon] could do."²³⁵ However, the hospital was unable to find any records of the committee's deliberations after 1996. The surgeon died in 2003. In response to the oversight at the hospital, the Québec Medical Association (QMA) issued a policy requiring HIV-positive physicians to disclose their HIV-status to their superiors, and hospitals to determine, after consulting with experts, the precautions that should be taken.²³⁶ Both the QMA and the Québec Minister of Health and Social Services ruled out mandatory testing of physicians.²³⁷

The International Labour Organization Code of Practice On HIV Testing²³⁸

Testing

Testing for HIV should not be carried out at the workplace except as specified in this code. It is unnecessary and imperils the human rights and dignity of workers: test results may be revealed and misused, and the informed consent of workers may not always be fully free or based on an appreciation of all the facts and implications of testing. Even outside the workplace, confidential testing for HIV should be the consequence of voluntary informed consent and performed by suitably qualified personnel only, in conditions of the strictest confidentiality.

I. Prohibition in recruitment and employment

HIV testing should not be required at the time of recruitment or as a condition of continued employment. Any routine medical testing, such as testing for fitness carried out prior to the commencement of employment or on a regular basis for workers, should not include mandatory HIV testing.

2. Prohibition for insurance purposes

(a) HIV testing should not be required as a condition of eligibility for national social security schemes, general insurance policies, occupational schemes and health insurance.

(b) Insurance companies should not require HIV testing before agreeing to provide coverage for a given workplace. They may base their cost and revenue estimates and their actuarial calculations on available epidemiological data for the general population.

(c) Employers should not facilitate any testing for insurance purposes and all information that they already have should remain confidential.

3. Epidemiological surveillance

Anonymous, unlinked surveillance or epidemiological HIV testing in the workplace may occur provided it is undertaken in accordance with the ethical principles of scientific research, professional ethics and the protection of individual rights and confidentiality. Where such research is done, workers and employers should be consulted and informed that it is occurring. The information obtained may not be used to discriminate against individuals or groups of persons. Testing will not be considered anonymous if there is a reasonable possibility that a person's HIV status can be deduced from the results.

4. Voluntary testing

There may be situations where workers wish at their own initiative to be tested including as part of voluntary testing programmes. Voluntary testing should normally be carried out by the community health services and not at the workplace. Where adequate medical services exist, voluntary testing may be undertaken at the request and with the written informed consent of a worker, with advice from the workers' representative if so requested. It should be performed by suitably qualified personnel with adherence to strict confidentiality and disclosure requirements. Gender-sensitive pre- and post-test counselling, which facilitates an understanding of the nature and purpose of the HIV tests, the advantages and disadvantages of the tests and the effect of the result upon the worker, should form an essential part of any testing procedure.

5. Tests and treatment after occupational exposure

(a) Where there is a risk of exposure to human blood, body fluids or tissues, the workplace should have procedures in place to manage the risk of such exposure and occupational incidents.

(b) Following risk of exposure to potentially infected material (human blood, body fluids, tissue) at the workplace, the worker should be immediately counselled to cope with the incident, about the medical consequences, the desirability of testing for HIV and the availability of post-exposure prophylaxis, and referred to appropriate medical facilities. Following the conclusion of a risk assessment, further guidance as to the worker's legal rights, including eligibility and required procedures for workers' compensation, should be given.

Accommodation at work – making the workplace work

Accommodation means the steps that must be taken to make the workplace a place where people with disabilities can perform the essential duties of their job. Accommodation means removing the barriers (physical barriers, attitudes, and policies) that limit the right of people with disabilities to work without discrimination based on their disability. To work or continue working, some people living with HIV/AIDS may need accommodation of their disability – to manage episodic periods of fatigue and illness, to go for medical appointments, or to attend to their health in other ways. Examples of accommodation include flexible working hours, a change in shift, time off, or a switch to part-time work.

In the 1997-1998 survey of people living with HIV/AIDS, those who were looking for work were asked about the benefits and accommodations they would like to have. They identified: no loss in financial or disability benefits (64 percent), reduced or flexible hours (63 percent), more understanding attitudes toward HIV (52 percent), extended sick leave (45 percent), and more time for medical appointments (45 percent). The greatest concerns that these people had about returning to work were: losing disability benefits (70 percent), losing drug benefits (69 percent), losing extended health-care coverage (59 percent), having time off for medical appointments without losing pay or job (51 percent), and disclosing their HIV status (51 percent).²³⁹

People living with HIV/AIDS have a right to accommodation in the workplace. They need not disclose they have HIV/AIDS to obtain accommodation, although they may need to provide medical confirmation of their disability and the limitations it places on their ability to perform their job. According to human rights law in Canada, employers have a legal duty to accommodate the individual needs of employees with disabilities, including people living with HIV/AIDS, to the point of undue hardship. As summarized by a provincial human rights commission:

The Supreme Court of Canada has ruled that employers, unions and service providers have a legal duty to take reasonable steps to accommodate individual needs to the point of undue hardship. To substantiate a claim of undue hardship, an employer or service provider must show that they would experience more than a minor inconvenience. In many cases, accommodation measures are simple and affordable and do not create undue hardship.... Undue hardship occurs if accommodation would create onerous conditions for an employer or service provider, for example, intolerable financial costs or serious disruption to business.... [This would not normally include] overtime or leave costs that the employer or service provider can tolerably bear.²⁴⁰

Workplace policies and education

Policies and education about HIV/AIDS in the workplace are meant to ensure that the rights of people living with HIV/AIDS – including the right to freedom from harassment and discrimination, and the right to accommodation – are protected, respected, and fulfilled. There are numerous resources available to assist employers in developing policies and educating their employees (see box).

In a survey of 16 large corporations canvassed by the Canadian AIDS Society and the Canadian Working Group on HIV and Rehabilitation in 2000, most indicated that they had written policies for general disability or life-threatening illnesses, but not policies specifically for HIV/AIDS. Many of the policies were developed between the mid-1980s and mid-1990s. And while the corporations held educational activities when the policy was first introduced, most had not done additional education since that time. Only one corporation regularly updated its policy, whenever it received revised guidelines from its international parent company.²⁴¹

According to the AIDS service organizations who were also surveyed in the study, it is important that employers remain aware of current issues facing people living with HIV/AIDS in the workplace. To be effective, educational and awareness-raising activities about HIV/AIDS in the workplace need to be ongoing.²⁴²

HIV and the Workplace : The Canadian AIDS Society Guide to an HIV-Friendly Workplace ²⁴³

What should the workplace policy on **HIV/AIDS** cover?

- the employee's right to work as long as health allows and right to job accommodation
- the employee's right to confidentiality
- the employee's eligibility for benefits
- reference to relative legislation
- the manager's/supervisor's responsibilities, the employee's responsibilities
- co-worker's responsibilities, and how the company will deal with any co-worker issues (eg, refusal to work with someone with HIV)
- the company's responsibility for educating employees about HIV and the risks of transmission
- the steps the company will take to provide a supportive environment for people with HIV or other chronic/life-threatening illnesses

What do employees need to know?

- what HIV infection and AIDS are
- how the virus is transmitted
- the actual risks in the workplace
- how HIV affects people who are infected
- the rights of people who are infected
- the company's policy
- what they can do to help co-workers who are infected (eg, be understanding and supportive).

