

# **CANADIAN ABORIGINAL AIDS NETWORK**

## **Report of the Aboriginal Consultation of the National AIDS Strategy Phase I - II**



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## 1.0 Introduction

The Canadian Aboriginal AIDS Network undertook an evaluation of the National AIDS Strategy (NAS) Phase I (1989 - 1992) and Phase II (1993 - 1998) during the period of September 22 to October 10, 1997.

The goals of the consultation were:

- to determine the level of success of the National AIDS Strategy to date in the Aboriginal milieu;
- to obtain a national perspective of Aboriginal Human Immunodeficiency Virus (HIV) and the Acquired Immunodeficiency Syndrome (AIDS) work done to date;
- to search for new ideas and approaches in renewing the efforts of prevention and the spread of HIV among Aboriginal people; and
- to obtain a better understanding of care, treatment and support issues associated with AIDS that require further research and community initiatives.

Clarence Cook & Associates Consulting Group, an Aboriginal management consulting and facilitating firm in Winnipeg, Manitoba, was contracted to design and complete the national Aboriginal evaluation of the NAS Phase I & II, under the direction of the Canadian Aboriginal AIDS Network.

This report:

highlights the original goals, themes and strategic areas of the National AIDS Strategy;

outlines the original recommendations of the Joint National Committee (JNC) created in 1989 by the Department of National Health and Welfare, hereafter referred to as Health Canada in this report;

provides a summary of the Aboriginal HIV/AIDS work to date;

reports on the focussed evaluation of the National AIDS Strategy with eleven national Aboriginal organizations and thirty representatives of Aboriginal communities;

reviews new perspectives and ideas for renewing the effort of education and prevention work in the Aboriginal milieu; and

outlines key options given during consultation process and provides five recommendations.



## 2.0 Background to the field of Aboriginal HIV/AIDS work in Canada

### 2.1 National AIDS Strategy (NAS)

The NAS Phase I - II laid out a blueprint for policy, general program development and strategic initiatives from 1989 to 1998. Within this national strategy the educational strategies, developed by the JNC on Aboriginal AIDS Education and Prevention, provided a blueprint for work in the field of Aboriginal HIV/AIDS. These strategies were considered a notable achievement supported by the federal government in the areas of education and prevention.<sup>1</sup>

The goals, themes and strategic areas of the NAS Phase I - II are applicable to the Canadian Aboriginal peoples. The implementation of NAS I - II policies, programs, program resources and strategic initiatives should be examined in view of the following section on the National Strategy on Aboriginal AIDS Education and Prevention.

#### *Goals*

- To stop the transmission of the human immunodeficiency virus (HIV)
- To search for effective vaccines, drugs and therapies
- To treat, care for and support people infected with HIV, their caregivers, families and friends.

#### *Themes*

- Enhancing partnerships
- Recognizing HIV disease as a chronic and progressive condition
- Health promotion for people living with HIV disease and AIDS
- Creating supportive social environments
- Promoting and sustaining healthy behaviour

#### *Strategic Areas*

- Education and prevention
- Community development and support for non-governmental organizations
- Care, treatment and support
- Research and epidemiological monitoring
- International activities

#### *National AIDS Strategy Phase I - II (1989 - 1998)*

Health Canada identified as early as 1990 that “high risk factors have been identified<sup>2</sup> in the Aboriginal population and that to address these, Health Canada, would use the findings of the JNC to launch two national knowledge, attitudes and behaviour (KAB) studies and “implement a new program for Aboriginal peoples which includes support to community groups in areas such as public awareness and education, as well as training and development models<sup>3</sup>.

Both KAB studies, one on Canadian Youth and AIDS by Queens University and another examining On-Reserve Youth in the Atlantic Provinces, appear to have had little impact on the work in the field of Aboriginal HIV/AIDS during NAS I - II.

There was no Aboriginal component of the NAS - Phase II explicitly articulated to the Aboriginal population

or adopted by Health Canada to effectively measure goals, components and objectives, programs or resources spent within the last five years.

## 2.2 National Strategy on Aboriginal AIDS Education and Prevention

On April 12, 1989, the JNC<sup>4</sup> was formed with a mandate to develop a culturally-appropriate National Aboriginal AIDS Education and Prevention Strategy by December 15, 1989. This section briefly outlines the work on Aboriginal education and prevention strategies developed by this partnership. Two documents were produced as a result of the work of the JNC, a "Findings Document" and "Recommendations for a National Strategy on Aboriginal AIDS Education and Prevention." A brief review of these original recommendations provides an important and fundamental framework for exploring the success of the NAS - Phase I and II since 1989.

### Recommendations for a National Strategy on Aboriginal AIDS Education and Prevention 1990

#### *Goals of Aboriginal AIDS work*

1. To increase general awareness and knowledge about HIV transmission, infection and the development of HIV spectrum diseases and AIDS in the Aboriginal population;
2. To reduce the transmission of the (HIV) virus through education and prevention measures aimed at promoting responsible behaviour such as safe sex practices and safer injection drug practices;
3. To encourage and support sustained behaviour change through community understanding and action;
4. To encourage individuals who may be at a greater risk of contracting the (HIV) virus to accept personal responsibility for changing unsafe practices;
5. To assist Aboriginal communities to help those who are HIV positive and are expressing HIV spectrum diseases and AIDS; and
6. To assist Aboriginal community in addressing the social and economic impacts of HIV spectrum diseases and AIDS.

