HIV/AIDS and Discrimination: A Discussion Paper

by Theodore de Bruyn

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SUMMARY

Why Is This *Discussion Paper* Needed?

In 1995, during Phase I of the Joint Network/CAS Project on Legal and Ethical Issues Raised by HIV/AIDS, over sixty individuals and organizations identified discrimination as one of eight "top priority" legal and ethical issues raised by HIV/AIDS in Canada. Three years later, in January 1998, participants in a national workshop on discrimination and HIV/AIDS confirmed that:

- discrimination against people with HIV/AIDS is still pervasive in Canada;

- discrimination touches every aspect of the lives of people with HIV/AIDS;

- discrimination is becoming more subtle and hard to redress;

- discrimination has a significant impact on the health and well-being of people with HIV/AIDS and of populations affected by HIV/AIDS.

What Are the Issues?

First, although human rights statutes in Canada provide some essential basic protections for people with HIV/AIDS and populations affected by HIV/AIDS, a description and analysis of the experience of stigma and discrimination in the context of the HIV epidemic cannot be limited to attitudes and actions that are actionable under human rights law. Discrimination in the context of the HIV epidemic encompasses a broad range of attitudes and actions, including:

- stigmatizing attitudes as well as discriminatory actions;
- direct, indirect, and systemic forms of discrimination;
- anticipated discrimination as well as actual discrimination;
- legal forms of discrimination as well as illegal forms of discrimination;
- the private sphere as well as the public sphere; and
- stigma and discrimination that is related to HIV/AIDS (eg, based on sexual orientation or drug use) as well as stigma and discrimination that is directly a result of perceived or actual HIV status.

Second, the nature of the HIV epidemic in Canada in 1998 and of Canada's response to the epidemic have a bearing on stigma and discrimination as they are now experienced by people with HIV/AIDS:

- the epidemic is expanding, particularly among marginalized populations who typically experience many layers of stigma and discrimination - not only stigma and discrimination based on HIV status - and have few resources or little support in seeking redress;
- the restructuring of the health system and the devolution of authority for programs may result in fewer programs with a specific focus on HIV/AIDS, resulting in systemic neglect of needs that are unique to or disproportionately found among people with HIV/AIDS or populations affected by HIV/AIDS;
- the advent of protease inhibitors and combination antiretroviral therapies has been accompanied by new forms of discrimination, including restrictive assessments of disability, greater visibility at work and vulnerability to discrimination at work, inequitable access to therapies among diverse populations, and failure to observe guidelines regarding informed choice in HIV testing and treatment.

Third, while there are common elements to the experience of stigma and discrimination among the diverse populations affected by HIV/AIDS, there are also features that are specific to particular populations. Any response to stigma and discrimination in the context of the HIV epidemic must identify and address the specific ways in which stigma and discrimination affect gay and bisexual men, transgendered people, drug users, Aboriginal people, sex workers, prisoners, women, heterosexual men, children and their families, and youth.

What Does the *Discussion Paper* Contain?

The *Discussion Paper* reviews:

- definitions of discrimination that are current in Canada and internationally;
- the nature of stigma, discrimination, and vulnerability in the context of the HIV epidemic;
- stigma and discrimination that people with HIV/AIDS currently experience in their families and communities, at work, in housing, in health care settings, in obtaining insurance coverage or benefits (particularly private medical and disability insurance), and in policies restricting travel or immigration;
- specific patterns of stigma and discrimination that populations affected by HIV/AIDS experience, and the impact of stigma and discrimination on their health and well-being in the context of the HIV/AIDS epidemic; and
- various ways to respond to stigma and discrimination, including education (public education, professional education, and focused education), redress (human rights law, the *Canadian Charter of Rights and Freedoms*, and other forms of legal or procedural redress), and advocacy.

What Are the Goals of the *Discussion Paper*?

The goals of the *Discussion Paper* are:

- to show how pervasive stigma and discrimination are in the lives of people with HIV/AIDS and populations affected by HIV/AIDS;
- to document the impact of stigma and discrimination on the health and well-being of people with HIV/AIDS and populations affected by HIV/AIDS;

- to recommend basic elements of a concerted effort to prevent, redress, and eliminate HIV/AIDS-related stigma and discrimination.

The *Discussion Paper* does not presume to be definitive in its description of HIV/AIDS-related stigma and discrimination, or in its recommendations as to how to respond to such stigma and discrimination. Rather, it is hoped that the *Discussion Paper* will stimulate:

- increased awareness of HIV/AIDS-related stigma and discrimination;

- further documentation of stigmatizing or discriminatory attitudes, actions, or systems;

- further analysis of the complexities and effects of HIV/AIDS-related stigma and discrimination;

- further discussion and deliberation on how to respond to HIV/AIDS-related stigma and discrimination; and

- increased resolve to address HIV/AIDS-related stigma and discrimination.

What Does the *Discussion Paper* Conclude?

The *Discussion Paper* concludes that, in addition to being unwarranted and unjust in most circumstances, discrimination against people with HIV/AIDS or populations affected by HIV/AIDS has serious consequences. These include (but are not limited to):

- vulnerability to HIV infection, particularly among young gay and bisexual men, drug users, Aboriginal people, prisoners, and sex workers;

- failure to prevent HIV infection, both among populations identified as being "at risk" for HIV infection and among populations not so identified;

- stress associated with HIV status, secrecy about HIV status, and social isolation because of HIV status - all adversely affecting the psychological health of people with HIV/AIDS;

- harassment from employers or colleagues; insufficient accommodation of health-related needs at work; reluctance to claim medical or disability benefits for fear of being harassed, laid off, or fired; being laid off or fired;

- denial of housing by landlords because of HIV status, sexual orientation, or source of income;

- reluctance to access health-care services, because of stigmatizing or discriminatory attitudes and remarks;

- delayed diagnosis and substandard treatment for HIV infection and HIV/AIDS-related diseases and opportunistic infections;

- insufficient or no insurance coverage for disability or drugs;

- exclusion from or underrepresentation in research on HIV/AIDS, resulting in insufficient information on HIV prevention, care, and treatment in certain populations; and

- restrictions on travel to foreign countries.

The *Discussion Paper* further concludes that a concerted effort is required on the part of governments, human rights commissions, community and national organizations, professional associations, schools, workplaces, and researchers to prevent, redress, and eliminate stigma and discrimination associated with HIV/AIDS. The *Discussion Paper* recommends that a framework for action on HIV/AIDS-related discrimination be developed in Phase III of the National AIDS Strategy, with specific provision for:

- 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 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 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 with HIV/AIDS and populations affected by HIV/AIDS;

- education and training to promote and foster non-stigmatizing and non-discriminatory attitudes and practices among professionals, particularly those who provide care to people with HIV/AIDS on an occasional basis;

- education for children and youth, 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 underrepresented 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.

The *Discussion Paper* notes, finally, that many of the issues raised by stigma and discrimination have been treated in recent reports on specific aspects of the HIV epidemic, namely, HIV testing and confidentiality; criminal law and HIV/AIDS; gay and lesbian legal issues and HIV/AIDS; women and HIV/AIDS; children and HIV/AIDS; HIV/AIDS and injection drug use; care, treatment, and support of injection drug users with HIV/AIDS; street-involved people and HIV/AIDS; prisoners and HIV/AIDS; Aboriginal people and HIV/AIDS; vocational and rehabilitation services; community-based prevention research; and research on HIV/AIDS and drug use. These reports, and their conclusions, recommendations, or guidelines, provide essential direction for policy and programs that will, along with achieving other objectives, reduce the extent and the impact of HIV/AIDS-related stigma and discrimination.

Next Steps

The *Discussion Paper* will be sent to a broad range of individuals and organizations active in HIV/AIDS issues and human rights, and their comments and input will be solicited. In particular, they will be asked for their views on what the next components of the project on discrimination should be.

In addition, fact sheets on HIV/AIDS-related stigma and discrimination will be developed and disseminated. These fact sheets will summarize the contents of the *Discussion Paper* in an easy-to-read format, incorporating suggestions and information provided by the individuals and organizations who receive the *Discussion Paper*.

For Further Information ...

contact Ralf Jürgens, Project Manager, at (514) 987-3000 ext 8773#; fax: (514) 987-3422; email: ralfj@aidslaw.ca

Further Copies of this *Discussion Paper* can be retrieved at the website of the Canadian HIV/AIDS Legal Network at www.aidslaw.ca or ordered through the National AIDS Clearinghouse. Tel: (613) 725-3434; fax: (613) 725-9826; email: aids/sida@cpha.ca

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INTRODUCTION

As part of the Joint Project on Legal and Ethical Issues Raised by HIV/AIDS (see Appendix C), the Canadian HIV/AIDS Legal Network (Network) and the Canadian AIDS Society (CAS) are undertaking a Project on HIV/AIDS and discrimination. The Project is funded by the HIV/AIDS Prevention and Community Action Programs and the AIDS Care, Treatment and Support Program, Health Canada, under the National AIDS Strategy, Phase II.

Purpose of the *Discussion Paper*

> AIDS presents a challenge because responses to it have affected all human rights and fundamental freedoms; thereby it also represents an opportunity to reaffirm and reinforce human rights standards as they relate to HIV/AIDS and to the entire field of health.[1]

The purpose of this *Discussion Paper* is to:

- document the extent to which stigma and discrimination touch almost every aspect of the lives of people with and affected by HIV/AIDS;
- describe the impact of stigma and discrimination on those infected and affected by HIV/AIDS;
- identify the connections between stigma, discrimination, and vulnerability among those

infected and affected by HIV/AIDS; and

- make general recommendations as to the efforts required to prevent, counter, and redress HIV/AIDS-related discrimination and stigma.

Scope of the *Discussion Paper*

The *Discussion Paper* aims to provide an overview that is comprehensive but not exhaustive. In other words, it reviews many of the areas and ways in which people infected with and affected by HIV/AIDS currently experience discrimination in Canada, but it does not undertake a complete and thorough investigation of every aspect of those experiences. To do so would require several separate discussion papers.

Many aspects of HIV/AIDS-related stigma and discrimination have been treated in the various discussion papers and final reports that have been produced by the Network and CAS, both as part of the Joint Project on Legal and Ethical Issues and as independent projects. These include papers and reports on:

- HIV/AIDS in prisons;[2]

- criminal law and HIV/AIDS;[3]

- HIV testing and confidentiality;[4]

- gay and lesbian legal issues and HIV/AIDS;[5]

- discrimination, HIV/AIDS, and Aboriginal people.[6]

- HIV testing and confidentiality issues for Aboriginal people;[7]

- HIV/AIDS and Income Security.[8]

This *Discussion Paper* builds on and complements this work, as well as that of organizations of people with HIV/AIDS and AIDS service organizations across the country.

Sources of the *Discussion Paper*

The *Discussion Paper* is based on:

- interviews with individuals and organizations across Canada in December 1997 and January 1998 (see Appendix B);[9]
- observations and analysis provided by participants in a workshop on discrimination and HIV/AIDS, held on 15 January 1998 as a satellite of the 1998 Canadian HIV/AIDS Skills Building Symposium (see Appendix B);[10]
- information provided by human rights commissions and HIV/AIDS legal clinics;
- reports produced by governmental and non-governmental agencies; and
- academic and scientific literature (see Bibliography).[11]

Why a Paper on Discrimination?

An Epidemic of Stigma

Ten years ago, in 1988, Gregory Herek and Eric Glunt described the public reaction to AIDS in the United States as an "epidemic of stigma."[12] This figure of speech has turned out to be more appropriate than one would wish, for in many ways the stigma of HIV/AIDS has had an even wider reach and a greater effect than the virus itself. The stigma of HIV/AIDS affects the lives not only of people with HIV/AIDS, but also of their lovers, families, and caregivers. It involves not only those who are the objects of stigma, but also those who stigmatize them, whether by their attitudes or their actions, in the community, on the job, in professional capacities, in public office or in the media. It adds new prejudices to old, and transfers the accumulated effects of these prejudices from one group of people to another. In fact, it leaves no one untouched, affecting both those who readily associate with the stigmatized and those who would prefer not to associate with them.

This epidemic of stigma has consequences. It can result in attitudes and actions that may prevent those who are living with HIV/AIDS from seeking or obtaining the health care and social support they require. Adults with HIV/AIDS have lost their jobs or been denied employment, insurance, housing, and other services. Children with HIV/AIDS have been denied day care. Because of their beliefs and values, people have been disposed not to provide information about preventing the transmission of HIV, and have supported laws and policies that render the stigmatized more vulnerable to HIV infection. Stigma, in other words, has contributed to unwarranted discrimination against people with or associated with HIV/AIDS.

In view of the fear and experience of HIV/AIDS-related discrimination, various bodies recognized that programs to prevent the transmission of HIV had to be accompanied by measures to prevent discrimination. In the United States, the Institute of Medicine-National Academy of Sciences Committee for the Oversight of AIDS Activities concluded that "fear of discrimination is a major constraint to the wide acceptance of many potentially effective public health measures. Public health programs will be most effective if they are accompanied by clear, strict sanctions to prevent unwarranted discrimination against those who are HIV-infected or at risk for infection."[13] In Canada, in a background paper to the report on AIDS of the Royal Society of Canada, David Roy observed that "the *central moral issue* raised by HIV and AIDS is: how can we effectively protect society against the spread of HIV infection and AIDS and simultaneously protect seropositive people and AIDS patients against unjust discrimination and against unnecessary constraints on their human rights and civil liberties."[14]

Precisely because protecting people from discrimination - both discrimination based on HIV status and discrimination based on other characteristics, such as sexual orientation - was seen to be integral to preventing the spread of HIV and providing appropriate care and support to people with HIV, many countries, including Canada, committed themselves to protecting the human rights of people with or affected by HIV/AIDS. Thus, in setting out a framework for action on AIDS in the 1990s, the federal government included among its guiding principles the principle of equal rights:

> Persons with HIV and AIDS must be allowed to participate fully and with dignity in the life of their community. They have the same rights as other Canadians to confidentiality, community support and appropriate health care. They also have the right to live their lives without discrimination.[15]

In accordance with that commitment, the National Advisory Committee on AIDS established a Working Group to survey the situation nationally and advise the Minister of National Health and Welfare with respect to issues of human rights as they pertained to people affected by HIV in Canada. The report of the Working Group made numerous recommendations in the areas of human rights legislation and policy; HIV infection and employment; public health and involuntary measures; immigration, international travel, and HIV infection; HIV infection in correctional facilities; HIV infection and Canada's Aboriginal communities; HIV infection and women; children and HIV infection; the design of clinical trials and access to investigational therapies; and Canada's role in the global response to AIDS.[16] The Working Group concluded:

> Although HIV infection has affected all sectors of Canadian society, to date it has had a particularly severe impact upon groups that have traditionally suffered wrongful discrimination. Comprehensive protection of the rights of persons with HIV must, therefore, also include measures to prevent discrimination on grounds closely related to

HIV infection, including discrimination on the basis of sexual orientation, race, mental or physical disability (including people with hemophilia) and people who are sex industry workers, injection drug users, and children.[17]

The Situation in 1998

The situation has changed since 1988. Stigma and discrimination associated with HIV/AIDS are still pervasive, but the forms they take and the context in which they are experienced have changed. These changes have serious implications for people with HIV/AIDS and people affected by HIV/AIDS. Participants in the January 1998 workshop on discrimination and HIV/AIDS noted the following key aspects of the current situation:

- The epidemic of HIV infection is expanding among diverse populations, many of them marginalized within Canadian society. While some aspects of HIV-related discrimination are the same for all these populations, in other ways the experience and impact of discrimination are unique to the various identities that are assumed by or assigned to people with or affected by HIV/AIDS. The most marginalized among people with HIV/AIDS experience many layers of stigma and discrimination. They also have the least resources or support in seeking redress.

- With the restructuring of the health system and the devolution of authority for programming, there is considerable uncertainty about the funding and quality of HIV/AIDS programs in future. There may be fewer programs with a specific focus on HIV/AIDS, resulting in systemic neglect of needs that are unique to or disproportionate among people with HIV/AIDS or the populations most affected by HIV/AIDS. At the same time, organizations that provide specific services to people with HIV/AIDS or populations affected by HIV/AIDS are faced with increasing demands, which they must meet with the same level of resources or reduced resources. The difficulty of meeting these demands is all the greater when the populations that need to be served are different; one program will not fit all.

- With the advent of protease inhibitors and combination therapies, many - but not all - people with HIV/AIDS are living longer and enjoying better health. While the benefits of these development have been great, they have also been accompanied by new risks for people with HIV/AIDS. There is a renewed impetus to adopt traditional public health measures, such as nominal reporting of HIV infection and increased partner notification efforts. There is also a prevailing sense that people with HIV/AIDS can now lead "normal" lives, and a tendency to become more restrictive in determining whether people with HIV/AIDS qualify for disability benefits. The fact that people with HIV/AIDS are still vulnerable to stigma and discrimination is forgotten in these discussions. In many

> ways, the era of combination therapies has exposed people with HIV/AIDS to greater threat of discrimination. One participant in the workshop stated: "I was able to remain invisible living with HIV until two years ago. Now I have to carry my bag of medications around all the time - I am always visible. I carry my stigma around."
>
> • The era of combination therapies is also raising new concerns about the ethics of informed choice in treatment decisions made by people with HIV/AIDS. There are reports that people feel pressured by their physicians to begin treatment with the latest generation of HIV drugs, and of instances where people have been denied services or fear losing their physician if they refuse to begin treatment. There are also questions about equity in treatment and access to care for marginalized populations, and about the extent to which they are provided with the supports that may be necessary to assist them in maintaining the complicated regimes of combinations of drugs.
>
> • While discrimination is still pervasive, it has become more subtle and less explicit. In the past, for example, people may have been fired outright when it was discovered they were HIV-positive. Today they may be laid off for what are ostensibly other reasons or they may be harassed and pressured to the point that they quit their jobs or go on disability. Fear of being identified at work and of losing their job in fact prevents some people from taking HIV-related medications, as a recent study among people with HIV/AIDS in Montréal found.[18]

These observations are a reminder not only that, even as the epidemic changes, stigma and discrimination continue to have an enormous impact on the lives of people with HIV/AIDS. They are also a reminder that decisions about the direction that policy and programs should take in response to the changing epidemic need to be based on, among other considerations, a full analysis and assessment of the impact of stigma and discrimination on the people infected and affected by HIV/AIDS. In what follows, this *Discussion Paper* will identify many of the areas that require attention.

Definition of HIV/AIDS-Related Discrimination

The UNAIDS Definition

The Joint United Nations Programme on HIV/AIDS (UNAIDS) has developed a protocol for the identification of discrimination against people with HIV/AIDS. According to the protocol, HIV/AIDS-related discrimination is defined as follows:

> Any measure entailing any arbitrary distinction among persons depending on their confirmed or suspected HIV serostatus or state of health.[19]

The protocol distinguishes between legitimate and illegitimate discrimination. *Illegitimate* discrimination is unjustified, disproportionate, and arbitrary. A measure or an action is *unjustified* if it lacks rational and objective reasons. It is *disproportionate* if the means employed and their consequences far exceed or do not achieve the aims pursued. It is *arbitrary* if it seriously infringes the rights of the individual and is not necessary to protect the health of others.[20]

The protocol recognizes that "[d]iscrimination against people living with HIV/AIDS also extends to those with whom AIDS is associated in the public mind (homosexuals, prostitutes, drug addicts, hemophiliacs, and family members and associates of HIV-positive people)."[21]

The New South Wales Anti-Discrimination Board Definition

In 1991 the Anti-Discrimination Board in the state of New South Wales, Australia, held a public inquiry into HIV/AIDS-related discrimination. The Board observed that HIV/AIDS-related discrimination can take a variety of forms, which may be more or less obvious:

> It can range from almost imperceptible attitudinal hostility through to physical violence. It can manifest itself in forms which appear reasonable and justifiable, or in extremes of pathological behaviour. It is sometimes blatantly explicit, but more often subtle, sophisticated and difficult to define.[22]

The Board identified eight forms of discrimination:[23]

- *direct discrimination*: discrimination that is explicitly based on characteristics of or attributed to the individual against whom the discrimination is directed, including characteristics attributed on the basis of stereotyping.

- *indirect discrimination*: discrimination that is based on the establishment of rules, policies or conditions that do not in themselves appear discriminatory, but that have the effect of discriminating against particular groups of people who are unable, or less able, to comply with the conditions.

- *reactive discrimination*: discrimination that occurs when a person is confronted with someone who is, or who is assumed to be, a member of a group against which the person holds strong prejudices; such discrimination is not intentional or planned.

> • *proactive discrimination*: discrimination that is intentional and planned; it is often found in the development of policies, procedures, and rules that have as their purpose to preclude certain groups, or to exclude them if they are found to be present.
>
> • *passive discrimination*: discrimination that occurs by failure to act, when the particular needs of particular groups are not met, often with the justification of providing equal treatment for all, but, in fact, failing to meet the special needs of some.
>
> • *scapegoating*: discrimination that seeks to subject people to punishment, usually on the basis that they are to blame for some social evil, and that involves actively seeking out and victimizing the objects of prejudice.
>
> • *harassment*: discrimination that involves subjecting a person to psychological, emotional, and sometimes physical discomfort, because of characteristics s/he has or are attributed to him/her; it may range from refusal to acknowledge or deal with a person, through indirect and direct verbal ridicule or abuse, to interference with property, and to the extreme of physical assault.
>
> • *vilification*: discrimination that involves making statements about a group of people on the basis of their characteristics or of stereotypical assumptions about them that bring members of the group into hatred, ridicule or contempt.

Human Rights Law in Canada

There is no single definition of discrimination in Canadian law. Although the anti-discrimination statutes specify certain prohibited actions and frequently add that one may not "discriminate against" someone on one of these prohibited grounds, none of the statutes, except for the Manitoba Code and the Québec Charter, provides a definition of the term "discriminate."[24] It has been left to tribunals and courts to determine what constitutes discrimination in a particular case.[25] A definition provided by McIntyre J of the Supreme Court of Canada, referring to section 15 of the *Canadian Charter of Rights and Freedoms*, is now frequently cited:

> I would say then that discrimination may be described as a distinction, whether intentional or not but based on grounds relating to personal characteristics of the individual or group, which has the effect of imposing burdens, obligations, or disadvantages on such individual or group not imposed on others, or which withholds or limits access to opportunities, benefits, and advantages available to other members of society. Distinctions based on personal characteristics attributed to an individual solely on the basis of association with a group will rarely escape the charge of discrimination, while those based on an individual's

> merits and capabilities will rarely be so classed.[26]

It is common, in human rights law, to distinguish between direct (or overt) discrimination, indirect (or adverse effect) discrimination, and systemic discrimination. Direct or overt discrimination occurs in applying criteria that explicitly discriminate against an individual or group on the basis of some personal characteristic (eg, job criteria that explicitly exclude women). Indirect or adverse effect discrimination occurs in applying criteria that, while apparently neutral, have the effect of discriminating against an individual or group distinguished by some personal characteristic (eg, job criteria that effectively exclude women, such as being at least 6 feet tall and weighing at least 180 pounds). Systemic discrimination occurs when prevailing attitudes and practices within an organization or a society lead to the exclusion or disadvantage of a particular group; these attitudes and practices need not necessarily be expressed in criteria that discriminate directly or indirectly, but nevertheless have the effect of excluding the group from consideration or benefit.

Human rights law recognizes that discrimination may not be intentional, or that the intent in a given case may not be malicious or evil. The discriminatory effects of indirect or systemic discrimination, for example, may be unintended, or they may be the unanticipated result of good intentions. An allegation of discrimination, therefore, need not imply an accusation of bigotry or malice, although in certain cases the discrimination may be motivated by these attitudes. Furthermore, although in most cases it is necessary to prove that the differential act or treatment had an adverse impact on the individual or group in question, it is not always necessary to demonstrate this. Moreover, tribunals have been prepared to accept subjective interpretations of adversity (such as, eg, a serious affront to dignity) as well as objective interpretations (such as, eg, exclusion from employment).[27]

Human rights statutes specify prohibited grounds of discrimination and the areas in which discrimination is prohibited. Typically, human rights statutes in Canada require equal treatment in the provision of services, goods and facilities, in accommodation, in employment, in membership in a trade union, trade or occupational association or self-governing profession, and in the right to form contracts. Discrimination in these areas is prohibited on such grounds as 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.[28] Human rights statutes normally do not apply to discrimination in private relations, such as between friends, within family, or in casual encounters not associated with provision of a service.

HIV infection is considered a disability or handicap within the meaning of human rights legislation in all jurisdictions in Canada. Accordingly, redress can be sought for discrimination on the grounds of HIV infection in the areas specified in human rights legislation. Other prohibited grounds, such as sexual orientation or sex or place of origin, may also be relevant for people living with or associated with HIV/AIDS.[29]

The Approach Taken in the *Discussion Paper*

The approach taken in this *Discussion Paper* is a broad one, similar to (and in some ways broader than) that of the New South Wales Anti-Discrimination Board. The *Discussion Paper* considers:

- stigma as well as discrimination;
- direct, indirect, and systemic forms of discrimination;
- unintended as well as intentional effects;
- legal forms of discrimination as well as illegal forms of discrimination;
- the private sphere as well as the public sphere; and
- stigma and discrimination that is related to HIV/AIDS (eg, based on sexual orientation or drug use) as well as stigma and discrimination that is directly a result of perceived or actual HIV status.

In taking this broad approach, the governing principle of the *Discussion Paper* has been to recognize the full extent of discriminatory treatment and adverse effects associated with HIV/AIDS. For people with HIV/AIDS, some of the more painful or burdensome aspects of the way they are treated have to do either with treatment that is either not actionable under law (such as HIV-related stigma) or with treatment that is legal (such as denial of disability insurance). While it may be difficult or impossible to seek legal redress for these forms of discrimination, it is important to acknowledge their impact and to pursue other ways of preventing them or compensating for them. It is also necessary to consider whether laws, policies, and practices that are currently accepted should be changed because of their disproportionate adverse effects on populations affected by HIV/AIDS. For example, the epidemic of HIV infection among injection drug users is leading to a renewed debate about the effects of Canada's drug laws on public health, drug users, and professionals who work with drug users. Although it is not expected that there will be consensus regarding the conflict of values that is often implicit in stigma and discrimination associated with HIV/AIDS, there must be room to consider whether conventions, policies and laws may be failing ethical tests that strive for human dignity and social equity.

In what follows, it is assumed that discrimination is unwarranted or illegal unless otherwise stated, by specifying, for example, "warranted discrimination" or "legal discrimination."

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FOOTNOTES

[1] Centre for Human Rights. *Report of an International Consultation on AIDS and Human Rights, Geneva, 26-28 July 1989.* New York: United Nations, 1991, at 10.

[2] R Jürgens. *HIV/AIDS in Prisons: Final Report*. Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1996.

[3] R Elliott. *Criminal Law and HIV/AIDS: Final Report*. Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1997.

[4] R Jürgens, M Palles. *HIV Testing and Confidentiality: A Discussion Paper*. Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1997; R Jürgens. *HIV Testing and Confidentiality: Final Report.* Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998.

[5] J Fisher et al. *Gay and Lesbian Legal Issues and HIV/AIDS: Final Report*. Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998.

[6] S Matiation. *Discrimination, HIV/AIDS and Aboriginal People: A Discussion Paper*. Canadian HIV/AIDS Legal Network, 1998.

[7] S Matiation. *HIV Testing and Confidentiality: Issues for the Aboriginal Community: A Discussion Paper*. Canadian HIV/AIDS Legal Network, 1998.

[8] Canadian AIDS Society. Poverty, Discrimination and HIV/AIDS. A Brief to the Parliamentary Sub-Committee on HIV/AIDS. October 1996; L Locas et al. *Income Security Project. Phase II: Private Insurance Component.* Ottawa: Canadian AIDS Society, 1996.

[9] Unless otherwise indicated by a footnote, all accounts of stigma and discrimination cited in this paper were provided by individuals interviewed or participants in the workshop on discrimination and HIV/AIDS.

[10] See note 9, supra.

[11] A working bibliography of approximately 500 items was selected from the available literature. The academic and scientific literature was identified from references in the literature and by searching such databases as AIDSline, Medline, LegalTrac, and Sociofile.

[12] GM Herek, EK Glunt. An Epidemic of Stigma: Public Reactions to AIDS. *American Psychologist* 1988; 43(11): 886-891.

[13] National Academy of Sciences. *Confronting AIDS: Update 1988.* Washington, DC: National Academy Press, 1988. Cited in RJ Blendon, K Donelan. Discrimination against People with AIDS: The Public's Perspective. *New England Journal of Medicine* 1988; 319(15): 1022-1026 at 1022.

[14] DJ Roy. HIV Infection and AIDS: Ethical Issues. In: Royal Society of Canada. *AIDS: A Perspective for Canadians. Background Papers.* Ottawa: Royal Society of Canada, 1988, 315-331 at 317 (italics in original).

[15] Health and Welfare Canada. *HIV and AIDS: Canada's Blueprint.* Ottawa: Minister of Supply and Services, 1990, at 39.

[16] National Advisory Committee on AIDS. *HIV and Human Rights in Canada.* Ottawa: National Advisory Committee on AIDS, 1992, at 9.

[17] Ibid.

[18] See infra, notes 81 and 85.

[19] UNAIDS. Protocol for the Identification of Discrimination against People Living with HIV. Geneva: UNAIDS, 1996, at 5.

[20] Ibid at 6-7.

[21] Ibid at 5.

[22] New South Wales Anti-Discrimination Board. *Discrimination - The* Other *Epidemic. Report of the Inquiry into HIV and AIDS Related Discrimination.* The Board: 1992, at 5.

[23] Ibid at 9-14, paraphrasing or quoting definitions provided by the Board.

[24] WS Tarnopolsky et al. *Discrimination and the Law in Canada*. 5th Release. Toronto: Richard De

Boo, December 1997, at 4-1.

[25] On what follows, see Tarnopolsky et al at 4-29 to 2-56.18(12); J Keene. *Human Rights in Ontario*. 2nd ed. Scarborough: Carswell, 1992, at 5-13.

[26] *Andrews v Law Society (British Columbia),* [1989] 1 SCR 143 at 174-175; cited by Tarnopolsky et al, supra, note 24 at 4-5.

[27] Keene, supra, note 25 at 10.

[28] The list of protected areas and prohibited grounds varies according to jurisdiction.

[29] See, further, the discussion on redress, infra.

HIV/AIDS and Discrimination: A Discussion Paper
by Theodore de Bruyn

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DIVERSITY, STIGMA, DISCRIMINATION, AND VULNERABILITY

When one begins to look at the experiences of people with HIV/AIDS, two things stand out. The first is the diversity of people with HIV/AIDS. The second is how often and in how many ways people with HIV/AIDS are stigmatized or discriminated against. Sometimes it appears as if the various people with HIV/AIDS have only two things in common: HIV infection and HIV-related stigma and discrimination.

Stigma and discrimination feed on cultural differences and block out common humanity.[30] This happens through social processes whereby

- particular aspects of some people with HIV/AIDS, such as sexual orientation or drug use, are magnified to the exclusion of the individual humanity of each person with HIV/AIDS and the diversity of all people with HIV/AIDS (stereotyping);
- the negative associations of these magnified aspects are combined with or transferred to the negative associations that have developed around HIV infection;
- people with HIV/AIDS are seen by others primarily in light of these magnified aspects and their negative associations (stigmatization);
- the negative associations of HIV/AIDS lead people - inadvertently or deliberately - to shun, avoid, shame, degrade or discriminate against people with HIV/AIDS;
- some people feel justified in acting toward people with HIV/AIDS on the basis of their prejudices and misperceptions, to the point of excluding people with HIV/AIDS from services, support, benefits, and opportunities that they would otherwise enjoy;

- living with HIV/AIDS becomes living with stigma and discrimination, either anticipated or actual.

The cumulative effect of HIV/AIDS-related stigma and discrimination is to objectify, marginalize, and exclude people with HIV/AIDS. Those who were already objectified, marginalized and excluded are pushed even further from a recognition of shared humanity and from the support of human society.

This section of the *Discussion Paper* reviews:

- the complex nature of HIV/AIDS-related stigma;

- the range of discriminatory attitudes and actions that flow from HIV/AIDS-related stigma; and

- the ways in which stigma and discrimination contribute to the vulnerability of people living with or affected by HIV/AIDS at the societal, programmatic, and personal levels.

Stigma

> [T]he stigmatized are a category of people who are pejoratively regarded by the broader society and who are devalued, shunned or otherwise lessened in their life chances and in access to the humanizing benefits of free and unfettered social intercourse.[31]

Stigma "is a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons."[32] People who are stigmatized are usually considered deviant or shameful for some reason or other, and as a result are shunned, avoided, discredited, rejected, restrained or penalized. As such, stigma is an expression of social and cultural norms, shaping relationships among people according to those norms. Stigma marks the boundaries a society creates between "normals" and "outsiders," between "us" and "them."

Multiple Dimensions of Stigma

HIV/AIDS is not alone among illnesses and diseases in being marked by stigma. Other conditions, such as epilepsy, mental illness, cancer, tuberculosis, and syphilis, have been stigmatized and stigmatizing, both in the past and the present. What distinguishes HIV/AIDS from many illnesses and diseases, however, are the many dimensions of HIV/AIDS-related stigma. Research into HIV/AIDS-related stigma has found that people with HIV/AIDS are stigmatized because:[33]

- HIV/AIDS is associated with behaviours that are already stigmatized or considered deviant, particularly homosexuality and injection drug use;
- people with HIV/AIDS are thought to be responsible for having contracted HIV;
- HIV/AIDS is a life-threatening disease;
- people are afraid of contracting HIV; and
- the religious or moral beliefs of others lead them to conclude that having HIV/AIDS is the result of a moral fault, such as promiscuous or deviant sex, that deserves punishment.

It is the combination of these stigmas, together with their strength, that makes it so difficult to overcome HIV/AIDS-related stigma. Education about HIV/AIDS may reduce HIV/AIDS-related stigma; a more accurate perception of the risk of contracting HIV has been associated with less hostility toward people with HIV/AIDS.[34] But HIV/AIDS-related stigma can persist in the face of education about HIV/AIDS. A Canadian study that compared the attitudes of university students toward a homosexual or heterosexual male described as being healthy or as having terminal cancer, venereal disease, or AIDS, found that despite a considerable level of knowledge about AIDS among the students, they had more negative attitudes toward a person with AIDS than one with cancer and that, regardless of differences in AIDS knowledge among students, they all maintained a greater social distance from the person with AIDS. The study also found that students evaluated a heterosexual person with AIDS more favourably than a homosexual person with AIDS.[35]

Other researchers report similar findings.[36] A study of attitudes among students in the United States toward an HIV-infected co-worker found, for instance, that "the attitudes of people who were antihomosexual were unaffected by the AIDS-education film, whereas the attitudes of those who were not antihomosexual were more positive after viewing the film."[37] Likewise, a Belgian study found that older, less-educated people who expressed a general distrust of others were both less knowledgeable about the transmission of HIV and about protective measures, and held segregationist attitudes toward people with HIV.[38] The authors remark:

> We might think that these discriminatory attitudes are explained to a great extent by ignorance. However, this interpretation is not enough. We know, for example, that a common way to construct one's identity and strive to fit in with one's entourage is to create 'out groups', that is, claim a distance between oneself and others groups. Such a strategy, in which people with HIV and the whole problem of AIDS are lumped together, may be at work here.[39]

The result, for people with HIV/AIDS, is that they may be treated differently based on the attitudes of others about the disease. People respond more positively and are more inclined to help when they believe that the person with HIV/AIDS was not responsible for the HIV infection, while they respond more negatively and are less inclined to help when they have a negative attitude toward homosexuality and a fear of HIV infection.[40]

Felt versus Enacted Stigma

Studies of stigma related to HIV/AIDS, as well as other illnesses such as epilepsy, have drawn a distinction between "felt" and "enacted" stigma. Felt stigma refers to the shame associated with the illness and the fear of being discriminated against on account of the illness; enacted stigma refers to actual experiences of discrimination. Research into stigma associated with epilepsy found that felt stigma was far more prevalent than enacted stigma. Felt stigma tended to precede rather than follow enacted stigma; in fact, one effect of felt stigma was to reduce the possibility of enacted stigma or actual experiences of discrimination, since individuals who felt stigmatized by their epilepsy attempted to conceal it in order to protect themselves from potential discrimination.[41]

The distinction between felt and enacted stigma appears to be valid for HIV/AIDS-related stigma as well. A survey of attitudes among passersby in the street and among people with HIV in Glasgow and Edinburgh, Scotland, found that, although people with HIV held more liberal views on HIV than the passersby, the passersby held more liberal views than people with HIV credited them with. Both people with HIV and the passersby felt that the attitude of the general public was more hostile to HIV/AIDS than their own. Nevertheless, there were large discrepancies between the passersby and people with HIV/AIDS in regard to "victim blaming" (in response to such statements as "people with HIV should be ashamed of themselves" and "people with HIV have nothing to feel guilty about") and in regard to restrictions that should be placed on people with HIV (in response to such statements as "prisoners with HIV should be segregated" and "it is safe for people with HIV to work with children" and "people with HIV must expect some restrictions on their freedoms"). Such restrictive views were held by a minority of respondents who tended to be older.[42]

The stories that follow in later sections of this *Discussion Paper* show that felt stigma or anticipated discrimination has an enormous impact on people with HIV/AIDS. Discovering that one is HIV-positive brings with it a multitude of anxieties and concerns that issue simply from the fear and uncertainty about how other people will react. These anxieties and concerns prevent people with HIV/AIDS from disclosing their HIV status to family or friends and benefiting from their support, from seeking or obtaining employment, from accessing health-care benefits, health-care services, or other services.

Moreover, it is clear from the stories told by people with HIV/AIDS that they do *in fact* experience stigma and discrimination. The range of such discriminatory attitudes and actions is the subject of the next section.

Discrimination

Research and inquiries into discrimination against people with HIV/AIDS has shown that it can touch on almost every aspect of a person's life. Surveys of people's attitudes and opinions about such things as working with someone with HIV/AIDS, housing for people with HIV/AIDS, or isolation of people with HIV/AIDS have found that a substantial minority hold highly discriminatory views. A review of 53 states in the US and international opinion surveys conducted between 1983 and 1988 found that, for instance, 32 percent of respondents would allow physicians to choose whether to treat someone with HIV/AIDS, 25 percent of respondents would refuse to work alongside someone with HIV/AIDS, around a third of respondents said they would keep their own child out of school to avoid contact with a student with AIDS, and 17 percent supported a landlord's right to evict people with HIV/AIDS from their homes.[43]

Such attitudes persist despite education about the fact that there is no risk of HIV infection in everyday settings and activities. The 1992 French survey of knowledge, attitudes, behaviours and practices, *Les Comportements sexuels en France*, found that 14 percent of men and 13 percent of women would refuse to work with an HIV-positive person, and 41 percent of men and 40 percent of women would refuse to leave their children or grandchildren in the company of an HIV-positive person, while 9.2 percent of respondents would agree to the isolation of people with AIDS, 10.1 percent would not agree to have an AIDS-patient centre next door, and 6.5 percent would agree to the right to fire a person who had AIDS.[44] A Belgian survey produced comparable results, with 10.2 percent of respondents refusing to work with an HIV-positive person, 36 percent refusing to leave their children or grandchildren in the company of an HIV-positive person, 6.1 percent agreeing to the isolation of people with AIDS, 17.4 percent not agreeing to have an AIDS-patient centre next door, and 8.2 percent agreeing to the right to fire a person who has AIDS.[45]

It is difficult to determine the extent to which discriminatory attitudes result in discriminatory actions (although it is apparent how such attitudes will contribute to an environment in which people with HIV/AIDS feel stigmatized). However, it is clear from reports and litigation that people with HIV/AIDS have experienced unfair discrimination in a wide range of areas.

United States

A review of litigation and reports pertaining to HIV/AIDS discrimination in the United States that was undertaken in the latter half of the 1980s[46] - roughly coterminous with the review of opinion survey noted above[47] - discusses numerous cases in the following areas:

- *education*: children denied state education, given homebound instruction, singled out as different or isolated at school, required to disclose their HIV status.

- *employment*: dismissal without medical evidence, notice or a hearing; demotion to positions of lower experience and skill; denial of insurance benefits to pay for AIDS-related expenses; reduction in salary; harassment; dishonourable discharge from the National Guard; and numerous cases involving health care workers, workers who provide services for children, and food handlers.

- *housing and property*: eviction; locking out or harassing a tenant; refusal to provide necessary repairs for a tenant; reneging on a contract to purchase a property because the previous owner had AIDS; difficulty in placing AIDS patients in skilled nursing facilities; personal and professional housing discrimination against health professionals providing services to people with HIV/AIDS.

- *public accommodations*: discrimination in private physicians' offices; refusals to provide personal services at a nail salon, an airline, a television studio, and a spiritual retreat; refusal to provide or exorbitant fees for funeral services.

- *insurance*: conflict between standard insurance underwriting practices and nondiscrimination principles which, thus far, have been decided in favour of the actuarial principles of the insurance industry.

- *health care*: treatment withheld from patients infected with HIV or provided in a way that shows inexcusable lack of respect, empathy, and care; access denied to HIV/AIDS treatments or clinical trials; dismissal of HIV-positive health care providers or excessive limitations on their rights to practice.

Australia

In 1991 the Anti-Discrimination Board in the state of New South Wales, Australia, held a public inquiry into the issue of HIV/AIDS-related discrimination. The Board had accepted complaints of HIV/AIDS-related discrimination since 1985, and had come to the conclusion both that the number of complaints received were "nowhere near representative of the extent of discrimination experienced by people infected with HIV or ill with AIDS" and that the "actual level of discrimination which occurs in relation to HIV and AIDS is totally disproportionate to the number of people infected or to any rational examination of the causes for concern about transmission of the virus."[48]

The inquiry, report and recommendations of the Board are perhaps the most comprehensive in any jurisdiction to date. The Board discussed and made recommendations regarding HIV/AIDS-related discrimination in the following areas: the media, accommodation (public housing, private accommodation), education, employment, services (home care, child care, the funeral industry), health care (general practitioners, hospitals, dentists, surgeons), ambulance and emergency services, autopsies, infected health-care workers, health care in rural areas, law (Public Health Act, Crimes Act, Drug Misuse and Trafficking Act), police, custodial institutions (prisons, juvenile institutions), and superannuation and insurance.[49]

The Board also identified a broad range of individuals or groups that have been affected by HIV/AIDS-related discrimination, including homosexual men, injection drug users, people with blood disorders, sex workers, ethnic minorities, transsexuals, people with intellectual disabilities, people who have become infected with HIV through blood transfusion, blood products, transplants or other medical procedures, those who are associated with people with HIV, women, and people living in rural areas.[50]

Canada

B.C. Civil Liberties Association

The only investigation of HIV/AIDS-related discrimination in Canada, undertaken in 1988-89 by the B. C. Civil Liberties Association, received reports of 83 cases of discrimination.[51] These reports, which the Association believed represented only a portion of actual incidents at the time, were in the following areas:

- *housing*: 9 cases, primarily refusal to provide rental accommodation to people with HIV/AIDS or to AIDS service organizations.
- *employment*: 32 cases, 8 in the food service industry, 7 in health care, 9 in other areas of employment, and 8 in unidentified areas of employment.
- *access to health care*: 14 cases, 5 concerning access to dental care, 9 concerning access to other medical care.
- *public services*: 8 cases.
- *other*: 20 cases.

In two areas, the B.C. Civil Liberties Association deemed it necessary to provide an extensive commentary and critique of current policies and practices: the treatment of people with HIV/AIDS in correctional facilities, and dental care.

Human Rights Commissions

HIV/AIDS is now considered a disability or handicap under the terms of human rights legislation in every jurisdiction in Canada, and is thus a prohibited ground of discrimination in the areas protected under that legislation. However, since human rights commissions deal with complaints as they are brought forward by individuals, they do not have data on the full extent to which people with HIV/AIDS actually experience discrimination. Only a small percentage of people who experience discrimination make a complaint to a human rights commission. This is due to a number of reasons: the matters over which human rights commissions have jurisdiction, the areas in which they offer protection from discrimination, the long time it often takes to bring a complaint to resolution, the modest damages or settlements that are afforded. (Human rights law and procedures are discussed in more detail in the chapter on responding to stigma and discrimination later in the *Discussion Paper*.)

HIV/AIDS Legal Clinics

In the absence of comprehensive and thorough data on instances of discrimination related to HIV/AIDS in Canada, it is useful to look at the case loads of legal clinics serving people with HIV/AIDS. At the present time, there are several HIV/AIDS legal clinics in Canada. Although not all the cases they deal with have to do with discrimination, the wide range of issues on which people with HIV/AIDS seek legal advice and assistance is an indication of the many areas in which people with HIV/AIDS may have problems in obtaining services. For example, the profile of areas on which the HIV/AIDS Legal Clinic of Ontario was approached for advice in 1996 is as follows:[52]

Issue	**1996** **%**
Government income maintenance	10.56
Housing	11.73
Insurance	8.48
Wills and substitute decision making	14.49
Bankruptcy	4.44
Human rights[53]	4.04
Criminal /Prison law	8.49
Health Issues (excluding malpractice)	3.12

Employment	3.26
Immigration	5.22
Family	3.00
Miscellaneous other civil law[54]	23.17

Comparison with the case loads of other legal clinics in the province of Ontario is instructive. The vast majority - over 70 percent - of calls are about income maintenance or housing issues. This is not true of people with HIV/AIDS. As the staff of the HIV/AIDS Legal Clinic of Ontario observe, HIV status permeates every aspect of the lives of people with HIV/AIDS, raises a wide range of problems, and creates a broad demand for information and advice.[55]

Vulnerability

Whether people resist the discriminatory attitudes and actions of others or whether they accept them, those attitudes and actions affect the way people see themselves, their social networks, their opportunities, and their rights or entitlements. Aside from the fact that discrimination is wrong and unjust, it raises questions about how it affects the course of HIV infection in populations and in individuals. How does discrimination make people more vulnerable to HIV infection? How does discrimination make people with HIV infection more vulnerable to sickness and death?

AIDS in the World "proposed that vulnerability could be considered on three interdependent levels: personal, programmatic, and societal."[56] In *AIDS in the World II*, Mann and Tarantola describe these levels as follows:[57]

> • *Personal vulnerability* to HIV/AIDS focuses on the various factors in an individual's development or environment that render him/her more or less vulnerable, such as physical and mental development, knowledge and awareness, behavioural characteristics, life skills, and social relations.
>
> • *Programmatic vulnerability* focuses on the contributions of HIV/AIDS programs toward reducing or increasing personal vulnerability. This includes information and education, health and social services, and human rights programs.
>
> • *Societal vulnerability* focuses directly on the contextual factors that define and constrain personal and programmatic vulnerability. This includes such issues such as political structures, gender relationships, attitudes to sexuality, religious beliefs, and poverty.

Stigma and discrimination operate at all of these levels:

> • At the *societal level* stigma and discrimination on the basis of race, gender, sexual orientation, drug use, criminal status, or imprisonment results in economic, political, legal and social disadvantages that marginalize people, render them more vulnerable to HIV infection or disease progression, and deprive them of appropriate programs and services.
>
> • At the *programmatic level* stigma and discrimination can lead to programs not being available or being offered in ways that do not empower, respect the dignity of, or meet the needs of people with HIV/AIDS or people vulnerable to HIV infection.
>
> • At the *personal level* stigma and discrimination are experienced directly in day-to-day occurrences with family, friends, service providers, and the public, as well as indirectly in the conditions created by discrimination at the societal level and the limitations imposed by discrimination at the programmatic level.

The stories recounted in the research for this *Discussion Paper* show that all people with HIV/AIDS experience stigma and discrimination in some form or other at one or more of these levels. As Mann and Tarantola observe, however, those who are most disadvantaged or disempowered by the contextual factors that contribute to societal vulnerability are the most vulnerable to the HIV epidemic:

> The history of AIDS has shown that HIV can enter a community or country in many different ways. In each country, where and among whom HIV enters obviously defines the early history of the epidemic. Thus, in the United States and France, white gay men were first noted to be affected; in Brazil, first cases occurred among members of the "jet set" in Rio and São Paulo; in Ethiopia, AIDS was initially noted among the social elite. However, with time, as the epidemic matures, it evolves and moves along a clear and consistent pathway, which, although different in its details within each society, nevertheless has a single, vital, and common feature. For in each society, those people who were marginalized, stigmatized and discriminated against - before HIV/AIDS arrived - have become over time those at highest risk of HIV infection. Regardless of where and among whom it may start within a community or country, the brunt of the epidemic gradually and inexorably turns towards those who bear this societal burden. Thus in the United States, the epidemic has turned increasingly toward "minority" populations in inner cities, injecting drug users, and women. In Brazil, the HIV epidemic now rages through heterosexual transmission in the *favelas* of Rio de Janeiro and São Paulo. In Ethiopia, HIV is concentrated among the poor and dispossessed. The French have a simple term which says it all: HIV is now becoming a problem mainly for *les exclus* - the "excluded ones" living at the margins of society.[58]

This observation underscores the importance of recognizing how discrimination at the societal and programmatic levels has a profound impact on how a given individual can protect her/himself from HIV infection or maintain her/his health, safety, and welfare while living with HIV/AIDS.

