

# Alberta Aboriginal HIV Strategy 2001-2004

Spring 2001



Health  
Canada

Santé  
Canada

**Alberta**  
HEALTH AND WELLNESS

# STRATEGY

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HEALTH AND WELLNESS

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Please note that since the publication of this document, the Feather of Hope Aboriginal AIDS Prevention Society, which is referred to, is no longer operating. Other organizations, as mentioned in the document, continue to address HIV issues in Aboriginal communities.

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*A special thank-you to the Aboriginal community, who developed the Tree of Creation, for permission to use the Tree of Creation on the cover of this report.*

*Copies of the above documents are available as follows:*

- *English versions are available from Health Canada and Alberta Health and Wellness by contacting the Communications Branch:*
  - *Health Canada—(780) 495-2651*
  - *Alberta Health and Wellness—(780) 427-7164*
- *French versions are available from Health Canada (780) 495-2651*

# ALBERTA ABORIGINAL HIV STRATEGY 2001-2004

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## INTRODUCTION

Aboriginal people<sup>1</sup> are over-represented with the risk factors that lead to HIV infection and disease surveillance data suggest that the level of infection is rising. In Canada, the HIV risk for Aboriginal people is five times higher than that for the general population. In Alberta, between 1993 and 1998, 26% of newly diagnosed HIV-positive cases were Aboriginal. In Edmonton in 1998, 25% of the new cases at the HIV Clinic were Aboriginal while less than 4% of the total population in Edmonton is Aboriginal. The HIV issues for the Aboriginal people are serious, adding to an already complex and long standing array of health and social challenges that face Aboriginal people and their communities<sup>2</sup>.

### **The call for action**

Given this situation, the Alberta Aboriginal HIV/AIDS Strategy, a three year project, was initiated by Health Canada and Alberta Health in 1996. The major deliverables were completed by an Aboriginal Consultant, Denise Lambert and consisted of a literature review and a project report on the current HIV situation and challenges facing Aboriginal people and the actions required to address them. An evaluation of the three year project was also carried out. Following this work, another project was undertaken to work with all key stakeholders to finalize the strategies to be undertaken and the major roles and responsibilities to be carried out by each of the stakeholders in addressing the HIV challenges. This latter project, contracted to KPMG, consisted of a review of all work completed to date and a one day retreat with representatives from the major stakeholders groups.

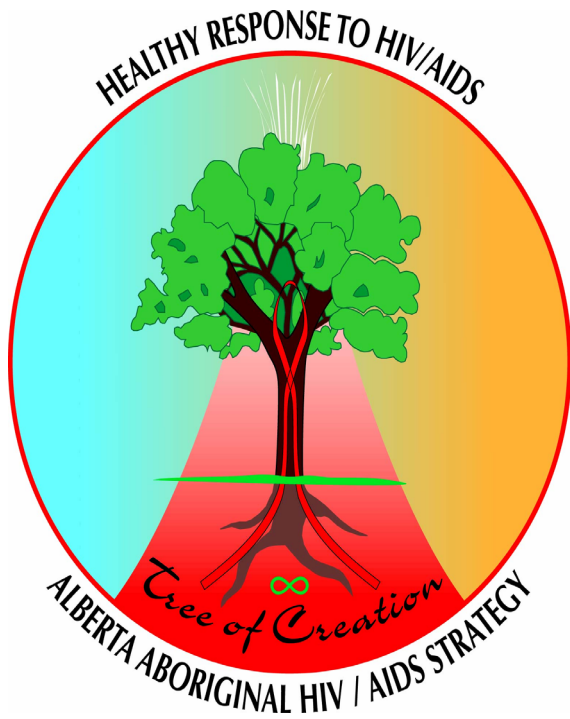
### **The birth of the Tree of Creation**

The Aboriginal HIV/AIDS Strategy called for a culturally appropriate approach to the prevention of HIV and for the care and support of Aboriginal people with HIV/AIDS. Aboriginal communities took the lead by developing a vision that would see their people taking a healthy response to HIV/AIDS—where their communities are aware of and understand HIV/AIDS and where their people who are living with HIV/AIDS are accepted and supported. This vision resulted in the development of a planning tool called the Tree of Creation. Use of the tree recognized and celebrated the connection between the Aboriginal people and the land. Each part of the tree symbolized an important component of the planning.

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<sup>1</sup> *The definition of Aboriginal People includes First Nations, non-status Indian, Métis and Inuit people.*

<sup>2</sup> *Community includes reserves, settlements or urban settings.*



The **vision** is the ideal future we are working toward. It provides a shared viewpoint of how we will deal with the issue of HIV/AIDS.

The **two main branches** represent the various aspects of dealing with HIV/AIDS in the areas of Prevention, and Care and Support.

The **smaller branches** represent research and surveillance.

The **leaves** represent the roles and responsibilities we have in each aspect of Prevention, and Care and Support.

The **trunk** represents growth and action pursued by individuals, communities and organizations.

The **grassroots** represent the people of a community determining needs as opposed to the needs being defined outside of the community.

The **roots** represent the four core values of the strategy: life/family, sharing, honesty, and respect.

The **ribbon** (red) represents a link from the past (below the ground) to the present (above the ground) and to the future.

The outer **circle** (red) signifies blood of Aboriginal people.

All of these elements must be considered to deal effectively and efficiently with the issue at hand.

### The Aboriginal HIV challenge

The HIV prevention, education, care and support issues affecting the Aboriginal people are not unlike those affecting the rest of the population. However, the Aboriginal issues are more complex due to the numerous health and social issues facing many Aboriginal people and their communities:

- Injection drug use is one of the most prevalent risk factors exposing Aboriginal people to HIV. Underlying injection drug use may be histories of multiple abuse, addictions, poverty, and, overall, low self-esteem—all of these leading to poor choices and decision making.
- A high degree of movement between reserves and urban centres increases the exposure risk.
- Attitudes and beliefs of the Aboriginal people affect their sense of vulnerability to the disease and their comfort in addressing safe behaviours to prevent the spread of HIV. In some communities, strong disapproval is directed at sexuality education and homosexuality.
- Confidentiality fears, especially in small reserve communities and Métis settlements, may prevent some Aboriginal people from seeking testing.
- The passive role of the conventional healing system with its focus on the body and the active role of Aboriginal traditional healing with its focus on the holism of body, mind and spirit, creates confusion for some Aboriginal people.



## **The strategies**

Not only is a culturally appropriate approach a necessity, but a wholistic view of the broader issues within which HIV is placed also needs to be addressed. Strategies that address prevention and education to help Aboriginal communities become aware of and to respond to HIV are essential. Strategies to help Aboriginal people accept and support their people who are living with HIV are also important. Everyone has a role to play in responding appropriately and with determination to the HIV challenge.

## **Bringing it all together**

The problems, the issues, the vision and the recommended responses are documented in this report—the Alberta Aboriginal HIV Strategy, 2001-2004. This report consists of two major sections:

- **Section I—The Strategies**—the actions needed to address the Aboriginal HIV challenges. It contains information on seven major strategies that were identified by the Evaluation of the Alberta Aboriginal HIV/AIDS Strategy, and the corresponding roles and responsibilities to be taken by the stakeholders.
- **Section II—Creating the Vision**—contains the background information on the initial project completed for Alberta’s Aboriginal HIV/AIDS Strategy. Statistics on the HIV infection in the Aboriginal population, the development of a strategic planning tool called the Tree of Creation, the challenges to be overcome and the recommendations for addressing those challenges are described.

Each section is written in a different format. Section I mirrors the template that was used for Alberta’s overall HIV Strategy “HIV in Alberta 1998/99 – 2002: Alberta Health Strategy”. In this section, each issue and the goal responding to the issue are described, followed by a brief description of some of the measures that could be used to determine success in addressing the goal. Background information underlying that issue is then presented, followed by a description of the strategies and the role and responsibility of each major stakeholder. Section II is largely a narrative report, reflecting the information and vision as written by and for Aboriginal people.

# THE STRATEGIES

## BUILD CAPABILITIES IN ABORIGINAL COMMUNITIES

**ISSUE:** Additional capabilities are needed in Aboriginal communities to address HIV issues.

**GOAL:** Capabilities are strengthened within Aboriginal communities to enable them to effectively address HIV issues.

**KEY MEASURES:**

- Number of and level of community participation in local, regional, and provincial HIV workshops.
- Number and type of community activities and actions undertaken.
- Involvement of target groups in community HIV activities.
- Percent of community members actively involved in community HIV activities.
- Satisfaction level of participants with community HIV activities.
- Level of HIV awareness and satisfaction among community members.
- Level of leadership and support.
- Number and type of HIV requests from Aboriginal communities and the extent of follow-up taken.

*Note: Target group is defined broadly and may include all members of the community, the leadership and those who are at high risk of HIV infection. Each community needs to define its target group and the types of activities that they will do to address HIV.*

**BACKGROUND:**

- Aboriginal communities are striving to regain the strength and richness of their culture among a host of formidable health and social challenges.
- Honouring their traditional values of honesty, sharing, respect and faith, is part of rebuilding their people and their nations.
- HIV is one disease that has confronted Aboriginal communities and challenged their values as it is brought on through a lack of respect for oneself and others.
- The Alberta Aboriginal HIV project has initiated a community development process that is reaching into some of the Aboriginal communities. Using the strategic planning model called the “The Tree of Creation”, Aboriginal community leaders and others are beginning to understand the complexities underlying HIV.
- Aboriginal community leaders and other members are beginning to discuss their roles and responsibilities in providing prevention and support programs for their people.
- Given the complexities of HIV and the other challenges being addressed by Aboriginal communities, the existing momentum using a culturally appropriate, community development approach, needs to continue.