#### *Five components to facilitate the goals of the Aboriginal AIDS work*

1. General awareness and education campaigns
2. Community-based initiatives
3. AIDS as a priority issue
4. Directed Research
5. Monitoring the Strategy

#### *Nineteen general recommendations (abbreviated)*

1. a specific strategy for Aboriginal AIDS Education & and Prevention;
2. that Aboriginal AIDS [work] be community-based;
3. that available financial resources be allocated to community-based groups;
4. that Aboriginal human resource development be supported through training and information sharing;
5. that linkages be established between existing groups and Aboriginal communities;
6. that "culturally transportable" or adaptable general awareness messages be developed;
7. that AIDS education and prevention efforts also be developed for specific target groups within the Aboriginal population;
8. that Aboriginal AIDS education and prevention activities designed for the whole community be initiated;
9. that HIV seroprevalence studies be undertaken;
10. that access to confidential and free testing be made available;
11. that obstacles posed by the health care system to Aboriginal people be [...] specifically identified;
12. that condoms and needle exchange programs be readily available;
13. that Knowledge, Attitude and Behavioural studies be undertaken to facilitate planning, designing, implementation and as a means of evaluating the effectiveness;

14. that quality research efforts be supported which examine the sexuality and the sexual behaviours;
15. that research efforts be supported to examine the role of traditional medicine and healing;
16. that research efforts be supported to examine the economic impact of AIDS;
17. that quality research efforts be supported to examine the implications of AIDS on the Health Transfer [process];
18. that the involvement of Canada's Aboriginal people in an international conference of indigenous people and AID be supported;
19. that a mechanism be implement to facilitate the ongoing involvement of Aboriginal people in monitoring the effectiveness of the National AIDS Strategy.



### 3.0 Aboriginal AIDS cases and HIV transmission/infection

The trends over time for the reported cases of AIDS, according to the Laboratory Centre for Disease Control (LCDC), clearly indicate increasing numbers. Among 8,659 AIDS cases with known ethnic status, 246 were Aboriginal. The latest figures provided by the LCDC demonstrates the increasing numbers from 1.5% (1984 - 1988) to 3.1% (1989 - 1992) to 5.6% during the period of 1993 - 1996.<sup>5</sup>

The progression of the virus, as translated by reported AIDS cases with known ethnic status indicates a major gap in that AIDS data reflect patterns of HIV infection approximately 7 - 10 years in the past.<sup>6</sup>

The reported data in transmission of HIV and infection, as captured by provincial HIV testing surveillance systems, provide useful indicators to better understand the seriousness of the Aboriginal HIV/AIDS epidemic in certain "hotspots," though no decisive national Aboriginal HIV/AIDS epidemiological report exists for all Aboriginal intervenors to effectively employ in their work. In 1996 for example, 17% of new positive tests in British Columbia (126 out of 713) were Natives and Metis as compared to 13% (91 out of 688) in 1995. As compared to the general population, it was determined that more young Aboriginal people are testing positive (sic), as described in the Report of the 2<sup>nd</sup> Aboriginal HIV/AIDS Surveillance and Research Meeting document, May 1997.

Anecdotal evidence of the number of Aboriginals who are HIV positive is estimated to be approximately 2,500 to 3,000 as of October 10, 1997. These numbers combine both knowledge of the front-line Aboriginal HIV/AIDS work, Aboriginal AIDS Service Organizations and the limited number of studies available.<sup>7</sup>

It is clear that the HIV epidemic is shifting. Intravenous drug use (IDU) has been identified as a major risk factor, Aboriginal AIDS cases are younger and more likely to be women, and Aboriginal people are over-represented in groups at high risk for HIV infection.<sup>8</sup> It is also clear that additional HIV data is needed to appraise more recent trends and shifts in the epidemic.

At present, all qualitative and epidemiological evidence points to an epidemic of HIV transmission and infection in the Aboriginal population of Canada.



## 4.0 Aboriginal HIV/AIDS work

As stated in “Section 2.1 - National AIDS Strategy,” no explicit Aboriginal component of the National AIDS Strategy - Phase II was created and adopted that could be objectively measured and examined in light of the original desired results. NAS - Phase I produced some early documentation that acts as a guide to this report.

The strategic centres for Aboriginal HIV/AIDS funds with Health Canada during Phase I - II became the Medical Services Branch (MSB) - On-Reserve Community-Based AIDS Program and the Health Promotion and Programs Branch (HPPB) via the AIDS Community Action Program (ACAP) and AIDS Care, Treatment and Support Programs. These Health Canada programs under MSB and HPPB provided the majority of funding for urban community-based initiatives, on-reserve initiatives and Aboriginal-specific projects.

In review of the following national Aboriginal HIV/AIDS work, the general description of the existing Aboriginal HIV/AIDS organizations and intervenors characterizes a local development approach of Aboriginal community-based initiatives.<sup>19</sup>

The principal Aboriginal AIDS Service Organizations (AASOs), developed from partial or full funding from one of/or a combination of the above Health Canada programs and have assumed a full workload in developing a local Aboriginal response to HIV/AIDS. These are:

PEI/NF/ NB/NS	Atlantic First Nations AIDS Task Force
INUIT	Pauktuutit Inuit Women's Association
QC	Urban Aboriginal AIDS Awareness
ON	Two-spirited People of the First Nations
MB	Manitoba Aboriginal AIDS Task Force
SK	All Nations Hope AIDS Network
AB	Feather of Hope Aboriginal AIDS Prevention Society
BC	Healing our Spirit BC First Nations AIDS Society

In a few short years, these “AASOs have become leaders in the Aboriginal AIDS movement in Canada.”<sup>20</sup> These organizations have produced key tools in the HIV/AIDS field, some of which are:

- Culturally-appropriate HIV/AIDS Awareness Manual;
- Educator Training Program Manual;
- National Inuit HIV/AIDS and STDs training workshop;
- First Nations Palliative Care Training and Manual;
- HIV/AIDS research and fund-raising;
- HIV/AIDS policy development;
- HIV/AIDS on-site Educator training program;
- Culturally-appropriate HIV/AIDS education and prevention;
- Elder and APHA retreats; and a
- Volunteer Training Program.

Some of these groups began their work in 1990 - 1991 at the local level (others as late as 1993), working with individuals, concerned Aboriginal individuals groups and organizations. In 1992 after a report completed by the “National Aboriginal Consultation on HIV/AIDS Care and Treatment,” these AASOs created a national network intending on implementing an APHA action plan developed in 1992 by a new National Aboriginal PHA Network (NAPHAN).

NAPHAN was subsequently incorporated in April 1994 and in December 1994, a name change was

undertaken and NAPHAN became known as the Canadian Aboriginal AIDS Network (CAAN). Two national projects were undertaken by CAAN in February 1995, a four day National Meeting plus an Aboriginal Training Module that addressed the support, treatment and care of APHAs.