It is impossible or futile to address personal vulnerability without addressing the societal and programmatic context in which such vulnerability is embedded, including the discriminatory dimensions (unintentional as well as intentional) of that societal and programmatic context. For example, women have experienced discrimination when their physicians have failed to advise them about HIV testing, have discouraged them from being tested, or have associated risk of HIV infection with negative connotations of "promiscuity." Such discrimination cannot be adequately understood or addressed without addressing the cultural identities of women, perceptions of risk of HIV infection, and populations most affected by HIV infection among both women and physicians, and the practices of physicians in relation to women.[59] Similarly, the risk of HIV infection among injection drug users who inhabit impoverished urban centres with a high density of drug users is in part (and arguably in large part) an effect of the criminal status of drug use in Canadian law, a legislated form of discrimination against drug users.[60] Likewise, the risk of HIV infection experienced by Aboriginal peoples as a result of their overrepresentation among drug users and in prison populations cannot be understood or addressed without recognizing the events and structures, both past and present, that have contributed to substance abuse, migration, unemployment, cultural displacement and despair among Aboriginal peoples in Canada.[61] So too, an environment that does not acknowledge and respect the sexual identities of gay and bisexual youth, that does not provide support at home or at school for the coming-out process, and that tolerates high levels of violence and abuse against gay men contributes to the many risks to the health of gay and bisexual youth, including the risks of HIV infection.[62] Finally, any analysis of what makes people vulnerable to HIV infection or what makes people with HIV vulnerable to sickness and death must now take into account the role of poverty, independent of any risk factors, in leading to HIV infection and to sickness and death, and how the structures of our economy and our society benefit (discriminate in favour of) people with higher incomes or more wealth.[63]

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FOOTNOTES

[30] For a general discussion, see N Gilmore, MA Somerville. Stigmatization, Scapegoating and Discrimination in Sexually Transmitted Diseases: Overcoming "Them" and "Us." *Social Science and Medicine* 1994; 39(9): 1339-1358.

[31] AA Alonzo, NR Reynolds. Stigma, HIV and AIDS: An Exploration and Elaboration of a Stigma Trajectory. *Social Science and Medicine* 1995; 41(3): 303-315 at 304.

[32] Ibid at 304.

[33] For analyses of HIV/AIDS-related stigma, based on the available research, see L Peters et al. Public Reactions Towards People with AIDS: An Attributional Analysis. *Patient Education and Counseling* 1994; 24(3): 323-335 at 323-324; SD Johnson. Model of Factors Related to Tendencies to Discriminate Against People with AIDS. *Psychological Reports* 1995; 76(2): 563-572; Alonzo & Reynolds, supra, note 31 at 305.

[34] D Mondragón et al. Hostility to People with AIDS: Risk Perception and Demographic Factors. *Social Science and Medicine* 1991; 32(10): 1137-1142.

[35] TA Fish, BJ Rye. Attitudes Toward a Homosexual or Heterosexual Person with AIDS. *Journal of Applied Social Psychology* 1991; 21(8): 651-667.

[36] JB Pryor et al. The Instrumental and Symbolic Functions of Attitudes toward Persons with AIDS. *Journal of Applied Social Psychology* 1989; 19(5): 377-404.

[37] JB Pryor et al. Fear and Loathing in the Workplace: Reactions to AIDS-Infected Co-Workers. *Personality and Social Psychology Bulletin* 1991; 17(2): 133-139.

[38] J Marquet et al. Public Awareness of AIDS: Discrimination and the Effects of Mistrust. In D FitzSimons et al, eds. *The Economic and Social Impact of AIDS in Europe*. London: National AIDS Trust, 1995, 219-233 at 226-228.

[39] Ibid at 230. In general, the level of AIDS knowledge is higher among people with more education, among younger people, and (in the United States) among white people. It is lower among people with strong religious beliefs, conservative political convictions, or restrictive views about people with HIV/AIDS. See A Peruga, DD Celentano. Correlates of AIDS Knowledge in Samples of the General Population. *Social Science and Medicine* 1993; 36(4): 509-524.

[40] Peters et al, supra, note 33 at 330.

[41] A Jacoby. Felt versus Enacted Stigma: A Concept Revisited. Evidence from a Study of People with Epilepsy in Remission. *Social Science and Medicine* 1994; 38(2): 269-274 at 270, describing the research of G Scrambler, A Hopkins. Being Epileptic: Coming to Terms with Stigma. *Sociology of Health and Illness* 1986; 8: 26-43.

[42] G Green. Attitudes Towards People with HIV: Are They as Stigmatizing as People with HIV Perceive Them to Be? *Social Science and Medicine* 1995; 41(4): 557-568. Green registers a number of caveats about the results of the study, including the possibility that many people in the general population may act in a stigmatizing manner despite claiming to hold non-stigmatizing attitudes, as well as the difficulty of accounting for the "double-stigma" of attitudes towards HIV and attitudes towards gay men and drug users.

[43] Blendon & Donelan, supra, note 13. In 1989 the United Nations Sub-Commission on the Prevention and Protection of Minorities appointed a Special Rapporteur to investigate discrimination in the context of HIV/AIDS. The Special Rapporteur released a preliminary report in 1991 (document no. E/CN.4/Sub.2/1991/10), a progress report in 1991 (document no. E/CN.4/Sub.2.1991/10), a final report in 1992 (document no. E/CN.4/Sub.2/1992/10), and conclusions and recommendations in 1993 (document no. E/CN.4/Sub.2/1993/9). These reports were not available to the author.

[44] Marquet et al, supra, note 38 at 228.

[45] Ibid at 229.

[46] LO Gostin. The AIDS Litigation Project. A National Review of Court and Human Rights Commission Decisions, Part II: Discrimination. *Journal of the American Medical Association* 1990; 263 (15): 2086-2093.

[47] Supra, notes 13 and 43.

[48] Supra, note 22 at iii.

[49] Ibid at 16-66, with examples, analysis, and recommendations for action.

[50] Ibid at 67-80, in the order presented, with some modification.

[51] B.C. Civil Liberties Association. *AIDS Discrimination in Canada: A Study of the Scope and Extent of Unfair Discrimination in Canada against Persons with AIDS, and Those Known or Feared to be HIV Positive*. Vancouver: B.C. Civil Liberties Association, 1989.

[52] R Carey. Provision of Legal Services to Persons with HIV or AIDS: Barriers and Trends. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 9-11.

[53] This category includes only human rights law. In many cases of adverse treatment, other areas of law may provide more practical or effective remedies.

[54] This category includes medical malpractice, other tort-based actions, non-profit incorporations, tax issues, drawing up affidavits and other documents required by law, and any other matters that are presented to the clinic.

[55] Personal communication with R Carey, 19 January 1998.

[56] J Mann et al, eds. *AIDS in the World*. Cambridge, MA: Harvard University Press, 1992, 577-602, as described by J Mann, D Tarantola, eds. *AIDS in the World II: Global Dimensions, Social Roots, and Responses*. New York: Oxford University Press, 1996, at 441.

[57] For a more detailed analytical framework of these three levels of vulnerability, see Mann & Tarantola at 441-462.

[58] Ibid at 464.

[59] LA Jackson et al. HIV-Positive Women Living in the Metropolitan Toronto Area: Their Experiences and Perceptions Related to HIV Testing. *Canadian Journal of Public Health* 1997; 88(1): 18-22.

[60] CN Mitchell. A Justice-Based Argument for the Uniform Regulation of Psychoactive Drugs. *McGill Law Journal* 1986; 31: 212-263.

[61] See supra, note 6.

[62] SL Martindale et al. Evidence of Psychologic Distress in a Cohort of Young Gay/Bisexual Men. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 8A. Abstract no. 102.

[63] LE Krueger et al. Poverty and HIV Seropositivity: The Poor are More Likely to Be Infected. *AIDS* 1990; 4(8): 811-814. MT Schechter et al. Higher Socioeconomic Status is Associated with Slower Progression of HIV Infection Independent of Access to Health Care. *Journal of Clinical Epidemiology* 1994; 47(1): 59-67; RS Hogg et al. Lower Socioeconomic Status and Shorter Survival Following HIV Infection. *The Lancet* 1994; 344: 1120-1124.

HIV/AIDS and Discrimination: A Discussion Paper

by Theodore de Bruyn

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CURRENT PROBLEMS
FOR PEOPLE WITH HIV/AIDS

Introduction

Although the complex of stigma and discrimination varies with the diverse populations affected by HIV/AIDS, there are many common aspects to the experience of stigma and discrimination among people with HIV/AIDS. This section of the *Discussion Paper* reviews these common aspects, while the next will examine the dimensions of stigma and discrimination that are specific to the diverse populations affected by HIV/AIDS.

When people with HIV/AIDS describe their experience of the stigma and discrimination associated with the disease, it is clear that stigma and discrimination:

- HIV disease; runs through the entire experience of
- is often very subtle and hard to redress;
- contributes to the isolation, lack of security, and hardship that people experience; and
- is very painful and stressful for people with HIV/AIDS and their families.

This section will describe, with examples,[64] the many contexts into which stigma and discrimination intrude, and how stigma and discrimination affect the lives of people with HIV/AIDS and their families. Although the section will raise only some of the more pressing problems faced by people with HIV/AIDS (it is not possible to be exhaustive in this short survey), it nevertheless demonstrates what one participant in the workshop on discrimination and HIV/AIDS termed "the unique character of the disease" - the fact that, for people with HIV/AIDS, no area of life is untouched by stigma and no area of life is invulnerable to discrimination.

Family and Community

Stigma, Stress, Secrecy, and Isolation

When people discover that they are HIV-positive, one of the first things they have to decide is whether to tell family or friends. Because of the stigma associated with HIV/AIDS and the potential for discrimination, people with HIV/AIDS have to be careful about whom they tell:

> I feel it's stressful cause I have to be careful not to tell the family members who can't be told. They will shun us for sure. They are very paranoid about this disease. Nothing you tell them will make any difference.[65]
>
> Hearing negative comments about people with HIV really eats away at me. For example, I've heard people say people with AIDS should be put on a desert island. That makes me feel I should say something like you're talking about me. I'm one of those people. But I always end up holding back my comments.[66]
>
> Most of my stress is about disclosure and discrimination regarding HIV.[67]

Anticipating such reactions, or having experienced them, can lead to isolation:

> For the first four years (after diagnosis) I lived on my own, kept to myself. One of the reasons I became more public is that I decided that no one should have to go through the hell that I went through.
>
> Lately I have been wanting to isolate myself from people too, because I am afraid of getting hurt. I am real picky about my friends. I don't want people throwing stuff in my face or going behind my back. There are too many eyes out there watching what we do, listening to what we say. So I have been isolating myself.[68]

Secrecy is complicated, and takes its own toll, both on the person with HIV/AIDS and his/her caregivers:

> The whole issue of secrecy is always on my mind - what people would think and do (if they knew): explaining the medical condition to my older child, explaining HIV to the affected (infected) child, always thinking about who can be trusted, issues at school, confidentiality, feeling responsible even though I am aware of universal precautions.[69]
>
> I haven't disclosed about my daughter's HIV status beyond our immediate family. It's difficult to keep a secret. I keep my visits to the child's HIV clinic a secret. I can't bring anyone along with me to help me when I'm doing the one and a half hour drive during the day. It's terrible living with the secret.[70]

Even if the reaction of family and friends may be supportive, the person with HIV/AIDS, and their immediate family or partners, must live with the dilemma and risk of deciding when to tell and what to say:

> The current problem is that nobody knows. I find this very difficult to keep it a secret. I have a good friend whom I could see telling, but I have to prepare her. I am now afraid she will reject me.[71]

One can never be sure of the reaction, good or bad:

> We lost our best friends - a couple. These friends feared that their son would get HIV. But we've picked up some good friends since they learned of the child's diagnosis. People that we might not have met so there was some good. A nurse friend became more distant. My brother no longer visits.[72]

As a result, opportunities for support are lost:

> I found out that I had HIV when my child was diagnosed at 6 months. The child died at 9 months. We said the cause was CMV, not AIDS. I had tenants at the time. They had a grandfather who was dying of AIDS, but they said that he was dying of cancer. So each of us missed the chance of support. They eventually moved away, and later I went public about HIV/AIDS. I did a spot for the local newspaper, which they found out about when they came back for a visit. It was then that they told me that their grandfather also had AIDS. It made me so angry about the stigma around HIV. It kept us both from recognizing and supporting each other.

Stigma and the resulting stress, isolation, and lack of social support have significant negative impacts on the health of people with HIV/AIDS.[73] Research has found that social support is associated with psychological well-being among people with HIV/AIDS.[74] Those who feel stigmatized by HIV/AIDS -

both those infected and those affected by the disease - and lack the supports they consider helpful are more likely to experience symptoms of depression.[75] There is also some evidence that stress has a negative effect on the human immune system, and that social support (which people who are isolated due to stigma lack) can moderate the effects of stress on the immune system.[76]

Living in Smaller Communities

> I went to the post office to mail a package. The clerk knows a lot about my business - that I receive mail from an AIDS organization, that I get cheques from the provincial and federal government. I got the stamps for the parcel, licked them, and pasted them on. I handed it to the clerk and she said, "What do you want me to do with that?" "I don't know," I replied, "What do you want *me* to do with it?" "I don't care what you do with that," she answered. "Well, *I* do," I said, "I care where it goes." The clerk took my package and threw it on the bench behind her. There were other people there who saw it all.

For people living in smaller communities, where it is hard to remain anonymous, the need for secrecy is often greater than in cities. People with HIV/AIDS must sometimes go to great lengths to protect their confidentiality:

A woman receiving support from an AIDS service organization feared that, if she cashed a cheque from the organization at her local credit union, everyone would know that she was HIV-positive. The organization paid the support by way of a personal cheque instead.

People drive into Edmonton or Calgary to get medical care. Even if care is available locally, they are afraid of discrimination.

People with HIV/AIDS report that, when they disclose their HIV status, the response of the community is often more supportive than anticipated. But the impact of negative reactions in a small community is perhaps greater, since other avenues of support may be less available. Therefore, there is silence and secrecy, at great cost not only to the person with HIV/AIDS but also the family of the person.[77]

When people with HIV/AIDS go public in a smaller community, it usually falls to them or to their families and friends to educate the community about HIV/AIDS. This can be rewarding, and can succeed in creating a supportive environment. But it is an additional responsibility for the person with HIV/AIDS or their family. And, as one person observed, it can all come too late:

> The biggest challenge is ending the isolation in rural communities. A person living with HIV/AIDS died in a community of less than 200 people. While the person was sick, no

> one came by, not even the Red Cross or other organizations who regularly come to the door to ask for donations. It was only after the person died that people finally came around. If it's the community's first experience of HIV/AIDS, it's like hell on earth for the person living with HIV/AIDS.

Cultural Communities

People with HIV/AIDS who identify with a specific ethnic or cultural community experience stigma and discrimination from others within their community. Various incidents are reported regarding, for example:

- *gay men:* Some gay men are open. Others will have nothing to do with you. When you go into a gay bar, there are all kinds of signals. People know that you are HIV-positive.

- *Aboriginal people:* "[T]here is one woman who found out that she was HIV positive. When she went home every dish that she uses her mother washed it down with bleach. I went there several times to tell people that when somebody comes back home with this virus, you love them support them, hug them be affectionate with them and this one lady apparently did not listen. She made her daughter feel small, made her feel dirty. This really hurt."[78]

- *members of ethnocultural communities:* A man who is HIV-positive is unable to tell others in his community that he is living with HIV. The men in his ethnic community will automatically assume that he is gay or that he is an active drug user. Being identified as either a homosexual or an active drug user in this community carries a considerable stigma. The result is a deep sense of isolation. The individual spends a great deal of time at home alone.

- *members of the Deaf community:* The Deaf living with HIV/AIDS are fearful of rejection from other members of the Deaf community if it becomes known that they are HIV-positive.

The experience of stigma and discrimination within a specific community is complicated by the fact that the community is already a minority in society as a whole and often marginalized or discriminated against. This has implications for both the person with HIV/AIDS and for the community. For the person with HIV/AIDS, it means that there may be no where else to go once one has been isolated within one's own community. For the community, it means that it is difficult to address issues associated with vulnerability to HIV infection (such as sexual activity, homosexuality, and relations between men and women) and supporting people with HIV/AIDS. A national study of six ethnocultural communities in Canada found, for instance, that all the communities consistently reported discrimination within the predominant culture, and that this affects the way the communities deal with sensitive issues. As one individual reported:

> We're afraid of airing our dirty laundry in a hostile environment. [We have this assumption that] whatever is happening that is divisive in our community will ultimately be used against us. We're afraid that we'll be labelled.[79]

Employment and Workplace

The workplace remains a potentially unsafe environment for people with HIV/AIDS, whether they are currently at work, returning to work, or looking for work for the first time.[80] Employers may:

- breach confidentiality regarding HIV status;
- fail to accommodate the needs of people with HIV/AIDS regarding the duties they are able to perform, the schedule and side effects of their regimen of drugs, time required for medical appointments, or leave required for temporary illnesses;
- lay off people with HIV/AIDS because of the cost of group disability insurance or group drug insurance premiums; or
- tolerate an environment in which other employees harass, avoid, or ostracize people with HIV/AIDS.

Although not all employers, supervisors, and coworkers react badly when they discover that a person is HIV-positive, disclosure at work remains risky. A recent survey in Québec found that among workers who disclosed their HIV status, one in five had problems with their employer.[81] Others report:

> A few people at work know I'm positive and I get treated pretty fairly, but I'm getting harassed because of sick time - having to take time off work with decreased pay for physical and emotional health. I've talked to my doctor about going on disability but he says I'm too physically healthy right now. I know I can go on disability for emotional instability, but I don't want to be pegged as that.[82]
>
> Recently I had a client who experienced workplace HIV discrimination. Given that he worked in a large and seemingly progressive urban workplace, he felt it would be safe to disclose his HIV-positive health status. Regrettably, he experienced harassment from his supervisor, deliberately inconvenient and health-compromising shift assignments, regular

> harassment about the time he took off work to attend necessary medical appointments, and deliberately cruel workplace assignments when he was feeling ill as a result of medication side effects.

The risks of disclosure are now being felt not only by people who are working when they discover that they are HIV-positive, but also by people who decide to return to work because treatment with a combination of antiretroviral drugs has sufficiently restored their health. A Toronto study on returning to work found that half of the respondents (10 of 21) were concerned about disclosing their HIV status.[83] Similarly, others report:

> An employee with a large telecommunications firm has been on disability for two years. His condition has improved with combination therapies, and he would like to return to work. But he fears the reaction of other employees who may know that he has HIV/AIDS. And he is afraid that the company will lay him off after he returns to work, because of the expense involved in drug costs and workplace accommodations.
>
> We were called to support the workplace in responding to needs of the worker returning to work. After consultation with the worker and the supervisor, we decided that workplace education would be a helpful place to start. I would come in, do AIDS 101 [and] AIDS in the Workplace, and then the worker would disclose to people in his department. Regrettably, the company chose not to heed my suggestions to train all the employees in the company. As a consequence, I was called back three months after the initial successful department training. Word had spread through the entire company that a man with AIDS was working in their building. The ensuing hysteria resulted in people refusing to come on to the floor where the man worked, requests for separate bathrooms, requests for a separate fridge and staffroom, etc.

Anticipating such reactions, people with HIV/AIDS may prefer not to return to a previous place of employment, and may prefer to seek employment in an environment that would be more supportive or where their HIV status is not known.[84] However, this may not always be possible. After a period out of the workforce, they may have lost skills and may require training. They may not be able to afford further training, and (if they are on long-term disability) their insurer may be unwilling to pay for it. Looking for work in a new area, without seniority or benefits, is also risky, particularly if one has to explain a gap in work experience. People who have benefits with their previous employment may simply not be able to risk moving to new employment.

The new antiretroviral drug regimes have brought new workplace hazards. People taking these drugs must adhere to strictly regimented dosage schedules complicated by food and drug interactions, and they often suffer side effects. The drug regime and its side effects can lead to de facto disclosure of HIV status. Employers or coworkers may not accommodate the needs associated with these regimes. As one person reported:

> A person living with HIV/AIDS was told to remove the pills from his desk - something he did in order to remind himself to take them - because they made other employees uncomfortable; a minor example, yet still telling: why were the other employees not educated?

Even more serious, when employers are directly involved in providing drug insurance coverage for their employees, people with HIV/AIDS may not claim their benefits for fear of disclosure, harassment, and being fired. This is frequently a problem in small or mid-size firms, where the employer processes insurance claims on behalf of the employees. The risks associated with claiming benefits affect people's decisions about taking medications: the Québec survey, noted above, found that fear of a breach of confidentiality in relation to insurance - as well as fear of being identified at work and fear of losing one's job - were among the reasons that 11 percent of respondents did not take antiretroviral drugs.[85] In addition, when group insurance premiums rise because of the costs of an employee's drugs, discriminatory actions may follow. Employers and coworkers may either opt to change the policy so as to limit insurance coverage (which affects people with HIV/AIDS disproportionately), or the employer may fire or lay off the person with HIV/AIDS.

Faced with the hazards involved in returning to work, people with HIV/AIDS need accurate information about their rights and responsibilities with regard to private and public insurance coverage of long-term disability, drugs, and other medical expenses. However, making inquiries is itself risky. It could result in being pressed back to work or in being cut off long-term disability benefits, since physicians and insurers define disability solely on the basis of virological and immunological markers (CD4 cell counts and viral load measurements) without taking into account the psychosocial functioning of the individual and other quality-of-life issues. People with HIV/AIDS may even be reluctant to seek information through their union local - normally an intermediary in instances where it is necessary to protect the confidentiality or the position of the employee - for fear of negative reactions or breach of confidence among coworkers.

Housing

Discrimination by Landlords

People with HIV/AIDS continue to be vulnerable to discrimination in the area of housing, particularly in the private rental market:

> One individual who was renting a room in the house of an elderly couple was kicked out when they became aware of his HIV status. He had been renting the room for about a year.
>
> A man who had rented a house for four years and had a good relationship with his

> landlord during that time recently became involved with a local AIDS organization, and as a result his HIV status became known in his community. Shortly thereafter his relationship with his landlord changed. Repairs were not made, and the rent was increased beyond the approved rated. Twice the man had to apply to the provincial tenant's association for redress. He was successful, but his relationship with his landlord remains difficult.

The problem is compounded when, as one individual reported, a landlord refuses to rent to a person with HIV/AIDS because the individual is on social assistance. Such discrimination could become legal in some jurisdictions. In Ontario, for example, Bill 96, *An Act to Consolidate and Revise the Law with Respect to Residential Tenancies*, could allow for future regulations that would permit landlords to use income information such as type or source of income, or a maximum 30 percent rent-to-income ratio rule to screen tenants.[86] The Ontario Human Rights Commission has long held that there is no business case for tenant selection based on either source of income or rent-to-income ratios except to establish eligibility for subsidized housing. The Chief Commissioner has advised the government of Ontario that regulations allowing screening based on income information will effectively authorize discrimination against people on social assistance and other people, including those with disabilities:

> [R]ent-to-income ratios have demonstrated adverse impact not only on persons on public assistance, but also on senior citizens, persons with disabilities and single mothers. Women's shelters have also pointed out that women who are denied housing because of income criteria may return to abusive spousal relationships to secure housing for themselves and their children.[87]

Lack of Appropriate Housing

Stories like these - and the distress and hardship they cause for the individuals involved - must be seen in the context of poverty, marginalization, and homelessness among people with HIV/AIDS. Many people with HIV/AIDS live on a reduced income - often long-term disability benefits or social assistance - and face numerous expenses, including the costs of drugs, nutritional supplements, and transportation for medical appointments. The housing options available to such people in the private rental market and in public housing are limited and insufficient. There is a lack of affordable rental housing for lower-income people (who make up a high percentage of renters) in the private rental market, and there is a very small stock of subsidized public and non-profit housing.[88] Buying a home is out of the question. Even those who might be able to afford a home are refused mortgages or mortgage insurance on account of their HIV status.

People with HIV/AIDS require housing that is:[89]

- *adequate*: warm, mold-free, easy to keep hygienically clean, and safe, quiet and secure;

- *accessible*: physically accessible, with the space and supports necessary for people with HIV/AIDS, their dependents, and their caregivers, and close to shops, public transport, medical and social services;

- *affordable:* at poverty level, or on income that fluctuates with the episodic character of HIV disease;

- *available*: particularly in inner cities, where many people with HIV live or move to in order to obtain services.

Not having housing that is adequate, accessible, affordable, and available has numerous consequences for people with HIV/AIDS, including:

- the adverse effects on mental and physical health of living in damp, drafty, poorly ventilated, cold or improperly heated housing;[90]

- not being able to afford the food that they or their dependents need, because most of their monthly income goes to pay the rent;

- not being able to afford medications or other supplements not paid for by insurance plans.

To this must be added the increased risk of HIV infection associated with homelessness in various populations.[91]

In short, the issue for people with HIV/AIDS - many of whom are marginalized or on low incomes - is not only unlawful discrimination or harassment by an individual landlord or neighbour based on one's HIV status or source of income. It is also the lack of adequate, accessible, affordable, and available housing for people on low incomes - a problem that is a function of lawful discrimination based on ability to pay in the private rental market.[92] Both problems require redress.

Health Care

In the first decade of the epidemic, there were flagrant and explicit examples of discrimination against people with HIV/AIDS in health-care settings.[93] These included refusing to provide care, avoiding or neglecting patients, and making prejudicial remarks. Such incidents have decreased as health-care providers have become more knowledgeable and experienced in caring for people with HIV/AIDS. But there are still examples of inappropriate treatment - both inadvertent and deliberate, sporadic and systematic - of people with HIV/AIDS.

Primary Care

A common experience of people who are not readily identified with a "risk group" - women, heterosexual men, older people - is that their physician was unwilling to test them or failed to diagnose HIV-related symptoms:[94]

> I went to the doctor for more than six years complaining of chronic vaginal yeast infections, of lower abdominal problems, a lot of things that admittedly could be symptoms of other things, but we ruled those out. After six years you've gone down the list for those, but at no point did this woman doctor ever suggest the possibility of an HIV test.[95]
>
> A woman of sixty-two years was sick for two years before being tested for HIV. The physician would not believe that she was HIV-positive, and dismissed her complaints as those of an old, hysterical woman with the flu.
>
> A heterosexual man suffered from pneumonia on and off for three years. With the last occurrence, he was admitted to a hospital where he was attended by a specialist who finally diagnosed that his pneumonia was related to HIV.

People who report such experiences feel the effects of stigma in two ways. First, they do not consider asking for an HIV test, and their physician does not consider offering them a test, in part because of the stigma associated with HIV and with risky behaviours. Then, when the test turns out to be positive, people find the reactions of their physicians to be stigmatizing. There may be implicit or explicit assumptions of "promiscuity" or drug use.

Discrimination of this sort is as much a reflection of a lack of training and experience among health-care providers as it is an expression of beliefs and attitudes. Studies among physicians and nurses in Canada show that those with more experience in caring for people with HIV/AIDS are more knowledgeable about HIV/AIDS care.[96] They also show that there is room for improvement, not only in knowledge and practices but also in attitudes, among those with little or no experience with people with HIV/AIDS.

People with HIV/AIDS and AIDS service organizations continue to report that some physicians and dentists refuse to see people with HIV/AIDS. In the past, there have been problems particularly with dentists refusing to provide care.[97] A recent study of dentists in Québec found that although many have a strong intention to provide care to people with HIV/AIDS, 25 percent of the respondents expressed a low intention to provide care. The authors conclude that "[c]ontinued education programs to dentists should focus on increasing self-efficacy to cope with the difficulties of providing dental care to HIV+/

AIDS patients as well as on the importance to respect the Dental Association's code of ethics."[98]

Hospital Services

Hospitals that specialize in HIV/AIDS care appear, for the most part, to provide services in a way that is knowledgeable, supportive, and non-discriminatory vis-à-vis people with HIV/AIDS. There are difficulties, however, in hospitals that see fewer people with HIV/AIDS:

> If [an HIV-positive person] tries to access health care at a suburban Toronto hospital, they would likely have a higher chance of experiencing HIV-related discrimination at some point in their hospital care. Knowledge, skilled practice, training and policy are lacking outside of urban core areas.
>
> A Montréal hospital that admits only about forty-five AIDS patients per year places them in a particular ward at the end of a hallway on a particular floor, regardless of the basis for their treatment. Some of the hospital cleaning staff refuse to work in this ward. Staff schedules and work areas are adjusted accordingly. The hospital has given training in universal precautions, but has never provided HIV/AIDS training to its support staff.

Confidentiality, Disclosure, and the Need to Know

Disclosure of HIV status continues to have many consequences for people with HIV/AIDS and their families. For the safety, security, and peace of mind of people with HIV/AIDS, it is essential that people with HIV/AIDS have control over the disclosure of their HIV status, that they are assured of the confidentiality of their medical records, and that they do not experience discrimination in health-care settings.[99]

Under Canadian law, physicians and other health-care providers have a duty of confidentiality to their patients. There are exceptions to this duty, but as a general principle, the right to privacy with regard to medical information remains paramount in Canada.[100]

There continue to be problems with confidentiality of HIV status and other medical information related to HIV/AIDS. They include problems in defining possible exceptions to the principle of confidentiality, maintaining confidentiality in an extended system of medical care, providing and enforcing effective guarantees of privacy, and implementing medical information systems with wider and easier access to confidential information.[101]

Several of these problems emerged in the interviews for this *Discussion Paper*. As regards confidentiality in health-care settings, there were instances of inappropriate practices:

> A physician in the emergency ward of a Montréal hospital remarks out loud to a person seeking care: "So you're HIV-positive." The ward is full of people who hear the remark.
>
> A person with HIV/AIDS attends a dentist's office for surgery for the first time. HIV is stamped on the front of the file, and the file is passed from person to person in the office.

When it comes to preserving confidentiality in extended health-care systems, such as hospitals, it is very difficult, if not impossible, for people to retain control over medical information pertaining to them. In such circumstances, people on low incomes are more exposed to loss of confidentiality than people with high incomes. People on low incomes must often disclose information to obtain services, whereas people with high incomes can seek private services, and service providers make assumptions, based on class, of their own need for information and their clients need for confidentiality.[102] Concern about lack of control as to what information service providers may legitimately require and about the assumptions that service providers make in using information has left many people with HIV/AIDS very uneasy about the introduction of computerized medical information systems in Canada. Such systems - particularly the so-called "smart cards" that register HIV status - would considerably widen access to confidential medical information, and may be accompanied by legislation that effectively protects the health-care provider from liability for releasing medical information.

The debate regarding the need to know an individual's HIV status remains unresolved, particularly in the case of emergency service providers and prison staff. Although most occupational parenteral exposures to HIV do not transmit HIV infection, there is a risk of infection that varies according to the circumstances of the injury.[103] Most (but not all) occupational exposures to HIV in Canada could have been prevented by adhering to universal precautions,[104] as recommended by the Canadian Medical Association.[105] It is not possible here to address all aspects of the debate regarding the need to know. But it is important to note that, from the point of view of the person with HIV/AIDS, disclosure of HIV status can lead to discrimination, such as refusal to treat:

> Ambulance personnel will refuse to treat an individual whom they know to be HIV-positive. They will simply transport the individual, without even administering pain medication.

It should be added that, on the basis of the policy of the Canadian Medical Association on HIV infection in the workplace, the Canadian Human Rights Commission does not generally accept HIV infection as a *bona fide* justification for refusing to provide emergency rescue services.[106]

Drug Therapy

With the advent of protease inhibitors and other new drugs, people with HIV/AIDS confront an array of choices and decisions around drug therapies. They must weigh the potential benefits of a particular combination of drugs against the side effects of the drugs, the demands of the dosage regime, the possibility of drug resistance, and what they anticipate might be their drug requirements in the future.

In making these choices, some people with HIV/AIDS report feeling pressured by their physicians to take the new drugs, even so far as to be denied services if they do not take them. Others report feeling pressured to go back to work solely on the basis of the virological and immunological markers associated with their current drug regime, without considering other health issues or the potential negative consequences of returning to work. Regardless of what the physician may have intended in these instances, these reports point to the need to reaffirm the right of an individual to informed choice in all medical procedures that affect his or her person, as well as the need to empower and support people in making those choices. It also points to the need for physicians to be alert to their responsibilities in the ethical conduct of informing patients and enabling them to make decisions regarding their treatment.

Discrimination of another kind may occur in the case of people whom physicians perceive to be unable to maintain the regime required for treatment with antiretroviral drugs that is most effective and least likely to result in drug resistance. Physicians may refuse to prescribe antiretroviral drugs to drug users and homeless people for fear that they will not be able to maintain the drug regime. Again, the decision not to prescribe (like the decision to prescribe) may be made without considering the right of the individual to an informed choice or without examining the supports that might assist an individual to maintain the drug regime. To make such a determination solely on the grounds that an individual is a drug user or is homeless is unethical and discriminatory.

Medical Procedures Not Related to HIV/AIDS

There are reports that decisions about what procedures are to be made available to people with HIV/AIDS are being made without an appropriate or consistent rationale or without taking into account the current prognosis for these people.

> A person with HIV/AIDS required cardiac care. The first hospital to which the individual applied refused to do the procedure. The second hospital moved the individual to the top of the list.

Problems of this nature have been documented in studies, for example, of the attitudes of neonatologists toward aggressive treatment of non-HIV-related conditions in newborns at risk for HIV.[107] They underscore the importance of up-to-date information and education among specialists about treatment and prognosis for people with HIV/AIDS, so that deliberations about the benefits and drawbacks of non-HIV-related treatment are made with a full awareness of the health status, life expectancy, and quality of life of people with HIV/AIDS. Otherwise, people with HIV/AIDS will suffer discrimination based on misinformed perceptions of their prognosis.

Community-Based Services

The diversity of people infected and affected by HIV in Canada has increased over the last decade. Community-based AIDS organizations and public health services now face a variety of populations with different cultural identities, lifestyles, ways of interacting, experience in accessing services, degrees of isolation, individualism or solidarity. These populations have diverse needs when it comes to HIV/AIDS-related education, prevention, treatment, care, and support.

A number of difficulties have arisen in this context. First, funding for AIDS organizations and HIV/AIDS programs has remained constant or has been reduced, while the demand and the diversity of needs have increased. Staff struggle to maintain established programs while at the same time developing new programs. This has led to allegations of (inadvertent) discrimination by those populations (new or old) that are not as well served as others.

Second, in developing programs for specific populations not easily reached by mainstream programs, there may be tension between the specific population and the AIDS organizations over the population's control over the program and influence within the organization. Representatives of minority populations speak of "tokenism" and "paternalism" when they are consulted primarily in order to enable mainstream organizations to meet funding requirements for government programs and when they are not given a full voice on the boards of the organizations serving their population.

Third, there have been instances of discrimination between people of diverse cultures served by the same AIDS organization:

> A man who is bisexual is unable to discuss his sex life in a drop-in centre for people with HIV and AIDS. Every time he discusses sex with women, he is ridiculed by the gay men present. And yet the gay men in the centre discuss their sex lives frequently.
>
> A man refuses to come to [an organization's] Christmas party - an event frequented by 169 clients and volunteers - because he sees it as a "gay" dance and cannot accept open homosexuality.
>
> Long-time clients of a drop-in centre tell the director, "Don't worry; we're weeding them

out." They are referring to clients who inject drugs.

Insurance

People with HIV/AIDS depend on public or private insurance for health care, drugs, and income support. It is a testimony to Canada's universal public health-care insurance that coverage for physicians' services and hospital care is not among the larger problems that people with HIV/AIDS must deal with in the area of insurance. In this regard, the experience of people with HIV/AIDS in Canada contrasts markedly with the experience of people with HIV/AIDS in the United States, where employment-based private health-care insurance is the norm.[108] But income support and drug coverage is another matter.

The Canadian AIDS Society outlined many of the problems associated with income support and drug insurance in its brief on poverty, discrimination and HIV/AIDS to the Sub-Committee on HIV/AIDS.[109] Most of these problems relate to criteria for eligibility for public and private insurance coverage and benefits - practices that are currently considered to be lawful in discriminating among applicants for coverage or among benefits claimants. If anything, the problems have become more urgent with the advent of combination drug therapies.

Definition of Disability

The definition of disability used to determine eligibility for benefits under public and private insurance plans has historically been based on a pattern of long-term, permanent disability. Such definitions are not appropriate to the cyclical and episodic nature of HIV disease. People with HIV/AIDS may experience periods of relatively good health that are interrupted by periods of illness severe enough to require hospitalization or extended care at home.

Although combinations of drugs including protease inhibitors have dramatically improved the health status of many people with HIV/AIDS, they have made problems of definition of disability even more acute. Combination therapies have had a dramatic effect in lowering viral load and raising counts of CD4 cells in many people with HIV/AIDS. However, the drugs are ineffective for 20 percent of people with HIV disease over the short to mid term, and may be ineffective for 50 percent or more over the long term.[110] Moreover, an individual's ability to function depends on more factors than virological and immunological markers alone. Nevertheless, assessment of disability is increasingly being made solely on the basis of these markers, without a complete assessment of health status and quality of life that includes psychosocial well-being and treatment side effects, as well as physical functioning.

Two problems have emerged in this regard.[111] First, people who receive benefits and their physicians are under constant demand to provide additional medical information to prove that they are still eligible for disability benefits. Second, there is an increasing trend toward out-and-out denial for short- and long-term benefits, as insurers fail to acknowledge the fact that some people cannot take protease inhibitors, that treatment is often accompanied by debilitating side effects, that improved physical, mental and emotional health status is not immediate, and that indicators other than physical functioning must be taken into account.

Exclusion Criteria in Private Income Insurance Plans

As a recent review of private insurance plans (including plans for life insurance, which are not considered here) observes, the insurance industry is a private for-profit industry that has "the power to decide, according to criteria recognized within this industry (particularly risk sharing), who can be insured, who cannot be insured, and who must pay a higher premium."[112] On the basis of these criteria, insurers may exclude people with HIV/AIDS from coverage or benefits.

Whereas in other circumstances discrimination based on HIV status would be a violation of human rights codes, the existing codes in Canada offer a defence to insurance companies that exempts them from the requirement of non-discrimination provided that they do so on "reasonable and *bona fide*" grounds.[113] These grounds permit insurance plans to exclude individuals with a pre-existing condition or handicap (such as HIV/AIDS) from coverage.[114] What constitutes "reasonable" grounds, however, is open to question. In the early 1980s, the Alberta and Saskatchewan Human Rights Commissions analyzed the reasonableness, for example, of actuarial estimates based on sex, age, marital status, family status, and handicap. The reports found that "mortality tables based on such distinctions are frequently inaccurate, that classifications are arbitrary and misleading, and that risk is far more accurately predicted on the basis of such factors as amount of exercise taken, smoking, weight, stress and geographic location."[115] However, to date the courts in Canada have upheld the defence afforded to insurance companies to exclude individuals on grounds that would otherwise be prohibited under human rights statutes.[116]

Exclusion criteria affect people with HIV/AIDS in a number of ways. They may not qualify for income insurance, first of all, on account of a pre-existing condition of HIV disease. This is particularly relevant today, since the median age of HIV infection is declining and more people are becoming infected before entering the workforce. If a person does qualify for coverage (or qualified in the past before acquiring HIV), they may be forced to remain with their present employer (even if they would prefer to change employment), since it is unlikely that they will qualify for coverage with a new employer. If they are receiving disability benefits but wish to return to work, they may be discouraged from doing so if the terms of their coverage limits their entitlement to further benefits should their health deteriorate again.

Public Income Support Programs

To obtain income in periods of short- or long-term disability, people with HIV/AIDS turn to Employment Insurance, disability benefits under the Canada Pension Plan, and, as a last resort, social assistance in the form of welfare and family benefits. These programs present a variety of problems for people with HIV/AIDS, largely because they are not designed for people with cyclical or episodic illness. As a result, people with HIV/AIDS may be adversely affected by the rules of these programs. Several common scenarios may be cited as examples.

A survey conducted by the Canadian AIDS Society in 1995 found that 25 percent of respondents were working for an average of 13 hours per week.[117] At present, to claim Employment Insurance benefits, an individual must have worked at least 700 hours (or 20 full-time weeks) since their last claim. People with HIV/AIDS may not have been able to work for that length of time since their last illness. If so, they would be ineligible for benefits, even though they have made an effort to remain employed and not go on social assistance.

In the 1995 survey, 23 percent of respondents listed the Canada Pension Plan as their main source of income. Provisions for those who may return to work have improved under the Plan. Benefits continue to be paid for three months once someone returns to work, and benefits can be restored without the need to qualify again within the first year after returning to work. However, the amount of the benefit is calculated on the basis of contributions paid into the Plan throughout one's working history. Those who have a short work history - again, an increasing proportion of people with HIV/AIDS - receive only the minimum payment.

People without sufficient income from other sources are forced to rely on provincial social assistance programs. One of the benefits of receiving social assistance is that these programs provide enhanced drug coverage. In fact, because of the high cost of their medications, many people with HIV/AIDS are forced to quit work and go on social assistance to obtain drug coverage. Indeed, people who would prefer to work are counseled to go on welfare instead.[118] But income received from social assistance does not meet the needs or requirements of people with HIV/AIDS vis-à-vis housing, food, transportation, child care, or other forms of support.

In short, if people were not poor when they contracted HIV, they rapidly become poor.[119] A recent study of families affected by HIV/AIDS found that over half of the parents reported a family income of less than $20,000, and the great majority - 87 percent - reported an annual income of $30,000 or less. Thirty-one percent of these families were on welfare.[120] Similarly, a study among women with HIV/AIDS in British Columbia found that 51 percent had annual incomes of less than $20,000.[121]

Drug Insurance

The problems people with HIV/AIDS experience in obtaining coverage or benefits for HIV/AIDS drugs through their employment have been noted above in the section on discrimination in the workplace. Insurance companies have raised their overall premiums for health coverage to cover the costs of pharmaceutical claims. In order to be able to keep premiums down, insurers offer plans and employers adopt plans that limit claims to a set amount, for example $2000. This barely covers one month's worth of drugs for a person with HIV/AIDS.[122] As one individual testified before the Parliamentary Sub-Committee on HIV/AIDS:

> I'm just going to give you examples from my own life. I spend approximately $350 a month on vitamin and mineral supplements alone. Nobody reimburses me for any of the costs of those drugs. I also take a prophylaxis for two diseases, the herpes family of viruses and pneumonia. That costs me approximately $400 per month. I'm also on an anti-retroviral drug cocktail of three drugs that costs me $1,130 per month - and I'm basically considered, at this point, reasonably healthy with my 112 CD4 cells.[123]

Some provinces have instituted catastrophic drug coverage for individuals who are employed but cannot afford their medications. However, in the case of such programs as the Trillium Plan in Ontario, people with HIV/AIDS are still required to pay for the drugs initially, and then must apply to be reimbursed up to a deductible amount calculated on their earnings.[124] This creates undue hardship for many people with HIV/AIDS.

In addition to these lawful disadvantages and difficulties, people with HIV/AIDS also encounter unlawful discrimination related to drug coverage. As already discussed, people making claims for drug benefits through their employer have suffered breaches of confidentiality and subsequent harassment or dismissal. Consequently, many people with HIV/AIDS are reluctant to claim drug benefits, even if they are entitled to them.

Obtaining Information and Advice

The criteria that determine whether people with HIV/AIDS qualify for coverage or are eligible for benefits under public and private insurance plans are detailed and complex. They are also open to interpretation and discretion. Problems in determining eligibility for coverage and benefits are likely to become more acute as insurers dispute the medical grounds on which individuals make claims.

People with HIV/AIDS often require assistance in:

- getting information, whether about their entitlements through group insurance plans at work or their eligibility under public assistance programs;
- applying for benefits;
- obtaining proof of disability from their physician;
- appealing decisions by the insurer; or
- obtaining redress in the event of discriminatory actions or decisions.

However, in many circumstances, even seeking such information can be risky. Consulting one's employer may lead to harassment or dismissal. People may be reluctant to approach their union local, for fear of stigma or discrimination. Legal advice is often required. In one legal clinic for people with HIV/AIDS, a third of the people seeking advice do so in regard to insurance matters. However, not all people with HIV/AIDS have easy access to legal clinics or can afford legal counsel.

Travel and Immigration

Travel

According to Section 19(1)(a) of Canada's *Immigration Act*, visitors to Canada must meet two criteria before being allowed to enter the country:[125] they must not represent a danger to public health and safety, and their admission must not place excessive demand on Canada's health and social services systems.

Prior to 1991, the government considered people with HIV/AIDS a danger to public health and safety, and would not admit them as visitors to the country. In April 1991, the government changed this policy, and stated that "visitors with AIDS or HIV infection will be treated in exactly the same manner as any other visitor to Canada." After this announcement there were still a few instances when people with HIV/AIDS were denied entry as visitors to Canada. In 1994, the Minister of Immigration clarified the government's position, stating:

- a diagnosis of HIV/AIDS is not in itself a barrier to visiting Canada;
- persons living with HIV/AIDS do not generally represent a danger to the public under Section 19 of the *Immigration Act*;

- the issue is therefore whether visitors living with HIV/AIDS would place excessive demand on the Canadian health-care system;

- it is not normally expected that visitors with HIV would place any demand on the health-care system;

- therefore, for the vast majority of short-term visits by persons living with HIV/AIDS, the excessive demand criterion would likely not be invoked;

- the excessive demand criterion will only be invoked if there is reason to believe a person would need medical treatment while in Canada, although even in this case a person may still be able to enter the country if he or she had made arrangement for treatment and payment;

- the carrying of HIV/AIDS medication is not a ground for refusing admission; and

- the government will provide immigration officers with thorough information on the travel policy and implement a training program on HIV/AIDS for immigration officers.

This training program has since been implemented, and since that time there have been few stories of denied entry or harassment at border crossings. However, Canadians with HIV/AIDS may be denied entry as visitors to countries, such as the United States, whose policy is more restrictive. People have been denied entry to the United States simply because they have HIV/AIDS-related literature in their possession.

Immigration

People who wish to immigrate to Canada must meet the same criteria as visitors to Canada: they must not represent a danger to public health and safety, and they must not place excessive demand on Canada's health and social services. Currently, it is Canadian policy that people with HIV/AIDS who wish to immigrate to Canada do not represent a danger to public health and safety, but would place an excessive demand on Canada's health and social services. As a result, applicants who are found to be HIV-positive are assessed as "medically inadmissible" and will normally not be allowed to immigrate to Canada.[126]

There are two points at which Canadian policy may be (or become) discriminatory. The first is in identifying applicants who are HIV-positive. It is currently not Canadian policy to require that all applicants to Canada be tested for HIV. The examining physician may require an HIV test based on a number of possible indications,[127] but physicians in Canada have been instructed that "[c]ountry of origin, race, gender, and sexual orientation, by itself is NOT a sufficient reason to warrant a screening test for HIV."[128] However, the policy on HIV testing is being reviewed, and HIV testing may become routinely required of applicants. There have been calls for mandatory HIV testing of all applicants for permanent residence in Canada, and denial of landed immigrant or refugee status to all who are found to be HIV-positive. Such a policy would not involve a fair assessment as to whether an individual actually is likely to impose an excessive demand on Canada's health and social services, given the long period of asymptomatic HIV infection. It would also reinforce the prejudices of those who see immigrants as carriers of disease - whereas the HIV epidemic is already established in Canada, and the effect of migration would be minimal[129] - and would stigmatize potential and landed immigrants in Canada.

The second point at which Canadian policy may be discriminatory is in determining what constitutes "excessive demand." The federal government has been in the process of developing new regulations regarding medical admissibility for several years. A 1993 draft of the new regulations stated that "applicants for immigration would be medically admissible where, over five years, they would not cost the Canadian health care system more than the average Canadian citizen or permanent resident. Thus ? early' cases of HIV would be admissible to Canada."[130] Subsequently, it appeared that the five-year "window of comparison" would be abandoned. Whatever the final determination regarding HIV, if the criteria and protocol for determining excessive demand are not equitable for all medical conditions that could possibly result in excessive demand and are not fairly applied to all prospective immigrants, the regulations will be discriminatory against people with HIV/AIDS (or people with other medical conditions that are singled out for particular attention).

Beyond these two points, there are other considerations that cannot be discussed here, but should be noted:[131]

- the ethics of using technology to screen applicants for immigration, particularly as genetic screening tools become available;
- the adequacy of cost-benefit analysis (including the very concept of "excessive demand") in evaluating the worth of a potential immigrant, and of classes of immigrants, to Canada;
- humanitarian considerations in immigration policy; and
- the impact of Canada's screening policies on applicants in their home country, given the human rights violations experienced by people with HIV/AIDS in many parts of the world.

Perverse Interactions of Federal and Provincial Legislation

The interaction between provincial legislation governing health-care insurance and federal legislation governing immigration has resulted in discrimination against HIV-positive spouses of HIV-negative landed immigrants in Canada.[132] HIV-positive spouses are often admitted to Canada on a Minister's Permit, which gives non-Canadians the legal right to reside in Canada despite the fact that, because of their HIV status, they are medically inadmissible as a landed immigrant. After someone admitted on a Minister's Permit has resided in Canada for five years, s/he can be landed despite medical inadmissibility for landed status. In the interval, the individual is not classified as a permanent resident and has fewer rights than the HIV-negative relative. In addition, the individual has to wait longer before being eligible for citizenship in Canada.

In Ontario, certain categories of people admitted into Canada on a Minister's Permit are denied medical coverage under the Ontario Health Insurance Program. This category includes family-sponsored immigrants who are medically inadmissible. In addition to discriminating between categories of people with a Minister's Permit - other categories of people admitted on a Minister's Permit are granted medical coverage - this practice places a heavy burden on people who will eventually become landed immigrants and Canadian citizens. The lack of medical coverage deters them from seeking health care, and may very well increase the burden on the health-care system when they do become eligible for coverage.

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FOOTNOTES

[64] Unless otherwise noted, the stories and reports that follow were provided by individuals interviewed in the preparation of this *Discussion Paper* or by participants in the 15 January 1998 workshop on discrimination and HIV/AIDS.

[65] RS Goldie et al. *Children Born to Mothers with HIV: Psychosocial Issues for Families in Canada Living with HIV/AIDS.* Toronto: The Hospital for Sick Children, 1997, at 85.

[66] Ibid.

[67] Ibid.

[68] *Healing Our Nations*. 4th Canadian Aboriginal Conference on HIV/AIDS and Related Issues. Halifax, November 1996, at 71.

[69] Goldie et al, supra, note 65 at 86.

[70] Ibid at 85.

[71] Ibid at 86.

[72] Ibid at 87.