Programs to educate workers about HIV/AIDS and protect the rights of people living with HIV/AIDS have an effect not only in the workplace but also in the community. They can help to prevent HIV transmission and to improve care, treatment, and support of people living with HIV/AIDS. Recognizing this, the International Labour Organisation (ILO) has developed a Code of Practice on HIV/AIDS and the World of Work (see box).²⁴⁴ The code was developed and has been endorsed by governments, employers, and workers (the "tripartite structure" of the ILO).²⁴⁵ It includes chapters on:²⁴⁶

- key principles; •
- general rights and responsibilities;
- prevention through information and education;
- training;
- testing; and
- care and support.

Labour unions in Canada could contribute significantly to the implementation of the code in Canadian workplaces. Canadian unions have initiatives specifically for women; gay, lesbian, bisexual, and trans people; visible minorities; and people with disabilities.²⁴⁷ These areas of policy, advocacy, education, and bargaining are relevant to people living with HIV/AIDS or vulnerable to HIV. There is some evidence to suggest that there needs to be greater awareness of the rights of people living with HIV/AIDS on the part of unions. HIV-positive individuals who have lost their jobs or experienced discrimination at work have not always found their union to be supportive or effective in addressing their grievances.248

Some unions are in favour of mandatory HIV testing of people who have been the source of an occupational exposure to body fluids. However, mandatory testing in this context infringes the rights of people living with HIV/AIDS and does not meeting the legal test required to justify such an infringement.²⁴⁹

Read more about

The International Labour Organization Code of Practice on HIV/AIDS and the World of Work at

www.ilo.org/public/english/ protection/trav/aids/code/ languages/index.htm

The Canadian AIDS Society Guide to an HIV-Friendly Workplace at

www.cdnaids.ca/web/ repguide.nsf/cl/cas-rep-0181

» Youth and Education

GOAL 13

Culturally sensitive, age-appropriate, accurate, and non-judgmental education and support for children and youth with regard to:

- their sexuality and the sexuality of others
- sexual activity and the skills to practise sex safely ٠
- HIV/AIDS and sexually transmitted infections
- alcohol and other drugs, and how to reduce their potential harms ٠
- human rights in the context of the HIV/AIDS epidemic (eg, the rights of people living with HIV/AIDS; of women and girls; of gay, lesbian, bisexual, and trans people; of people who use drugs).

Action 13.1

Provincial/territorial departments of education ensure that schools deliver curriculum on sexual health, alcohol and other drugs, and human rights.

Action 13.2

Provincial/territorial departments of education ensure that school-based curriculum includes culturally sensitive, age-appropriate, accurate, and nonjudgmental education about:

- one's sexuality and the sexuality of others
- sexual activity and the skills to practise sex safely
- HIV/AIDS and sexually transmitted infections
- alcohol and other drugs, and how to reduce their potential harms
- ٠ human rights in the context of the HIV/AIDS epidemic (eg, the rights of people living with HIV/AIDS; of women and girls; of gay, lesbian, bisexual, and trans people; of people who use drugs).

Action 13.3

Provincial/territorial departments of health ensure that HIV prevention is integrated into existing sexual and reproductive health services for youth (as well as adults).

Action 13.4

Provincial/territorial departments of health ensure that harm reduction is integrated into existing information, outreach, and treatment services for youth who use drugs (as well as adults).

Youth need age-appropriate, culturally sensitive, and non-judgmental information, skills building, and services in the schools and in the community about sexual health and substance use. Such programming must be inclusive of different sexual identities, to support youth who are exploring their gay, lesbian, bisexual, or trans identities. It must also include alternatives to abstinence-based approaches to sexual health or substance use, to protect the health of youth who are experimenting sexually or who are using substances. Failure to provide such resources to youth may be indirect or systemic discrimination.

Sexual health

In 2002 the Council of Ministers of Education commissioned a national survey on the sexual health of youth in grades 7, 9, and 11 in Canada.²⁵⁰ The 2002 survey brought to light a number of areas for concern (page numbers in parentheses):

- The study achieved only one-third of its desired sample size 11,074 students instead of the desired 33,000 - because of difficulties in obtaining consent from school jurisdications and from schools (2, 10-11).
- School is the main source of information about human sexuality, puberty, and birth control for students in grade 9, and the main source of information about HIV/AIDS for students in grades 9 and 11 (50-51). Those who spent more time learning about HIV/AIDS in grades 9 and 11 were more knowledgeable about it (70). But 27 percent of students in grade 7 and 14 percent of students in grades 9 and 11 reported that they spent no time learning about HIV/AIDS in the past two years, and 39, 35, and 38 percent, respectively, in grades 7, 9, and 11 reported that they had spent one or two hours (52). Some students - 12 percent of boys and 16 percent of girls in grade 11 - did not know where their peers would likely go to get a condom (49).

- Students surveyed in 2002 had lower levels of knowledge than students surveyed in 1989.²⁵¹ Only 40 percent of students in grade 9 and only half of students in grade 11 knew that Vaseline is not a good lubricant to use with a condom (56-57). Some students incorrectly believed that condoms provide 100 percent protection against HIV/AIDS (56-57). About two-thirds of students in grade 7 and half of students in grade 11 incorrectly believed that there are vaccines available to prevent HIV/AIDS (56-57). About the same proportion did not know that there is no cure for HIV/AIDS (58).
- Between 1989 and 2002 there was a modest improvement in attitudes toward people living with HIV/AIDS. In 2002 slightly fewer students said that they could not be a friend of someone who has HIV/AIDS, or that people who have HIV/AIDS get what they deserve, or that people who have HIV/AIDS should not be allowed to serve the public. But about 10 percent still say that they could not be a friend of someone who has HIV/AIDS and that people who have HIV/AIDS get what they deserve. About 60 percent still say that people who have HIV/AIDS should not be allowed to serve the public. The percentage of male students who hold these attitudes is larger than the percentage of females (73-74).
- The survey identified various factors associated with sexual risk-taking among youth. These included having a disability (111-113); having a poor experience at school (114-116); having low self-esteem, particularly among girls (123-126); using drugs or alcohol before sex, particularly for girls (123); and partying a lot (126-127). Bullying has been associated with sexual risk-taking, and being bullied may contribute indirectly to vulnerability.252 Almost half of male students said that they had bullied another student in the past two months (43 percent in grade 7, 48 percent in grade 9, and 48 percent in grade 11), and between one-third and one-quarter of female students said they had done so (34 percent in grade 7, 35 percent in grade 9, and 26 percent in grade 11) (33). Between one-quarter and onethird of students reported that they had been made fun of in the last two months because of the way they look or talk (33-34). About the same proportion responded that rumours or mean lies had been spread about them (34). Around one-quarter said they experienced sexual jokes, comments, or gestures in the past two months (35). The incidence of sexual jokes and gestures increased significantly for girls from grade 7 (20 percent) to grade 9 (32 percent) (35). The survey did not distinguish whether the bullying was homophobic in nature. As discussed below, gay, lesbian, bisexual, or trans youth are often targets of bullying.

The staff at YouthCO,²⁵³ a youth-driven organization that provides peer-based services to youth on HIV/AIDS and related issues, provide further insight into the realities of youth.²⁵⁴ They note that education about HIV/AIDS, sexual health, and drug use in the schools continues to emphasize abstinence models: abstinence from sex outside of marriage, and abstinence from drug use. They encounter resistance to providing information about safer sex (such as use of

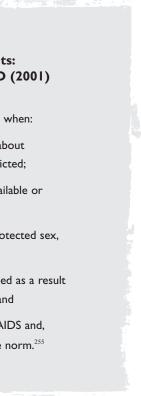
condoms), developing practical skills around negotiating safer sex, providing information about harm-reduction approaches to drug use, and providing the necessary tools to reduce the harms of drug use (such as clean syringes), especially to street-involved youth.