Since 1995, CAAN has undertaken a joint project with the Canadian AIDS Society that included three regional networking sessions and two national stakeholder meetings, with the local AASOs acting as sponsors for the national projects. The AASOs undertook these initiatives while accepting the fact that the national network initiative has been consistently impeded by the lack of operational funds, research and policy development funds, as well as funds that would allow the national organization to become increasingly proactive in the Aboriginal HIV/AIDS field in Canada.

Despite the serious financial and human resource limitations and the resulting internal struggles of attempting to develop an infrastructure, CAAN has remained a key stakeholder in the Aboriginal HIV/AIDS field of work. The commitment of the AASOs to develop and maintain a national presence and educate the Aboriginal societies (in its many complex facets), on HIV and AIDS has remained stable and constant, despite the aforementioned limitations.

The local development approach to regional organizations has resulted in AASOs who have been key actors, within their specific regions, in developing distinct educational and awareness responses to Aboriginal HIV/AIDS.

The concentration of funds toward these off-reserve non-governmental organizations and towards specific Aboriginal projects (or Aboriginal-specific initiatives) has resulted in the actual national infrastructure of AASOs who are community-based organizations with extensive knowledge of ,and experience in, national, regional and provincial issues.

In addition to the aforementioned AASOs, other Aboriginal individuals / groups / organizations who have joined the work are:

Ontario Aboriginal HIV/AIDS Strategy  
Ontario First Nations HIV/AIDS Education Circle  
AIDS Yukon Alliance  
National Indian and Inuit Community Health Representative Organization

This list does not include the many First Nation On-Reserve, Metis and Inuit individuals and organizations who have increasingly realized the profound impact of HIV on their communities and who have endeavoured to dedicate resources, in one form or another, to address the issues and concerns of HIV/AIDS. Neither does this list include the many outstanding Aboriginal Persons living with HIV/AIDS (APHAs) who have given their time and voice to this work.

In this section of this report there are two areas of concern that should be noted in developing a thorough and better understanding of the Aboriginal HIV/AIDS field work in Canada.

#### *Concern #1*

The first concern relates specifically to the lack of available written research and documentation that details HIV/AIDS initiatives destined towards First Nation On-reserve and the Inuit. It is a fact that many First Nation communities and Tribal Councils operate with a large degree of autonomy.

During the consultation process of CAAN, it was clear that there are specific First Nation On-reserve and Inuit initiatives of interest to other national/regional/local Aboriginal stakeholders, but that these initiatives lack a

mechanism to exchange information with other intervenors that could assist others in re-thinking local strategies.

The Assembly of First Nations (AFN) did initiate a National Roundtable on HIV/AIDS and First Nation populations in March 1994 and is presently collaborating on a Health Economic Impact Study with the University of British Columbia. In addition, AFN has produced a Training Manual for HIV/AIDS Education. There are on-going discussions on implementing a "First Nations Resilience Project." Some examples of other sponsors of First Nation On-reserve initiatives are, but not limited to<sup>111</sup>:

Swampy Cree Tribal Council in 1990  
AIDS and Tobacco campaign by the Government of Northwest Territories in 1990  
Chiefs of Ontario and the Ontario Aboriginal AIDS Educators Committee  
Union of Ontario Indians  
Alberta Indian Health Care Commission

The expressed need for policy research and service development in Education, Prevention, Care and Support and impact studies on proposed cut-backs to the Non-Insured Health Benefits appear to have garnered little or no support from Health Canada. There appears to be no demonstrable increase in research initiatives during NAS - Phase II that could act as a guide and enlighten the general field work of Aboriginal HIV/AIDS.

#### *Concern #2*

The second concern is a serious lack of Aboriginal HIV/AIDS information and knowledge in Quebec. One project, the Urban Aboriginal AIDS Awareness Project based out of the Native Friendship Centre in Montreal from January 1995 - March 1997 has completed its project goals and objectives and has subsequently closed. The Quebec Provincial HIV/AIDS Strategy has just recently completed an evaluation of its provincial strategy and some information may be available here.

The work in the field of Aboriginal HIV/AIDS may be occurring for some First Nation On-reserve, Off-reserve and Inuit communities and organizations, however there exists no adequate explicit indicators that allow intervenors to form a reasonable opinion on the general level of Aboriginal knowledge and awareness of HIV/AIDS. It is known that the James Bay Cree and Inuit of Nunavik have undertaken certain initiatives and that the Community Health Representatives tend to be responsible for HIV/AIDS in their communities. But there remains a responsibility for governments and non-governmental organizations to ensure that Aboriginal HIV/AIDS work is pro-active and consistent at all levels of governments.



## 5.0 Methodology of CAAN Consultation

The breadth of the goals, themes and the strategic areas of the NAS - Phase I & II, and the lack of clearly defined and adopted Aboriginal goals/themes/objectives by Health Canada, made it difficult for the CAAN to design clear and open questions that were accessible to all levels of Aboriginal HIV/AIDS educators, intervenors and individuals/families affected by HIV.

The geographical regions utilized for the consultation were Atlantic Canada (Newfoundland, Labrador, Nova Scotia, Prince Edward Island, New Brunswick), Central Canada (Ontario, Quebec), South West (Manitoba, Saskatchewan, Alberta, British Columbia) and North West (Yukon, Northwest Territories).

The focused sampling of fifty telephone interviews was set at Inuit (12%), First Nation on-reserve (34%), First Nation off-reserve (34%), Metis (20%) utilizing the document "Canadian Aboriginal AIDS Network - Aboriginal Questions" and open-ended questions.

### Tentative Regional and Nations Representation in the Sample

Region / Nation	Inuit	FNOR	FNOFR	Metis	Total
Atlantic Canada	0	1	1	2	4
Central Canada	2	6	6	4	18
South West	2	9	10	3	24
North West	2	1	0	1	4
Total	6	17	17	10	50

### Real Regional and Nations Representation in the Responses

Region / Nation	Inuit	FNOR	FNOFR	Metis	Undetermined	Total
Atlantic Canada	2	1	1	0	0	4
Central Canada	1	5	1	0	2	9
South West	0	2	7	4	1	14
North West	1	1	1	0	0	3
National Organizations	0	3	3	2	3	11
Total	4	12	13	6	6	41

Thirteen National Aboriginal organizations were also identified by CAAN as key stakeholders in the national telephone consultation and possible individual interviewees were subsequently identified. These interviewees responded to the same process described in the paragraph above.

