Aboriginal People and HIV/AIDS: Legal Issues

info sheet 1

This info sheet explains why, at this point in the HIV/AIDS epidemic, addressing legal issues relating to Aboriginal people and HIV/AIDS is important; explains what the main legal issues are; and emphasizes that a response to Aboriginal HIV/AIDS-related issues must start from an understanding of the racism, discrimination, and cultural denigration experienced by Aboriginal people in Canada and must include consideration of broad social, cultural, economic, and political issues affecting Aboriginal communities.

ISSUES

WHY A PROJECT ON LEGAL ISSUES RELATING TO ABORIGINAL PEOPLE AND HIV/AIDS?

Based on the reports of Aboriginal AIDS workers and organizations, and the prevalence of risk factors, there is a serious HIV/AIDS epidemic in the Aboriginal population of Canada.

In *HIV/AIDS Epidemiology among Aboriginal People in Canada*, from the Bureau of HIV/AIDS, STD and TB Epi Update Series, May 1998, the Laboratory Centre for Disease Control (LCDC) reports the proportion of AIDS cases attributed to Aboriginal people increased from two percent before 1989 to more than 10 percent in 1996-97. Recent data (1993-97) from British Columbia, Alberta, and Saskatchewan show that Aboriginal people comprise 15 percent, 26 percent, and 43 percent respectively of newly diagnosed HIV-positive cases.

Also of concern, LCDC reports that Aboriginal AIDS cases are younger on average than non-Aboriginal AIDS cases (29.8 percent versus 18.6 percent diagnosed at less than 30 years of age), and that Aboriginal AIDS cases are more likely than non-Aboriginal AIDS cases to be attributed to injection drug use, particularly in women. In some cities up to 75 percent of clientele using inner-city services such as needle exchanges are Aboriginal.

Evidence suggests that the HIV epidemic among Aboriginal people shows no signs of abating.

HOW CAN ABORIGINAL HIV/AIDS-RELATED ISSUES BE ADDRESSED?

Aboriginal people in Canada have suffered from the ongoing effects of cultural denigration, racism, and colonialism. The legacy of this experience is apparent: on average, Aboriginal people have higher rates of incarceration, higher rates of suicide, drug and alcohol use, more poverty, and poorer health than the non-Aboriginal population of Canada. These are risk factors for HIV.

In these circumstances, it is important that Aboriginal HIV/AIDS-related issues be addressed in a comprehensive, coordinated, and holistic fashion, with a view to broader socioeconomic, health, and cultural issues.

WHAT ARE THE LEGAL ISSUES?

Discrimination: HIV/AIDS-related discrimination continues to be a problem in Canada. The discrimination experienced by Aboriginal people generally adds to the level of discrimination against Aboriginal people

This is one of a series of nine info sheets on Aboriginal People and HIV/AIDS: Legal Issues

ISSUES
(Info Sheet 1)

DISCRIMINATION
(Info Sheet 2)

HUMAN RIGHTS LAW
(Info Sheet 3)

DEALING WITH DISCRIMINATION
(Info Sheet 4)

JURISDICTIONAL BARRIERS
(Info Sheet 5)

HEALTH CARE,
(Info Sheet 6)

CONFIDENTIALITY
(Info Sheet 7)

HIV TESTING
(Info Sheet 8)

ACCESS TO HIV TESTING
(Info Sheet 9)

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living with or affected by HIV/AIDS experienced both within and outside Aboriginal communities.

Jurisdictional issues: Addressing problems of discrimination for Aboriginal people living with or affected by HIV/AIDS is made more difficult by the complicated jurisdictional divisions that affect Aboriginal people. Jurisdictional divisions also complicate the sources and effectiveness of funding for HIV/AIDS services and programs for Aboriginal people. The Aboriginal population in Canada is not homogenous: Métis and First Nations people and the Inuit experience different levels of service depending on where they live, and for First Nations people, whether they are part of treaties or members of a band makes a difference.

Testing and confidentiality: The significance of where you live for an Aboriginal person is shown by differences in the accessibility of HIV testing and in the confidentiality issues related to testing that arise for Aboriginal people.

HIV/AIDS-related discrimination, jurisdictional divisions, funding problems, and testing and confidentiality issues complicate the development of a comprehensive and coordinated response to HIV/AIDS in Aboriginal communities.

WHAT CONCLUSIONS CAN BE DRAWN?

Three broad themes can be developed:

1. A response to Aboriginal HIV/AIDS-related issues must start from an understanding of the racism, discrimination, and cultural denigration experienced by Aboriginal people in Canada and must include consideration of broad social, cultural, economic, and political issues affecting Aboriginal communities.

2. With the negotiation of new treaties, self-government initiatives, and health transfer arrangements, among other developments, this is a period of dramatic change for First Nations, Métis, and Inuit communities. Despite the ravages of racism and oppression, there is a resurgence of Aboriginal culture and community in Canada. During this process, it is important that attention be directed toward HIV/AIDS issues for Aboriginal people.

3. The success of HIV/AIDS programs and services for Aboriginal people will depend on the extent to which Aboriginal expertise guides, directs, and implements the process.

