



# An Epidemic of Stigma and Discrimination

*Since the beginning of the HIV/AIDS epidemic, there has been a second epidemic – one of stigma and discrimination. Today, 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.*

This is one of a series of eight info sheets on HIV/AIDS and Discrimination.

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*When one ... look[s] 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.*

*– HIV/AIDS and Discrimination: A Discussion Paper*

## The Epidemic of Stigma

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 affects not only those who are stigmatized, but also those who stigmatize them through their attitudes or their actions – in the community, on the job, in professional capacities, in public office, or in the media. Often, the stigma of HIV/AIDS adds new prejudices to old.

## Consequences

This epidemic of stigma has consequences: people with HIV/AIDS have been prevented from seeking or obtaining the health care and social support they require; adults with HIV/AIDS have lost their jobs or have been denied employment, insurance, housing, and other services; children with HIV/AIDS have been denied day care.

Stigmatization has also been a barrier to prevention efforts: because of their beliefs and values, some people (and governments) have chosen to withhold information about preventing the transmission of HIV, and have supported laws and policies that make the victims of stigma more vulnerable to HIV infection.

## The Current Situation

*One Step Forward ...*

The early societal panic about AIDS has diminished. The federal and several provincial

human rights commissions have adopted policies that clearly state that disability or handicap provisions in existing human rights acts protect people with HIV against discrimination. More and more Canadians know someone who lives with HIV or has died of AIDS, prominent celebrities have announced that they are HIV-positive, and AIDS activists have won admiration in many quarters of society. These developments have somewhat lessened fears that the inevitable result of infection with HIV is complete social isolation.

*... But Discrimination Remains Pervasive*

Nevertheless, today stigma and discrimination associated with HIV/AIDS are still pervasive in Canada, although the forms they take and the context in which they are experienced have changed.

- The epidemic of HIV infection is expanding among diverse populations, many of whom live on the margins of Canadian society: injection drug users, prisoners, Aboriginal people, young gay men, women. While many aspects of HIV-related discrimination are the same for all populations, in some ways the experience and impact of discrimination are unique to specific populations. The most marginalized people living with HIV experience many forms of stigma and discrimination. They also have the least resources or support to enable them to fight back.
- 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 these therapies have produced considerable benefits, the often-made presumption that people with

HIV/AIDS can now lead “normal” lives is dangerous. For example, it has resulted in a tendency to become more restrictive in determining whether they 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 a greater threat of discrimination. As one person 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. There are reports that people with HIV/AIDS have been pressured by their physicians to begin treatment with the latest generation of HIV drugs and have been denied services if they refuse to begin treatment.
- There continue to be problems of access to care for marginalized populations.
- People with HIV/AIDS are often not provided with the support they need to assist them in maintaining the complicated combination therapy regimens.

Discrimination 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 “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.

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# Stigma and Discrimination: Definitions and Concepts

*This info sheet defines and discusses stigma and discrimination in the context of HIV/AIDS.*

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## Two Things in Common

When one looks 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.

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

## Stigma

Stigma “is a powerful and discrediting social label that radically changes the way individuals view themselves and are viewed as persons.” People who are stigmatized are usually considered deviant or shameful, and as a result are shunned, discredited, rejected, or penalized.

HIV/AIDS is not alone among 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. People with HIV/AIDS are stigmatized because:

- HIV/AIDS is a life-threatening disease;
- people are afraid of contracting HIV;
- HIV/AIDS is associated with behaviours that are already stigmatized or considered deviant, particularly homosexual sex and injection drug use;
- people with HIV/AIDS are often thought to be responsible for having contracted the disease; and
- religious or moral beliefs lead some people 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.

## Felt and 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.

People with HIV/AIDS often experience stigma and discrimination. In addition, felt stigma or anticipated discrimination has an enormous impact on their lives. Discovering that one is HIV-positive brings with it a multitude of anxieties and concerns that result from the fear and uncertainty about how other people will react. These anxieties and concerns may 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.

people). It can touch on almost every aspect of a person’s life. In Canada, cases of discrimination have been documented in many areas, including housing, employment, prisons, access to health care, and access to public services.