## **STRATEGIES: ROLES AND RESPONSIBILITIES**

### **Aboriginal Organizations**

Aboriginal organizations offering HIV prevention and care and support include, but are not limited to:

- Feather of Hope Aboriginal AIDS Prevention Society.
  - Kimamow Atoskanow Foundation.
  - Native Friendship Centres.
  - Nechi/Poundmakers (provide venue/resource people for training).
- 
- Train community HIV peer educators, focusing on the appropriate peer group.
  - Advocate on behalf of communities about HIV awareness.
  - Ensure community has up-to-date resources.
  - Provide community developers across the province to assist the Aboriginal communities through developing community-identified HIV strategies.
  - Ensure communities take follow-up actions.
  - Provide provincial networking regarding HIV issues and plans.
  - Conduct community satisfaction and follow-up actions within six months of the community activity.
  - Work with other service providers including Community Health Nurses (CHNs), Community Health Representatives (CHRs) and community HIV organizations within the area.

### **Aboriginal Communities**

- Follow-through on community education/workshops e.g., peer educators.
- Conduct training sessions/conferences.
- Allocate resources to address HIV issues.
- Build community partnerships and networks (within the community and outreach to other communities).
- Keep community leadership informed and involved.
- Ensure HIV education is part of school education.
- Build own community plans for addressing HIV (each community to determine their own needs and their measures of success).

### **Other Organizations Addressing HIV and the Aboriginal Population**

- Other organizations have a role in providing training resources and direct services, including information exchange. These organizations are:

- Alberta Community Council on HIV (ACCH)<sup>3</sup> which includes:
  - AIDS Bow Valley
  - AIDS Calgary Awareness Association.
  - AIDS Jasper
  - Central Alberta AIDS Network
  - Feather of Hope Aboriginal AIDS Prevention Society (FOHAAPS)
  - HIV/AIDS Network of South Eastern Alberta Association
  - HIV Edmonton
  - Interfaith Centre for AIDS/HIV Resources and Education
  - Kairos House
  - Lethbridge HIV Connection
  - Living Positive
  - Safeworks
  - Streetworks
  - HIV North
  - Wood Buffalo HIV and AIDS Society
- HIV clinics, and the
- SHARP Foundation.

### **Regional Health Authorities**

- Provide education, care and support to both Aboriginal and non-Aboriginal persons.
- Provide culturally appropriate services and accessible services.
- Work with Bands/Health Centres, as needed, to address HIV needs (recognizing the mobility of Aboriginal people) of off-reserve/settlement Aboriginal people.
- Include Aboriginal people in decision-making.

### **Alberta Health and Wellness**

- Allocate resources.
- Ensure delivery of quality health services through RHAs and other organizations.
- Facilitate and provide promotion, prevention, and protection activities.
- Work with other government ministries and help with facilitating their related Aboriginal programming.
- Support, acknowledge and encourage culturally relevant HIV care and support and, prevention services.

### **Health Canada**

- Provide national linkage and coordination role (resource sharing) (Population and Public Health Branch - PPHB).
- Educate other government ministries/facilitate their related programming (PPHB).
- Allocate resources (PPHB and First Nations and Inuit Health Branch – (FNIHB)).
- Ensure delivery of quality health services within First Nations communities (FNIHB).
- Set national program and service standards (PPHB).
- Provide promotion, prevention and protection activities (PPHB and FNIHB).
- Support, acknowledge and encourage culturally relevant HIV care and prevention services (FNIHB).
- Continue the Canadian Strategy on HIV/AIDS with support for Aboriginal HIV work (PPHB).

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<sup>3</sup> See Appendix for a listing of addresses.

## BUILD STRONG PARTNERSHIPS

**ISSUE:** Stronger partnerships between Aboriginal communities, regional health authorities, HIV agencies and other service organizations addressing Aboriginal needs (e.g., substance use, housing, prisons) are needed.

**GOAL:** Partnerships and networks are strengthened between Aboriginal communities, regional health authorities, HIV agencies and other service organization addressing Aboriginal needs (e.g., substance use, housing, prisons).

**KEY MEASURES:**

- Number, type and duration of joint initiatives.
- Level of participation and satisfaction with joint initiatives.
- Level of satisfaction with ongoing working relationships.
- Number and type of joint board/committee memberships.
- Number of and participation in joint program and service planning services.

**BACKGROUND:**

- A vast range of resources are required to support the ongoing needs and challenges facing Aboriginal people, including those who leave their First Nation communities and migrate to urban centres.
- Many organizations already exist with the mandate to provide health and social services to Aboriginal people, both living on and off reserve/settlement. However, many of these organizations also work in isolation, not building on the strengths that each one has nor generating a synergy to address the complex issues and needs, such as HIV, facing Aboriginal people.
- Relationships among major service providers need to be fostered and partnerships developed to bring together the best of resources that each has to offer in HIV education, prevention, harm reduction, care and support programs, including programs that address other related needs such as housing and substance misuse.
- Calgary Urban Aboriginal Outreach Project is a joint initiative among a number of organizations under the umbrella of the Aboriginal Cluster of the Calgary Coalition on HIV and AIDS. This project educates the Aboriginal street community about healthy lifestyles and high-risk activities for HIV/AIDS infection.
- Feather of Hope Aboriginal AIDS Prevention Society (FOHAAPS) is a member of the Alberta Community Council on HIV.
- “Committee on Aboriginal HIV in Alberta” meets three or four times a year, with representatives from across Alberta, to share information and to provide an opportunity for skill development.
- Lethbridge ‘MUST’ Project—Mobile Urban Street Team—represents a partnership between the City of Lethbridge and the Sik-Ooh-Kotoki Friendship Society and is supported by numerous agencies and service providers, as well as business people. The project aims to meet the needs of people on the street, provide advocacy and follow-up with services, resources and other initiatives such as harm reduction, medical services and addictions treatment.

## **STRATEGIES: ROLES AND RESPONSIBILITIES**

### **Aboriginal Organizations**

- Continue to provide a presence on various committees, consortia, etc.
- FOHAAPS invite and encourage community involvement (on Full Circle, etc.).
- FOHAAPS provide other organizations, committees etc., with ongoing and current information on FOHAAPS initiatives.
- Ensure community developers network with the various stakeholders in their respective areas.
- Provide education on HIV to other organizations (i.e., housing organizations, etc.).
- Link with existing databases to establish Aboriginal information that can be accessed by all Aboriginal communities (to help smooth and assist different community initiatives).
- Create and distribute a province-wide quarterly HIV/cultural newsletter.

### **Aboriginal Communities**

- Participate on committees and attend workshops to become more knowledgeable on HIV to serve their communities and to seek out partnership opportunities.
- Assign a person to represent agency/community on HIV issues.
- Ensure community representatives are accessible to local and outside people/groups, e.g., FOHAAPS Regional Community Developer.
- Conduct regular meetings with agencies/groups involved and have minutes of meetings posted or available for the public.
- Ensure person assigned to represent agency/group/community is committed to HIV prevention.

### **Other Organizations Addressing HIV and the Aboriginal Population**

- Work with Aboriginal communities and organizations to facilitate cross-cultural understanding and enhance working relationships and service referrals.
- Work to build partnerships with Aboriginal communities and organizations.
- Invite Aboriginal representatives to sit on local HIV (or related) committees, Community Planning Committees (CPCs), and Board of Directors for AIDS Service Organizations (ASOs).

### **Regional Health Authorities**

- Enhance working relationships between settlement and off-reserve Aboriginal organizations and communities, RHAs and HIV organizations.
- Include Aboriginal participation in decision-making.
- Collaborate with Health Canada regarding on-reserve services.
- Work with governments and community HIV organizations in mobilizing a community-based response to HIV.

**Alberta Health and Wellness**

- Provide resources as available to support inter-jurisdictional collaboration.
- Work toward removing inter-jurisdictional barriers by continuing to use a joint funding/planning model with Health Canada.
- Work with other ministries/organizations to address factors such as poverty, housing, violence, drug abuse and alcoholism that increase the risk of becoming HIV-infected.
- Provide resources, as available, to support the Alberta Community HIV Fund.

**Health Canada**

- Encourage development and maintenance of partnerships (FNIHB and PPHB).
- Work on reducing inter-jurisdictional barriers (FNIHB and PPHB).

## ENHANCE CARE AND SUPPORT SERVICES

**ISSUE:** More care and support services are needed for Aboriginal people who are infected and affected by HIV.

**GOAL:** Appropriate care and support services for Aboriginal people infected and affected by HIV are accessible when required.

**KEY MEASURES:**

- Use of medical and other health care services.
- Availability, accessibility and use of traditional medicines and Aboriginal health practices.
- Number and type of accessible health care and support options for Aboriginal people.
- Level of awareness and knowledge about the management of HIV.
- Level of satisfaction in the Aboriginal communities with medical, health and other services received.

**BACKGROUND:**

- Although the proportion of Albertans who are Aboriginal is approximately 4.6% (Statistics Canada, 1996), Aboriginal people represent approximately 25% of the total number of HIV-positive clients seen in the clinics serving northern Alberta.
- The physical and psychosocial impact of HIV on individuals and their families is well researched. Dual diagnosis such as T.B. and HIV or a mental illness and HIV compound the health problems. The HIV condition is further compounded by poverty that may adversely affect housing conditions, eating practices, and sense of self worth.
- HIV affects all infected Aboriginal people, their families, and their communities. The direction of Aboriginal leadership in each community can influence either positively or negatively how infected persons and their families are regarded. A continuum of services is required to meet the needs of Aboriginal individuals and their families who are HIV-positive over the length of their illness.
- Currently, Health Canada, through the First Nations and Inuit Health Branch, funds and coordinates the delivery of community-based health services to Status Indians living on reserve. Hospitals, nursing stations, health centres and various other health facilities deliver services. Health Canada may also supplement some provincial/territorial health care services.
- Aboriginal people are also entitled to services provided under the Alberta Health Care Insurance Plan.
- Conventional health care is available to Aboriginal people as it is to all Albertans. However, awareness of and access to existing Aboriginal-specific programs and services may be a problem.
- In addition, traditional treatments that actively involve Aboriginal persons with Aboriginal practitioners that embrace the holism of body, mind and spirit, may be lacking or underdeveloped.



