Assembly of First Nations

HIV/AIDS Action Plan

February 2001

This Action Plan is in response to the serious threat that the Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) poses to our people (First Nations) and

communities. Research shows that among First Nations' peoples, HIV infection has reached very high proportions and threatens to become a full-blown epidemic as it has moved from a disease that first took a devastating toll on our Two-Spirit First Nations' peoples, to one that is now also infecting an increasing number of First Nations' women and youth. Today, the main transmission of the disease into First Nations' communities is injection drug use and "unprotected sex." Aboriginal people [who make up 3% of the total population in Canada] now represent 5% (2,740/49,800) of Canada's prevalent HIV infections (Health Canada, Centre for Infectious Disease Prevention and Control, 2000).

This 10-point Action Plan was developed in consultation with Aboriginal healthcare workers, professionals and leaders, from across the country who attended a national meeting concerning HIV/AIDS and First Nations entitled, "National HIV/AIDS Leadership Conference: Breaking Down the Barriers - Addressing the Emerging Epidemic" held in Regina from March 14-16, 2000.

The recommendations made by those in attendance at the National HIV/AIDS Leadership Conference have been categorized into 4 program components to be addressed as part of a five-year plan. Program components have been identified as:

A) Lobbying and Advocacy;
B) Health Promotion and Disease Prevention
C) Care, Treatment and Support; and
D) Research and Evaluation.

The following illustrates the 10-point plan, which was developed in consultation with those health care workers, professionals and First Nations' leadership in attendance at the National HIV/AIDS Leadership Conference:

1. Role Modelling and Public Support

Provide leadership on HIV/AIDS issues
Program Component: ***Lobbying and Advocacy***

- First Nation healthcare workers and professionals are strongly urging First Nations' chiefs, provincial and territorial organizations (PTOs) and tribal councils to provide leadership and commitment in the face of the HIV/AIDS crisis. As one Ontario lobbyist expressed, *"Five minutes of attention from a chief carries more weight that a whole national strategy in motivating people at the community level."* Healthcare workers ask that chiefs, members of council and other community leaders wear the "Red Ribbon," attend HIV/AIDS information sessions and take part in activities such as the *Annual AIDS Walk*.

Recognition of the role of inmates
Program Component: ***Lobbying and Advocacy;***
Health Promotion and Disease Prevention

- Many First Nations' youth look up to men and women who may be incarcerated. If these men and women can be enlisted in the campaign against AIDS, they can be a powerful voice in warning the young about the dangers of the disease, providing information about how the youth can protect themselves from becoming exposed to HIV.
- Former inmates can stress first-hand, the importance of staying out of prison. Community Crime Prevention and Anger Management programs also contribute to HIV prevention, because they keep people out of prisons where HIV infections are quite probable.

2. Traditional Healing Practices

Use of traditional First Nations healing practices
Program Component: ***Lobbying and Advocacy; Care, Treatment and Support***

- Traditional healers must have as equal access to their clients as western medical doctors have in the treatment of the disease. In Latin American clinics, traditional healers work side by side with licensed medical doctors. This practice should be promoted in Canada (which could require development of occupational standards or potential self-regulation by healers).

- Opportunities for integration of First Nations' traditional ceremonies, alternative medicine as well as western medical forms of treatment must be provided.

Protect intellectual property rights of First Nations drug and herbal remedies
Program Component: ***Care, Treatment and Support***

- As multi-national pharmaceutical companies research new drug treatments for HIV/AIDS, they are increasingly moving into the area of traditional North American medications and medicinal plants, and ignoring the indigenous peoples' intellectual property rights to these traditional pharmaceuticals. National and international law in this area must be enforced to protect indigenous people's ownership of their traditional knowledge. Action should be taken to enforce the clause on protection on intellectual property rights of Indigenous Peoples contained in the Declaration of the International Society of Ethnobiologists, tabled at the 5th International Congress on Ethnobiology, Nairobi, Kenya in 1996.

Develop effective standards on dietary supplements and herbal remedies
Program Component: ***Care, Treatment and Support***

- Since many persons living with HIV/AIDS (PHAs) use nutrition and herbs as HIV therapy - with or without use of HIV medication/drugs - research on the effective use of such remedies is warranted. First Nations use of dietary supplements and herbal

remedies must be supported while ensuring the safety of PHAs.

3. Traditions and Cultural Practices

Use First Nations languages in health promotion
Program Component: ***Health Promotion and Disease Prevention***

- First Nations languages and traditions must continue to be revived in all areas of health care and in daily life. It is important that the translations are accurate and pre-planned at the community level. This is important not only for the Elders, who may not understand English or French, but also, for the young. One of the great risk factors of HIV/AIDS is low self-esteem and nothing helps more in regaining self-esteem than for cultures and individuals to retain their language.
- Traditional and Cultural Teachings outline personal responsibility for one's own body. Today's media views sex, alcohol and drug use as recreation and does not stress the importance of responsibility and insight on how they impact on one's body and their future.