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Aboriginal People and HIV/AIDS: Legal Issues

info sheet 2

This info sheet explains the context of HIV/AIDS-related discrimination among Aboriginal people, discusses how discrimination is experienced by Aboriginal people living with or affected by HIV/AIDS, and explains how discrimination contributes to the spread of HIV among Aboriginal people.

DISCRIMINATION

THE CONTEXT OF DISCRIMINATION

Aboriginal people living with or affected by HIV/AIDS experience discrimination in many of the same ways that non-Aboriginal people do. What differentiates discrimination against Aboriginal people living with or affected by HIV/AIDS is the history of oppression and social disintegration experienced by First Nations, Métis, and Inuit communities.

The deplorable extent of the health and social problems in the Aboriginal population represents a human rights failure in Canada. Aboriginal people sustain a disproportionate share of the burden of physical disease and mental illness. The high incidence in the Aboriginal population of problems such as domestic violence, suicide, and alcohol abuse reflect conditions of poverty, political alienation, and racial discrimination.

The context of oppression makes work in the area of HIV/AIDS frustrating for Aboriginal AIDS workers and activists. The discrimination experienced by Aboriginal people is both systemic, reflecting a structure that has either historically excluded or sought the assimilation of Aboriginal people, and directly individualized.

HOW IS DISCRIMINATION EXPERIENCED?

The combination of racism, homophobia, and AIDSphobia means Aboriginal people living with or affected by HIV/AIDS are one of the most marginalized groups in Canada. The following reflect stories of discrimination described during the consultations for the Project:

- An Aboriginal man with AIDS became ill and went to emergency at a Winnipeg hospital. While awaiting treatment the man became agitated, and security guards escorted him out of the hospital without treatment, allegedly remarking that the man was drunk. The next day the man went to another hospital, where he died. This incident occurred in December 1998.

- There are stories of Aboriginal people living with or affected by HIV/AIDS being driven from their home communities. There is often fear of disclosing HIV status because of homophobia and AIDSphobia, and concerns about ostracism.

- Poverty forces many young people to take up the sex trade and drug-related activities to survive.

This is one of a series of nine info sheets on Aboriginal People and HIV/AIDS: Legal Issues

ISSUES
(Info Sheet 1)

DISCRIMINATION
(Info Sheet 2)

HUMAN RIGHTS LAW
(Info Sheet 3)

DEALING WITH DISCRIMINATION
(Info Sheet 4)

JURISDICTIONAL BARRIERS
(Info Sheet 5)

HEALTH CARE,
(Info Sheet 6)

CONFIDENTIALITY
(Info Sheet 7)

HIV TESTING
(Info Sheet 8)

ACCESS TO HIV TESTING
(Info Sheet 9)

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- Two-spirited people (gay, lesbian, bisexual, and transgender people) are often seen as unhealthy, sinful, and/or unbalanced. The atmosphere in some communities is homophobic.

- HIV/AIDS-related discrimination in health care continues, particularly for Aboriginal people. Both in cities and small communities, some doctors are not knowledgeable about HIV.

- There are often problems with confidentiality in small communities.

- A study in Alberta revealed that Aboriginal people using emergency facilities at a hospital in Edmonton were given substandard treatment. Discrimination in health care is acute, particularly for street-involved and inner-city Aboriginal people.

- Members of a community refused to visit a woman with HIV or her family for fear that her whole family might be infected and that HIV might be contagious.

- Some bands cannot deal with HIV/AIDS at all because they are overwhelmed by the demands of other problems.

These stories suggest that discrimination against Aboriginal people living with or affected by HIV/AIDS comes from a variety of sources, from band administrators and community members to health practitioners and the public at large. Discrimination is often associated with misunderstandings about HIV/AIDS, is often reinforced by other social problems and other forms of discrimination, and finds its roots in a history of oppression and cultural denigration.

WHAT IS THE LINK BETWEEN DISCRIMINATION AND THE SPREAD OF HIV?

Two issues with respect to discrimination and the HIV epidemic can be distinguished: the personal impact of discrimination on Aboriginal people living with or affected by HIV/AIDS, and the way that discrimination contributes to the prevalence of risk factors for HIV infection among Aboriginal people.

The systemic and individualized discrimination experienced by Aboriginal people generally, and by Aboriginal people living with or affected by HIV/AIDS in particular, contributes to the impact of HIV/AIDS on Aboriginal communities. Factors adding to a higher risk of HIV transmission in Aboriginal communities include: high rates of sexually transmitted diseases and teenage pregnancy, which are evidence of unsafe sex; low self-esteem; high rates of sexual and physical violence; lack of access to health information and facilities; drug and alcohol use; and poor health in general.

The prevalence of risk factors for HIV in the Aboriginal population reflects the history of racism and oppression experienced by Aboriginal people in Canada.

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Aboriginal People and HIV/AIDS: Legal Issues

info sheet 3

This info sheet explains how human rights statutes apply to Aboriginal people, and the protection they do – or do not – afford. It points out that, although HIV-positive Aboriginal people experience discrimination, they seldom seem to seek redress under human rights legislation. Other approaches to discrimination, including HIV/AIDS-related education, are viewed as more effective.

