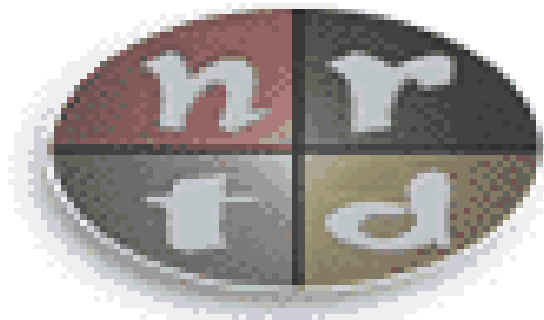


# **National Round Table Discussions - Project Summary Report -**



**National Round Table Discussions**

**The Canadian Aboriginal AIDS Network  
409-396 Cooper Street  
Ottawa, Ontario  
K2P 2H 7**

---

Respectfully Submitted by: DM Jake Linklater



## Table of Contents

Table of Contents	3
National Round Table Discussions Project Summary Report	5
National Round Table Discussions – Questions for future considerations	9
Edmonton Round Table Discussion	11
Quebec City Round Table Discussion	15
Vancouver Round Table Discussion	19
Winnipeg Round Table Discussion	23
Iqaluit Round Table Discussion	27
Going Forward Together: Evaluation Report	31
HIV/AIDS and Aboriginal People in Canada: A discussion paper on the capacity of the community to respond	43



## **Introduction:**

On October 04, 1998 the Canadian Aboriginal AIDS Network (CAAN) entered into an agreement with the Prevention and Community Action Program of the Health Promotion and Programs Branch in Health Canada. The project was well under way by the time the project coordinator, DM Jake Linklater was contracted by CAAN to perform the various duties outlined in the agreement.

CAAN entered into the agreement with the expectation of strengthening their organizational capacity, image, and leadership role within the Aboriginal community.

## **Project Purpose:**

The purpose of the National Round Table Discussions was to facilitate the development of funding guidelines and criteria for the Prevention and Community Action Program of Health Canada. As well, to submit the developed guidelines and criteria to the National Aboriginal Reference Group on HIV/AIDS for their review, comment and ratification. The guidelines and criteria are to reflect an Aboriginal specific program initiative:

*Designed and developed for Aboriginal people, by Aboriginal people.*

## **National Round Table Discussion Goal:**

To provide an opportunity for key stakeholders working with HIV/AIDS issues affecting Aboriginal Peoples living in urban, rural & non-reserve settings.

To provide an opportunity for stakeholders to provide input and feedback on the development of funding guidelines for the Canadian Strategy on HIV/AIDS \$ 1.2M in contribution funding for urban, rural & non-reserve Aboriginal HIV/AIDS project initiatives.

## **Project Overview:**

The intent of the project was to solicit input from the Aboriginal community in the development of Aboriginal specific HIV / AIDS administrative guidelines for funding . The five major Aboriginal organizations and community based HIV / AIDS urban organizations were invited to participate. Cook Consulting was contracted by Health Canada to conduct this work.

Initially, the process developed to gather this input was to be executed through national surveys to be administered across Canada and this was to be further complimented by the establishment of a reference group comprised of board members and/or employees of Aboriginal political and service delivery organizations.

Leading up to the first meeting of the newly augmented reference group (November 16, 1998), later to be called the National Aboriginal Reference Group on HIV/AIDS (NARGHA), its role and capacity was established. During this first meeting the group rejected the plan to implement national surveys across Canada, rejected the Canadian Policy & Research Network document and renamed the discussion panels to “Round Table Discussions” as opposed to “Circle Councils”.

Over the course of the next three months, the National Aboriginal Reference Group on HIV/AIDS selected the Round Table discussion participants through a sub-committee. This sub-committee was developed and designed to act as a coordinating mechanism to assist the process throughout the extent to consultation process.

The lead on the round table discussions was Cook Consulting with administrative support contributed by the CAAN project coordinator. Cook Consulting was responsible for the selection of the Round Table discussion facilitators, the recording of the round table discussions, developing reports for each Round Table and completing the final report to be later submitted to Health Canada.

Health Canada participants provided information and actively participated during the consultation process in capacities such as resource people, and small group facilitators.

Round Table discussions were held in Edmonton, Alberta; Quebec City, Quebec; Vancouver, British Columbia; Winnipeg, Manitoba; Iqaluit, Northwest Territories (Nunavut); and finally in Halifax, Nova Scotia. The sixth and final Round Table discussion was facilitated in a closing or wrap up fashion to the process based on the recommendations of the project technical team.

### **CAAN'S Role:**

The role of the CAAN Board members that participated at these Round Table discussions was to provide to the Round Table participants with a historical perspective on HIV / AIDS and the issues facing Aboriginal communities. After several attempts to achieve this goal, a recommendation was put forward by the technical team to discontinue this role and objective. However, the Board of Directors that did participate ensured each Round Table discussion was balanced with the perspective and insight relating to HIV/AIDS in the Aboriginal community. From start to finish CAAN was the administrative body for this initiative.

My role as the project coordinator, was to provide administrative support for the Round Table discussions and NARGHA meetings. Another role was to participate during the drafting of the terms of reference concerning the Round Table discussions and with the coordination of disseminating all relevant information compiled and produced by Cook Consulting from the Round Table discussions.