## **STRATEGIES: ROLES AND RESPONSIBILITIES**

### **Aboriginal Organizations**

- Work with agencies for the availability of culturally sensitive care and support services for the Aboriginal population.
- Work as advocates for Aboriginal Persons having HIV/AIDS (APHAs) regarding medical care.
- Work with agencies to create a healthy holistic/friendly/understanding environment in home communities for APHAs wishing to return “home” to be cared for.

### **Aboriginal Communities**

- Updated information is provided on an ongoing basis about care and support needs, i.e., universal precautions, medications, nutrition.
- Facilitate support from the Aboriginal Leaders in their communities.
- Provide social services/child welfare/health services/mental health/NNADAP.
- Develop community HIV-specific policy and procedures manual.
- Provide training for families and volunteers.
- Provide respite care.

### **Other Organizations Addressing HIV and the Aboriginal Population**

- Provide care and support services, as appropriate.
- Provide a forum to address care and support issues in the Aboriginal community.

### **Regional Health Authorities**

- Provide prevention, care and support services to the Aboriginal population within their region who live on settlements or off-reserve, and collaborate with Health Canada regarding on-reserve services.
- Facilitate interaction between service providers and Aboriginal communities to identify and address barriers to services.
- Ensure delivery of quality, accessible health services for care, treatment and support including HIV testing and counselling.

### **Alberta Health and Wellness**

- Provide resources as available to sustain HIV care and support services.
- Facilitate HIV training for Aboriginal health and social services providers.
- Provide funding for HIV clinics in Edmonton and Calgary and specific anti-retroviral therapies through the extraordinary drug cost program.

### **Health Canada**

- Ensure frontline staff has access to information and skill development opportunities to care for or assist with HIV management (FNIHB).
- Explore care and support options with First Nations and Aboriginal Service Organizations (FNIHB).
- Facilitate interactions between service providers and First Nations to identify and address barriers to service (FNIHB).

## USE SAFER SEX AND HARM REDUCTION PRACTICES

**ISSUE:** Safer sex and harm reduction practices need to be consistently used, especially among Aboriginal populations at higher risk of contracting HIV (i.e., prisoners, Intravenous Drug Users (IDUs), youth, women).

**GOAL:** Safer sex and harm reduction practices are understood and used by Aboriginal people, including prisoners, IDUs, youth and women.

**KEY MEASURES:**

- Level of awareness and knowledge regarding safer sex and harm reduction practices.
- Use of condoms and needle exchange programs.
- Number of and enrolment in alcohol and drug treatment programs.
- Number and location of alternative methods of HIV testing.
- Number of HIV tests by age and gender.
- Rate of new HIV infections.

**BACKGROUND:**

- HIV can be spread through needle and equipment sharing with infected injection drug users, unsafe sexual activity with infected persons, and through HIV-infected women to their babies during pregnancy, delivery and breast feeding.
- HIV is 100% preventable through elimination of risky behaviours or harm reduction techniques. In the Aboriginal population, such risky behaviour is often rooted in social and economic distress.
- Many Aboriginal people who get infected are street-involved and dealing with addictions and may suffer from a lack of clarity in their decision-making. Poor self-esteem may also influence the choices that they make.
- Injection drug use is an increasing source of HIV infection and may be more dangerous than the actual drug use. Injection drug use is the most prevalent exposure factor for Aboriginal people.
- Harm reduction techniques are important to reduce the risk of transmitting HIV and other diseases through drug use. Such techniques include needle exchange and availability, methadone programs, education and outreach programs.
- In 1999, 200 known cases of HIV/AIDS were reported among incarcerated persons, more than 10 times the rate in the Canadian population at large (Canadian HIV/AIDS Legal Network, 1999, HIV/AIDS and Hepatitis C in Prisons: The Facts). A tendency towards high risk behaviours, especially drug use, increases the probability of contracting HIV in prison.
- Aboriginals are over-represented among inmate populations. In the Prairie Region of the Correctional Service of Canada, Aboriginal people account for 64 percent of the inmate population.

- HIV is increasing among youth in general, increasing the probability of infection among Aboriginal youth. Thirty-one percent of Aboriginals who have AIDS are under the age of 30, meaning they were probably infected in their late teens or early twenties.
- Many people with new HIV infections are women. The proportion of women among adult Aboriginal AIDS cases is higher than among adult non-Aboriginal AIDS cases—15.9% versus 7%.
- The high birth rate among Aboriginal women, including teenagers, indicates unsafe sexual practices and is a risk for the Aboriginal population. The risk of mother-to-infant spread of HIV can be reduced substantially with proper combinations of anti-viral drugs.
- The TIPITALK Website is a project of the Treaty 7 CHR AIDS Committee. This school-based health website offers First Nations youth an opportunity to discuss sexuality issues, identify common concerns and identify how sexuality problems affect their personal and community health.
- Lethbridge ‘MUST’ Project—Mobile Urban Street Team—represents a partnership between the City of Lethbridge and the Sik-Ooh-Kotoki Friendship Society and is supported by numerous agencies and service providers, as well as business people. The project aims to meet the needs of people on the street, provide advocacy and follow-up with services, resources and other initiatives such as harm reduction, medical services and addictions treatment.

## **STRATEGIES: ROLES AND RESPONSIBILITIES**

### **Aboriginal Organizations**

- Facilitate the development of Aboriginal-specific programs (run by Aboriginals for Aboriginals) such as needle exchanges in communities, prison outreach, etc.
- Assist other agencies in the provision of “Streetwise” services—continue to support urban youth education regarding HIV.
- Continue to provide free condoms.
- Continue to bring culturally specific and appropriate prevention/education programs and information sessions to those in prisons, group homes, addictions facilities.
- Provide information regarding female condoms, etc.
- Assist existing HIV community initiatives.

### **Aboriginal Communities**

- Facilitate condom accessibility/initiatives.
- Support and provide sex education programs—school, prenatal classes, utilize web site.
- Provide needle exchange programs as appropriate.
- Provide workshops on HIV education and prevention.
- Utilize NNADAP program, addictions services.
- Utilize mental health services, i.e., self-esteem classes.
- Promote abstinence where appropriate.

### **Other Organizations Addressing HIV and the Aboriginal Population**

- ACCH:
  - Collaborate in the planning, coordination, delivery and evaluation of HIV programs and services including those for Aboriginal communities and people.

- ACCH and others:
  - Collaborate with Aboriginal communities, organizations and individuals regarding HIV prevention programming and work cooperatively to enhance impact.
  - Continue doing effective HIV outreach and education including those for Aboriginal communities and people.
  - Provide needle exchange programs, as appropriate.

### **Regional Health Authorities**

- Provide HIV prevention programming to offenders, ex-offenders and their families.
- Provide training/in-services for corrections staff, as appropriate.
- Provide harm reduction programming including needle exchange programs, as appropriate.
- Ensure HIV prevention programming is relevant and accessible to the Aboriginal people, targeting Aboriginal youth and women.

### **Alberta Health and Wellness**

- Support existing harm reduction programs, where appropriate, including needle exchange programs through grant funding to the Alberta Community HIV Fund.
- Provide leadership for the multi-sectoral, intergovernmental HIV prevention among Non-Prescription Needle Users Consortium (NPNU Consortium).
- Through the NPNU Consortium Aboriginal, Women and Youth Task Groups, identify programming and service delivery issues as well as best practices relating to HIV and injection drug use.
- Provide resources as available to sustain HIV prevention programming.
- Work with Alberta Justice and FNIHB to procure, develop and provide HIV resources to support prevention programming for offenders and ex-offenders.

### **Health Canada**

- Encourage development of Harm Reduction Models (FNIHB and PPHB).
- Distribute Harm Reduction Models (FNIHB and PPHB).

## INCREASE CULTURALLY APPROPRIATE RESOURCES

**ISSUE:** More culturally appropriate information and educational resources are needed.

**GOAL:** Culturally appropriate information and educational resources are available for Aboriginal people

**KEY MEASURES:**

- Number and use of culturally appropriate educational, promotional and informational resources.
- Use of TIPITALK website.
- Distribution of (i.e., location, accessibility) culturally appropriate educational, promotional and informational resources.
- Number and reach of HIV-related campaigns.
- Level of HIV education incorporated into school, sexuality and parenting programs.
- Level of awareness and knowledge about HIV among community members; including those at risk.

**BACKGROUND:**

- Much of the work presently being done to address Aboriginal HIV is not culturally appropriate and therefore, may be considered ineffective, inefficient or insufficient.
- Much of the Aboriginal HIV education and prevention lacks connectedness with Aboriginal communities. Programs may be developed in isolation of the Aboriginal people or communities. An understanding of Aboriginal culture and the active participation of Aboriginal people in the development of programs and resources are essential.
- One provincial organization currently exists with the mandate to address Aboriginal HIV—the Feather of Hope Aboriginal AIDS Prevention Society (FOHAAPS)—located in Edmonton. The organization provides training to communities that request it as well as some minimal support services.
- Other organizations developing in the province (Kimamow Atoskanow Foundation, Northern Alberta and Southern Alberta HIV/AIDS Working Committees) are early in their formation but are working with some other organizations to address Aboriginal HIV issues.
- The TIPITALK Website is a project of the Treaty 7 CHR AIDS Committee. This school-based health website offers First Nations youth an opportunity to discuss sexuality issues, identify common concerns and identify how sexuality problems affect their personal and community health.
- Calgary Urban Aboriginal Outreach Project is a joint initiative among a number of organizations under the umbrella of the Aboriginal Cluster of the HIV/AIDS Strategies (HAS) Coalition in Calgary. The project educates the Aboriginal Street community about healthy lifestyles and high-risk activities for HIV infection.
- The provincial HIV “We’re all affected” campaign—is a mobile, interactive and educational exhibit consisting of display panels, tabletop displays, interactive consoles and videos all designed to introduce the general public to HIV and invite them to learn more. The materials used can be selected to address the needs of various target audiences in Alberta.