HIV/AIDS and Human Rights: Young People in Action. UNESCO (2001)

Young people are at greater risk of HIV infection when

- access to clear and non-judgmental information about sexually transmitted diseases is difficult and restricted;
- confidential HIV testing and counselling is not available or not adapted to meet the needs of youth;
- they lack the power to refuse unwanted or unprotected sex, within and outside of marriage;
- sexual orientation or sexual behaviour is concealed as a result of social, cultural, religious, or legal prohibitions; and
- local communities reject people living with HIV/AIDS and, as a result, secrecy about HIV/AIDS becomes the norm.²⁵⁵

YouthCO also has found that there is insufficient awareness and recognition of the diversity of youth on the part of educators and social service providers.²⁵⁶ Youth experience stigmas not only associated with their age, but also their race, gender, sexual orientation, and social class. For gay, lesbian, bisexual, and trans youth, the prevailing heterosexual values and messages in school and in society fail to validate and foster the open discovery or exploration of sexual identity among youth.²⁵⁷ Gay, lesbian, bisexual, and trans youth continue to experience abuse and violence,²⁵⁸ without appropriate protection from the authorities or without appropriate treatment and support from health or social services. Some gay, lesbian, bisexual, and trans youth drop out of school as a consequence;²⁵⁹ they are at increased risk of turning to the streets, sex work, and drug use. Dropping out of high school, homelessness, involvement in the sex trade, and drug use are all associated with HIV infection among young gay and bisexual men in Canada.²⁶⁰



Hostility toward gay, lesbian, bisexual, and trans youth

Hostility toward gay, lesbian, bisexual, and trans youth in school and society has been observed in numerous studies.²⁶¹ Homophobic and transphobic hostility contributes to internalized homophobia, shame, low self-esteem, dropping out of school, becoming street-involved and homeless, and high rates of suicide and attempted suicide.

A survey on the health and wellness of gay, lesbian, bisexual, and trans people in Ottawa found that depression was an issue for 62 percent of teens and half of youth under the age of 25. Almost half of those under the age of 25 and 55 percent of teens said they were not getting the help they needed for depression. Over a third of teens and a quarter of youth had felt suicidal. A third of those under the age of 25 have no regular health-care provider. More than half of those who are students do not feel safe all the time at school. While there have been some improvements in certain schools (particularly those in which a teacher is openly gay and is prepared to support students), there are still many instances of phobia, often fostered unwittingly, among teachers and students toward gay, lesbian, bisexual, and trans youth.²⁶²

Studies in British Columbia have found that young gay and bisexual men have little realistic or appropriate education in sexual safety in high school. They appear to be learning the ropes of gay sexuality without adequate information about sexually transmitted diseases, risk behaviours, or available testing.²⁶³ The researchers also found that young gay and bisexual men (under the age of 30) experienced more anti-gay violence (45 percent of men), most of it verbal, than older men (approximately one-third of men).²⁶⁴

Sexual health programs for youth in the schools and in the community need to provide alternatives to heterosexist, abstinence-based models. They need to promote awareness and understanding of youth exploring or questioning their sexuality or gender. They should provide instruction on safer sex practices and techniques. They need to facilitate access to condoms and other tools for preventing sexually transmitted infections among youth who are sexually active. They should provide appropriate counselling and referral around issues of sexuality, sexual orientation, or gender. In order to be most effective, these programs must also be supported by monitoring and enforcement of policies prohibiting bullying, verbal abuse, and physical attacks.

The Canadian Guidelines for Sexual Health Education²⁶⁵

The goals of sexual health education are:

- to help people achieve positive outcomes (e.g. self-esteem, respect for self and others, non-exploitive sexual relations, rewarding sexual relationships, the joy of desired parenthood); and
- to avoid negative outcomes (e.g. unintended pregnancy, HIV/ sexually transmitted infections, sexual coercion, sexual dysfunction).

Effective sexual health education should be provided in an age-appropriate, culturally sensitive manner that is respectful of individual choices and that:

- Focuses on the self-worth and dignity of the individual.
- Helps individuals to become more sensitive and aware of the impact of their behaviour on others. It stresses that sexual health is an interactive process that requires respect for self and others.
- Integrates the positive, life-enhancing and rewarding aspects of human sexuality while also seeking to reduce and prevent sexual health problems.
- Is based on a life span approach that provides information, • motivational support and skill-building opportunities that are relevant to people at different ages and stages in their lives.
- Is structured so that changes in behaviour and attitudes happen • as a result of informed individual choice. They are not forced upon the individual by an external authority.
- Does not discriminate on the basis of race, ethnicity, gender, • sexual orientation, religious background, or disability in terms of access to relevant information.
- Provides accurate information to reduce discrimination based . on race, ethnicity, gender, sexual orientation, religious background and disability.
- Encourages critical thinking about gender-role stereotyping. • It recognizes the importance of gender-related issues in society, the increasing variety of choices available to individuals and the need for better understanding and communication to bring about positive social change.

Sexual health education involves a combination of educational experiences that allows individuals to do the following:

- to acquire knowledge that is relevant to their specific sexual health issues:
- to develop the motivation and personal insight that they will • need to act on the knowledge;
- to acquire the skills necessary to enhance sexual health and avoid negative sexual health outcomes; and
- ٠ to help create an environment that is conducive to sexual health.

Use of alcohol and other drugs

Use of alcohol and other drugs among youth can contribute to unplanned and unsafe sexual activity,266 as well as other health risks and problems. Several provinces and territories in Canada have conducted surveys recently of the use of alcohol and other drugs among students.²⁶⁷ Two maritime provinces have recently surveyed students about the school-based education they receive concerning alcohol and other drugs. In Nova Scotia the percentages of junior high school students who recalled classes on alcohol, tobacco, other drugs, and decision-making ranged from 73 percent to 84 percent. The percentages of senior high school students who recalled such classes ranged from 48 percent to 60 percent.²⁶⁸ The New Brunswick survey similarly found that "more junior high than senior high students recalled having classes on alcohol, tobacco and other drugs. Some students felt a need for more sex and drug education and for different approaches to drug education." ²⁶⁹

What some students are saying:

"Our grade 9 PDR has not taught us much. We have only had a few classes and all we talked about was gambling. A police officer came in to talk to us about drugs once. That's it. The teacher doesn't seem to understand what it's like as a teenager faced with drugs and alcohol. It's hard to say no."

"I feel we should have more classes on decision making, peer pressure, assertiveness and refusal skills. If teachers would teach their students more about these problems, maybe we could prevent some of these things."

- female student, grade 10²⁷¹

"I think that there should be someone come in and talk to us about drugs and maybe bring in the different types of drugs. So for the people that don't know about it could learn and see what it looks like. I think we should be taugh on [sic] how to put on a condom."

- female student, grade 10²⁷²

"If kids knew more about STDs they would probly [sic] think twice before having unsafe sex. Mabey [sic] even sex all together [sic]. I think it is the government's job to make sure we know about safe-sex, we have a right to know and be safe."

"Drugs and alcohol are too frequently used. It's scary and discouraging. School doesn't help, and this is where we spend most of our time. We need to be helped, not lectured. Too many are in trouble (addiction) now. We've done a couple of surveys with horrible results, but it's still ignored."