My responsibilities were to oversee the travel and accommodation logistics for all the participants throughout the Round Table discussions. These arrangements were confirmed and finalized through correspondence via fax, telephone and letter. Round Table discussion conference facilities were arranged, equipped and supplied as well as furnished with refreshments. Similar arrangements were accorded to the National Aboriginal Reference Group on HIV/AIDS during their meetings as well.

Activity reports and other project update information were provided to the CAAN Board such as financial monitoring reports and verbal perspectives during the duration of the project. Files related to the project were established and maintained and are readily available to the CAAN Board in hard copy and diskette form.

### **Expected Outcomes:**

The end product of the project will be the developed administrative funding guidelines for the Prevention

and Community Action Program within the Health Promotion and Programs Branch of Health Canada.

Within the final report to be produced by Cook Consulting, all of the recommendations and feedback from each Round Table were to be incorporated pertaining to the development of the administrative funding guidelines. Health Canada was then to contract an Aboriginal consultant to develop these administrative guidelines based on the report. An editorial review committee was then to be struck for the sole purpose to review the administrative guidelines for funding before they were to be examined and deliberated on in one final consultative process. This process will be guided in a focus test of the document with key stakeholders that participated previously during the Round Table discussions.

Once this final consultative process is complete, Health Canada will then develop a review committee based on the outcomes and recommendations of the focus test group. The review committee will comprise of Aboriginal representatives from each of the sub-groups identified within past and present federal department protocol. These sub-groups are First Nations, Metis, and Inuit.

A date is yet to be determined by Health Canada for their Call for Proposals as it relates to the \$1.2M Aboriginal specific HIV/AIDS funding initiative.

### **Reflections:**

The most apparent and constant theme that became prevalent during the Round Table discussions was “Community Development” and “Integrative problem solving”.

The goal of integration, according to Health Canada was to focus on those most at risk and increase public accountability. This I believe was and will be the ongoing problem that will face this initiative because, decision making often involves “conflict of interest”. Groups, or factions within groups, perceive each other as desiring mutually exclusive goals. Thus, they compete, entering into a power struggle hoping that the other side will yield their position.

An integrative approach to conflict and policy development searches for solutions to problems that benefit everyone. A novel approach, but problematic. The initiator of this approach must first realize that this route of problem solving can be better understood and accepted if the target group has the fundamental and practical knowledge of this principle.

Although the technical goals and objectives of the Round Table consultations were met, the goal of integration, in my opinion, can not unless the stakeholders involved are informed on the varying components of integrative solutions.

The main issue that was most prevalent among the stakeholders, was resources. Is there enough to go around ? and, Will it accomplish the work required while at the same time meeting the goal of public accountability? Basically, which approach can make an effective impact regarding resource allocation and community development.

Unfortunately, it has been my experience that when groups are faced with scarce resources, as such is the case here. Groups often become competitive and encounter forms of strife, warring over who gets the biggest piece or slice of the pie. Subsequently, it is often the groups less capable of responding to competition and competitive environments that accept the inevitability of scarce resources - without fully

exploring options that might expand the piece or slice. This to me, is not community development.

Now, the question remains:

“Who will bare the responsibility of this and what will be the next approach utilized?”

### **Conclusion:**

Given the difficult circumstances around this consultation process, such as endeavouring to foster inclusiveness and the difficult issues the community was forced to grapple with, such as limited dollars and shortfalls in organizational capacity, a majority of the participants agreed that the experience was a good one. The new players established from this process also agreed that many new ideas were taken away, information was shared and local, regional, and territorial issues were understood and brought to light in a larger context.

Three broad conclusions can be drawn from this consultative process:

The first being, that the Inuit requirements of culturally appropriate prevention material command a detailed and thorough plan for this group to effectively and efficiently respond to HIV/AIDS;

The second being, that First Nations although equipped with a significant body of prevention material, requires an electronic or physical document centre that could serve to encourage and stimulate this group to continue with past, present, and future initiatives within the HIV/AIDS field; and,

The third being, that the Metis requirements are mirrored within the Inuit campaign to develop and design appropriate prevention material for their populations within settlements and rural districts of Canada.

PCAP is starting from where ACAP left off, thus becoming the new weigh station for what is inadequate and impractical within our health and social service system. As a result of this initiative to consult with Aboriginal populations and as a result to undertake an approach to strengthen community development and collaboration among Aboriginal organizations, the initiative presented the intended populations with confusion. To best support community development and collaboration, the community-based Aboriginal AIDS service sector must be in support and possess the capability to reposition their movement.

This in turn created an oversight during the initiative. Community representatives and the new players brought in, did not and could not differentiate between strengthening the community and strengthening community organizations. Therefore, more emphasis on strategy must be redesigned and re-engineered by PCAP to meet and arm an Aboriginal response to resolve, prevent and slow the transmission of HIV/AIDS among Aboriginal populations.

In conclusion, it is important to understand that all documentation is subject to review by Health Canada before it is released to all stakeholders of this project.

Meegwetch!, Thank You!, Merci!