Four different perspectives from the Aboriginal community milieu were also carefully planned and sought:

- Aboriginal Person living with HIV/AIDS
- Aboriginal family affected by HIV/AIDS
- Aboriginal HIV/AIDS front-line (volunteer/remunerated)
- Aboriginal AIDS Service Organization (direct/indirect)

During a period of eleven business days, 22 September to 7 October, a national telephone consultation was

undertaken from the offices of the CAAN.

The gathered information from the telephone interviews and the returned questionnaires of the identified focused sampling were then treated individually to develop theme categories. Each response was enumerated in its appropriate category.

#### 5.1 Multiple Choice Questions

For Questions #1, 3, 6 and 7. A Likert Scale of 1 - 4 was decided upon as to have a firm opinion sought from all individuals/organizations. Some individual responses inserted 2.5.

#### 5.2 Open Responses (compiled)

Each question was completed with an individual or group of individuals by a focused telephone interview. The interviewee was then asked open questions dealing with specific problems and/or initiatives that could initiate "effective and positive change" in the field of Aboriginal HIV/AIDS work.

## 6.0 Compiled Results - Multiple Choice/Open Responses

This section describes the compiled responses given during the CAAN consultation.

### Questionnaire Results: Multiple Choice

	# 1	# 2	# 2.5	# 3	# 4
Q # 1	2	4	3	22	10
Q # 3	27	10	0	3	1
Q # 6	24	11	0	3	3
Q # 7 a	14	9	2	8	8
Q # 7 b	27	9	1	1	3
Q # 7 c	27	12	1	0	1

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### 6.1 *Question #1- Do you think the National AIDS Strategy has been successful in reaching the Aboriginal population since 1989? Why or why not?*

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#### Multiple Choice

Seventy-eight percent (78%) found that the Strategy has not been successful. Almost one-quarter (24%) responded “no success,” over half (54%) responded “3” to what could be qualified as a poor success.

Seven (7%) were neutral and 15% thought it had been a little or very successful.

#### Open Responses (*compilation*)

The compiled responses indicate that even if we make the hypothesis that everybody was in contact with the available information on HIV/AIDS at one point, there are few who considered that this information was prepared for them. Consequently, the education and prevention message failed to convince the Aboriginal people to change their behaviours.

As one intervenor from the Gaspé Peninsula from Quebec stated:

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

There is no doubt that the subject of HIV/AIDS is difficult to discuss for a large portion of the Aboriginal population in Canada.

HIV/AIDS is regarded as a gay sex disease, a white-man’s disease and/or a far-away disease. The Aboriginal individual “perception filter” appears to immediately focus on “gay sex disease” and “sexuality.” Sexuality does not seem to be open for discussion in most Aboriginal families, even though most individuals possess some form of knowledge/understanding or experience in this area.

In addition, the Aboriginal people and organizations were not included in the implementation process of the NAS I - II for a long time. The information and resources of HIV/AIDS were difficult to get to individuals due to a lack of resources and the Aboriginal individual worrying about confidentiality.

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6.2 *Question #2- How could the NAS improve the efficiency of reaching, sensitizing and serving the Aboriginal population on HIV/AIDS across Canada?*

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The Aboriginal people must trust the process, the message and the messenger.

An example of the lack of trust in research is when one HIV Seroprevalence Study participant, who was remunerated to complete a survey form in downtown Vancouver, very aptly said:

*“what they (Seroprevalence Study Project Leaders) didn’t know and didn’t ask in this survey were things like working as a prostitute. If the tricks approached and said they would pay an extra \$20 if I didn’t use a condom, well..., prostitutes just wanted a fix, they wanted the extra 20 dollars”*

While the questionnaire served a purpose of encouraging the individual to think about the impact of her lifestyle on her immediate family, extended family and community, the study results missed an important clue to better understanding the knowledge, attitudes and behaviours of a very specific, marginalized, high-risk group. As the participant explicitly stated, had the study leaders been Indian “I would have let them know this immediately.”<sup>12</sup>

It is clear from the majority of compiled responses that the Aboriginal people, communities and organizations must lead the process for their people and control the resources. It is equally clear that communities (Inuit, reserves and urban) must have access to their own resources.

Adapted working tools must be developed that are user-friendly. In addition, there should be increased outreach, an update of videos should be occurring and more importantly, Aboriginal people should be leading a proactive information campaign.

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6.3 *Question #3- Do you think that more effective specific communication tools should be developed under the National AIDS Strategy in order to reach Aboriginal People? If you agree, what education and communication tools would increase awareness and change behaviours (please give examples)?*

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#### Multiple Choice

Two-thirds of the respondents totally agreed and nearly one quarter (24%) agreed.

#### Open Responses

Every tool should be decided upon, designed, developed and implemented under Aboriginal control. It was explicitly stated that all education programs and manuals should reflect Aboriginal cultures, and that there needs to be more emphasis on the oral and visual aspects of culture. Some of these tools should target the youth and families.

The dissociation of the youth from the family system (isolating the youth outside the confines of family in workshops/schools, etc) in combination with a difficult subject and the peer pressure, is not allowing the message of HIV infection and transmission to be presented to a receptive audience.

A renewed information campaign should use Aboriginal role models as spokespersons and maximize the impact of the message.

Another method would be having anonymously accessible information in an accessible language, straight forward and clear. Other methods would be using direct contacts and maximizing the oral and visual aspects of culture and designing interactive methods.

The most frequently suggested possibilities were an Internet Aboriginal HIV/AIDS Website and an internet capacity for e-mail and chat-rooms for information exchange, plus a 1-800-Aboriginal HIV/AIDS anonymous line that responds in a frank and direct manner to all questions and situations on Aboriginal HIV/AIDS issues.

In addition, it was expressed that the radio in the North (CBC North, community radio stations) have not been employed to their fullest potential by Aboriginal HIV/AIDS educators and intervenors. A unique suggestion, that was echoed by other interviewees, was to approach the CBC Program "North of 60" and urge them to create an episode or a series of episodes on Aboriginal HIV/AIDS and the impact on the community.

It was very clear in the majority of responses that an Aboriginal led information campaign should be dynamic and positive, criticizing that the past information campaigns were perceived to be dark and bleak in tone, colours and the choice of words/phrases.