## Discrimination

The Joint United Nations Programme on HIV/AIDS has defined HIV/AIDS-related discrimination as follows:

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

Discrimination against people with HIV/AIDS also extends to those with whom AIDS is associated in the public mind (homosexuals, sex workers, drug users, hemophiliacs, and family members and associates of HIV-positive

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## HIV/AIDS and Discrimination

# Stigma and Discrimination: The Consequences

*This info sheet discusses how stigma and discrimination affect the spread of HIV infection and the life of people with HIV/AIDS.*

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## The Impact on Prevention

HIV-related stigma and discrimination – and stigma and discrimination on the basis of race, gender, sexual orientation, drug use, criminal status, or imprisonment – make people more vulnerable to HIV infection and make people with HIV/AIDS more vulnerable to sickness and death.

Vulnerability can be personal or societal. *Personal vulnerability* to HIV/AIDS refers to the various factors in an individual's development or environment that make them vulnerable – factors such as physical and mental development, knowledge and awareness, behavioural characteristics, life skills, and social relations. *Social vulnerability* is related to the contextual factors in society that affect personal vulnerability – factors such as political structures, gender relationships, attitudes to sexuality, religious beliefs, and poverty.

It is impossible to understand personal vulnerability without addressing the contextual factors related to social vulnerability. For example:

- *Gay and bisexual men:* An environment that does not acknowledge and respect the sexual identities of gay and bisexual youth, that does not provide support at home and at school for the coming-out process, and that tolerates high levels of violence and abuse against gay men, contributes to the risk of HIV infection among this population.
- *Injection drug users:* The fact that injection drug users face a high risk of HIV infection is, to a significant degree, the result of the criminal status of drug use in Canadian law, a legislated form of discrimination against drug users.
- *Aboriginal people:* The risk of HIV infection experienced by Aboriginal peoples as a result of their overrepresentation among drug users and prisoners cannot be understood without acknowledging the events and structures, both past and present, that have contributed to substance use, migration, unemployment, cultural displacement, and despair among Aboriginal peoples in Canada.

All people living with HIV experience stigma and discrimination in some form or other. However, those who are the most disadvantaged or

disempowered are the most vulnerable to HIV. The history of the epidemic has shown that those people who were marginalized, stigmatized, and discriminated against before HIV/AIDS arrived have become those at highest risk of HIV infection.

### **The Impact on the Lives of People with 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:

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

### **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 and friends. Because of the stigma associated with HIV/AIDS and the potential for discrimination, people with HIV/AIDS are often afraid to tell others about their serostatus:

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.

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.

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 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.

When people disclose, they 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.

As a result, opportunities for support are lost:

I found out that I had HIV when my child was diagnosed at six months. The child died at nine 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.

Stigma and the resulting stress, isolation, and lack of social support have significant negative impacts on the health of people with HIV. People who feel stigmatized by HIV/AIDS and who lack the support they require are more likely to experience symptoms of depression. As well, there is some evidence that stress has a negative effect on the immune system.

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## HIV/AIDS and Discrimination

# Examples of Stigma and Discrimination

*This info sheet provides some examples of stigma and discrimination experienced by people living with HIV in three specific areas: employment, health care, and insurance.*

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## Employment

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. People with HIV/AIDS in the workplace:

- have experienced breaches of confidentiality regarding their HIV status;
- have often not had their needs accommodated with respect to the duties they are able to perform, the schedule and side effects of their drug regimen, the time required for medical appointments, and the need for leave for temporary illnesses;
- have experienced cuts to their benefits or have been laid off because of the cost to the employer of disability insurance or drug insurance premiums;
- have sometimes not claimed their benefits – or may not take antiretroviral therapy at all – for fear of disclosure, harassment, and being fired; and
- have sometimes found themselves in an environment in which they have been harassed, avoided, or ostracized.

While the new antiretroviral drug regimes have brought better health for some, and the possibility of returning to work, they have also brought new workplace hazards. People taking these drugs must adhere to strictly regimented dosage schedules and they often suffer side effects. This can lead to de facto disclosure of HIV status. In addition, employers or co-workers 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?

## 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. These included refusing to provide care, avoiding or neglecting patients, and making prejudicial remarks. Such incidents have decreased, but there are still many examples of inappropriate treatment:

- Some health-care workers continue to refuse to treat people with HIV/AIDS.
- People with HIV/AIDS are sometimes refused medical procedures not related to HIV/AIDS, such as cardiac care.