**National Round Table Discussions  
- Questions for Future Consideration -**

1. Who will decide the evaluation of the presented proposals submitted from Aboriginal AIDS Service Organizations?
2. What will be the grievance process for those that feel they need to request an independent review of their rejected proposal?
3. How much background information on the submitting organizations will be required? (Organizational Inventory)
4. Will a specific community profile be required? (Rural, Urban Centre, Urban Suburb, Remote Fly-In, Population Breakdown, or Population Size)
5. Who will decide “need” if there is no allocation formula developed?
6. What will be the “Rules of Termination” for a funded project that is not meeting the basic guidelines? What are the obligations of each party if termination takes place?
7. How and who will address boundary/jurisdictional issues?
8. Are there going to be future commitments by Health Canada to campaign for inter-governmental partnerships to ease the anticipated burden once the call for proposals have been issued to the Aboriginal HIV/AIDS community?
9. Will rules of confidentiality be developed for all stakeholders once the administrative guidelines have been implemented by Health Canada? And, who will develop and design these governing rules of confidentiality?
10. What kind of partnerships will fit into the Prevention and Community Action Programs mandate when submitting a proposal? And, what is prevention and who will determine what prevention is when proposals are submitted from the Aboriginal HIV/AIDS community?



# **National Round Table Discussion**

Report of the Edmonton Round Table Discussion  
Inn on the 7<sup>th</sup>, February 12 - 13, 1999  
Edmonton, Alberta

Discussion on Urban, Rural & Non-reserve Administrative Guidelines for Funding  
February/March 1999

## ***Introduction***

The National Aboriginal Reference Group on HIV/AIDS (NARGHA) is overseeing the national round table discussion process with the express purpose of obtaining feedback on proposed administrative guidelines for funding urban, rural and non-reserve HIV/AIDS initiatives in the Aboriginal population across Canada. This funding is made available by Health Canada, Health Promotions and Programs Branch under the Canadian Strategy on HIV/AIDS.

The Edmonton candid review, of six (6) topics (*see below*) and twenty-four (24) questions, was the first of five discussions with the purpose of seeking input on HIV/AIDS issues in the Aboriginal population from the local, regional and national levels.

Eighteen (18) Aboriginal participants, five (5) federal health individuals and one (1) provincial health representative and three (3) support staff used this process for two days to bring their concerns and issues on Aboriginal HIV/AIDS in their region to the table.

## **Objectives of the National Round Table Discussion**

The objectives of the National Round Table Discussion are:

1. To provide an opportunity for round table participants to share their insight regarding HIV/AIDS and Aboriginal Peoples in Canada.
2. To provide an opportunity for round table participants to offer input to the design & development of funding guidelines for \$1.2 Million in contribution funding for urban, rural & non-reserve Aboriginal HIV/AIDS projects across Canada.

## ***Process***

It is recognized that each province and geographical region of Canada is very different and that the approach to round table discussions will be different from one site to another.

Therefore, a flexible agenda was designed by NARGHA in order to respect regional diversity.

## ***Day 1***

The first day of the Edmonton Round Table was facilitated using a Talking Circle under the guidance of Elder, Christine Daniels, and a facilitator, Mac Saulis, Carleton University, Faculty of Social Work.

The Talking Circle allowed the multifaceted knowledge, experience, ideas and analysis of the last decade of Aboriginal HIV/AIDS work to be expressed in an open and honest manner. It also highlighted the many different approaches that have been developed in the Aboriginal HIV/AIDS health field.

By the end of the Day 1, participants had a better understanding of the complexity and different levels of work being undertaken in the Aboriginal HIV/AIDS health field and each individual had the opportunity to express their opinion and provide their perspective to the whole group.

In the evening, a number of individuals gathered for an evening feast and enjoyed the opportunity of creating new friendships.

## ***Day 2***

The second day of the Edmonton Round Table discussion was centered on small group discussion of the following six topics with a total of twenty-four (24) questions guiding small group discussion.

1. Defining Need and Assessing Need
2. Long Term versus Short Term Project Funding
3. Reviewing Project Proposals
4. Project Management
5. Evaluation
6. Regional/National Allocations

Some of the results of these topics with 24 questions were:

- the desire for a community driven process of determining need;
- a need to pro actively network across Canada and share successful models;
- pointed discussion as to number of months that define long-term;
- suggestions for determining a project's value;
- a clear sense of where the evaluation dollars should come from and a suggested process
- for using evaluations effectively in project work; and a
- a proposed model for allocating the \$1.2 million across Canada.

Day 2 became animated and full of ideas and suggestions when each small group had the opportunity to present their responses to the 24 questions to the larger group of participants. Many different opinions were expressed and duly noted for further analysis after data collection is terminated.

## ***Conclusion***

The Edmonton Round Table was the first of five round tables and therefore a full report cannot be prepared for distribution until the candid review process is complete on March 21, 1999.

The data collection process must remain independent in each region in order to allow a clear sense of regional diversities, priorities, similarities, and problems.

A full report will be prepared for the National Aboriginal Reference Group on HIV/AIDS (NARGHA) for their consideration during the process of development and approval of final administrative guidelines for accessing the \$1.2 million for HIV/AIDS health work in urban, rural and non-reserve settings for the Aboriginal population in Canada.