Recognize the role of the Two-Spirit First Nations' peoples
Program Component: ***Lobbying and Advocacy***

- Health care workers and professionals dealing with HIV/AIDS point to a real problem in discrimination against gay and/or the Two-Spirit First Nations' peoples, who may avoid HIV testing and treatment because of fear of discrimination. The delay in seeking treatment is given as one of the reasons First Nations' people diagnosed with HIV/AIDS live only 50% as long as non-First Nations' people diagnosed with the HIV/AIDS. As one HIV/AIDS worker put it, *"Some young men would rather die than let anyone know they are gay."* The solution is to educate people of the traditionally respected role that Two-Spirit First Nations' peoples played in most communities, and to thus remove the stigma that has been associated with this group.

Use First Nations knowledge in health promotion
Program Component: ***Health Promotion and Disease Prevention***

- In any popular health education program, it is important to make it understandable to people. We must use methods of communicating information to the people in ways that they can readily understand it.

4. Research

Support principles of First Nations' ownership, control, access and possession (OCAP) of research and evaluation.
Program Component: ***Research and Evaluation***

- Before we can act, we must have the information and we must be in control of it. We must build on the successful First Nations owned and controlled "Regional Health Surveys" to gather our own data while preserving a large measure of local control.

- We need to gain control of the new Health Canada information gathering tools that are now being introduced into our communities, like the computerized Health Information System (HIS), to ensure that First Nations have the information they require to build the programs needed to address the HIV/AIDS crisis.

First Nations must develop their own institutions for research, evaluation and training
Program Component: ***Research and Evaluation***

- As part of controlling our own information, we need to build up our own expertise to ensure the highest quality and consistency of the information produced and data collected.

Support research on sexual transmitted infections (STIs) and related risk behaviours
Program Component: ***Research and Evaluation***

- HIV/AIDS is a difficult disease to track because of its long incubation period; and unless people are tested, there is no way of knowing the exact extent of the problem. Gathering information on other STIs (a co-factor of HIV transmission) and high-risk behaviors is the best way to estimate the extent of the problem we are facing today and, equally important, the threat posed in the future.

Support health promotion specific to children, youth and women
Program Component: ***Health Promotion and Disease Prevention***

- Recent studies show that HIV is attacking First Nations' women in alarming numbers, and through perinatal infection, First Nations' infants and children. It is imperative that First Nations' women be given the information and tools they need to prevent the infection. It is also essential that children and youth are instructed from an early age, about the disease, and about the behaviors that will put them at risk.

5. Policy Formulation and Program Planning

Involve First Nations in program planning and evaluation
Program Component: ***Health Promotion and Disease Prevention***

- First Nations' people with HIV/AIDS have different needs from non-First Nations with HIV. They have shorter survival times after diagnosis and this means different palliative care needs. The pattern of the disease is also distinctly different among First Nations, with one main source of transmission through injection drug use (IDU). As one healthcare worker put it, (among First Nations' peoples) *"the basic risk is caused by post-colonial stress syndrome and its symptoms of low self-esteem, denial and abuse."* Only First Nations' people, who understand what underlies destructive behaviors such as IDU and subsequent risk of HIV transmission, can hope to design the programs and services needed to attack the disease at its source. First Nations have to

confront this crisis with our own culture-based service delivery practices and "open-door" services.

Promote healthy child development
Program Component: ***Health Promotion and Disease Prevention***

- The under 15 year-old age group is the largest part of the First Nations population. We must focus on "street-proofing" them by teaching them about risks of HIV and how to protect themselves.
- Healthy child development is crucial in developing resilience to the behaviours that lead to HIV/AIDS. We have to link programs such as early childhood education to HIV/AIDS awareness programs. Programs that focus on prevention must be started before children begin engaging in high-risk activities.
- We must foster self-esteem, particularly in the 7-12 year old age group whose support systems and facilities may be less than optimal. We need safe playgrounds, recreation facilities and injury prevention programs to ensure they grow up healthy and strong – physically, mentally and spirituality.

6. Lobbying

Address inter-jurisdictional issues
Program Component: ***Care, Treatment and Support***

- First Nations' health care professionals and workers have urged that in tracking and treating HIV/AIDS, the approach be coordinated between the community and urban centres. But jurisdictional issues must be addressed between provincial and federal governments to ensure that coordinated services can be provided to the infected and affected individuals and communities.