## EXAMPLES OF STIGMA AND DISCRIMINATION

- Primary-care physicians often do not offer HIV testing or fail to diagnose HIV-related symptoms among people who are not readily identified with a “risk group”.
- In contrast to hospitals that specialize in HIV/AIDS care (which appear, for the most part, to provide services in a way that is knowledgeable, supportive, and non-discriminatory), there are many difficulties in hospitals that see fewer HIV patients.
- Breaches of confidentiality remain frequent.
- Some physicians refuse to prescribe combination therapies for certain groups of people – such as drug users and the homeless – because they assume these people will not be able to maintain the drug regimen.

### Insurance

People with HIV/AIDS depend on public or private insurance for health care, drugs, and income support. Thanks to Canada’s universal public health-care insurance, coverage for physicians’ services and hospital care is not among the larger problems that people with HIV/AIDS must deal with. But income support and drug coverage is another matter.

#### *Definition of disability*

The definition 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 may experience periods of relatively good health that are interrupted by periods of severe illness. Although combinations of drugs including protease inhibitors have dramatically improved the health status of many people with HIV, they have made problems of definition of disability even more acute. There is an increasing trend toward out-and-out denial for short- and long-term benefits: insurers fail to acknowledge that some people cannot take protease inhibitors, that treatment is often accompanied by debilitating side effects, that improved health status is not immediate, and that indicators other than physical functioning must be taken into account.

#### *Exclusion criteria in private income insurance plans*

Exclusion criteria affect people with HIV/AIDS in a number of ways. They may not qualify for income insurance on account of a pre-existing condition of HIV disease. 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.

#### *Drug insurance*

People with HIV/AIDS experience multiple problems in obtaining coverage or benefits for HIV/AIDS drugs through their employment. For example: (1) Insurers offer plans and employers adopt plans that limit claims to a set amount, for example \$2000 a year. This barely covers one month’s worth of drugs for a person with HIV/AIDS; (2) While some provinces have instituted catastrophic drug coverage for individuals who are employed but cannot afford their medications, people are still required to pay for the drugs initially, and must then apply to be reimbursed. (3) People making claims for drug benefits through their employer have suffered breaches of confidentiality and subsequent harassment or dismissal.

### Other Areas of Discrimination

These are not the only areas where discrimination occurs. Other areas include housing, travel and immigration, family and community, and community-based services (consult *HIV/AIDS and Discrimination: A Discussion Paper* for examples).

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# The Impact of Stigma and Discrimination

*This info sheet examines the effects of stigma and discrimination on two specific populations – injection drug users and women. It also provides a list of other affected populations.*

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The patterns and effects of stigma and discrimination vary among the diverse populations affected by HIV/AIDS. While some aspects of discrimination are common to all affected populations, others are specific to particular populations.

## Injection Drug Users

*I also need a family physician. They won't take [drug] users.*  
– Drug user, Vancouver, 1998

Drug use is a powerful source of stigma. People who have acquired HIV through injection drug use live with a double stigma. The stigma is reinforced by the fact that drug use is illegal, and by the use of coercive measures against drug users, such as police surveillance, criminal prosecution, and criminal penalties.

### *Illegal status*

The illegal status of drugs contributes to the high-risk injecting behaviours of injection drug users. Socio-economic disadvantages also increase the risk of HIV infection among this population. So do barriers such as inadequate or inappropriate services, and professional attitudes and practices that are controlling and demeaning.

### *Barriers to care, treatment, and support*

Injection drug users living with HIV experience problems when they seek care, treatment, and support. For example:

- 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.
- Service providers 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.
- Injection drug users may be required to abstain from using drugs as a condition of treatment and care.
- Health and social programs are often 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.
- Injection drug users frequently report that they are not given adequate pain relief.
- Some injection drug users are not offered the current standard of care because it is assumed that they

will not be able to maintain the demanding drug regimens.

## 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.*  
— Goldie et al., 1997

In heterosexual relations, women are, in general, more vulnerable to HIV infection than men. 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 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.

### *Impact of violence*

Violence against women contributes directly to the spread of HIV infection among women. Women with a history of sexual assault often engage in behaviours that put them at greater risk of HIV infection. Fear of violence may 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.

### *Delayed diagnosis*

The common perception that only men who have sex with men, drug users, and sex workers are at risk of HIV infection has prevented women from seeking HIV testing. This perception has also led physicians

not to offer HIV testing to women and to fail to diagnose HIV-related symptoms in women. Frequently, the result is delayed diagnosis and delayed treatment for women.