#### *One Example of input into National Round Table Discussion process*

One group presented a model of evaluation using and developing knowledge and experience based on the Medicine Wheel and the Four Seasons.

Spring	- Where you got involved
Summer	- Evaluation
Fall	- Results
Winter	- Reap the benefits and continue the growth

This important input into Aboriginal HIV/AIDS health work is fundamental in ensuring that HIV/AIDS projects direct the energies and resources of community-based groups towards effective prevention and education work with the many different Aboriginal target groups in Canada.

The development of an Aboriginal short/long-term effective HIV/AIDS project management and evaluation approach to administering public monies could include some of the following elements. The following elements are based on the book "The Sacred Tree" published by Four Worlds International Institute for Human and Community Development. (*Web Site: <http://nucleus.com/4worlds/>*) The comparison is an example only and is intended only to further reflection and thought on planning , administering and evaluating the work of Aboriginal HIV/AIDS monies in an efficient and effective manner across Canada.

#### **SPRING**

EAST - A place of beginning  
Ability to see through complex situations  
Capacity to analyze  
Capacity to believe in unseen  
Seeing situations in perspective

#### **NEW PROJECT PLANNING**

The Planning Function - Management  
Evidence-based project value  
Population Health Principles  
Project Vision and/or Mission  
Project time limits & boundaries

#### **SUMMER**

SOUTH - A place of getting ready  
Determination to fulfill the purpose and goals  
Goal Setting  
Compassion  
Generosity

#### **NEW PROJECT PARTNERS**

The Organizing Function - Management  
Terms of Reference outlining role and responsibilities  
Working with target groups/populations  
Involving target groups in all project phases  
Learning to work with new partners

## **AUTUMN**

WEST - A place of testing  
Capacity to remain faithful to goals  
Respect for other's beliefs

Testing of the will

Commitment to struggle to assist  
development of the people

## **WINTER**

NORTH - The dawning place of wisdom  
A place of remembering, synthesizing  
Lessons of things that end

Capacity to finish what we begun  
original project proposal  
Seeing how all things fit together

## **IMPLEMENTING PROJECT ACTIVITIES**

The Implementing Function - Management  
Actions consistent with projects' objectives  
Forum/process for project stakeholders to provide  
internal, ongoing evaluation  
Provide project team with structure/process for team  
building and conflict resolution  
Ensuring team's personal limits/  
boundaries are respected, balanced and recognized.

## **EVALUATING PROJECTS ACTIVITIES**

The Evaluation Function - Management  
Reviewing intended/unintended results  
Understanding success and identifying weak spots  
for the next time.  
Full completion of project activities as prepared in  
  
Providing wrap-up and closure for all project  
partners

# **National Round Table Discussion**

Report of the Quebec Round Table Discussion  
Hotel Radisson, February 19 - 20, 1999  
Quebec City, Quebec

Discussion on Urban, Rural & Non-reserve Administrative Guidelines for Funding  
February/March 1999

## ***Introduction***

The National Aboriginal Reference Group on HIV/AIDS (NARGHA) continued the national round table discussion process with the express purpose of obtaining feedback on proposed administrative guidelines for funding urban, rural and non-reserve HIV/AIDS initiatives in the Aboriginal population across Canada.

This funding is made available by Health Canada, Health Promotions and Programs Branch under the Canadian Strategy on HIV/AIDS.

The Quebec City candid review, of six (6) topics with twenty-four (24) questions, was the second of five discussions with the purpose of seeking input on HIV/AIDS issues in the Aboriginal population from the local, regional and national levels.

The six topics discussed in a round table process were:

1. Defining Need and Assessing Need
2. Long Term versus Short Term Project Funding
3. Reviewing Project Proposals
4. Project Management
5. Evaluation
6. Regional/National Allocations

## ***Participants***

Sixteen (16) Aboriginal participants, two (2) federal health representatives, two (2) support staff, an Elder and a facilitator used the large group round table process for individuals to highlight and discuss their concerns and issues on Aboriginal HIV/AIDS in their respective fields of health work to the table.

## ***Process***

Quebec City employed the large group round table approach where each individual had the opportunity to respond to the six topics and twenty-four questions. There were several individuals whose first language was French therefore simultaneous translation was provided to facilitate discussion and input on all topics.

The two day meeting was opened and closed by Huron-Wendat Elder, Raymond Gros-Louis. The

facilitation work was done by Mac Saulis, Carleton University, Faculty of Social Work.

### *Day 1*

During day one, after the opening of the day by Elder, Raymond Gros-Louis and the general opening comments and discussion of the various prevention efforts in HIV/AIDS (First Nation & MSB, process and recommendations, etc), participants concentrated on the first topic - Defining Need and Assessing Need.

Two important subjects emerged from the general discussion during the afternoon of day one, these being:

1. Training and Capacity Building; and,
2. A clear need for increased links between community groups and other Aboriginal health and HIV/AIDS resources.

Training and capacity-building became an immediate focus as individuals expressed the need and desire for support and professional development for health workers, front-line community-based HIV/AIDS workers and train the trainer approaches for effective HIV/AIDS prevention work with different target groups in Aboriginal communities. It was clearly underlined that participants felt that these training dollars should come from Health Canada, but be outside the \$1.2M.