HUMAN RIGHTS LAW

WHAT LEGISLATION DEALS WITH HUMAN RIGHTS?

In all jurisdictions in Canada medical conditions related to HIV infection are recognized as “physical disabilities” or “handicaps,” and are therefore within the scope of the prohibited grounds of discrimination enumerated in human rights statutes. The comprehensiveness of this protection varies somewhat from jurisdiction to jurisdiction.

Generally speaking, human rights statutes apply to governmental and non-governmental actors in the areas of employment, services, and accommodation.

An additional source of legal protection for individuals who experience HIV/AIDS-related discrimination is the *Canadian Charter of Rights and Freedoms*. The Charter applies to governments and matters falling within the authority of governments.

HOW DO HUMAN RIGHTS STATUTES APPLY TO ABORIGINAL PEOPLE?

The jurisdictional divisions that have been imposed on Aboriginal people complicate the application of human rights legislation, particularly with regard to the distinction between on and off reserve.

Provincial statutes: The human rights statute of a province applies to human rights complaints that arise within the jurisdiction of that province. With respect to Aboriginal people, a provincial statute would be the appropriate avenue for a human rights complaint in circumstances including the following:

- an Aboriginal person living off reserve is discriminated against by an individual or by an enterprise that is not federally regulated;
- an Aboriginal person is discriminated against with respect to a service or enterprise provided by a provincial government on or off reserve; and
- an Aboriginal person living on reserve is discriminated against by an individual or enterprise located on reserve that is not connected to the band council or the federal government and does not operate in a federally regulated industry.

Discrimination experienced by a Métis or Inuit person residing in a province generally falls under category 1 above – the provincial statute applies.

The federal statute: The *Canadian Human Rights Act* (CHRA) applies to the federal government and agencies of the federal gov-

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The CHRA applies to band councils and their enterprises except where s 67 of the CHRA applies. Section 67 operates to immunize the provisions of the *Indian Act* and actions taken pursuant to the *Indian Act* from complaints under the CHRA.

The *Indian Act* confers on band councils authority to make certain by-laws, including those regulating health and residence on reserve. By-laws are subject to ministerial review. Band councils can also make band council resolutions (BCRs), which are not subject to review and can relate to virtually any matter arising on reserve.

The case law suggests that the gap in human rights law created by s 67 is not wide but that it is a cause for concern to individuals who may experience discrimination flowing from the *Indian Act*, or from band councils or federal departments or agencies operating pursuant to the *Indian Act*, including Aboriginal women, two-spirited people (gay, lesbian, bisexual, and transgender people), and people with HIV. This issue is relevant to status Indians as defined by the *Indian Act*.

The Charter: From a legal point of view, the *Indian Act* establishes a system of band governance whereby band councils exercise delegated powers under the authority of the federal government. Where Parliament or a legislature has delegated a power of compulsion to a body or person, the Charter will apply to the delegate. Band councils and their representatives operating pursuant to the *Indian Act* are therefore subject to the provisions of the Charter. The Charter is available to fill the gap in human rights legislation created by s 67 of the CHRA.

More controversial is the question of the application of the Charter to Aboriginal governments exercising inherent powers of self-government enshrined in s 35 of the *Constitution Act, 1982*. The federal government takes the position that self-government agreements must provide that the Charter applies to Aboriginal governments and related institutions.

It is the position of the Royal Commission on Aboriginal Peoples (RCAP) that Aboriginal governments occupy the same basic position relative to the Charter as the federal and provincial governments. RCAP suggests that in its application to Aboriginal governments, the Charter should be interpreted in a manner that allows considerable scope for distinctive Aboriginal philosophical outlooks, cultures, and traditions, while respecting individual rights.

ARE HUMAN RIGHTS STATUTES BEING USED?

Aboriginal people with HIV/AIDS experience discrimination. Nonetheless, few people report cases that involve recourse to the human rights system. Other approaches to discrimination are viewed as more effective, including HIV/AIDS-related education.

In no circumstances is HIV/AIDS-related discrimination justified. HIV/AIDS issues need to be addressed with compassion, caring, and understanding.

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Aboriginal People and HIV/AIDS: Legal Issues

info sheet 4

This info sheet suggests a number of non-legal approaches to dealing with HIV-related discrimination against Aboriginal people. It emphasizes the importance of education by and for Aboriginal people and of involving Aboriginal leaders in HIV/AIDS issues.

DEALING WITH DISCRIMINATION

WHAT IS THE LEGAL APPROACH TO HIV/AIDS-RELATED DISCRIMINATION?

A number of approaches to improving the human rights situation of Aboriginal people living with or affected by HIV/AIDS were suggested throughout the discussions undertaken for this project. Significantly, very few of those consulted, particularly from the Aboriginal community, expressed much faith in human rights legislation.

The human rights system in Canada involves an adversarial process that is generally initiated by the filing of a complaint by an individual who experiences discrimination. The appropriate human rights agency investigates the complaint and determines whether a complaint has merit, settlement is possible, or a hearing required.

WHAT ARE THE PROBLEMS WITH THE LEGAL APPROACH?