[73] As a national study concluded almost a decade ago: see Federal Centre for AIDS Working Group on HIV Infection and Mental Health. *Ending the Isolation. HIV Disease and Mental Health in the Second Decade.* Ottawa: Minister of Supply and Services, 1992, at 52.

[74] For a concise summary of the literature, see G Green. Stigma and Social Relationships of People with HIV: Does Gender Make a Difference? In: L Sherr et al, eds. *AIDS as a Gender Issue: Psychological Perspectives*. London: Taylor and Francis, 1996, 46-63 at 48.

[75] RB Hays et al. Disclosing HIV Seropositivity to Significant Others. *AIDS* 1993; 7(3): 425-431; MS Miles et al. Personal, Family, and Health-Related Correlates of Depressive Symptoms in Mothers with HIV. *Journal of Family Psychology* 1997; 11(1): 23-34; A Demi et al. Effects of Resources and Stressors on Burden and Depression of Family Members who Provide Care to an HIV-Infected Woman. *Journal of Family Psychology* 1997; 11(1): 35-48.

[76] J Littrell. How Psychological States Affect the Immune System: Implications for Interventions in the Context of HIV. *Health and Social Work* 1996; 21(4): 287-295; G Kadushin. Gay Men with AIDS and their Families of Origin: An Analysis of Social Support. *Health and Social Work* 1996; 21(2): 141-149 at 143; S Cohen, TA Wills. Stress, Social Support, and the Buffering Hypothesis. *Psychological Bulletin* 1985; 98(2): 310-357.

[77] F McGinn. The Plight of Rural Parents Caring for Adult Children with HIV. *Families in Society* 1996; 77(5): 269-278 at 272.

[78] *Healing Our Nations,* supra, note 68 at 71.

[79] S Manson Singer et al. Many Voices - Sociocultural Results of the Ethnocultural Communities Facing AIDS Study in Canada. *Canadian Journal of Public Health* 1996; 87(Suppl 1): S26-32 at S28. For a description of the study, see A Adrien et al. Overview of the Canadian Study on the Determinants of Ethnoculturally Specific Behaviours Related to HIV/AIDS. *Canadian Journal of Public Health* 1996; 87 (Suppl 1): S4-10.

[80] For an overview of workplace experiences, with numerous examples, see BD Adam, A Sears. *Experiencing HIV: Personal, Family and Work Relationships*. New York: Columbia University Press, 1996, at 112-137; G Green. Processes of Stigmatization and Impact on the Employment of People with HIV. In D FitzSimons et al, eds. *The Economic and Social Impact of AIDS in Europe*. London: National AIDS Trust, 1995, 251-262 at 255-259.

[81] Y Jalbert. Triple-Drug Therapy and Return to Work: Results of a Québec Survey. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 13-14. Of the 59 respondents who were working, half had disclosed their HIV status. A similar rate of disclosure was found in a study of people with HIV/AIDS in Newfoundland in 1991-92, where, out of 25 people, 10 were employed and, of these, 4 had disclosed their HIV status. Of these 4, one was laid off and another fired as a result of telling their employer. See M Laryea, L Gien. The Impact of HIV-Positive Diagnosis on the Individual. Part 1: Stigma, Rejection, and Loneliness. *Clinical Nursing Research* 1993; 2(3): 245-266 at 254.

[82] Goldie et al, supra, note 65 at 93.

[83] I Grubb, C McClure. *Back to the Future: A Feasibility Study on Return-to-Work Programming for People Living with HIV/AIDS*. Toronto: AIDS Committee of Toronto, 1997, at 26-27.

[84] Jalbert, supra, note 81.

[85] Ibid.

[86] Ontario Human Rights Commission. *Annual Report 1996-97*. Toronto: The Commission, 1997, at 37.

[87] Ibid at 37-38.

[88] S Manson Willms et al. *Choice, Voice and Dignity: Housing Issues and Options for Persons with HIV Infection in Canada. A National Study*. Vancouver: Centre for Human Settlements, University of British Columbia, 1991, at 14-16. When this work was published, lack of housing was most acute for injection drug users, women with children, and people who were impoverished before their diagnosis of HIV infection (see ibid, at iii-iv). Today, one could add others to this list, for example, the mentally ill living with HIV/AIDS.

[89] Ibid at 17-25.

[90] A Hendriks, S Leckie. Housing Rights and Housing Needs in the Context of AIDS. *AIDS* 1993; 7 (Suppl 1): S271-S280 at S274.

[91] Ibid at S273-S274. For recent evidence of the risk of HIV infection associated with unstable housing, see SA Strathdee et al. Needle Exchange Is Not Enough: Lessons from the Vancouver Injecting Drug Use Study. *AIDS* 1997; 11(8): F59-F65.

[92] For a discussion of housing as a right, with particular reference to European decisions, see Hendriks & Leckie, supra, note 90 at S272-S273.

[93] See KV Heath et al. HIV/AIDS Care Giving Physicians: Their Experience and Practice Patterns. *International Journal of STD & AIDS* 1997; 8(9): 570-575 at 570, and the literature cited there; JA Kelly et al. Stigmatization of AIDS Patients by Physicians. *American Journal of Public Health* 1987; 77(7): 789-791; JA Kelly et al. Nurses' Attitudes Towards AIDS. *The Journal of Continuing Education in Nursing* 1988; 19(2): 78-83.

[94] This was a frequent observation in the consultations undertaken for this paper.

[95] House of Commons of Canada. 35th Parliament, 2nd Session. Sub-Committee on HIV/AIDS of the Standing Committee on Health. Meeting no. 10, 5 November 1996.

[96] Heath et al, supra, note 93; KV Heath et al. Physician Concurrence with Primary Care Guidelines for Persons with HIV Disease. *International Journal of STD & AIDS* 1997; 8(10): 609-613; ME Taggart et al. Attitudes d'infirmières francophones face au sida. *L'infirmière canadienne* 1992; 88(1): 48-52.

[97] B.C. Civil Liberties Association, supra, note 51 at 26-31; B Guillot-Hurtubise. Dentist Found Guilty of Discrimination. *Canadian HIV/AIDS Policy & Law Newsletter* 1995; 1(4): 1, 14-15.

[98] G Godin et al. Understanding Dentists' Decision to Provide Dental Care to HIV Seropositive/AIDS Patients. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases 1997*; 8(Suppl A): 20A. Abstract no. 149.

[99] M Shaw et al. Survey of Patients' Views on Confidentiality and Non-Discrimination Policies in General Practice. *British Medical Journal* 1996; 312(7044): 1463-1464.

[100] For a full discussion of the main exception in the area of HIV/AIDS - partner notification - see Jürgens & Palles, supra, note 4 at 213-263. It is important to note that when notifying a third party the identity of the HIV-positive individual should not be disclosed; see Federal/Provincial/Territorial Advisory Committee on AIDS Working Group on Partner Notification. *Guidelines for Practice for Partner Notification in HIV/AIDS.* January 1997, at 6-7. In practice, the third party may deduce the identity of the HIV-positive individual - perhaps incorrectly, and with damaging consequences.

[101] Jürgens & Palles, supra, note 4 at 252.

[102] KH Brown. Descriptive and Normative Ethics: Class, Context and Confidentiality for Mothers with HIV. *Social Science and Medicine* 1993; 36(3): 195-202.

[103] JL Gerberding. Occupational HIV Infection. *AIDS* 1997; 11(Suppl A): S57-S60. The average risk of infection is 0.32 percent (21 infections following 6498 needle punctures or similar injuries; 95% confidence interval, 0.18-0.46).

[104] LR Deschamps et al. National Surveillance of Occupational Exposure to HIV in Canada. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 25A. Abstract no. 212.

[105] HIV Infection in the Workplace. *Canadian Medical Association Journal* 1993; 148(10): 1800A-D.

[106] Infra, note 180.

[107] BW Levin et al. The Treatment of Non-HIV-Related Conditions in Newborns at Risk for HIV: A Survey of Neonatologists. *American Journal of Public Health* 1995; 85(11): 1507-1513.

[108] Adam & Sears, supra, note 80 at 138-157.

[109] See supra, note 8.

[110] British Columbia Persons With AIDS Society and Health Canada. Vocational and Rehabilitation Services in the Context of HIV Infection: Issues and Guiding Principles (Draft). January 1998, at 11.

[111] Carey, supra, note 52 at 11.

[112] Locas et al, supra, note 8 at 12.

[113] Ibid at 56-62.

[114] The specific terms vary depending on the nature of the plan, particularly whether the employees pay the entire premium or whether the plan is offered by employers with few employees.

[115] Keene, supra, note 25 at 197 and 219-220.

[116] Ibid at 198-199; Locas, supra, note 8.

[117] For this, and the remaining discussion in this section, see Canadian AIDS Society, supra, note 8 at 8-9.

[118] Personal communication on file with the author.

[119] NE Kass et al. Changes in Employment, Insurance, and Income in Relation to HIV Status and Disease Progression. *Journal of Acquired Immune Deficiency Syndromes* 1994; 7: 86-91.

[120] Goldie et al, supra, note 65 at 23-24.

[121] CM Kirkham, D Lobb. The B.C. Positive Women's Survey: Sociodemographic Characteristics, Health Status and Attitudes Towards Medical Care. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Tu.C.2447.

[122] Canadian AIDS Society, supra, note 8 at 9.

[123] Supra, note 95.

[124] Ibid.

[125] For this and what follows, see Travel and Immigration: Policy for Persons Living with HIV/AIDS. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(2): 14-15.

[126] For this and what follows, see R Jürgens. Immigration Policy May Be Reviewed to Require Routine HIV Testing of Immigrants. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 16-18.

[127] For details, see ibid at 16.

[128] Ibid (emphasis in original).

[129] J Decosas, A Adrien. Migration and HIV. *AIDS* 11(Suppl A): S77-S84 at S77.

[130] Jürgens, supra, note 126.

[131] See ibid.

[132] For what follows, see R Carey. Challenging Ontario's Denial of Medical Care to HIV-Positive Immigrants. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 18-19.

HIV/AIDS and Discrimination: A Discussion Paper

by Theodore de Bruyn

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Note to browsers: For ease of loading, this long chapter has been divided into two different pages. When downloading or printing, keep in mind that each of the pages must be opened in order to access the entire chapter.

THE EXPERIENCE OF SPECIFIC POPULATIONS

The patterns and effects of stigma and discrimination vary among the diverse populations affected by HIV/AIDS. While there are similarities in the experiences of different populations (as discussed above), there are also features that are specific to particular populations. These features either are not encountered by other populations or are experienced differently.

This section of the Paper aims to describe stigma and discrimination as experienced by specific populations affected by the HIV epidemic in Canada. The differentiation of populations affected by HIV/AIDS is a social and cultural construction. Such differentiation may itself contribute to discrimination,[133] as when drug users or sex workers are vilified as "vectors of disease." On the other hand, the failure to recognize and acknowledge publicly the experiences of a particular population in the course of the HIV/AIDS epidemic has also led to neglect and avoidance of that population's needs, as gay men have found in the "de-gaying" of AIDS.[134] In the judgment of the author, the dangers of neglecting the experiences of people exceed the dangers of stereotyping the experiences of people. Accordingly, this section of the discussion paper proceeds by populations, however imperfectly described or designated.

Gay and Bisexual Men

> Anyone who believes a gay man can explore the experience of being at risk for HIV disease without considering the experience of being gay is hopelessly mistaken.[135]
>
> The family of a gay man living with HIV/AIDS in a smaller Canadian province wanted nothing to do with him. When he was ill, they were told he was dying of cancer. His mother was aware that he was dying of AIDS and arranged for billeting in a larger city in that province with the help of an AIDS service organization. She paid for the services in cash, and also made a cash donation after his death, because she did not want her credit union to know that she was making contributions to an AIDS service organization.
>
> Two men applied to rent an apartment. One of them gave the name of an organization of people with HIV/AIDS as a reference. He also had to indicate that he was on social assistance. The landlord called the organization to find out if he could catch AIDS. He was worried that they would come all over the carpet, and that he would become infected if he had to clean the apartment after they left. The two men were denied the apartment.
>
> The education co-ordinator [in an AIDS service organization] is not comfortable with gay and lesbian issues. ... [The executive director of an AIDS service organization] puts a damper on any initiatives that come out of [the men who have sex with men program]. He wants us to work within a certain framework - visible but not too visible.[136]

Epidemiology

Health Canada reports that "[t]he HIV/AIDS epidemic in Canada is no longer as concentrated among men who have sex with men as it was in the early-to-mid 1980s, but this group is still a significant part of the epidemic": [137]

- 72.5 percent (10,943) of the total number of AIDS cases (15,101) reported to Health Canada were attributed to men who have sex with men, and an additional 4.3 percent

(655) were attributed to the combined category of men who have sex with men and use injection drugs;

- the annual number of AIDS cases attributed to men who have sex with men leveled off from 1992 to 1994 and has decreased since then, but the proportion of AIDS cases attributed to the combined category of men who have sex with men and use injection drugs has steadily increased (4.9 percent in 1996).

- the number of new cases of HIV infection among men who have sex with men as a proportion of the total number of new cases has been decreasing since the mid 1980s. However, at the end of the 1980s there appears to have been a resurgence of HIV infection among younger men who have sex with men.[138] The rate of infection in a cohort of gay and bisexual men in Vancouver between the ages of 18 and 30 was 3.1 percent as of December 1996, twice as high as the authors of the study expected;[139] and

- a significant proportion of men who have sex with men continue to have unprotected anal sex with both regular and casual partners.

Patterns of Stigma and Discrimination

As the *Final Report* on gay and lesbian legal issues and HIV/AIDS documents, prejudice against homosexuality has resulted in a predominantly negative legal, social, and cultural environment for gay men, lesbians, and bisexuals:[140]

- gay and lesbian adolescents have little support within their family, among their peers, and at school in recognizing and affirming their sexual orientation and in developing relationships with other gays and lesbians.

- an overwhelming majority of gay men and lesbians have been verbally abused, and many gay men and lesbians have been threatened, chased or followed, assaulted, or otherwise abused.

- same-sex sexual activity was until recently considered a crime, and the *Criminal Code* still includes provisions that discriminate on the basis of sexual orientation, including legal age of consent for anal intercourse.

- literature and information about same-sex relationships have been censored by schools and libraries, and literature and information about same-sex sexual activities (including safe-sex educational materials) have been seized by Canada Customs.

- sexual orientation was only recently made a prohibited ground of discrimination in the *Canadian Human Rights Act* (after almost two decades of struggle to realize this basic protection), and has not yet been made a prohibited ground of discrimination in the human rights legislation of Alberta, Prince Edward Island, and the Northwest Territories.

- gay men and lesbians in a same-sex relationship are not assured of the right or access to employment benefits, may experience discrimination based on sexual orientation in obtaining custody of or access to children or in other parenting arrangements, cannot sponsor their partners for immigration under the family class, and are vulnerable to exclusion in the event of the illness or death of their partner.

The early prevalence of HIV/AIDS among gay men in North America has resulted in an enduring association between HIV/AIDS and homosexuality. The predominantly negative attitudes toward homosexuality have influenced people's attitudes and behaviour toward people with HIV/AIDS in general, and gay and bisexual men in particular.[141] As a result:

- people have a more negative attitude toward people with HIV/AIDS than they do toward people with other diseases, regardless of the sexual orientation or presumed cause of infection of the person living with HIV/AIDS;

- people have a more negative attitude toward gay men with HIV/AIDS than toward other people with HIV/AIDS, are more likely to blame gay men for being HIV-positive, and are less inclined to help gay men with HIV/AIDS;

- people with HIV/AIDS may be stigmatized and discriminated against because they are assumed to be homosexual; and

- gay and bisexual men are stigmatized and discriminated against because they are assumed to be HIV-positive or the cause of the HIV epidemic.

Research has shown that people who support the rights of same-sex couples to marry, adopt or have children, and enjoy the same employment benefits as heterosexual couples, have less fear of AIDS.[142]

It is important to note that men who have sex with men may not identify as gay or bisexual and may have a very loose association with the "gay community."[143] The categories "men who have sex with men," "bisexual," and "gay" comprise a diversity of identities, cultures and behaviours. The degrees to which men considered under these categories may have appropriated the negative stereotypes and stigmas associated with homosexual activity or identity in their surrounding culture will vary.[144]

Impact of Stigma and Discrimination

Vulnerability to Infection

A comparison of two cohorts of gay men in Vancouver - one recruited between 1982 and 1984 (the Vancouver Lymphodenopathy AIDS Study), the other recruited since 1995 (the Vanguard Project) - shows that there has been a decline in the frequency of high-risk sexual behaviours among gay and bisexual men over the decade.[145] At the same time, a significant proportion of gay men and bisexual men (particularly young men) continue to engage in risky sexual behaviour.[146]

As the section on gay, lesbian and bisexual youth (below) discusses more fully, growing up and coming out in an unsupportive or hostile environment contributes to risk of HIV infection and other risks to health and well-being. The Vanguard Project found that, among 147 young gay and bisexual men, 18 percent had experienced domestic violence, 11 percent had experienced gay bashing, 25 percent had experienced sexual abuse, 55 percent had seriously considered suicide, and 33 percent had attempted suicide. Twenty-two percent had been diagnosed with a mental disability or mood disorder, most commonly depression.[147] The authors conclude:

> A disturbing proportion of young [men who have sex with men] report having considered suicide or made suicide attempts, which is consistent with high levels of depression. Various other forms of violence appear to be common for young [men who have sex with men]. The relationship between violence and HIV requires further investigation. Along with other forms of psychologic distress - including depression, substance abuse and homophobia - violent life experiences likely impact negatively on self-esteem and negotiating skills, which could in turn lead to heightened vulnerability to HIV infection.[148]

Testing and Confidentiality

For men who have sex with men, whether or not they identify as gay or bisexual, taking an HIV-antibody test has both personal and social consequences. The decision to take the test may involve overcoming a number of fears, including the fear of being infected with HIV, of having infected others, of illness or death resulting from HIV infection, of disclosure as a gay or bisexual man or as a person with HIV, or of stigma or discrimination based on HIV status or sexual orientation.

Toward the end of the 1980s, as the prospects for treatment improved, gay and bisexual men were encouraged to be tested. At the same time, AIDS organizations pressed for wider access to anonymous testing in order to assure people of complete confidentiality. Even so, a national survey of gay and bisexual men in Canada in 1991-92 found that the probability of expressing an intention to take an HIV-antibody test varied between 2 percent and 94 percent, and that an individual's personal evaluation of the consequences of taking the test was the most important variable in determining the probability of expressing an intention to take it.[149] The authors describe the significance of their findings as follows:

> The intention to take the test is mainly affected by attitudes. According to the theoretical framework adopted for this study, "attitude" is defined as a personal evaluation of the consequences of adopting a given behaviour. Such factors as the possibility of having one's name on a government list or having one's career or insurance affected define one's attitude to taking the test. Perceived lack of anonymity seems to be a dominant attitudinal determinant.[150]

Numerous studies suggest that availability of anonymous testing encourages people to come forward to be tested, particularly those who are at greatest risk for HIV infection.[151] Of particular significance for gay and bisexual men is the finding of a study on the effect of a decision to discontinue anonymous testing in 82 of 100 counties in North Carolina in 1991. There was a 12.4 percent decrease in testing of gay men in counties that ended anonymous testing; gay and bisexual men accounted for 10 percent of all tests in counties that retained anonymous testing, but 4 percent of all tests in counties that discontinued it.[152] As long as the social environment is hostile to gay and bisexual men, HIV testing programs must take into account the risks - perceived as well as actual - that an HIV test entails for gay and bisexual men.

Disclosure and Concealment

> I have always hidden my homosexual tendencies from my family and friends. To now come out and say I am gay and I have AIDS, it's a double stigma. Unfortunately, the stigma attached is attached to you at the time you need support, you are afraid of dying, and you are hurting pretty badly. I am better off passing as normal.[153]

This observation from a gay man living in Newfoundland is a reminder that for gay and bisexual men, disclosure of HIV status is a double-edged sword. As the authors of a study of disclosure among gay men observe:

> It may open up the opportunity to receive social support. However, it may also lead to added stress, due to stigmatization, discrimination and disruption of social relationships. Conversely, concealing one's HIV status from significant others can be stressful in itself and can interfere with obtaining and adhering to potentially critical medical treatments. Concealment can also have negative effects on significant others' well-being, since they may experience guilt, confusion or anger when they find out about the individual's illness (especially if this occurs after the individual is very sick or has died).[154]

Gay men with HIV/AIDS are more likely to disclose their HIV status to their lover or their closest friends, whom they perceive to be more helpful and supportive, and less likely to disclose to their family, coworkers or employer.[155] The reasons for not disclosing include fear of discrimination (particularly at work) and the desire to conceal one's homosexuality. As one man put it, "My parents don't know I'm gay."[156] Disclosure of HIV-status and sexual orientation to one's family often occur at the same time:

> The level of denial and crisis in families who were not aware of a son's homosexuality until a diagnosis of AIDS may be fairly high. Among men who have already revealed their sexual orientation to their families, the stigma of a diagnosis of AIDS may reopen old wounds as family members are forced by the crisis of the illness to once again confront and express their feelings regarding sexual orientation. Disclosure of homosexuality to parents is often more difficult than disclosure to others because parental reaction is usually negative and the family perceives the disclosure as a crisis. Depending on their value system, parents may apply stereotypes about homosexuality to their son, perceiving him as a potential child molester or a sinner condemned to everlasting punishment. Also, parents may fear that others in their social network will apply similar negative values to the whole family, leading to isolation and ostracism.[157]

Disclosure may be particularly problematic for bisexual or heterosexual men if they are divulging previous same-sex activity for the first time:

> At the time I told my wife, my fiancée, I told her about me having experienced being with a man before and so this was the first time this subject had even come into the light. She didn't have any suspicion or inclination so it was kind of hard to deal with.[158]

Not all families, however, respond negatively.[159] It is significant that one gay man gauged his family's likely response to his HIV status according to their prior response to his sexual orientation:

> I didn't really have that much fear they wouldn't accept me because they knew from a very young age that, you know, from thirteen that I was gay. ... They were very, very supportive right from the very beginning.[160]

Caregivers of gay or bisexual men with HIV/AIDS are also adversely affected by the stigma of HIV/AIDS and homosexuality. As one study found, going public as a caregiver can mean harassment, rejection, and the loss of jobs, friends and housing.[161] The authors report that "[g]ay caregivers who were less open about their sexual orientation usually were very cautious about going public, especially outside of the gay community," while parents "often perceived themselves failures as parents, or were accused of poor parenting by others."[162]

Employment

As noted above, gay and bisexual men are less likely to disclose their HIV status to co-workers and employers than to lovers and friends.[163] The association between fear of AIDS and aversion to homosexuality means that disclosing HIV status may mean encountering homophobic attitudes.[164] As one gay man recounted:

> One day on the floor where we were discussing this whole issue of AIDS and homosexuality and that kind of thing, one person said, they should all be isolated in a commune or shot. Now this is a nurse I worked with for a year and a half, shoulder to shoulder....[165]

AIDS may be used to harass gay men:

> I heard they caught wind that I was gay. I had a pop or coffee sitting there. "Don't forget that he has AIDS."[166]

People may incorrectly assume that a gay man has HIV:

> A gay man was laid off from his job as a caretaker for a large condominium when his employer concluded, incorrectly, that he was HIV-positive because he had been ill.

Gay men may be fired or may resign for fear of discrimination once it becomes known that they or their lover are HIV-positive.[167]

The report of a recent survey of people with HIV/AIDS in Québec notes that there are three types of "silence" at work - silence about sexual orientation, silence about HIV status, and silence about HIV medications.[168] People who are currently not working would rather not return to their previous employer because of the level of stress and discrimination and the attitude of their employer. They would prefer to work in a context that is more open to sexual orientation, HIV seropositivity, and combination therapy. Gay and bisexual men are more likely to disclose their HIV status when their employer is aware of their sexual orientation and when their employer is gay or bisexual.[169]

Discrimination and harassment in the workplace on the basis of sexual orientation is prohibited by human rights legislation in all jurisdictions except Alberta, Prince Edward Island, and the Northwest Territories. However, as the *Final Report* on gay and lesbian legal issues and HIV/AIDS observes, the difficulty in a human rights complaint is that discriminatory attitudes are often subtle, and that it is not always easy to prove that a particular decision was based on sexual orientation, disability, or indeed any specific prohibited ground of discrimination.[170] In addition, the complaints procedure is time-consuming, slow in providing redress, and emotionally draining, thereby discouraging individuals from lodging or pursuing their complaints.

Health Care

In order to recognize the risk of HIV infection, provide appropriate counselling and testing, and early treatment, it is important that physicians in general be knowledgeable about and comfortable with men who have sex with men. This involves such things as taking a history of sexual orientation and sexual activity, assessing risks of transmitting or acquiring HIV, and taking a history of sexually transmitted diseases - practices that are not routine for all physicians.

A study of 300 physicians attending AIDS-related continuing education courses in Ohio between 1987 and 1989 found that only 42.4 percent routinely took a history of sexually transmitted diseases, only 24.7 percent routinely assessed the risk of transmitting or acquiring HIV, and only 17.6 percent routinely took a history of sexual orientation. Parallel studies were conducted at the same time among gay men. Less than half (41.6 percent of 573 men) had discussed their sexual orientation with their personal physician. When asked why they had not, 74 percent responded that they were never asked.[171] Thus, an opportunity to establish an open relationship between physicians and men who have sex with men, as well as to provide education about HIV/AIDS and early testing for HIV, was lost.

There is evidence that these problems continue today. A study of the experiences of gays, lesbians, bisexuals, and transsexuals with physicians in Ontario found that 41 percent of physicians do not discuss safe sex with their clients.[172] Twenty-eight percent of clients also experienced discrimination because of HIV. It is possible that the practices of physicians who specialize in HIV/AIDS care are more appropriate.[173] Nevertheless, two individuals consulted in the preparation of this Paper reported that physicians in two smaller cities were known to hold positions or make remarks that gay men found objectionable. In one case, the physicians was the only specialist for a large northern region. Conversely, an AIDS support worker stressed how hanging a rainbow flag in the emergency room in a hospital in a large metropolitan area was an important symbol of acceptance for the large gay, lesbian and bisexual population served by the hospital.

End-of-Life Decisions

Lack of acceptance of the sexual orientation of a gay man with HIV/AIDS can, together with the stigma of HIV/AIDS, create conflict within his family of origin or between his family of origin and his lover or partner.[174] In the event of a crisis (such as decisions about health care for a person who is incapacitated) or death, the law privileges the family of origin. As the *Final Report* on gay and lesbian legal issues and HIV/AIDS notes:

> If a person living with HIV or AIDS has not planned in advance of his/her death or incapacity, his/her same-sex partner will have almost no recourse for making decisions about that person's health care, administering finances and property, or claiming a share in the deceased partner's estate. The partner of the deceased may have a claim based on common law remedies (such as resulting or constructive trusts) or a claim for compensation for having cared for the deceased, but there is no statutory right to a share of the estate or to be appointed to administer the estate.[175]

Same-sex partners can take steps to protect their position, and laws in Newfoundland, Nova Scotia, Québec, Ontario, Manitoba, and British Columbia specifically permit individuals to designate who can make health-care decisions when they become incapacitated.[176] But the law still substantially privileges biological families over same-sex partners.

Transgendered People

> Like many of my sisters and brothers I have felt like a freak of nature, and had a sense of not belonging anywhere. When on the streets, I was accepted and validated, and was able to escape from the realities of being transgendered. I did not need to adjust to the real world and the expectations of others. In the straight world we were abandoned, forgotten, and occupied a social status reminiscent of earlier times. In the real world there was no human rights protection, and no dignity for the transgendered.[177]

Transgendered people - a term that applies to transsexuals, transvestites, drag queens, and cross-dressers[178] - are exposed to humiliation, degradation, and discrimination at almost every turn. Many transgendered people are rejected by their families. They are not universally welcome within the gay and lesbian communities. Few workplaces are accepting and accommodating of their identity and dress. Police tend to be polite until they see identification papers, at which point their attitude changes.[179] Health care and social service providers may be insensitive, referring, for example, to transgendered people by their sexual identity, not their gender identity. In hospitals and prisons transgendered people are lodged with people of their sex rather than their gender. In prison the risk of violence and coercive sex is high, particularly for those whose sex is male but whose gender is female. In short, transgendered people are rejected, isolated, closeted, and vulnerable within society.

This has numerous consequences in the context of the HIV/AIDS epidemic. Because of their rejection by society, many transgendered people end up on the street as sex workers or injection drug users. On the street, their risk of HIV infection is high. It is estimated that 70 to 80 percent of transgendered people on the streets in Vancouver are HIV-positive.[180] Many HIV-positive transgendered people do not attend HIV clinics because their gender is not acknowledged and affirmed.[181] Health-care providers may not be sufficiently knowledgeable of and sensitive to the hormonal and psychosocial needs of transgendered people with HIV/AIDS.[182] Transsexuals with HIV/AIDS are refused at gender clinics if they disclose that they are HIV-positive. In one case, a physician agreed to perform the surgery requested by a transsexual, but for a surcharge of $5000 over the regular fee. It can be difficult for HIV-positive transgendered people to obtain services they require to maintain their physical appearance, such as electrolysis. Protecting and preserving one's gender in hospitalization and in making funeral arrangements is difficult.[183]

Recognizing the consequences of isolation and discrimination against transgendered people in the context of HIV/AIDS, health-care providers and community workers have developed peer-driven programs for transgendered street people and clients of HIV clinics. Such programs have provided support to transgendered people who otherwise would not approach more traditional organizations.[184] One initiative, a support group for transgendered people with HIV/AIDS at a primary care clinic, reports:

> Transsexual patients stated a dramatic increase in trust for their health care providers over the 2 years. The number of clinic appointments missed by all the group decreased from 64% in 1994 to 12% in 1995. The group developed their own community within the clinic, shared HIV and transgender information, provided mutual support, and fought discrimination.[185]

However, targeted programs and specialist health care must be accompanied by protection from discrimination in law, policy, and practice. Currently, there is no explicit protection for transgendered people in human rights legislation in Canada; transgendered people lodge complaints on related prohibited grounds, such as sex, mental and physical disability, and sexual orientation.[186] Only if transgendered people enjoy the same rights, freedoms, and opportunities afforded others in Canada, and are not ostracized by society, will the conditions that place transgendered people at risk of HIV infection be ameliorated.[187]

Injection Drug Users

> I don't like the abuse people take whether it's because they drink rice wine, use drugs or because they are mentally ill. Poor bashing is easy to get away with. The poor don't have the ear of the press.[188]

Why should people be homeless, sick, beat up, etc. because they use drugs? It's not important if people use or not - they deserve to be treated compassionately. When wealthy people use drugs it is private because they are not homeless shooting up on the streets.

The illegality of the drugs causes damage, not necessarily the drug itself. Did I have to be degraded and criminalized to stop? I think I felt worse about my self and may have used more and longer as a result.

People have to see a reason to stop and degradation is not a reason to stop - it's often a reason to use.

A non-judgmental place is the key to a successful place for users. A place where we can help each other. We can say to each other, "It's okay to be who you are and I accept you where you are now whether you are using or not."

When does the addict see anything ever happening? Only when we overdose or get HIV or endocarditis - the rest is a lot of gum flapping.

Addicts are considered the lowest of the low. My name is mud. I used to teach elementary school and was a psychologist assistant. The assumptions made about me because I am identified as a drug addict are that I have no self-esteem, no respect for my body and that I am not capable of anything. No one listens to me - nothing I say is taken seriously. I have a problem. I am an addict. I don't need to be insulted, discredited, humiliated and ignored.

Current Epidemiology

Health Canada reports that "[i]n 1996, approximately half of the estimated 3,000-5,000 HIV infections which occurred in Canada were among injection drug users, illustrating the significance of this group in the current Canadian epidemic":[189]

> • For men, the proportion of AIDS cases attributed to injection drug use has increased from 1.0 percent during the period before 1989, to 2.6 percent during 1989-92, to 5 percent during 1993-96. For women, the proportion of AIDS cases attributed to injection drug use during the same periods has increased even more dramatically, from 6 percent to 15 percent to 25 percent.
>
> • Prevalence of HIV infection among injection drug users in Toronto has increased from 4.5 percent in 1991-92 to 7.6 percent in 1993-1994; in Montréal, from 5 percent prior to 1988 to 19.7 percent in 1996; and in Vancouver, from 4 percent in 1992-93 to 23 percent in 1996-97.
>
> • Estimates of the incidence of HIV infection among injection drug users, as reported in various studies, are as follows: 5-6 new infections per 100 injection drug users per year (100 person-years) in Montréal during the early 1990s; 5 new infections per 100 person-years in Vancouver in 1992-93; 18.6 new infections per 100 person-years in a cohort in Vancouver in 1996-97; and 5.4 new infections per 100 person-years among needle exchange attenders in Ottawa and Québec.

Recent studies indicate that lending and borrowing of needles and other injection equipment is relatively common among injection drug users in Canada:[190]

- Among 1006 injection drug users enrolled in a study in Vancouver, 40 percent had either borrowed or lent needles, and 11 percent of HIV-positive users and 25 percent of HIV-negative users consistently used bleach.[191]

- Among 2458 injection drug users recruited at needle exchanges in Ottawa and in the province of Québec, 40 percent had injected with borrowed used needles in the preceding six months.[192]

Injection drug users also report unprotected sex with regular, casual, and commercial sex partners.[193] Among injection drug users recruited at needle exchanges in Ottawa and in the province of Québec:[194]

- 79.3 percent of women and 73.6 percent of men never or only sometimes used condoms with regular partners. Of the men, 4.4 percent had a regular male partner, and of these 72.5 percent never or only sometimes used condoms.

- 54.9 percent of women and 56.7 percent of men never or only sometimes used condoms with casual partners. Of the men, 6.8 percent had casual male partners, and of these 75 percent never or only sometimes used condoms.

- 40 percent of women and 7.1 percent of men reported having male commercial sex clients, and of these 35.5 percent of women and 63.9 percent of men did not consistently use condoms.

Patterns of Stigma and Discrimination

Drug use is a powerful source of stigma, and people who have acquired HIV through injection drug use, like those who have acquired HIV through same-sex activity, live with a double stigma. A study of public attitudes in Australia in 1990 found that drug users who contracted HIV through needle sharing attracted the most blame (92 percent), the least sympathy (18 percent), and the most calls for them to pay for their own treatment (70 percent).[195] Similarly, a random-sample survey conducted in the United States in 1990-91 found that 20.5 percent of the respondents thought that "people who got AIDS through sex or drug use have gotten what they deserve."[196]

The stigma of drug use is reinforced by the illicit status of drug use in law, and by the application of coercive measures, including police surveillance, criminal prosecution, and criminal penalties, against illicit drug users. The legislation is, arguably, itself discriminatory. When one compares illicit drugs with similar licit drugs in terms of their pharmacological action, their psychotropic effects, the damage they may cause to the user's health, their potential for dependency or abuse, and their social consequences, the criminal penalties applied to illicit drug use are not proportional to the harm incurred and do not match comparable penalties to comparable offences.[197]

In addition, the legislation is discriminatory in its effects. The prohibition of drugs and the application of criminal sanctions, compounded by existing patterns of discrimination based on race and income, has a disproportionate effect on impoverished and minority populations. The greater availability, lower price, and increased use of heroin and cocaine in poor, minority ghettos in the United States, for example, can be traced to the longstanding practice of white middle-class authorities to contain "vice" in its successive forms - prostitution, gambling, alcohol, marijuana, heroin, and cocaine - to minority ghettos.[198] Today, although as many whites as blacks use drugs in the United States, blacks are overrepresented among the users that require treatment for drug abuse or drug dependence.[199] Blacks and Hispanics are also vastly overrepresented among prisoners convicted of drug felonies in the United States. As a report on drug sentencing in New York State observes:

> In New York state, almost 30,000 people a year are indicted for drug felonies, and 10,000 are sent to prison; approximately 90 percent of them are blacks and Hispanics. In New York, as throughout the United States, drug felonies are the single most significant factor underlying the remarkable growth of the prison populations.[200]

Canada has its own parallels in this regard. Currently Aboriginal peoples are overrepresented among inner-city injection drugs users and among attenders of needle exchange programs.[201] Likewise, both Aboriginal peoples and injection drug users are overrepresented in prison populations.[202] Many drug users are socially and economically disadvantaged. A study of 582 injection drug users in Toronto found that 12.7 percent had an elementary school education, that 72.2 percent had a high-school education, that only 22.5 percent were permanently employed, and that only 36 percent lived in their own residence, while the rest lived in a shelter (14 percent), a room rented on a daily or weekly basis (16 percent), or had no fixed address (11.5 percent).[203] Similarly, among injection drug users enrolled in a recent study in Vancouver, 81 percent had less than a high-school education, 62 percent were living in unstable housing, and 28 percent had a high level of depression.[204]

The marginalized status of drug users profoundly affects the way they are treated by others. Users attending meetings of the Vancouver Area Network of Drug Users (VANDU) attest to numerous discriminatory and degrading experiences:

> My brother and sister couldn't get a hold of me at my hotel. We had a death in the family and when they came to pick me up they wouldn't let them upstairs to get me or go up to tell me they were here to get me. I missed the funeral. It makes me mad. I have no where else to live.
>
> [A certain hospital] is a nightmare! They throw people out. I've really behaved well and I

> still get thrown out. Every time I go there they treat me like shit. Recently I broke my ankle. I was given crutches and told to leave. The next day they called my mom and asked her to contact me to tell me to come back as my ankle was broken. They wouldn't believe me.
>
> I also need a family physician. They won't take users.
>
> Some police are really dirty. ... I've been beaten up a few times. They sometimes pepper spray you and leave you in the alley.
>
> What about cops helping us with landlords evicting us when we've paid our rent? I've had a very bad experience with this. Police could really be of help to people down here in this way and they aren't.
>
> Does anything ever happen to hotel owners as a result of these violations [room violations, guest fees, illegal evictions]? Where is the City in all this? Where are the by-law enforcement officers?

In other words, drug users find that they are denied the legal protections, health services, and social supports that others enjoy.

Impact of Stigma and Discrimination

Vulnerability to Infection

The high-risk injecting and sexual behaviours among injection drug users are, in part, an effect of the illicit status of drugs and other restrictions on drug users.[205] The illicit status of drugs drives up their price, leading users to take the drugs in the most efficient manner possible (injection) rather than by less efficient but safer means (oral consumption). Substitutes that could be taken orally are either prohibited (heroin) or, if they are available, are medically regulated (methadone). As a result of both policies and practices governing the sale of syringes, drug users do not have ready access to syringes in community pharmacies,[206] and needle exchanges may impose limitations that do not meet the needs of drug users (such as limits on the number of syringes exchanged at one time).[207] To this must be added other features of the illicit drug market, such as having to use drugs of uncertain quality and purity, being vulnerable to coercion or violence, or in some cases resorting to property crime or commercial sex to pay for drugs.

Socioeconomic disadvantages contribute further to the risk of HIV infection among drug users. The Vancouver study, noted above,[208] found that HIV-positive injection drug users were disproportionately of Aboriginal origin, and were significantly more likely to have less than a high-school education, to live in unstable housing, and to reside in the poorest postal district in Canada. The sociodemographic characteristics of low education and unstable housing - along with the behavioural characteristics of commercial sex work, borrowing used needles, injecting with others, being an established injection drug user, and attending a needle exchange program more than once per week - independently predicted HIV-positive status among injection drug users.

Programmatic barriers in the form of inadequate or inappropriate services, as well as professional attitudes and practices that are controlling and demeaning, are also factors in the HIV epidemic among drug users. Noting that Vancouver has an HIV incidence of 18.6 percent among injection drug users despite the fact that Vancouver has the largest needle exchange program in North America, the authors of the Vancouver study comment:

> In Vancouver, NEP [needle exchange programs] were introduced early, but access to drug and alcohol treatment, methadone maintenance and counselling services remain inadequate. As early as 1990, the lack of appropriate services for addictions treatment in British Columbia, especially for cocaine users, was identified as a major barrier encountered by Vancouver's NEP attenders, among whom there was already a marked demand for HIV-related counselling. This situation continues at present. Our results do not argue against the overall effectiveness of NEP as an HIV intervention, but rather, they lead us to propose that without adequate and appropriate community-wide interventions such as addictions treatment, detoxification and counselling, stand-alone NEP may be insufficient to maintain low HIV prevalence and incidence for an indefinite period.[209]

The importance of providing a broad range of interventions is reinforced by evidence from Amsterdam, where, as the authors of the Vancouver study note, "a continuum of harm-reduction activities was associated with lower HIV incidence and needle-sharing behaviours, but there was no evidence of a protective effect for single interventions like NEP or methadone maintenance."[210] Providing such a range of interventions requires, as the Task Force on HIV, AIDS, and Injection Drug Use recommends, eliminating the barriers that professional and public attitudes, as well as the design and delivery of programs, place in the way of integrated, accessible, suitable, flexible, and respectful services for drug users.[211]

HIV/AIDS Care, Treatment, and Support

A recent report on the care, treatment and support of drug users with HIV/AIDS describes the difficulties that they often encounter when they seek drug treatment, health care, or social support.[212] Service providers may be reluctant to offer service or may do so with an attitude of disrespect because they consider injection drug users to be disruptive or manipulative. Professionals may be unwilling to accept a drug user's choice to continue using drugs or may be reluctant to work with what they consider to be difficult clients. Organizations that are not experienced in working with injection drug users - including established HIV/AIDS organizations - may offer programs that are inappropriate or may be less ready to serve them relative to other populations with which they have more experience or more success. Health and social programs may be designed to address a single problem, rather than the multiple problems that drug users present, and consequently may have neither a sufficient range of services nor a flexible enough set of criteria to be able to serve drug users well.

The clinical care of drug users with HIV/AIDS is complicated by the need to attend to both drug treatment and HIV/AIDS treatment. There are a number of areas where the care that is delivered may be discriminatory. One is the area of pain medication. Drug users frequently report that they are not given adequate pain relief. Pain medication that is offered to other people with HIV/AIDS is not available to them. Another area of concern is antiretroviral therapy. There is considerable fear that drug users will not be offered the current standard of care because it is assumed that they will not be able to maintain the demanding drug regimens. Abstinence as a condition of treatment and care is another area where drug users may experience discrimination. Physicians may be unwilling to provide treatment unless a drug user agrees to discontinue using and enter drug treatment. Similarly, restrictions on drug use in residential facilities may effectively exclude or deter drug users from care.

As the report on the care, treatment and support for injection drug users with HIV/AIDS observes,[213] there are numerous legal and ethical issues involved in providing care to injection drug users, in large part owing to the illicit status of the drugs used, concern for professional safety and liability, and prevailing norms and attitudes among health-care providers. For example, health-care providers may perceive an irreconcilable ethical contradiction between preventing illicit drug use and enabling or permitting a drug user to continue to inject. Physicians may be liable to professional discipline or criminal prosecution if they do not follow professional guidelines or government regulations in the prescription of psychoactive drugs. Health-care facilities may face legal problems if they allow illicit drugs on the premises.

While these ethical and legal dilemmas require careful deliberation, it is not acceptable to make decisions without considering the full range of options available (including innovative approaches), obtaining accurate information about the real (rather than stereotypic or imagined) risks to drug users, and, most importantly, recognizing the rights of drug users to health care and treatment. This is especially pertinent in decisions about antiretroviral treatment of HIV in drug users, given the requirements that current drug regimens place on people with HIV - regimens that are demanding by any standard, and not only for drug users. As the Task Force on HIV, AIDS, and Injection Drug Use states:

> It must be recognized that injection drug users living with HIV are individuals, suffering in a myriad of ways, and in need of the best possible interventions, tailored to their unique situations. They retain all the rights of every other citizen, and must therefore be given equal access to a continuum of services, as well as the dignity of making their own decisions. If lack of compliance with a drug treatment is feared, then the patient must be supported to ensure adherence to the treatment regime, just as any other individual is, whether diagnosed with diabetes, epilepsy or another condition. Bias against treating

> [injection drug users] is unjustified and unacceptable.[214]

Research and Information

The care and treatment of drug users in general, and of drug users with HIV/AIDS in particular, is limited by gaps in research and by difficulty in getting accurate information about illicit drugs. The gaps in research are a result, among other things, of norms and practices that effectively exclude drug users from research, neglect areas of research that are relevant to drug users, or prevent innovative research on drug use. For example, drug users may be excluded arbitrarily as participants in clinical research, without due consideration to the individual characteristics of drug users and potential support for their participation. Research into such questions as the interactions between approved therapies and illicit drugs may be hindered by the stigma associated with drug use, lack of interest in the pharmaceutical industry, and the illicit status of the drugs. Innovative research, such as clinical trials on the prescription of heroin and cocaine, is difficult to initiate, given the prevailing models of drug treatment and public and professional attitudes toward illicit drugs.[215]

HIV, Drug Use, and Disability

Human rights legislation and human rights commissions in Canada have afforded protection to people who have been or are dependent on alcohol or drugs. The *Canadian Human Rights Act* recognizes previous or existing dependence on alcohol or a drug as a disability within the meaning of the *Act*,[216] and the Ontario Human Rights Commission, in a complaint against Imperial Oil Limited, determined "that drug abuse and drug dependence both constitute a handicap within the meaning of the [*Ontario*] *Human Rights* Code."[217]

However, in an environment that regards drug use as a choice, a vice, and a crime, considerable education and advocacy will be required to ensure that the rights of drug users are protected and that drug addiction is recognized as a disability. For example, Bill 142 in Ontario, an Act to amend the law related to social assistance, excludes persons whose only substantial restriction in activities of daily living is attributable to the unauthorized use or the cessation of use of alcohol, a drug or some other chemically active substance, from eligibility for income support.[218] The first draft of the bill excluded persons whose impairment is the result of unauthorized use of alcohol, drugs or other substances from the definition of disability,[219] but this was subsequently amended to exclude such persons only from eligibility.

Bill 142 makes an exception for a person "who, in addition to being dependent on or addicted to alcohol, a drug or some other chemically active substance, has a substantial physical or mental impairment, whether or not that impairment is caused by the use of alcohol, a drug or some other chemically active substance."[220] In Vancouver, drug users report that "[s]ome people are getting HIV on purpose to get the increased welfare for the disabled."[221] The terms placed on the eligibility for income support in Bill 142 may have the same perverse effect in Ontario.

Participation of Drug Users

One of the guiding principles of the report of the Task Force on HIV, AIDS, and Injection Drug Use is that "[t]hose using the services must be involved in the processes which affect them - the development of policy and programmes."[222] This is fundamental to health promotion - "the process of enabling people to increase control over, and to improve, their health"[223] - and is reflected again and again in what drug users say:

> People are not empowered - they have no control over their lives. Administered welfare treats people like children. It's insulting and disempowering. Too many service agencies take the same approach. There are no services around to really help you get a life. The main way to get empowered is to get decent housing.[224]
>
> If we're such garbage, why are we still alive? Because we believe we're not garbage. Junkies have strong spirits despite being called everything bad you can think of.[225]
>
> Well, we know that users aren't going to go away. Nothing to force users to stop using works - not beatings, pepper spraying, arresting - not hate, overdoses, poison in the drugs - nothing stops a person using drugs unless they decide to quit.[226]

The marginalization of drug users, combined with individual preferences of drug users and the predominantly criminal or medical perspective applied to drug users, creates many barriers to health promotion, to the organization of drug users, and to including drug users in developing policies and programs. Simply disclosing drug use is unsafe. Drug users who are employed risk losing their job and other benefits, such as the opportunity to obtain a mortgage or insurance. Drug users who are unemployed and are dependent on social assistance may lose income support (as, for example, under Bill 142 in Ontario) or may be required to enter into treatment with little or no choice as to the kind of treatment that they believe will be best for them.

Involving drug users is, however, essential if patterns of discrimination, exclusion, and coercion are to be broken. As the Task Force on HIV, AIDS, and Injection Drug Use recommends, drug users must be actively involved in policy development, program planning, implementation, and evaluation. In addition, community-based peer-support and advocacy groups for drug users must be developed. These are first steps, among others, in any strategy to overcome discrimination against drug users among professionals, service providers, and the general public.[227]

Aboriginal People

> I work on the reserve. On the reserve they don't understand at all about HIV. They're afraid of HIV. I'd lose my job and they'd run me right off the reserve. They believe you can catch HIV by kissing. But they believe it will never happen to them. Some friends who know my daughter is on the street but don't know she is HIV-positive say to me they pray she doesn't contract HIV.[228]
>
> In 1994, I believe it was the Assembly of First Nations and the Royal Commission who did a report on First Nations Suicide Issues. I believe it was called, Bridging the Gap. And in this report, I wanted to find a mention of First Nations homosexuality, of Two-Spiritedness, a mention of it. And unless you knew what you were looking for, unless you could read very small print between the lines, it was mentioned, but not very strongly. And I found an injustice in that. It is unjust that we as First Nations people, have become so suppressed by the Roman Catholic Church, by colonialism and a lot of other things, by the residential schools. So we no longer respect Two-Spirited people for who they are. That we no longer revere them for the spiritual people that they are, that we are, and we always will be, we always have been.[229]
>
> Many Aboriginal people experience racism in health care and social assistance settings. Some people do not trust Western medicine and practitioners. Some people are not comfortable using mainstream testing facilities. In some cases this reflects cultural difference rather than direct racism.[230]
>
> One person who works for an AIDS organization related a story about waiting for a doctor for half an hour after the time of her appointment. When asked why she was being passed over in favour of other patients, the receptionist replied, "Oh, I thought you didn't have a job."[231]

Current Epidemiology

Health Canada reports that, although there are limits to the information available on the HIV epidemic among Aboriginal people, "it is clear that some Aboriginal communities are at increased risk for HIV infection because of their low socioeconomic status, poor health condition, and high rates of sexually transmitted diseases."[232]

- The proportion of AIDS cases among Aboriginal people, as a percentage of all AIDS cases, has risen steadily over the past decade, from 1.5 percent before 1989 to 3.1 percent during 1989-92 and 5.6 percent during 1993-96.