Some training areas mentioned during day one were training of community-based HIV/AIDS staff in sexuality, local health workers on issues of healing, peer youth leadership on HIV/AIDS, training for parents on talking to children/youth on sexuality and helping front-line staff with health issues.

In addition, individuals highlighted a clear need for increasing vertical and horizontal links with other stakeholders in HIV/AIDS, including aboriginal and non-aboriginal, efforts and initiatives.

### *Day 2*

Day two of the round table discussion process in Quebec City covered the remaining five topics of the Round Table Discussion process.

Participants offered many important insights into their respective efforts and the difficulties that they encounter in Aboriginal HIV/AIDS issues and concerns.

While many important critiques and observations of work in the Aboriginal HIV/AIDS field were offered and general suggestions, as to the administrative and process orientated matters, were brought forward, two important topics were highlighted during day two by participants.

- B. A need for a holistic community-based approach to address HIV, possibly through broad issues like sexuality.
- C. A need for a project review process that is equal, representative and inclusive.

Because of the tight time-frame, participants did not have the time to articulate the basic tenets and principles of a holistic community-based approach in the HIV/AIDS health field, but several individuals

discussed new approaches to discussing HIV prevention under the topic of “healthy sexuality” with children, youth, incarcerated Aboriginal individuals and parents.

Secondly, there was good discussion around the process of new project proposals for the upcoming year - 2000 - and a review process that respects the local and regional levels and their important work to date.

It was highlighted in a couple of comments, that Health Canada is an partner in the HIV/AIDS prevention work to date and this was explicitly acknowledged was Quebec City Round Table Discussion participants.

### ***Conclusion***

The Quebec City round table discussion on urban, rural and non-reserve administrative guidelines for funding (\$1.2M) was an informative, enlightening and well-structured process with participants providing open and honest opinions on administrative guidelines for funding.

A couple of important propositions that were brought forward during the two day discussion by participants were:

- The need for evaluation training for community-based Aboriginal organizations that may undertake the prevention work when administrative guidelines are in place.  
  
This should be provided by Health Canada and be paid by Health Canada outside of the \$1.2M.
- In addition, all projects should be evaluated from the beginning to the end.



# **National Round Table Discussion**

Report of the Vancouver Round Table Discussion  
Coast Plaza, February 26 - 27, 1999  
Vancouver, British Columbia

Discussion on Urban, Rural & Non-reserve Administrative Guidelines for Funding  
February/March 1999

## ***Introduction***

The National Aboriginal Reference Group on HIV/AIDS (Representatives: Alex Archie & Duane Etienne) was in Vancouver on February 26 - 27, 1999 to oversee the national round table discussion process with the express purpose of obtaining feedback on proposed administrative guidelines for funding urban, rural and non-reserve HIV/AIDS initiatives in the Aboriginal population across Canada.

The Vancouver candid review was the third of five discussions with the purpose of seeking input on HIV/AIDS issues in the Aboriginal population from the local, regional and national levels.

Eighteen (18) Aboriginal participants, five (5) federal health individuals, one (1) Medical Services Branch representative and three (3) support staff used the small focus group process for two days to examine concerns and issues on Aboriginal HIV/AIDS. Each group then reported to the larger group at the end of the two day review.

## ***Objectives of the National Round Table Discussion***

The objectives of the National Round Table Discussion are:

1. To provide an opportunity for round table participants to share their insight regarding HIV/AIDS and Aboriginal Peoples in Canada.
2. To provide an opportunity for round table participants to offer input to the design & development of funding guidelines for \$1.2 Million in contribution funding for urban, rural & non-reserve Aboriginal HIV/AIDS projects across Canada.

## ***General overview of some topics discussed***

The Vancouver small groups examined the six topics and twenty four questions and highlighted some different opinions, as compared to Edmonton and Quebec City round tables.

But in many aspects, the Aboriginal HIV/AIDS health worker feedback resembled that of the Prairies and Eastern Canada.

In defining and assessing need that addresses local and regional HIV/AIDS issues, British Columbia participants clearly outlined at the beginning that it was important to be as inclusive as possible and that partners/partnerships were a critical success factor in Aboriginal HIV prevention and education work.

The Canadian Strategy on HIV/AIDS three main policy objectives of sustainability & integration, increased focus on those most at risk, and increased public accountability brought forward the real need for, as B.C. participants stated, enhanced linkages, increased partnerships and increased peer review of work done in the Canadian Aboriginal HIV/AIDS health field.

The Aboriginal Person living with HIV/AIDS (APHA) and his/her important contribution to the HIV/AIDS health work was discussed and two very important elements were brought forward for the consideration of other B.C. participants and to the attention of the National Round Table process.

1. A suggestion of linking APHAs and Elders together in a national retreat; and,
2. A need to broaden the base of APHA involvement and being careful not to burnout APHAs in the Aboriginal HIV/AIDS health work at the local, regional and national levels.

In discussing the review of project proposals, a number of Inuit participants at the Vancouver Round Table highlighted that the Inuit had some very specific concerns regarding Inuit involvement in the Aboriginal HIV/AIDS health work. (*There will be an Inuit specific consultation on March 19 - 21, 1999 in Iqaluit*).