A backlog in cases, extensive delays, the inaccessibility of the process, problems associated with funding cuts in the system, and unsatisfactory remedies make the human rights system less than ideal, particularly for people living with or affected by HIV/AIDS.

The human rights system is underutilized by Aboriginal people, particularly those who experience HIV-related discrimination. There is a perception that the complaints process does not reflect the circumstances of Aboriginal people. In addition, the process is seen as inappropriate for complaints by Aboriginal people against Aboriginal organizations, employers, or governments.

NON-LEGAL APPROACHES TO HIV/AIDS-RELATED DISCRIMINATION

There are a number of non-legal approaches to problems of discrimination against Aboriginal people living with or affected by HIV/AIDS:

Education: Misinformation about HIV/AIDS contributes to discrimination both within Aboriginal communities and in the rest of Canada. Education efforts must continue in First Nations, Métis, and Inuit communities. It is widely recognized that education is a crucial component in both addressing the discrimination that often accompanies HIV/AIDS and in reducing the spread of HIV. It is important, however, that HIV/AIDS education initiatives for Aboriginal people take into account broader health and social issues, including the impact of a foreign culture on community practices and traditions, the effects of residential schools and assimilationist policies, and the high incidence of other health problems.

This is one of a series of nine info sheets on Aboriginal People and HIV/AIDS: Legal Issues

ISSUES
(Info Sheet 1)

DISCRIMINATION
(Info Sheet 2)

HUMAN RIGHTS LAW
(Info Sheet 3)

DEALING WITH DISCRIMINATION
(Info Sheet 4)

JURISDICTIONAL BARRIERS
(Info Sheet 5)

HEALTH CARE,
(Info Sheet 6)

CONFIDENTIALITY
(Info Sheet 7)

HIV TESTING
(Info Sheet 8)

ACCESS TO HIV TESTING
(Info Sheet 9)

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Health practitioners and others working in mainstream services must also be exposed to information about Aboriginal living conditions, cultures, and traditions.

Engaging the leadership: The involvement of Aboriginal leaders in HIV/AIDS issues is important to help overcome homophobia, AIDSphobia, and reluctance to deal openly with sexuality and lifestyle issues, all of which hamper education and prevention initiatives and contribute to HIV/AIDS-related discrimination. Leadership is also necessary at the provincial and federal government levels to address HIV/AIDS issues for Aboriginal people.

Aboriginal control and participation: Throughout the process leading to self-government, Aboriginal people have emphasized the importance of Aboriginal control of, and participation in, decision-making affecting Aboriginal communities. The field of HIV/AIDS is no different. Due to their personal experience with HIV/AIDS, Aboriginal HIV/AIDS workers and Aboriginal people living with or affected by HIV/AIDS have a particularly significant contribution to make to the development of a legal, educational, and health-care framework addressing HIV/AIDS issues, and should be prominently featured in the design of HIV/AIDS initiatives.

SUMMARY

1. Problems with the human rights complaints system make it ineffective for everyone, but especially for Aboriginal people. Efforts must be directed toward improving this system.

2. An important response to HIV/AIDS-related discrimination is to reduce such discrimination through education and community engagement, with the assistance of community leaders.

3. The best people to guide the development of a comprehensive HIV/AIDS framework for Aboriginal people are Aboriginal people themselves, particularly those who have been personally affected by HIV either through their work or through their own experience as a person with HIV.

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Aboriginal People and HIV/AIDS: Legal Issues

info sheet 5

This info sheet discusses jurisdictional barriers and their impact on HIV/AIDS programs, care, treatment, and support; and suggests ways to overcome these barriers.

JURISDICTIONAL BARRIERS

WHAT ARE THE JURISDICTIONAL BARRIERS FOR ABORIGINAL PEOPLE?

"Jurisdiction" means the legal authority of one order of government to legislate with respect to a subject matter. The term is also used here to refer to the authority of certain entities to manage or administer with respect to a subject matter.

There are three orders of government that have powers and responsibilities affecting Aboriginal people: federal, provincial/territorial, and Aboriginal (including band councils and Aboriginal political entities exercising self-governing powers). There are also a number of entities such as government departments and Aboriginal organizations that exercise management and administrative authority with respect to certain subject matters. The relationship between these governments and political/administrative entities is complicated.

As a result of this complexity, Aboriginal people encounter jurisdictional barriers with respect to HIV/AIDS programs, care, treatment, and support.

Divisions between federal and provincial governments

Territoriality issues between governments can hamper the coordination of efforts at controlling the spread of HIV/AIDS. Territoriality disputes often involve both the federal and provincial governments trying to reduce their fiduciary responsibilities to Aboriginal people. The result can be a policy vacuum or service patchwork.

The Royal Commission on Aboriginal Peoples (RCAP) supports cooperative, coordinated action by all three orders of government, and recommends the institution of a framework for discussion of Aboriginal issues, with a view to establishing collaborative measures to resolve problems. Nowhere is cooperation and coordination more important than with respect to HIV/AIDS.