- female student, grade 9²⁷⁰

- female student, grade 9²⁷³

- student, grade 10²⁷⁴

Read more about

the Canadian Youth, Sexual Health and HIV/AIDS Study at www.cmec.ca/publications/aids/

UNESCO's kit for youth on HIV/AIDS and human rights at

http://unesdoc.unesco.org/ images/0012/001264/ 126403e.pdf

Studies of school-based education on drugs have found that approaches that focus on providing information and encouraging abstinence, such as the DARE (Drug Abuse Resistance Education) program, do not change behaviour.²⁷⁵ Researchers have suggested that it would be more effective to acknowledge that youth experiment with substances, and to enter into an open and honest dialogue with youth about how to reduce the harms associated with substance use.²⁷⁶ This includes accurate information about substances and their effects, non-judgmental discussion of what youth are taking, and building their skills to avoid using substances or reduce the potential harms of doing so.²⁷⁷ It also includes helping youth to deal with pressures related to their peers, families, and communities, since these factors increase the risk of substance use. Factors that protect against substance use include individual histories, family life, peer influences, level of involvement at school, and the condition of communities and neighbourhoods.²⁷⁸

» Immigrants and Refugees

GOAL 14

Policies and procedures used to judge applicants for immigration to Canada do not unnecessarily and irrationally exclude HIV-positive applicants.

Action 14.1

The Minister of Citizenship and Immigration leads the decision by cabinet to amend the definition of "excessive demand" so that it takes into account an applicant's potential contribution to Canada when determining whether an applicant for immigration should be excluded from Canada because of medical inadmissibility.

GOAL 15

HIV testing, clinical examinations, and follow-up of HIV-positive tests among applicants for immigrant and refugee status conforms to Canadian medical standards and guidelines.

Action 15.1

Citizenship and Immigration Canada trains, remunerates, and monitors physicians in Canada and abroad who test applicants for HIV, to ensure that these physicians provide pre- and post-test counselling in conformity with Canadian standards and guidelines.

Action 15.2

Citizenship and Immigration Canada provides information on, and helps immigrants and refugees access, HIV/AIDS and related health and social services through governmental and community-based settlement programs. The information should be culturally and linguistically appropriate and should be developed in collaboration with immigrant and refugee organizations.

Immigration and Refugee Protection Act

The Immigration and Refugee Protection Act, and regulations made under that Act, became law on 28 June 2002.²⁷⁹ Under section 38(1) of the Act, people who are not Canadian citizens or permanent residents (together called "foreign nationals" under the Act) can be refused entry into Canada based on their medical condition. Under the Act, foreign nationals can be refused entry if, because of their medical condition, they are likely to be a threat to public health or safety, or if they would place excessive demands on health and social services. All foreign nationals applying for permanent residence in Canada and certain applicants for temporary residence are required to undergo an immigration medical examination, which includes an HIV-antibody test for all persons aged 15 years or over.²⁸⁰

Since people living with HIV/AIDS do not pose a threat to public health or safety, it would be discriminatory to exclude them from entering or remaining in Canada on this basis. Initially, the government was proposing to do so. But in response to severe criticism, the government withdrew the proposal and continued its long-standing policy of not considering people living with HIV/AIDS a threat to public health and safety.²⁸¹

Canada does exclude people living with HIV/AIDS on the grounds that they may place excessive demands on health and social services. Section 1(1) of the Immigration and Refugee Protection Regulations defines "excessive demand" as:

(a) a demand on health services or social services for which the anticipated costs would likely exceed average Canadian per capita health services and social services costs over a period of five consecutive years immediately following the most recent medical examination required by these Regulations, unless there is evidence that significant costs are likely to be incurred beyond that period, in which case the period is no more than 10 consecutive years; or (b) a demand on health services or social services that would add to existing waiting lists and would increase the rate of mortality and morbidity in Canada as a result of the denial or delay in the provision of those services to Canadian citizens or permanent residents.²⁸²

Several categories of persons are exempt from the excessive-demand provisions. They include refugees (whether applying inside or outside Canada) and certain sponsored applicants for permanent residence in the family class (spouses, common-law partners, and dependent children).

In 2002 Canada turned away 75 people with HIV on excessive-demand grounds, and admitted 207 people with HIV.²⁸³ In 2003, Canada accepted 677 HIV-positive immigrants and refugees, representing an acceptance rate of 87 percent.²⁸⁴ Most immigrants and refugees living with HIV who are accepted were exempt from the excessive-demand provisions.

Concerns about the Immigration and Refugee Protection Act and Regulations

When the Immigration and Protection Refugee Act was being developed, the Canadian HIV/AIDS Legal Network raised a number of concerns about the proposed legislation.²⁸⁵ Some of these have been addressed. But others that are potentially or actually discriminatory have not been addressed.

First, as stated in the Legal Network's brief, a ten-year projection period for assessing potential demand on health and social services is inappropriately long:

The costs for treatment are variable over time, not just with treatment of HIV/AIDS but of other medical conditions as well. This is due not only to medical advances, but also to marketplace considerations that affect various components of the cost of treatment (e.g., prices of drugs). Any projection of costs beyond a five-year period would likely be inaccurate, particularly where HIV/AIDS is concerned where new therapies are being developed regularly. In addition, having a 10-year projection

period for some diseases and a lower projection period for others raises constitutional questions about discrimination based on disability; it would impose a higher burden under the law on some people than on others, based on disability.²⁸⁶

Second, potential contributions, both economic and non-economic, are not considered in determinations of when demands are "excessive":

The definition of "excessive demand" proposed under the Regulations differs from the definitions of "excessive demand" suggested by international organizations such as the United Nations and the World Health Organization. The World Health Organization, for example, has stated that when a state considers excluding a person on "excessive cost" grounds, it should do so only if "the cost of the financial support exceeds the benefits that are expected from the traveller." If the goal of any exclusion on "excessive demand" grounds is indeed to protect the public purse generally and the health-care system particularly, then contributions by each immigrant to the domestic economy and hence to the health-care system must be also taken into account. The proposed policy only considers the "demands" a potential immigrant might make on health or social services systems, and ignores their likely financial and other contributions to Canada.²⁸⁷

Third, the process of HIV testing can lead to physical and psychological harms. HIV testing must conducted with appropriate pre- and post-test counselling. This counselling should address the implications for the applicant of an HIVpositive result, given the stigma and discrimination associated with HIV/AIDS, the potential lack of legal protections in the applicant's country of origin, and the lack of access to HIV/AIDS treatment, care, and support in many countries.²⁸⁸ The Legal Network opposed the introduction of mandatory HIV testing of applicants. Once mandatory testing was instituted, the Legal Network argued that

Citizenship and Immigration Canada must ensure that examining physicians in Canada and outside Canada observe appropriate standards for HIV testing with regard to specific informed consent, and pre-and post-test counseling, as articulated in the *Counselling Guidelines for HIV Testing* prepared under the auspices of the Canadian Medical Association. Canada has at least a moral responsibility to ensure that examining physicians appointed by Canada do HIV testing only with informed consent, and with adequate pre- and post-test counseling. Failure to do so can constitute cruel, inhuman, or degrading treatment.²⁸⁹

Finally, HIV testing of applicants for immigrant or refugee status has implications for the care and services provided to those who are admitted into Canada. According to one organization working with immigrants and refugees of African and Caribbean origin: Those who test positive, mostly of African or Caribbean descent, are finding themselves ill prepared to deal with their HIV status and have little or no knowledge of services available to support them. This sort of environment feeds stigma and discrimination.²⁹⁰

One avenue to provide support is through settlement and training programs for newcomers to Canada:

We need to extend [HIV/AIDS] education beyond the school system to include adult learning programs such as the Language Instruction for Newcomers to Canada and English as a Second Language programs, skill development training programs for newcomers, settlement programs, and refugee and immigrant shelters. These form the entry point into services for many new African and Caribbean immigrants and refugees.291