### *Needs of women ignored*

HIV testing, counseling, and treatment for women usually focuses on the risks of transmission of HIV from mother to child and often ignores the needs of the women themselves.

### *Inadequate research*

There has been a lack of research on HIV disease in women. In addition, there has been a disproportionate emphasis on pregnancy in research on women. This was so particularly in the early stages of the epidemic.

### *Unequal access*

For social and economic reasons, many women with HIV do not have equal access to care and treatment.

## Other Affected Populations

Many other populations experience their own patterns of HIV-related stigma and discrimination. These populations include:

- gay and bisexual men;
- transgendered people;
- Aboriginal people;
- sex workers;
- prisoners;
- heterosexual men;
- children and their families; and
- youth.

Consult *HIV/AIDS and Discrimination: A Discussion Paper* for a description of discrimination in each of these populations.

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# 6

## HIV/AIDS and Discrimination

# Responding to Stigma and Discrimination – Part I

*This fact sheet proposes one way of responding to stigma and discrimination against people with HIV/AIDS and populations affected by HIV/AIDS: education. It discusses how education can be used to reduce stigma and discrimination. Info sheet 7 discusses two more ways of responding to stigma and discrimination: redress and advocacy.*

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Education is 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 the following reasons:

- Stigma and discrimination often occur in settings not covered by human rights legislation, such as within families, among friends or acquaintances, or in casual encounters.
- 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.
- Only a small percentage of people who experience discrimination seek redress even when legal or procedural avenues are available to them.
- Policies and practices that stigmatize or discriminate may do so unintentionally. A process of education is required to bring such unintended effects to people's attention and to effect changes in the offending policies and practices.

Three kinds of educational programs have a role in reducing or eliminating HIV-related stigma and discrimination: public education, professional education, and focused education.

## Public Education

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; and the rights of populations affected by HIV/AIDS.

## Professional Education

Professionals play a major role in preventing or reducing stigma and discrimination against people with HIV or populations affected by HIV/AIDS. This role extends not only to their own attitudes and practices, but also to the

influence that they have over the attitudes and practices of others.

The stigmatizing and discriminatory effects of professional policies and practices may be more inadvertent than deliberate. In response, therefore, often what is needed is not only education about non-stigmatizing and non-discriminatory approaches to dealing with people with HIV or populations affected by HIV/AIDS, but also information about HIV/AIDS that is up-to-date, comprehensive, and holistic.

### Focused Education

Focused education – ie, educational programs for specific communities, populations or contexts – is required to allay fears, increase awareness and sensitivity, and provide correct information to those who interact with people with HIV and their families. The goal of focused education is to create an environment in which people with HIV and their families can live without fear of stigma and discrimination.

One place where focused education is important is the workplace. To create a supportive and safe environment in the workplace for people with HIV, it is not enough simply to develop policies regarding HIV/AIDS in the workplace. It is also necessary to mount an educational program that

- will 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 on how to combat discrimination toward people with HIV.

Other examples of where focused education campaigns could be developed include:

- local communities (urban or rural) where people with HIV reside;
- children, staff, and parents associated with child care centres; and
- people involved in the school system.

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# Responding to Stigma and Discrimination – Part 2

*This info sheet discusses how redress and advocacy can be used to reduce HIV-related stigma and discrimination.*

This is one of a series of eight info sheets on HIV/AIDS and Discrimination.

- An Epidemic of Stigma and Discrimination (Info Sheet 1)
- Stigma and Discrimination: Definitions and Concepts (Info Sheet 2)
- Stigma and Discrimination: The Consequences (Info Sheet 3)
- Examples of Stigma and Discrimination (Info Sheet 4)
- The Impact of Stigma and Discrimination (Info Sheet 5)
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- Responding to Stigma and Discrimination – Part 2 (Info Sheet 7)
- Conclusions and Recommendations (Info Sheet 8)



## Redress

People who have experienced HIV-related discrimination may seek redress under a variety of statutes, regulations, and codes of conduct in Canada. 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.

### Landmark decisions

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 may be protected under the term “physical disability.”
- 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 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 co-workers or customers.
- In *Thwaites v Canada (Armed Forces)* (1993), the tribunal determined that whenever 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.
- 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.