Interdepartmental barriers

A number of federal government departments have responsibilities that relate to Aboriginal people, including Health Canada, Indian and Northern Affairs, and Correctional Services. Although HIV/AIDS issues arise in all of these departments, interdepartmental divisions persist.

Divisions among Aboriginal people

Artificial jurisdictional distinctions divide the Aboriginal community against itself in many ways. The historical territories of First Nations, Métis, and Inuit communities have

This is one of a series of nine info sheets on Aboriginal People and HIV/AIDS: Legal Issues

ISSUES
(Info Sheet 1)

DISCRIMINATION
(Info Sheet 2)

HUMAN RIGHTS LAW
(Info Sheet 3)

DEALING WITH DISCRIMINATION
(Info Sheet 4)

JURISDICTIONAL BARRIERS
(Info Sheet 5)

HEALTH CARE,
(Info Sheet 6)

CONFIDENTIALITY
(Info Sheet 7)

HIV TESTING
(Info Sheet 8)

ACCESS TO HIV TESTING
(Info Sheet 9)

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been disturbed by the imposition of provinces and reserves and by resettlement policies. Further, the interests and circumstances of on and off reserve, treaty and non-treaty, Métis, and Inuit groups are very different. In some cases imposed jurisdictional distinctions lead to conflict within the Aboriginal community.

It is important to respect the diversity of the Aboriginal community and allow self-naming by First Nations, Métis, and Inuit groups without a loss of services. It is also important to recognize that these diverse groups also share many interests and some problems, including a rising incidence of HIV. Creating linkages is important in the fight against HIV, a disease that respects no boundaries.

HOW CAN JURISDICTIONAL BARRIERS BE OVERCOME?

The need for coordination with respect to Aboriginal HIV/AIDS programs and services has long been identified as a priority by Aboriginal organizations.

The following initiatives help to overcome jurisdictional barriers:

Working groups: Interdepartmental and cross-jurisdictional working groups can be used to share information and develop coordination in policies and programs. However, in order for such initiatives to be effective, Aboriginal input must be included in the planning and decision-making process.

Aboriginal HIV/AIDS strategies: The first Aboriginal HIV/AIDS strategy took shape in Ontario in 1994. The focus of the Ontario Strategy is on Aboriginal community-based design, development and delivery of services and programs that are Aboriginal-directed.

The newest comprehensive strategy is at the implementation stage in British Columbia. The BC strategy seeks to overcome jurisdictional barriers and establish a long-term framework for HIV work involving Aboriginal people. There is a strong commitment to make the strategy Aboriginal-designed and directed.

In 1995, an Aboriginal HIV/AIDS project was initiated in Alberta with the support of provincial Aboriginal leaders. The Alberta project sought to maximize Aboriginal control of HIV/AIDS initiatives for Aboriginal people and to unite cross-jurisdictional interests. The funding for the Project ended, however, in the spring of 1998.

No other province or territory has an Aboriginal-specific HIV/AIDS strategy.

Canadian Aboriginal AIDS Network (CAAN): CAAN seeks to improve coordination between organizations and individuals working in the field of Aboriginal people and HIV/AIDS across the country, and to be a national voice on HIV/AIDS issues for Aboriginal people.

It is also important to recognize the work of Aboriginal HIV/AIDS organizations that are not affiliated with CAAN.

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Aboriginal People and HIV/AIDS: Legal Issues

info sheet 6

This info sheet explains how health-care services are provided to Aboriginal people, and what funding is available for HIV/AIDS-related activities directed at Aboriginal communities. It then mentions some areas of concern to Aboriginal people in the area of health care.

HEALTH CARE

WHY ARE HEALTH-CARE ISSUES IMPORTANT?

Aboriginal people have the highest levels of poor health in Canada, due to poverty, racism, and denigration of cultural traditions. The legacy of ill health contributes to a higher risk of HIV infection among Aboriginal people.

WHAT HEALTH-CARE SERVICES ARE THERE FOR ABORIGINAL PEOPLE?

Federal and provincial governments support an array of services related to Aboriginal health care.

Reserves and some Inuit communities benefit from targeted health and social service funding from the federal government, primarily through the Medical Services Branch of Health Canada (MSB). This funding supports such services as: health stations providing fairly extensive outpatient health services; health centres providing more limited public health services; and Community Health Nurses and Community Health Representatives.

The federal government also supports a number of residential treatment centres and hospitals providing services exclusively to First Nations and Inuit patients.

The provinces are responsible for most other hospital services and medical professionals working with Aboriginal people living on and off reserve. In addition, some provinces have developed health-care initiatives focused on Aboriginal people, such as the Ontario Aboriginal HIV/AIDS Strategy and the BC Aboriginal HIV/AIDS Strategy.

WHAT HIV/AIDS-RELATED FUNDING IS AVAILABLE FOR ABORIGINAL PEOPLE?