"Service providers are becoming overloaded with dealing with immigration issues and often need to focus on medical issues. There is a strong need for individuals who are experts in HIV related information as it relates to the law. These experts should be connected to health centres and [AIDS service organizations]. It is also essential to have advocates working on implementing changes to the immigration process that alleviate some of the difficulties that [people living with HIV/AIDS] face with respect to the *immigration process.*" ²⁹²

UK All-Party Parliamentary Group on AIDS (APPG AIDS) Releases Report on Migrants and HIV/AIDS²⁹³

The All-Party Parliamentary Group on AIDS was concerned about the growing stigma that surrounds people with HIV in the UK, in particular against migrants and asylum seekers. The APPG AIDS recognized the increasing pitch of the debate and, with the support of the All-Party Parliamentary Group on Refugees, decided to investigate the reality behind the headlines. How significant an impact are migrants with HIV having on UK health and social care services; what reception and treatment do they receive once they are in the country; how has government policy responded to the challenges to this point; and, most important, what can be done to improve the situation for everyone infected and affected by HIV in the UK? At a series of four hearings the APPG AIDS gathered evidence from individuals throughout the UK, including HIV specialist clinicians, GPs, solicitors, national AIDS organizations, communitybased organizations, and migrants currently living with HIV.

The Members made the following recommendation to the UK government:

- Do not adopt a policy of mandatory testing upon entry.
- Support policies that encourage HIV testing for the purpose of • ensuring more effective access to treatment and care.
- Do not detain, solely for immigration purposes, individuals with ٠ serious communicable diseases if it cannot provide for their care inside removal centres.
- Develop and implement national best practice guidance on asylum seekers living with HIV that involves both [the National Asylum Support Service] and Social Services responsibilities, including training for senior personnel in both agencies on how to monitor and maintain good practice; this includes a revision of the dispersal and benefits system.
- Work to finalize the Doha trade negotiations with regard to ٠ international treatment access, to channel increased resources to health systems in developing countries, and increase long-term support to initiatives like the Global Health Fund.

Read more about

Questions & Answers : Canada's Immigration Policies as They Affect People Living with HIV/AIDS, at

www.aidslaw.ca/Maincontent/ issues/Immigration/Immigration Q&A2003.pdf

HIV/AIDS and Immigration : Final Report, at

www.aidslaw.ca/Maincontent/ issues/Immigration/finalreport/ Immigration2001E.pdf

Migration and HIV: Improving Lives in Britain, via www.appg-aids.org.uk/ publications.htm

» International Cooperation

GOAL 16

Access to prevention tools (including vaccines and microbicides), health care (including access to HIV antiretroviral medication and treatment for drug addiction), and legal protections. Access is based on rights guaranteed in international human rights law.

Action 16.1

The federal government increases its contribution to the Global Fund to Fight AIDS, Tuberculosis and Malaria, and other international initiatives designed to increase access to HIV/AIDS drugs and health care in developing countries.

Action 16.2

The federal government works to increase access to HIV/AIDS drugs and diagnostic tools in developing countries, using compulsory licences where necessary, in accordance with the Doha Declaration on the TRIPS Agreement and Public Health.

Action 16.3

The Canadian International Development Agency funds partnerships between organizations in Canada and in developing countries to:

- promote the rights of people living with HIV/AIDS and vulnerable to HIV
- advocate for rights-based changes to policies nationally and internationally
- share best practices in fighting stigma and discrimination.

Canada's effort to reduce stigma and discrimination in the context of the HIV/AIDS epidemic cannot be limited to within its borders. Canada can use international cooperation and engagement to help other countries tackle stigma and discrimination. People who come to Canada from other parts of the world bear witness to how stigma and discrimination in their countries of origin affects their lives, both here and in their country of origin.²⁹⁴ For example, as a Caribbean woman who discovered she was HIV-positive while on holiday in Canada stated:

I don't want to go back home, everybody knows me and my husband. He used to go and come. When he became HIV+, they called back home. Now they all know. It is like headline news in my country. It is not that anybody will kill me if I went home, but people are not educated about HIV, they are afraid to be around you. If you are working and the boss knows you are HIV+, he can fire you. The government can't protect you, there are no laws in place.... I have six children, four of whom depend on me. I couldn't go to the funeral due to immigration reasons.... I have put in my refugee claim but my hearing is not till next year. I can't work, I can't go back home, I am separated from my children and I have HIV²⁹⁵

The World AIDS Campaign on stigma, discrimination, and human rights called attention to the fact that lack of access to HIV antiretroviral drugs enhances or advances HIV/AIDS-related stigma and discrimination in many countries:

The perceived "untreatability" of AIDS is a key factor contributing to the stigmatization of many of those affected. As long as HIV/AIDS continues to be equated with serious illness and death, public attitudes toward the epidemic seem likely to be slow to change. For this reason, as well as on grounds of equity and justice, efforts are being made to extend the availability of antiretroviral drugs.²⁹⁶

"Where treatment and care are available, the stigma attached to HIV may be reduced, meaning that people are more likely to come forward for testing, counselling and to access prevention services. There is evidence from pilot sites for the provision of antiretrovirals (ARVs) in South Africa that reduction in stigma is associated with expanded treatment access. Reduction in stigma provides a more supportive environment for prevention work in general and in particular it makes it easier to involve people with HIV in prevention strategies."²⁹⁷ Canada has declared its commitment to support international cooperation, foster international partnerships, and support initiatives such as the Global Fund to Fight AIDS, Tuberculosis and Malaria.²⁹⁸ Paul Martin, Prime Minister of Canada, has declared that Canada has a leadership role in taking actions such as the provision of inexpensive HIV drugs in Africa:

We are the ... first country to say we're going to get cheap drugs to Africa to deal with HIV/AIDS. Certain countries have got to step forward and say, hey, there's a leadership role that's required here, there's a set of values that we have and we think that the rest of the world ought to hear.299

Canada can contribute to reducing HIV/AIDS-related stigma and discrimination in other parts of the world by:

- · vigorously supporting the human rights of people living with HIV/AIDS and people vulnerable to HIV in bilateral, multilateral, and international relationships and forums;
- · fulfilling commitments made under the Declaration of Commitment on HIV/AIDS:
- · generously contributing to international initiatives that aim to increase access to HIV/AIDS vaccines, microbicides, drugs, and health services in developing countries; and
- supporting partnerships between Canadian organizations, organizations in developing countries, and international organizations that aim to promote and protect the human rights of people living with HIV/AIDS or vulnerable to HIV.

Read more about

an agenda for action on HIV treatments, vaccines, and microbicides at www.aidslaw.ca/Maincontent/ issues/vaccines/vaccines_ agenda.htm

global access to HIV treatments at www.aidslaw.ca/Maincontent/ issues/care-treatment.htm#B2 **Two Years After the Declaration of Commitment:** A Long Way to Go to Protect Human Rights

In 2003, UNAIDS issued a report based on on the responses it received from 100 countries on their implementation of the Declaration of Commitment on HIV/AIDS. Thirty-eight percent of countries, including almost one-half of those in sub-Saharan Africa, have yet to adopt legislation to prevent discrimination against people living with HIV/AIDS. Only 36 percent of countries have legal measures in place to prohibit discrimination against populations that are vulnerable to HIV. Even though numerous and well-documented inequities contribute to the vulnerability of women and girls, nearly one-third of countries lack policies that ensure women's equal access to critical prevention and care services.300

STRENGTHENING RESEARCH AND EVALUATION

» Participatory and Inclusive Research

GOAL 17

Greater capacity for participatory research, and greater inclusion of disadvantaged populations, in HIV/AIDS research in Canada.