- Sex with men and injection drug use account for the majority of the 210 Aboriginal male AIDS cases, and injection drug use and heterosexual sex account for the majority of the 39 Aboriginal female AIDS cases.

- Aboriginal AIDS cases are more likely to be younger, to be women, and to be attributed to injection drug use than non-Aboriginal AIDS cases.

- Recent data from British Columbia and Alberta show that Aboriginal people account for 15 to 26 percent of newly diagnosed HIV-positive cases, and that injection drug use and heterosexual activities are the most significant risk factors.

- Aboriginal people are overrepresented in groups at high risk for HIV infection, including injection drug users, clientele using inner-city services, men who have sex with men, and prison inmates.

Patterns of Stigma and Discrimination

Aboriginal people with HIV/AIDS live with many layers of stigma and discrimination. These may include, in addition to being HIV-positive and being an Aboriginal person, being a woman, a two-spirited person, a substance user, a sex worker, or in prison.

Aboriginal Status

As Stefan Matiation observes, what differentiates discrimination against Aboriginal people living with or affected by HIV/AIDS is the history of oppression and social disintegration that has been meted out to First Nations, Métis, and Inuit in Canada.[233] This history has resulted in a maze of interconnected spiritual, communal, social, economic and political problems that strain the resources, the will, and the spirit of Aboriginal communities. Therefore, improving the health and well-being of Aboriginal people (including those with HIV/AIDS) means addressing the causes of cultural dislocation, ruptures within families, violence within families, substance use, chronic poverty, unemployment, poor housing and utilities, environmental destruction, lack of information and services, and lack of control over resources and programming.[234]

Gender Disparity

Women have been doubly disadvantaged as a result of the influence of colonial attitudes and the restrictions of the *Indian Act* upon Aboriginal society. For much of this century, Aboriginal women were denied a vote in band elections, could not own or inherit property, and lost their Aboriginal status upon marrying a non-Aboriginal man. Aboriginal women have been subject to degrading sexual and racial stereotypes in both non-Aboriginal and Aboriginal communities, and they continue to experience high levels of emotional and physical abuse from Aboriginal men. This violence is itself related to the disastrous consequences of racism and oppression within Aboriginal communities, and in particular among Aboriginal men - high unemployment, poor housing, poor self-esteem, self-hatred, and substance use.[235]

Two-Spirited People

Sixty percent of known Aboriginal AIDS cases in Canada are among men who have sex with men, and an additional 14 percent are among men who have sex with men and who are injection drug users.[236] There is little acceptance of or support for two-spirited people in many Aboriginal communities. Many two-spirited people have lived away from their communities for years and feel rejected because they are two-spirited or because of their HIV status.[237] The effects of this are felt by both two-spirited people and heterosexual Aboriginal men. Because many two-spirited people feel unwelcome, they do not care about their own lives and engage in unsafe behaviours. Because many heterosexual Aboriginal men regard HIV/AIDS as a "gay disease," they also do not practise safer sex.[238] In addition, homophobia is one of the main barriers to Aboriginal leaders taking action on HIV/AIDS issues.

Substance Use

The rupture of family and community bonds, personal histories of abuse, lack of opportunity and employment, displacement in a non-Aboriginal environment, poverty, and despair have led many Aboriginal people into substance use. Currently in Canada, Aboriginal people are overrepresented among inner-city injection drug users and among clientele using inner-city services.[239] This not only contributes to a greater risk of HIV infection; it also introduces a further layer of stigma and discrimination.

Impact of Stigma and Discrimination

Poor Health and Well-Being

The effects of two centuries of racism, oppression, and displacement are evident in the current health status of Aboriginal people. As the Royal Commission on Aboriginal Peoples notes:[240]

- life expectancy at birth is about seven to eight years less for registered Indians than for Canadians generally;
- the death rate among Aboriginal infants is twice as high as the national average;
- infectious diseases of all kinds are more common among Aboriginal people than others;
- the incidence of life-threatening degenerative conditions (previously uncommon in the Aboriginal population) is rising;
- overall rates of injury, violence, and self-destructive behaviour are disturbingly high; and
- rates of overcrowding, educational failure, unemployment, welfare dependency, conflict with the law and incarceration all point to major imbalances in the social conditions that shape the well-being of Aboriginal people.

Vulnerability to HIV Infection

Many of the factors that contribute to higher risk of HIV infection relate directly or indirectly to the patterns of discrimination noted above. These factors include:[241]

- high rates of sexually transmitted diseases;[242]
- high rates of teenage pregnancy, indicating a lack of safe-sex practices and a higher risk to youth;
- low self-esteem, particularly among two-spirited people;
- high rates of sexual and physical violence;
- drug and alcohol abuse;

- lack of access to health information and facilities; and
- poor health in general.

Denial and Avoidance within Aboriginal Communities

Aboriginal leaders have been slow to recognize and respond to the presence of HIV/AIDS among Aboriginal peoples. There have been a number of reasons for this. HIV/AIDS has been seen as "a disease of gay white men in the cities."[243] Band councils have many pressing issues to deal with, and few resources with which to do so.[244] The majority of Aboriginal people with HIV/AIDS are not living on reserve, and are therefore not within the jurisdiction of First Nations and Inuit leaders. As a result, there is considerable concern at present that, as authority for health services is transferred to First Nations, funding and programs for services for people with HIV/AIDS will be inadequate.[245]

People within Aboriginal communities have also been reluctant to address HIV/AIDS because of the shame and stigma associated with homosexuality and other sexuality issues. These attitudes themselves compound the problems of trying to reduce the risks of HIV infection among Aboriginal people. As one individual put it:

> In our communities, we have been doing workshops on HIV/AIDS and we have tried so many ways: a doctor, an [Aboriginal person with HIV/AIDS] and a two-day workshop with youth, young adults, and elders. The first time the kids were horrible. We are having a hard time, especially with the elders, it is so sad we really don't know what to do. This is a very touchy subject. Risk behaviour is very high around here.[246]

Moreover, as Matiation reports,

> HIV/AIDS workers cannot simply go into communities and talk about HIV/AIDS. All the issues around HIV and public health in Aboriginal communities must be addressed, including the impact of a foreign culture on community practices and traditions, residential schools, assimilationist policies, health problems, sexual and physical abuse, and alcohol. All these topics make it difficult to talk about sexuality issues.[247]

Disclosure and Rejection within Aboriginal Communities

Because of the shame and stigma associated with HIV/AIDS in Aboriginal communities, confidentiality of HIV status is very important. However, it is often hard to ensure confidentiality in Aboriginal communities, not only because of improper disclosure by health-care providers, but also because of word spread by relatives, friends and acquaintances in small communities.[248]

The reaction, upon finding out that someone is HIV-positive, has included ostracism, avoidance, and denial of services.[249] In the face of these kinds of reactions, one of the three priorities cited most often (after the issues of funding and poverty) in the Aboriginal consultations on Phase III of the National AIDS Strategy was "access to home communities with adequate services, and without fear of discrimination."[250]

Treatment in Non-Aboriginal Settings

The majority of Aboriginal people with HIV/AIDS live in cities, not in remote communities. Although more services relating to HIV/AIDS or to substance use are available in cities, these may be provided in ways that are discriminatory, particularly to those who are at greater risk of HIV infection, such as drug users or sex workers:

> A study in Alberta revealed that Aboriginal people using emergency facilities at a hospital in Edmonton were given sub-standard treatment. Aboriginal people face systemic discrimination in health care. This is particularly acute for inner-city and street-involved people.[251]

The first step to treating Aboriginal people - including those with HIV/AIDS - with dignity is, clearly, to provide them with services of the same quality as those provided to others. But it also means affirming the insights and practices of Aboriginal cultures (which are diverse) in developing and delivering programs, as well as incorporating traditional healers and healing practices into those programs.[252]

Jurisdictional Barriers

The Royal Commission on Aboriginal Peoples found that the belief in the interconnectedness of all the elements of life and living is central to Aboriginal perspectives on health and healing:

> The idea brought forward perhaps most often was that health and welfare systems should reflect the interconnectedness of body, mind, emotions and spirit - and of person, family, community and all life - which is essential to good health from an Aboriginal point of view.[253]

However, as many of the presenters to the Commission observed, the separation of resources and programs into isolated streams according to jurisdiction (federal or provincial/territorial, on-reserve or off-reserve, health services or social services, etc), as well as the Western approach of specialization and expertise in health care and social services (each problem with its particular specialist), has presented many barriers to a holistic and interconnected approach to the health and social problems within Aboriginal communities.[254]

The lack of coordination and collaboration due to jurisdictional divisions has been a major and persistent problem for HIV/AIDS programming in Canada.[255] There are a number of initiatives under way that are intended to improve coordination and collaboration in HIV/AIDS programming - multilateral working groups, provincial Aboriginal AIDS strategies, the Canadian Aboriginal AIDS Network.[256] To the extent that these initiatives result in HIV/AIDS programs designed by, appropriate to, and controlled by Aboriginal people (recognizing the diversity of First Nations, Inuit and Métis cultures), they move beyond the discrimination (lawful though it may be) inherent in the bureaucratic structures (federal, provincial, and Aboriginal) that are the legacy of the *Constitution Act* and the *Indian Act* - structures designed for, rather than by, Aboriginal people.

Sex Workers

> Because women involved in street prostitution are stigmatized by society, they cannot count on basic rights such as confidentiality, health care, protection by the police or access to other services.[257]
>
> In relation to HIV/AIDS, prostitute women are usually viewed as vectors of transmission rather than people in need of treatment/support.[258]
>
> The well-being of women involved in street prostitution depends as much on access to adequate legal and social counselling and education resources as it does on safety tips and health care.[259]

Current Epidemiology

There is considerable variation in the practices of sex workers and the conditions affecting their health and safety. Studies of HIV infection among sex workers often draw on samples that are not necessarily representative of all types of sex workers. As a result, it is difficult to generalize about the risks to the health of sex workers, including the risk of HIV infection, from one locale to another. Nevertheless, recent reviews of the literature offer the following observations:[260]

- In Canada, as in other parts of the developed world, the prevalence of HIV infection among female sex workers who do not use drugs is lower than the prevalence of HIV infection among male sex workers and among sex workers who use drugs.[261]

- Risks to health and safety, including risk of HIV infection, vary with the type of sex worker: street prostitutes, escorts or prostitutes who work indoors (often in so-called brothels), and women who work in bars or saunas and provide sexual services, usually on a part-time basis. Street prostitutes have tended to be overrepresented in studies of sex workers, so that one must be cautious in generalizing on the basis of such studies about the risks to the health of other types of sex workers.

- There is a high rate of condom use with clients among female sex workers who do not use drugs. This practice, already established before the onset of the HIV epidemic, has contributed to relatively low rates of HIV infection among these sex workers. However, factors such as inexperience on the streets, threats of violence, economic pressure, and drug use can affect sex workers' ability to refuse clients who do not wish to use a condom. In addition, familiarity with regular clients, which can blur the lines between commercial sex and private sex, can lead to inconsistent condom use.[262]

- There is a much lower rate of condom use with personal partners among female sex workers. There are a number of reasons for this: condoms are associated with "work" and are a barrier to intimacy; condoms represent a breach of trust in the relationship; the woman may be attempting to become pregnant; there may be a threat of violence in the relationship. As a result, sex workers may be more at risk in their private lives than through their work.[263]

- Poverty, socioeconomic discrimination based on gender and race, a history of sexual abuse, homelessness, lack of education, and drug use are factors in people's decisions to provide sexual services and in people's risk of HIV infection in providing such services. People consulted in the preparation of this *Discussion Paper* observed, for example, that single mothers tend to work the streets at the end of the month, when their income from social assistance has run out. In Toronto, the disproportionate number of street prostitutes who are black is thought to be an effect of racial discrimination and lack of employment for blacks.[264] A study of male sex workers in Vancouver found that, relative to other gay and bisexual men, male sex workers were significantly more likely to be younger, non-white, less educated, live in unstable housing, have a low income, and report non-consensual sex, sex at a younger age, and drug use.[265] An investigation into the determinants of trading sex for drugs among 6004 drug users in the United States found that trading sex for drugs was significantly associated (in order of decreasing statistical strength) with being female, homelessness, lack of employment, and crack cocaine use.[266]

Patterns of Stigma and Discrimination

Sex workers live and work in an environment that stigmatizes and marginalizes them in many ways. Personal and public disapproval of sex work is expressed in the attitudes of communities, politicians, and service providers, in local by-laws and police surveillance, and in the criminal status of prostitution. Many sex workers are further marginalized by involvement with the street, poverty, race, alcohol and drug use, and, as with bisexual or transgendered sex workers, sexual identity.

Street prostitutes are often the most marginalized of sex workers. Street prostitution is illegal, whereas escort services are not - a discriminatory feature of the law that has an adverse effect on poorer sex workers. Street prostitutes are more vulnerable to harassment, and are more likely than other types of sex workers to be arrested for soliciting and imprisoned.[267]

The HIV epidemic has heightened and exposed the vulnerability of sex workers to discriminatory attitudes, attention, and regulation. Sex workers have been characterized as "vectors of transmission," a phrase that ignores the fact that many sex workers use condoms more consistently than other populations, that they frequently exercise more responsibility than their clients, and that they are generally at a higher risk of infection from their clients than vice versa.[268] Research on sex workers has focused more on their working lives than their private lives, even though many sex workers may be more at risk in the latter than the former.[269] Certain countries, such as the United States, have introduced regulatory regimes comprised of mandatory HIV testing and detention, overemphasizing, disproportionately, the role that sex workers play in HIV transmission.[270] Confidentiality of HIV status is often breached, particularly for street prostitutes. Word of HIV status is spread not only by other prostitutes, but also by public officials. In the consultations for this *Discussion Paper*, an incident was reported, for example, in which police, when detaining an HIV-positive prostitute, loudly announced for all to hear that she was HIV- positive.

The prospect of criminalizing HIV transmission is ominous for sex workers:

> [A]s a prostitute, you could be blamed as an easy scapegoat for someone else's unsafe behaviour. You're an easily identifiable target and the potential for this is really high.[271]

Indeed, in the *Thissen* case an HIV-positive prostitute was charged with aggravated assault for biting a police officer, although the risk of infection from biting was extremely small.[272] As Elliott observes, the charge was a misguided overreaction by police and prosecutors: "while there is no question that biting someone constitutes an assault, the HIV-positive status of the accused does not render a mere bite an 'aggravated' assault."[273] Media reports of the case did not question the charge or the sentence; in fact, a Toronto radio host suggested that the accused should have been executed rather than given a sentence of two years in prison.[274]

Impact of Stigma and Discrimination

Such attitudes, laws, and policies regarding sex work affect the health, well-being and safety of sex workers, particularly street prostitutes, and increase their vulnerability to HIV infection. Sex workers are often disinclined to access health and social services on account of the stigma associated with their occupation.[275] By-laws regulating their activity, along with police surveillance, may push them into less safe neighbourhoods, away from drop-in centres, and beyond the range of outreach workers.[276] Consequently, as one person in the workshop on discrimination and HIV/AIDS reported, sex workers are driven away from needle exchanges and other services aimed at protecting their health. The illegal status of their activity can prevent sex workers from prosecuting abusive clients and protecting themselves from HIV infection:

> The criminalization of sex for money means that hookers who are subject to abuse from their customers are less able to report their abusers. It also makes it difficult for them to insist on condom use with their customers, and thus increases their chances of becoming infected. In conversations I had with a number of women who were raped by their customers, without condoms, they said that because their work is illegal they are not willing to prosecute these men. Instead, they maintain a "bad date" list and disseminate it to other hookers.[277]

Decriminalization and Protection from Discrimination: Key to Effective HIV Prevention

According to a recent review of international policies and programs, there have been three strategies to control HIV infection among sex workers: regulating sex workers by mandatory HIV testing, treatment, and in some cases detention; providing accessible and appropriate services for sex workers through targeted programs and specialist clinics; and enhancing the ability of sex workers to safeguard their health and improve their position in the industry.[278] The review observes that there is no evidence that the first strategy, regulation, has prevented HIV transmission:

> Indeed, it has been argued that repression exacerbates the problem since sex workers are further marginalized from health services in the attempt to evade state restrictions on their work.[279]

Decriminalization and anti-discriminatory measures, on the other hand, have been effective in reducing the risk of sexually transmitted diseases and HIV infection:

> [D]ecriminalisation of prostitution and anti-discriminatory measures have been associated with low levels of infection and almost universal condom use. In New South Wales, Australia, and in the Netherlands, legal and social changes appear to have paved the way for more effective health interventions within the sex industry.[280]

The review concludes that a combination of the second and third strategies is required:

> Targeted programmes are important in the short term for those with higher prevalences of infection, including groups of prostitutes. Specialist health care is an important occupational service for sex workers, regardless of the relative prevalence of infection. However, targeted control programmes and specialist health services can only complement, not replace more broadly based interventions to the sex industry as a whole and a general health infrastructure.[281]

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FOOTNOTES

[133] C Waldby et al. Epidemiological Knowledge and Discriminatory Practice: AIDS and the Social Relations of Biomedicine. *Australian and New Zealand Journal of Sociology* 1995; 31(1): 1-14.

[134] Mann & Tarantola, supra, note 56 at 431-432; Fisher et al, supra, note 5.

[135] Federal Centre for AIDS Working Group on HIV Infection and Mental Health, supra, note 73 at 44. Unless otherwise noted, the stories and reports that follow were provided by individuals interviewed in the preparation of this *Discussion Paper* or by participants in the 15 January 1998 workshop on discrimination and HIV/AIDS.

[136] Canadian AIDS Society. *Critical Work: Sustaining Men Who Have Sex With Men Programs in Canada*. Ottawa: Canadian AIDS Society, 1997, at 24, 26.

[137] Health Canada. *HIV/AIDS Epi Update: HIV and AIDS Among Men Who Have Sex with Men.* Ottawa, November 1997.

[138] P Yan et al. Estimation of the Historical Age-Specific HIV Incidence in Canada. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Tu.C.573.

[139] SA Strathdee et al. HIV Prevalence, Incidence and Risk Behaviours Among a Cohort of Young Gay/Bisexual Men. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 24A. Abstract no. 204.

[140] Fisher et al, supra, note 5.

[141] Pryor et al, supra, note 36; Pryor et al, supra, note 37; Fish & Rye, supra, note 35; BA Le Poire. Attraction toward and Nonverbal Stigmatization of Gay Males and Persons with AIDS: Evidence of Symbolic over Instrumental Attitudinal Structures. *Human Communication Research* 1994; 21(2): 241-279; Peters et al, supra, note 33; Johnson et al, supra, note 33.

[142] T O'Hare et al. Fear of AIDS and Homophobia: Implications for Direct Practice and Advocacy. *Social Work* 1996; 41(1): 51-58. See also Le Poire, supra, note 141.

[143] Adam & Sears, supra, note 80 at 67-70; T Myers et al. Variations in Sexual Orientations Among Men Who Have Sex with Men, and Their Current Sexual Practices. *Canadian Journal of Public Health* 1995; 86(6): 384-388; E Nonn et al. Dimensions identitaires, appartenance à la communauté gaie et prévention contre le virus du sida. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 9A. Abstract no. 104; E Nonn et al. Construction de l'échantillon à partir d'une population difficile à définir: Diversité versus représentativité. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 9A. Abstract no. 107.

[144] See, eg, JP Stokes et al. Comparing Gay and Bisexual Men on Sexual Behaviours and Attitudes Relevant to HIV/AIDS. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Tu.C.2404.

[145] PGA Cornelisse et al. A Comparison of Risk Factors for HIV Transmission Between Two Cohorts of Gay Men (1982-84 vs. 1995). XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Tu.C.2393.

[146] Ibid; Strathdee et al, supra, note 139; A Dufour et al. Risk Behaviour and HIV Incidence among

Omega Cohort Participants: Preliminary Data. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 23A. Abstract no. 201; T Myers et al. Bisexual Men and HIV in Ontario: Sexual Risk Behaviour with Men and with Women. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 23A. Abstract no. 203. For evidence of continuing high risk behaviour in the United States, see LA Valleroy et al. HIV and Risk Behaviour Prevalence among Young Men Who Have Sex with Men Sampled in Six Urban Counties in the USA. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Tu.C.2407.

[147] SL Martindale et al. Evidence of Psychologic Distress in a Cohort of Young Gay/Bisexual Men. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 8A. Abstract no. 102. These findings are comparable to those of other studies on the risks faced by gay youth, as reviewed in Health Canada. *The Experiences of Young Gay Men in the Age of HIV*. Ottawa: Minister of Supply and Services, 1996, at 12-13.

[148] Martindale et al, supra, note 147. Similarly, a survey of 1314 bisexual men in Ontario found that 26.4 percent of the men had a history of nonconsensual sex, and that, among those who had had sex with both men and women in the year prior to the survey (1013), men with a history of nonconsensual sex were significantly more likely to report unsafe sex with both male and female partners; see C Strike et al. Nonconsensual Sex and Unsafe Sexual Behaviour: Results from the Bisex Survey. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 14A. Abstract no. 124.

[149] T Myers et al. *The Canadian Survey of Gay and Bisexual Men and HIV Infection: Men's Survey*. Ottawa: Canadian AIDS Society, 1993, at 57. In a subsequent report of the findings, the researchers report that study participants with a positive attitude toward being tested had a 40-45 times greater odds of intention to be tested compared with those with a negative attitude. Low and high intenders differed on each one of the four items included in the "reasons for not taking the test" scale: "I do not want to know," "I do not want my name on a government list," "It could affect my career or insurance," and "It could affect my relationships." See G Godin et al. Understanding the Intention of Gay and Bisexual Men to Take the HIV Antibody Test. *AIDS Care* 1997; 9(1): 31-41.

[150] Myers et al, supra, note 149 at 71.

[151] Jürgens & Palles, supra, note 4 at 60-63, citing extensive literature at nn 164 and 165.

[152] I Hertz-Picciotto et al. HIV Test-Seeking Before and After Restriction of Anonymous Testing in North Carolina. *American Journal of Public Health* 1996; 86(10): 1446-1450.

[153] Laryea & Gien, supra, note 81 at 254.

[154] RB Hays et al, supra, note 75 at 425.

[155] Ibid at 427-428; G Kadushin. Gay Men with AIDS and their Families of Origin: An Analysis of Social Support. *Health and Social Work* 1996; 21(2): 141-149, at 143, and the literature cited there; JM Simoni et al. Disclosing HIV Status and Sexual Orientation to Employers. *AIDS Care* 1997; 9(5): 589-599, at 591, and the literature cited there.

[156] Hays et al, supra, note 75 at 429-430.

[157] Kadushin, supra, note 155 at 143-144, and the literature cited there.

[158] Adam & Sears, supra, note 80 at 105.

[159] Ibid at 102-106.

[160] Ibid at 95.

[161] GM Powell-Cope, MA Brown. Going Public as an AIDS Family Caregiver. *Social Science and Medicine* 1992; 34(5): 571-580 at 575-576.

[162] Ibid.

[163] Supra, note 155.

[164] Pryor et al, supra, note 37.

[165] Adam & Sears, supra, note 80 at 125.

[166] Ibid.

[167] Ibid at 132-133.

[168] Jalbert, supra, note 81.

[169] Simoni et al, supra, note 155.

[170] Fisher et al, supra, note 5.

[171] LH Calabrese et al. Physicians' Attitudes, Beliefs, and Practices Regarding AIDS Health Care

Promotion. *Archives of Internal Medicine* 1991; 151(6): 1157-1169.

[172] B Tremble et al. Health Care and Social Service Needs of Gays, Lesbians, Bisexual and Transsexual Communities in Ontario. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Pub. D.1465.

[173] Eighty-nine percent of the physicians who responded in the study of Heath et al, supra, note 93, had provided care to gay or bisexual men.

[174] Kadushin, supra, note 155 at 144-145.

[175] Fisher et al, supra, note 5 at 90.

[176] Ibid.

[177] D Brady et al. Transgendered People, Discrimination, and HIV/AIDS. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(3): 6-7 at 6.

[178] As Brady et al, ibid, explain, transsexuals are people who are born with a core gender identity that is not congruent with their external genitalia. Some transsexual people choose hormone treatment and/or sex-reassignment surgery to bring their genitalia into line with their core gender identity. Cross-dressers are people who dress all the time as members of the opposite gender. Transvestites dress in clothes of the other gender usually in the context of erotic play. Drag queens are often performance artists. Transsexuals, cross-dressers, and transvestites may be gay or straight; drag queens are all gay men. The discussion that follows focuses primarily on transsexuals.

[179] Given the process required to change name and gender in official documents, transgendered people often carry identification that does not correspond to their gender identity and their chosen name.

[180] Brady et al, supra, note 177 at 7.

[181] This was reported in consultations for this *Discussion Paper*. See also JM Grimaldi, J Jacobs. HIV/AIDS Transgender Support Group: Improving Care Delivery and Creating a Community. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Tu.D.2953.

[182] MJ Bennett et al. An Ethnographic Study of HIV Infected Male-to-Female Transgendered Clients. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Tu.D.2954.

[183] Grimaldi & Jacobs, supra, note 181.

[184] Brady et al, supra, note 177.

[185] Grimaldi & Jacobs, supra, note 181.

[186] Brady et al, supra, note 177.

[187] See also the recommendations in Fisher et al, supra, note 5 at 56.

[188] This comment and those that follow are from minutes of meetings of drug users in Vancouver.

[189] Health Canada. *HIV/AIDS Epi Update: HIV/AIDS Among Injection Drug Users in Canada*. Ottawa, November 1997.

[190] Ibid.

[191] SA Strathdee et al. Needle Exchange Is Not Enough: Lessons from the Vancouver Injecting Drug Use Study. *AIDS* 1997; 11(8): F59-F65, at F61.

[192] R Parent et al. HIV Among IDUs: Second Surveillance Year of the Survidu Network. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 27A. Abstract no. 220.

[193] Health Canada. *HIV/AIDS Epi Update: Risk Behaviours Among Injection Drug Users in Canada*. Ottawa, November 1997.

[194] Ibid, with reference to Parent et al, supra, note 192.

[195] New South Wales Anti-Discrimination Board, supra, note 22 at 68.

[196] GM Herek, JP Capitanio. Public Reactions to AIDS in the United States: A Second Decade of Stigma. *American Journal of Public Health* 1993; 83(4): 574-577, at 575.

[197] Mitchell, supra, note 60 at 221-237.

[198] W Kornblum. Drug Legalization and the Minority Poor. In: R Bayer, GM Oppenheimer, eds. *Confronting Drug Policy: Illicit Drugs in a Free Society*. New York: Cambridge University Press, 1993, at 115-135.

[199] DB Kandel. The Social Demography of Drug Use. In: Bayer & Oppenheimer, supra, note 198, 24-79 at 63-67.

[200] Cruel and Unusual: Disproportionate Sentences for New York Drug Offenders. *Human Rights Watch* 1997; 9(2), from a summary posted on the Internet at http://www.hrw.org

[201] Health Canada, supra, note 189.

[202] Ibid.

[203] P Millson et al. Prevalence of Human Immunodeficiency Virus and Associated Risk Behaviour in Injection Drug Users in Toronto. *Canadian Journal of Public Health* 1995; 86(3): 176-180.

[204] Strathdee et al, supra, note 191 at F61-F63.

[205] E Oscapella. Criminal Law and Drugs. In: *Second National Workshop on HIV, Alcohol, and Other Drug Use Proceedings. Edmonton, Alberta. February 6-9, 1994.* Ottawa: Canadian Centre on Substance Abuse, 1994, at 38-40.

[206] For variations in provincial policies, professional practices, and professional views concerning dispensing syringes to injection drug users, see T Myers et al. The Role of Policy in Community Pharmacies' Response to Injection Drug Use: Results of a Nationwide Canadian Survey. *AIDS & Public Policy Journal* 1996; 11(2): 78-88.

[207] In Montréal, a policy of one-for-one exchange, intended to encourage multiple visits and binding to a multifaceted prevention program, was abandoned when it was discovered that frequent attenders of needle exchange services had a higher rate of seroconversion than non-attenders. See J Bruneau et al. High Rates of HIV Infection among Injection Drug Users Participating in Needle Exchange Programs in Montreal: Results of a Cohort Study. *American Journal of Epidemiology* 1997; 146(2): 994-1002 at 1001.

[208] Strathdee et al, supra, note 191 at F61-F63.

[209] Ibid at F63-64.

[210] Ibid at F64, citing EJC van Ameijden et al. Injecting Risk Behaviors among Drug Users in Amsterdam, 1986 to 1992, and Its Relationship to AIDS Prevention Programs. *American Journal of Public Health* 1994; 84: 275-281. See also Bruneau et al, supra, note 207 at 1001.

[211] *HIV, AIDS and Injection Drug Use: A National Action Plan.* May 1997, at 18-21.

[212] D McAmmond. *Care, Treatment and Support for Injection Drug Users Living with HIV/AIDS. A*

Consultation Report. March 1997, at 9-12

[213] Ibid at 9-15.

[214] Supra, note 211 at 22, noting, in this regard, that "[t]he Portland Hotel in downtown Vancouver is an excellent model of how adherence to drug therapies can be facilitated. 60% of residents are HIV positive. A nurse visits three times a day to ensure proper medication is distributed: needles are available at the front desk."

[215] These and other recommendations are included in the report of the Task Force on HIV, AIDS, and Injection Drug Use, supra, note 211 at 23.

[216] Section 25.

[217] *Entrop and Ontario Human Rights Commission v Imperial Oil Limited* (1997), Ontario Court of Justice, Court File No 597/96.

[218] Bill 142, 28 November 1997, Sched. B, section 5(2).

[219] Bill 142, June 12, 1997, Sched. B, section 4(2): "A person is not a person with a disability if the person's impairment is caused by the presence in the person's body of alcohol, a drug, or some other chemically active substance that the person has ingested, unless the alcohol, drug or other substance has been authorized by prescription as provided for in the regulations."

[220] Supra, note 218, Sched. B, section 5(3).

[221] Comment from minutes of a meeting of drug users in Vancouver.

[222] Supra, note 211 at 12.

[223] J Epp. Achieving Health for All: A Framework for Health Promotion. *Canadian Journal of Public Health* 1986; 77(6): 393-424 at 400.

[224] Comment from minutes of a meeting of drug users in Vancouver.

[225] Ibid.

[226] Ibid.

[227] Supra, note 211 at 18.

[228] Goldie et al, supra, note 65 at 75.

[229] *Healing Our Nations*, supra, note 68 at 68.

[230] S Matiation, supra, note 7 at 4.

[231] S Matiation, supra, note 6 at 5.

[232] Health Canada. *HIV/AIDS Epi Update: HIV/AIDS Epidemiology among Aboriginal People in Canada*. Ottawa, November 1997.

[233] Matiation, supra, note 6 at 3-4.

[234] Royal Commission on Aboriginal Peoples. *Report of the Royal Commission on Aboriginal Peoples.* Vol. 3: *Gathering Strength*. Ottawa: Minister of Supply and Services, 1996.

[235] Ibid at 54-86.

[236] Health Canada, supra, note 232.

[237] A McLeod. *Aboriginal Communities and HIV/AIDS. A Joint Project with the Canadian AIDS Society and the Canadian Aboriginal AIDS Network.* Ottawa: Canadian AIDS Society, 1997, at 10.

[238] *Healing Our Nations*, supra, note 68 at 22.

[239] Health Canada, supra, note 189.

[240] Royal Commission on Aboriginal Peoples, supra, note 234 at 108.

[241] Matiation, supra, note 231 at 6-7.

[242] Health Canada, supra, note 232.

[243] McLeod, supra, note 237 at 12.

[244] Matiation, supra, note 6 at 12-13.

[245] S Matiation. *HIV/AIDS and Aboriginal People: Problems of Jurisdiction and Funding. A Discussion*

Paper. Montréal: Canadian HIV/AIDS Legal Network, 1998, at 21.

[246] Canadian Aboriginal AIDS Network. *Report of the Aboriginal Consultation of the National AIDS Strategy Phase I-II*. September 22 - October 10, 1997. Ottawa: Canadian Aboriginal AIDS Network, 1997, at 12.

[247] Matiation, supra, note 6 at 29.

[248] Matiation, supra, note 7 at 23-27.

[249] Matiation, supra, note 6 at 5-6.

[250] Canadian Aboriginal AIDS Network, supra, note 246 at 21.

[251] Matiation, supra, note 6 at 6.

[252] Royal Commission on Aboriginal Peoples, supra, note 234 at 209-215.

[253] Ibid at 205.

[254] Ibid at 207.

[255] Matiation, supra, note 245.

[256] Ibid at 29-34.

[257] K Herland. Mobilisation/Intervention - What Have We Learned? - Commercial Sex Workers. In: C Hankins, L Hum, eds. *Women and HIV National Workshop*. Montréal, 13-14 March 1995. Montréal: McGill AIDS Centre, 1995, at 24.

[258] Ibid.

[259] Ibid.

[260] LA Jackson, A Highcrest. Female Prostitutes in North America: What Are Their Risks of HIV Infection? In Sherr et al, supra, note 74 at 149-162 (which presents information obtained through extensive discussions with current and former female prostitutes in major cities in Canada); S Day, H Ward. Sex Workers and the Control of Sexually Transmitted Disease. *Genitourinary Medicine* 1997; 73: 161-168.

[261] Jackson & Highcrest, supra, note 260 at 154-155; Day & Ward, supra, note 260 at 163. For a summary of seroprevalence studies among sex workers in Canada, see Division of HIV Epidemiology, Laboratory Centre for Disease Control, Health Canada. *Inventory of HIV Incidence and Prevalence Studies in Canada*. May 1997, at 31.

[262] Jackson & Highcrest, supra, note 260 at 152-154, 155-156; Day & Ward, supra, note 260 at 165.

[263] Jackson & Highcrest, supra, note 260 at 156-158.

[264] Jackson & Highcrest, supra, note 260 at 153-154.

[265] ML Miller et al. Characteristics of Male Sex Trade Workers Enrolled in a Prospective Study of HIV Incidence. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 8A. Abstract no. 101.

[266] WN Elwood et al. Powerlessness and HIV Prevention among People Who Trade Sex for Drugs. *AIDS Care* 1997; 9(3): 273-282 at 282.

[267] Jackson & Highcrest, supra, note 260 at 152.

[268] K Bastow. Prostitution and AIDS. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(2): 12-13 at 12.

[269] Jackson & Highcrest, supra, note 260 at 149.

[270] Day & Ward, supra, note 260 at 163-164; Elliott, supra, note 3 at 19.

[271] Elliott, supra, note 3 at 50, citing B Wolgemuth.

[272] Elliott, supra, note 3, Appendix B at 13-14. For an up-date, see R Elliott. Justice Delayed and Denied in Biting Case. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 44.

[273] Ibid at 73

[274] Ibid at 17.

[275] K Herland. Stella: Addressing Sex Workers' Risk for HIV/AIDS in Context. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Th.C.4640.

[276] Bastow, supra, note 268 at 13.

[277] Ibid.

[278] Day & Ward, supra, note 260 at 163.

[279] Ibid at 164.

[280] Ibid at 166; see also Bastow, supra, note 268 at 13, n 18.

[281] Ibid at 167.

HIV/AIDS and Discrimination: A Discussion Paper

by Theodore de Bruyn

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Note to browsers: For ease of loading, this long chapter has been divided into two different pages. When downloading or printing, keep in mind that each of the pages must be opened in order to access the entire chapter.

This page contains part 2 of Chapter 4, "The Experience of Specific Populations." Part 2 has five sections:

Prisoners

Current Epidemiology

It is difficult to provide a comprehensive picture of the HIV epidemic among prisoners in federal and provincial penitentiaries in Canada. There have been a number of studies of prisoners in particular institutions or in certain regions, but one must be cautious in generalizing from one institution or region to another. Nevertheless, the information that is available is cause for grave concern:

- In November 1996, the Correctional Service of Canada (CSC) reported that as of September 1996, 128 inmates out of 14,000 were known to be HIV-positive. This represented an increase of around 45 percent from the number of inmates who were known to be HIV-positive in April 1994.[282]

- CSC estimates that the prevalence of HIV infection among federal inmates is 10 times higher than that in the general population.[283]

- Two comprehensive studies of inmates entering provincial prisons found an HIV prevalence of about one percent.[284] At the time, HIV prevalence in the general population was estimated to be 0.15 percent.

- Studies conducted in various prisons between 1988 and 1994 found HIV prevalence ranging from a low of zero percent (among young offenders) to a high of 9.8 percent (among women inmates).[285] The prevalence of HIV infection is considerably higher among inmates with a history of injection drug use, ranging from zero percent (among young offenders) to 16.5 percent (among women inmates).[286]

- A 1995 survey of 4285 male inmates in federal penitentiaries found that 11 percent reported having injected drugs since coming to their current institution, 6 percent reported having had sex with another inmate since coming to their current institution, 45 percent reported having had a tattoo done in prison, and 17 percent reported having had their skin pierced in prison.[287] Of those who had injected since coming to their institution, 17 percent reported that the equipment they used was not clean, and 27 percent did not know if the equipment was clean.[288] Of those who had had sex since coming to their institution, 67 percent had not used a condom.[289]

- A 1995 survey of 39 randomly selected inmates in provincial and federal institutions in Ontario found that 28 percent (11 of 39) reported injecting in prison since 1985 and that 5 percent (2 of 39) reported injecting in prison during the past year. Nearly one-quarter of those who had ever injected drugs said that they first injected in prison.[290] When asked about sexual activity in the past year, almost three-quarters reported engaging in sexual activity. Of these, 47 percent reported anal and/or vaginal intercourse, and none reported using a condom.[291]

- HIV infection among injection drug users attending a needle exchange program in Québec City has been associated with a history of incarceration,[292] and HIV infection among male inmates at the Québec Detention Centre has been associated with having injected during incarceration.[293]

Patterns of Stigma and Discrimination

Prisoners are affected not only by stigma and discrimination related to HIV/AIDS, same-sex sexual activity, and drug use, but also by stigma and discrimination related to a criminal record and incarceration, and as well by discrimination based on gender, class, and race.

Societal Attitudes

With regard to attitudes toward prisoners at the societal level, the emphasis is often on protecting the public from prisoners to the exclusion of concern about the rights and well-being of prisoners. Such attitudes may be expressed most crudely in sentiments about "locking them up and throwing away the key." They may be reflected in opinions that prisoners are receiving too many benefits and too few penalties. They can be implicit in discussion of problems with the correctional system that place most or all of the blame on the prisoner, without considering the relationship between prisoners and the correctional system or between the correctional system and society.

Attitudes of this sort have an impact on the lives of prisoners. Politicians are hesitant to initiate controversial programs such as needle exchange in prisons, despite their potential to protect prisoners from HIV infection, because the public could react negatively both to supplying prisoners with equipment to inject drugs and to the admission that drugs are available in prisons. Prison administrations and prison staff may view all aspects of inmates' lives through the lens of safety and security, without giving due consideration to such things as inmates' right to confidentiality of medical information or right to health and health care.

Programmatic Discrimination

At the programmatic level, prisoners are discriminated against whenever they are denied a standard of public health and health care comparable to that available in the community. The *World Health Organization Guidelines on HIV Infection and AIDS in Prison*, revised in 1993,[294] state that:

> - all prisoners have the right to receive health care, including preventive measures, equivalent to that available in the community without discrimination, in particular with respect to their legal status or nationality;
>
> - preventive measures for HIV/AIDS in prisons should be complementary and compatible with those in the community, and should be based on risk behaviours actually occurring in prisons, notably needle sharing among injecting drug users and unprotected sexual intercourse;
>
> - prison administrations have a responsibility to define and put in place policies and practices that will create a safer environment and diminish the risk of transmission of HIV to prisoners and staff alike.[295]

Failure to provide accessible HIV testing, to protect the confidentiality of prisoners with HIV/AIDS, to provide a standard of HIV/AIDS care equal to that in the community, to provide a range of drug treatment programs comparable to those available in the community, to introduce measures that reduce the harms of injecting drugs (such as provision of bleach and sterile syringes), to make condoms and dental dams easily and discreetly available to prisoners, to provide education and information about HIV/AIDS, safer sex, and ways to reduce the harms of drug use - failure in undertaking any of these programs would constitute discrimination in terms of the WHO *Guidelines*. In Canada, this has been emphasized in both the 1994 Report of the Expert Committee on AIDS and Prisons (ECAP Report)[296] and in the 1996 *Final Report* prepared as part of the HIV/AIDS Legal Network and the Canadian AIDS Society Joint Project on Legal and Ethical Issues Raised by HIV/AIDS (*Final Report*).[297] There are numerous examples of failures of this kind in Canada (discussed below, in the section on the impact of stigma and discrimination).

Personal Attitudes

At the personal level, attitudes about HIV/AIDS, about same-sex sexual activity, and about drug use can affect relations among prisoners as well as between prisoners and staff. A recent study of inmates in federal and provincial institutions in Ontario found that, for a third of the respondents, one of the strategies they use to protect themselves from HIV infection in prison is to avoid or scare off people with HIV/AIDS, or to avoid sharing food or utensils.[298] The study also found that fear of being labeled gay by fellow inmates prevents men from asking for or picking up condoms.[299] It is reported that inmates in a same-sex relationship often face the biggest barriers to accessing condoms or dental dams, because they are afraid that they will be discovered and separated in the institution.[300]

In prison, the stigmas associated with HIV/AIDS are compounded by confinement. For example, one inmate with HIV/AIDS, who was housed in the general population but whose HIV status was not known to others, decided not to access the canteen. It is customary to share food that is purchased there; otherwise one is accused of hoarding. This inmate feared that if he shared food and his HIV status later became known, there would be negative repercussions from other inmates because of their fears about getting HIV/AIDS, even if such fears had no basis in fact. On the other hand, if he did not share food, he would be accused of hoarding. Hence his decision simply to avoid the canteen.[301]

Impact of Stigma and Discrimination

Vulnerability to Infection

> Preventive measures for HIV/AIDS in prison should be complementary to and compatible with those in the community. Preventive measures should also be based on risk behaviours actually occurring in prison, notably needle sharing among injection drug users and unprotected sexual intercourse.[302]

The potential for prisoners to protect themselves from HIV infection is determined not only by their own attitudes and behaviours, but also by the availability of protective measures and the support that is provided for using those measures effectively. Currently, only certain protective measures - information, condoms, and bleach for sterilizing injecting and tattooing equipment - are available in Canadian federal prisons and in most but not all provincial prisons. Sterile needles and syringes and sterile tattooing and piercing equipment are not available. Methadone maintenance programs, which reduce the need to inject illicit drugs among those dependent on heroin, are available in some provincial prisons, particularly in British Columbia, and in federal institutions to prisoners who received methadone prior to entering prison, but are not yet offered to inmates who wish to begin treatment in prison.[303] All of these means of preventing HIV infection are available in the community.

The 1995 survey of male inmates in federal institutions found that 46 percent thought that inmates are in more danger of contracting HIV in prison than in the community,[304] and that 36 percent felt that they needed more help to protect themselves against HIV/AIDS in their institution.[305] When asked what help they needed, 58 percent said more information, 32 percent said anonymous testing, 14 percent said condoms, 34 percent said bleach for sterilizing needles, 35 percent said bleach for sterilizing tattooing equipment, 30 percent said sterile needles and syringes, and 32 percent said sterile tattooing equipment. These percentages tended to be higher in maximum-security institutions.[306]

Failure to provide the tools *and* create the environment in which those tools can be used safely and effectively places inmates at greater risk of HIV infection. Studies in Canada and elsewhere have found that, while injection drug users inject less frequently in prison than in the community,[307] the rate at which they share injecting equipment is far higher in prison than in the community and the methods they use to clean their equipment are often inadequate.[307] The 1995 survey of male inmates in federal institutions found that, when asked what inmates typically use to clean their needles or works, respondents thought that 23 percent often or always used cold water, 50 percent often or always used bleach, 22 percent often or always used alcohol, and 30 percent often or always used other methods.[309] Often the circumstances in which drugs are injected in prison militate against effective cleaning: inmates speak of urgency, secrecy, fear of being caught, the desire to get high at all costs, being too high to clean or care, being unprepared to clean their equipment, as barriers to safe injecting.[310] As one inmate remarked:

> If they got the drugs and there is only one fit ... they are going to use that fit because they got the dope. And, they don't care who's going to use it after that. And who says after doing that one they are going to care about washing it or cleaning it.[311]

Similarly, in regard to the use of condoms when having sex, the 1995 survey of male inmates in federal institutions found that 90 percent of inmates thought that 8 percent or less of the population used condoms when having sex.[312] Only 33 percent of those who had had sex reported that they had used a condom.[313] The reasons for this are numerous, but include fear of being labeled gay or being suspected of transporting contraband:[314]

> "Guys are not gonna ask for condoms for sex in their cells because they don't want a guard

> or anybody to know that they engage in gay or homosexual sex."[315]
>
> "The other thing of requesting condoms is that if they don't know you're engaging in homosexual sex, their immediate thought is, 'Okay, you're using it to transport drugs.'"[316]

Clearly, failure to make condoms *easily and discreetly* accessible compounds these fears and contributes to lack of protection in sexual activity among inmates:

> That there is access to condoms within the prison gives us some consolation, however, it is situated in plain view of the nursing staff, or whoever else might be on the other side of the one way glass. Anyone wanting the condoms must then worry about being seen by staff, and may opt not to use the protection in fear of being discriminated against.[317]

Experience and research in the community has shown that no single prevention measure - condoms, bleach, sterile injecting equipment, methadone - is in and of itself sufficient to prevent the transmission of HIV or to reduce the harms of drug use.[318] What is required is an integrated set of tools and programs, adapted to the structure of prison life and to prison culture, that not only provide the means to protect oneself, but also a safe and supportive environment in which to use those means. Programs that combine, for example, bleach distribution with peer inmate education and staff education have been successful in Canada.[319] Similarly, inmate and staff education have been integral to the success of syringe exchange programs in prisons in Europe.[320] The wider context of inmates' lives is also important, as researchers found in discussions with inmates in federal and provincial institutions in Ontario:

> When asked about what they felt could be done to reduce injection drug use inside prison, inmates suggested more access to drug programs, access to more effective programs, access to more work and/or recreational programs, more connection with the outside, and increased self-esteem."[321]

The recommendations of the 1996 *Final Report* provide direction on how to remove the disadvantages that prisoners confront in protecting themselves from HIV infection and preventing the transmission of HIV, so that, as the WHO *Guidelines* state, preventive measures for HIV/AIDS in Canadian prisons are complementary to and compatible with those in the community.

Breach of Confidentiality

> Information on the health status and medical treatment of prisoners is confidential and should be recorded in files available only to health personnel.[322]

> Information regarding HIV status may only be disclosed to prison managers if the health personnel consider, with due regard to medical ethics, that this is warranted to ensure the safety and well-being of prisoners and staff, applying to disclosure the same principles as those generally applied in the community.[323]

As the ECAP Report states, "[d]irectives of the Commissioner of the Correctional Service of Canada expressly state that offenders have the same rights to confidentiality of information obtained by a health-care professional as exist in the general community."[324] However, as the Report observes,

> Little goes on in prisons that is not almost immediately known by almost all inmates and staff, and it has been said that when an HIV-positive person is in prison, her or his health status is usually circulated among both correctional officers and inmates.[325]

The Report recommended that "procedures be reviewed in every federal correctional institution to ensure that the confidentiality of medical information is protected, in particular information regarding the HIV status of inmates."[326]

In evaluating CSC's response on this issue, the 1996 *Final Report* found that "many prison officials and staff continue to insist on a 'need to know' the HIV status of prisoners."[327] This information can easily become widely known. There have been reports, for example, that in provincial prisons photographs of inmates in staff offices on the range have been marked by red dots or by the note "use universal precautions," effectively disclosing HIV status to inmates as well as staff.

Disclosure of HIV status has significant consequences for inmates within the confines of prison. Some prisoners with HIV/AIDS choose to enter into protective custody; others remain in the general population. Reasons for choosing protective custody include not only stigma, discrimination, and risks to safety due to HIV status, but also other stigma, discrimination, and risks to safety for other reasons, such as being identified as transgendered or as gay.[328] Peer-based outreach, education, and support programs, incorporating face-to-face encounters with people with HIV/AIDS, are essential to creating a more supportive and accepting environment for prisoners with HIV/AIDS.[329]

In order to prevent unwarranted disclosure of HIV status, federal and provincial institutions should adopt the recommendations of the 1996 *Final Report* on confidentiality and disclosure of medical information, which call for clear definition of the circumstances under which HIV status may be disclosed, for model procedures to protect the confidentiality of medical information, and for education of staff on issues pertaining to HIV testing and confidentiality, including confidentiality of medical information, the absence of a "need to know" prisoners' HIV status, and the risk or absence of risk of transmission of HIV.[330]

Substandard Medical Care

> At each stage of HIV-related illness, prisoners should receive appropriate medical and psychosocial treatment equivalent to that given to other members of the community.[331]
>
> Prisoners should have access to information on treatment options and the same right to refuse treatment as exists in the community.[332]
>
> Prisoners should have the same access as people living in the community to clinical trials of treatments for all HIV/AIDS-related diseases.[333]
>
> Prison medical services should collaborate with community health services to ensure medical and psychological follow-up of HIV-infected prisoners after their release if they so consent.[334]

Under the *Corrections and Conditional Release Act*, CSC is under an obligation to provide every inmate with "essential health care that conforms to professionally accepted standards."[335] However, as Sébastien Brousseau of the Office des droit des détenu(e)s du Québec observed in his testimony before the Parliamentary Sub-Committee on HIV/AIDS:

> In penitentiaries, the administrative authorities have broad discretionary powers to decide what is essential or not. Too often, essential care is defined as minimum care. The absence of exclusive and detailed legislative provisions on health care in penal institutions, accompanied by broad administrative authority, leaves the door open to abuse. Considering that Correctional Services of Canada discharges its obligation by providing only essential health care, we believe discrimination does exist since the general population can obtain much more than essential care in any hospital or neighbourhood clinic. While in prison, people with AIDS have difficulty gaining access to specialized care and experimental treatment. They have trouble seeing a doctor on a frequent and regular basis.[336]

The 1996 *Final Report* states:

> Most prison health-care services do their best to provide inmates living with HIV or AIDS with optimal care, and often inmates are referred to outside specialists for HIV-specific diagnosis and treatments. However, on some occasions, the Project has heard from inmates that they were receiving care and treatment of significantly lower quality than that received before coming to prison, or before being referred to the particular institution at which they were currently staying.[337]

It also raises a number of specific concerns about the care of prisoners with HIV/AIDS:

> (1) the increase in the number of sick inmates - prisons are not equipped to deal with inmates who require long-term, ongoing care and treatment; (2) the difficulty of obtaining narcotics routinely given for pain relief to patients on the outside - in prison, these narcotics are often denied even to those in severe pain; and (3) the difficulty of accessing investigational drugs or non-conventional therapies, although in its response to ECAP's *Final Report* CSC promised to facilitate inmates' access to specialized or experimental treatments.[338]

These concerns were reiterated in consultations for this *Discussion Paper*.[339] If anything, the emergence of combinations of antiretroviral therapies as the standard of care has exacerbated the difference in treatment available to inmates compared to treatment available in the community. The regime that is stipulated for a particular combination of drugs - ingestion at specific intervals, with or without food - is not followed in prison, because it does not fit in with the prison routine. Prisoners routinely miss medications when they go to court, when they are transferred, or when they are released; contingency plans that are customary to ensure that inmates with tuberculosis or diabetes receive their medication are, apparently, not made for prisoners with HIV/AIDS. Given the need to adhere closely to drug regimens in order to avoid the development of drug resistance, these failures are cause for serious concern.