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6.4 *Question #4- Do you believe that there should be more research oriented toward determinants and risk behaviour for Aboriginal Peoples in order to develop new communication tools? If yes, how would you find more research helpful in your work?*

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Eighty percent (80%) of respondents replied that research would be very useful or moderately useful and assist in the designing HIV/AIDS information that would have a greater impact on the Aboriginal populations.

It was clear that research should explore ways to develop new educational tools and increase the efficiency of the prevention message. The responses from the survey group were widely varied, although four principal statements appeared consistently and should be emphasized:

that the target population of research should be intravenous drug-users, sex trade workers and the Aboriginal youth & family;

that more research was required to better understand the dynamics of self-esteem among youth and APHAs (STD problem, saying "no," APHAs and drug therapies);

that migration patterns of Aboriginal peoples and the resulting impact on HIV infection need to be understood; and

that research in how to involve the family and community in education and prevention should be immediately initiated.

Research, in short, should target individual risk behaviours, migration patterns, Aboriginal families and communities in order to maximize education and prevention efforts.

It was also suggested that research should study Aboriginal traditions and treatments that could help the prevention work and support the Aboriginal people infected/affected by HIV/AIDS.

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6.5 *Question #5- Given the cultural and regional diversity of the Canada Aboriginal populations, how could a renewed National AIDS Strategy effectively recognize, support and assist the different Aboriginal populations for funding allocations and coordination purposes in order to better reflect the Aboriginal reality?*

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The compiled result of responses, again multivariate and all pertinent, appear to indicate that once Aboriginal peoples will be responsible for their own HIV/AIDS intervention process, they will have to define roles and responsibilities among themselves and demonstrate that they can work together and coordinate their efforts to reverse the HIV epidemic thereby reducing the rate of infection in the Aboriginal community.

Networking and coordination were identified as key issues the majority of the consulted people, but again roles, responsibility and coordination must be clearly defined and established for all intervenors.

A possible key to reach a collaborative and coordinated effort may be concentrating energies on an identified need for a standardized "Community HIV/AIDS Aboriginal Intervention Model". A model that could serve as an important tool to address the different target groups of education and prevention messages, identify the major resistance barriers and suggest how to diffuse these perceptions and prejudices while leading Aboriginal individuals to a better understanding of healthy sexuality, of saying "no," of negotiation and self-respect.

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6.6 *Question #6- In your opinion, would a Provincial Aboriginal Strategy for HIV/AIDS in your province/territory be beneficial? If yes, what should its role be? If no, please explain.*

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#### Multiple Choice

Eighty-five percent (85%) thought it would be very or moderately beneficial, more specifically, nearly three-fifths (58%) of respondents found that a Provincial Aboriginal Strategy would be very beneficial and over one-quarter (27%) rated it a "2" or as being beneficial. Fourteen (14%) said it would have little or no benefits.

#### Open Responses

Overwhelmingly, the coordination role was the first to be mentioned. The second compiled response was to gather and provide information (particularly with the Quebec French respondents) and the third response was to assist in development of an Aboriginal Holistic Health Strategy that is inclusive of all Aboriginal individuals.

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6.7 *Question #7- Consider how some or all of the following mechanisms for the National AIDS Strategy - Phase III might better coordinate its activities, organize its services and create an effective tracking system of Aboriginal HIV infection and treatment? Would you support a:*

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#### Multiple Choice

##### A. Health Canada National Aboriginal HIV/AIDS Program

The scale tends toward strongly supporting and supporting with fifty-five percent (55%), forty percent (40%) giving no support or definitely not supporting and five percent (5%) deciding to create a 2.5 response.

##### B. National Aboriginal HIV/AIDS Organization

Eighty-seven percent (87%) of people would support or strongly support the idea and 10% would not.

### C. Adoption of specific Aboriginal Objectives in the National AIDS Strategy III?

Ninety-four percent (94%) supported the adoption of specific Aboriginal Objectives in Phase III of the National AIDS Strategy.

#### Open Responses

Health Canada was generally perceived as paternalistic and therefore, Aboriginal people and organizations did not grant them a lot of credibility. And yet, the need to continue working on mutually agreed upon solutions overshadowed the frustration of working with inadequate funds, inadequate research data and inadequate pertinent and relevant information.

There is a clear need for a National Aboriginal HIV/AIDS Organization and yet, it was clearly articulated that there was definitely no need for another level of bureaucracy. There were some individuals who called for a National Aboriginal Committee (or Advisory Committee) on HIV/AIDS combining all sectors of Aboriginal HIV/AIDS work - professionals, para-professionals, front-line workers, APHAs and families of APHAs.

However, it was often clearly stated however, that the ultimate responsibility should be at the community level and that the National Aboriginal entity should not be a bureaucracy. It was mentioned that the National Aboriginal Organization should be an easily adaptive structure with a small Board of Directors. Some said that the Assembly of First Nations should be involved. Another idea was that the National structure should be linked to a proposed National Native Institute of Health.

Due to level of various open responses to this question, it was difficult to clearly define tendencies in the open responses and the reader should rely upon the multiple choice responses to questions #7 before taking into consideration the open responses.

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#### 6.8 *Question #8- What are the three specific priority needs/considerations for Aboriginal people living with HIV/AIDS that you believe are highest priorities for action in a renewed National AIDS Strategy Phase III?*

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The number one concern was a funding issue for APHAs and the issues of "poverty", the three most often cited priorities after this front-line reality are the following:

1. Better care and access to care in the cities, the communities and at home (with traditional components).
2. Better access to information on treatment, rights, lifeskills, choices, etcetera.
3. Access to home communities with adequate services, and without fear of discrimination.

There were particular mentions and concerns raised about the APHAs in Correctional Centres, for the support for APHA families and the need for a 1-800 Aboriginal Telephone line for Aboriginal HIV/AIDS issues. Also, it was often mentioned that education and prevention should be a top priority in care, treatment and support.



## 7.0 Random Comments (*direct and paraphrased*)

We need to look at training young people, arming them with information and skills to be able to go into the community to be educators, real training in healthy sexuality, choice and negotiation

What is needed is an experiential process whereby information is given and becomes action in the kind of choices that you make and remembering your role in the seven generations.