Action 17.1

The Canadian Institutes of Health Research negotiate a memorandum of understanding with community-based organizations and community-based researchers regarding the principles, mechanisms, direction, and funding of the community-based research program in HIV/AIDS.

Action 17.2

The Canadian Institutes of Health Research take steps to ensure that disadvantaged populations are included in clinical, epidemiological, and social scientific HIV/AIDS research in accordance with principles of nondiscrimination, and receive a fair share of the benefits of that research.

Among the human rights of people living with HIV/AIDS or vulnerable to HIV are the right to enjoy the benefits of scientific progress and its applications and the right to active, free, and meaningful participation in society.³⁰¹ Participatory research aims to ensure that the people studied are part of the design, implementation, reporting, and use of research. Participatory research is especially necessary when the people who are being studied have been marginalized by society. It tries to ensure that the needs of the people studied are met by research, that their knowledge is incorporated, that their rights are respected in research, and that they benefit from the results of research.

Participatory research in HIV/AIDS can be advanced by both university-based and community-based researchers. However, some community organizations have found that their research needs are not easily met by university-based researchers. In part, this is due to the expectations and incentive structures that universities place on their faculties.³⁰² Aboriginal organizations in particular have articulated the right to self-determination in research. They have championed ownership, control, access, and possession as principles of active participation in research (see box).

Ownership, Control, Access, Possession³⁰³

OCAP is an important term in HIV/AIDS research in Aboriginal communities. It indicates that Aboriginal people have relinquished the notion of "being researched" and have taken up the call to become active participants in the research process.

What do we mean by ownership?

By ownership we mean, Aboriginal people will have authority over the research process as well as the products of research. Ownership extends to programs, the results of programs, and intellectual property that are not only unique but exclusive to the Aboriginal HIV/AIDS community.

What do we mean by control?

By control we mean that Aboriginal people are in charge of the process....This includes decision-making regarding defining research objectives, outlining research questions, and about how data should be collected and analyzed, and about reporting of findings.

What do we mean by access?

By access we mean, not only do we as Aboriginal people know our audience best, but that we have the RIGHT to access and use information. Access means that the research findings will be shared and used by the community where the research is done, to help improve programming and policy in the research area.

What do we mean by possession?

Possession is the activity of managing or exerting control over something.... Aboriginal people have the right to self-determination and this includes the right to possess the findings of research.

In recent years the Canadian Strategy on HIV/AIDS has attempted to build the research capacity of community organizations through the Community-Based Research Program.³⁰⁴ Through this program and other initiatives, there have been major gains in community research capacity and in the number of community-based research studies conducted across Canada. These gains include:

- the development of the HIV Community-Based Research Network, an interactive virtual network of community-based researchers, at www.hiv-cbr.net;
- capacity building in community-based research in Aboriginal communities;
- studies documenting the realities of diverse populations affected by HIV/AIDS, including the realities of discrimination (see box).

Community-based research across Canada: documenting the reality of HIV/AIDS

- Learning About HIV/AIDS in the Meshwork: The Nature and Value of Indigenous Learning Processes in Community-based HIV/AIDS Organizations ³⁰⁵
- The Silent Voices of the HIV/AIDS Epidemic: African and Caribbean Women ³⁰⁶
- Unlocking our Futures: A National Study on Women, Prisons, HIV and Hepatitis C ³⁰⁷
- Voices for Dignity: A Call to End the Harms Caused by Canada's Sex Trade Law ³⁰⁸
- Sex Now by the Numbers: A Statistical Guide to Health Planning for Gay Men ³⁰⁹

Participatory research will continue to be key to ensuring that the realities of people living with HIV/AIDS and people vulnerable to HIV, including realities of stigma and discrimination, are documented. Such documentation, in turn, enables advocates to identify and provide evidence of deficiencies in order to press for change.

At the same time, people and professions who have traditionally conducted research without a community orientation also have an obligation to respond to the needs and priorities of the populations affected by the HIV/AIDS epidemic in Canada. As stated in the *Tri-Council Policy Statement on the Ethical Conduct for Research Involving Humans*, researchers, research institutions, and research ethics boards have an obligation to ensure that disadvantaged individuals and groups receive a fair share of the benefits of research. This means both that researchers and research ethics boards may not discriminate against or exclude disadvantaged groups, and that researchers and research ethics boards may have a duty to include disadvantaged groups.³¹⁰

» Evaluation of Interventions

GOAL 18

Evidence of the effectiveness of interventions designed to reduce HIV/AIDSrelated stigma and discrimination, and of interventions designed to overcome discriminatory barriers in programs, services, accommodation, and employment.

Action 18.1

Governments should provide funding for rigorous, long-term evaluation of selected key interventions to reduce HIV/AIDS-related stigma and discrimination and to overcome discriminatory barriers in programs, services, accommodation, and employment.

Evaluation is an indispensable component of any intervention. It is particularly important when an intervention aims to remedy unmet needs, is controversial, or is complex.

An international review of interventions to reduce HIV/AIDS-related stigma found relatively few published evaluations. Many of these evaluations were not sufficiently rigorous, and did not measure change in attitudes and behaviour over time. The authors comment:

This review tells us that almost everything appears to work, at least in the short term and on a small scale. But we need experiments and programs that scale up efforts to combat stigma. We need evidence of multi-channel, comprehensive programs, targeting whole communities, not only health workers or [people living with HIV/AIDS], whose lives are centered within complex worlds in their own communities and whose reaction to the stigma of AIDS will be influenced by the community's norms. In such comprehensive programs, once stigma has been reduced, does it remain at a low level? In effect "What drives stigma" is an especially important and complex question given the rapidly changing and dynamic situation that surrounds the epidemic.³¹¹

It is essential that the actions proposed in this plan of action be evaluated to determine their effectiveness:

- · changing attitudes and behaviour in local communities through a combination of public campaigns, work with the media, and one-to-one contact;
- introducing measures or services currently denied to certain people living with HIV/AIDS or vulnerable to HIV; or
- advocating for the human rights of people living with HIV/AIDS or those vulnerable to HIV.

SUMMARY OF GOALS AND ACTIONS

PARTICIPATION OF PEOPLE LIVING WITH **HIV/AIDS AND VULNERABLE TO HIV**

GOAL I

Participation of people living with HIV/AIDS and vulnerable to HIV in all aspects of the plan of action.

Action 1.1

Governments and other organizations implementing the plan of action take all necessary steps to involve people living with HIV/AIDS and vulnerable to HIV in the design, planning, implementation, and evaluation of their actions.

Action 1.2

Governments provide sufficient and stable funding for long-term communitybased programs to implement actions. This should include funding for advocacy work by or for people living with HIV/AIDS and vulnerable to HIV.



TACKLING STIGMATIZING ATTITUDES

» Changing Public Attitudes

GOAL 2

Greater public support for people living with HIV/AIDS or vulnerable to HIV.

Action 2.1

Political and community leaders make public statements of support for people living with HIV/AIDS or vulnerable to HIV, including:

- the Prime Minister and federal ministers
- provincial premiers and ministers
- municipal representatives
- religious and other community leaders.

Action 2.2

Political and community leaders speak out against intersecting forms of stigma and discrimination affecting people living with HIV/AIDS or vulnerable to HIV, including discrimination against:

- Aboriginal people
- gay, lesbian, bisexual, and two-spirited people
- ethnic minorities, immigrants, and refugees
- people on low income or on social assistance
- people who use drugs
- sex workers
- trans people.