There are also continuing reports that prisoners with HIV/AIDS do not receive adequate medication for pain.[340] Prisoners with HIV/AIDS have been summarily cut off from pain medication, without due process, on the grounds that they were hoarding drugs. The problems are compounded by attitudes toward drug users. Drug users typically require higher dosages of pain relief than non-users because of the tolerance that drug users develop to narcotics. Inmates requesting higher dosages of pain medication may be perceived as wanting to "get high" in prison. In the absence of pain medication, inmates may resort to illicit drugs to manage their pain.

Many of these failings were brought to light in a recent inquest into the care and treatment of Billy Bell, an inmate who died of AIDS-related causes at the Regional Hospital Unit of Kingston Penitentiary. At the inquest into Billy Bell's death,

> a specialist from the HIV clinic at the Kingston General Hospital, Dr Sally Ford, testified about how the prison failed to provide Billy the quality care that her patients outside the prison receive. The prison pharmacy would run out of doses of AZT and Billy would miss his dose days at a time. Billy experienced difficulty accessing proper pain management medication, lack of compassion from staff, and dangerous delays in the diagnosis of AIDS-related illnesses. It was a chaplain, not the prison health staff, who suggested that his chronic migraine headaches might be caused by the deadly meningitis.[341]

In addition, when Billy Bell was released to a halfway house in Toronto, six months before his death, no arrangements were made for his medical care. After hearing the evidence at the inquest, the coroner's jury recommended, among other things,

> - that CSC "review and upgrade their palliative care approach" to meet "the principles and practices developed by the Canadian Palliative Care Association";
>
> - that pain management be available to prisoners; and
>
> - that proper pre-release planning be done.[342]

Again, the recommendations of the 1996 *Final Report* regarding the health care of prisoners with HIV/AIDS set out directions that would eliminate discrimination of this sort.

Failure in Palliative Care and Compassionate Release

> If compatible with considerations of security and judicial procedures, prisoners with advanced AIDS should be granted compassionate early release, as far as possible, in order to facilitate contact with their families and friends and to allow them to face death with dignity and in freedom.[343]

The degrading way in which several prisoners with HIV/AIDS have died in Canadian penitentiaries exposes how societal attitudes, combined with programmatic failures, can result in a reprehensible violation of human dignity. On 30 January 1995, Pierre Gravel was found dead in a bathtub in a federal correctional facility in Montréal. A few days earlier he had been denied parole on humanitarian grounds because the National Parole Board believed that the security risk was too high.[344] On 15 May 1996, Billy Bell died alone in his cell in the Regional Hospital Unit of the Kingston Penitentiary. A report on his death states:

> Billy was terrified at the prospect of dying in prison. Despite his expressed wish that he not be left to die alone, and assurances to his family that the prison would contact them so that they could be by his side, Billy died alone in his cell. The circumstances so outraged one of the prison chaplains that he left a note on a colleague's door, stating "Billy Bell died tonight, like a dog in a back kennel." Another prison chaplain resigned over the treatment Billy received.[345]

Like Pierre Gravel, Billy Bell had recently been denied parole. The fact that both these inmates were refused parole so shortly before their death, coupled with the degrading way in which they died, calls into question the credibility of CSC's acceptance of the recommendation of the ECAP Report regarding the early release of inmates with progressive life-threatening diseases, including AIDS.[346] Part of the difficulty is the weight given to security concerns - undue weight, in the judgement of external observers of decisions to date[347] - in the National Parole Board's hearings of requests for parole on humanitarian grounds.

In evaluating CSC's record on compassionate release, the 1996 *Final Report* notes that ECAP's recommendation has been unevenly implemented, and comments:

> Such examples of uneven implementation have been deplored not only by prisoners, but also by health-care staff, who have complained that CSC is not enforcing its own rules. It has been suggested that CSC release clear guidelines and enforceable national standards and that prison administrations be held accountable for their timely and consistent implementation.[348]

Likewise, at the inquest into Billy Bell's death, the attorney acting on behalf of Prisoners with HIV/AIDS Support Action Network suggested that "CSC implement a real compassionate release process, including criteria and application and appeal processes," and, further, "that compassionate release decisions be taken out of the hands of the National Parole Board [and] be heard by tribunals combining representation from medical experts, community members, and the [National Parole Board]."[349] After hearing the evidence, the coroner's jury recommended that "CSC revise its Compassionate Release Program ... to increase the influence of the palliative care team in the Parole Board's decision-making process."[350]

Women

> It's really hard having to go over my story with doctors, dentists, optometrists, gynecologists, therapists, emergency rooms, each nurse that comes on shift if you're in the hospital. Each one will ask: "How did you get it?" I usually respond: "Does it matter? I have it. That's all that's necessary for you to know." They always look at you sideways, or nonchalant, never straight in the eye. Be up-front with me. There should be no discrimination based on how you got it.[351]
>
> I felt dirty, I felt I was toxic and I deserved it. I still feel poisonous.[352]
>
> With the amount of money I'm given for food, I'm not able to adequately feed three children and myself without some sacrifice of nutrition, usually for myself. And I'm given $20 a month for my nutritional needs and to supplement with vitamins costs $75 a month.[353]

Current Epidemiology

Health Canada reports that "Canadian women are increasingly becoming infected with HIV, especially those who use injection drugs and whose sexual partners are at increased risk for HIV."[354]

> • The proportion of AIDS cases among women has increased from 6.2 percent of all AIDS cases before 1990 to 6.9 percent during 1990-95 and 10.6 percent in 1996.
>
> • The proportion of AIDS cases among women attributed to injection drug use has increased dramatically from 6.5 percent before 1990 to 19.5 percent during 1990-95 and 25 percent in 1996.
>
> • It is estimated that by the end of 1996, 4000 to 5000 women in Canada were living with HIV, out of an estimated total of 32,000 to 42,000 people with HIV.
>
> • Women accounted for 19 percent of all HIV-positive test reports in 1995 that included information on gender. Injection drug use was a risk factor for 20 percent of these HIV-positive women.
>
> • HIV prevalence studies among pregnant women in Canada indicate an average rate of HIV infection of about 3-4 per 10,000 women.

Stigma and Discrimination in the Context of the HIV/AIDS Epidemic

Vulnerability to Infection

Women are, in general, more vulnerable to HIV infection than men in heterosexual relations.[355] The reasons for this are not only biological and epidemiological, but also socioeconomic, related to inequalities in the position and power of women and men. A woman's safety in sexual relations may be compromised by, for example, the norms that men (and her partner in particular) have about using condoms, the potential for violence or abuse in the relationship, and the extent to which the woman depends economically or socially on her partner. As Travers and Bennett observe:

> Research indicates that men, and to a lesser extent women, generally have negative perceptions about condom use, and the negotiation of safe sex practices with male partners, particularly the use of condoms, is difficult for many women. A major reason for this difficulty is that women require the cooperation of men, and inequalities of power where one member is in a subordinate role compromise the negotiation process.[356]

Violence against women in our society contributes to risk of HIV infection among women. A 1984 study of child sexual abuse in Canada found that 53 percent of females and 31 percent of males had been victims of unwanted sexual acts and that 80 percent of these incidents occurred when they were children or adolescents.[357] One half of Canadian women over the age of 16 report violence at the hand of an intimate partner.[358] This has serious implications for women's risk of HIV infection. A history of sexual assault is associated with numerous behaviours that place women at greater risk of HIV infection;[359] a recent study among HIV-positive women in British Columbia found that 45 percent had experienced sexual abuse as a child.[360] Fear of violence will prevent women from negotiating safer sex with their partners. The effects of abuse - poor self-esteem, shame, isolation, fear of being abandoned - also keep women from seeking information and support about HIV prevention.[361]

HIV Testing, Counselling, and Diagnosis

There are a number of ways in which practices of HIV testing and counselling among women are, on the one hand, influenced by stigma and discrimination or, on the other hand, fail to take stigma and discrimination into account. Women are adversely affected, first of all, by perceptions that *only* men who have sex with men, drug users, and sex workers are at risk of HIV infection. Such perceptions have prevented women from seeking HIV testing.[362] They have also led physicians not to offer HIV testing and counselling to women whom they do not perceive to be at risk for HIV infection.[363] This was a common complaint in the consultations for this *Discussion Paper*. The outcome for women is serious. Bias due to perceptions of risk, along with failure to recognize symptoms of HIV disease in women, can result in delayed diagnosis and delayed treatment for women.[364] On the other hand, when women seek HIV testing, they are often required to answer questions about drug use and sexual activity *before* they are given access to a test. Women find these inquiries stigmatizing and difficult to challenge, given differences in power and (frequently) gender between the woman and her health-care provider.[365]

Second, testing and counselling practices among women have been influenced by discrimination based on race and ethnic origin. A study of HIV testing experiences among women in Montréal found that 11 percent of the women were tested without their knowledge, and that a higher proportion of these women were of Haitian or African origin.[366] As Hankins comments:

> In a country where HIV testing is to be performed only under conditions of informed consent following a pre-test counselling session, the high proportion of women, and in particular of women of Haitian or African origin, tested without their knowledge must be considered alarming. Physicians and HIV testing services need to be reminded of the national guidelines against testing without consent and of the importance of obtaining fully informed consent.[367]

Third, testing and counselling among women has been closely associated with prenatal care. The issues of HIV infection, pregnancy, and preventing HIV transmission to the child are important to women, and, given the benefits of early detection for both the woman and her child, it should be standard practice to offer HIV testing to pregnant women.[368] Nevertheless, to associate HIV testing only or primarily with prenatal care is discriminatory. It precludes the provision of HIV testing, diagnosis and care to women who are not considering or seeking to have a child, and ignores the value of HIV testing for a woman in her own right, apart from her decision to have a child.

Finally, the concern to prevent transmission of HIV from mother to child has led to policies or practices that depart from the norm of informed consent for HIV testing and autonomy in decisions about having a child. Various approaches have been taken in North America to HIV testing among pregnant women: counselling all pregnant women about HIV and offering them an HIV test (routine offer of testing); including HIV testing in the list of routine prenatal laboratory tests, with the proviso that the women may choose not to have the test (routine testing); and mandatory testing.[369] A recent review of these approaches concluded:

> Routine or mandatory testing is not justified. It is not the "least restrictive, least invasive, likely to be effective, reasonably available approach" because there is reason to believe that the vast majority of pregnant women will willingly undergo an HIV test when the risks and advantages of seeking such a test are fully explained to them: when properly informed and supported in their decision-making, pregnant women will do what is best for themselves and their babies without coercion. In addition, testing alone is not effective in achieving the goal of reduced HIV transmission from mother to child, and treatment cannot and should never be coerced. Any mandatory intervention, including testing and mandatory treatment, would enormously interfere with the autonomy rights of the child.[370]

It is important to recognize the potential implications that a positive result may have for a woman, both if she is pregnant and if she is not, and to give these implications due consideration in pre- and post-test counselling and support.[371] There is a risk that a woman may be rejected, abandoned, or assaulted by her partner when she discloses her HIV status.[372] These problems are compounded if her partner is her main source of income and support. Whether or not her partner is supportive, a woman and her partner face decisions about having a child. There are reports that women have been discouraged from having children, counselled to abort their child, and even sterilized - evidence of the risk of inappropriate and coercive interventions that are prejudicial to a woman's right to autonomy and informed choice.[373] And if the woman already has children, there are all the considerations about the impact of the HIV diagnosis on her children.[374]

Research and Information on HIV Disease in Women

Historically, there has been a lack of research on HIV disease in women. An analysis of the literature on HIV/AIDS listed on Medline reveals that publications on women made up only 4.1 percent of the literature from 1985 to 1990 and 7.5 percent of the literature from 1990 to 1995.[375] Sherr eloquently summarizes the injustice of this systemic discrimination:

> Despite the fact that women have been infected from the start of the epidemic, the move to focus on women, include them in studies, consider treatment trials and even to track the natural history of HIV in women occurred late in the day. The inclusion of female-specific manifestations of HIV disease has also only recently been considered in the arena of AIDS-defining illness. This may have led to devastating effects on rights and financial support entitlements of women compared with men.[376]

In addition, there was a disproportionate emphasis on pregnancy in some of the earliest research on women.[377] As a result, there are gaps in our understanding of the determinants of risk and infection among women, the manifestation and treatment of HIV disease in women, and the psychosocial and socioeconomic dimensions of prevention, care, treatment, and support among women with HIV/AIDS.[378]

Research specific to women in Canada is beginning to address these gaps, but barriers to research among women persist. Research protocols may not specifically require sufficient numbers of women to achieve statistical significance. Clinical trials may automatically exclude women who are pregnant or of child-bearing age without offering the woman and her physician an opportunity to deliberate on the potential risks of participating and come to a decision that respects the principles of non-maleficence, beneficence, and justice in clinical research. Research programs often do not accommodate the needs of women who are caregivers or on low income: visits are scheduled at times at which women cannot participate, no provision is made for child care, and transportation is not provided.

As the draft Tri-Council *Code of Ethical Conduct for Research Involving Humans* observes:

> While some research is properly focused on particular populations that do not include or only include a very few women, in most studies women should be represented in proportion to their presence in the population affected by the research. In designing and implementing research projects, particular attention also should be paid to the need to include women of colour, women who are members of cultural or religious minorities, and women who are socially or otherwise disadvantaged.[379]

Achieving this goal will require addressing, in an intentional way, the barriers that prevent women from participating in research, including such practical concerns as scheduling, child care, transportation, and payment. Not to address those barriers in effect discriminates against many women who would otherwise benefit from participation in HIV/AIDS research.

Psychosocial and Socioeconomic Needs of Women with HIV/AIDS

A woman's experience of HIV disease is affected by her roles at home, at work, or in the community. Women in Canada generally earn less than men, are less likely to be in a position of power than men, enjoy fewer career opportunities than men, and receive fewer employment benefits than men.[380] Women are less likely to be employed than men, and more likely to be working part-time.[381] Men are more likely than women to have access to employee benefits, specifically disability insurance, medical benefits, and dental benefits.[382] Women are twice as likely as men to describe their main activity as caring for a family and working, and half as likely to describe it as simply working for pay or profit.[383] Eighty-five percent of single-parent families are headed by women.[384] Women are more likely than men to have given informal care to family and friends and to have received informal care from family and friends. The chances that women had provided care increases as their income increases, whereas it does not for men.[385]

Given these patterns and inequalities in the roles and incomes of women and men, it is not surprising that the psychosocial and socioeconomic dimensions of HIV disease are different for women than men. Research has found that women experience more social support than men, but that at the same time they feel more stigma associated with HIV disease than men.[386] It has been suggested that this is partly due to frequent associations of HIV infection among women with drug use and promiscuity, and partly due to women's closer contact with family and friends in their caregiving roles, which makes them more vulnerable to stigmatizing behaviour.[387] Analyses of data gathered in the preparation of *Ending the Isolation*[388] found that "women reported higher distress than men in terms of being discriminated against, feelings of isolation, anger, depression, self-blame and guilt, fear of dying and rejection by family or friends."[389] More recent studies report similar findings.[390]

Women's role as caregivers and their overall lower income have a significant impact on their own care as people with HIV/AIDS. It has been found that women with HIV/AIDS "will usually place their health last after their children, spouse, and parents," and that women "are perceived as being able to take care of themselves and their families without other support."[391] Many women with HIV/AIDS have pressing financial needs, and the pressures are greater for women who are caring for children as well as themselves. In Montréal, for example, it was found that 63 percent of women involved in a needs assessment required some financial assistance; the percentage was highest among women of Haitian or African origin, who represented by far the majority of women with children.[392] In a recent survey of women with HIV/AIDS in British Columbia, 53 percent of the women were mothers, and 51 percent reported an average household income of less than $20,000.[393] It is reported that women with low incomes and children are forced to choose between their HIV-related needs - drug treatments, nutritional supplements and complementary therapies - and the needs of their children, particularly at the end of the payment period for social assistance.[394] In addition to financial assistance, support may be required for child care, housekeeping, and transportation. Failure to provide for these needs - financial and otherwise - in a way that takes sufficient account of women's roles as caregivers and their overall lower income in effect means that many women with HIV/AIDS do not have equal access to care and treatment.

Barriers to HIV Prevention and Care among Lesbians

As the *Final Report* on gay and lesbian legal issues and HIV/AIDS observes, "[d]iscriminatory attitudes, ignorance about homosexuality, a pathologizing approach to homosexual orientation, and the assumption that patients as a whole are heterosexual lead gay men and lesbians to use health services less or to fear using them."[395] Commenting on lesbians in particular, Ramsay has said,

> many lesbian health problems are the same as those of heterosexual women, our experience with the health care system is radically different. ... For the most part, lesbians must deal with health professionals who know very little about us and the realities of our lives, and who can be quite open about their contempt for us. This makes us feel powerless and vulnerable. ... The result is that many of us do not seek health care when we need it because we are afraid of being ignored, isolated, or abused.[396]

There is evidence that lesbians do not receive the information and care that they require in the context of the HIV/AIDS epidemic. An Australian study of the experiences of women with HIV/AIDS found, for example, that "a few of the lesbians interviewed indicated that their doctors were trying to convince them to 'admit' that they had unprotected sex with men, had worked as a sex worker or had shared needles."[397] AIDS workers in Canada report that they receive calls from lesbians who believe that they are not at risk of HIV infection because they do not have sex with men. Research indicates that lesbians may be at risk of HIV infection from a range of behaviours, including sexual activity with women as well as men.[398] Alienation from the health care system, coupled with misinformation among health-care providers, does little to reduce the vulnerability of lesbians to such risks.

Heterosexual Men

Current Epidemiology

Although the data on HIV infection among heterosexual men are limited, they suggest that heterosexual men continue to be at risk of HIV infection.[399] Health Canada reports:

> • As of 30 June 1997, there were 913 reported cases of AIDS among adult men in which HIV was thought to have been transmitted by heterosexual contact. Of these, 460 cases were among men originating from a country where the predominant means of transmission is heterosexual contact, and 453 cases were attributed to sexual contact with a person who is HIV-positive or at increased risk of HIV infection.[400]

> • Between 1 November 1985 and 31 December 1994, there were 629 positive test reports in Canada among men originating from a country where the predominant means of transmission is heterosexual contact or among men whose exposure was attributed to sexual contact with a person who is HIV-positive or at increased of HIV infection.[401] However, positive test results do not provide information about HIV infection among people who have not been tested,[402] and it can be assumed that many heterosexual men have not been tested for HIV.
>
> • A 1997 survey found that among adults aged 20 to 45, 8.4 percent of men reported having two or more sexual partners within the previous year. The survey also found that among men who reported having one or more non-regular partners in the last year, 27.7 percent did not use a condom the last time they had sexual intercourse with a non-regular partner.[403]

Stigma and Discrimination in the Context of the HIV/AIDS Epidemic

In the consultations for this *Discussion Paper*, two concerns emerged regarding stigma and discrimination as it relates to heterosexual men, beyond the common concerns that affect all people with HIV/AIDS. The first relates to HIV prevention, testing, diagnosis, and treatment among heterosexual men. The association of HIV/AIDS with "risk groups" has made heterosexual men, like others who are not readily identified with HIV/AIDS, invisible in the HIV epidemic. This can result in failure among health-care providers to recognize HIV-related symptoms among heterosexual men or offer HIV testing to heterosexual men, as discussed above.[404] The result is delayed diagnosis and treatment. Prevailing attitudes that associate HIV/AIDS with "risk groups" can also lead heterosexual men to believe that they are not at risk of HIV infection, so that they do not take precautions that will prevent the transmission of HIV. And it contributes to an absence of prevention efforts among heterosexual men as well as difficulties in getting their attention. In short, a large portion of the population is neglected. This neglect has implications for the health not only of heterosexual men but also of their female partners. To take one example - prenatal care - one commentator observes:

> Much of the attention is focused on the woman, with scant attention paid to her partner who may be infected, may possibly be the source of her infection, and who also has a key role to play in future planning for the baby. Fathers are so overlooked in the HIV area that they are rarely consulted, tested simultaneously or involved in any safe sex dialogue. This is an enormous shortcoming given that male to female transmission is more probable than female to male, and given that social support and the family nature of HIV infection are fundamental elements in coping with, and adjustment to, this life-threatening condition.[405]

A second concern raised by some heterosexual men relates to their visitation and custody rights in child custody disputes. In one case, a man reported that his spouse was claiming sole custody rights, on the grounds that he was unfit as a parent because of his HIV status. It was argued that at some point in the future he would be incapable of being a "proper parent" because of his illness - an argument that one would scarcely make with regard to children who are not the centre of a custody dispute, but who nevertheless have one parent with HIV/AIDS. Justice Michael Kirby has made some acute observations about the obligations of the judiciary in this regard:

> Some of the most difficult decisions arise in the area of family law. Cases have been decided whereby a child was denied access to a father found to be HIV-positive. The basis of the decision, however was not any real risk to the child, but that it was "not unreasonable" for the child's mother to have concerns without the risk of infection from fatherly social contact. This was an irrational fear, and the judge should not have given effect to it. A better approach was suggested in another case, where a wise judge held that it was a more appropriate response to the risk of stigmatization to bring the child up in a way that assists him or her in coping with it, and not to shield the child from realities altogether.[406]

Children and Their Families

> If my neighbors found out they could make us feel uncomfortable. They may not let my daughter play with their children. They may not want us in the swimming pool and hot tub. They might leave the pool when we went in. I've even thought if it became known we have HIV it might be hard to sell our home because people may say - that's where the AIDS family lived.[407]

> I was upset by discrimination I experienced by a social agency who was providing assistance in child care during periods of illness. I was angry because my son was discriminated against because of me.[408]

> People know [the] child's diagnosis. The parents at the nursery school wanted to boot her out of school. The nursery school was worried about community reaction. The school had an information meeting for parents. This meeting ended up being very public - media, radio and TV got involved. My sister was too scared to phone me. She was afraid she could get HIV. She has never come to see me since I adopted this child. We lost our best friends since they learned of the child's diagnosis. The parents at the school now become very involved. Suddenly parents want to volunteer in the class. One little boy in the class said: "My dad said I'm not supposed to play with [the child]. I'm not even supposed to sit beside her. My brother and sister no longer visit us.[409]

Current Epidemiology

Perinatal Transmission

Health Canada reports that, as of 30 June 1997, 78 percent (123 of 158) of AIDS cases among children had been attributed to perinatal transmission.[410] As Health Canada states:[411]

> • Perinatal (or vertical) transmission of HIV is the transmission of HIV from an HIV-infected pregnant woman to her newborn child. Transmission can occur during gestation (in utero), during delivery, when the fetus makes contact with maternal blood and mucosa in the birth canal, and after delivery, through breastmilk.
>
> • There are many factors that may influence transmission of infection from mother to infant, including maternal viral load, mode of delivery, timing of delivery after rupture of membranes, and length of time breastfeeding. In developed countries, such as Canada, where feeding supplements are readily available as safe alternatives to breast milk, an HIV-positive woman is recommended not to breastfeed her infant.
>
> • Detecting HIV infection before or during pregnancy can reduce the likelihood of vertical transmission (from mother to infant) by up to 67 percent if the woman and her child are offered timely antiretroviral treatment.
>
> • All pregnant women, and women considering becoming pregnant, should have access to prenatal care, which includes the offer of HIV testing as well as appropriate counselling and care.

As of 30 December 1995, 551 infants in Canada were known to have been perinatally exposed to HIV. Of these, 234 infants are confirmed as having been infected with HIV.[412]

HIV-Affected Families

Families are affected by HIV in a variety of ways: one or both parents may be infected with HIV; one or more children may be infected with HIV; some or all children may not be infected ("affected children"); children of HIV-positive parents may be cared for by grandparents.

A recent study of families living with HIV/AIDS in Canada found that one-quarter of families had both parents living with HIV; more than one-third of families had a single parent living with HIV; nearly one-third of families had only the mother living with HIV; in nearly half of families two generations were infected with HIV; and the majority of children (68 percent) living with parents or grandmothers were not HIV-positive.[413] Of the participants in this study, 45 percent of the parents were currently married, 27 percent were single but living with a partner, and 20 percent were single and living without a partner.[414] The age of children in these families ranged from several months to 18 years.[415] Over half of the parents reported a family income of less than $20,000, and the great majority (87 percent) reported an annual income of $30,000 or less.[416]

Stigma and Discrimination in the Context of the HIV/AIDS Epidemic

Disclosure and Secrecy

In the study discussed above, fear of discrimination, particularly as it affects children, was a concern for over one-third of the parents.[417] As the quotations at the beginning of this section show, one of the main reason parents decided to keep HIV status a secret was to protect their children from hurtful incidents or exclusion.[418]

However, keeping HIV status a secret is complicated for families. Parents must consider not only what their children may know, but also what their own friends and relatives may know, what their children's friends may know, what the parents of their children's friends may know, what staff at daycare or school may know, and so on. The potential for inadvertent disclosure is ever-present. Family and friends may comment without intending any harm; young children may mention something without realizing what it means for others.

> Mostly [I'm] worried about how people will treat them [the children]. I haven't told them about my diagnosis because I don't want them to take those words to school and daycare. I just don't think it's fair for my children to be judged and they probably will be, even though they're negative.[419]

All this takes its toll. Almost half of the parents involved in the study of HIV-affected families were concerned with disclosure and secrecy.[420] As one parent stated:

> The whole issue of secrecy is always on my mind - what people would think and do [if they knew], explaining the medical condition to my older child, explaining HIV to the affected [infected] child, always thinking about who can be trusted, issues at school, confidentiality, feeling responsible even though I am aware of universal precautions.[421]

Invariably, disclosure of HIV status - whether it is the parent or the child who is HIV-positive - has consequences for the whole family. This has implications not only for the social support of the family,[422] but also for advocacy and education among parents and families. As a social worker put it, "If a mother goes public about her HIV status on television, the child gets it the next day at school."[423]

Discrimination in Daycare Centres

There have been a number of incidents where the discovery of the HIV status of a child in a daycare centre has led to a crisis or to the expulsion of the child. The issue came to public attention in Québec in January 1994 when "Baby J" was expelled from a daycare centre once it became known that the medication she was required to take was AZT.[424] A subsequent consideration of the issue by the Québec Human Rights Commission determined that excluding a child from daycare solely on the grounds of HIV status is a prohibited ground of discrimination based on handicap, since the risk of transmission of HIV in a daycare setting is almost nil.[425] The Commission also recommended education of daycare staff and parents on bloodborne diseases and on the rights of children with bloodborne diseases, in order to avoid or lessen crises when a child's HIV status becomes known.[426]

Such education has been provided in Québec, and has increased the level of knowledge and improved the attitudes of staff and parents.[427] Before the program, 73 percent of respondents thought that parents must notify the daycare worker if their child is HIV-positive, 39 percent thought that daycare administrators must inform parents of the presence of an HIV-positive child, 51 percent felt that a child with HIV represents a danger to other children in the daycare, and 45 percent stated that they would not allow their child to be in a group with an HIV-positive child. After the education program, respondents holding these views decreased to 12 percent, 3 percent, 12 percent, and 14 percent respectively. Nevertheless, it is reported that many daycare centres are still inhospitable to children with HIV.[428]

Discrimination at School

Families must be careful about what they disclose at school because of the stigma associated with HIV/AIDS and the potential for discrimination. When the child is HIV-positive, parents sometimes advise the principal of the school, who may also inform the school nurse or counsellor. A similar arrangement may be made when the parent is HIV-positive. Such arrangements appear to work well for some families, and can afford both parents and child the support they need:

> My oldest child learned about our HIV status and was upset learning that I have the infection. My child didn't know how to deal with it. All he thought was my mom and dad are going to die. He started having temper tantrums. It was hard because I didn't know any mothers with HIV who had children. So I met with school staff and explained what was

> happening and asked for counselling. And now the counsellor will bring in the younger child and myself and spouse for counselling.[429]

When the parent is HIV-positive, the child may ask the parent to come to school to discuss this with the class, at a time when the child is ready. Often this has proved to be a good experience for parent, child, and the students in the class.[430] But at the same time it demonstrates the obvious - that knowledge, understanding, and support cannot be taken for granted.

A 1987 survey of attitudes about HIV/AIDS among young people found that 55 to 77 percent of young people thought that students with HIV infection should be allowed to attend regular school classes, but fewer agreed that people with HIV/AIDS should be allowed to be teachers.[431] Even fewer thought that people with HIV/AIDS should be allowed to serve the public as waiters, chefs, or hair stylists, or to work in hospitals. The authors commented:

> It would seem that the closer the potential for contact, the less tolerant young people become.[432]

Only 11 to 25 percent of young people stated that they could not befriend someone who has AIDS.[433] At the same time, some youth believed that people with HIV/AIDS were getting what they deserved (7 to 16 percent) or thought that they should be quarantined (13 to 24 percent).[434]

Educational programs about sexuality and HIV/AIDS can change attitudes among young people. A recent evaluation of the grade 9 program *Skills for Health Relationships* found that students in the program became more compassionate toward people with HIV/AIDS.[435]

Youth

Current Epidemiology

Health Canada reports that, "[a]s the HIV epidemic evolves, more and more infections are occurring in young people."[436] The estimated median age of infection has decreased from 29.6 years for the period between 1975 and 1984 to 24.5 years for the period between 1985 and 1990.

While information on HIV infection and risk behaviours among youth is incomplete, there are indications of high-risk behaviour among youth in general and among street youth and gay, lesbian, and bisexual youth in particular:

- A recent school survey in Nova Scotia found that approximately 61 percent of grade 12 students reported having sexual intercourse in the year prior to the survey, and that of these only 32 percent always used condoms.[437]

- A 1992 survey in western Canada found that 52 percent of 17-year-old women and 55 percent of 17-year-old men had had sexual intercourse, and that of these, 45 percent of the women and 57 percent of the men had used a condom the last time they had sexual intercourse.[438]

- The rate of infection in a cohort of gay and bisexual men in Vancouver between the ages of 18 and 30 was 3.1 percent as of December 1996, twice as high as the authors of the study expected.[439] In this cohort, 11 percent reported unprotected receptive anal intercourse with a non-regular partner, and 19 percent reported unprotected insertive anal intercourse with a non-regular partner.[440]

- Recent studies of street youth indicate that 85 to 98 percent have had sexual intercourse. Over 60 percent had their first sexual intercourse before the age of 13.[441] Among street youth, sexual intercourse at a young age is predictive of increased numbers of partners.[442] Rates of STDs are much higher among street youth than among school dropouts living at home and among first-year college students, and increase in a linear fashion as number of partners increases.[443]

- In a study of street youth in Montréal, 2 percent of the study participants were found to be HIV-positive. Injection drug use and prostitution were important risk factors.[444]

Stigma and Discrimination in the Context of HIV/AIDS

Education about Sexuality and HIV/AIDS in Schools

Educational programs about sexuality and HIV/AIDS in schools necessarily involve, implicitly or explicitly, a consideration of morals, values, stigmas and taboos related to sexuality, sexual activity, and HIV/AIDS. Depending on their values and attitudes, students, teachers, parents, and school board members may object to an education program that does not give preference to abstaining from sexual relations outside of marriage, that provides information on safer sex (particularly condoms), or that presents same-sex relations and activity as having equal value as heterosexual relations and activity.

The Council of Ministers of Education in Canada has taken an active role in developing, implementing and evaluating educational programs about sexuality and HIV/AIDS. In the past five years, the Council, with the support of Health Canada, developed, implemented, and evaluated a demonstration grade 9 program entitled *Skills for Healthy Relationships.* An evaluation of the outcomes of the program found that students who participated in the program became more understanding and accepting of homosexuality and more compassionate toward people with HIV/AIDS than students in the comparison group. Students in the demonstration program also became more knowledgeable about HIV/AIDS and more ready to communicate about past sexual experiences, to refuse sex, and to communicate about using condoms. In addition, they were more able to obtain condoms, to purchase them without embarrassment, and to use them properly.[445]

Although public school curricula in Canada include education programs on sexuality, local school boards often have discretion over what components of the program they will implement, principals and teachers can influence the way in which the program is delivered, and parents may opt to withdraw their children from the program. As a result, the education that students receive may be affected in a number of ways:

- it may not include information on safer sex;
- it may not include components aimed at developing skills in making decisions about sexual activity and in using condoms;
- it may not include education about homosexuality as part of normal adolescent sexual development; and
- it may not include education about non-discrimination vis-à-vis gay men and lesbians.

The Council of Ministers of Education has commissioned a research study to assess the factors that contribute to or hinder effective implementation and delivery of sexuality education programs. The results of this study are expected to become available in 1998. They should assist in identifying what has enabled school boards and educators to deliver (or prevented them from delivering) comprehensive and effective sexuality and HIV/AIDS programs that include, in the range of options, information about safer sex, same-sex orientation, and non-discrimination.

Gay, Lesbian and Bisexual Youth

Young people who are attracted to others of the same sex grow up in a world in which, more often than not, all of the approved references and models are heterosexual. Consequently, as they discover their sexuality and develop their social identity, they do not enjoy an environment that permits them to explore openly their sexuality and their identity, to befriend easily peers of a similar sexual orientation, and to anticipate readily the support of family. On the contrary, they are likely to grow up in an environment where derogatory remarks about gay men and lesbians are common, where they keep same-sex desires a secret from peers and families, and - for a significant number of youth - where they themselves have experienced abuse and even violence.

Gay, lesbian, and bisexual youth, in other words, grow up in a world that discriminates against them at the societal, programmatic, and personal levels.[446] At the societal level, stigma and discrimination are expressed in assumptions, norms, values, models, messages, laws, and institutions that are prevailingly heterosexual, that privilege heterosexuals, that deny the validity or the value of same-sex identity and sexuality, and that tolerate or foster abuse and violence against gay men, bisexuals and lesbians. At the programmatic level, stigma and discrimination are expressed in such things as lack of information about homosexuality and bisexuality, censorship of books dealing with same-sex issues, lack of supportive educational and counselling programming in schools, negative representations of homosexuality in religious education, inadequate protection from the police and the courts, and no recognition or inappropriate treatment from health and social services. At the personal level, stigma and discrimination are experienced in the attitudes, remarks and actions of peers, in silence about homosexuality within families, in negative reactions when coming out to family and peers, and in experiences of violence and abuse.

All of this takes its toll. As one review of the literature observes:

> Gay youth are prone to feelings of poor self-esteem, negative self-image, negative identity, isolation, fears, anxiety, self-hatred, demoralization, inferiority and depression which can lead to serious psychological problems, alcohol and drug abuse, or suicide.[447]

Specifically, for gay and bisexual youth, the process of expressing their sexuality and coming out entails an increased risk of HIV infection. In their early sexual experiences, gay and bisexual youth frequently engage in unprotected sex with anonymous partners.[448] Often the coming-out process is itself followed by a burst of sexual activity, usually without protection. A qualitative study involving 26 gay youth in Montréal found that all of those who had come out to their parents (15 youth) had receptive anal intercourse, mostly without a condom, just after telling their parents. The study also found that the number of sexual partners tended to increase after coming out, and that most of the youths who came out left the family home.[449] With few resources and little work experience, youth who choose - or are forced - to leave home may end up living on the street, where prostitution and drug use increase the risks of HIV infection.[450] It has been observed that gay youth are overrepresented among street youth in certain US cities,[451] and that street youth have a two to ten times higher prevalence of HIV disease than other samples of adolescents.[452]

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FOOTNOTES

[282] O Ingstrup, Commissioner, Correctional Service Canada, in testimony before the Parliamentary Sub-Committee on HIV/AIDS, House of Commons of Canada, 35th Parliament, 2nd Session, Meeting no. 12, 16 November 1996.

[283] Ibid.

[284] DA Rothon et al. Prevalence of HIV Infection in Provincial Prisons in British Columbia. *Canadian Medical Association Journal* 1994; 151(6): 781-787; LM Calzavara et al. Reducing Volunteer Bias: Using Left-Over Specimens to Estimate Rates of HIV Infection among Inmates in Ontario, Canada. *AIDS* 1995; 9(6): 631-637; LM Calzavara et al. The Prevalence of HIV-1 Infection among Inmates in Ontario, Canada. *Canadian Journal of Public Health* 1995; 86(5): 335-339.

[285] Health Canada, supra, note 261 at 29.

[286] Ibid.

[287] Correctional Service Canada. *1995 National Inmate Survey: Final Report - Main Appendix*. Ottawa: Correctional Research and Development, 1996, at 348, 368, 374, 376.

[288] Ibid at 349.

[289] Ibid at 369.

[290] LM Calzavara et al. *Understanding HIV-Related Risk Behaviour in Prisons: The Inmates' Perspective*. Toronto: HIV Social, Behavioural and Epidemiological Studies Unit, Faculty of Medicine, University of Toronto, 1997, at 12.

[291] Ibid at 17.

[292] C Poulin et al. Prevalence and Incidence of HIV among Injecting Drug Users (IDU) Attending a Needle Exchange Program (NEP) in Québec City. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 27A. Abstract no. 218.

[293] A Dufour et al. Prevalence and Risk Behaviours for HIV Infection among Inmates of a Provincial Prison in Quebec City. *AIDS* 1996; 10(9): 1009-1015 at 1012.

[294] WHO. *World Health Organization Guidelines on HIV Infection and AIDS in Prison*. Geneva: WHO, 1993. The full text of the *Guidelines* can be found in the March 1998 reprint of Jürgens, supra, note 2, Appendix 5.

[295] Jürgens, supra, note 2 at 88.

[296] Expert Committee on AIDS and Prisons. *HIV/AIDS in Prisons. Final Report. Summary Report and Recommendations. Background Materials*. Ottawa: Minister of Supply and Services Canada, 3 vols, 1994.

[297] Jürgens, supra, note 2.

[298] Calzavara, supra, note 290 at 23, 26-27.

[299] Ibid at 29.

[300] Personal communication with R Lines, 3 February 1998.

[301] Ibid.

[302] WHO, supra, note 294 at 1 (Guideline 4).

[303] R Jürgens. Methadone, But No Needle Exchange Pilot in Federal Prisons. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 26-27; DA Rothon. Methadone in Provincial Prisons in British Columbia. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 27-29.

[304] Correctional Service Canada, supra, note 287 at 332.

[305] Ibid at 323.

[306] Ibid at 324-333.

[307] Calzavara, supra, note 290 at 14; K Dolan et al. HIV Risk Behaviour of IDUs Before, During and After Imprisonment in New South Wales. *Addiction Research* 1996; 4(2): 151-160; A Taylor et al. Outbreak of HIV Infection in a Scottish Prison. *British Medical Journal* 1995; 310: 289-292; J Nelles, A Fuhrer. *Drug and HIV Prevention at the Hindelbank Penitentiary. Abridged Report of the Evaluation Results*. Berne: Swiss Federal Office of Public Health, 1995.

[308] Taylor, supra, note 307; D Shewan et al. Behavioural Change Amongst Drug Injectors in Scottish Prisons. *Social Science and Medicine* 1994; 39(11): 1585-1586; D Shewan et al. Prison as a Modifier of

Drug Using Behaviour. *Addiction Research* 1994; 2(2): 203-215.

[309] Correctional Service Canada, supra, note 287 at 354-359.

[310] L Calzavara et al. Reducing HIV Transmission among IDUs in Prison: The Inmates' Perspective. *Canadian Journal of Infectious Diseases* 1995; 6(Suppl B): 36B. Abstract no. 404.

[311] Calzavara et al, supra, note 290 at 14.

[312] Correctional Service Canada, supra, note 287 at 366.

[313] Ibid at 369.

[314] Calzavara, supra, note 290 at 29.

[315] Ibid.

[316] Ibid.

[317] Jürgens, supra, note 2 at 20, citing Salisbury and Smith.

[318] See, eg, AA Gleghorn et al. Inadequate Bleach Contact Times During Syringe Cleaning Among Injection Drug Users. *Journal of Acquired Immune Deficiency Syndromes* 1994; 7(7): 767-772; Strathdee et al, supra, note 209; Van Ameijden et al, supra, note 210.

[319] TL Nichol. Bleach Kit Distribution Pilot Project in a Canadian Federal Institution. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. We.D.356. For a detailed description of the project, see Jürgens, supra, note 2 at 9-12.

[320] R Meyenberg et al. *Infektionsprophylaxe im Niedersächsischen Justizvollzug:*

Eröffnungsbericht zum Modellprojekt. Oldenburg: Bibliotheks- und Informationssystem

der Universität Oldenburg, 1996, at 79-83; J Jacob, H Stöver. Germany - Needle Exchange in Prisons in Lower Saxony: A Preliminary Review. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 30-31. For an overview of needle exchange programs in European prisons, see Jürgens, supra, note 2 at 54-65.

[321] Calzavara et al, supra, note 290 at 4.

[322] WHO, supra, note 294 at 4 (Guideline 31).

[323] Ibid (Guideline 32).

[324] Supra, note 296 at 7.

[325] Ibid.

[326] Ibid.

[327] Jürgens, supra, note 2 at 101.

[328] Ibid.

[329] R Lines, L Ferguson. A Peer Driven AIDS Outreach, Education and Support Program Targetting Prisoners. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. We.D.350; C Ploem, A Toepell. Pilot Inmate AIDS Peer Education Project. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. We.D.354. For more information on the latter, see Jürgens, supra, note 2 at 16-17.

[330] Ibid at 102.

[331] WHO, supra, note 294 at 5 (Guideline 34).

[332] Ibid (Guideline 36).

[333] Ibid (Guideline 38).

[334] Ibid (Guideline 40).

[335] Ingstrup, supra, note 282.

[336] S Brousseau, Coordinator, Office des droits des détenu(e)s du Québec, in testimony before the Parliamentary Sub-Committee on HIV/AIDS, House of Commons of Canada, 35th Parliament, 2nd Session, Meeting no. 12, 16 November 1996.

[337] Jürgens, supra, note 2 at 112-113.

[338] Ibid at 113.

[339] Lines, supra, note 300.

[340] Ibid.

[341] R Lines. Death Exposes Treatment of Prisoners Living with HIV/AIDS. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 29-30 at 29.

[342] Ibid at 30.

[343] WHO, supra, note 294 at 7 (Guideline 51).

[344] J-P Fontaine Védrine, Psychologist, Office des droits des détenu(e)s du Québec, in testimony before the Parliamentary Sub-Committee on HIV/AIDS, House of Commons of Canada, 35th Parliament, 2nd Session, Meeting no. 12, 16 November 1996; see also J-C Bernheim, J Montreuil. AIDS, Prisons and Parole. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(2): 20-21.

[345] Lines, supra, note 341 at 29.

[346] Supra, note 296 at 29-30.

[347] Fontaine Védrine, supra, note 344.

[348] Jürgens, supra, note 2 at 21.

[349] Lines, supra, note 341 at 30.

[350] Ibid.

[351] Goldie et al, supra, note 65 at 92.

[352] Ibid at 82.

[353] Ibid at 54.

[354] Health Canada. *HIV/AIDS Epi Update: HIV and AIDS among Women in Canada*. Ottawa, November 1997.

[355] L Sherr. Tomorrow's Era: Gender, Psychology and HIV Infection. In: L Sherr et al, eds, supra, note 74, 16-45 at 20-23.

[356] M Travers, L Bennett. AIDS, Women and Power. In: Sherr et al, eds, supra, note 74, 64-77 at 68.

[357] National Forum on Health. An Overview of Women's Health. In: *Canada Health Action: Building on the Legacy*. Vol. 2: *Synthesis Reports and Issues Papers*. Ottawa: The Forum, 1996, at 7.

[358] Ibid.

[359] AL Bedimo et al. History of Sexual Abuse Among HIV-Infected Women. *International Journal of STD & AIDS* 1997; 8(5): 332-335 at 334.

[360] Kirkham & Lobb, supra, note 121.

[361] J Madsen. Double Jeopardy: Women, Violence and HIV. *Vis-à-vis* 1996; 13(3): 1, 3.

[362] LA Jackson et al. HIV-Positive Women Living in the Metropolitan Toronto Area: Their Experiences and Perceptions Related to HIV Testing. *Canadian Journal of Public Health* 1997; 88(1):18-22, at 20-21.

[363] KA Phillips et al. HIV Counseling and Testing of Pregnant Women and Women of Childbearing Age by Primary Care Providers: Self-Reported Beliefs and Practices. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 1997; 14(2): 174-178.

[364] Ibid; Jackson et al, supra, note 362 at 22.

[365] S Lawless et al. Dirty, Diseased and Undeserving: The Positioning of HIV Positive Women. *Social Science and Medicine* 1996; 43(9): 1371-1377 at 1373.

[366] C Hankins. HIV Counselling and Testing Issues for Women - Testing Experiences of HIV+ Women, Montréal. In: Hankins & Hum, supra, note 257 at 17.

[367] Ibid.

[368] On the benefits of early detection of HIV, see N Haley. HIV Testing for Women - Timing/ Reproductive Choices/Provincial and Other Recommendations. In*:* Hankins & Hum, supra, note 257 at 18-20.

[369] Jürgens & Palles, supra, note 4 at 120-134.

[370] Ibid at 133.

[371] For a summary of issues associated with pregnancy, HIV testing and counselling, the effects of a positive diagnosis, and decisions related to having a child, see Sherr, supra, note 355 at 25-27; DL Lamping, D Mercey. Health-Related Quality of Life in Women with HIV Infection. In: Sherr et al, supra, note 74, 78-98, at 81.

[372] KH Rothenberg, SJ Paskey. The Risk of Domestic Violence and Women with HIV Infection: Implications for Partner Notification, Public Policy, and the Law. *American Journal of Public Health* 1995; 85(11): 1569-1576, at 1570. Madsen, supra, note 361.

[373] Lamping & Mercey, supra, note 371 at 81; Lawless et al, supra, note 365 at 1374; P Lester et al. The Consequences of a Positive Prenatal HIV Antibody Test for Women. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 1995; 10(3): 341-349, at 343-344; Travers & Bennett, supra, note 356 at 72.

[374] Goldie et al, supra, note 65 at 85, 93. These issues are discussed below in the section on children and families.

[375] Sherr, supra, note 355 at 16-17.

[376] Sherr, supra, note 355 at 20.

[377] Ibid at 17-18; CA Hankins, MA Handley. HIV Disease and AIDS in Women: Current Knowledge and a Research Agenda. *Journal of Acquired Immune Deficiency Syndromes* 1992; 5: 957-971, at 957.

[378] Hankins & Handley, supra, note 377; Hankins & Hum, eds, supra, note 257 at 30-31.

[379] Tri-Council Working Group. *Code of Ethical Conduct for Research Involving Humans*. Ottawa: The Medical Research Council of Canada, The Natural Sciences and Engineering Research Council of Canada, The Social Sciences and Humanities Research Council of Canada, July 1997, at VI-4.

[380] National Forum on Health, supra, note 357 at 5.

[381] Ibid.

[382] Federal, Provincial and Territorial Advisory Committee on Population Health. *Report on the Health of Canadians: Technical Appendix*. Ottawa: Minister of Supply and Services, 1996, at 154-155.

[383] Ibid at 46.

[384] National Forum on Health, supra, note 357 at 22.

[385] Federal, Provincial and Territorial Advisory Committee on Population Health, supra, note 382 at 136-137.

[386] Green, supra, note 74 at 54-57.

[387] Ibid at 56-57.

[388] Supra, note 73.

[389] Lamping & Mercey, supra, note 371 at 85, and the publications cited there.

[390] KL Hackl et al. Women Living with HIV/AIDS: The Dual Challenge of Being a Patient and Caregiver. *Health and Social Work* 1997; 22(1): 53-62, at 54 and 57; Lester et al, supra, note 373 at 345.

[391] J Allen. Needs Assessment for Women Living with HIV - Nova Scotia. In: Hankins & Hum, supra, note 257 at 11.

[392] S Gendron. Needs Assessment for Women Living with HIV - Montréal. In: Hankins & Hum, supra, note 257 at 10.

[393] Kirkham & Lobb, supra, note 121.

[394] M Hébert, personal communication, 17 December 1997.

[395] Fisher et al, supra, note 5 at 105.

[396] H Ramsay. Lesbians and the Health Care System. Invisibility, Isolation and Ignorance - You Say You're a What? *Canadian Woman Studies* 14; 3: 22-27 at 23, with reference to ML Adams. You're All Right So Long As You Act Nice: Lesbians' Experience of the North American Health Care System. *Fireweed*, Spring 1989.

[397] Lawless et al, supra, note 365 at 1373.