In July 1997 the Minister of Health announced the federal government's intention to renew a national HIV/AIDS strategy. The new Canadian Strategy on HIV/AIDS (CSHA) involves annual funding of $42.2 million. The CSHA has the following goals:

- prevent the spread of HIV in Canada;
- find a cure;
- find and provide effective vaccines, drugs and therapies;
- ensure care, treatment and support for Canadians living with HIV/AIDS, their caregivers, families and friends;
- minimize the adverse impact of HIV/AIDS on individuals and communities; and
- minimize the impact of social and eco-

This is one of a series of nine info sheets on Aboriginal People and HIV/AIDS: Legal Issues

ISSUES
(Info Sheet 1)

DISCRIMINATION
(Info Sheet 2)

HUMAN RIGHTS LAW
(Info Sheet 3)

DEALING WITH DISCRIMINATION
(Info Sheet 4)

JURISDICTIONAL BARRIERS
(Info Sheet 5)

HEALTH CARE,
(Info Sheet 6)

CONFIDENTIALITY
(Info Sheet 7)

HIV TESTING
(Info Sheet 8)

ACCESS TO HIV TESTING
(Info Sheet 9)

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nomic factors that increase individual and collective risk for HIV.

"Aboriginal communities" are a program component of the CSHA. Annual funding of $3.4 million has been allocated for Aboriginal communities, of which $1.1 million is allocated for on-reserve issues (administered by MSB); $1.5 million is allocated for non-reserve issues (administered by Health Promotions and Programs Branch of Health Canada); and $800,000 annually is designated for research on Aboriginal people and HIV/AIDS.

In addition, MSB has annual funding of $2.5 million outside of the CSHA for HIV/AIDS issues on reserve.

Some of the other program components of the CSHA include prevention, community development, care, treatment and support, legal and ethical issues, and correctional services. As Aboriginal HIV/AIDS issues cross the boundaries between these program components, proposals from Aboriginal HIV/AIDS organizations and service providers for funding for projects in these program areas should be encouraged.

WHAT CHANGES IN HEALTH CARE ARE OF CONCERN TO ABORIGINAL PEOPLE?

Regionalization: The present fiscal climate has resulted in cost-cutting in Canada's health-care system, accompanied by a shift in administrative control to the provinces. There is concern that regionalization and downsizing in health care may result in the disintegration of coordination in HIV/AIDS services and in diminished health-care standards overall.

Health transfer: Health transfer is an important issue for First Nations people living on or off reserve. Since the introduction in 1986 of the Indian Health Transfer Policy, many First Nations communities have begun to exercise administrative authority for community health services. Generally, transfer communities are provided global funding within which they set the priorities ("envelope funding"), although provincial health laws generally apply.

MSB has designated an amount of funding within the envelope that band councils are supposed to use specifically for HIV/AIDS-related work. This funding is distributed to bands in accordance with a formula based on population and other factors. In many cases the amount of money received per band is not enough to support much HIV/AIDS-related work.

Many have expressed concerns about health transfer:

- HIV may be low on the list of band priorities due to homophobia, AIDSphobia, and limited resources to deal with other pressing health issues.
- Health transfer may limit the access of Aboriginal people living off reserve to health programs, and reduce the portability of treaty health rights.

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Aboriginal People and HIV/AIDS: Legal Issues

info sheet7

This info sheet explains why confidentiality is so important in the context of HIV/AIDS, discusses some of the problems experienced in protecting it, and suggests ways to ensure that it is safeguarded.

CONFIDENTIALITY

WHY IS CONFIDENTIALITY IMPORTANT?

Discrimination and stigmatization continue to be experienced by those living with or affected by HIV/AIDS. HIV/AIDS-related discrimination is exacerbated by the vulnerability to further stigmatization of certain groups, including injection drug users, prison populations, men who have sex with men, and women. A person who is Aboriginal and HIV-positive can be among the most marginalized in Canada.

Confidentiality is critical in reducing the experience of discrimination and stigmatization related to testing positive for HIV, and in increasing the number of people who seek voluntary testing for HIV and treatment.

WHAT PROBLEMS ARE THERE FOR ABORIGINAL PEOPLE WITH RESPECT TO CONFIDENTIALITY?

For many reasons protecting confidentiality is difficult and often unrealistic.

Confidentiality and health practitioners

In some provinces, provisions in public health legislation impose a duty of confidentiality on public health officials. In addition, physicians have a legal and ethical duty of confidentiality to their patients, although there are situations where a breach of confidentiality is thought to be justified.

Despite such legal and ethical duties, many Aboriginal people tell stories about breaches of confidentiality by health-care practitioners, including physicians, Community Health Representatives, and clinic staff. Such breaches are often the result of misunderstandings about HIV or are due to local gossip. It must be emphasized that most health-care practitioners are professional in this regard, but that the perception that practitioners do not respect confidentiality exists.

In response to these issues, the need for confidentiality policies has been widely recognized, and such policies have been implemented by some Aboriginal communities and health organizations. It is important that confidentiality policies affecting Aboriginal people be ratified by Aboriginal governments, where applicable, and be designed and implemented by members of Aboriginal communities.