Action 2.3

٠

Governments fund national and community organizations to conduct yearround campaigns with strong local community involvement to change negative attitudes toward people living with HIV/AIDS or vulnerable to HIV. These campaigns address, as required by the local situation, intersecting attitudes toward:

- Aboriginal people
- gay, lesbian, bisexual, and two-spirited people
- people from countries where HIV/AIDS is endemic
- people on low income or on social assistance
- people who use drugs
- sex workers
- trans people
- women.

» Informing Media Coverage

GOAL 3

Non-stigmatizing, informed media coverage of HIV/AIDS, people living with HIV/AIDS, and people vulnerable to HIV.

Action 3.1

Governments fund national and community organizations to develop programs, staff, tools, and training to:

- develop media relations
- inform media coverage of issues affecting their populations
- respond to media misrepresentation of issues affecting their populations.

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» Supporting People Living with HIV/AIDS and People Vulnerable to HIV

- relations with intimates, friends, family, and community
- barriers to services
- becoming an advocate.

GOAL 4

Access to peer-based programs tailored to the unique needs of people living with HIV/AIDS and people vulnerable to HIV.

Action 4.1

Governments integrate peer-based programs into their health strategies and programs for people living with HIV/AIDS and those vulnerable to HIV. The terms of reference, principles, and best practices for these strategies and programs must be developed with input from peers living with HIV/AIDS and from communities vulnerable to HIV.

Action 4.2

Governments provide sustained and sufficient funding for peer-based programs for people living with HIV/AIDS. The programs are tailored to their unique circumstances, and address such issues as:

- dealing with diagnosis ٠
- harm reduction in sexual activity and drug use ٠
- socioeconomic realities of living with HIV/AIDS ٠
- dealing with stigma and discrimination
- relations with intimates, friends, family, and community ٠
- barriers to services
- becoming an advocate.

Action 4.3

Governments provide sustained and sufficient funding for peer-based programs for people vulnerable to HIV. The programs are tailored to their unique circumstances, and address such issues as:

- ٠ harm reduction in sexual activity and drug use
- socioeconomic realities that increase vulnerability to HIV infection ٠
- dealing with stigma and discrimination ٠

ADVOCATING FOR RIGHTS

» Strengthening Community-**Based Education and Advocacy**

GOAL 5

Sustained advocacy for the rights of people living with HIV/AIDS or vulnerable to HIV.

Action 5.1

Governments provide long-term operational funding for national and community organizations to:

- advocate for the rights of people living with HIV/AIDS or vulnerable to HIV
- educate others about these rights
- provide training
- build networks ٠
- develop and share resources
- plan and implement joint action.

» Greater Awareness of Human Rights

» Access to Legal Information and Advice

GOAL 6

Greater awareness among people living with HIV/AIDS and vulnerable to HIV of their human rights and of their options when their rights have been violated.

Action 6.1

Governments and human rights commissions fund the development and distribution of easy-to-use tools that explain human rights, violations of human rights, and options for redress to people living with HIV/AIDS or vulnerable to HIV.

Action 6.2

Governments and human rights commissions tailor the above tools and distribution for populations whose legal circumstances are unique, such as:

- Aboriginal people
- immigrants and refugees
- prisoners.

Action 6.3

Governments and human rights commissions fund training for communitybased workers to use the above tools with people living with HIV/AIDS or vulnerable to HIV, and to support them in making decisions when their rights have been violated.

GOAL 7

Access to legal assistance for people living with HIV/AIDS or vulnerable to HIV who choose to seek redress against discrimination or other human rights violations.

Action 7.1

Governments fund the development, maintenance, and distribution of resources to support community workers and lawyers in addressing legal issues, including discrimination and other human rights violations, faced by people living with HIV/AIDS or vulnerable to HIV.

Action 7.2

Governments fund the development and implementation of a plan to strengthen relations and referrals between community organizations and lawyers in private practice.

Action 7.3

National and community organizations working on HIV/AIDS collaborate with other organizations to advocate for an adequately funded legal aid system, with sufficient dedicated resources for civil and administrative law.

» Working with Human Rights Commissions

GOAL 8

Widespread awareness of the rights of people living with HIV/AIDS or vulnerable to HIV, and timely redress for violations of rights.

Action 8.1

Human rights commissions collaborate with national and community organizations working with people living with HIV/AIDS or vulnerable to HIV to:

- raise awareness among staff of the commissions about issues faced by people living with HIV/AIDS or vulnerable to HIV
- ٠ develop educational and advocacy resources for use in the community
- identify and remove barriers to people seeking redress. ٠

Action 8.2

Aboriginal organizations advocate for the repeal of section 67 of the Canadian Human Rights Act and identify culturally appropriate ways to promote human rights in Aboriginal communities.

ACCESSING PROGRAMS, SERVICES, ACCOMMODATION, AND EMPLOYMENT

» Community HIV/AIDS Education and Prevention

GOAL 9

Targeted, culturally specific HIV/AIDS education and prevention programs for populations vulnerable to HIV, commensurate with rates of HIV prevalence and incidence in those populations.

Action 9.1

Governments ensure that funding levels and allocations for targeted, culturally specific HIV/AIDS education and prevention programs are commensurate with rates of HIV prevalence and incidence.

Action 9.2

Governments require that the design and delivery of HIV/AIDS education and prevention programs are tailored to the culture, needs, and points of access for the population to be reached.

Action 9.3

Community organizations delivering HIV/AIDS education and prevention programs are accountable for their effectiveness in meeting the needs of specific vulnerable populations.

Action 9.4

Governments provide sustained funding for self-governing organizations and networks of people vulnerable to HIV, in order to increase their involvement in designing, planning, implementing, and evaluating HIV/AIDS education and prevention programs.

» Health Services

GOAL 10

Education, training, systems, and practices in client-centred health care that explicitly address intersecting forms of discrimination toward populations affected by HIV/AIDS:

- Aboriginal people ٠
- gay, lesbian, bisexual, and two-spirited people ٠
- ethnic minorities, immigrants, and refugees
- people who use drugs
- prisoners ٠
- sex workers
- trans people
- . women

Action 10.1

Educational institutions training health-care providers (eg, medical schools, nursing schools, community colleges) include curriculum on the right to nondiscrimination in health care and on attitudes, practices, and systems that meet the specific needs of the above populations.

Action 10.2

Professional associations (physicians, nurses, pharmacists, home-care workers, etc) provide continuing education on the right to non-discrimination in health care and on attitudes, practices, and systems that meet the specific needs of the above populations.

Action 10.3

Governments take steps to remedy deficiencies in prevention, support, care, and treatment programs that effectively discriminate against the above populations, such as:

- lack of support to gay, lesbian, bisexual, two-spirited, and trans people • in the coming-out process or the process of gender identity
- ٠ lack of access to harm-reduction tools in prisons
- lack of access to harm-reduction tools in the community ٠
- lack of access to different models of drug treatment, including low-• threshold programs, in the community
- barriers to accessing HIV antiretroviral drugs in the community ٠
- interruption of HIV antiretroviral drugs in prisons. ٠

» Housing

GOAL II

Access to affordable, adequate, and accessible housing for people living with HIV/AIDS.

Action 11.1

Governments increase the supply of subsidized housing and establish procedures to facilitate access to subsidized housing for people living with HIV/AIDS and vulnerable to HIV.

See also actions in the section "Advocating for Rights."