Alberta, Female, Frontline ASO

The strategy is not reaching Aboriginal people, if it is limited at the macro level in funding, then nothing gets done at the local level. There should be a central funding agency, someone developing and monitoring a database, and information applied at the local level, [...]know the tracking system and focus on the end product, include greater input by people at the community level.

Ontario, Male, Frontline Health Worker

[Remember] inter-generational colonization and the fact that you don't have to live the life to live the effect. There does exist various ways of de-colonizing through grieving and healing of personal losses.

You can't touch the sexuality subject with some on-reserve, there is so little privacy that most people are jealous of what little privacy they have left, this is definitely a factor.

The message of HIV/AIDS is getting out there, but not in a manner that the information is understood and translated into behaviour, the information doesn't give the individual "light" and ways of making a personal meaning of the message.

Programming doesn't actively engage members of the family systems. Anything that happens within one system usually affects another, [if it has happened to the son or to mom, then dad and little brother are going to definitely feel and see the results].

British Columbia, Male, Frontline Health, On-reserve

The original consultations called for a national allotment for Aboriginal people. There should be specific Aboriginal objectives and having funds allotted to them. Allow the Aboriginals to develop objectives. We all need to go back and think the whole thing through, a re-thinking process that involves the youth, psychologists and people with an understanding of human behaviour. The harm reduction model may work in the city but not in an isolated environment where people "are free from bad influences."

Ontario, Male, Researcher, Urban

We have to remember the generational issues here, issues have to be relevant from one generation to another and in this issue the parents are refusing to acknowledge the issue.

Ontario, Male, Metis, Urban

Perhaps we should be trying education and training modules for young people and the elementary schools and have the parents involved in their children's education and have special workshops, with the parents and guardians.

Alberta, Female, Metis, Urban

Most people know about determinants and behaviour, one project we were involved with and shed some very important light for us was a youth who did a peer youth survey. In it, the youth peers (on-reserve) said "we know about HIV/AIDS and all that stuff! Teach us how to say no and mean it!"

Manitoba, Female, Frontline, On-reserve

[To respect the different Aboriginal groups] provide the funding to a central Aboriginal group of a National Advisory committee that is aware of all the issues.

Yukon, Male, Frontline Health, Off-reserve

The priority number one for APHAs is to teach the family and children about HIV/AIDS.

Ontario, Female, Frontline Health, On-reserve

There needs to be social epidemiological findings to make evidence-based decisions, stronger coordination with on/off reserve groups, including the Metis and Inuit and a national program should be financially monitored and overlooked by HPPB and not MSB.

Ontario, Male, Frontline Health, Off-reserve

There should be a CBC North of 60 AIDS show, or otherwise a commercial on HIV/AIDS

Alberta, Male, APHA, off/on-reserve

Health Canada can't continue with patronizing and giving a few bucks, the Community Health Representatives are ideal candidates to do training in the communities, and yet they remain inadequately trained.

Quebec, Female, Front-line Health, on-reserve

Let our regional agencies have a better go at it, the funds have given peanuts and no intensive sustained approach to HIV/AIDS education has been maintained, it is token funding that is not enough to get down and dirty. We need an Inuit-based information campaign.

Labrador, Female, Front-line Health, Inuit

We need to consider a multi-level targeting of information.

Manitoba, Female, Front-line, Urban City

We don't know much about the AIDS Strategy, we don't know what it is, maybe we have seen some of it on television? We should be provided with a menu of choices that fit our particular circumstances. We could follow up on a type of model that worked on HIV & STDs that discussed oppression and power and STDs and Alcohol that got into power relationships between men and women. These are very positive and effective.

Nunavik, Quebec, Male, Front-line Health

A healthy sexuality approach would probably make a big difference.

Nunavik, Quebec, Female, Front-line Health, Inuk, Community

Our work is a two-edged sword. The kids are too smart for what they are getting, condoms and showing them how to use them will not work! If a sense of self is missing, the condom approach will not work. We need to re-open the whole concept of sexuality and re-work the approach, something along the line of a holistic health model.

Ontario, Female, Front-line Corrections, On-reserve

A non-Aboriginal organization is still telling Aboriginals what is wrong with them and how to fix it. A National Program would be far more effective if you had a National Aboriginal program and Aboriginal persons telling Aboriginals the problem and searching for the answers.

Alberta, Female, Urban, Non-Status Indian

We need to be going door to door and talking to family at their level.

Nova Scotia, Male, Family APHA

It is important for NAS III to recognize Aboriginal representation, all jurisdictions, to increase the number of effective networking tools and that they become included in the decision-making process.

British Columbia, Male, APHA, First Nation off-reserve.

NAS III needs to increase the capacity to act for the local, regional and national institutions, a capacity to design and deliver effective interventions, a capacity to provide information, a capacity to develop research methodologies that would be useful in day-to-day operations and improvement in the gathering of data. We need to look at a best-practices model on what works and what doesn't, user-friendly is a must. Funding should reflect the demographic realities of HIV/AIDS and linkages between on and off reserve need to be established. Our national guidelines, standards and protocols should come after trained individuals are in place. The local place is the place to gather information. Remember that this should be an inclusive approach, not based on politics and jurisdictions, get the money to the people who need the service.

Quebec, Male, Policy, Urban, First Nation off-reserve

Increase activities in and out of communities, hold regional conferences, this is best done by Aboriginal organizations, First Nation communities and individuals. Capacity building must occur in all communities.

Atlantic, Male, Health Liaison

A provincial model of information would help us in Quebec, our language problems are different, an AASO would definitely help to coordinate work in Quebec

Quebec, Male, APHA, Urban, First Nation off-reserve



## 8.0 Conclusion

In the planning, design, implementation of this consultation with the Aboriginal peoples, it became increasingly clear throughout the process that the Aboriginal peoples are not just one specific, marginalised interest in the general field of HIV/AIDS.

The Inuit of Nunavut, Nunavik and Labrador and those residing in urban and rural centres, have clearly indicated that, at present, their requirements of culturally appropriate education and prevention material are not being met. In addition, a local development approach to production of education materials and community responses to HIV/AIDS is not occurring. The general underlying obstacles to a common community philosophy towards HIV/AIDS resemble that of First Nations (on/off) and the Metis in the south, but the language, the cultural references and history are distinctly different. This reality has not yet been recognized in the field of HIV/AIDS.