Confidentiality and community

Many confidentiality problems for Aboriginal people with HIV/AIDS come down to the difficulty of remaining anonymous in smaller communities. Aboriginal communi-

This is one of a series of nine info sheets on Aboriginal People and HIV/AIDS: Legal Issues

ISSUES
(Info Sheet 1)

DISCRIMINATION
(Info Sheet 2)

HUMAN RIGHTS LAW
(Info Sheet 3)

DEALING WITH DISCRIMINATION
(Info Sheet 4)

JURISDICTIONAL BARRIERS
(Info Sheet 5)

HEALTH CARE,
(Info Sheet 6)

CONFIDENTIALITY
(Info Sheet 7)

HIV TESTING
(Info Sheet 8)

ACCESS TO HIV TESTING
(Info Sheet 9)

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ties are often small and closely knit. People know each other, even in some Aboriginal communities in urban areas. Confidentiality may be breached through gossip, rumours, discussion between friends, family and others, or through the effects of seemingly innocuous policies – for example, bills for health services may be sent back to the band council of a person being tested for HIV.

Because confidentiality is difficult to ensure in Aboriginal communities, education about HIV/AIDS is essential in reducing HIV/AIDS-related discrimination. With HIV/AIDS education, inappropriate responses to HIV may be replaced by caring, compassion, and community support. In such cases, confidentiality becomes less of an issue.

SUMMARY

1. Education about HIV/AIDS issues is an important component in reducing the impact of loss of confidentiality on people living with or affected by HIV/AIDS, and in reducing discrimination and improving a community's response to HIV/AIDS.
2. Where they have not already done so, health-care facilities that provide services to Aboriginal people and Aboriginal communities and organizations should develop confidentiality policies.
3. The confidentiality of a person who tests positive for HIV should be protected.
4. Aboriginal people should be involved in and guide the development of solutions to issues raised by partner notification in Aboriginal communities.

For further information on HIV testing and confidentiality, see also *HIV Testing and Confidentiality: Final Report* (Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998; the report can be obtained from the Canadian HIV/AIDS Clearinghouse at the address below).

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Aboriginal People and HIV/AIDS: Legal Issues

info sheet 8

This info sheet discusses some of the issues relating to HIV testing that are particularly relevant to Aboriginal people in Canada.

HIV TESTING

WHY IS HIV TESTING IMPORTANT?

The fact that only a small number of Aboriginal people seek voluntary testing for HIV is cause for concern. It means that Aboriginal people with HIV/AIDS are often diagnosed and first receive treatment at late stages in their illness.

Approaches to promoting HIV testing among Aboriginal people must address broader issues, including the experience of racism, oppression, and cultural denigration, and the accompanying prevalence of social, economic, and health problems.

With improvements in treatment options, early detection of HIV infection is increasingly important.

WHAT ARE THE ISSUES?

In *HIV Testing and Confidentiality: Final Report*, the Canadian HIV/AIDS Legal Network reports that in Canada a consensus emerged in the late 1980s that, except in a few well-defined circumstances, people should be tested for HIV only:

- with their informed, voluntary and specific consent;
- when counselling and education before and following testing are available and offered; and
- when confidentiality of results or anonymity of testing can be guaranteed.

Unfortunately, HIV testing available to Aboriginal people often does not meet these basic conditions. This contributes to the low number of Aboriginal people being tested and to the risk that the disproportionate impact of HIV on the Aboriginal community will continue to rise.

In the context of HIV testing, the following issues are particularly relevant to Aboriginal people:

Control and ownership of research and data involving Aboriginal people: Anonymous unlinked seroprevalence studies ("blind studies") rely on HIV tests conducted on blood specimens drawn for another purpose. Personal identifiers are stripped from the blood so the results of the test cannot be linked to the individual. Blind studies are used for research in the surveillance of HIV infection in sample populations.

Testing for research purposes is regarded as controversial by many Aboriginal people. There is a feeling that there must be a better compromise between collecting information about rates of HIV infection and respecting principles of Aboriginal control and ownership of research and data.

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ISSUES
(Info Sheet 1)

DISCRIMINATION
(Info Sheet 2)

HUMAN RIGHTS LAW
(Info Sheet 3)

DEALING WITH DISCRIMINATION
(Info Sheet 4)

JURISDICTIONAL BARRIERS
(Info Sheet 5)

HEALTH CARE,
(Info Sheet 6)

CONFIDENTIALITY
(Info Sheet 7)

HIV TESTING
(Info Sheet 8)

ACCESS TO HIV TESTING
(Info Sheet 9)

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The Canadian Guidelines on Ethical and Legal Considerations in Anonymous Unlinked HIV Seroprevalence Research (*Canadian Medical Association Journal* 1990; 143: 625-627; revised *CMAJ* 1992; 146: 1743-1744) state that universal access to individual voluntary testing under prescribed conditions of informed consent, pre- and post-test counselling, and confidentiality is a prerequisite to blind studies. In too many cases this prerequisite is not met in studies involving Aboriginal people. The development of appropriate conditions for HIV testing should be a priority.

Finally, the training and employment of Aboriginal people in the conduct of this research should be emphasized as a crucial component of Aboriginal capacity-building in this area.

Accessible options for HIV testing that overcome problems of remoteness, cultural difference, and reluctance to use mainstream facilities: Access to testing issues are discussed in more detail in info sheet 9 in this series: *Access to HIV Testing*.