## **STRATEGIES: ROLES AND RESPONSIBILITIES**

### **Aboriginal Organizations**

- Create a culturally appropriate resource centre/base.
- Help to identify Elders within Alberta who can be available for community support.
- Continue to provide culturally relevant workshops, posters, pamphlets, condom jackets, and HIV information.
- Encourage the relationship between Elders and youth.
- Encourage the involvement of Elders in any HIV initiative or education process.
- Encourage traditional values and practices in communities, organizations and meetings, as appropriate.

### **Aboriginal Communities**

- Procure and develop, as necessary, appropriate literacy and culturally appropriate pamphlets, including visual aids.
- Provide access to resources.
- Advocate for required human and financial resources.

### **Other Organizations Addressing HIV and the Aboriginal Population**

- ACCH and others
  - deliver appropriate audio-visual and print resources including those applicable to Aboriginal organizations, communities and individuals, as appropriate.
  - provide a forum for an exchange of print resources including those applicable to Aboriginal organizations, communities and individuals, as appropriate.

### **Regional Health Authorities**

- Procure, develop and provide culturally sensitive/targeted resources in support of HIV education.

### **Alberta Health and Wellness**

- Procure, develop and provide culturally sensitive print and audio resources and media messages, when appropriate.

### **Health Canada**

- Distribute resources (FNIHB).
- Facilitate development of resources (FNIHB and PPHB).
- Allocate resources (FNIHB and PPHB).

## DEMONSTRATE EFFECTIVENESS OF HIV PROGRAMS

**ISSUE:** Evidence on the effectiveness and efficiency of Aboriginal HIV programs and services continues to be needed.

**GOAL:** The effectiveness and efficiency of Aboriginal HIV programs and services are assessed and documented on a regular basis.

**KEY MEASURES:**

- Number of HIV program evaluations conducted and analyzed.
- Percent of program and training objectives achieved.
- Proportion of total program budget allocated to administration vs. direct service delivery.
- Estimated costs/client (participant) per service unit.
- Estimated service unit costs.

**BACKGROUND:**

- Measuring and monitoring the effectiveness and efficiency of any health program is important to ensure that it is accomplishing what it sets out to accomplish, and is doing so in an efficient manner with an appropriate use of allocated resources.
- HIV programs and services, including those targeted at the Aboriginal population, also need to be evaluated for their effectiveness and efficiency.
- Considerable funding has been made available through the federal and provincial governments. Federally, the National AIDS Strategy and the First Nations and Inuit Health Programs Directorate have contributed funding for prevention and education initiatives involving Aboriginal leaders, Elders, care givers and other Aboriginal people.
- Provincially, funding has been provided for Aboriginal HIV projects and increased funding has been provided to community organizations to help them increase their role in addressing HIV in the Aboriginal population.
- Funding of community initiatives by the provincial and federal governments require evaluation and documentation. The resulting resources and reports are shared with other provincial and federal government departments.
- Attention to the design, implementation and outcomes of HIV programs and services, including those directed at Aboriginal populations, may be necessary to improve evaluation efforts.

## **STRATEGIES: ROLES AND RESPONSIBILITIES**

### **Aboriginal Organizations**

- Assist in developing an evaluation process for FOHAAPS.
- Assist in the development of evaluation tools for communities.
- Work with other organizations and communities to develop an accountability process, including the involvement of target group participants (who is being reached?) and the cultural appropriateness of methods for each area.

### **Aboriginal Communities**

- Allocate community funds and ensure accountability for their use.
- Participate in program evaluations.
- Participate in peer reviews.

### **Other Organizations Addressing HIV and the Aboriginal Population**

- ACCH and others:
  - Participate in research, evaluation activities and needs assessment as appropriate.

### **Regional Health Authorities**

- Monitor, report and evaluate services regarding HIV.
- Conduct, support or facilitate research aimed at preventing HIV and at supporting and treating those with HIV infection.
- Support cost effectiveness and program outcome studies.
- Conduct needs assessments as they relate to the Aboriginal population regarding prevention and management of HIV.

### **Alberta Health and Wellness**

- Continue to support the Alberta Heritage Foundation for Medical Research via the Health Services Research and Innovation Fund and the Swift Efficient Application of Research in Community Health (S.E.A.R.C.H.) Program.
- Support the network of individuals, universities, and other organizations involved in HIV research relating to HIV and the Aboriginal population.
- Support standards development and service performance.
- Support evaluation of programs through the Alberta Community HIV Fund.

### **Health Canada**

- Facilitate development of tools, and evaluation processes (FNIHB and PPHB).
- Provide roll-up of evaluation information from First Nations activities (FNIHB).



# ENHANCE HIV EPIDEMIOLOGICAL DATA

**ISSUE:** Epidemiological data on HIV in the Aboriginal population are lacking.

**GOAL:** Epidemiological data on HIV in the Aboriginal population are routinely collected and analyzed.

**KEY MEASURES:**

- Incidence and prevalence data on HIV infections in the Aboriginal population.
- Rate of HIV testing.
- Standardized reporting methods for HIV testing and HIV infections in the Aboriginal population.

**BACKGROUND:**

- An accurate picture of Aboriginal HIV in Alberta requires information about risk behaviours, outbreaks, disease trends, co-factors, incidence and prevalence of both HIV and AIDS.
- In Canada, all provinces collect information on AIDS cases. Interpretation of these data is problematic as AIDS diagnoses reflect infections that may have occurred as long as ten years ago. Complete information is subject to delays in reporting and ethnic origin is not always identified.
- Through Alberta's clinics, current and comprehensive information is available on Albertans with documented HIV infection who are receiving HIV care. Additional information on HIV testing is available from the Public Health Laboratories.
- The Aboriginal culture poses another challenge: *Some Elders tell us not to get caught up in the numbers. It isn't the numbers, but the people themselves who are important. The important thing is to create a safe secure environment for people to disclose HIV/AIDS status, without fear of rejection or prejudice.*
- All people involved in HIV programming, need to contribute to the development and interpretation of information and knowledge.
- Confidentiality is an important issue for those affected by HIV and needs to be understood by all those working in the HIV field.
- Collection of HIV data needs to be standardized to ensure consistent and similar information is being collected.

## **STRATEGIES: ROLES AND RESPONSIBILITIES**

### **Aboriginal Organizations**

- Assist in the distribution and explanation of current data (numbers).
- Encourage confidentiality for those being tested (trust in community care providers). Encourage and educate communities in this regard.
- Encourage and be advocates for appropriate testing standards.

### **Aboriginal Communities**

- Understand the statistics that are provided.
- Understand the risk factors.
- Ensure that confidentiality standards are developed and implemented.

### **Other Organizations Addressing HIV and the Aboriginal Population**

- ACCH and others:
  - Participate in defining the data required for surveillance and monitoring purposes, including those for Aboriginal organizations, communities and people.
  - Determine additional elements to be captured, reflecting the changing nature of the epidemic, including those for Aboriginal organizations, communities and people, as required.

### **Regional Health Authorities**

- Conduct HIV seroprevalence studies as appropriate among selected populations.
- HIV clinics continue to collect HIV data.
- Define, collect, analyze, and share HIV data as appropriate.

### **Alberta Health and Wellness**

- Define, collect, analyze and share information about findings and trends in HIV.
- Work with HIV clinics, RHAs, FNIHB, Community HIV Organizations, and other government departments, to understand and coordinate Aboriginal-related HIV statistics.

### **Health Canada**

- Work with Alberta Health and Wellness, First Nations, HIV clinics, and ASOs to develop acceptable formats to present data (FNIHB).

## CREATING THE VISION

### A. The Problem: A Snapshot

In 1980, Alberta recorded its first death from Acquired Immune Deficiency Syndrome (AIDS). The disease gradually claimed more and more lives until education and prevention strategies in the province began to take hold. Although AIDS and the virus that leads to AIDS, Human Immunodeficiency Virus (HIV) remain a significant health issue, nearly twenty years after that first death, the trend of infection has peaked and leveled off. In Alberta's general population, fewer people are contracting HIV.

However, the tapering trend is not mirrored within Alberta's more vulnerable populations. HIV festers in an atmosphere of social and economic marginalization. While the rate of infection has generally leveled off, HIV continues to devastate certain populations at an increasing rate. These groups include injection drug users, prison inmates, impoverished women and Canada's people of the land—Aboriginals.

The HIV risk is five times higher for Aboriginals than for those in the general population. In 1992, Health Canada reported 25 cases of Aboriginal people with AIDS. In 1999, that number had grown to 371. An increase from 1% of AIDS cases in 1990 to 15% of AIDS cases in 1999.<sup>4</sup>

The number of adult female Aboriginals with AIDS is disproportionate to the number of adult female cases within the general population (22.2% vs. 7.7%). AIDS cases among younger Aboriginals compared to those in the general population is 28.6% vs. 17.1% (diagnosed at less than 30 years of age).<sup>4</sup>

In Alberta, the statistics are similarly disturbing. The University of Alberta HIV Clinic reports 23% of new HIV patients in Northern Alberta are Aboriginal, while Aboriginals make up just 6% of the population. In Edmonton, where less than 4% of the population is Aboriginal, 25% of the 75 new cases of HIV reported in 1998 were Aboriginal.

Alberta's first peoples face yet another challenge in their checkered history. The strength of Aboriginal language, tradition and culture has been shaken by epidemics of flu, smallpox, tuberculosis and addiction. Non-Aboriginal policies and practices such as the introduction of reserves and residential schools, the outlaw of spiritual practices and the development of myriad of government departments and regulations have eroded traditional roles and practices and created systemic dependency. Such influences are the foundation of today's social and economic atmosphere for Aboriginals, and affect the tenacity of HIV among Aboriginal people.

And yet resolve stands strong. This era of self-determination encourages Aboriginals to act positively in face of the threat of HIV. The problem is visible, and the signs are all around. Aboriginal people living with HIV within their community, family—and within their own bodies—have been involved in the creation and growth of awareness around the issues.