[398] S Barkan et al. Sexual Identity and Behaviour among Women with Female Sexual Partners: The Women's Interagency HIV Study (WHS). XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Tu.C.2476; JM Marrazzo et al. HIV-Related Risk Behaviour in a Community-Based Sample of Women Who Have Sex with Women. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Tu.C.2483.

[399] For a review of trends in the United States, where the number of cases of heterosexually acquired AIDS has steadily increased over the last decade, see JJ Neal et al. Trends in Heterosexually Acquired AIDS in the United States, 1988 through 1995. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 1997; 14(5): 465-474.

[400] Health Canada. *AIDS in Canada: Quarterly Surveillance Update*. Ottawa, August 1997, at 8.

[401] Health Canada. *HIV in Canada: Surveillance Report for the Period 1985-1995*. Ottawa: December 1996, at 9.

[402] See ibid at 2-3 for this and other important limitations on conclusions that can be drawn from positive test reports.

[403] Health Canada. *HIV/AIDS Epi Update: Sexual Risk Behaviours of Canadians*. Ottawa: November 1997.

[404] Supra, note 94.

[405] Sherr, supra, note 355 at 28.

[406] M Kirby. The Judicial Response to HIV/AIDS. *International Journal of STD & AIDS* 1997; 8(4): 265-271, at 269. For more information on custody cases involving HIV/AIDS, see Fisher et al, supra, note 5 at 77-79.

[407] Goldie et al, supra, note 65 at 85.

[408] Ibid.

[409] Ibid at 87.

[410] Health Canada. *Perinatally Acquired HIV Infection*. Ottawa, November 1997.

[411] Ibid.

[412] SM King et al. The Canadian Perinatal HIV Surveillance Program. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Mo.C.1404.

[413] Goldie et al, supra, note 65 at 28-29.

[414] Ibid at 25.

[415] Ibid at 22.

[416] Ibid at 23.

[417] Ibid at 30.

[418] Ibid at 85.

[419] Ibid at 86.

[420] Ibid at 30.

[421] Ibid at 86.

[422] Supra, notes 74-75.

[423] Hébert, supra, note 394.

[424] K Beaugé. Daycare Centres: Another Area of Concern. *Canadian HIV/AIDS Policy & Law Newsletter* 1995; 1(2): 5. See also J Dussault. HIV/AIDS and Child Care. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(3): 7-9.

[425] D Charpentier. Le droit au service de garde pour les enfants atteints du VIH/SIDA. Document adopté à la 392e séance de la Commission tenue le 19 mai 1995, par sa résolution COM-392-6.1.2. Montréal: Commission des droits de la personne du Québec, 1995.

[426] Ibid.

[427] A Renaud et al. Knowledge and Attitude Assessment of Quebec Daycare Workers and Parents Regarding HIV/AIDS and Hepatitis B. *Canadian Journal of Public Health* 1997; 88(1): 23-26.

[428] Hébert, supra, note 394.

[429] Goldie et al, supra, note 65 at 94.

[430] Participants in a workshop entitled Forgotten Grievers: Issues for Children and Youth Affected by HIV, 1998 Canadian HIV/AIDS Skills Building Symposium, 18 January 1998.

[431] AJC King et al. *Canada Youth and AIDS Study*. Kingston: Social Program Evaluation Group, Queen`s University, 1988, at 68.

[432] Ibid.

[433] Ibid at 70.

[434] Ibid.

[435] See infra, note 445.

[436] Health Canada. *HIV/AIDS Epi Update: Sexual Risk Behaviours of Canadians*. Ottawa: November 1997.

[437] Ibid.

[438] Ibid.

[439] Strathdee et al, supra, note 139.

[440] Health Canada, supra, note 137, referring to Strathdee et al, supra, note 139.

[441] Ibid.

[442] NE MacDonald et al. Canadian Street Youth: Correlates of Sexual Risk-Taking Activity. *Pediatrics Infectious Disease Journal* 1994; 13(8): 690-697, at 695.

[443] Ibid at 694.

[444] E Roy et al. Risk Factors for HIV Infection in Street Youth. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Tu.C.2629.

[445] WK Warren, MA King. *Development and Evaluation of Skills for Healthy Relationships: An AIDS/STD/Sexuality Program for Grade 9 Students. Summary*. Kingston: Social Program Evaluation Group, Queen's University, 1996, at 5-7.

[446] This summary is based on, but cannot reproduce, more complete discussions elsewhere. See, eg, Health Canada, supra, note 147 at 17-21; Fisher et al, supra, note 5; MS Schneider, ed. *Pride & Prejudice: Working with Lesbian, Gay and Bisexual Youth*. Toronto: Central Toronto Youth Services, 1997.

[447] Health Canada, supra, note 147 at 12. See also M Radkowsky, LJ Siegel. The Gay Adolescent: Stressors, Adaptations, and Psychosocial Interventions. *Clinical Psychology Review* 1997; 17(2): 191-216.

[448] Ibid at 14.

[449] Y Jalbert. The Coming Out Process among Gay Youth and the Impact on the Health Services. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 13A. Abstract no. 121.

[450] Health Canada, supra, note 147 at 15; Roy, supra, note 444.

[451] Health Canada, supra, note 147 at 15, citing G Kruks. Gay and Lesbian Homeless/Street Youth: Special Issues and Concerns. *Journal of Adolescent Health* 1991; 12(7): 515-518, at 516. Preliminary results from a study of street youth in Montréal found that 17 percent of participants had a homo/bisexual partner. Univariate analysis found that having a homo/bisexual partner was associated with HIV infection, but the variable did not remain significant in a multivariate model. See Roy et al, supra, note 444.

[452] Health Canada, supra, note 147 at 15, citing CA Campbell, MD Peck. Issues in HIV/AIDS Service Delivery to High Risk Youth. *Journal of Gay and Lesbian Social Services* 1995; 2(3/4): 159-177.

HIV/AIDS and Discrimination: A Discussion Paper
by Theodore de Bruyn

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RESPONDING TO STIGMA AND DISCRIMINATION: EDUCATION, REDRESS, ADVOCACY

There are, broadly defined, three ways of responding to stigma and discrimination against people with HIV/AIDS and populations affected by HIV/AIDS. These are:

- *education:* public education, professional or provider education, and focused or local education about HIV/AIDS and about stigma and discrimination;

- *redress:* human rights complaints, claims made on the basis of the *Canadian Charter of Rights and Freedoms,* civil actions, private criminal prosecution, complaints to professional licensing bodies, workplace grievance procedures, etc.

- *advocacy:* organizing communities; gathering information; documenting problems; lobbying for change in government policies, education programs, business practices, professional practices, legal protections; monitoring progress; etc.

Education

Role of Education

Education will continue to be a key component in any strategy to reduce or prevent stigma and discrimination against people with HIV/AIDS and populations affected by HIV/AIDS, for a number of reasons:

- Experiences of stigma and discrimination often occur in settings that are not covered by human rights legislation, such as within families, among friends or acquaintances, or in casual encounters. These experiences may, in fact, be the most painful for people with HIV/AIDS. These experiences also have serious consequences, contributing to the isolation of people with HIV/AIDS and to the marginalization, vulnerability to HIV infection, and general health risks of certain stigmatized populations, such as gay and bisexual men, injection drug users, Aboriginal people, sex workers, and prisoners.

- The goal is to prevent or reduce the stigma and discrimination that is associated with HIV/AIDS or that contributes to HIV infection, not to respond to it after it has occurred. While redress mechanisms may effect systematic changes, they are primarily intended to satisfy individual complainants. As such, they provide remedies after discrimination has occurred, rather than prevent discrimination from occurring. In addition, they do not necessarily help to change the beliefs and attitudes that contribute to stigma and discrimination: for this, education is required.

- Only a small percentage of people who experience discrimination seek redress even when legal or procedural avenues are available to them. It takes energy, time, and money to document one's experiences, seek legal counsel, begin an action, and persist until there is a settlement or a decision. Moreover, even if the decision is in one's favour, the victory may be largely moral, coming too late to be of much practical significance and affording relatively little by way of financial compensation. People with HIV/AIDS have to determine whether it is worth it to them to take such action, given the state of their health, their financial resources, and their other priorities. Many choose not to invest their energy in what is likely to be a contentious and acrimonious process.

- Actions and policies that stigmatize or discriminate may do so unintentionally. A process of education and development is required to bring such unintended effects to people's attention and to bring about changes in policies and practices.

Education will not change everyone's attitudes or prevent stigma and discrimination in every instance. As was noted above, people who have strong negative views about homosexuality or drug use, for example, are unlikely to be influenced by education about HIV/AIDS and HIV/AIDS-related stigma and discrimination.[453] Surveys show that stigmatizing attitudes toward people with HIV/AIDS persist in a minority of the general population,[454] and research has demonstrated that negative attitudes toward, for example, homosexuality contribute significantly to such stigmatizing attitudes.[455] In general, the level of HIV/AIDS knowledge is higher among people with more education, among younger people, and (in the United States) among white people. It is lower among people with strong religious beliefs, conservative political convictions, or restrictive views concerning people with HIV/AIDS.[456]

Three kinds of educational programs have a role in reducing or eliminating stigma and discrimination against people with HIV/AIDS and populations affected by HIV/AIDS: public education, professional or provider education, and focused or local education.

Public Education

> Education and prevention strategies must protect the rights of persons living with HIV/AIDS, persons at risk for infections and affected communities.[457]

Public education is required to maintain or increase knowledge and awareness in the general population about: the modes of transmission of HIV; the fact that in everyday activities there is virtually no risk of transmission of HIV; the risks of infection associated with certain behaviours; ways to prevent transmission of HIV; the rights of people with HIV/AIDS; and the rights of populations affected by HIV/AIDS.

It is not possible to discuss here the various components of effective public education in these areas. It is important to note, however, that reaching an audience with messages that increase awareness and reduce discrimination can be complex and difficult, in part because messages designed to increase knowledge about HIV transmission can, inadvertently, contribute to a blaming attitude toward people with HIV/AIDS. By emphasizing, for example, condom use as a method to prevent HIV transmission, education can increase the sense of personal responsibility associated with HIV infection, thereby contributing to the stigma that often accompanies illnesses perceived to include an element of personal control.[458] This kind of interaction between educational strategies and anti-discrimination goals suggests that:

- various public education strategies with specific but different aims are required;

- public education should include specific strategies aimed at reducing HIV/AIDS-related stigma and discrimination;

- research and evaluation are needed to identify strategies that are effective in overcoming the fears and prejudices that people hold about sex, homosexuality, and drug use, as well as HIV/AIDS; and

- public policy and legal protection prohibiting discrimination against people with HIV/AIDS and populations affected by HIV/AIDS is an indispensable complement to educational initiatives.

Professional or Provider Education

> Education can help alleviate obstacles to care such as discrimination, indifference and fear.[459]

Professionals and other workers have a major responsibility in preventing or reducing stigma and discrimination against people with HIV/AIDS or populations affected by HIV/AIDS. This responsibility includes not only their own attitudes and practices, but also the influence that they have over the attitudes and practices of others.

The areas in which professionals and other workers have responsibility are numerous: child care, primary and secondary education, professional education, primary health care, institutional health care, palliative care, pharmacies, drug treatment services, social services, housing services, legal services, policing, corrections. The kinds of professionals or workers involved are also numerous: day-care workers, teachers, health and social service educators, deans of health science faculties, primary care physicians, specialist physicians, nurses, home care providers, palliative care providers, institutional staff, community outreach workers, drug treatment workers, hospice and housing staff, employment insurance workers, social assistance workers, police, police college staff, Crown attorneys, judges, correctional officers, correctional case managers, parole board members.

The stigmatizing and discriminatory effects of professional policies and practices may be more inadvertent and unintentional than deliberate and intentional. Often, what is needed to avoid stigma and discrimination may be not only advice on non-stigmatizing and non-discriminatory approaches to dealing with people with HIV/AIDS or populations affected by HIV/AIDS, but also information about HIV/AIDS that is up-to-date, comprehensive, and holistic. Professional or provider education may therefore require information on:

- modes of transmission of HIV;
- occupational risks of infection and protection against infection;
- non-stigmatizing and inclusive HIV testing and diagnostic practices;
- cyclical and episodic variability of HIV disease;
- holistic and comprehensive assessment of functioning, health, and well-being of a person with HIV/AIDS;
- outcomes of drug treatments, including quality-of-life measures as well as safety and efficacy measures;

- contributors to HIV infection and disease progression among populations most at risk of HIV infection, including information on income, housing, employment, and social support;

- research and pilot projects in Canada and elsewhere in the world that depart from conventional practices in HIV prevention, such as provision of syringes in prisons or prescription of heroin or cocaine for drug users;

- the rights of people with HIV/AIDS;

- the rights of populations affected by HIV/AIDS;

- ethical conflicts between established professional practices and emerging needs or risks among populations affected by HIV/AIDS;

- protections provided by human rights legislation in Canada; and

- the roles and responsibilities of professionals in reducing misconceptions about HIV/AIDS and risk behaviours, and in combating discriminatory attitudes and practices.

The greatest challenges in professional education are, however, not so much in the content of the education as in the processes of designing and delivering educational programs. These challenges include:

- ensuring that people with HIV/AIDS and populations affected by HIV/AIDS are involved in the design and delivery of educational programs;

- obtaining support within professional faculties, licensing bodies, and associations for continuing education on HIV/AIDS, discrimination, and human rights;

- extending the reach of educational programs or best practices to professionals who have occasional contact with people with HIV/AIDS or populations affected by HIV/AIDS;

- sustaining and/or revising educational programs over time, in order to reach successive generations of professionals with current information; and

- developing a participatory ethical framework in which to resolve perceived or real conflicts between professional practices and the needs of people with or at risk of HIV/AIDS, such as, for example, perceived conflicts between residential or housing regulations and continuing drug use.

During the national consultations undertaken to plan for Phase III of the National AIDS Strategy in

Canada, people identified professional education as a priority in all areas of HIV/AIDS work: education, prevention, care, treatment and support.[460] They suggested a variety of training mechanisms, including "updating professional curricula, peer education, nurse tutor networks, train-the-trainer, community partnerships, a national data bank of recognized trainers, links to accreditation, and a roving national training institute."[461]

Focused or Local Education

> Push for more education of the school system, universities and employers to reduce discrimination.[462]

Focused (or local) education refers to educational programs and activities for specific communities, populations, or contexts. It includes education that is tailored to:

- the particular issues faced by the diverse populations affected by HIV/AIDS, and the language, culture, methods, and media best suited to address those issues;
- local communities where people with HIV/AIDS reside, whether within larger cities or smaller towns and rural areas;
- children, staff and parents associated with child-care centres;
- children, youth, staff, parents and board members within the school system;
- employers and employees in the workplace.

Focused educational programs and activities are required to allay fears, increase awareness and sensitivity, and provide correct information to those with whom people with HIV/AIDS and their families interact, whether daily or occasionally, in the community, at school or at work. The goal of such programs and activities is to prevent stigmatizing or discriminatory reactions toward people with HIV/AIDS and to create an environment in which people with HIV/AIDS and their families can live without fear of stigma and discrimination.

In the consultations undertaken for this *Discussion Paper*, people identified several features of the educational activities in which they had been involved, and how these features contributed to the success of the activity.

- The initiative often falls to people with HIV/AIDS or populations affected by HIV/AIDS. Although this is a common phenomenon of human engagement - people are most often engaged by issues that touch them, their families, or their friends - it adds to the concerns, responsibilities, and risks of people with HIV/AIDS, their families, and their communities. Moreover, it should be noted that under human rights law certain parties, such as employers or school authorities, have an obligation to protect people from harassment or discrimination based on or associated with HIV status.

- Face-to-face encounters between people with HIV/AIDS and their audiences go a long way toward changing attitudes. However, while such meetings are a valuable and effective means of education, they add to the work and the risks of people with HIV/AIDS. When people with HIV/AIDS choose to do this work, it is important that they and their families are prepared for public disclosure and are supported so as to make the experience safe and rewarding. It is also important to protect people from overwork and burnout as educators and advocates.

- Preparation and follow-through are key. Ideally, organizations and communities should be proactive rather than reactive in providing education about HIV/AIDS and the populations affected by HIV/AIDS. Moreover, in being proactive, they should anticipate what are likely to be reactions from members of the organization or community to a person with HIV/AIDS, and they should plan a thorough and extended educational program. This is particularly important in schools and workplaces. For example, to create a supportive and safe environment in the workplace for people with HIV/AIDS, it is not enough simply to develop policies regarding HIV/AIDS in the workplace. It is also necessary to mount an educational program to inform staff about the policies and the principles behind the policies, deal with issues that often arise around HIV/AIDS, dispel myths and fallacies about HIV/AIDS and populations affected by HIV/AIDS, and provide clear direction to counter discrimination toward people with HIV/AIDS.[463]

One of the main barriers to implementing educational programs in certain contexts is lack of support or opposition in the community, among leaders, or within management. Stigma and discrimination are themselves barriers to reducing stigma and discrimination. For example, although model curricula have been developed for education in the schools around sexuality, self-esteem, life skills, and HIV/AIDS, school boards and staff in individual schools have opposed or resisted implementing them. Similarly, AIDS educators belonging to certain ethnocultural or cultural communities have found it difficult to obtain support from leaders within their community for education regarding sexuality, risk behaviours, and HIV/AIDS. In effect, societal and personal values, as well as stigmas and taboos around risk behaviours and affected populations, result in programmatic discrimination - discrimination that some consider justified.

There is no easy way to resolve the conflict of values, morals, and rights that are implicit or explicit in these kinds of disputes.[464] Some AIDS educators consulted in the preparation of this *Discussion Paper* choose not to work under terms that prevent them from providing essential information about HIV/AIDS, such as information about safer sex and safer injecting practices. Other AIDS educators will provide as much information as they can without offending the sensibilities or standards of the community or its leaders. The least that can be said is that while there may be legal recourse in some situations - it remains to be seen, for example, how the appeal before the BC Supreme Court to quash the decision of a school board in Surrey to prohibit the use of books depicting same-sex parents in kindergarten and Grade 1 will be decided[465] - often these kinds of conflicts are not easily adjudicated by legal means. Difficult and limited though dialogue, education, and advocacy may be under these circumstances, they remain a way (often the only way) to try to raise awareness and reduce stigma and discrimination.

Community Participation

In the consultation regarding Phase III of the National AIDS Strategy, people stressed repeatedly that it is essential to involve people who are infected, at risk or affected in developing policies, designing programs, and making decisions. This pertains as much to educational programs as to other areas of activity.[466]

There are many practical reasons for involving people with HIV/AIDS and populations affected by HIV/AIDS in educational initiatives. For example,

- they know when attitudes or actions are stigmatizing or discriminatory. Others may not be sensitive to this, particularly when the stigmatization or discrimination is inadvertent and unintentional;

- they can suggest, based on good experiences, models for relating to and serving people with HIV/AIDS or populations affected by HIV/AIDS; and

- they are effective in raising awareness and creating sensitivity through face-to-face meetings and by providing accounts of their experience in published or visual materials.

More important, there is a fundamental principle at issue here. People who are the objects of stigma and discrimination should not be excluded from efforts to prevent stigma and discrimination. This principle is basic to the Guidelines on HIV/AIDS and Human Rights, adopted by the Second International Consultation on HIV/AIDS and Human Rights.[467] Only when people who are the objects of practices that, intentionally or unintentionally, discriminate against them are accepted and given credence in discussions and decisions about policies and programs will discriminatory practices be prevented or modified. Otherwise the views and experiences of people who are the objects of discriminatory practices will either not be taken into account or will be discounted - one of the reasons that institutional or professional practices may be inadvertently discriminatory or stigmatizing.

Redress

People who have experienced discrimination on account of HIV status, association with HIV, or another reason may seek redress under a variety of statutes, regulations, and codes of conduct in Canada, some of which provide explicit protections of rights and freedoms, others of which do not. These include human rights statutes and procedures; the *Canadian Charter of Rights and Freedoms*; civil action; criminal prosecution; complaints procedures of professional licensing bodies; and workplace grievance procedures. This section will discuss in some detail opportunities for redress arising from human rights statutes and procedures and the Charter, and will briefly review the remaining means of redress.

Human Rights Statutes

All jurisdictions in Canada - federal, provincial, and territorial - have enacted human rights statutes. Typically, these statutes provide protection against intentional acts of discrimination, unintentional forms of discrimination, harassment, and discrimination by association in the following areas: notices, signs, symbols, advertisements and messages; goods, services, facilities and accommodation; leasing of commercial or residential properties; employment; and membership in organizations.

The grounds on which discrimination is prohibited may 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.[468]

These grounds are subject to certain statutory exceptions, such as those provided for "affirmative action" programs, or those that are found to be "reasonable and *bona fide*" in the circumstances, such as a *bona fide* occupational requirement.

Human rights legislation applies to both government (or public) and non-government (or private) actors. The federal statute, the *Canadian Human Rights Act*, applies to federal government departments, Crown corporations and agencies, and federally regulated businesses such as banks, airlines, railways, the CBC and Canada Post. The provincial and territorial statutes apply to actors not covered by the *Canadian Human Rights Act.*

It is the function of human rights commissions to receive complaints from individuals, investigate them, and determine whether to take up the complaint. In taking up a complaint, the commission may attempt to settle it, dismiss it, or refer it to a tribunal (or board of inquiry) for a decision. Typically, only a small percentage - about 10 percent in Ontario, for example - of complaints are referred to a tribunal. People consulted in the preparation of this *Discussion Paper* cited a number of reasons for this: lack of sufficient evidence for a given complaint, failure on the part of commission staff to investigate complaints sufficiently, cuts in budgets and reductions in staff of human rights commissions.

If a tribunal finds in favour of the complainant, the remedies it could provide include monetary compensation for expenses incurred or wages lost, monetary compensation for injury to dignity or emotional distress, affirmative action, accommodation required in the workplace, education in the workplace, an injunction, or a fine. Typically, the compensation provided in human rights decisions is not as great as compensation achieved through successful litigation in the courts.

A human rights complaint may have a beneficial outcome even when the decision of a tribunal is not in favour of the complainant. In setting out its decision, for example, the tribunal may establish principles of non-discrimination that can be applied to other cases of discrimination, even though the particular complaint under consideration is dismissed on the facts of the case.

HIV/AIDS-Related Discrimination

Human rights tribunals have delivered a number of landmark decisions with regard to HIV/AIDS-related discrimination:

- In *Biggs and Cole v Hudson* (1988), the tribunal ruled that people who are HIV-positive, who are diagnosed as having or are perceived to have AIDS, who belong to groups widely regarded as especially vulnerable to HIV infection but who are not HIV-positive or whose HIV status is unknown, or who associate with people who belong to such groups or who are HIV-positive, may be protected under the term "physical disability."[469]

- In *Fontaine v Canadian Pacific Limited* (1990), a case involving a cook whose employment was terminated after it was discovered that he was HIV-positive, the tribunal accepted scientific testimony that it is extremely unlikely that HIV would be transmitted through casual social contact, that there is no evidence of transmission in food or from contact with blood as a result of cuts in the skin, that there should be no restriction on people who are HIV-positive in the food-processing industry, and that there is no basis for fear among coworkers or customers.[470]

- In *Thwaites v Canada (Armed Forces)* (1993), the tribunal determined that "[w]henever an employer relies on health and safety considerations to justify its exclusion of the employee, it must show that the risk is based on the most authoritative and up-to-date medical, scientific and statistical information available and not on hasty assumptions, speculative apprehensions or unfounded generalizations."[471]

- In *Québec (Commission des droits de la personne du Québec) and PM v. GG and Ordre*

> *des dentistes du Québec* (1995), the tribunal found that there is no reason to distinguish between asymptomatic and symptomatic HIV infection in determining whether one has a "handicap" within the meaning of human rights law. The stigmatization, social rejection, and fear of rejection resulting from HIV-positive status are as much related to a "handicap" as the functional disabilities associated with symptomatic HIV infection or AIDS.[472]

There are a number of prohibited grounds of discrimination under which people with HIV/AIDS and populations affected by HIV/AIDS may seek redress. To date, most complaints have dealt with discrimination related to disability or handicap, and discrimination related to sexual orientation.

Disability

Today, all jurisdictions in Canada recognize HIV infection, HIV-related illness, and AIDS as a "disability" or "handicap" within the meaning of human rights statutes. Persons who are entitled to protection under the statutes include persons who are HIV-positive; persons who have AIDS or HIV-related medical conditions; persons who are believed or perceived to be HIV-positive or to have AIDS or HIV-related medical conditions; persons who are associated with persons who are HIV-positive, who have AIDS, or who have HIV-related medical conditions; and being a partner or a family relation of a person who is HIV-positive, who has AIDS, or who has an HIV-related medical condition.

The kinds of actions that may be considered discriminatory under these statutes include, for example, having been:[473]

- 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 employment-related 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 a superiors or co-workers;
- harassed by a landlord, building superintendent, or other tenants.

In the past decade, the Canadian Human Rights Commission has received 46 signed complaints related to HIV/AIDS. Of these, 20 were related to provision of services, 24 to employment, and 2 to policy. Thirty-nine complaints are closed; of these, 17 were dismissed, 4 were settled, 6 were deemed not to require a tribunal hearing, 1 was heard by the Federal Court Trial Division, and in 11 cases there were no further proceedings. The number of complaints received to date by provincial and territorial human rights commissions that provided information for this *Discussion Paper* are as follows: more than 60 in British Columbia, 4 in Manitoba, at least 3 in Nova Scotia, none in Prince Edward Island, 5 in Newfoundland, none in Yukon, and none (since 1995) in the Northwest Territories.[474]

Several human rights commissions in Canada have established policies on specific points related to HIV/AIDS-related discrimination. These include such matters as *bona fide* occupational requirements or justifications, duty to accommodate the needs of people with HIV/AIDS, testing for HIV infection as a requirement for employment, privacy and confidentiality.

Bona fide occupational requirement, bona fide justification, duty to accommodate

In cases of direct discrimination, where a practice or a rule explicitly discriminates against an individual or group on the basis of a prohibited ground, employers or service providers are required to justify their practice on the basis of some specific statutory exception, exemption or defence, such as a *bona fide* occupational qualification (in the case of employment) or a *bona fide* justification (in the case of services). In cases of indirect (or adverse effect) discrimination, where an apparently neutral rule or practice has a disparate impact on individuals or groups, with the effect of causing discrimination on a prohibited ground, the employer is required to show that the discriminatory practice is "rationally related" to the activity in question and that reasonable steps, short of "undue hardship," have been taken to accommodate the needs of the individual or group that is adversely effected.[475] The duty to accommodate the needs of a person with HIV/AIDS "might involve taking steps to redefine work duties and providing temporary work assignments to accommodate health-related absences."[476] The standard of undue hardship "takes into consideration costs, available sources of funding, as well as health and safety factors."[477]

The Canadian Human Rights Commission has stated 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."[478] The Commission adds, further, 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."[479]

In its latest review of this policy, the Commission provided further precision on a number of points:[480]

> (1) HIV-positive health-care workers: The Commission concurs with the policy of the Canadian Medical Association,[481] which states that "[h]ealth care workers with HIV infection should be afforded the opportunity to compete for jobs and continue to work at their usual occupation as long as they meet acceptable performance standards and are mentally and physically able to perform the essential components of work safely, efficiently, and reliably."
>
> (2) Travel required of HIV-positive employees to foreign countries that require HIV testing of non-nationals: "employers requiring employees to travel to countries which require HIV testing should take reasonable steps to avoid negative employment consequences for employees who are HIV positive."
>
> (3) Risks to public safety arising from AIDS dementia complex: "It is ... unlikely that an employer would be able to establish a [*bona fide* occupational requirement] based on the concern of the sudden onset of dementia as evidence suggests this condition is a complication of advanced HIV disease."
>
> (4) Refusal to provide services, such as emergency rescue services, to a person who is HIV-positive on the grounds that to do so would pose an unacceptable risk of infection: the Canadian Medical Association has concluded that the risk of transmission in such instances is extremely low, and recommends that, as a general measure to minimize the risk of infection, workers take reasonable precautions when handling human blood or other body fluids capable of transmitting HIV. Therefore, the Commission "would not generally accept a [*bona fide* justification] based on an alleged danger to the service provider."
>
> (5) Employee or customer concerns about dealing with a person who is HIV-positive: "It is well established that employee or customer preference is not a legitimate reason for a discriminatory action. Therefore, employee or customer concerns about dealing with a person who is HIV positive can not be the basis for a [*bona fide* justification]."

Testing for HIV infection as a requirement for employment

In the view of the Ontario Human Rights Commission, testing for HIV infection would constitute a "medical examination." Accordingly, the Commission's policy on employment-related medical information would apply to HIV testing. This policy "does not allow employers to subject job applicants to any type of medical examination before a conditional offer of employment is made. After the person is hired, medical tests designed to identify employees with disabilities may constitute a breach of the [*Ontario Human Rights*] *Code* if the disability being tested for is not a reasonable and *bona fide* concern with regard to the job performed. In most settings, it is unlikely that testing for HIV infection or other protective measures would be necessary or justifiable."[482] Similarly, the Canadian Human Rights Commission states, "HIV positive persons pose virtually no risk to those with whom they interact in the workplace. The Commission, therefore, does not support pre or post employment testing for HIV. Such testing could result in unjustified discrimination against people who are HIV positive."[483]

Privacy and confidentiality

As the Ontario Human Rights Commission states, "[i]t is essential to ensure the maximum degree of privacy and confidentiality when medical information is legitimately required for health protection and promotion or other purposes. This applies in all situations and circumstances including hospitals, health clinics, insurance company records, employee's files, etc. In employment settings, all health assessment information, including HIV testing results, should remain exclusively with the examining physician and away from an employee's personnel file in order to protect the confidentiality of the information."[484]

Sexual Orientation

Sexual orientation is a prohibited ground of discrimination in the human rights statutes of all jurisdictions in Canada except Prince Edward Island, Alberta, and the Northwest Territories. Human rights complaints on this prohibited ground (whether explicitly stated or read into the statute) have been important means of redressing one of the principle sources of stigma and discrimination associated with HIV/AIDS, namely, fear, aversion, and discrimination against gay men, lesbians, bisexuals, and transgendered people. It is not possible within the limits of this *Discussion Paper* to discuss how human rights legislation, as well as other means of protection or redress, have been applied to gay men, lesbians, bisexuals, and transgendered people. Comprehensive discussions are available elsewhere.[485]

Limitations of Human Rights Protections and Procedures

There are a number of concerns about the limitations of human rights legislation and procedures as a means to protect people with HIV/AIDS or populations affected by HIV/AIDS from discrimination.

Many are frustrated with lengthy delays in processing complaints, failure to investigate complaints, the small number of complaints that are referred to a tribunal, and the relatively modest remedies that tribunals provide. Human rights commissions, for their part, are understaffed, underfunded, and overworked.[486] They cannot take on every complaint, but must prosecute those that they believe will be most likely to advance human rights. One of the issues here is the inadequate funding of human rights commissions by governments. Another is the inadequacy of systems that cannot handle the myriad of individual complaints that come forward. The result is justice denied for many complainants, as

Michelle Falardeau-Ramsay, Chief Commissioner of the Canadian Human Rights Commission, recently observed in a trenchant comment:

> We have to devise a system where it won't take five years to get remedial action, because it's far too long. We don't want to be dealing with the grandchildren of the complainant. I prefer to deal with the complainants themselves.[487]

Some would prefer to return to the tort of discrimination as a civil cause of action, and be able to litigate on behalf of plaintiffs in court. However, the Supreme Court of Canada ruled in *Seneca College v Bhadauria* that the enactment of human rights legislation forecloses any civil action based on discrimination that is prohibited by that legislation.[488] In a case of discrimination on a prohibited ground within the meaning of human rights legislation, a person cannot begin a civil cause of action, but must proceed by way of a complaint to a human rights commission. The exclusive jurisdiction of human rights commissions in matters of discrimination has the advantage that, if the commission takes up a complaint and refers it to a tribunal, the costs of the investigation and the hearing are borne by the commission. However, if the commission decides not to investigate the complaint or refer it to a tribunal, the complainant's only recourse is to seek, through litigation at the complainant's expense, a judicial review of the commission's decision and an order compelling it to investigate the matter or refer it to a tribunal.

It is generally recognized, by human rights commissions as well as their critics, that procedures designed to deal with individual complaints are not well-suited to preventing discrimination or addressing systemic discrimination.[489] In a partial effort to rectify this, human rights commissions issue policy statements setting out standards that, if followed, will prevent discrimination. These include the policies on HIV/AIDS cited above. But human rights commissions do not have the resources or authority to be more proactive. They are not able, for example, to audit policies and practices of employers so as to determine whether these policies and practices discriminate directly or indirectly.[490] Moreover, some forms of discrimination, such as discrimination against poor people, are not even covered under human rights legislation. As Falardeau-Ramsay states:

> One of the shortcomings of almost all Canadian human-rights laws ... is that they ignore poverty and homelessness as grounds for discrimination.[491]

This has obvious relevance to many people with HIV/AIDS and many populations affected by HIV/AIDS.[492]

HIV infection is currently recognized as a disability within the meaning of human rights legislation in Canada. There is concern, however, that a narrower definition of disability may be applied to exclude people who are HIV-positive but asymptomatic. Recently in the United States, a number of courts have taken the view that HIV infection per se is not a disability.[493] The courts have placed the burden of proof on the plaintiff to demonstrate that his/her HIV status is an impairment that substantially limits a major life activity, as stipulated in the Americans with Disabilities Act. This assessment "often focuses heavily on factors unrelated to whether or not the individual *requires* protection from discrimination."[494] The accounts reported in this *Discussion Paper* clearly show that the very perception that one is HIV-positive can lead to discrimination, regardless of one's level of impairment. Although the most recent decision from a human rights tribunal in Canada affirms that asymptomatic HIV status constitutes a "handicap" within the meaning of human rights law,[495] the developments in the United States are a cause for concern.

As noted in the discussion of stigma and discrimination affecting drug users,[496] human rights legislation and human rights commissions in Canada have afforded protection to people who have been or are dependent on alcohol or drugs. However, as was also observed above, in an environment that regards drug use as a choice, a vice, and a crime, considerable education and advocacy will be required to ensure that the rights of drug users are protected and that drug addiction is recognized as a disability. Exclusion of drug users from social benefits and coercive approaches to treatment not only discriminate against drug users. They are unlikely to induce drug users to discontinue using, and are very likely to increase the risk of harm from drug use, as the comments from drug users cited above testify.[497]

For Aboriginal peoples, human rights legislation and procedures may not be particularly useful or inviting as a way to address discrimination.[498] Many Aboriginal people will not even consider lodging a complaint because they are worn down by racism, do not think things will change, or are afraid of the consequences. In addition, the human rights system does not reflect Aboriginal values and is in many ways alien to Aboriginal ways of resolving differences. Furthermore, s 67 of the *Canadian Human Rights Act* exempts any provision of the *Indian Act*, or any provision made under or pursuant to that *Act*, from the provisions of the *Canadian Human Rights Act*. Included in the provisions of the *Indian Act* is the authority conferred on band councils to enact by-laws and band council resolutions that could potentially or inadvertently discriminate against people with HIV/AIDS. Finally, jurisdictional distinctions between Aboriginal peoples create considerable confusion about what human rights legislation applies in a given situation. For these reasons, a recent review of the situation concluded that "recourse to human rights legislation is not the best approach to reducing discrimination around HIV/AIDS for Aboriginal people."[499]

The Canadian Charter of Rights and Freedoms

The *Canadian Charter of Rights and Freedoms* applies to the Parliament and government of Canada and the legislature and government of each province.[500] This includes the legislation, regulations, and actions of the government at the federal, provincial/territorial, and municipal levels, but excludes private action in which government is not involved.

There are three provisions respecting "equality rights" in the Charter - sections 15, 17, and 28:[501]

> 15.(1) Every individual is equal before and under the law and has the right to 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.
>
> (2) Subsection (1) does not preclude any law, program or activity that has as its object the amelioration of conditions of disadvantaged individuals or groups including those that are disadvantaged because of race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.
>
> 27. This Charter shall be interpreted in a manner consistent with the preservation and enhancement of the multicultural heritage of Canadians.
>
> 28. Notwithstanding anything in this Charter, the rights and freedoms referred to in it are guaranteed equally to male and female persons.

Other sections of the Charter may also be relevant, for example:

> s 2(b), which guarantees freedom of thought, belief, opinion, and expression, including freedom of the press and other media of communication;
>
> s 7, which guarantees the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice;
>
> s 8, which guarantees the right to be secure against unreasonable search or seizure;
>
> s 9, which guarantees the right not to be arbitrarily detained or imprisoned; and
>
> s 12, which guarantees the right not to be subjected to any cruel and unusual treatment or punishment.

These rights and freedoms are subject, as s 1 states, "only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society."

The provisions of the Charter are not only relevant to claims of discrimination on the basis of HIV status. They are also relevant to claims of discrimination against marginalized populations affected by HIV/AIDS. Thus, for example, the discriminatory effect of Ontario regulations governing eligibility for health-care insurance for certain immigrants living in Canada on a Minister's Permit has been challenged on the basis of s 15(1) of the Charter.[502] Similarly, it has been argued that denying prisoners access to sterile needles and/or bleach is a violation of ss 7, 12, and 15(1) of the Charter.[503] So too, gay men and lesbians have made a number of gains in remedying legislation and regulations that discriminate against same-sex orientation or relations.[504]

Given that some of the populations most at risk of HIV infection, such as drug users, are not merely vulnerable to personal discrimination, but are also disadvantaged under Canadian law and subject to restrictive regulations and programs, the Charter could play an important role in altering the legislative and programmatic context for populations affected by HIV/AIDS. In this regard, it may be useful to review what is required to establish a claim of discrimination under s 15(1) and achieve a remedy.

From *Andrews* to *Egan*

In *Andrews v Law Society of British Columbia,*[505] McIntyre J set out a procedure of analysis to determine whether there has been discrimination on a prohibited ground and whether the discrimination is saved under s 1 of the Charter. There are four questions to be considered in this analysis:[506]

> 1. Is there unequal treatment? That is, does the impugned legislation, common law rule, or government policy or program's differential treatment of an individual or group infringe one of the four basic equality rights?[507] If not, the analysis is concluded.
>
> 2. Is there discrimination on the basis of an enumerated or analogous ground?[508] If not, the analysis is concluded.
>
> 3. Is the discrimination demonstrably justified in a free and democratic society? That is, is the impugned law, policy, or program saved under section 1? If it is saved, the analysis is concluded.
>
> 4. What remedy or remedies should be ordered?[509]

The second of these four questions, which requires a determination that the unequal treatment is discriminatory, is central to the analysis. McIntyre J provided a definition of discrimination, cited earlier in this *Discussion Paper,*[510] that depends on two considerations:

> First, does "the differential treatment [have] the effect of imposing a burden, obligation or disadvantage not imposed upon others or of withholding or limiting access to opportunities, benefits and advantages available to others"? Second, does the personal characteristics upon which the differential treatment is based "[fall] within the grounds enumerated in the section or within an analogous ground, so as to ensure that the claim fits within the overall purpose of s. 15; namely, to remedy or prevent discrimination against groups subject to stereotyping, historical disadvantage and political and social prejudice in Canadian society"?[511]

If the unequal treatment is found to be discriminatory under s 15, the analysis proceeds to a consideration as to whether the discrimination is saved under s 1.[512] Here the onus is on the government to convince the court that the discrimination should be permitted. This involves what is known as the two branches of the *Oakes* test. The first branch considers the validity of the legislative objective, and the second branch considers the validity of the means chosen to achieve the objective. In considering the latter, "[t]he government must establish that the means chosen for achieving the objective are reasonable and demonstrably justified. This is a 'proportionality test' which requires the court to balance the interests of society with those of individuals and groups. The proportionality test has three components."[513]

> First, the measures adopted must be carefully designed to achieve the objective in question. They must not be arbitrary, unfair, or based on irrational considerations but rather must be rationally connected to the objective.[514]
>
> Second, the means should interfere as little as possible with the Charter-guaranteed right or freedom....[515]
>
> [Third,] there must be proportionality between the deleterious effects of the measures that are responsible for limiting the Charter rights or freedoms in question and the objective served by the measures and also proportionality between the deleterious and salutary effects of the measures.[516]

The procedure set out by McIntyre J held until the controversial 1995 decision of the Supreme Court of Canada on three equality cases, *Thibaudeau v Canada, Miron v Trudel,* and *Egan and Nesbit v Canada*.[517] The last of these cases challenged the definition of "spouse" in the *Old Age Security Act* as limited to persons "of the opposite sex." A minority of justices imported the analysis based on s 1 into the analysis based on s 15, thereby abandoning the separation that McIntyre had maintained between these two stages of analysis. In addition, there was a diversity of opinion among the justices as to how to approach a determination that unequal treatment is discriminatory. The outcome, in the *Egan* case, was that sexual orientation was recognized as a prohibited ground of discrimination, but the court was prepared to tolerate the discrimination for an indeterminate period because, in the deciding opinion of Sopinka J, "equating same-sex couples with heterosexual spouses, either married or common law, is still generally regarded as a novel concept" and the federal government is to be allowed further time in addressing the claims of gays and lesbians to equal benefits.[518]

Subsequent to the *Egan* decision, decisions of lower courts and tribunals in cases dealing with discrimination on the basis of sexual orientation have gone in a variety of directions, some mechanically applying *Egan*, others requiring the government to remedy the situation.[519] They demonstrate the fits and starts that may be involved in redressing discrimination against a marginalized population affected by HIV/AIDS. If anything, remedying legislation and regulations that discriminate against drug users or sex workers will be as challenging as remedying legislation and regulations that discriminate against gays and lesbians.

Other Avenues of Redress

There are other ways of remedying discrimination besides human rights complaints and Charter claims. While it is beyond the scope of this *Discussion Paper* to discuss these avenues in detail, they should be noted.

People who have experienced discrimination on the basis of HIV/AIDS or of belonging to a population affected by HIV/AIDS may have grounds for a civil cause of action.[520] Recently, for example, the courts have been willing to accept claims of negligence against employers who have not met the standard of care required for HIV-positive employees, including freedom from unwarranted stress or harassment of the employee.[521] Similarly, there have been several legal actions in Australia by prisoners alleging negligence on the part of the state or the correctional authority in preventing the transmission of HIV.[522] Although the Australian cases were not finally successful, such actions may have other benefits, such as judicial recognition of a duty to care in a particular circumstance affecting a person with HIV/AIDS or people at risk of HIV infection.[523]

In certain cases there may be grounds for a private criminal prosecution for criminal negligence. Individual citizens have the legal right to launch a private criminal prosecution, although the public prosecutor may at any point intervene to stay the prosecution or to assume it. A criminal prosecution for criminal negligence differs from a civil action for negligence in that the perpetrator is held personally responsible. It could be argued that, for example, prison authorities who fail to distribute condoms, bleach or sterile syringes might be criminally negligent if HIV infection occurs in prison as a result of such failure.

People who have experienced what they consider to be bad, inappropriate or incompetent treatment by a physician have a number of avenues of recourse. They may make a formal complaint with the physician's licensing body, such as a provincial college of physicians and surgeons. When an individual makes a formal complaint, there follows an investigation of the complaint, the result of which may lead to a review of the case by an adjudicating body. The body may decide to take no further action if the evidence does not suggest wrongdoing, caution the physician, investigate the case further to determine, for instance, whether the physician is incapacitated, or refer the case for disciplinary proceedings if there is evidence of professional misconduct or incompetence.[524] This procedure, however, provides no compensation or further remedy to the complainant. An alternative would be to litigate for medical malpractice in the courts. However, such actions are expensive and lengthy, and are therefore beyond the resources of most people with HIV/AIDS.[525]

Other means of redress in cases of HIV/AIDS-related discrimination may include making a complaint to an institutional or governmental ombudsperson, making a grievance against an employer, or seeking the assistance of one's union.

The Burden Placed on the Complainant

The burden of starting an action, keeping a record of events, and bearing the costs of an action (except in human rights proceedings) falls to the person who has suffered the wrong. Much as this may add to the injustice already borne, it is a feature of our adversarial system of justice. Individuals must assess the value to them and to others of starting an action, as well as the risks and costs in terms of publicity, health, stress, expense, time, and energy.

In preparing a prospective complaint, it is important to keep a detailed and specific record of events and to save any evidence that might be used in an action.[526] This can be stressful and time-consuming, but it is often essential to the success of an action.

Advocacy

The Role of Advocacy

Advocacy has been central to the effort to support people with HIV/AIDS, prevent the transmission of HIV/AIDS among marginalized populations, and protect the human rights of people with HIV/AIDS and populations affected by HIV/AIDS. In Canada and throughout the world, advocates have worked within their communities and their countries to give voice to the concerns of people with HIV/AIDS. They have developed strategies to address HIV/AIDS within their communities. They have lobbied governments for policies, programs, and resources that meet the needs of people with HIV/AIDS and populations affected by HIV/AIDS in ways that are culturally appropriate, effective, non-discriminatory, and just. They have been at the forefront, along with others, in the effort to advance and protect the human rights of people with HIV/AIDS and populations affected by HIV/AIDS.

Advocates and advocacy have a number of roles in preventing and remedying discrimination against people with HIV/AIDS and populations affected by HIV/AIDS. These include:

- developing organizations and creating opportunities for people with or affected by HIV/AIDS to express their views and plan their strategies;

- recognizing and describing HIV/AIDS-related stigma and discrimination as it is experienced by people with or affected by HIV/AIDS;

- documenting, analyzing, and publicizing instances of HIV/AIDS-related stigma and discrimination;

- supporting those who have experienced stigma and discrimination, whether by accompanying them to meetings and appointments, advocating on their behalf, or assisting in some procedure of redress;

- intervening on behalf of people with HIV/AIDS or populations affected by HIV/AIDS in legal proceedings, legislative processes, policy development, the media at the local, regional, and national levels;

- working with public officials, professionals, and the private sector to develop programs that will prevent or reduce discriminatory behaviour in the general public, among professionals and providers, in the workplace, at school, and within specific communities;

- working with researchers to ensure that research is ethical, that studies include affected populations, and that the affected populations benefit from the outcomes of research;

- advocating with politicians and public officials to ensure that governments in Canada implement the Guidelines on HIV/AIDS and Human Rights, as adopted by the United Nations Commission on Human Rights Second International Consultation on HIV/AIDS and Human Rights in September 1996 (see Appendix A);[527] and

- monitoring Canada's performance in meeting its international treaty obligations pertaining to human rights,[528] particularly as they apply to HIV/AIDS, but also in concert with organizations advocating on other or related issues.

Current Challenges

People consulted in the preparation of this *Discussion Paper* identified a number of impediments to or challenges in advocating against stigma and discrimination.

First, there are barriers to developing organizations and involving affected people at the community level. The stigma associated with HIV/AIDS and the risk of discrimination is itself a barrier. In addition, people may not become involved in HIV/AIDS activities because of their own cultural norms, because they are not readily identified or reached within the general population, or because they are not supported in such practical needs as child care, transportation, convenient scheduling of activities, and so on. Furthermore, among drug users, sex workers, and prisoners there are legal and institutional impediments to organizing and advocacy.

Second, community-based organizations and non-governmental organizations have not developed systems to document and analyze cases and trends in HIV/AIDS-related stigma and discrimination. Nor do they currently have the resources to do so. Several people commented that community-based organizations and non-governmental organizations should designate staff positions at the regional and national level to which reports of discrimination could be referred, information on discrimination could be coordinated, and strategies to investigate, research, analyze, publicize, redress and prevent discrimination could be developed. Such a program would require a commitment from participating organizations and support from provincial and federal funding programs for community-based initiatives.

Third, there are a limited number of lawyers or legal clinics that specialize in issues relating to HIV/AIDS. These are concentrated in cities, particularly in Vancouver, Toronto, Ottawa, and Montréal. Legal aid in general is underfunded, and the resources of legal clinics specializing in HIV/AIDS are limited. As a result, people may not have access to legal counsel that is knowledgeable about HIV/AIDS-related issues, and advocates may be prevented from taking cases because the expense is prohibitive or their time is committed.

Fourth, Phase I and Phase II of the National AIDS Strategy did not designate legal, ethical, and human rights issues as a specific area of activity, with its own objectives, resources and programs. Instead, activities related to these issues have been subsumed under other areas of the Strategy. In the absence of long-term, multi-year funding, it has been difficult to build the required infrastructure across Canada, coordinate the development of priorities and programs, and sustain activities and expertise from year to year. The fact that Phase III (1998-2003) will include a specific component on legal, ethical, and human rights issues must therefore be seen as a positive development.

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FOOTNOTES

[453] Pryor et al, supra, note 37; Marquet et al, supra, note 38.

[454] Green, supra, note 42 at 558; Marquet et al, supra, note 38; Herek & Capitanio, supra, note 196.

[455] Peters et al, supra, note 33; Johnson, supra, note 33.

[456] A Peruga, DD Celentano. Correlates of AIDS Knowledge in Samples of the General Population. *Social Science and Medicine* 1993; 36(4): 509-524.

[457] *National AIDS Strategy: Phase III Consultation. A Summary Report of Results*. University of Toronto: Centre for Health Promotion, October 1997, at 22.

[458] Peters et al, supra, note 33 at 332-333.

[459] *National AIDS Strategy: Phase III Consultation*, supra, note 457 at 22.

[460] *National AIDS Strategy: Phase III Consultation*, supra, note 457 at 21-22, 29.

[461] Ibid at 21.

[462] Ibid at 25.

[463] See, eg, S Belgrave. One Employer's Approach to Employee Education. In: D FitzSimons et al, eds. *The Economic and Social Impact of AIDS in Europe*. London: National AIDS Trust, 1995, at 357-363. Recent examples of resources for workplace policies and education programs in Canada include *SIDA en milieu de travail: Guide d'information et d'intervention.* Montréal: Comité sur le sida en milieu de travail, 1997; Canadian Public Health Association. AIDS and Workplace Policy. The Association: March 1997; Health Canada. *The Business Case for HIV/AIDS. What Can You Do?* Ottawa: Minister of Supply and Services, 1996.