Support the need for multi-year program funding
Program Component: ***Lobbying and Advocacy***

- First Nations' health care workers and professionals point out that the current single-year funding means staff have to be laid off and programs left in "limbo" while funding is sought. To be sustainable, to retain trained staff and to reap the benefits of their HIV/AIDS programs over the long-term, the program funding must also be long-term. The leadership must lobby the government for multi-year health services for communities.

Increase human and financial resources
Program Component: ***Lobbying and Advocacy***

- First Nations now have the highest rate of HIV/AIDS in the country, and current government funding does not reflect this. Our health care workers find themselves having to beg and borrow resources simply to run a local HIV/AIDS health promotion and prevention program. Funding is urgently needed for programs targeted at First Nations' youth, women, inmates/prisoners and Two-Spirit peoples.

7. Promotion of Services

Market availability of services
Program Component: ***Lobbying and Advocacy***

- Time after time, First Nations' healthcare workers told us that they had no resources even to publicize to the community what services were available. We have to get them the resources they need to inform people where and how they can get help. The work by non-First Nations organizations in this area doesn't reach our peoples, because non-aboriginal AIDS service organizations (ASOs) tend to be ignorant of our cultural history and diversity.

Provide safe environment for PHAs who want to come home
Program Component: ***Care, Treatment and Support***

- Many of the First Nations' people with HIV/AIDS are living in urban centres. We have to makes sure we are ready to accept their return "home". To ensure their welcome, band councils can pass resolutions explicitly recognizing the rights of PHAs to pursue activities such as attending school, attaining employment, occupying a residence, and other rights and privileges granted to them as band and community members.

- Band councils should put in place confidentiality and safety considerations to protect, support and respect the PHA, as well as health care workers and professionals. Disrespectful treatment will allow HIV to flourish due to ignorance.

- As part of the preparation for dealing with the disease, communities must also be aware of the costs of the HIV/AIDS drugs when they are arranging federal government health transfer agreements. These drugs can run as high as $5,000 a month per person, and because of the nature of the disease communities will have to look at these costs not only for the next year or two, but for ten or twenty years into the future.

8. Education and Training

Educate health and community workers
Program Component: ***Health Promotion and Disease Prevention***

- All health and community workers, including National Native Alcohol and Drug Abuse Program (NNADAP) and Aboriginal Head Start (AHS) workers, should have basic information about HIV/AIDS and an understanding of HIV prevention and treatment

issues.

Support health workers on confidentiality and privacy issues
Program Component: ***Health Promotion and Disease Prevention***

- Health workers have a very difficult task in dealing with HIV/AIDS. They are sometimes caught between a band council's wish to know sensitive HIV information in the community, and their need to protect the privacy of PHAs. It is important to allow health care workers to work unobstructed on this difficult issue.

9. Treatment

Involve First Nations in drug monitoring
Program Component: ***Care, Treatment and Support***

- Since PHAs are choosing to use HIV anti-retroviral drug therapy (HIV medications/drugs) to decrease the amount of HIV in their blood, First Nations must be involved in studies that investigate the efficacy, effectiveness and use of such drugs. For example, clinical trials and economic evaluations of anti-retroviral drug therapy.

- The majority of clinical trials have been performed on non-First Nations men who have sex with men (MSM) living in urban areas. HIV/AIDS and HIV/AIDS-specific medications may affect First Nations' people differently. Issues must be taken into consideration including how the medications affect women, some of which may be pregnant. Other co-existing health issues must also be taken into consideration, which may not have been explored in the mainstream, such as co-infection with tuberculosis and diabetes, which are prevalent in First Nations.

Increase accessibility of HIV-related drugs to PHAs
Program Component: ***Care, Treatment and Support***

- Current Health Canada, First Nations and Inuit Health Branch (FNIHB), Non-Insured Health Benefits Program (NIHB) paperwork in getting essential medication for HIV positive and AIDS patients is extremely cumbersome. Negotiations with NIHB must be undertaken to find a way around this, particularly as new treatments become available, some of which, have not yet been included on the FNIHB, NIHB drug formulary. In addition, some treatments are being "de-listed" from the formulary, which are impacting on the care and treatment of individuals living with HIV/AIDS.

10. Building Safe Environments

Develop legislation to support safe communities
Program Component: ***Health Promotion and Disease Prevention***

- Safe, healthy and happy children/youth will be at a far lower risk of HIV/AIDS infection than troubled children/youth. Within families, encourage training in anger management and promote self-esteem among the young to reduce self-destructive coping mechanisms and risk-taking behavior.

- Undertake crime prevention activities and do not tolerate "bootleggers" and drug dealers in the community.

- Keep our youth from ending up in the environments where they will be most at risk, mainly, the streets and in prisons.