HIV and AIDS are diseases that respect no cultural boundaries. And yet the strength of the Aboriginal culture is a component in the survival of the first peoples against this latest threat to Aboriginal spiritual and physical health. The Alberta Aboriginal HIV/AIDS Strategy was designed by Aboriginals for the use of policy makers and community leaders in planning for issues of prevention and care. It is a unique tool for a unique people.

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<sup>4</sup> *HIV/AIDS Epi Update. HIV and AIDS Among Aboriginal People in Canada. Bureau of HIV/AIDS, STD and TB Update Services. Laboratory Centre for Disease Control. Health Canada. April 2000.*

## **B. Alberta Aboriginal HIV/AIDS Strategy: Project Background**

The number of HIV infections among Aboriginal people is a growing concern. The need to develop and sustain high quality and culturally appropriate social, medical and educational programs for all Albertans is identified. The requirement to support vulnerable populations to participate in and take initiative for designing their own information, resources and service approaches is recognized. AIDS can be fatal, yet it's a 100% preventable disease. Co-ordination of initiatives is key in containing the epidemic.

Health Canada and Alberta Health in response to these issues initiated the Alberta Aboriginal HIV/AIDS Strategy. The three year, \$190,000 project was announced by Federal Health Minister David Dingwall and Alberta Health Minister Halvar Johnson in July, 1996.

Together with the leadership of Aboriginal communities, the goal of the strategy was to provide a culturally appropriate approach to the prevention of HIV among Aboriginals, as well as the care and support of Aboriginal people with HIV.

Preparing the strategy involved developing processes to:

- Assist communities to understand and discuss the implications of HIV for their communities.
- Discuss appropriate components of HIV prevention programming.
- Discover how communities can take action to prevent the spread of HIV infection and plan for the subsequent programming initiatives.
- Plan for the care and support of community members who have or are directly affected by HIV.

Ultimately, the future direction of this strategy is that Alberta's Aboriginal communities are aware of and understand HIV and people living with HIV are accepted and supported. In short, the future holds a healthy response to HIV.

### **Going back to the people of the land: the process used**

Two components were key to the development of the strategy. The first, a detailed literature review was helpful in assessing the present situation and opportunities for change. The second, consultation with various interest groups, including on-reserve and off-reserve Aboriginals and Aboriginal and/or HIV focused agencies, was invaluable in establishing a workable strategy to address HIV in Aboriginal communities.

The initial step in building the Alberta Aboriginal HIV/AIDS Strategy was assembling a team. An Aboriginal consultant with a health administration and counselling background acted as project co-ordinator. To support the consultant an Advisory Committee was struck, made up of community leaders, personnel from various Friendship Centres, Elders and agency representatives. The project was also supported by two program managers; one from the Medical Services Branch, Health Canada and the other from Alberta Health.

#### **1. Literature Review**

A detailed review of HIV/AIDS literature was conducted in the Spring of 1996 which categorized information into three main tracks: Prevention and/or Education, Care and Support. These categories were further broken down into Aboriginal Specific, General and Further Reading. The Canadian AIDS Society and the Canadian Aboriginal AIDS Network recognized this review as "one of the best HIV/AIDS Aboriginal literature reviews in Canada".

In total, the literature review team surveyed 156 documents, reports, papers and articles. All works reviewed were categorized with source information and key words. Those with high relevance to the Alberta Aboriginal HIV/AIDS Strategy were also summarized briefly with a list of salient points.

## 2. Identification of Interest Groups

Various interest groups were engaged to define clear principles that would guide the strategy. Allowing people to define a common vision and acknowledging different values and beliefs laid the foundation for this strategy.

The strategy identified three categories of interest groups:

- **Primary interest group.** The Alberta Aboriginal HIV/AIDS Strategy was designed chiefly by **Aboriginal people**. Key groups within the Aboriginal population were especially in focus, as were groups that work directly with Aboriginal HIV issues.
- **Secondary interest groups** included **organizations** concerned with Aboriginal people and/or HIV.
- **Third interest group** included various **government departments** that were consulted in their role of policy makers, past, present and future.

The participating groups in each interest group follow.

1. Primary Interest Group: Aboriginal People	
<ul style="list-style-type: none"> <li>• Aboriginal and Métis people, on and off-reserve.               <ul style="list-style-type: none"> <li>– Elders.</li> <li>– Youth.</li> <li>– Aboriginal political leadership.                   <ul style="list-style-type: none"> <li>• Tribal Councils.</li> <li>• Band Councils.</li> <li>• Métis settlement leaders.</li> <li>• Health Advisory committee.</li> </ul> </li> <li>– Aboriginal inmates.</li> <li>– Young Offenders.</li> <li>– Patients with alcohol and drug treatment centres.</li> <li>– People with HIV.</li> <li>– Family members or other support people for people with HIV.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Front-line health workers.               <ul style="list-style-type: none"> <li>– Health Centre directors and staff.</li> </ul> </li> <li>• Aboriginal AIDS Service Organizations or Initiatives.               <ul style="list-style-type: none"> <li>– Feather of Hope Aboriginal AIDS Prevention Society.</li> <li>– Kimamow Atoskanow Foundation.</li> <li>– Northern Alberta HIV/AIDS Working Committee.</li> <li>– Southern Alberta HIV/AIDS Working Committee.</li> </ul> </li> </ul>
2. Secondary Interest Groups: Organizations	
<ul style="list-style-type: none"> <li>• Native Friendship Centres.</li> <li>• Regional Health Authorities.</li> <li>• Indian Health Care Commission.</li> </ul>	<ul style="list-style-type: none"> <li>• AIDS Service Organizations</li> <li>• HIV Community Planning Committees</li> </ul>
3. Third Interest Group: Government Policy Makers	
<ul style="list-style-type: none"> <li>• Provincial Government Departments<sup>5</sup>.               <ul style="list-style-type: none"> <li>– Alberta Health.</li> <li>– Alberta Family and Social Services</li> <li>– Alberta Community Development.</li> <li>– Alberta Justice.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>– Alberta Education               <ul style="list-style-type: none"> <li>• Primary.</li> <li>• Secondary.</li> <li>• Post secondary.</li> </ul> </li> <li>• Health Canada<sup>6</sup> <ul style="list-style-type: none"> <li>– Medical Services Branch</li> <li>– Health Promotion and Programs Branch (AIDS Community Action Program).</li> </ul> </li> </ul>

<sup>5</sup> The names of the provincial government departments reflect the names prior to the reorganization in 1999.

<sup>6</sup> The names of the federal government branches reflect the names prior to the reorganization in 2000.

## **C. The Tree of Creation**

The consultation process took the form of workshops and meetings with the various interest groups. During consultation, a symbol called the Tree of Creation was developed to set the strategy-building process on a nature-based, culturally appropriate course. Use of the tree recognizes and celebrates the connection to the land that the Aboriginal people hold. The tree is versatile and can be used for a variety of issues facing Aboriginal people.

The following description was derived from the whole of the information collected during the consultation process.

### **1. The Roots: Building on the foundations of the past through identification of values**

The values of Aboriginal people are at the root of the HIV/AIDS Strategy. These values identify what is of primary importance in planning and implementing the Strategy.

- **Life/Family:** We believe our people and our communities are important.
- **Sharing:** We believe in communication. We believe we must learn to work together, all contributing to a common goal.
- **Honesty:** We believe the facts must be presented in a manner that we, as Aboriginal people, can relate to and understand.
- **Respect:** We respect the individual, rights and honour of all creatures of our sacred mother earth.

Supporting the roots are the beliefs the community has about HIV. The values and beliefs together form the guiding principles from which the Aboriginal community operates and monitors action.

### **2. The Grassroots: Development of guiding principles**

The grassroots represent the people of a community determining needs as opposed to the needs being defined outside the community. Also at the root of the Tree of Creation response to HIV/AIDS is a set of guiding principles that emerged from values. These principles are universal and guide the Alberta Aboriginal HIV/AIDS strategy and the action it takes.

- HIV is preventable.
- Change is possible.
- Do not judge or try to change others. Each person must develop an individual response to HIV.
- HIV programs demand commitment and shared vision to ensure ongoing education and support to individuals and communities.
- Personal healing issues must be addressed before working with others.
- We have a responsibility to work together and share what we know.
- We respect the holistic approach to this issue.

### **3. The Trunk: Examining the present**

The trunk flows from the grassroots where the community determines the need and course of action they wish to pursue. The trunk represents growth and action pursued by individuals, communities and organizations.

### **4. Guiding the growth of the Tree of Creation: Creation of a vision**

Seeking guidance from spiritual leaders and elders, the consultation process incorporated traditional insights into the purpose of looking beyond the present to visualize an ideal future and clarify individual roles in this world. The process was the foundation of the vision statement, which nourishes the Tree of Creation.

### ***Vision Statement***

Our communities are aware of and understand HIV/AIDS and people living with HIV/AIDS are accepted and supported.

### ***Short version:***

Healthy response to HIV/AIDS.

## **5. The Branches: Recommendations**

The two main branches represent the various aspects of addressing HIV in the areas of prevention, and Care and Support. The smaller branches represent research and surveillance. With a clear view of the current situation and a vision for the future, recommendations for action were developed. These are explored in the Opportunities section.

## **6. The Leaves: Roles and Responsibilities**

Thousands of tiny leaves blossom to create the beauty of a tree. Using the Tree of Creation model, these leaves represent the roles and responsibilities we have in each aspect of Prevention, and Care and Support.

## **D. Findings: What's happening now—Infection and Prevention Issues**

In order for recommendations to successfully address the issues around Aboriginal HIV in Alberta, the strategy, through research and consultation sought to build an accurate picture of these issues: the facts and beliefs around HIV. The literature review and the consultation process jointly supplied this information.

### **1. Who is infected? And how are those infected exposed to HIV/AIDS?**

The latest available statistics on AIDS came from Health Canada's Laboratory Centre for Disease Control (LCDC) and were assembled in December 1998. It is important to recognize that just over half of AIDS cases reported to LCDC include the ethnic origin of the individual. Therefore, the number of Aboriginal people who have AIDS is likely to be underestimated. These statistics reflect national information and are not limited to Alberta.