The Inuit participants clearly stated the need for:

1. Underlining the importance and respecting the Inuktuutit language and dialects;
2. Using existing means of effective communication in the North, such as the radio; and,
3. Building on existing processes already in place in the north when it came to Aboriginal HIV/AIDS health initiatives.

The review process, as outlined by B.C. participants, should be carefully framed to ensure that the review structure is balanced, that the “veterans” of Aboriginal HIV/AIDS work in their respective regions are included, creating a process/structure for outside individuals who can participate and give “expert” advice on advancing HIV education and prevention work, and most importantly, being sure to involve APHAs.

The size of the review structure(s) needs to be limited in order to be efficient.

It was suggested that in ‘demonstrating project need’, perhaps including “evidence of prevalence” would allow for other health issues such as the sexually transmitted disease (STD) rates, alcohol and addiction statistics to be included, in demonstrating a need for the project.

In the topic of project management, it became clear that there is a need for flexibility on the application forms and the actual process.

The evaluation topic (public accountability CSHA principle) highlighted, once again, the extreme uneasiness with this issue and highlights an emerging need to begin the development of two or three models of evaluation processes/structures, where community-based groups can participate in the design and development of the model(s) that they can implement and use effectively when and where necessary.

Here, the British Columbia participants clearly outlined some of the reasons for the uneasiness in with “evaluating” in the following format:

**Challenges**

Aboriginal communities feel threatened by evaluation  
“Policing”  
never been integrated into projects - always external  
what funder wants

**Strengths**

community affected should be involved  
“trust” by involving evaluation at beginning of project  
can gain from lessons  
view results as constructive

The participants brought forward, however, that evaluation should be seen as vehicle for change & improvement for effective Aboriginal HIV/AIDS prevention and education.

***Conclusion***

The Vancouver Round Table process was an important third step in obtaining feedback on the development of administrative guidelines for \$1.2M in urban, rural and non-reserve Aboriginal HIV/AIDS initiatives.

The round table process allow provided a collegial environment for input by all participants. The Vancouver participants, as well as the Edmonton & Quebec City, expressed their impatience to see the final report once the Round Table process is completed on March 21, 1999 in Iqaluit, Northwest Territories.



# **National Round Table Discussion**

Report of the Winnipeg Round Table Discussion  
Crown Plaza, March 12 - 13, 1999  
Winnipeg, Manitoba

Discussion on Urban, Rural & Non-reserve Administrative Guidelines for Funding  
February/March 1999

## ***Introduction***

The National Round Table Discussions on HIV/AIDS completed the First Nation, Métis, Urban Aboriginal and Aboriginal data collection phase in Winnipeg, Manitoba.

The express purpose of this Winnipeg candid review was to obtain feedback on proposed administrative guidelines for funding urban, rural and non-reserve HIV/AIDS initiatives in the Aboriginal population across Canada from the local, regional and national levels.

Eighteen (27) Aboriginal participants, five (4) federal health individuals, one (1) Medical Services Branch representative and three (3) support staff used the small focus group process for two days to examine concerns and issues on Aboriginal HIV/AIDS. Each group, then reported to the larger group at the end of the Day 2 for general review and additional comments.

During the reporting of small group work (Day 2), it was brought to the attention of the larger group the importance of education, as early as the childhood stage in life.

One group presented the image of a mother & child and highlighted the fact that trust/values were of vital importance and that '*working together*' in HIV/AIDS prevention efforts should be the focus of community health promotion.

## ***Objectives of the National Round Table Discussion***

The objectives of the National Round Table Discussion were:

1. To provide an opportunity for round table participants to share their insight regarding HIV/AIDS and Aboriginal Peoples in Canada.
2. To provide an opportunity for round table participants to offer input to the design & development of funding guidelines for \$1.2 Million in contribution funding for urban, rural & non-reserve Aboriginal HIV/AIDS projects across Canada.

## ***Defining Need and Assessing Need***

The Winnipeg feedback on defining and assessing need outlined general education and prevention efforts that need to be undertaken at an individual, family, community or nation level.

As outlined in the graph at the end of this report entitled 'Targeting HIV Education', HIV and AIDS education in Aboriginal communities is a multi-layered and a multi-faceted effort that requires different approaches for different age groups, different roles/responsibilities of the genders and the many different environments that touch the daily lives of community members.

Here, the HIV/AIDS front line work needs to adapt the message '*content*' but also the message '*container*' in order that the message be understood and lead toward behavior change in condom use, harm reduction techniques, parent & child openness and willingness to discuss issues of sexuality and health promotion/protection work.

An important suggestion by the Winnipeg Round Table participants (echoing a suggestion brought forward in Edmonton) was creating a forum for Canadian APHAs to get together at a National Retreat with Elders for a retreat on healing and sharing.

### ***Long-term versus Short Term Project Funding***

The proposed period of long-term funding of 18 - 36 months and the short-term period of 3 - 18 months were generally accepted as reasonable definitions by the Winnipeg participants.

### ***Reviewing Project Proposals***

The Winnipeg candid review participants highlighted some important concerns (not all listed here) in the process of project/proposal review. They underscored the:

- need for an appeal process;
- recommendation of a regional reviews;
- need for a clear terms of reference for review process, ensuring a proper representation of First Nation, Métis, Urban Aboriginal and Aboriginal; and
- the need for the review process to be 1 to 2 month maximum.