Culturally appropriate pre-and post-test counselling: Many indicate that adequate pre- and post-test counselling is not being provided by all health practitioners and that the quality of counselling is greater in testing clinics. HIV/AIDS education for health-care practitioners, both in smaller communities and cities, and including Community Health Representatives, is therefore much needed and should be an ongoing process.

In addition, many Aboriginal people may be more comfortable receiving counselling from trained Aboriginal counsellors, as cultural differences may affect the success and value of counselling sessions.

Training and employment of Aboriginal people in care, treatment, and support and in counselling is a crucial component of Aboriginal capacity-building in the field of health care.

Confidentiality, particularly in smaller communities: Confidentiality issues are discussed in more detail in info sheet 7 in this series: *Confidentiality*.

For further information on HIV testing and confidentiality, see also *HIV Testing and Confidentiality: Final Report* (Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998; the report can be obtained from the Canadian HIV/AIDS Clearinghouse at the address below).

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Aboriginal People and HIV/AIDS: Legal Issues

info sheet9

This info sheet discusses barriers to access to testing for Aboriginal people, and ways to overcome them.

ACCESS TO HIV TESTING

HIV TESTING AND ABORIGINAL PEOPLE

Aboriginal people can receive HIV testing off reserve from any provincial or territorial institution or clinic that can conduct the test. In addition, a small number of testing clinics or programs specifically designed for Aboriginal people are available in a few cities such as Vancouver and Toronto.

On reserve, Aboriginal people can generally be tested for HIV at the community health centre by a community health nurse (CHN). Most reserves have a CHN and health centre, although in smaller communities the CHN may divide time between a number of communities.

ANONYMOUS TESTING

Anonymous testing is testing in which the results can be linked to the patient by a code known only by the patient.

Non-nominal testing is testing in which results can be linked to the patient by a code known by the patient and by the physician.

Nominal testing is testing in which results are linked to the patient by a personal identifier.

Anonymous testing is highly regarded as it encourages people to be tested, particularly those most at risk for HIV; and anonymous testing facilities often offer "best practice" pre- and post-test counselling.

Although anonymous testing sites may be available in most major cities, they are inaccessible to Aboriginal people living in remote communities. In addition, some Aboriginal people may not feel comfortable using mainstream facilities; others might prefer to see a non-Aboriginal practitioner or testing site in order to increase the sense of confidentiality.

In smaller Aboriginal communities, anonymous testing may not preserve confidentiality. In such cases, it is particularly important to undertake efforts to make testing acceptable by creating a safe environment in the community through the elimination of discrimination through educational efforts, and to offer quality, culturally appropriate pre- and post-test counselling.

ACCESS TO TESTING

In many ways, Aboriginal people face greater barriers to accessible HIV testing than most other Canadians.

Barriers to testing: Barriers to testing for Aboriginal people include the following:

- An Aboriginal person may have to travel

This is one of a series of nine info sheets on Aboriginal People and HIV/AIDS: Legal Issues

ISSUES
(Info Sheet 1)

DISCRIMINATION
(Info Sheet 2)

HUMAN RIGHTS LAW
(Info Sheet 3)

DEALING WITH DISCRIMINATION
(Info Sheet 4)

JURISDICTIONAL BARRIERS
(Info Sheet 5)

HEALTH CARE,
(Info Sheet 6)

CONFIDENTIALITY
(Info Sheet 7)

HIV TESTING
(Info Sheet 8)

ACCESS TO HIV TESTING
(Info Sheet 9)

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long distances at great expense to take advantage of an anonymous testing facility, or even to get tested at a local health centre by a CHN who may visit a community only once a month.

- The period between taking the test and getting the result can be longer in rural and some reserve communities and may require two expensive trips – one for the test and one for the result.
- Confidentiality concerns regarding local testing facilities and smaller communities can reduce the number of people seeking testing.
- Culturally based differences can make mainstream facilities less accessible for some Aboriginal people.
- In a few cities – Halifax, Montréal, Toronto, Winnipeg, Regina, Edmonton, and Vancouver – Aboriginal AIDS organizations are available to provide support services and testing. Many of these organizations are under severe demands for their services and lack sufficient resources to respond to the needs of all those who seek their assistance.

Access to testing and HIV/AIDS education: Educational resources that reflect the values, experiences, culture, and languages of Aboriginal communities are imperative in overcoming fear, denial, and discrimination related to HIV/AIDS and HIV testing. HIV/AIDS education may reduce concerns about confidentiality and encourage people to seek testing.

SUMMARY

1. Barriers to HIV testing for Aboriginal people need to be removed. Aboriginal AIDS organizations and others in the Aboriginal community should be consulted to determine the best approach to improving the accessibility of HIV testing for Aboriginal people.
2. Provincial, territorial, federal, and Aboriginal government health providers should work together to develop accessible options for HIV testing, including anonymous testing. At a minimum, this would involve the establishment of anonymous HIV testing facilities in various locations in each province and territory, and a commitment to encourage and facilitate anonymous testing to the greatest extent possible, in combination with quality pre- and post-test counselling.
3. HIV/AIDS education for Aboriginal people should continue to be emphasized in order to help reduce stigmatization related to HIV testing.

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