Of a total of 321 reported Aboriginal AIDS cases, 263 affected were male and 58 were female.

Source of infection	% of male	% of female
Sex with men	57.4	-
IDU	19.4	53.4
Sex with men and IDU	12.9	-
Heterosexual contact	4.9	29.3
Blood/clotting factors	0.8	6.9
Perinatal transmission	1.5	5.2
Unknown	-	5.2

Generally, injection drug use (IDU) is the most prevalent exposure factor for Aboriginal people of both genders. Adult Aboriginal AIDS cases are more likely than adult non-Aboriginal AIDS cases to have their exposure category attributed to injection drug use (32.8% vs. 7.8% for men, 56.4% vs. 17.7% for women).

Other statistics available from LCDC, report that Aboriginal AIDS cases are younger than non-Aboriginal AIDS cases (29.3% vs. 17.6% were diagnosed at less than 30 years of age). As well, the proportion of women among adult Aboriginal AIDS cases is higher than among adult non-Aboriginal AIDS cases (17.5% vs. 6.4%).

HIV data are helpful in predicting future trends among AIDS in Aboriginals. Data from 1993-98 show that 26% of newly diagnosed HIV-positive cases in Alberta were Aboriginal, and that IDU and heterosexual behaviours were the most significant risk factors. Sixty percent of new HIV-positive tests among Aboriginals were attributed to injection drug use. Thirteen percent were attributed to heterosexual contact.<sup>7</sup>

## **2. What behaviours lead to infection?**

HIV is transmitted from person to person via blood, semen, vaginal fluids and breast milk.

- In the case of injection drug use, HIV is spread through sharing of injection equipment.
- HIV is spread sexually (both heterosexually and when men have sex with men) when condoms or barrier-type protection is not used during sexual activity.
- HIV-infected women can also pass HIV to their babies during pregnancy, delivery and breastfeeding.
- Historically, HIV has been spread through infected blood products used in medical procedures, but due to stringent testing procedures, this risk has been reduced to nil.

HIV is 100% preventable through elimination of risky behaviours or harm reduction strategies. However, in the Aboriginal population, such behaviour is often rooted in social and economic distress. Many who get infected are street-involved and dealing with addictions and may suffer from a lack of clarity in their decision-making. Poor self-esteem also influences choices made.

Any plan to prevent HIV infection in Aboriginal people must look not only at the behaviours, but the stories behind the behaviour. In general, Aboriginal tradition and culture has been eroded by historical events such as the establishment of reserves and the creation of dependency on government, removing children to residential schools, medical epidemics and the introduction of alcohol.

An Aboriginal individual has a greater than average chance of suffering from the off-shoots of a fragile society. Specifically, an Aboriginal person:

- May have suffered or be suffering from physical, emotional or sexual abuse.
- May be addicted to drugs or alcohol.
- May be living in poverty.
- May have a lower self-worth.

These are all potential causes of poor choices and decision making.

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<sup>7</sup> *HIV/AIDS Epi Update. Bureau of HIV/AIDS, STD and TB Update Services. Laboratory Centre for Disease Control. Health Canada. May 1999*



### ***Of Special Note: Harm Reduction Explained***<sup>8</sup>

With injection drug use being one of the primary means of HIV transmission many with an interest in public health believe the spread of HIV in this manner is more of a risk than the dangers of drug use itself. The term harm reduction refers to efforts to reduce the risk of transmitting HIV and other diseases through drug use rather than eliminating drug use altogether. And although elimination of drug use is not the first priority of harm reduction, it can be an element of the policy.

Harm reduction strategies can include:

- **Needle exchange and availability**  
Access to sterile needles and syringes can reduce the possibility of needle sharing among injection drug users and provide an outreach opportunity for health care workers.
- **Methadone programs**  
In many countries, methadone is offered through public health initiatives to stabilize, detoxify and treat heroin users. Studies demonstrate that methadone availability is helpful in diminishing the users' involvement in crime and helping them gain control of their lives. In Canada, methadone programs are at present limited.
- **Education and outreach programs**  
Public health workers educate drug users on reducing the risks associated with using drugs through safer injecting practices. Workers distribute educational material, needles, condoms and bleach kits and help users contact other services.
- **Law enforcement policies**  
Some public health officials have engaged law enforcement agencies as an important front line contact with drug users to improve the prevention and treatment of drug problems, particularly with respect to the spread of HIV infection among injection drug users. Elements of this policy can include referring users to services, supporting needle exchange, and generally working to steer users away from crime and imprisonment, instead diverting them to treatment. In Canada, there has been a general shift toward community policing that may improve the chances of law enforcement involvement in harm reduction.
- **Prescribing of drugs**  
The concept behind prescribing otherwise illegal drugs is connected to reducing criminal activity and needle sharing, measures a user may take to support his or her habit. Such programs need to be conducted with control and in conjunction with other programs to improve the user's living conditions. In Canada, British Columbia is looking into prescribing programs as an aspect of their harm reduction policy.
- **Tolerance areas**  
Some European centres have attempted to centralize drug use to certain areas where users can inject in a relatively safe environment where clean equipment, advice and medical attention are available. This approach also aims to keep other neighbourhoods safe and free of drug use.

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<sup>8</sup> *Canadian Centre on Substance Abuse (CCSA) National Working Group On Policy. Harm Reduction: Concepts and Practice: Policy Discussion Paper*

### **3. Where are people getting infected?**

The locale of Aboriginal people is a consideration in planning an HIV strategy. Forty-three percent of Alberta's Aboriginal population live on reserves or Métis settlements while 57% live in urban centres (1996 Census). However, the high degree of movement of Aboriginal people between their home communities and urban centres, coupled with the HIV risk that exists in the inner city, allows for the possibility that HIV is introduced to previously unexposed populations.

There is a very real prospect of disparity in resource allocation between on and off-reserve Aboriginal population. Aboriginal communities, with their leadership and existing social infrastructure represent an easier opportunity for implementing programs. Reserves have been identified as the areas for the most potential for success and, therefore, the most obvious choice for funding agencies with limited resources. However, Aboriginal people living off-reserve are as vulnerable, if not more so, to the threat of HIV infection. In addition, many have the disadvantage of being estranged from their communities of origin and are unfamiliar with available resources and traditional support.

#### ***Of Special Note: Canada's Prisons***

HIV is an area in focus for the Correctional Service of Canada (CSC). According to CSC's 1998 Performance Report, in 1997, there were 158 known cases of HIV and 20 cases of AIDS in Canadian institutions. This translates into an infection rate more than 10 times the rate in the Canadian population at large. Other statistics show the number of infected inmates has been steadily increasing.

The tendency of inmates towards high-risk behaviours before incarceration contributes to HIV in the prison environment. As well, drug use, prison violence and crowded living conditions put inmates at risk. For example, in 1997, a Nova Scotia inmate infected with Hepatitis B, Hepatitis C and AIDS admitted sharing injection equipment with 20 other inmates during a recent incarceration.

Thus, while inmates are identified as a population vulnerable to HIV, Aboriginals are over-represented within inmate populations. Aboriginal prison populations increased in 1997/98 and are expected to continue to increase, especially in the Prairie region, due to higher incarceration rates coupled with a birth rate that is greater than the Canadian average. Sixteen percent of offenders in institutions and 10% in the community are Aboriginal.

#### ***Attitudes and beliefs within Aboriginal communities towards HIV***

Part of the challenge of developing a unified strategy in response to HIV is that the Aboriginal population is composed of individuals with unique backgrounds, education, living conditions, attitudes and beliefs. Many programs blanket the Aboriginal population as a whole, ignoring the individuals within. Attitudes and beliefs among Aboriginals vary as much as in any other group. The following list identifies some of these beliefs learned during the development of the Alberta Aboriginal HIV/AIDS Strategy.

- **Who is affected by HIV?**
  - HIV doesn't affect me. No one close to me is affected.
  - If a person lives a certain way, certain things will come their way. These lessons transcend generations. Some people are destined for certain things based on how their ancestors behaved.
  - Only people who participate in anal intercourse can get HIV.
  - Some people have unprotected sex to get pregnant. Pregnancy is sometimes seen as a rite of passage. Becoming pregnant means independence. It may also be an escape route from a family that is abusive or not meeting the needs of young women.
  - HIV is a non-native disease.
  - Some elders believe this disease comes from overindulgence.
  - Not all Aboriginal leaders will admit that HIV is a real and present threat to their people.

- **What does HIV say about Aboriginal culture?**
  - HIV is a great teacher. Because HIV is transmitted through human behaviour, it teaches people to live healthier.
  - You cannot have a needle in one hand and sweetgrass in the other. People need to choose one road or the other.
  - The behaviours that lead to HIV are stepping away from tradition. Aboriginals need to reset community standards. For example, the act of physical union between man and woman is sacred, and is forged to bring forth life.
  - Aboriginal communities are small and intimate. Many do not want to be tested for HIV should their friends and relatives find out.
- **How can the problems around HIV be solved?**
  - HIV is another example of the systemic damage of contact with Europeans. Non-Aboriginals do not approach these issues as a whole; government tries to deal with problems affecting Aboriginal people individually (HIV, tuberculosis, fetal alcohol syndrome) when all of them are linked.
  - HIV is preventable, but it is not a matter of a quick fix, like teaching people to use condoms or clean needles. Finding a solution means getting at the root of the problems that cause damaging behaviour.
  - The Creator will protect (me) from this disease.
  - Aboriginal people need to be involved in planning around HIV.
  - Some inmates believe they should live separately from HIV infected inmates.
- **Views on sexuality as it relates to HIV**
  - Some Aboriginal women do not insist on safer sex practices because to do so is outside of traditional gender roles. Some fear abandonment and rejection from their partner.
  - People should be able to do whatever they want to be happy.
  - Some people are two spirit people. This means they have the spiritual gift of housing both the male and female spirit. In contemporary times, two-spirit is often how gay and lesbian Aboriginal people identify themselves. They are a part of Aboriginal culture.
  - Talking about sexuality means sexual activity is being promoted.
  - Many Aboriginal people are reluctant to talk about sex and sexuality. It brings up old wounds since some were abused sexually as children.
  - There is a strong disapproval of homosexuality among some Aboriginals. This makes it hard for many to come forward for education, testing and care.