The First Nations, on-reserve and off-reserve, have generated a significant body of educational material and community responses to HIV/AIDS, but this information has no central electronic or physical documentation centre that serves to encourage and stimulate all Aboriginal populations in research of past, present and new initiatives. Neither was it recognized by NAS I - II, contrary to the recommendation in 1990, that there exists special interests (specific target groups) with Aboriginal populations, such as gay, two-spirited people, women, injection drug users, youth, inmates and sex trade workers.

The Metis clearly indicated a need for Metis-specific educational and prevention materials and a more intensive campaign to educate all levels of their settlements and communities about HIV/AIDS. While a common community philosophy towards HIV/AIDS and the issues of sexuality may not be in existence at this present time, a commitment of working towards and better informing the general Metis population is evident.

The National AIDS Strategy in Phase I - II did not succeed in stopping the transmission of HIV in the Aboriginal peoples. The reported data, as referred to on page 5 of this consultation report, continues to indicate an increase of AIDS cases.<sup>113</sup> This serious situation is compounded by the lack of an Aboriginal HIV infection tracking system, nationally and provincially.

In respect to the goals developed by the JNC (not all goal specifically referred to in this consultation report) NAS I - II did increase a general awareness about HIV transmission, infection and the development of HIV spectrum diseases and AIDS in the Aboriginal population. However, general consultation feedback appears to indicate that this awareness is limited to specific segments within the overall Inuit population, the First Nation (on/off) population and the Metis population. Overall, Aboriginal peoples are still resistant and unreceptive to HIV/AIDS (AIDS 101 for example) education material and prevention approaches.

The NAS I - II, does appear to have encouraged and attempted to respect a local development approach to the work in the field of Aboriginal HIV/AIDS, and thereby attempting to encourage and enhance their partnership with Aboriginal peoples. As articulated by the consultation respondents, however, it is clear that this partnership is perceived, and felt to be, a Health Canada -determined and -driven process.

Can a National AIDS Strategy - Phase III improve this situation?

As stated earlier, Aboriginal people must trust the process, the message and the messenger.

The process implemented under Phase I - II has engendered an unstable and unbalanced relationship between the different jurisdictions and the multi-faceted reality of the Aboriginal peoples in Canada. A new process is urgently required on the part of Health Canada. The Aboriginal respondents have indicated their willingness and commitment to address the issues and concerns of HIV/AIDS in the Aboriginal populations with resources

that will permit a coordinated, collaborative and intensive campaign to stop or reduce the transmission of HIV.

Under NAS I - II, a body of educational materials and prevention tools were developed by the Aboriginal peoples. There remain however some fundamental realizations on the part of the Aboriginal peoples who have laboured long and hard in this field of work:

1. There exists no coordination linkage between existing HIV/AIDS resources and new, emerging local efforts that permit new entrants to seize quickly upon what has been done, what can be "culturally transportable" and who to ask for information and guidance in developing new local strategies;
2. That emphasis on oral and visual culture needs to be paid more attention to; and
3. That the message of HIV/AIDS (AIDS 101, for example) must be re-worked, and built upon, and a new approach put into place that is designed, developed and implemented by Aboriginal peoples. Consultation respondents felt that this new message should centre on Healthy Sexuality, Choice, Negotiation and saying "No." This is one option for further exploration.

There exists a real need to continue fundamental research in epidemiology and research oriented towards determinants and risk behaviour, at the local level, provincial level, regional level and national level. Aboriginal people recognize the intrinsic value of all levels of research, but remain distrustful and sceptical of an approach that is initiated from "top-down." A process to implement new research initiatives in this field must build upon a cooperative and collaborative approach and attempt to address the unstable and unbalanced relationship that describes the present situation in the general field of Aboriginal HIV/AIDS work.

In respect to the cultural and regional diversity of the Aboriginal peoples, there is no easy conclusion that can be drawn. The general observations appear to be that a serious and fundamental step by Health Canada that recognizes past work and consolidates the present infrastructure in increased funding would probably lead to serious inroads in breaking barriers in prejudices and ignorance and lay fundamental "signposts" for all to follow in a Phase III. In addition, responsibility must be shared with Aboriginal peoples to define roles, responsibilities and create a strategic financial plan with clear objectives to obtain future desired results.

In respect to Provincial Strategies, it is felt that any National Aboriginal HIV/AIDS program or organization has a responsibility to encourage new provincial strategies, inform provincial stakeholders where requested, to guide provincial stakeholders in similar initiatives, to advise and act as networking body and support provincial where needed. Here, the capacity to respond can only come with better linkages and sharing of information and resources.

A future National AIDS Strategy - Phase III should lay-out a clear strategy of action, both within Health Canada and in the Aboriginal field of HIV/AIDS work. The NAS I - II failed to articulate and adopt clear objectives for all Aboriginal intervenors to use in evaluating their work. This is specifically highlighted in the response to the proposed adoption of specific Aboriginal objectives in Phase III. It is clear that the Aboriginal HIV/AIDS infrastructures are becoming well-versed in designing, organizing, implementing and evaluating their work and need to create some very specific objectives and goals at the national level. In respect to Health Canada, a streamlining of HPPB and MSB in order to provide collaborative and strong coordination would assist work in the field of Aboriginal HIV/AIDS. Perhaps a greater role and responsibility to the departmental Aboriginal AIDS Committee to ensure co-funding and collaboration becomes an integral internal process between departmental programs

Lastly, the issue of education and prevention in the Aboriginal communities has shifted to issues and concerns

## 9.0 Key Options suggested in Consultation Process

These options represent a variety of the responses received and are not exclusive. Further examination and development are likely needed.