[464] D Defert. AIDS as a Challenge to Religion. In: Mann & Tarantola, supra, note 56 at 447-452.

[465] R Matas. Religious Leaders Unite Behind Trustees' Ban on Gay Books. *Globe and Mail* 19 February 1998, at A7.

[466] *National AIDS Strategy: Phase III Consultation*, supra, note 457 at 22, 30, 36.

[467] Infra, note 527.

[468] For the specific inclusions and wording of the various statutes, see the relevant sections in Tarnopolsky et al, supra, note 24.

[469] 9 CHRR, D/5391 at para 40353, 40360; cf Tarnopolsky et al, supra, note 24 at 7A-15.

[470] 11 CHRR, D/288 at para 41.

[471] 19 CHRR, D/259 at para 106. A subsequent appeal of the tribunal's decision before the Federal Court Trial Division, *Canada (Attorney General) v Thwaites* (1994), 21 CHRR D/224, was dismissed.

[472] 24 CHRR, D/21 at para 157-158, with extensive discussion of Canadian and American law at para 40-122.

[473] The following are cited as examples in an information sheet published by the Ontario Human Rights Commission, Know Your Rights: AIDS and AIDS-Related Illness and the Human Rights Code.

[474] All human rights commissions in Canada were contacted in the consultations for this *Discussion Paper*. Replies were received from the Canadian Human Rights Commission and the human rights commissions of Newfoundland, Prince Edward Island, Nova Scotia, Ontario, Manitoba, British Columbia, Yukon, and the Northwest Territories. Additional documentation was provided by several respondents. This was supplemented by research by the author, but what follows does not presume to be exhaustive.

[475] See Tarnopolsky et al, supra, note 24 at 4-42 to 4-56.18(12).

[476] Ontario Human Rights Commission. Policy on HIV/AIDS-Related Discrimination. November 1996, at 3.

[477] Ibid.

[478] Canadian Human Rights Commission. Policy on HIV/AIDS. June 1996.

[479] Ibid, as established in the decision of the Canadian human rights tribunal in the case of Simon Thwaites, supra, note 471.

[480] Canadian Human Rights Commission. Background Notes: CHRC Policy on HIV/AIDS. June 1996. See also, Canadian Human Rights Commission Releases Revised Policy on HIV/AIDS. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 3(1): 7-8.

[481] Supra, note 105.

[482] Supra, note 86 at 4-5.

[483] Supra, note 478.

[484] Supra, note 482 at 5.

[485] Fisher et al, supra, note 5; DG Casswell. *Lesbians, Gay Men, and Canadian Law*. Edmond Montgomery Publications Ltd, 1996.

[486] On this and what follows, see Casswell, ibid at 51.

[487] M Philp. Rights Panels Losing to Abuse, Commission Says. *Globe and Mail* 25 March 1998, at A3.

[488] Casswell, supra, note 485 at 50-51; Keene, supra, note 25 at 267-269.

[489] WW Black. *B.C. Human Rights Review. Report on Human Rights in British Columbia.* Vancouver: Ministry Responsible for Multiculturalism and Human Rights, 1994, at 14-19, 29-31; Philp, supra, note 487.

[490] J Dwyer, personal communication on file with the author, 24 December 1997.

[491] Philp, supra, note 487.

[492] Supra, notes 88, l19-121, 188, 393-395.

[493] R Jürgens. Your Health is Back. Now You May Lose Your Protection against Discrimination. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 3-5, citing WE Parmet, DJ Jackson. No Longer Disabled: The Legal Impact of the New Social Construction of HIV. *American Journal of Law & Medicine* 1997; 23(1): 8-43.

[494] Ibid at 3.

[495] Supra, note 472.

[496] Supra, notes 216 and 217.

[497] Supra, note 188.

[498] For what follows, see Matiation, supra, note 6 at 13-29.

[499] Ibid at 45.

[500] Section 32(1).

[501] Tarnopolsky et al, supra, note 24 at 16-1.

[502] Carey, supra, note 52 at 10, and supra, note 132.

[503] R Elliott. Prisoners' Constitutional Right to Sterile Needles and Bleach. In R Jürgens. *HIV/AIDS in Prisons: Final Report.* Montréal: Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1996, Appendix 2.

[504] Fisher et al, supra, note 5; Casswell, supra, note 485.

[505] [1989] 1 SCR 143.

[506] Casswell, supra, note 485 at 64.

[507] The four basic equality rights are equality before the law, equality under the law, equal protection of the law, and equal benefit of the law. See ibid at 62.

[508] An enumerated ground is a ground explicitly identified in s 15. An analogous ground is a ground that the court determines to be encompassed within s 15. To date, the Supreme Court of Canada has identified three analogous grounds: being a non-citizen permanent resident, marital status, and sexual orientation. See ibid at 75-77.

[509] Possible remedies include striking the statute down, severing the offending provision of the statute, reading the statutory provision as though certain words were not in it, amending the statutory provision by reading certain words into it, or any of the above but temporarily suspending the court's order in order to give Parliament or the legislature an opportunity to amend the offending statute. See ibid at 84-89.

[510] Supra, note 26.

[511] Casswell, supra, note 485 at 71-72, citing *R v Swain* [1991] 1 SCR 933 at 992; 63 CCC (3d) 481 at 520, and *Rodriguez v British Columbia (Attorney General)*, [1993] 3 SCR 519 at 546; 107 DLR (4th) 342 at 360-361.

[512] On what follows, see ibid at 80-82.

[513] Ibid at 80.

[514] Ibid at 81.

[515] Ibid.

[516] Ibid at 82.

[517] Ibid at 82-84.

[518] [1995] 2 SCR 513 at 576. See, for summary and analysis, Fisher et al, supra, note 5; Casswell, supra, note 485 at 371-411.

[519] Fisher et al, supra, note 5 at 66-71.

[520] Casswell, supra, note 485 at 50, citing cases in respect of "wrongful dismissal from employment, intentional affliction of mental suffering, or for abatement of rent under a tenancy agreement."

[521] Carey, supra, note 52 at 10.

[522] I Malkin. The Role of the Law of Negligence in Preventing Prisoners' Exposure to HIV While in Custody. In Jürgens, supra, note 2, Appendix 1 at 2-4; I Malkin. Australia ? Not Giving Up the Fight: Prisoners' Litigation Continues. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 32-33.

[523] Jürgens, ibid at 9-10.

[524] This summary is based on information obtained from the Ontario College of Physicians and Surgeons. Practices in other provinces may vary.

[525] Carey, supra, note 52 at 11.

[526] See, eg, the suggestions in the pamphlet produced by the Canadian Human Rights Commission. Filing a Complaint with the Canadian Human Rights Commission. Ottawa: Minister of Supply and Services, 1994.

[527] United Nations Commission on Human Rights. *Second International Consultation on HIV/AIDS and Human Rights (Geneva, 23-25 September 1996). Report of the Secretary General.* 20 January 1997 (document no. E/CN.4/1997/37). An abbreviated version of the Guidelines is provided in the *Canadian HIV/AIDS Policy & Law Newsletter* 1998; 3(2/3): 1, 45-49, reprinted as Appendix A below. For a convenient summary of the Guidelines and an advocate's guide on how to use them, see International Council of AIDS Service Organizations. *NGO Summary of the International Guidelines on HIV/AIDS and Human Rights*. 1997; International Council of AIDS Service Organizations. *An Advocate's Guide to the International Guidelines on HIV/AIDS and Human Rights*. October 1997.

[528] For the texts of international instruments pertaining to human rights, see UNAIDS. *The UNAIDS*

Guide to the United Nations Human Rights Machinery for AIDS Service Organizations, People Living with HIV/AIDS, and Others Working in the Area of HIV/AIDS and Human Rights. Geneva: Joint United Nations Program on HIV/AIDS, 1997, at 27-64. For a full discussion of the development of international human rights law, and its relevance to HIV/AIDS, see LO Gostin, Z Lazzarini. *Human Rights and Public Health in the AIDS Pandemic*. New York: Oxford University Press, 1997.

HIV/AIDS and Discrimination: A Discussion Paper

by Theodore de Bruyn

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CONCLUSION AND RECOMMENDATIONS

What people with HIV/AIDS face by way of stigma and discrimination are complexities that seem at times to defy both comprehension and action. The stigmas associated with HIV/AIDS or with the populations affected by HIV/AIDS are many, and they interact with one another in ways that place all people with HIV/AIDS at a disadvantage relative to people affected by other illnesses or conditions.[529] No area of the lives of people with HIV/AIDS is untouched by stigma and discrimination - family dynamics, community relations, employment, housing, health care, insurance, income support, travel and immigration.[530]

Discrimination against people with HIV/AIDS or populations affected by HIV/AIDS is in most instances unwarranted and unjust. This, in and of itself, is sufficient reason, ethically, for a society to take steps to prevent, redress, and eliminate discrimination. In addition, discrimination against people with HIV/AIDS or populations affected by HIV/AIDS has serious consequences. These include:

- vulnerability to HIV infection, particularly among young gay and bisexual men, drug users, Aboriginal people, prisoners, and sex workers;

- failure to prevent HIV infection, both among populations identified as being "at risk" for HIV infection and among populations not so identified;

- stress associated with HIV status, secrecy about HIV status, and social isolation because of HIV status - all adversely affecting the psychological health of people with HIV/AIDS;

- harassment from employers or colleagues; insufficient accommodation of health-related needs at work; reluctance to claim medical or disability benefits for fear of being harassed, laid off, or fired; being laid off or fired;

- denial of housing by landlords because of HIV status, sexual orientation, or source of income;

- reluctance to access health-care services, because of stigmatizing or discriminatory attitudes and remarks;

- delayed diagnosis and substandard treatment for HIV infection and HIV/AIDS-related diseases and opportunistic infections;

- insufficient or no insurance coverage for disability or drugs;

- exclusion from or underrepresentation in research on HIV/AIDS, resulting in insufficient information on HIV prevention, care, and treatment in certain populations; and

- restrictions on travel to foreign countries.

The populations affected by HIV/AIDS are diverse; many aspects of their vulnerability to stigma and discrimination and of their experience of stigma and discrimination are unique.[531] As a result, different strategies are required to reduce the impact of stigma and discrimination in different contexts and among different populations, recognizing the specific problems faced by each population and how those problems are conditioned by, for example, gender, race, sexual orientation, socioeconomic status, legislated constraints or inequities, and access to resources and advocates.

It is not possible here to outline what must be done with regard to every aspect of stigma and discrimination as it affects diverse people with HIV/AIDS and populations affected by HIV/AIDS. This would require a degree of specificity beyond the scope of this Paper. Nor is it necessary to provide such a detailed outline, because much of the work has already been done, in numerous reports and recommendations on the issues discussed in this Paper. The existing work has the added strength of integrating steps that would reduce stigma and discrimination or the impact of stigma and discrimination into a comprehensive assessment of all the issues that need to be considered, including those that do not relate specifically or directly to stigma and discrimination. Some of the more recent reports and recommendations or guidelines that are relevant include:

- *HIV Testing and Confidentiality: Final Report*;[532]

- *Criminal Law and HIV/AIDS: Final Report*;[533]

- *Gay and Lesbian Legal Issues and HIV/AIDS: Final Report*;[534]

- *Women and HIV National Workshop*;[535]

- *Children Born to Mothers with HIV: Psychosocial Issues for Families in Canada Living with HIV/AIDS*;[536]

- *HIV, AIDS and Injection Drug Use: A National Action Plan*;[537]

- *Care, Treatment and Support for Injection Drug Users Living with HIV/AIDS*;[538]

- Guidelines on Ethical and Legal Considerations in Research on HIV/AIDS and Drug Use at the Community Level;[539]

- *Sharing the Energy: A National Workshop on Street-Involved People and HIV/AIDS*;[540]

- *HIV/AIDS in Prisons: Final Report of the Expert Advisory Committee on AIDS and Prisons*;[541]

- *HIV/AIDS in Prisons: Summary Report and Recommendations of the Expert Committee on AIDS and Prisons*;[542]

- *HIV/AIDS in Prisons: Final Report* of the Canadian HIV/AIDS Legal Network and CAS;[543]

- *Discrimination, HIV/AIDS and Aboriginal People: A Discussion Paper*;[544]

- *HIV Testing and Confidentiality: Issues for the Aboriginal Community: A Discussion Paper*;[545]

- Vocational and Rehabilitation Services in the Context of HIV Infection: Issues and Guiding Principles (Draft);[546] and

- *Concepts, Definitions and Models for Community-Based HIV Prevention Research in Canada*.[547]

In addition, the Guidelines on HIV/AIDS and Human Rights provide a framework in which to assess the extent to which, in acting on the above reports and recommendations, Canada is fulfilling its obligations under international human rights law.[548]

The recommendations that follow have a more limited objective than those that have already been made in the above reports. Their purpose is to identify some essential steps that should be taken in Phase III of the National AIDS Strategy in order to make progress in the effort to recognize, prevent, and redress HIV/AIDS-related stigma and discrimination.

Strategic Framework

> States should establish an effective national framework for their response to HIV/AIDS which ensures a coordinated, participatory, transparent and accountable approach, integrating HIV/AIDS policy and programme responsibilities, across all branches of Government.[549]

HIV/AIDS-related stigma and discrimination are reflected in personal attitudes, community values, professional practices, programming in the areas of health, education, social assistance, legal services, and policy and law in such matters as drug policy, prostitution, and sexual orientation. Accordingly, addressing HIV/AIDS-related stigma and discrimination requires a strategic framework that identifies what should be done at the community, regional, and national levels in such areas as:

- data gathering, analysis, and advocacy;
- legal services;
- law reform;
- public education;
- professional education and training;
- education for children and youth;
- workplace policies and education;
- research priorities, participation, and ethics; and
- monitoring and evaluation.

In particular, there should be specific and explicit objectives in Phase III of the National AIDS Strategy that identify how publicly funded HIV/AIDS initiatives in community development, education and prevention, epidemiology, care, treatment and support, research, human rights, legal issues, and policy development will address HIV/AIDS-related stigma and discrimination.

Recommendation 1

> **1.1 Phase III of the National AIDS Strategy should develop a framework for action on HIV/AIDS-related stigma and discrimination, with specific and explicit objectives for each of the program areas of the Strategy, in consultation with community-based HIV/AIDS organizations, national HIV/AIDS organizations, human rights organizations, human rights commissions, and experts in law and policy.**

Community Participation

> States should ensure, through political and financial support, that community consultation occurs at 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.[550]

People with HIV/AIDS and the populations affected by HIV/AIDS are in the best position to identify the stigma and discrimination they experience, to describe the effects of stigma and discrimination on their lives and health, and to state what they would consider to be non-stigmatizing and non-discriminatory treatment. It was noted at the outset of this Paper that not all discrimination is intentional or malevolent; some of it is inadvertent or systemic. By involving people with HIV/AIDS and the populations affected by HIV/AIDS in designing, implementing, and evaluating policies and programs, there is a greater likelihood that policies and programs will not be discriminatory and will help to eliminate stigma and discrimination (along with accomplishing whatever other objectives the policies and programs are intended to achieve).

Recommendation 2

> **2.1 Federal and provincial/territorial governments should involve people with HIV/AIDS, representatives of populations affected by HIV/AIDS, and AIDS service organizations in the design, implementation, and evaluation of policies and programs in HIV/AIDS as well as related areas of activity, such as drug policies and programs, corrections, housing, employment, income support, and disability insurance.**

Data Gathering, Analysis, and Advocacy

> Collection of complaint data by [community-based organizations] and [non-governmental organizations] is vital to inform Governments and the international community where the most serious HIV-related human rights problems are occurring and what effective action should be implemented in response.[551]

Currently, information on cases of HIV/AIDS-related stigma and discrimination is not gathered or analyzed in a systematic way in Canada. Complaints received by human rights commissions represent only a fraction of what people with HIV/AIDS or populations affected by HIV/AIDS experience, inasmuch as an incident may not be actionable under the terms of human rights law or as individuals choose, for a variety of reasons, not to make a complaint. Community-based organizations or networks are familiar with the range and frequency of stigmatizing or discriminatory experiences, but do not have the staff, capacity, protocols, and systems regionally and nationally to gather the information, analyze the information, and advocate on the basis of the analysis. Such capabilities are required in order to document the impact of HIV/AIDS-related stigma and discrimination, as well as to provide the evidence that may lead to policies and programs that remedy rather than perpetuate or contribute to HIV/AIDS-related stigma and discrimination.

Recommendation 3

> **3.1 Community-based organizations comprised of people with HIV/AIDS and/or populations affected by HIV/AIDS, in consultation and collaboration with human rights organizations, human rights commissions, lawyers and researchers with expertise in HIV/AIDS and human rights, should identify the funding, staff, protocols, systems, and networks that are required at the regional and national levels in order to gather and analyze information on HIV/AIDS-related stigma and discrimination in Canada.**
>
> **3.2 Community-based organizations comprised of people with HIV/AIDS and/or populations affected by HIV/AIDS, in consultation and collaboration with human rights organizations, human rights commissions, lawyers and researchers with expertise in HIV/AIDS and human rights, should identify the processes that should be established to identify areas of priority in gathering information, analyzing information, developing policy, and advocacy with regard to HIV/AIDS-related stigma and discrimination.**
>
> **3.3 The federal and provincial/territorial governments should provide funding through their community-based HIV/AIDS, health promotion, and human rights**

> **programs to support the infrastructure required to gather information, analyze information, develop policy, and advocate with regard to HIV/AIDS-related stigma and discrimination.**

Legal Services

> States should implement and support legal services that will educate people affected by HIV/AIDS about their rights, provide free legal services to enforce those rights, develop expertise on HIV-related legal issues and utilize means of protection in addition to the courts, such as offices of Ministries of Justice, ombudspersons, health complaint units and human rights commissions.[552]

People who have experienced discrimination as a result of their HIV status or their association with a population affected by HIV/AIDS may require specialized legal advice, but are often not able to afford such advice. Likewise, community-based organizations, in supporting people with HIV/AIDS or populations affected by HIV/AIDS, need access to legal counsel familiar with the problems encountered by people with HIV/AIDS and knowledgeable in the available avenues for redress. It is essential that legal clinics specializing in HIV/AIDS issues be supported at the regional level, and that networks of lawyers providing advice to people with HIV/AIDS be developed. It is also necessary to develop ways to provide legal support to people with HIV/AIDS in smaller centres or rural areas by, for example, creating links with legal clinics in larger centres.

Recommendation 4

> **4.1 Provincial/territorial governments and provincial/territorial law societies should provide support, within their systems of legal aid, for specialized legal services for people with HIV/AIDS and populations affected by HIV/AIDS.**
>
> **4.2 Legal clinics and lawyers that specialize in case law relating to HIV/AIDS, together with community-based organizations serving people with HIV/AIDS and populations affected by HIV/AIDS, should develop collaborative networks to facilitate access to legal advice on issues and incidents of HIV/AIDS-related stigma and discrimination.**

Law Reform

> States should review and reform criminal laws and correctional systems to ensure that they are consistent with international human rights obligations and are not misused in the context of HIV/AIDS or targeted against vulnerable groups.[553]
>
> States should enact or strengthen anti-discrimination and other protective laws that protect vulnerable groups, people living with HIV/AIDS and people with disabilities from discrimination in both the public and private sectors, that will ensure privacy and confidentiality and ethics in research involving human subjects, emphasize education and conciliation and provide for speedy and effective administrative and civil remedies.[554]

The persistence of HIV/AIDS-related discrimination, the evolution of the HIV epidemic, the limitations of current human rights legislation in Canada, and the direct or indirect impact of laws and policies in areas not explicitly identified with human rights (such as drug laws and policies, and laws and policies relating to sex work) - all point to the need for ongoing review and reform of laws and regulations in Canada, as well as the interpretation and enforcement of laws and regulations, that have an adverse effect on the HIV epidemic, on people with HIV/AIDS, and on populations affected by HIV/AIDS. This activity is an extension of the work of data gathering, analysis, and advocacy, but requires specific knowledge and expertise in the areas of law in question.

Although human rights tribunals have delivered several important decisions regarding the rights of people with HIV/AIDS, there are also a number of drawbacks to the human rights procedures at present. These include procedural delays, failure to investigate complaints thoroughly, the small number of cases that can be or are referred to human rights tribunals, and the limitations of an individual complaints system in preventing discrimination. These drawbacks call into question the practical value of human rights legislation and human rights commissions for most people who experience HIV/AIDS-related discrimination. Human rights commissions are themselves aware of these difficulties, and some are taking steps to address them. In their efforts to reform human rights legislation and procedures in Canada, human rights commissions should incorporate, along with analyses of other areas of discrimination, analysis of the full spectrum of HIV/AIDS-related discrimination, including those areas not currently or easily actionable under human rights law.

Several human rights commissions in Canada have been proactive in developing policies on the rights of persons with HIV/AIDS or populations affected by HIV/AIDS. Those that have not taken this step should consider doing so, and those that have already developed policies should review them periodically to ensure that they address the kinds of discrimination that are currently affecting people with HIV/AIDS or populations affected by HIV/AIDS. For example, human rights commissions may need to review their policies on discrimination on grounds of mental or physical disability to ensure that their interpretation of the definition of disability encompasses the episodic and cyclical nature of HIV disease, the psychosocial dimensions of HIV disease as well as physical functioning and immunological markers, and disability due to alcohol or drug addiction.

Recommendation 5

> **5.1 Within the framework for action on HIV/AIDS-related stigma and discrimination, to be developed in Phase III of the National AIDS Strategy, there should be a specific initiative to identify areas of law and of law enforcement that contribute to HIV/AIDS-related discrimination or have an adverse effect on people with HIV/AIDS and/or populations affected by HIV/AIDS, and to recommend reforms in these areas of law and law enforcement.**
>
> **5.2 Human rights commissions, in consultation with community-based organizations and lawyers specializing in HIV/AIDS case law, should develop and/or review policies on the rights of people with HIV/AIDS and populations affected by HIV/AIDS. These policies should address issues that emerge as the HIV epidemic, treatment options, and prognosis for people with HIV/AIDS evolve, including (but not restricted to) such issues as definition of disability; actuarial grounds for excluding people with HIV/AIDS from insurance coverage or benefits; workplace accommodation; and discrimination based on socioeconomic status, source of income, or homelessness.**
>
> **5.3 Human rights commissions and departments of justice should continue their efforts to reform human rights legislation and procedures so as to make them more responsive and effective in dealing with discrimination in general and HIV/AIDS-related discrimination in particular. These reforms should render human rights law and procedures more responsive to the full spectrum of HIV/AIDS-related discrimination, including those areas not currently or easily actionable under human rights law.**

Public Education

> States should promote the wide and ongoing distribution of creative education, training and media programmes explicitly designed to change attitudes of discrimination and stigmatization associated with HIV/AIDS to understanding and acceptance.[555]

As the Guidelines on HIV/AIDS and Human Rights note:

> The use of formal standards and their implementation through government processes and law alone cannot change negative attitudes and prejudices surrounding HIV/AIDS into respect for human rights. Public programming explicitly designed to reduce stigma has been shown to help create a supportive environment which is more tolerant and understanding.[556] ... The aim should be to challenge ignorant beliefs, prejudices and

> punitive attitudes by appealing to human compassion and identification with visible individuals. Programming based on fear can be counter-productive by engendering discrimination through panic.[557]

Public education has a role to play in dispelling myths and stereotypes about HIV/AIDS, providing information about the rights and dignity of people with HIV/AIDS and populations affected by HIV/AIDS, and creating a supportive environment for people with HIV/AIDS. Research, planning, and evaluation are required, however, to determine what will be most effective in achieving these goals within the limits of resources available for public education campaigns at the local, regional and national levels. The public education campaigns that were delivered during Phase II of the National AIDS Strategy should provide the basis for such an assessment (along with evaluations of public education campaigns delivered elsewhere in the world), and consultation with community-based organizations, national organizations, and the media should assist in identifying the kind of programming that is required in Phase III of the National AIDS Strategy.

Recommendation 6

> **6.1 Health Canada and provincial/territorial ministries of health should, in collaboration with national and/or local community-based organizations, identify the public education that is currently required to dispel stigmatizing myths and assumptions associated with HIV/AIDS, evaluate the type of programming that is likely to be most effective, and allocate resources to support such programming based on a joint assessment of the contribution of public education relative to other means of reducing stigma and discrimination.**

Professional Education

Health Canada, in collaboration with professional associations, has developed *A Comprehensive Guide for the Care of Persons with HIV Disease* comprised of modules pertaining to adults; infants, children and youth; nursing care; palliative care; and psychosocial care. As these modules are revised and as other modules are completed, it will be important to incorporate information and guidelines that will help professionals and other service providers recognize HIV/AIDS-related stigma and discrimination in their own practices or in the practices of others, develop or foster non-stigmatizing and non-discriminatory practices, and provide appropriate support to people with HIV/AIDS as they deal with the experience and impact of stigma and discrimination. In this regard, in keeping with Recommendation 2, the participation of the community in revising and developing the modules is essential.

Professionals, current and prospective, require not only guidelines in non-stigmatizing and non-discriminatory attitudes and practices, but also education and training in such attitudes and practices.

This includes not only professional attitudes and practices relating to the lifestyle or identity of people with HIV/AIDS and populations affected by HIV/AIDS (such as sexual orientation or drug use), but also attitudes and practices contributing to failure to diagnose HIV infection (such as failure to offer HIV testing to women or heterosexual men) or attitudes and practices that contribute to increased risk of HIV infection (such as limiting the therapeutic options available to drug users). It is especially important to provide education and training to professionals who have only occasional or irregular contact with people with HIV/AIDS. This requires a concerted effort on the part of professional associations and university faculties.

Recommendation 7

> **7.1 In revising or adding modules in the *Comprehensive Guide for the Care of Persons with HIV Disease*, Health Canada, in collaboration with professional associations, providers skilled in the care of people with HIV/AIDS and community representatives, should ensure that professionals have information and guidelines to assist them in delivering non-stigmatizing and non-discriminatory care. Particular attention should be given to appropriate care for gay and bisexual men, drug users, Aboriginal people, and sex workers, as well as populations not readily associated with HIV/AIDS, such as women and heterosexual men.**
>
> **7.2 Professional associations and professional faculties, in collaboration with providers skilled in the care of people with HIV/AIDS and community representatives, should undertake professional education and training that will develop non-stigmatizing and non-discriminatory attitudes and practices among providers working with the diverse populations affected by HIV/AIDS. This education and training should be provided both in degree programs for professionals and in continuing education for professionals.**
>
> **7.3 Professional associations and professional faculties should develop and implement, as an objective within Phase III of the National AIDS Strategy, a strategy to enhance the skills of professionals who provide care to people with HIV/AIDS on an occasional basis.**

Education for Children and Youth

> States should ensure the access of children and adolescents to adequate health information and education, including information related to HIV/AIDS prevention and care, inside and outside school, which is tailored appropriately to age level and capacity and enables them to deal positively and responsibly with their sexuality.[558]

The need for education for children and youth on issues related to HIV/AIDS, sexuality, drug use, and human rights will be ongoing. This requires more widespread and effective delivery of curricula on HIV/AIDS, sexuality, drug use, and human rights in the schools. It also requires alternative means of reaching children and youth outside the school setting, particularly children and youth who are marginalized, who have a history of physical or sexual abuse, or who are street-involved. And, depending on the cultural or religious values of the local community, it may require ongoing dialogue and discussion of the conflict or convergence of values in providing children and youth with information about sexuality, safer sex, and safer drug use.

Recommendation 8

> **8.1 The Council of Ministers of Education should establish objectives for Phase III of the National AIDS Strategy with a view to fostering widespread and effective delivery of curricula designed (with appropriate consideration given to the stage of development of the students) to reduce discriminatory attitudes around HIV/AIDS and sexuality, foster healthy attitudes and behaviours, and provide accurate information about HIV disease and the prevention of HIV infection.**
>
> **8.2 Health Canada and provincial/territorial ministries of health and community or social services should support efforts by community-based organizations and social agencies to reach children and youth - particularly marginalized, abused, or street-involved children and youth - with peer-based and client-determined programs that are non-judgmental, build self-esteem, reduce stigma, and provide information that youth require, in their language.**
>
> **8.3 Local community-based organizations should pursue the avenues they deem to be appropriate and acceptable in concert with cultural and religious organizations and institutions, including schools, to increase knowledge about HIV/AIDS, awareness of the impact of stigma and discrimination in the context of HIV/AIDS, and tolerance for diversity.**

Workplace Policies and Education

The emergence of new drug therapies has heightened the need for policies and education in workplaces about HIV/AIDS, the rights of employees with HIV/AIDS, and non-discrimination with regard to people with HIV/AIDS. While people with HIV/AIDS appreciate the benefits of being able to continue working or to return to work, they also confront problems resulting from disclosure of HIV status at work, insufficient accommodation of their health needs, fear of breach of confidentiality in making insurance claims, harassment, being laid off, and being fired. What is required are not only policies protecting the rights of people with HIV/AIDS, but also concerted effort on the part of employers to provide education about HIV/AIDS in the workplace and to protect the rights of employees with HIV/AIDS.

Recommendation 9

> **9.1 Health Canada and provincial/territorial ministries of health, in collaboration with national organizations, local community-based organizations, and human rights commissions, should provide resources, promote guidelines, and foster new and expanded initiatives to develop and implement HIV/AIDS policies and education in the workplace, while maintaining current initiatives. These activities should address current problems of harassment and discrimination, including breach of confidentiality, failure to accommodate health needs, and inadequate criteria for assessing HIV/AIDS-related disability.**

Research Priorities, Participation, and Ethics

Many populations affected by HIV/AIDS have been underrepresented in research on HIV/AIDS, have not shared equitably in the benefits of research, and are vulnerable to stigma and discrimination both in the research process and in the application of research findings. These populations seek to increase their participation in HIV/AIDS research, to identify research priorities that are relevant to them, to play a role in designing and implementing research, and to be involved in ethical review of research. There are numerous issues to be addressed in this regard, including, for example, ensuring sufficient representation of women, children, or drug users in clinical trials; anticipating potential negative impact of research among drug users on participants of research; ensuring genuine and informed choice in recruiting people with HIV/AIDS who are naive with respect to antiretroviral drugs into clinical trials; and supporting the complex arrangements and accountabilities involved in community-based research.

There is a continuing potential for established traditions of research and lines of inquiry to perpetuate patterns of systemic discrimination in research. To break with those patterns requires a concerted, deliberate, and reflective effort on the part of researchers, their academic institutions, research funding agencies, and research participants.

Recommendation 10

> **10.1 In Phase III of the National AIDS Strategy, the Ministerial Council on HIV/AIDS, in collaboration with the National Health Research and Development Program, should develop a mechanism with significant community participation to identify priorities in areas of research that have been underrepresented in**

> **proportion to current trends in the HIV epidemic.**
>
> **10.2 In Phase III of the National AIDS Strategy, the Canadian Association for HIV/AIDS Research, in collaboration with national HIV/AIDS organizations and the National Health Research and Development Program, should develop guidelines and criteria for inclusion of populations affected by HIV/AIDS in research, and should promote these guidelines and criteria among researchers, peer-review committees, and community-based organizations.**
>
> **10.3 The Ministerial Council on HIV/AIDS should monitor the need for consultations, guidelines or mechanisms for the ethical review of HIV/AIDS research, as required by current or emerging dilemmas in HIV/AIDS research that are not adequately treated by existing guidelines, such as the draft *Code of Ethical Conduct for Research Involving Humans.***

Monitoring and Evaluation

> Standard-setting and promotion of HIV-related human rights standards alone are not enough to address human rights abuses in the context of HIV/AIDS. Effective mechanisms must be established at the national and community levels to monitor and enforce HIV-related human rights.[559]

As stated in the preamble to these recommendations, the specific steps required to overcome the barriers that discrimination and inequality place in the way of preventing HIV infection among and of providing care and treatment for gay and bisexual men, drug users, Aboriginal people, sex workers, prisoners, women and others, have been identified in numerous reports. The recommendations listed above do not and cannot encompass the range and specificity of those reports.

There is clearly a need for an annual evaluation of the progress that has been made in implementing the recommendations set out in these reports, as well as the recommendations set out in this *Discussion Paper*. The framework for action on HIV/AIDS-related discrimination should include a plan for the annual monitoring and evaluation of progress made to prevent, redress, or eliminate HIV/AIDS-related stigma and discrimination, including direct, indirect, and systemic forms of discrimination. This monitoring and evaluation plan should identify specific desired outcomes, agencies responsible for achieving those outcomes, and agencies responsible for ensuring independent evaluation of the achievement of those outcomes. This monitoring and evaluation plan should, where possible, build on or be incorporated into the overall monitoring and evaluation plan of Phase III of the National AIDS Strategy, and should be subject to the approval of the Ministerial Council on HIV/AIDS.

Recommendation 11

> **11.1 Health Canada, in consultation with community-based HIV/AIDS organizations, national HIV/AIDS organizations, professional associations, human rights organizations, and human rights commissions, should develop a plan to monitor and evaluate annually efforts to prevent, redress, or eliminate HIV/AIDS-related discrimination, including direct, indirect, and systemic discrimination.**
>
> **11.2 This monitoring and evaluation plan should identify specific anticipated outcomes, agencies responsible for achieving those outcomes, and agencies responsible for ensuring independent evaluation of the achievement of those outcomes.**
>
> **11.3 The monitoring and evaluation plan should be subject to the approval of the Ministerial Council on HIV/AIDS.**

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FOOTNOTES

[529] As reviewed in the section on diversity, stigma, discrimination, and vulnerability, supra.

[530] As reviewed in the section on current problems for people with HIV/AIDS, supra.

[531] As reviewed in the section on the experiences of specific populations, supra.

[532] Supra, note 4.

[533] Supra, note 3.

[534] Supra, note 5.

[535] Supra, note 257.

[536] Supra, note 65.

[537] Supra, note 211.

[538] Supra, note 212.

[539] *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 61-62.

[540] Canadian AIDS Society. *Sharing the Energy: A National Workshop on Street-Involved People and HIV/AIDS*. Ottawa: Canadian AIDS Society, 1995.

[541] Supra, note 296.

[542] Ibid.

[543] Supra, note 2.

[544] Supra, note 6.

[545] Supra, note 7.

[546] Supra, note 110.

[547] D Allman et al. *Concepts, Definitions and Models for Community-Based HIV Prevention Research in Canada, and a Planning Guide for the Development of Community-Based Prevention Research*. Toronto: HIV Social, Behavioural and Epidemiological Studies Unit, Faculty of Medicine, University of Toronto: 1997.

[548] Supra, note 527, and Appendix A.

[549] Ibid at 29 (Guideline 1).

[550] Ibid at 31 (Guideline 2).

[551] Ibid at 32.

[552] Ibid at 39 (Guideline 7).

[553] Ibid at 34 (Guideline 4).

[554] Ibid at 35 (Guideline 5).

[555] Ibid at 44 (Guideline 9).

[556] Citing R Feachem. *Valuing the Past, Investing in the Future: Evaluation of the National HIV/AIDS Strategy 1993-4 to 1995-6.* Canberra: Commonwealth Department of Human Services and Health, 1995, at 190-192.

[557] Guidelines on HIV/AIDS and Human Rights, supra, note 527 at 45.

[558] Ibid at 43.

[559] Ibid at 47.

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by Theodore de Bruyn

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BIBLIOGRAPHY OF WORKS CITED

"H" onward
"P" onward

Adam BD, A Sears. *Experiencing HIV: Personal, Family and Work Relationships*. New York: Columbia University Press, 1996.

Adams ML. You're All Right So Long As You Act Nice: Lesbians' Experience of North American Health Care System. *Fireweed.* Spring 1989.

Adrien A et al. Overview of the Canadian Study on the Determinants of Ethnoculturally Specific Behaviours Related to HIV/AIDS. *Canadian Journal of Public Health* 1996; 87(Suppl 1): S4-10.

Allen J. Needs Assessment for Women Living with HIV - Nova Scotia. In: C Hankins, L Hum, eds. *Women and HIV National Workshop. Montréal, March 13-14, 1995*. Montréal: McGill AIDS Centre, 1995, 11.

Allman D et al. *Concepts, Definitions and Models for Community-Based HIV Prevention Research in Canada, and a Planning Guide for the Development of Community-Based Prevention Research.* Toronto: HIV Social, Behavioural and Epidemiological Studies Unit, Faculty of Medicine, University of Toronto: 1997.

Alonzo AA, NR Reynolds. Stigma, HIV and AIDS: An Exploration and Elaboration of a Stigma Trajectory. *Social Science and Medicine* 1995; 41(3): 303-315.

Barkan S et al. Sexual Identity and Behaviour among Women with Female Sexual Partners: The Women's Interagency HIV Study (WHS). XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Tu.C.2476.

Bastow K. Prostitution and HIV/AIDS. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(2): 12-14.

B.C. Civil Liberties Association. *AIDS Discrimination in Canada: A Study of the Scope and Extent of Unfair Discrimination in Canada against Persons with AIDS, and Those Known or Feared to be HIV Positive.* Vancouver: B.C. Civil Liberties Association, 1989.

Beaugé K. Daycare Centres: Another Area of Concern. *Canadian HIV/AIDS Policy & Law Newsletter* 1995; 1(2): 5.

Bedimo AL et al. History of Sexual Abuse Among HIV-Infected Women. *International Journal of STD & AIDS* 1997; 8(5): 332-335.

Belgrave S. One Employer's Approach to Employee Education. In: D FitzSimons et al, eds. *The Economic and Social Impact of AIDS in Europe.* London: National AIDS Trust, 1995, 357-363.

Bennett MJ et al. An Ethnographic Study of HIV Infected Male-to-Female Transgendered Clients. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Tu.D.2954.

Bernheim J-C, J Montreuil. AIDS, Prisons and Parole. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(2): 20-21.

Black WW. *B.C. Human Rights Review. Report on Human Rights in British Columbia.* Vancouver: Ministry Responsible for Multiculturalism and Human Rights, 1994.

Blendon RJ, K Donelan. Discrimination against People with AIDS: The Public's Perspective. *New England Journal of Medicine* 1988; 319(15): 1022-1026.

Brady D et al. Transgendered People, Discrimination, and HIV/AIDS. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(3): 6-7.

British Columbia Persons With AIDS Society and Health Canada. Vocational and Rehabilitation Services in the Context of HIV Infection: Issues and Guiding Principles (Draft). January 1998.

Brown KH. Descriptive and Normative Ethics: Class, Context and Confidentiality for Mothers with HIV. *Social Science and Medicine* 1993; 36(3): 195-202.

Bruneau J et al. High Rates of HIV Infection among Injection Drug Users Participating in Needle Exchange Programs in Montreal: Results of a Cohort Study. *American Journal of Epidemiology* 1997; 146(12): 994-1002.

Calabrese LH et al. Physicians' Attitudes, Beliefs, and Practices Regarding AIDS Health Care Promotion. *Archives of Internal Medicine* 1991; 151(6): 1157-1169.

Calzavara LM et al. Reducing HIV Transmission among IDUs in Prison: The Inmates' Perspective. *Canadian Journal of Infectious Diseases* 1995; 6(Suppl B): 36B. Abstract no. 404.

Calzavara LM et al. Reducing Volunteer Bias: Using Left-Over Specimens to Estimate Rates of HIV Infection among Inmates in Ontario, Canada. *AIDS* 1995; 9(6): 631-637.

Calzavara LM et al. The Prevalence of HIV-1 Infection among Inmates in Ontario, Canada. *Canadian Journal of Public Health* 1995; 86(5): 335-339.

Calzavara LM et al. *Understanding HIV-Related Risk Behaviour in Prisons: The Inmates' Perspective.* Toronto: HIV Social, Behavioural and Epidemiological Studies Unit, Faculty of Medicine, University of Toronto, 1997.

Campbell CA, MD Peck. Issues in HIV/AIDS Service Delivery to High Risk Youth. *Journal of Gay and Lesbian Social Services* 1995; 2(3/4): 159-177.

Canadian Aboriginal AIDS Network. *Report of the Aboriginal Consultation of the National AIDS Strategy Phase I-II. September 22 - October 10, 1997.* Ottawa: Canadian Aboriginal AIDS Network, 1997.

Canadian AIDS Society. *Critical Work: Sustaining Men Who Have Sex With Men Programs in Canada.* Ottawa: Canadian AIDS Society, 1997.

Canadian AIDS Society. Poverty, Discrimination and HIV/AIDS. A Brief to the Parliamentary Sub-Committee on HIV/AIDS. October 1996.

Canadian AIDS Society. *Sharing the Energy. A National Workshop on Street-Involved People and HIV/AIDS. Workshop Report.* Ottawa: Canadian AIDS Society, 1995.

Canadian Human Rights Commission. Background Notes: CHRC Policy on HIV/AIDS. June 1996.

Canadian Human Rights Commission. Filing a Complaint with the Canadian Human Rights Commission. Ottawa: Minister of Supply and Services, 1994.

Canadian Human Rights Commission. Policy on HIV/AIDS. June 1996.

Canadian Human Rights Commission Releases Revised Policy on HIV/AIDS. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 3(1): 7-8.

Canadian Public Health Association. AIDS and Workplace Policy. March 1997.

Carey R. Challenging Ontario's Denial of Medical Care to HIV-Positive Immigrants. *Canadian HIV/ AIDS Policy & Law Newsletter* 1997; 3(2/3): 18-19.

Carey R. Provision of Legal Services to Persons with HIV or AIDS: Barriers and Trends. *Canadian HIV/ AIDS Policy & Law Newsletter* 1997/1998; 3(4)/4(1): 9-11.

Casswell DG. *Lesbians, Gay Men, and Canadian Law*. Edmond Montgomery Publications Ltd, 1996.

Centre for Human Rights. *Report of an International Consultation on AIDS and Human Rights, Geneva, 26-28 July 1989*. New York: United Nations, 1991.

Charpentier D. *Le droit au service de garde pour les enfants atteints du VIH/SIDA. Document adopté à la 392^{e} séance de la Commission tenue le 19 mai 1995, par sa résolution COM-392-6.1.2*. Montréal: Commission des droits de la personne du Québec, 1995.

Cohen S, TA Wills. Stress, Social Support, and the Buffering Hypothesis. *Psychological Bulletin* 1985; 98(2): 310-357.

Cornelisse PGA et al. A Comparison of Risk Factors for HIV Transmission Between Two Cohorts of Gay Men (1982-84 vs. 1995). XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Tu.C.2393.

Correctional Service Canada. *1995 National Inmate Survey: Final Report - Main Appendix*. Ottawa: Correctional Research and Development, 1996.

Cruel and Unusual: Disproportionate Sentences for New York Drug Offenders. *Human Rights Watch* 1997; 9(2).

Day S, H Ward. Sex Workers and the Control of Sexually Transmitted Disease. *Genitourinary Medicine* 1997; 73: 161-168.

Decosas J, A Adrien. Migration and HIV. *AIDS* 11(Suppl A): S77-S84.

Defert D. AIDS as a Challenge to Religions. In: J Mann, D Tarantola, eds. *AIDS in the World II: Global Dimensions, Social Roots, and Responses*. New York: Oxford University Press, 1996, 447-452.

Demi A et al. Effects of Resources and Stressors on Burden and Depression of Family Members who Provide Care to an HIV-Infected Woman. *Journal of Family Psychology* 1997; 11(1): 35-48.

Deschamps LR et al. National Surveillance of Occupational Exposure to HIV in Canada. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases*

1997; 8(Suppl A): 25A. Abstract no. 212.

Division of HIV Epidemiology, Laboratory Centre for Disease Control, Health Canada. *Inventory of HIV Incidence and Prevalence Studies in Canada*. May 1997.

Dolan K et al. HIV Risk Behaviour of IDUs Before, During and After Imprisonment in New South Wales. *Addiction Research* 1996; 4(2): 151-160.

Dufour A et al. Prevalence and Risk Behaviours for HIV Infection among Inmates of a Provincial Prison in Quebec City. *AIDS* 1996; 10(9): 1009-1015.

Dussault J. HIV/AIDS and Child Care. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(3): 7-8.

Elliott R. *Criminal Law and HIV/AIDS: Final Report.* Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1997.

Elliott R. Justice Delayed and Denied in Biting Case. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 44.

Elliott R. Prisoners' Constitutional Right to Sterile Needles and Bleach. In: R Jürgens. *HIV/AIDS in Prisons: Final Report.* Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1996. Appendix 2.

Elwood WN et al. Powerlessness and HIV Prevention among People Who Trade Sex for Drugs. *AIDS Care* 1997; 9(3): 273-284.

Epp J. Achieving Health for All: A Framework for Health Promotion. *Canadian Journal of Public Health* 1986; 77(6): 393-424.

Expert Committee on AIDS and Prisons. *HIV/AIDS in Prisons: Summary Report and Recommendations of the Expert Committee on AIDS and Prisons.* Ottawa: Minister of Supply and Services Canada, 1994.

Feachem R. *Valuing the Past, Investing in the Future: Evaluation of the National HIV/AIDS Strategy 1993-4 to 1995-6.* Canberra: Commonwealth Department of Human Services and Health, 1995

Federal Centre for AIDS Working Group on HIV Infection and Mental Health. *Ending the Isolation: HIV Disease and Mental Health in the Second Decade*. Ottawa: Minister of Supply and Services, 1992.

Federal, Provincial and Territorial Advisory Committee on Population Health. *Report on the Health of Canadians: Technical Appendix*. Ottawa: Minister of Supply and Services, 1996.

Federal/Provincial/Territorial Advisory Committee on AIDS Working Group on Partner Notification. *Guidelines for Practice for Partner Notification in HIV/AIDS*. January 1997.

Fish TA, BJ Rye. Attitudes toward a Homosexual or Heterosexual Person with AIDS. *Journal of Applied Social Psychology* 1991; 21(8): 651-667.

Fisher J et al. *Gay and Lesbian Legal Issues and HIV/AIDS: Final Report*. Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998.

FitzSimons D et al, eds. *The Economic and Social Impact of AIDS in Europe*. London: National AIDS Trust, 1995.

Gendron S. Needs Assessment for Women Living with HIV - Montréal. In: C Hankins, L Hum, eds. *Women and HIV National Workshop. Montréal, March 13-14, 1995*. Montréal: McGill AIDS Centre, 1995, 9-10.

Gerberding JL. Occupational HIV Infection. *AIDS* 1997; 11(Suppl A): S57-S60.

Gilmore N, MA Somerville. Stigmatization, Scapegoating and Discrimination in Sexually Transmitted Diseases: Overcoming 'Them' and 'Us'. *Social Science and Medicine* 1994; 39(9):1339-1358.

Gleghorn AA et al. Inadequate Bleach Contact Times During Syringe Cleaning Among Injection Drug Users. *Journal of Acquired Immune Deficiency Syndromes* 1994; 7(7): 767-772.

Godin G et al. Understanding Dentists' Decision to Provide Dental Care to HIV Seropositive/AIDS Patients. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 20A. Abstract no. 149.

Godin G et al. Understanding the Intention of Gay and Bisexual Men to Take the HIV Antibody Test. *AIDS Care* 1997; 9(1): 31-41.

Goldie RS et al. *Children Born to Mothers with HIV: Psychosocial Issues for Families in Canada Living with HIV/AIDS*. Toronto: The Hospital for Sick Children, 1997.

Gostin LO. The AIDS Litigation Project. A National Review of Court and Human Rights Commission Decisions, Part II: Discrimination. *Journal of the American Medical Association* 1990; 263(15): 2086-2093.

Gostin LO, Z Lazzarini. *Human Rights and Public Health in the AIDS Pandemic*. New York: Oxford University Press, 1997.

Green G. Attitudes Towards People with HIV: Are They as Stigmatizing as People with HIV Perceive Them to Be? *Social Science and Medicine* 1995; 41(4): 557-568.

Green G. Processes of Stigmatization and Impact on the Employment of People with HIV. In: D FitzSimons et al, eds. *The Economic and Social Impact of AIDS in Europe*. London: National AIDS Trust, 1995, 251-262.

Green G. Stigma and Social Relationships of People with HIV: Does Gender Make a Difference? In: L Sherr et al, eds. *AIDS as a Gender Issue: Psychosocial Perspectives*. London: Taylor and Francis, 1996, 46-63.

Grimaldi JM, J Jacobs. HIV/AIDS Transgender Support Group: Improving Care Delivery and Creating a Community. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Tu.D.2953.

Grubb I, C McClure. *Back to the Future: A Feasibility Study on Return-to-Work Programming for People Living with HIV/AIDS.* Toronto: AIDS Committee of Toronto, 1997.

Guillot-Hurtubise B. Dentist Found Guilty of Discrimination. *Canadian HIV/AIDS Policy & Law Newsletter* 1995; 1(4): 1, 14-15.

Hackl KL et al. Women Living with HIV/AIDS: The Dual Challenge of Being a Patient and Caregiver. *Health and Social Work* 1997; 22(1): 53-62.

Haley N. HIV Testing for Women - Timing/Reproductive Choices/Provincial and Other Recommendations. In: C Hankins, L Hum, eds. *Women and HIV National Workshop. Montréal, March 13-14, 1995.* Montréal: McGill AIDS Centre, 1995, 18-20.

Hankins C. HIV Counselling and Testing Issues for Women - Testing Experiences of HIV+ Women, Montréal. In: C Hankins, L Hum, eds. *Women and HIV National Workshop. Montréal, March 13-14, 1995.* Montréal: McGill AIDS Centre, 1995, 17.

Hankins CA, MA Handley. HIV Disease and AIDS in Women: Current Knowledge and a Research Agenda. *Journal of Acquired Immune Deficiency Syndromes* 1992; 5(10): 957-971.

Hankins C, L Hum, eds. *Women and HIV National Workshop. Montréal, March 13-14, 1995.* Montréal: McGill AIDS Centre, 1995.

Hays RB et al. Disclosing HIV Seropositivity to Significant Others. *AIDS* 1993; 7(3): 425-431.

Healing Our Nations. 4th Canadian Aboriginal Conference on HIV/AIDS and Related Issues. Halifax, November 1996.