### *Policy development*

Several human rights commissions in Canada have established policies on specific aspects of HIV/AIDS-related discrimination. For example:

- The Canadian Human Rights Commission has stated that health-care workers with HIV infection should be able 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.
- Both the Canadian Human Rights Commission and the Ontario Human Rights Commission have stated that pre- or post-employment testing for HIV cannot be justified.
- The Ontario Human Rights Commission has stated that all health-assessment information, including the results of HIV testing, should remain exclusively with the examining physician and be kept out of an employee’s personnel file in order to protect confidentiality.

### *Limitations*

There are, however, a number of concerns about the limitations of human rights legislation and procedures as a means to protect people with HIV/AIDS from discrimination: 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.

### **Advocacy**

Advocacy can help prevent and remedy discrimination against people with HIV and populations affected by HIV/AIDS. Advocates can take actions such as:

- describing HIV/AIDS-related stigma and discrimination experienced by people infected or affected by HIV/AIDS;
- documenting, analyzing, and publicizing instances of HIV-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 or populations affected by HIV/AIDS in legal proceedings, legislative processes, policy development, and the media;
- 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; and
- monitoring Canada’s performance in meeting its international treaty obligations pertaining to human rights, particularly as they apply to HIV/AIDS, but also in other areas (together with organizations involved in advocacy work on other or related issues).

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# Conclusions and Recommendations

*This info sheet identifies some essential steps that should be taken in Canada in order to make progress in the effort to recognize, prevent, and redress HIV/AIDS-related stigma and discrimination.*

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## No Area Is Untouched

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.

## Discrimination Is Unjust ...

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.

## ... and Discrimination Has Consequences

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.

## Different Strategies in Different Contexts

The populations affected by HIV/AIDS are diverse; many aspects of their vulnerability to, and experience

## CONCLUSIONS AND RECOMMENDATIONS

of, stigma and discrimination are unique. As a result, different strategies are required to reduce the impact of stigma and discrimination.

### Recommendations

The following recommendations identify some essential steps that should be taken in order to make progress in the effort to recognize, prevent, and redress HIV/AIDS-related stigma and discrimination (for the full text, consult *HIV/AIDS and Discrimination: A Discussion Paper*).

#### **Strategic framework**

- A framework for action on HIV-related stigma and discrimination should be developed within the context of the Canadian Strategy on HIV/AIDS.

#### **Community participation**

- People with HIV, representatives of populations affected by HIV/AIDS, and AIDS service organizations should be involved in the design, implementation, and evaluation of HIV/AIDS policies and programs.

#### **Data gathering, analysis, and advocacy**

- Funding should be provided to support the infrastructure required to gather information, analyze information, develop policy, and advocate with regard to HIV-related stigma and discrimination.

#### **Legal services**

- Support should be provided for specialized legal services for people with HIV and populations affected by HIV/AIDS.

#### **Law reform**

- A specific initiative should be included in the Canadian Strategy on HIV/AIDS to identify areas of law and law enforcement that contribute to HIV-related discrimination, and to recommend reforms in these areas.
- Efforts should continue to reform human rights legislation and procedures to make them more responsive and effective in dealing with

discrimination in general and HIV-related discrimination in particular.

#### **Public education**

- Resources should be allocated to design, develop, and implement education programs that will dispel stigmatizing myths and assumptions associated with HIV/AIDS.

#### **Professional education**

- Professional education and training should be undertaken to develop non-stigmatizing and non-discriminatory attitudes and practices among providers working with the diverse populations affected by HIV/AIDS.

#### **Education for children and youth**

- Curricula designed to reduce discriminatory attitudes around HIV/AIDS and sexuality, and provide accurate information about HIV disease and the prevention of HIV infection, should be developed and widely delivered.
- Efforts by community-based organizations and social agencies to reach children and youth with peer-based and client-determined programs should be supported.

#### **Workplace policies and education**

- Workplace policies and educational initiatives should address problems of harassment and discrimination, including: breach of confidentiality, failure to accommodate health needs, and inadequate criteria for assessing HIV-related disability.

#### **Research**

- A mechanism should be developed to identify priorities in areas of research that have not been sufficiently addressed in the context of current trends in the HIV epidemic.

#### **Monitoring and evaluation**

- A plan should be developed to monitor and evaluate annually efforts to prevent, redress, or eliminate HIV-related discrimination.

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