*To improve efficiency of reaching, sensitizing and serving the Aboriginal population, the consulting processing suggested the following options:*

- a. National Aboriginal AIDS Conferences
- b. National Aboriginal AIDS Organization
- c. 1- 800 - Aboriginal HIV/AIDS Telephone Number
- d. Internet Website of Aboriginal HIV/AIDS Information
- e. Internet Site for Chat-rooms and E-mail
- f. Holistic Health Strategy
- g. Audio-visual (new material and updated versions of existing)
- h. Development of a Health Sexuality Training Module
- i. Development of a Module on Negotiation, Choice and saying “no”
- j. Development of a National APHA Speaker Resource Network
- k. More training to existing Aboriginal HIV/AIDS educators and intervenors

*To develop more effective specific communication tools, the consulting process suggested the following elements:*

- a. Re-working of existing culturally-appropriate education tools to target the youth and the immediate family
- b. Re-working of existing education tools to target the youth his/her extended family
- c. Re-defining existing tools and developing new education tools that target the parents and Elders
- d. Development of a Healthy Sexuality Model
- e. Use new message and employ CBC North and Community Radio
- f. Approach North of 60 to do character, one episode or series of episodes on HIV/AIDS
- g. Internet Chat room with e-mail capacity for Aboriginal HIV/AIDS educators and intervenors
- h. Internet clearinghouse of Aboriginal education and prevention material available
- i. More training to existing Aboriginal HIV/AIDS educators and intervenors

*Key Research areas towards determinants and risk behaviour that the consulting process suggested are:*

- a. A better understanding and knowledge of intravenous drug-users and sex-trade workers and street youth
- b. More community-based research on relationship between Aboriginal Youth and the Family System
- c. Additional research to develop components of a model on a Healthy Sexuality Model
- d. Increased research targeting the dynamics of self-esteem in Aboriginal Youth and APHAs combined to reach a better understanding of individual risk behaviour
- e. More community based research on Negotiation, Choice and saying “no”
- f. Additional research that examines Aboriginal traditions and treatment that could be integrated into prevention work
- g. Additional research that examines Aboriginal traditions and treatment in order to support APHAs
- h. More community-based research and pilot projects in how to involve the family and community in the education and prevention effort
- i. Better understanding of effect of migratory Aboriginal population and the resulting impact of HIV infection
- j. Local community-based research on developing a Healthy Sexuality Model

*To effectively recognize, support and assist the different Aboriginal populations for funding allocations and coordination purposes, the consulting process suggested:*

- a. A national Aboriginal HIV/AIDS think-tank session regrouping individuals to re-work message, approach of message and strategize on new tools
- b. A national Aboriginal HIV/AIDS Strategy
- c. A National AIDS Strategy with specific Aboriginal objectives
- d. Standardized Community HIV/AIDS Aboriginal Intervention Model
- e. The development and coordination of an Inuit-specific designing, organizing and implementation of educational tools
- f. A coordinated Health Canada internal program regrouping on/off reserve in combination with an external National Aboriginal AIDS Organization
- g. Consolidate and build upon existing work, create core competencies in a National Aboriginal AIDS Organization having a role to inform, to guide, to advise and conduct research in the field of Aboriginal HIV/AIDS.

h. That a National Aboriginal AIDS Organization be funded through other units, such as the Coordination & Collaboration Unit, rather than the Medical Services Branch and that the National Organization adopt a clear plan of action for the period of Phase III.



## 10.0 Recommendations

### *Number One*

That the Canadian Aboriginal AIDS Network (CAAN) be funded with operational dollars from the Coordination and Collaboration allocations and not the Medical Services Branch.

This recommendation is given for three reasons:

1. MSB is limited to On-reserve and Inuit populations;
2. The MSB allocations are project oriented and time limited; and
3. An effective network for Aboriginals must transcend jurisdictional issues and serve all Aboriginal groups.

### *Number Two*

That more AASOs be funded in order to create a wider expertise who work exclusively in the HIV/AIDS field. As AASOs are depended upon for education and training, the present demand outweighs the supply. Further, existing AASOs must be able to increase their staffing levels in order to better target those segments of the Aboriginal population who have not been reached.

### *Number Three*

That the NAS structure within Health Canada overcome internal jurisdictional barriers and ensure better linkages inter and intras-departmentally, so as to maximize effect and minimize red-tape that impedes access to funding allocations. This includes more senior collaboration, more co-funding of projects and an increased sharing of information for all Aboriginal stakeholders.

### *Number Four*

That a National Aboriginal AIDS Strategy be created. There is extensive work needed to bring all stakeholders together, both new and old, in an inclusive and supportive manner. This national strategy should involve Provincial Aboriginal AIDS Strategies and thereby increase the knowledge for all national stakeholders. A National Aboriginal AIDS Organization should advocate the adoption and recognition of more Provincial Strategies to be established and funded at appropriate levels.

### *Number Five*

That National Aboriginal Conferences be recognized as key sources of presenting new resources and information, and offer training on these new developments. The focus of these conferences should be examined to maximize skills transfer and skills development and not just an exchange of information.



## Notes

- 1 Building an Effective Partnership: The Federal Government's Commitment to Fighting AIDS, Health and Welfare Canada, 1990, p.8.
- 2 Ibid.,p.10
- 3 Building an Effective Partnership: The Federal Government's Commitment to Fighting AIDS, Health and Welfare Canada, 1990, p.,10.
- 4 The JNC is described as a partnership including representatives from the eleven national organizations, Health and Welfare Canada and the Department of Indian and Northern Affairs. Recommendations for a National Strategy on Aboriginal AIDS Education and Prevention, Health and Welfare Canada, 1990, p.(i).
- 5 Memorandum provided to authors by Laboratory Centre for Disease Control, Health Canada, October 10, 1997
- 6 Epi Update, Bureau of HIV/AIDS and STD Update Series, LCDC, Health Canada, May 1997, p.54. (Footnote 7 re-integrated into text)
- 7 Canadian Aboriginal AIDS Network, September 30, 1997.
- 8 Epi Update, Bureau of HIV/AIDS and STD, LCDC, Health Canada, May 1997,p.53.
- 9 Aboriginal Communities and HIV/AIDS - Final Report, Canadian AIDS Society, Albert McLeod, March 1997, p.7-23.
- 10 Aboriginal Communities and HIV/AIDS - Final Report, Canadian AIDS Society, Albert McLeod, March 1997, p.7.
- 11 Bridging the Gap, Report on the National Roundtable on HIV/AIDS & First Nations Populations, March 15 - 16, 1994 pp.10 - 20.
- 12 Canadian Aboriginal AIDS Network - Aboriginal Questions Interviewee, 2 October 1997.
- 13 1993 - 1996 period is now reporting 5.6% increase as compared to 4.4% in May 1997, Memorandum dated 10 October 1997.