Health and Welfare Canada. *HIV and AIDS: Canada's Blueprint.* Ottawa: Minister of Supply and Services, 1990.

Health Canada. *AIDS in Canada: Quarterly Surveillance Update*. Ottawa, August 1997.

Health Canada. *HIV in Canada: Surveillance Report for the Period 1985-1995*. Ottawa: December 1996.

Health Canada. *HIV/AIDS Epi Update: HIV and AIDS Among Men Who Have Sex with Men*. Ottawa, November 1997.

Health Canada. *HIV/AIDS Epi Update: HIV and AIDS among Women in Canada*. Ottawa, November 1997.

Health Canada. *HIV/AIDS Epi Update: HIV/AIDS among Injection Drug Users in Canada*. Ottawa, November 1997.

Health Canada. *HIV/AIDS Epi Update: HIV/AIDS Epidemiology among Aboriginal People in Canada*. Ottawa, November 1997.

Health Canada. *HIV/AIDS Epi Update: Sexual Risk Behaviours of Canadians.* Ottawa, November 1997.

Health Canada. *Perinatally Acquired HIV Infection.* Ottawa, November 1997.

Health Canada. *The Business Case for HIV/AIDS. What Can You Do?* Ottawa: Minister of Supply and Services, 1996.

Health Canada. *The Experiences of Young Gay Men in the Age of HIV*. Ottawa: Minister of Supply and Services, 1996.

Heath KV et al. HIV/AIDS Care Giving Physicians: Their Experience and Practice Patterns. *International Journal of STD & AIDS* 1997; 8(9): 570-575.

Heath KV et al. Physician Concurrence with Primary Care Guidelines for Persons with HIV Disease. *International Journal of STD & AIDS* 1997; 8(10): 609-613.

Hendriks A, S Leckie. Housing Rights and Housing Needs in the Context of AIDS. *AIDS* 1993; 7(Suppl 1): S271-280.

Herek GM, EK Glunt. An Epidemic of Stigma: Public Reactions to AIDS. *American Psychologist* 1988; 43(11): 886-891.

Herek GM, JP Capitanio. Public Reactions to AIDS in the United States: A Second Decade of Stigma. *American Journal of Public Health* 1993; 83(4): 574-577.

Herland K. Mobilisation/Intervention - What Have We Learned? - Commercial Sex Workers. In: C Hankins, L Hum, eds. *Women and HIV National Workshop. Montréal, March 13-14, 1995*. Montréal: McGill AIDS Centre, 1995, 24.

Herland K. Stella: Addressing Sex Workers' Risk for HIV/AIDS in Context. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Th.C.4640.

Hertz-Picciotto I et al. HIV Test-Seeking Before and After Restriction of Anonymous Testing in North Carolina. *American Journal of Public Health* 1996; 86(10): 1446-1450.

HIV Infection in the Workplace. *Canadian Medical Association Journal* 1993; 148(10): 1800A-D.

Hogg RS et al. Lower Socioeconomic Status and Shorter Survival Following HIV Infection. *The Lancet* 1994; 344: 1120-1124.

House of Commons of Canada. 35th Parliament, 2nd Session. Sub-Committee on HIV/AIDS of the Standing Committee on Health. Meeting no. 10, 5 November 1996.

House of Commons of Canada. 35th Parliament, 2nd Session. Sub-Committee on HIV/AIDS of the Standing Committee on Health. Meeting no. 12, 26 November 1996.

International Council of AIDS Service Organizations. *An Advocate's Guide to the International Guidelines on HIV/AIDS and Human Rights*. October 1997.

International Council of AIDS Service Organizations. *NGO Summary of the International Guidelines on HIV/AIDS and Human Rights*. 1997.

Jackson LA, A Highcrest. Female Prostitutes in North America: What Are Their Risks of HIV Infection? In: L Sherr et al, eds. *AIDS As A Gender Issue: Psychosocial Perspectives*. London: Taylor & Francis, 1996, 149-162.

Jackson LA et al. HIV-Positive Women Living in the Metropolitan Toronto Area: Their Experiences and Perceptions Related to HIV Testing. *Canadian Journal of Public Health* 1997; 88(1):18-22.

Jacob J, H Stöver. Germany - Needle Exchange in Prisons in Lower Saxony: A Preliminary Review. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 30-31.

Jacoby A. Felt versus Enacted Stigma: A Concept Revisited. Evidence from a Study of People with

Epilepsy in Remission. *Social Science and Medicine* 1994; 38(2): 269-274.

Jalbert Y. The Coming Out Process among Gay Youth and the Impact on the Health Services. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 13A. Abstract no. 121.

Jalbert Y. Triple-Drug Therapy and Return to Work: Results of a Québec Survey. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/1998; 3(4)/4(1): 13-14.

Johnson SD. Models of Factors Related to Tendencies to Discriminate Against People with AIDS. *Psychological Reports* 1995; 76(2): 563-572.

Jürgens R. *HIV Testing and Confidentiality: Final Report.* Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998.

Jürgens R. *HIV/AIDS in Prisons: Final Report.* Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1996.

Jürgens R. Immigration Policy May Be Reviewed to Require Routine HIV Testing of Immigrants. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 16-18.

Jürgens R. Methadone, But No Needle Exchange Pilot in Federal Prisons. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 26-27.

Jürgens R, M Palles. *HIV Testing and Confidentiality. A Discussion Paper.* Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1997.

Jürgens R. Your Health is Back. Now You May Lose Your Protection against Discrimination. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 3-5.

Kadushin G. Gay Men with AIDS and their Families of Origin: An Analysis of Social Support. *Health and Social Work* 1996; 21(2): 141-149.

Kandel DB. The Social Demography of Drug Use. In: R Bayer, GM Oppenheimer, eds. *Confronting Drug Policy: Illicit Drugs in a Free Society*. New York: Cambridge University Press, 1993, 24-79.

Kass NE et al. Changes in Employment, Insurance, and Income in Relation to HIV Status and Disease Progression. *Journal of Acquired Immune Deficiency Syndrome*s 1994; 7: 86-91.

Keene J. *Human Rights in Ontario.* 2nd ed. Scarborough: Carswell, 1992.

Kelly JA et al. Nurses' Attitudes Towards AIDS. *The Journal of Continuing Education in Nursing* 1988; 19(2): 78-83.

Kelly JA et al. Stigmatization of AIDS Patients by Physicians. *American Journal of Public Health* 1987; 77(7): 789-791.

King AJC et al. *Canada Youth and AIDS Study*. Kingston: Social Program Evaluation Group, Queen's University, 1988.

King SM et al. The Canadian Perinatal HIV Surveillance Program. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Mo.C.1404.

Kirby M. The Judicial Response to HIV/AIDS. *International Journal of STD & AIDS* 1997; 8(4): 265-271.

Kirkham CM, D Lobb. The B.C. Positive Women's Survey: Sociodemographic Characteristics, Health Status and Attitudes Towards Medical Care. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Tu.C.2447.

Kornblum W. Drug Legalization and the Minority Poor. In: R Bayer, GM Oppenheimer, eds. *Confronting Drug Policy: Illicit Drugs in a Free Society*. New York: Cambridge University Press, 1993, 115-135.

Krueger LE et al. Poverty and HIV Seropositivity: The Poor are More Likely to Be Infected. *AIDS* 1990; 4(8): 811-814.

Kruks G. Gay and Lesbian Homeless/Street Youth: Special Issues and Concerns. *Journal of Adolescent Health* 1991; 12(7): 515-518.

Lamping DL, D Mercey. Health-Related Quality of Life in Women with HIV Infection. In: L Sherr et al, eds. *AIDS As A Gender Issue: Psychosocial Perspectives*. London: Taylor & Francis, 1996, 78-98.

Laryea M, L Gien. The Impact of HIV-Positive Diagnosis on the Individual, Part 1: Stigma, Rejection, and Loneliness. *Clinical Nursing Research* 1993; 2(3): 245-266.

Lawless S et al. Dirty, Diseased and Undeserving: The Positioning of HIV Positive Women. *Social Science and Medicine* 1996; 43(9): 1371-1377.

Le Poire BA. Attraction toward and Nonverbal Stigmatization of Gay Males and Persons with AIDS: Evidence of Symbolic over Instrumental Attitudinal Structures. *Human Communication Research* 1994; 21(2): 241-279.

Lester P et al. The Consequences of a Positive Prenatal HIV Antibody Test for Women. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 1995; 10(3): 341-349.

Levin BW et al. The Treatment of Non-HIV-Related Conditions in Newborns at Risk for HIV: A Survey of Neonatologists. *American Journal of Public Health* 1995; 85(11): 1507-1513.

Lines R. Death Exposes Treatment of Prisoners Living with HIV/AIDS. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 29-30.

Lines R, L Ferguson. A Peer Driven AIDS Outreach, Education and Support Program Targeting Prisoners. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. We.D.350.

Littrell J. How Psychological States Affect the Immune System: Implications for Interventions in the Context of HIV. *Health and Social Work* 1996; 21: 287-295.

Locas L et al. *Income Security Project. Phase II: Private Insurance Component.* Ottawa: Canadian AIDS Society, 1996.

MacDonald NE et al. Canadian Street Youth: Correlates of Sexual Risk-Taking Activity. *Pediatrics Infectious Disease Journal* 1994; 13(8): 690-697.

Madsen J. Double Jeopardy: Women, Violence and HIV. *Vis-à-vis* 1996; 13(3): 1, 3.

Malkin I. Australia - Not Giving Up the Fight: Prisoners' Litigation Continues. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 32-33.

Malkin I. The Role of the Law of Negligence in Preventing Prisoners' Exposure to HIV While in Custody. In: R Jürgens. *HIV/AIDS in Prisons: Final Report.* Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1996. Appendix 1.

Mann J, D Tarantola, eds. *AIDS in the World II: Global Dimensions, Social Roots, and Responses.* New York: Oxford Unversity Press, 1996.

Mann J et al, eds. *AIDS in the World.* Cambridge, MA: Harvard University Press, 1992.

Manson Singer S et al. Many Voices - Sociocultural Results of the Ethnocultural Communities Facing AIDS Study in Canada. *Canadian Journal of Public Health* 1996; 87(Suppl 1): S26-32.

Manson Willms S et al. *Choice, Voice and Dignity: Housing Issues and Options for Persons with HIV Infection in Canada. A National Study.* Vancouver: Centre for Human Settlements, University of British Columbia, 1991.

Marquet J et al. Public Awareness of AIDS: Discrimination and the Effects of Mistrust. In: D FitzSimons et al, eds. *The Economic and Social Impact of AIDS in Europe.* London: National AIDS Trust, 1995, 219-233.

Marrazzo JM et al. HIV-Related Risk Behaviour in a Community-Based Sample of Women Who Have Sex with Women. XI International Conference on AIDS, Vancouver, July 1996. Abstract Tu.C.2483.

Martindale SL et al. Evidence of Psychologic Distress in a Cohort of Young Gay/Bisexual Men. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 8A. Abstract no. 102.

Matas R. Religious Leaders Unite Behind Trustees' Ban on Gay Books. *The Globe and Mail.* 19 February 1998, A7.

Matiation S. *Discrimination, HIV/AIDS and Aboriginal People: A Discussion Paper.* Canadian HIV/AIDS Legal Network, 1998.

Matiation S. *HIV Testing and Confidentiality: Issues for the Aboriginal Community: A Discussion Paper.* Canadian HIV/AIDS Legal Network, 1998.

Matiation S. *HIV/AIDS and Aboriginal People: Problems of Jurisdiction and Funding: A Discussion Paper.* Canadian HIV/AIDS Legal Network, 1998.

McAmmond D. *Care, Treatment and Support for Injection Drug Users: Living with HIV/AIDS. A Consultation Report.* March 1997.

McGinn F. The Plight of Rural Parents Caring for Adult Children with HIV. *Families in Society* 1996; 77 (5): 269-278.

McLeod A. *Aboriginal Communities and HIV/AIDS. A Joint Project with the Canadian AIDS Society and the Canadian Aboriginal AIDS Network.* Ottawa: Canadian AIDS Society, 1997.

Meyenberg R et al. *Infektionsprophylaxe im Niedersächsischen Justizvollzug: Eröffnungsbericht zum Modellprojekt.* Oldenburg: Bibliotheks- und Informationssystem der Universität Oldenburg, 1996.

Miles MS et al. Personal, Family, and Health-Related Correlates of Depressive Symptoms in Mothers with HIV. *Journal of Family Psychology* 1997; 11(1): 23-34.

Miller ML et al. Characteristics of Male Sex Trade Workers Enrolled in a Prospective Study of HIV Incidence. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 8A. Abstract no. 101.

Millson et al. Prevalence of Human Immunodeficiency Virus and Associated Risk Behaviours in Injection Drug Users in Toronto. *Canadian Journal of Public Health* 1995; 86(3): 176-180.

Mitchell CN. A Justice-Based Argument for the Uniform Regulation of Psychoactive Drugs. *McGill Law Journal* 1986; 31: 212-263.

Mondragón D et al. Hostility to People with AIDS: Risk Perception and Demographic Factors. *Social Science and Medicine* 1991; 32(10): 1137-1142.

Myers T et al. Bisexual Men and HIV in Ontario: Sexual Risk Behaviour with Men and with Women. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 23A. Abstract no. 203.

Myers T et al. *The Canadian Survey of Gay and Bisexual Men and HIV Infection: Men's Survey*. Ottawa: Canadian AIDS Society, 1993.

Myers T et al. The Role of Policy in Community Pharmacies' Response to Injection Drug Use: Results of a Nationalwide Canadian Survey. *AIDS & Public Policy Journal* 1996; 11(2): 78-88.

Myers T et al. Variations in Sexual Orientations Among Men Who Have Sex with Men, and Their Current Sexual Practices. *Canadian Journal of Public Health* 1995; 86(6): 384-388

National Academy of Sciences. *Confronting AIDS: Update 1988.* Washington, DC: National Academy Press, 1988.

National Advisory Committee on AIDS. *HIV and Human Rights in Canada.* Ottawa: National Advisory Committee on AIDS, 1992.

National AIDS Strategy: Phase III Consultation. A Summary Report of Results. Toronto: University of Toronto, Centre for Health Promotion, October 1997.

National Forum on Health. *Canada Health Action: Building on the Legacy.* Vol. 2: *Synthesis Reports and Issues Papers*. Ottawa: The National Forum on Health, 1996.

Neal JJ et al. Trends in Heterosexually Acquired AIDS in the United States, 1988 Through 1995. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 1997; 14(5): 465-474.

Nelles J, A Fuhrer. *Drug and HIV Prevention at the Hindelbank Penitentiary. Abridged Report of the Evaluation Results.* Berne: Swiss Federal Office of Public Health, 1995.

New South Wales Anti-Discrimination Board. *Discrimination - The* Other *Epidemic. Report of the*

Inquiry into HIV and AIDS Related Discrimination. The Board: 1992.

Nichol TL. Bleach Kit Distribution Pilot Project in a Canadian Federal Institution. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. We.D.356.

Nonn E et al. Construction de l'échantillon à partir d'une population difficile à définir: Diversité versus représentativité. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 9A. Abstract no. 107.

Nonn E et al. Dimensions identitaires, appartenance à la communauté gaie et prévention contre le virus du sida. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 9A. Abstract no. 104.

O'Hare T et al. Fear of AIDS and Homophobia: Implications for Direct Practice and Advocacy. *Social Work* 1996; 41(1): 51-58.

Ontario Human Rights Commission. *Annual Report 1996-97.* Toronto: Ontario Human Rights Commission, 1997.

Ontario Human Rights Commission. Know Your Rights: AIDS and AIDS-Related Illness and the Human Rights Code.

Ontario Human Rights Commission. Policy on HIV/AIDS-Related Discrimination. November 1996.

Oscapella E. Criminal Law and Drugs. In: *Second National Workshop on HIV, Alcohol, and Other Drug Use Proceedings. Edmonton, Alberta. February 6-9, 1994.* Ottawa: Canadian Centre on Substance Abuse, 1994, 38-40.

Parent R et al. HIV Among IDUs: Second Surveillance Year of the Survidu Network. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 27A. Abstract no. 220.

Parmet WE, DJ Jackson. No Longer Disabled: The Legal Impact of the New Social Construction of HIV. *American Journal of Law & Medicine* 1997; 23(1): 8-43.

Peruga A, DD Celentano. Correlates of AIDS Knowledge in Samples of the General Population. *Social Science and Medicine* 1993; 36(4): 509-524.

Peters L et al. Public Reactions Towards People with AIDS: An Attributional Analysis. *Patient Education and Counseling* 1994; 24(3): 323-335.

Phillips KA et al. HIV Counseling and Testing of Pregnant Women and Women of Childbearing Age by Primary Care Providers: Self-Reported Beliefs and Practices. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 1997; 14(2): 174-178.

Philp M. Rights Panels Losing to Abuse, Commission Says. *The Globe and Mail*. Wednesday, 25 March 1998, A3.

Ploem C, A Toepell. Pilot Inmate AIDS Peer Education Project. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. We.D.354.

Poulin C et al. Prevalence and Incidence of HIV among Injecting Drug Users (IDU) Attending a Needle Exchange Program (NEP) in Québec City. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 27A. Abstract no. 218.

Powell-Cope GM, MA Brown. Going Public as an AIDS Family Caregiver. *Social Science and Medicine* 1992; 34(5): 571-580.

Pryor JB et al. Fear and Loathing in the Workplace: Reactions to AIDS-Infected Co-Workers. *Personality and Social Psychology Bulletin* 1991; 17(2): 133-139.

Pryor JB et al. The Instrumental and Symbolic Functions of Attitudes toward Persons with AIDS. *Journal of Applied Social Psychology* 1989; 19(5): 377-404.

Radkowsky M, LJ Siegel. The Gay Adolescent: Stressors, Adaptations, and Psychosocial Interventions. *Clinical Psychology Review* 1997; 17(2): 191-216.

Ramsay H. Lesbians and the Health Care System. Invisibility, Isolation and Ignorance - You Say You're a What? *Canadian Woman Studies* 14(3): 22-27.

Renaud A et al. Knowledge and Attitude Assessment of Quebec Daycare Workers and Parents Regarding HIV/AIDS and Hepatitis B. *Canadian Journal of Public Health* 1997; 88(1): 23-26.

Rothenberg KH, SJ Paskey. The Risk of Domestic Violence and Women with HIV Infection: Implications for Partner Notification, Public Policy, and the Law. *American Journal of Public Health* 1995; 85(11): 1569-1576.

Rothon DA et al. Prevalence of HIV Infection in Provincial Prisons in British Columbia. *Canadian Medical Association Journal* 1994; 151(6): 781-787.

Rothon DA. Methadone in Provincial Prisons in British Columbia. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 27-29.

Roy DJ. HIV Infection and AIDS: Ethical Issues. In: Royal Society of Canada. *AIDS: A Perspective for Canadians. Background Papers*. Ottawa: Royal Society of Canada, 1988, 315-331

Roy E et al. Risk Factors for HIV Infection in Street Youth. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Tu.C.2629.

Royal Commission on Aboriginal Peoples. *Report of the Royal Commission on Aboriginal Peoples.* Vol. 3: *Gathering Strength.* Ottawa: Minister of Supply and Services, 1996.

Schechter MT et al. Higher Socioeconomic Status is Associated with Slower Progression of HIV Infection Independent of Access to Health Care. *Journal of Clinical Epidemiology* 1994; 47(1): 59-67.

Schneider MS, ed. *Pride & Prejudice: Working with Lesbian, Gay and Bisexual Youth.* Toronto: Central Toronto Youth Services, 1997.

Scrambler G, A Hopkins. Being Epileptic: Coming to Terms with Stigma. *Sociology of Health and Illness* 1986; 8: 26-43.

Shaw M et al. Survey of Patients' Views on Confidentiality and Non-Discrimination Policies in General Practice. *British Medical Journal* 1996; 312(7044): 1463-1464.

Sherr L et al, eds. *AIDS as a Gender Issue: Psychosocial Perspectives*. London: Taylor and Francis, 1996.

Sherr L. Tomorrow's Era: Gender, Psychology and HIV Infection. In: L Sherr et al, eds. *AIDS As A Gender Issue: Psychosocial Perspectives.* London: Taylor & Francis, 1996, 16-45.

Shewan D et al. Behavioural Change Amongst Drug Injectors in Scottish Prisons. *Social Science and Medicine* 1994; 39(11): 1585-1586.

Shewan D et al. Prison as a Modifier of Drug Using Behaviour. *Addiction Research* 1994; 2(2): 203-215.

SIDA en milieu de travail: Guide d'information et d'intervention. Montréal: Comité sur le sida en milieu de travail, 1997.

Simoni JM et al. Disclosing HIV Status and Sexual Orientation to Employers. *AIDS Care* 1997; 9(5): 589-599.

Stokes JP et al. Comparing Gay and Bisexual Men on Sexual Behaviours and Attitudes Relevant to HIV/AIDS. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Tu.C.2404.

Strathdee SA et al. HIV Prevalence, Incidence and Risk Behaviours Among a Cohort of Young Gay/ Bisexual Men. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 24A. Abstract no. 204.

Strathdee SA et al. Needle Exchange Is Not Enough: Lessons from the Vancouver Injecting Drug Use Study. *AIDS* 1997; 11(8): F59-F65.

Strike C et al. Nonconsensual Sex and Unsafe Sexual Behaviour: Results from the Bisex Survey. 6th Annual Canadian Conference on HIV/AIDS Research, May 1997. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl A): 14A. Abstract no. 124.

Taggart ME et al. Attitudes d'infirmières francophones face au sida. *L'infirmière canadienne* 1992; 88 (1): 48-52.

Tarnopolsky WS et al. *Discrimination and the Law in Canada*. 5th Release. Toronto: Richard De Boo, December 1997.

Task Force on HIV, AIDS, and Injection Drug Use. *HIV, AIDS and Injection Drug Use: A National Action Plan*. May 1997.

Taylor A et al. Outbreak of HIV Infection in a Scottish Prison. *British Medical Journal* 1995; 310: 289-292.

Travel and Immigration: Policy for Persons Living with HIV/AIDS. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(2): 14-15.

Travers M, L Bennett. AIDS, Women and Power. In: L Sherr et al, eds. *AIDS As A Gender Issue: Psychosocial Perspectives*. London: Taylor & Francis, 1996, 64-77.

Tremble B et al. Health Care and Social Service Needs of Gays, Lesbians, Bisexual and Transsexual Communities in Ontario. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Pub. D.1465.

Tri-Council Working Group. *Code of Ethical Conduct for Research Involving Humans*. Ottawa: The Medical Research Council of Canada, The Natural Sciences and Engineering Research Council of Canada, The Social Sciences and Humanities Research Council of Canada, July 1997.

UNAIDS. Protocol for the Identification of Discrimination against People Living with HIV. Geneva: UNAIDS, 1996.

UNAIDS. *The UNAIDS Guide to the United Nations Human Rights Machinery for AIDS Service Organizations, People Living with HIV/AIDS, and Others Working in the Area of HIV/AIDS and Human*

Rights. Geneva: Joint United Nations Programme on HIV/AIDS, 1997.

United Nations Commission on Human Rights. *Second International Consultation on HIV/AIDS and Human Rights (Geneva, 23-25 September 1996). Report of the Secretary General*. 20 January 1997 (document no. E/CN.4/1997/37).

Valleroy LA et al. HIV and Risk Behaviour Prevalence among Young Men Who Have Sex with Men Sampled in Six Urban Counties in the USA. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Tu.C.2407.

van Ameijden EJC et al. Injecting Risk Behaviors among Drug Users in Amsterdam, 1986 to 1992, and Its Relationship to AIDS Prevention Programs. *American Journal of Public Health* 1994; 84: 275-281.

Vassal A et al. *Gay and Lesbian Legal Issues and HIV/AIDS: A Discussion Paper*. Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1997.

Waldby C et al. Epidemiological Knowledge and Discriminatory Practice: AIDS and the Social Relations of Biomedicine. *Australian and New Zealand Journal of Sociology* 1995; 31(1): 1-14.

Warren WK, MA King. *Development and Evaluation of Skills for Healthy Relationships: An AIDS/STD/ Sexuality Program for Grade 9 Students. Summary*. Kingston: Social Program Evaluation Group, Queen's University: 1996.

WHO. *World Health Organization Guidelines on HIV Infection and AIDS in Prison*. Geneva: WHO, 1993.

Yan P et al. Estimation of the Historical Age-Specific HIV Incidence in Canada. XI International Conference on AIDS, Vancouver, July 1996. Abstract no. Tu.C.573.

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by Theodore de Bruyn

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APPENDIX A

GUIDELINES ON HIV/AIDS AND HUMAN RIGHTS

The Guidelines on HIV/AIDS and Human Rights were adopted by the Second International Consultation on HIV/AIDS and Human Rights, convened in September 1996 by the United Nations High Commissioner/Centre for Human Rights and the Joint United Nations Programme on HIV/AIDS (UNAIDS).[1]

The Consultation

The Consultation, the second of its kind,[2] brought together 35 experts in the field of AIDS and human rights, comprising government officials and staff of national AIDS programs, people living with HIV/AIDS, human rights activists, academics, representatives of regional and national networks on ethics, law, human rights and HIV, and representatives of United Nations bodies and agencies, non-governmental organizations and AIDS service organizations (ASOs).

The Consultation had before it five background papers, commissioned for the purpose of eliciting specific regional and thematic experiences and concerns regarding HIV/AIDS and human rights. The papers had been prepared by the following non-governmental organizations and networks of people living with HIV/AIDS:

- the Alternative Law Research and Development Center (ALTERLAW) (Philippines);
- the Network of African People Living with HIV/AIDS (NAP+) (Zambia);
- Colectivo Sol (Mexico);
- the International Community of Women Living with HIV/AIDS (ICW+); and
- the Global Network of People Living with HIV/AIDS (GNP+).

Each of these groups was asked to identify the most important human rights principles and concerns in the context of HIV/AIDS, and concrete measures that States could take to protect HIV-related human rights.

In addition, the Consultation had before it draft guidelines on HIV/AIDS and human rights, prepared by Helen Watchirs (Australia) on the basis of the five regional background papers and other materials consulted. Finally, the London-based association Rights and Humanity conducted a global survey to review existing strategies and identify other measures necessary to ensure respect for human rights in the context of HIV/AIDS. An analysis of the 40 responses received to the survey was presented to the Consultation.

The Consultation formed four working groups to discuss and finalize the draft guidelines, and develop recommendations concerning strategies to ensure the dissemination and implementation of the guidelines.

Conclusions of the Consultation

> HIV/AIDS continues to spread throughout the world at an alarming rate. Close in the wake of the epidemic is the widespread abuse of human rights and fundamental freedoms associated with HIV/AIDS in all parts of the world.[3]

In response to this situation, the experts at the Consultation concluded the following:

> [10] (a) The protection of human rights is essential to safeguard human dignity in the context of HIV/AIDS and to ensure an effective, rights-based response to HIV/AIDS. An effective response requires the implementation of all human rights, civil and political,

> economic, social and cultural, and fundamental freedoms of all people, in accordance with existing international human rights standards.
>
> (b) Public health interests do not conflict with human rights. On the contrary, it has been recognized that when human rights are protected, less people become infected and those living with HIV/AIDS and their families can better cope with HIV/AIDS.
>
> (c) A rights-based, effective response to the HIV/AIDS epidemic involves establishing appropriate governmental institutional responsibilities, implementing law reform and support services and promoting a supportive environment for groups vulnerable to HIV/AIDS and for those living with HIV/AIDS.
>
> (d) In the context of HIV/AIDS, international human rights norms and pragmatic public health goals require States to consider measures that may be considered controversial, particularly regarding the status of women and children, sex workers, injecting drug users and men having sex with men. It is, however, the responsibility of all States to identify how they can best meet their human rights obligations and protect public health within their specific political, cultural and religious contexts.
>
> (e) Although States have primary responsibility for implementing strategies that protect human rights and public health, United Nations bodies, agencies and programmes, regional intergovernmental bodies and non-governmental organizations, including networks of people living with HIV/AIDS, play critical roles in this regard.

The Guidelines on HIV/AIDS and Human Rights

The Guidelines' purpose is to translate international human rights norms into practical observance in the context of HIV/AIDS. To this end, the Guidelines consist of two parts:

- the human rights principles underlying a positive response to HIV/AIDS; and
- action-oriented measures to be employed by Governments in the areas of law, administrative policy and practice that will protect human rights and achieve HIV-related public health goals.

A summary of the 12 guidelines for States follows:

> Guideline 1: States should establish an effective national framework for their response to HIV/AIDS which ensures a coordinated, participatory, transparent and accountable approach, integrating HIV/AIDS policy and programme responsibilities across all

branches of Government.

Guideline 2: 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 field of ethics, law and human rights, effectively.

Guideline 3: States should review and reform public health laws to ensure that they adequately address public health issues raised by HIV/AIDS, that their provisions applicable to casually transmitted diseases are not inappropriately applied to HIV/AIDS and that they are consistent with international human rights obligations.

Guideline 4: States should review and reform criminal laws and correctional systems to ensure that they are consistent with international human rights obligations and are not misused in the context of HIV/AIDS or targeted against vulnerable groups.

Guideline 5: States should enact or strengthen anti-discrimination and other protective laws that protect vulnerable groups, people living with HIV/AIDS and people with disabilities from discrimination in both the public and private sectors, ensure privacy and confidentiality and ethics in research involving human subjects, emphasize education and conciliation, and provide for speedy and effective administrative and civil remedies.

Guideline 6: States should enact legislation to provide for the regulation of HIV-related goods, services and information, so as to ensure widespread availability of qualitative prevention measures and services, adequate HIV prevention and care information and safe and effective medication at an affordable price.

Guideline 7: States should implement and support legal support services that will educate people affected by HIV/AIDS about their rights, provide free legal services to enforce those rights, develop expertise on HIV-related legal issues and utilize means of protection in addition to the courts, such as offices of ministries of justice, ombudspersons, health complaint units and human rights commissions.

Guideline 8: States, in collaboration with and through the community, should promote a supportive and enabling environment for women, children and other vulnerable groups by addressing underlying prejudices and inequalities through community dialogue, specially designed social and health services and support to community groups.

Guideline 9: States should promote the wide and ongoing distribution of creative education, training and media programmes explicitly designed to change attitudes of discrimination and stigmatization associated with HIV/AIDS to understanding and acceptance.

> Guideline 10: States should ensure that government and private sectors develop codes of conduct regarding HIV/AIDS issues that translate human rights principles into codes of professional responsibility and practice, with accompanying mechanisms to implement and enforce these codes.
>
> Guideline 11: States should ensure monitoring and enforcement mechanisms to guarantee the protection of HIV-related human rights, including those of people living with HIV/AIDS, their families and communities.
>
> Guideline 12: States should cooperate through all relevant programmes and agencies of the United Nations system, including UNAIDS, to share knowledge and experience concerning HIV-related human rights issues and should ensure effective mechanisms to protect human rights in the context of HIV/AIDS at international level.

Recommendations for Dissemination and Implementation

Participants at the Consultation considered strategies for dissemination and implementation of the Guidelines. Three groups of key actors were identified as being critical to the implementation of the Guidelines:

- States;
- the United Nations system and regional intergovernmental organizations; and
- non-governmental and community-based organizations.

States

> 14. States, at the highest level of Government (head of State, Prime Minister and/or relevant ministers) should promulgate the Guidelines and ensure that the political weight of the Government is behind the dissemination and implementation of the Guidelines throughout all branches of the executive, legislature and judiciary.
>
> 15. States, at highest level of Government, should assign appropriate governmental bodies/

staff with the responsibility to devise and implement a strategy for dissemination and implementation of the Guidelines and establish periodic monitoring of this strategy through, for example, reports to the Executive Office and public hearings. States should establish within the executive branch a staff member(s) responsible for this strategy.

16. States should disseminate the Guidelines, endorsed by the executive, to relevant national bodies, such as interministerial and parliamentary committees on HIV/AIDS and national AIDS programmes, as well as to provincial and local-level bodies.

17. States, through these bodies, should give formal consideration to the Guidelines in order to identify ways to build them into existing activities and prioritize necessary new activities and policy review. States should also organize consensus workshops with the participation of non-governmental organizations, community-based organizations and AIDS service organizations (ASOs), networks of people living with HIV/AIDS (PLHAs), networks on ethics, law, human rights and HIV, United Nations Theme Groups on HIV/AIDS, as well as political and religious groups:

> (a) To discuss the relevance of the Guidelines to the local situation, to identify obstacles and needs, to propose interventions and solutions and to achieve consensus for the adoption of the Guidelines;
>
> (b) To elaborate national, provincial and local plans of action for implementation and monitoring of the Guidelines within the local context;
>
> (c) To mobilize and ensure the commitment of relevant governmental officials to apply the Guidelines as a working tool to be integrated into their individual workplans.

18. States, at national, subnational and local levels, should establish mechanisms to receive, process and refer issues, claims and information in relation to the Guidelines and to the human rights issues raised therein. States should create focal points to monitor the implementation of the Guidelines in relevant government departments.

19. States, in ways consistent with judicial independence, should disseminate the Guidelines widely throughout the judicial system and use them in the development of jurisprudence, conduct of court cases involving HIV-related matters and HIV-related training/continuing education of judicial officers.

20. States should disseminate the Guidelines throughout the legislative branch of Government and particularly to parliamentary committees involved in the formulation of policy and legislation relevant to the issues raised in the Guidelines. Such committees should assess the Guidelines to identify priority areas for action and a longer-term strategy

to ensure that relevant policy and law are in conformity with the Guidelines. [back to the contents]

United Nations System and Regional Intergovernmental Bodies

21. The United Nations Secretary-General should submit the Guidelines to the Commission on Human Rights as part of the report on the Second International Consultation on HIV/AIDS and Human Rights.

22. The Secretary-General should transmit the Guidelines to heads of State:

> (a) Recommending that the document be distributed nationally through the appropriate channels;
>
> (b) Offering, within the mandates of UNAIDS and the United Nations High Commissioner/Centre for Human Rights, technical cooperation in facilitating the implementation of the Guidelines;
>
> (c) Requesting that compliance with the Guidelines be included in the national reports to existing human rights treaty bodies;
>
> (d) Reminding Governments of the responsibility to uphold international human rights standards in promoting compliance with the Guidelines.

23. The Secretary-General should transmit the Guidelines to the heads of all relevant United Nations bodies and agencies, requesting that they be widely disseminated throughout the relevant programmes and activities of the bodies and agencies. The Secretary-General should request that all relevant United Nations bodies and agencies consider their activities and programmes on HIV/AIDS in the light of the provisions of the Guidelines and support the implementation of the Guidelines at the national level.

24. The Commission on Human Rights and the Sub-Commission on Prevention of Discrimination and Protection of Minorities, as well as all human rights treaty bodies, should consider and discuss the Guidelines with a view to incorporating relevant aspects of the Guidelines within their respective mandates. Human rights treaty bodies, in particular, should integrate the Guidelines, as relevant, in their respective reporting guidelines, questions to States, and when developing resolutions and general comments on related subjects.

25. The Commission on Human Rights should appoint a special rapporteur on human rights and HIV/AIDS with the mandate, inter alia, to encourage and monitor implementation of the Guidelines by States, as well as their promotion by the United Nations system, including human rights bodies, where applicable.

26. The United Nations High Commissioner/Centre for Human Rights should ensure that the Guidelines are disseminated throughout the Centre and incorporated into the activities and programmes of the Centre, particularly those involving support to the United Nations human rights bodies, technical assistance and monitoring. This should be coordinated by a staff member with exclusive responsibility for the Guidelines. Similarly, the United Nations Division for the Advancement of Women should ensure the full integration of the Guidelines into the work of the Committee on the Elimination of Discrimination Against Women.

27. UNAIDS should transmit the Guidelines widely throughout the system - to co-sponsors of the UNAIDS Programme Coordinating Board, United Nations Theme Groups on HIV/AIDS, UNAIDS staff, including country programme advisers and focal points - and should ensure that the Guidelines become a framework for action for the work of the United Nations Theme Groups on HIV/AIDS and UNAIDS staff, including that Theme Groups use the Guidelines to assess the HIV-related human rights, legal and ethical situation in-country and to elaborate the best means to support implementation of the Guidelines at the country level.

28. Regional bodies (such as the Inter-American Commission on Human Rights, the Organization of American States, the African Commission on Human and Peoples' Rights, the Organization of African Unity, the European Commission on Human Rights, the European Commission, the Council of Europe, the Association of South-East Asian Nations, etc.) should receive the Guidelines and transmit them widely among members and relevant divisions with a view to assessing how their activities might be made consistent with the Guidelines and promote their implementation.

29. Specialized agencies and other concerned bodies (such as the International Labour Organization, the International Organization for Migration, the Office of the United Nations High Commissioner for Refugees, the United Nations Research Institute for Social Development and the World Trade Organization) should receive the Guidelines and transmit them widely among members and throughout their programmes with a view to assessing how their activities can be made consistent with the Guidelines and promote their implementation.

Non-Governmental Organizations

30. NGOs should implement the Guidelines within a broad framework of communication around HIV and human rights, including through the establishment of ongoing communication between the HIV/AIDS community and the human rights community by:

> (a) Establishing contacts at the international, regional and local levels between networks of ASOs and people living with HIV/AIDS and human rights NGOs;
>
> (b) Developing mechanism(s) for ongoing communication and dissemination and implementation of the Guidelines, such as a bulletin board and/or home page on the Internet allowing for input and exchange of information on human rights and HIV and database linkages between groups working on human rights and HIV;
>
> (c) Networking with human rights NGOs at meetings of United Nations human rights bodies;
>
> (d) Promoting discussion of the Guidelines in their newsletters and other publications, as well as through other media;
>
> (e) Developing an action-oriented and accessible version(s) of the Guidelines;
>
> (f) Developing a strategy and process for the dissemination of the Guidelines and seeking funding and technical cooperation with regard to the dissemination.

31. Non-governmental organizations at the regional level should:

> (a) Establish or use existing focal points to disseminate the Guidelines, with popularization and/or training;
>
> (b) Establish a regional "technical group" to introduce the Guidelines to the region;
>
> (c) Use the Guidelines as a tool for advocacy, interpretation, monitoring abuse and establishing best practice;
>
> (d) Prepare regular reports on the implementation of the Guidelines to human rights bodies (human rights treaty bodies and United Nations extra-conventional fact-finding mechanisms, such as special rapporteurs and

> representatives, as well as regional commissions) and other relevant international agencies;
>
> (e) Bring cases of HIV/AIDS-related discrimination and other violations of human rights in the context of HIV/AIDS to regional human rights judicial and quasi-judicial mechanisms.

32. NGOs at the national level, in order to advocate the Guidelines, should obtain consensus on their acceptance and establish a joint strategy with governmental and non-governmental partners as a baseline for monitoring the Guidelines, through the following means:

> (a) Hold national NGO strategy meetings on the Guidelines that include human rights NGOs (including women's organizations and prisoners' rights organization), ASOs, community-based organizations, networks on ethics, law, human rights and HIV and networks of people living with HIV/AIDS;
>
> (b) Hold meetings with national governmental human rights organisms;
>
> (c) Hold meetings with national Government (relevant ministries), legislative and judiciary;
>
> (d) Establish or use existing national focal points to gather information and develop systems of information exchange on HIV and human rights, including the Guidelines.

Commission on Human Rights Resolution

Since the Guidelines were adopted, the United Nations Commission on Human Rights passed resolution 1997/33,

- emphasizing, "in view of the continuing challenges presented by HIV/AIDS, the need for intensified efforts to ensure universal respect for and observance of human rights and fundamental freedoms for all to reduce vulnerability to HIV/AIDS and to prevent HIV/AIDS-related discrimination and stigma;"
- welcoming the report of the Secretary-General on the Second International Consultation on HIV/AIDS and Human Rights (E/CN.4/1997/37);

- inviting all States to consider the Guidelines;
- calling upon the United Nations High Commissioner for Human Rights, the Joint United Nations Programme on HIV/AIDS (UNAIDS), its co-sponsors and other partners to provide technical cooperation to States, upon the request of Governments when required, from within existing resources, with regard to the promotion and protection of human rights in the context of HIV/AIDS; and
- requesting the Secretary-General to solicit the opinion of Governments, specialized agencies, and international and non-governmental organizations and to prepare for consideration of the Commission at its fifty-fifth session a progress report on the follow-up to the present resolution.

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FOOTNOTES

[1] United Nations Commission on Human Rights. *Second International Consultation on HIV/AIDS and Human Rights (Geneva, 23-25 September 1996). Report of the Secretary General.* 20 January 1997 (document no. E/CN.4/1997/37). For other texts on HIV/AIDS and human rights, see, Guidelines on HIV/AIDS and Human Rights Adopted. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 1, 45-52.

[2] The first International Consultation on AIDS and Human Rights, organized by the United Nations Centre for Human Rights, in cooperation with the World Health Organization, had been held in Geneva from 26 to 28 July 1989. In the report of the first consultation (HR/PUB/90/2), the elaboration of guidelines on HIV/AIDS and human rights had already been proposed.

[3] Report of the Secretary-General, Commission on Human Rights, Fifty-third session, item 9(a) of the provisional agenda. United Nations publication E/CN.4/1997/37 of 20 January 1997.

HIV/AIDS and Discrimination: A Discussion Paper
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APPENDIX B

LIST OF ORGANIZATIONS CONSULTED AND WORKSHOP PARTICIPANTS

Organizations Consulted

Africans in Partnership Against AIDS	Toronto
AIDS Brandon	Brandon
AIDS Committee of North Bay and Area	North Bay
AIDS Committee of Toronto	Toronto
AIDS Community Care Montréal	Montréal
AIDS New Brunswick	Fredericton
AIDS Support Network of Prince Albert	Prince Albert
BC Civil Liberties Association	Vancouver
BC Coalition on People with Disabilities	Vancouver
Canadian Hemophilia Society, National Office	Montréal
Comité des personnes atteintes du VIH du Québec, Clinique juridique	Montréal

Deaf Outreach Project	Toronto
HIV and AIDS Legal Clinic of Ontario	Toronto
Hôpital Sainte-Justine, Service Social	Montréal
Human Rights Internet	Ottawa
Living Positive, Edmonton Persons Living With HIV Society	Edmonton
Newfoundland and Labrador AIDS Committee	St John's
Philip M MacAdam, Barrister and Solicitor	Ottawa
Positive Women's Network	Vancouver
Prisoners with HIV/AIDS Support Action Network	Toronto
Programme du sida en milieu de travail	Montréal
Smith and Huges, Barristers and Solicitors	Vancouver
Voices of Positive Women	Toronto
Vancouver Areas Network of Drug Users	Vancouver
Working Group in Relation to Children, Youth and Families Infected or Affected by HIV/AIDS	Toronto

Workshop Participants

Robert Allan	AIDS Coalition of Nova Scotia
Joan Anderson	AIDS Committee of Toronto

Christine Bennett	AIDS Saskatoon
Alex Campbell	Community AIDS Treatment Information Exchange, Toronto
Ruth Carey	HIV & AIDS Legal Clinic Ontario, Toronto
Richard Burzynski	ICASO, Toronto
Angela Favretto	HIV/AIDS Prevention and Community Action Programs, Health Canada, Ottawa
David Garmaise	Consultant, Ottawa
Diane Gobeil	Cactus
David Hoe	HIV/AIDS Policy, Coordination and Programs Division, Health Canada, Ottawa
Barbara Jones	HIV/AIDS Prevention and Community Action Programs, Health Canada, Ottawa
Henry Koo	AIDS Community Action Program, Health Canada, Vancouver
Daniel Ladell	Canadian AIDS Society, Toronto
Rosanne LeBlanc	Nova Scotia Advisory Commission on AIDS, Halifax
Johanne Leroux	Comité des personnes atteintes du VIH, Montréal
Rick Lines	Prisoners with HIV/AIDS Support Action Network, Toronto
Laverne Monette	Ontario Aboriginal HIV/AIDS Strategy, Toronto
Greg Robinson	AIDS Action Now! Toronto
Greg Sherwood	AIDS Brandon

David Thompson	AIDS Community Care Montréal
Monique Trempe	Comité des personnes atteintes du VIH, Montréal
Michael Wartman	Canadian AIDS Society, Moncton

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APPENDIX C

THE JOINT NETWORK/CAS PROJECT ON LEGAL AND ETHICAL ISSUES RAISED BY HIV/AIDS

Phase I

Phase II

The Project Partners

The Joint CAS/Network Project on Legal and Ethical Issues Raised by HIV/AIDS started in January 1995 with a five-month development initiative and entered into its second phase in June 1995.

Phase I

During Phase I (January to May 1995), the following activities and initiatives were undertaken:

- Existing resources addressing legal and ethical issues raised by HIV/AIDS were researched and documented. These resources have been evaluated and listed in an annotated bibliography, and included in a literature review.[1]
- Key legal and ethical issues raised by HIV/AIDS in Canada were assessed and prioritized. After extensive meetings with over sixty persons living with HIV/AIDS, representatives from community-based organizations, lawyers, academics, and government policy analysts active in the HIV/AIDS area, a list of eight topics was drawn up that includes legal and ethical issues identified as immediate priorities by the persons and organizations consulted. These are as follows:

  (1) legal issues raised by HIV/AIDS in prisons;

(2) criminal law and HIV/AIDS;
(3) gay and lesbian legal issues;
(4) testing and confidentiality;
(5) discrimination;
(6) access to health care;
(7) drug laws and policies;
(8) laws and policies regulating prostitution.

- A detailed plan for the production of resource documents on these issues was developed.
- Key people living with HIV/AIDS, representatives from community-based organizations, lawyers, academics, and government policy analysts active in the HIV/AIDS field were identified who would be potential participants in the preparation of the resource documents.
- The Project Coordinator contacted and met with a wide variety of governmental and non-governmental organizations, institutions and professional associations, to seek partnership support for the Project.

Phase II

After completion of Phase I, funding was obtained from the AIDS Care, Treatment and Support Program, Health Canada, the HIV/AIDS Prevention and Community Action Programs, Health Canada, the Correctional Service of Canada, and Justice Canada, to undertake Phase II of the Project. The goals of Phase II are to:

- stimulate discussion on the local, regional and national levels on legal and ethical issues raised by HIV/AIDS;
- develop a series of discussion papers on the eight priority legal and ethical issues identified during the development initiative;
- organize a series of workshops on these issues across Canada; and
- produce comprehensive resource documents on these issues that will assist Canada in its efforts to prevent the further spread of HIV and to care for those infected and affected by it.

As of March 1998, the Project had started working on legal issues raised by HIV/AIDS in prisons, criminal law and HIV/AIDS, gay and lesbian legal issues, and testing and confidentiality, and HIV and discrimination; had organized workshops on criminal law and HIV/AIDS, on gay and lesbian legal issues, on HIV testing and confidentiality, and on HIV/AIDS and discrimintation; and had produced the following resources:

- *HIV/AIDS in Prisons: A Discussion Paper* (November 1995)
- *Criminal Law and HIV/AIDS: A Discussion Paper* (April 1996)
- Bill C-8 - The Impact of Canada's Drug Laws on the Spread of HIV (April 1996)

- *HIV/AIDS in Prisons: Final Report* (September 1996)
- *HIV Testing and Confidentiality: A Discussion Paper* (March 1997)
- *Criminal Law and HIV/AIDS: Final Report* (March 1997)
- *Gay and Lesbian Legal Issues: A Discussion Paper* (July 1997)
- *HIV Testing and Confidentiality: Final Report* (March 1998)
- *Gay and Lesbian Legal Issues: Final Report* (March 1998)
- *HIV/AIDS and Discrimination: A Discussion Paper* (March 1998)
- *Canadian HIV/AIDS Policy & Law Newsletter* (vol 1, nos 1-4; vol 2, nos 1-4; vol 3, no 1)
- News from the Joint Project (issue 1, July 1995; issue 2, October 1995; issue 3, May 1996)

Most of these resources, and more information about the Joint Project, are also on the Legal Network's website, at www.aidslaw.ca

The Project Partners

Canadian HIV/AIDS Legal Network

The Network is the only national, community-based, charitable organization in Canada working in the area of policy and legal issues raised by HIV/AIDS. It was formed in November 1992 with the mandate to advance education and knowledge about legal, ethical, and policy issues raised by HIV/AIDS, and to promote responses to HIV infection and AIDS that respect human rights.

The Network provides services to persons living with HIV/AIDS, to those affected by the disease, and to persons working in the area by educating about, facilitating access to, and creating accurate and up-to-date legal materials on HIV/AIDS. It links people working with or concerned by relevant social and legal issues in order to limit the spread of HIV and to reduce the impact on those affected by HIV infection and AIDS.

In October 1994, the Network launched the *Canadian HIV/AIDS Policy & Law Newsletter*. The Newsletter is devoted to addressing the many legal, ethical and policy issues raised by HIV/AIDS. From the beginning, it has provided extensive coverage of issues raised by HIV/AIDS in prisons, in Canada and internationally. It serves as a means of educating policy-makers, lawyers and any other people with an interest in issues raised by HIV/AIDS about legal and policy developments, but also as a means of stimulating much-needed discussion about these issues.

Canadian AIDS Society

The Canadian AIDS Society is a national coalition that supports community action on HIV/AIDS issues in Canada. The Society represents more than 100 community-based organizations across the country, providing the bulk of education, support and advocacy programs and services for individuals and communities affected by HIV/AIDS.

The role of the Society is to speak as the national voice and to act as a national forum for a community-based response to HIV infection and AIDS. The Society also undertakes advocacy on behalf of people affected by HIV and AIDS, acts as a resource on HIV and AIDS issues for its member organizations, and coordinates community-based participation in a national strategy to combat HIV and AIDS. The Society carries out this role through national initiatives in prevention education, treatment, care and support.

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FOOTNOTE

.[1] R Jürgens. *Legal and Ethical Issues Raised by HIV/AIDS: Literature Review and Annotated Bibliography*. Canadian AIDS Society and Canadian HIV/AIDS Legal Network. Montréal, 1995.