» **Employment**

GOAL 12

Renewed efforts by governments, employers, and unions to promote and enforce laws and policies protecting the rights of people living with HIV/AIDS and those vulnerable to HIV in the workplace.

Action 12.1

HIV/AIDS organizations, employers, and unions collaborate to promote the employability and employment of people living with HIV/AIDS.

Action 12.2

Human rights commissions collaborate with employers, unions, and HIV/AIDS organizations to provide detailed and easy-to-understand information about the rights of people living with HIV/AIDS and people vulnerable to HIV in the workplace.

Action 12.3

Employers and unions review and update their policies on HIV/AIDS in the workplace, and renew their educational activities on HIV/AIDS in the workplace. These activities should include education about the rights of people living with HIV/AIDS as employees, co-workers, or recipients of services.

» Youth and Education

GOAL 13

Culturally sensitive, age-appropriate, accurate, and non-judgmental education and support for children and youth with regard to:

- their sexuality and the sexuality of others ٠
- sexual activity and the skills to practise sex safely ٠
- HIV/AIDS and sexually transmitted infections

- alcohol and other drugs, and how to reduce their potential harms ٠
- human rights in the context of the HIV/AIDS epidemic . (eg, the rights of people living with HIV/AIDS; of women and girls; of gay, lesbian, bisexual, and trans people; of people who use drugs)

Action 13.1

Provincial/territorial departments of education ensure that schools deliver curriculum on sexual health, alcohol and other drugs, and human rights.

Action 13.2

Provincial/territorial departments of education ensure that school-based curriculum includes culturally sensitive, age-appropriate, accurate, and nonjudgmental education about:

- one's sexuality and the sexuality of others •
- sexual activity and the skills to practise sex safely
- HIV/AIDS and sexually transmitted infections
- alcohol and other drugs, and how to reduce their potential harms
- human rights in the context of the HIV/AIDS epidemic . (eg, the rights of people living with HIV/AIDS; of women and girls; of gay, lesbian, bisexual, and trans people; of people who use drugs)

Action 13.3

Provincial/territorial departments of health ensure that HIV prevention is integrated into existing sexual and reproductive health services for youth (as well as adults).

Action 13.4

Provincial/territorial departments of health ensure that harm reduction is integrated into existing information, outreach, and treatment services for youth who use drugs (as well as adults).

» Immigrants and Refugees

» International Cooperation

GOAL 14

Policies and procedures used to judge applicants for immigration to Canada do not unnecessarily and irrationally exclude HIV-positive applicants.

Action 14.1

The Minister of Citizenship and Immigration leads the decision by cabinet to amend the definition of "excessive demand" so that it takes into account an applicant's potential contribution to Canada when determining whether an applicant for immigration should be excluded from Canada because of medical inadmissibility.

GOAL 15

HIV testing, clinical examinations, and follow-up of HIV-positive tests among applicants for immigrant and refugee status conforms to Canadian medical standards and guidelines.

Action 15.1

Citizenship and Immigration Canada trains, remunerates, and monitors physicians in Canada and abroad who test applicants for HIV, to ensure that these physicians provide pre- and post-test counselling in conformity with Canadian standards and guidelines.

Action 15.2

Citizenship and Immigration Canada provides information on, and helps immigrants and refugees access, HIV/AIDS and related health and social services through governmental and community-based settlement programs. The information should be culturally and linguistically appropriate and should be developed in collaboration with immigrant and refugee organizations.

GOAL 16

Access to prevention tools (including vaccines and microbicides), health care (including access to HIV antiretroviral medication and treatment for drug addiction), and legal protections. Access is based on rights guaranteed in international human rights law.

Action 16.1

The federal government increases its contribution to the Global Fund to Fight AIDS, Tuberculosis and Malaria, and other international initiatives designed to increase access to HIV/AIDS drugs and health care in developing countries.

Action 16.2

The federal government works to increase access to HIV/AIDS drugs and diagnostic tools in developing countries, using compulsory licences where necessary, in accordance with the Doha Declaration on the TRIPS Agreement and Public Health.

Action 16.3

The Canadian International Development Agency funds partnerships between organizations in Canada and in developing countries to:

- promote the rights of people living with HIV/AIDS • and vulnerable to HIV
- advocate for rights-based changes to policies nationally • and internationally
- share best practices in fighting stigma and discrimination.

STRENGTHENING RESEARCH AND EVALUATION

» Participatory and Inclusive Research

GOAL 17

Greater capacity for participatory research, and greater inclusion of disadvantaged populations, in HIV/AIDS research in Canada.

Action 17.1

The Canadian Institutes of Health Research negotiate a memorandum of understanding with community-based organizations and community-based researchers regarding the principles, mechanisms, direction, and funding of the community-based research program in HIV/AIDS.

Action 17.2

The Canadian Institutes of Health Research take steps to ensure that disadvantaged populations are included in clinical, epidemiological, and social scientific HIV/AIDS research in accordance with principles of non-discrimination, and receive a fair share of the benefits of that research.

» Evaluation of Interventions

GOAL 18

Evidence of the effectiveness of interventions designed to reduce HIV/AIDSrelated stigma and discrimination, and of interventions designed to overcome discriminatory barriers in programs, services, accommodation, and employment.

Action 18.1

Governments should provide funding for rigorous, long-term evaluation of selected key interventions to reduce HIV/AIDS-related stigma and discrimination and to overcome discriminatory barriers in programs, services, accommodation, and employment.

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APPENDICES

Appendix A : Members of the Advisory Committee

Bill Downer

AIDS Committee of Newfoundland and Labrador, St. John's (until December 2003)

Walter Cavalieri

Centre for Student Development and Counselling, Ryerson University HIV Social, Behavioural and Epidemiological Unit, Faculty of Medicine, University of Toronto

Barry Deeprose

Canadian Rainbow Health Coalition, Ottawa

Grace Getty

Faculty of Nursing, University of New Brunswick, Fredericton

Ken King

Canadian Working Group on HIV and Rehabilitation, Toronto

Michèle Lalonde Direction de la santé publique de Montréal-Centre, Montréal

Bob Mills

Canadian Representative to GNP+, Prairie Regional Representative Global Network of People Living with HIV/AIDS – North America (Bob Mills passed away on 8 October 2003)

Darlène Palmer CACTUS, Montréal

Michael R Smith

HIV/AIDS Policy Coordination and Programs Division Centre for Infectious Disease Prevention and Control Population and Public Health Branch, Health Canada (until October 2003)

Marcie Summers Positive Women's Network,Vancouver

Senait Teclom Women's Health in Women's Hands, Toronto

Albert McLeod Canadian Aboriginal AIDS Network, Ottawa (until December 2003)

NOTES

Appendix B : Participants in the Workshop to **Review the Draft Plan of Action**

John Ah Chong AIDS Community Care Montréal

Bronwyn Barrett Positive Women's Network

Marie-Hélène Bonin Canadian Labour Congress

Sheila Braidek Canadian Rainbow Health Coalition

lill Chettiar Vancouver Area Network of Drug Users

Ian Culbert Canadian HIV/AIDS Information Centre

Theodore de Bruyn Canadian HIV/AIDS Legal Network

Anne Marie DiCenso Prisoners with HIV/AIDS Support Action Network

Brenda Done Canadian Association of Nurses in AIDS Care

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Kim Thomas Canadian AIDS Society

Ingrid Wellmeier HIV/AIDS Policy Coordination and Programs Division Centre for Infectious Disease Prevention and Control Health Canada

Elana Wright Canadian HIV/AIDS Legal Network

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<i>Action</i>	60 Aggleton & Parker, supra, note 7 at 18.

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