#### **4. Current education and prevention strategies**

It is generally accepted by stakeholders including front-line workers and formal and informal support networks that the work that is presently being done in the area of Aboriginal HIV is not effective, efficient or enough.

Another problem area with Aboriginal HIV education and prevention is the lack of connectedness with Aboriginal communities. Professional/academic qualifications do not automatically prepare people to work with Aboriginal people. In addition, many organizations focus on the financial resources available to them when they name Aboriginal people as a target of their efforts, without understanding or contact with the people themselves.

At the present time there is one organization dedicated specifically to Aboriginals and HIV: the Feather of Hope Aboriginal HIV/AIDS Prevention Society (FOHAAPS), located in Edmonton. The main focus of FOHAAPS is to provide training to communities that request it. FOHAAPS also provides minimal support services.

Other groups dedicated to exploring issues around HIV include the Northern Alberta HIV/AIDS Working Committee, which is at the beginning stages of development and operates in conjunction with the Lesser Slave Lake Indian Regional Council in High Prairie.

Also taking first steps is the Southern Alberta HIV/AIDS Working Committee. The community health representatives are taking a lead role in ensuring that HIV becomes a priority in the area.

## **5. Funding**

Funding is a key resource for HIV prevention and care and support activities within communities. Many of those Aboriginal leaders who are aware of the problems around HIV are dissuaded from setting up prevention and educational programs in their communities because, although government funding is available, few of those in Aboriginal governments have been clearly advised or instructed to how to access that particular funding.

Funding has been provided for Aboriginal HIV initiatives. On a national level, the Government of Canada has dedicated funds to First Nations on-reserve (non-status First Nations access funds through general Health Canada HIV/AIDS programs) in the various phases of the National AIDS Strategy.

Phase I of the National AIDS Strategy (NAS) provided \$5.3 million between fiscal years 1988-89 and 1992-93. Phase II provided \$12 million through Health Canada's Medical Service Branch (MSB). Phase III raised awareness of HIV and AIDS in the Aboriginal population. Funding went towards various projects and initiatives such as AIDS prevention and education at both the national and local levels, Aboriginal teachings and involvement of elders in HIV and AIDS initiatives; training for health care workers; research; conference, workshops and symposiums.

Phase III of the NAS will incorporate feedback on the initial two phases of the strategy in order to make the strategy more relevant for Aboriginal people.

NAS funds are controlled by the First Nations and Inuit Health Programs (FNIHP) Directorate. For example, in 1997/98, the FNIHP Directorate provided funding to the Assembly of First Nations (AFN) to assist the organization in improving knowledge of HIV risks among First Nations people; to determine the prevalence of HIV within the communities; and to promote community-led measures in HIV prevention. The National Indian and Inuit Community Health Representatives Organization (NIICHO) also received funding to develop an HIV resource manual for community health. The manual includes HIV and AIDS epidemiology, treatment and community interventions, as well as traditional Aboriginal practices.

The Government of Alberta announced the Alberta Aboriginal HIV/AIDS Strategy. In 1997, the Alberta Government also announced funding for seven Aboriginal health projects, as well as \$15,000 for small projects in the AIDS arena.

In June 1999, the provincial government announced an increase in funding to help community groups fulfill their role in the government's new HIV Strategy. One of the targets of the provincial strategy (HIV in Alberta 1998/99-2002 Alberta Health Strategy) is the issue of the disproportionate number of infections among Aboriginal people.

## **E. Findings: Treatment, Care and Support Issues**

### **1. Testing and Diagnosis**

The challenges in the testing and diagnosis of HIV relate primarily to the lack of awareness about the disease. Those who do not know the behaviours that can lead to HIV infection will likely be unaware of the need for testing. This compounds treatment problems as early detection of HIV is key; current drug regimes can keep infected people healthy for a long time.

In addition, some people only seek medical assistance (of which testing may be a part) when they feel ill. Late onset of symptoms and attribution of symptoms to other ailments may delay diagnosis.

The stigma of HIV prevents some from seeking a test. Those living on-reserve or in other small communities may be reluctant to get tested for fear of others knowing.

It is especially important for pregnant women to be screened for HIV to prevent the transmission of the disease to the unborn child. However, anecdotal evidence suggests the pre-natal health of Aboriginal women is generally poorer than the norm. It is important to gain an accurate view of the Aboriginal situation: are Aboriginal women seeking and receiving adequate pre-natal care? If not, why not?

Follow-up counselling is an essential part of receiving the results of an HIV test. Behaviour can be affected by a negative and positive test. A negative test may lead those engaged in risky behaviour to believe they are safe and able to continue as they were. A positive test may encourage fatalism in the newly diagnosed. Both situations provide an opportunity for education and support.

## **2. Health Care Systems**

### ***Conventional***

The roles and responsibilities of the provincial, federal and Aboriginal governments with respect to Aboriginal health are constantly evolving.

Under the Constitution, “Indians and Lands reserved for the Indians” are a federal responsibility; this means the Canadian government can pass laws related to the health care of registered Indians and reserve communities. At the same time, the constitutional responsibility for health care rests with the provinces. First Nations governments in Alberta reinforce their treaty rights to comprehensive health care from the Government of Canada. Many First Nations’ governments have designated persons within their council to oversee health care.

There have been both general and specific commitments to working toward a time when First Nations have autonomy and control of their health programs and resources. Because the health status of Aboriginal people and communities varies, the challenge is to fit health care and First Nations’ roles in health care with the needs of each community.

Currently, Health Canada, through the First Nations and Inuit Health Branch, funds and co-ordinates the delivery of community-based health services to Status Indians living on reserve. Services are delivered by hospitals, nursing stations, health centres and various other health facilities. In some cases, care is provided by provincial government under contract to Health Canada.

Like other Albertans, Aboriginal people are entitled to services provided under the Alberta Health Care Insurance Plan. In addition, Health Canada supplements provincial/territorial health care plan services by providing for benefits not paid for by these and other third party coverage plans for registered Indians living on or off-reserve.

Thus, when an Aboriginal person is diagnosed with HIV, like other Canadians, they are eligible for conventional health care administered either by the provincial or federal government depending on where they live and their status.

The initial challenge to providing this care is removing barriers to it, ensuring Aboriginals are aware of and have access to ever improving treatments for HIV. In some cases, funding and resources may be available for HIV programs, but First Nations are not aware of them or do not understand how to access them.

## **Traditional**

The conventional health care system can sometimes be incongruous with the conception of health care that an Aboriginal person is familiar with. Many grew up with more traditional health therapies, often connected to the land. These therapies are often seen as alternatives to conventional health care and are frequently not held in the same esteem as Western methods.

Most Aboriginal people have experienced a blend of conventional and traditional treatments. It is important to recognize some fundamental differences between conventional and traditional Aboriginal health care. While conventional health care often assumes a passive role for the patient, Aboriginals are traditionally participants in their own healing. While conventional health care providers are specialized into caring, curing and counselling roles (and often further specialized within these streams), traditional practitioners perform many, if not all, roles. While conventional health care recognizes silent diseases and preventative treatment, traditional views often do not. And while traditional medicine embraces holism of body, mind and spirit, conventional medicine generally focuses on the body.<sup>9</sup>

### **3. Prisons**

In 1997, there were 158 known cases of HIV and 20 cases of AIDS in Canada's correctional institutions. The infection rate is more than 10 times that of the Canadian population at large. These numbers inspire Corrections Canada to act on prevention issues, but very little data are available on treatment, care and support of inmates with HIV. With Aboriginal people over-represented in the prison population, this is an area of concern.

In the provincial correctional system, one of the challenges with the issue of HIV in prison is that inmates often stay on a very temporary basis. The average stay is 45 days. After that, the prisoner and his or her health are no longer the responsibility of the institution. Any level of care in prison may be difficult to maintain upon release. In addition, half-way houses generally do not have the staff or training to deal with the seriously ill. A person with HIV can eventually become a patient first and a prisoner second. This challenges the role of correctional facilities.

### **4. How are people with HIV or AIDS regarded in their Aboriginal communities?**

Like people in general, each Aboriginal person has a unique response to the issue of HIV and the people affected by it. This response can be affected by the direction of leadership within the community. As Aboriginal leadership learns and makes commitments to support people with HIV, people follow with their own reaction and levels of support.

Although there is no gauge of general support for people with HIV in Aboriginal communities, people within these communities are often linked to one another through family ties and this can be expected to affect their response to the individual.

### **5. Who else is affected?**

When someone is dealing with HIV or AIDS, it can affect everyone close to that person. However, a debilitating or fatal disease has further effects on a community working to retain (and in some cases regain) their culture. Like other prolific illnesses or significant events in Aboriginal history (such as smallpox or the operation of residential schools) HIV affects the health of the individual and the Aboriginal culture.

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<sup>9</sup> Morse, Janice M, et al. "Cree Indian Healing Practices and Western Health Care: A Comprehensive Analysis". *Social Science and Medicine* 32.12 (1991): 1361-66.

At the same time, many Elders regard HIV as a great teacher. A careful response to HIV may strengthen the Aboriginal culture as Elders guide their peoples' experience with the disease and incorporate traditional values in the healing of individuals and communities.

## **6. Palliative care**

At this time, there are no Aboriginal-specific palliative care programs in place in Alberta. The care of individuals dying of AIDS-related causes remains unique to the person and their circumstances.

## **F. Opportunities to close the gap: recommendations for the future**

The Alberta Aboriginal HIV/AIDS Strategy has outlined several opportunities for ongoing work in the effort around HIV. These recommendations answer some of the gaps between what is currently happening and what the vision of the future is.