### ***Project Management***

The project management aspect of the CSHA proposal/project dollars brought forward some important steps to ensure the sustainability and integration of local, regional and national projects.

Here, participants underlined the importance of funded projects to:

- link and network in a pro-active manner with existing HIV/AIDS services;
- include a community profile in application to demonstrate where project will link;
- provide to community sound financial management and reporting practices; and,
- to acknowledge in funding amount the costs associated with project evaluation and accountants.

Candid Review participants agreed that community development is key and that project proposals should underline how health promotion and community development will be a part of a project's implementation process. In addition, it was mentioned, education efforts in non- HIV specific initiatives should be supported that can help prevent HIV, for example, a youth sexuality project.

## ***Evaluation***

Presented in the table below are some of the verbatim comments of the group that concentrated on the need for developing effective project evaluation models, with the design and development stage being assisted and/or driven by community groups.

- evaluation is essential to measurable outcomes of project/program.
- Aboriginal people and organizations need to consider cultural aspects and perspectives of evaluation.
- opportunity for it to be Aboriginal driven - accountability included.
- evaluation on projects, community should be key on deciding success and not the government.
- accountability to the people the project services and the community (groups need to remain accountable to the community).
- something standardized could help evaluate something at a national level.
- there needs to be capacity building process included for Aboriginal communities, in order to own the process of national evaluation.
- evaluation must work to improve the delivery of benefit to the community, by improving the work of those involved in the project- continuously - during the life of the project as well as reporting at the end.

## ***Regional/National Allocation***

The Winnipeg participants indicated the allocation of funds to existing Health Canada six regions is problematic as the HIV/AIDS problem is big and the amount of money (\$1.2M) is too small.

They felt that there needed to be a priority setting exercise on how the money should be spent/allocated in order to enhance and create the leverage for Aboriginal groups to effectively target HIV/AIDS project work across Canada.

In addition, Aboriginal groups need to access other areas of program funding (ACAP, PCAP, CTSP) in order to maximize opportunity and the results of their HIV education and prevention work.

In short, participants indicated a need for incremental steps to effectively decide upon allocation of the \$1.2M.

## ***Conclusion***

The Winnipeg Round Table completed the data collection among First Nations, Métis, Urban Aboriginal and Aboriginal in southern Canada. The feed back and candid review of the work book material, the draft guidelines and the Round Table process was successful in an independent data collection round table process.

The Iqaluit site, the last of the Round Tables, will specifically listen to feed back from Inuit participants, most coming from the new Territory of Nunavut.



# **National Round Table Discussion**

Report of the Iqaluit Round Table Discussion  
Frobisher Inn, March 21 - 22, 1999  
Iqaluit, Northwest Territories (Nunavut)

Discussion on Urban, Rural & Non-reserve Administrative Guidelines for Funding  
February/March 1999

## ***Introduction***

The National Round Table Discussions on urban, rural & non-reserve administrative guidelines for funding was completed on March 21 - 22, 1999 in Iqaluit, Northwest Territories (As of April 1, the Territory of Nunavut).

Seventeen (17) Aboriginal participants, two (2) support staff, two (2) community people, four (4) Health Canada representatives and one (1) Government of Northwest Territories representative attended the candid review. Participants discussed the HIV/AIDS health prevention work in the north, with the majority population being Inuit.

The northern HIV/AIDS health prevention and education work distinguishes itself from southern health work, due to the majority culture, the distance factor, the means of effective communication and different dialects, and the level of community development.

Additional local community work needs to be accomplished in developing new tools applicable to the Inuit reality - building on other HIV/AIDS prevention work. Links need to be developed to other HIV/AIDS resources and health resources in order to effectively undertake Inuit HIV/AIDS prevention and education efforts.

The participants of the candid review examined, as all other round tables, the following six categories, and some of the results are summarized as follows.

### ***A. Defining and Assessing Need***

The Iqaluit participants felt that 'everyone is at risk' and therefore there was some basic work to be undertaken in identifying a communications strategy for HIV/AIDS prevention/education. In addition, this required support with an expansion on 'virtual communications and education'.

Participants highlighted a real need for Internet access to information, , local workshops & consultations, regional symposiums with skills-building components and the need to link 'messages' with existing programs.

Actual sites designated as important for taking the prevention 'message' to, were school campaigns, public transportation, and the public service announcement on radio stations. Condom distribution was felt to be effective and important.

In addition, it was felt that there was a need for training and development for front-line workers to support and develop their capacities for effective community health work.

### ***B. Long term versus Short Term Project Funding***

Participants expressed that organizations whose primary mandate is HIV/AIDS (or whose mandate includes HIV/AIDS) should be eligible for the non-reserve funding. It was expressed that these projects/proposals could be integrated into other community services presently operating in Nunavut communities.

It was highlighted that event funding (special occasions) should be added as eligible projects/proposals and that it was important to add 'substance use' to health prevention & education work.

It was clearly stated that Nunavut was to be recognized as a region, thus working from a national perspective of seven regions (the six other being the Health Canada regions).