### ***Our communities are aware of and understand HIV/AIDS ...***

#### **1. Education: Put the truth out there**

- Develop a guidebook based on the Tree of Creation model to assist individuals and communities in development of their own response to the issues around HIV. Elders, youth, community health representatives (CHRs), health educators, and Aboriginal People Living with HIV should be involved in developing the guidebook.
  - Make the guidebook and a copy of the Strategy available to urban and rural Aboriginals in leadership roles.
  - Develop an information clearinghouse in the form of a newsletter for stakeholders.
  - Improve the health promotion resources such as pamphlets, posters, videos and condom packaging. Information should be relevant, attractively (yet discreetly) packaged and conveniently located where targeted groups frequent.
  - Change attitudes regarding workshops, i.e., one workshop or training session can solve the problem, you can only conduct a workshop if there is a budget.

#### **2. Provide adequate resources**

- Alberta Health and Wellness and First Nations and Inuit Health Branch engage a Community Developer to assist Aboriginal communities and organizations to continue the present momentum. The Community Developer engaged to take the Alberta Aboriginal HIV Strategy to the next phase should possess credibility respecting:
  - Aboriginal culture.
  - Medical community.
  - Aboriginal people living with HIV.
  - People at risk of contracting HIV.
- The Community Developer provides additional insights to Aboriginal communities respecting the social, cultural and economic factors that control and/or provide the context for HIV. This should be accomplished during workshops and other methods of consultation.

- Establish a funding committee to work with government to outline opportunities for funding, direct funding to the areas where it will have the greatest impact and ensure accountability of funding recipients.

### **3. Reduce the risk of behaviours leading to infection**

- Ensure that condoms are readily available to those who want to practice safer sex. Focus on vulnerable populations.
- Provide needle exchange service to those who want to inject without the risk of contracting HIV from someone's dirty needle.
- Develop a guide for those who do the testing and those who are tested.

### **4. Target vulnerable populations**

- **Prison**
  - Grant access to prisoner-operated tattoo artist
  - Change policy on tattoos to allow for safe equipment and sterilization procedures.
  - Provide Aboriginal-specific support circle in prison for those interested.
  - Provide information sheets with Aboriginal specific details for inmates to peruse privately, and give confidential access to support.
  - Ensure strategy follows inmate post-release.
  - Provide HIV testing for inmates and staff.
- **IDUs**—provide forum for discussion about harm reduction techniques as a short term solution.
- **Youth**—make HIV information mandatory in health, education and social programs. Inform parents and guardians of the content of sexual health prevention and education programs taking place in their communities.
- **Women**—collect more information about HIV and Aboriginal women. Because women are primary caregivers and are generally thought to be the backbone of Aboriginal societies, more information must be available both about and for Aboriginal women in the areas of prevention, care and support.

### **5. Increase effectiveness of the message**

- Assist communities to define their own culturally appropriate education methods.
- Ensure workshop providers realize that understanding and respecting local customs and moral values is a very important component in avoiding misunderstandings with community members about the kind of information or message they are presenting.
- Have Aboriginal persons having HIV/AIDS (APHAs) design and deliver programs.
- Consult cultural advisors on an on-going basis while materials are being developed and designed for use in Aboriginal communities.
- Improve the credibility of presentations on Aboriginal HIV related issues by having the presentations done by suitable Aboriginal speakers or those individuals that have been recommended by the Aboriginal community.
- Improve quality of Alberta-specific information—resources and statistics.
- Help communities gather community-specific information—resources and statistics.

### **6. Pursue activism**

- Ensure susceptible or target populations have awareness of action being pursued on their behalf and grant opportunity to get involved.



- Initiate a positive media campaign around the issues.
- Lobby for policy change that will have a direct impact on behaviours associated with HIV infection.

## **7. Create a network**

- Develop a mobile action plan—in order to co-ordinate HIV efforts, this program will ensure the appropriate resources are available to the right people in the right places at the right time and in the right way. This plan includes a gauge to assess community understanding and ability to provide a healthy response to HIV.
- Develop a fan-out information system via fax, phone or e-mail to get pertinent information out quickly and without burden on one person or organization.
- Focus on developing partnerships between Aboriginal communities, Regional Health Authorities, and various AIDS service organizations.
- Develop a network linking other HIV associations, health professionals, community care givers and Aboriginal organizations to avoid duplication of services and to keep workers informed of current trends and practices in the fight against the spread of AIDS.
- Develop a web page so people can learn about the Alberta Aboriginal HIV Strategy and share information.

## **8. Make information easy to access**

- Use the literature review as a database of information for prevention, care and support programming. Ensure it is continuously updated and available.

## **9. Continuous evaluation**

- Establish an efficiency auditing team—this group of people would be responsible for monitoring the action of HIV in Aboriginal communities in Alberta, including technical information, training and education approaches, funding of projects. This team could review and support community and agency action plans. The team could also act as a mediator or grievance board for companies regarding services.
- Establish community-based Quality Circles to assess prevention, care and support efforts. Ask the questions: Are we working together? Are we sharing responsibility? Do we discuss problems and investigate causes? Have we recommended solution and taken corrective action?
- Continue consulting communities about their beliefs and attitudes about HIV allowing information and feedback to inform the development of messages.

## **10. Testing and diagnosis**

- Remove barriers to testing, promote baseline and follow-up testing or re-testing particularly in correctional institutions.
- Support screening of pregnant women as part of their pre-natal care.
- Increase the reporting of HIV test results.
- Outline reporting protocol for service providers and ensure service providers know about services and standards for Aboriginal people.
- Increase accessibility to testing and education in social care facilities.
- Make sure human service workers know about testing procedures.
- Design a sexual health planning guide for use by individuals. It should include a list of resource people and a sexual health record to monitor fertility, examinations and window period.

## **11. Funding**

- Encourage funders to develop better monitoring and community evaluation process to get the right feedback on efforts. Insist on the feedback; conduct quarterly program reviews. Those that strive for effective and efficient use of resources will be willing to display their achievements as opposed to keeping them veiled in secrecy and inaccessible.

## **12. Training**

- Ensure training includes cultural sensitivity component.
- Set up an evaluation system of training processes.
- Ensure caregivers have home care training.

**... And people living with HIV and AIDS are accepted and supported.**

## **13. Acceptance**

- Create Aboriginal-specific support programs using the involvement of community members from Elders to public health nurses to help APHAs to feel supported, cared for and accepted in their communities.

## **14. Conventional health care systems**

- Improve access to treatment to ensure APHAs have quicker access to the medical care they need.
- Develop a leaflet to let people know what services are covered by Alberta Health and Wellness and which are covered by First Nations and Inuit Health Branch.
- Assist communities in developing policies and procedures to guide the coordinated action of community agencies and Regional Health Authority staff in the provision of care. This should also involve the development of a budget to fund the provision of service to community members.

## **15. Traditional/holistic health care**

- Recognize the importance of community-based knowledge versus strict reliance on scientific knowledge.

## **16. Support**

- Reduce any possibility of drain on people living with HIV by asking them specifically what they need, and targeting care initiatives to their needs.
- Provide therapy options to APHAs to promote discussion on issues such as loss of future, body image, control and dignity, sexuality, depression, suicide, anxiety, fatalism, isolation, loneliness, disclosure to family and friends, spiritual needs, loss, death and dying.
- Provide practical assistance to APHAs regarding wills and guardianship, finances, housing, roles, returning or seeking work.
- Provide medical information to APHAs such as understanding treatment options and information, dealing with positive or negative diagnosis, safer sex practices, complementary therapies, addictions, and reproductive choices.

## **17. Palliative care**

- Begin the process of developing a community model of hospice services. This would ensure the provision of compassionate care to Aboriginal people living with HIV in their own homes and

communities. The emphasis should be on services rather than building a hospice. A budget should accompany the community model of hospice services along with potential funding sources. This model should plan for:

- The designation of a coordinator to work collaboratively with each individual to simplify lines of communication for all involved, particularly the person living with HIV.
- Provision of service 24 hours/day. A palliative quick response team which responds to urgent needs may prevent unnecessary hospital admissions.

#### **G. How will we know when we get there?**

A healthy response to HIV can be gauged on many levels. Each person, community or organization has their own personal criteria for improvement in their response. These are some measures of success:

- Fewer new HIV infections in Aboriginal people.
- Clearly defined roles and responsibilities for communities, regional health authorities and AIDS Service Organizations (ASOs).
- Resources being used in an effective and efficient way.
- Organizations, communities and individuals have a clear view of their role in the fight against HIV.
- There is respect for the efforts of each other, including the ability to disagree while continuing to work towards consensus.

#### **H. Drawing conclusions—it's time to act**

In the past, Canada's first people were vulnerable to waves of epidemics. Smallpox wiped out entire bands. Tuberculosis killed Elders, leaders and children. Residential school programs separated an entire generation from their way of life. Addictions stunted tradition.

But these are different times. Aboriginal people are guiding an era of self-determination unprecedented in modern Canada. New epidemics are subject to a different degree of resolve than in the past. With the support of the Canadian government, Aboriginal leaders refuse the role of victim and take an active role in responding to diseases like HIV.

The challenge is major. The demonstrated vulnerability of the Aboriginal population of Alberta to HIV demands a response from people—people that make up groups and people that form the governments in Alberta: federal, provincial and Aboriginal. The findings of the Alberta Aboriginal HIV/AIDS Strategy provide not only an indication of the seriousness of the issue but also the breadth of opportunity for action. It is now time for those in power—from individuals in charge of their own bodies, minds and spirits, to governments in charge of entire nations—to focus resources on prevention of HIV and on caring for those already suffering.

These resources take many shapes: financial, material and human. The Canadian government holds a major share of these resources. However, they are useless without the strength of co-operation of Aboriginal people. The strongest response, the one that has the best chance of curing people of HIV, is the one that involves those people in all aspects of planning and execution.

AIDS is fatal. It kills people. It scars people. It's time to act.

## **Appendix Listing of Addresses**

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