### ***C. Reviewing Project Proposals***

The suggestion was to localize decision-making for project funding i.e. Inuit review committee. It was felt the process is about respect - respects for communities and populations. Here it appears that the Inuit prefer to prioritize local/regional projects before sending to a national Inuit review committee. The deadline for National review committee would be 4 weeks and then the deadlines for funding approval would be 2 weeks for government.

Due to the number of dialects of Inuktuutit that creates extra time/work in the communications field, it was suggested that:

- there is a need more lead time to submit a proposal and go through a community process;
- there is a need to provide for alternative forms of proposals, i.e., video proposals; and
- funding sources have to take responsibility for communications, i.e. translation \$, time.

### ***D. Project Management***

Project proposals, in Iqaluit participants' views, were to include everything (all plans) in the proposal and that these were to be community-driven.

Those requesting funding should have demonstrated proof that the community is involved at all levels, including proposal development & proposal submission, by way of letters of approval and support.

Proposals could be referenced checked from the community in order to ensure that "community driven be at the "root" of all proposals" (community driven, determined and owned).

Funding reviewers must recognize the willingness to do the work by communities and that mentoring by other community groups could be an important aspect in successful project completion.

### ***E. Evaluation***

Evaluation of projects was felt to be an important management tool that proposals should include as a part of the project plan. There is a need to share information, justifying the project needs as it helps to organize the project better. Also, it is an information tool for the funder on the project progress.

There was some discussion around the guidelines/national standard. Should funding come with guidelines and a template or should there be a national standard (participants questioned both terms - guidelines or standards)?

It was expressed by participants that guidelines are dangerous and that, in their view, standards are flexible.

### ***F. National Allocations***

Candid review participants from Iqaluit felt that a national allocation formula that is fair would be acceptable. However, it was important for the national committee to:

- understand issues in the north, 'it is costly' was an example;
- maintained as one national allocation that all regions can apply [to];
- understand concerns that local people may not have a voice regarding the decisions made on this matter; and
- define regional boundaries (Nunavut + 6 Health Canada regions).

Participants also brought forward the idea of having a 1-800# to be informed about the non-reserve HIV/AIDS funds available, the processes of follow-up & distribution of the funding.

### ***Conclusion***

The Iqaluit Round Table completed the national series of round tables on urban, rural and non-reserve administrative guidelines for funding, February/March 1999.

The Canadian Aboriginal AIDS Network has proposed to follow-up this series of round tables with two additional elements before returning the completed work to the National Aboriginal Reference Group on HIV/AIDS (NARGHA) on April 23, 1999.

During the week of April 12, a round table will occur with a group of Aboriginal persons living with HIV/AIDS (APHAs) in order to have their important input and their national perspectives.

During the week of April 19, 1999, a smaller group of the National Round Table participants will be attend a two-day focus group to collectively analyze the results, the recommendations and have the opportunity for final recommendations before the final results are analyzed by the National Reference Group on HIV/AIDS on April 23, 1999.

For further information, please e-mail or contact the Canadian Aboriginal AIDS Network, Ms. Sandra Green, Executive Director @ (613) 567 - 1817.



# **"Going Forward Together"**

## **A Survey/Council Circle Project to Identify Administrative Guidelines for Health Canada's Aboriginal HIV/AIDS Funding**

### **Evaluation Report**

June, 1999

Prepared By:



**The Hunter Courchene  
Consulting Group Inc.**



## **1.0 Introduction**

On October 4, 1998, the Canadian Aboriginal AIDS Network (CAAN) entered into a contribution agreement with the Prevention and Community Action Programs, HIV/AIDS Policy, Coordination and Programs Division of Health Canada. The purpose of the funding was “to provide input to the development of administrative guidelines for the management of specific HIV/AIDS funding for urban, rural and non-reserve Aboriginal HIV/AIDS initiatives” (CAAN Proposal September 10, 1998).

## **2.0 Purpose of this Evaluation**

The purpose of the evaluation is to determine the effectiveness with which the program has met its stated goal. The evaluation will determine the efficiency with which the program has been administered and will explore other evaluation issues identified by the Evaluation Working Group.

## **3.0 Evaluation Issues**

The evaluation of this project will focus on how effective the Round Table process has been in the development of administrative guidelines for the management of specific HIV/AIDS initiatives for urban, rural and non-reserve Aboriginal people living with or affected by HIV/AIDS.

The four (4) key components identified as relevant to the evaluation goals include the following:

- The Program Rationale;
- The Impacts and Effects of the Program;
- The Achievement of Stated Objectives; and
- Possible Alternatives.

### **3.1 Program Rationale**

*Program Rationale* issues focus on the continued relevance of the program in light of the present reality of HIV/AIDS for the urban, off-reserve Aboriginal population of Canada. The following questions will be addressed: Is the program still needed regardless of whether the program goals have been attained or not?; Are the mandate and objectives of the program adequately stated?

A good understanding of the program rationale will be developed by comparing the current program activities with the mandated objectives. By thoroughly examining the links between the program’s results, objectives and intended impacts, a clear picture will emerge regarding the program’s effectiveness and continued relevance.

### **3.2 Impacts and Effects**

An examination of the program’s *Impacts and Effects* implies an attempt to determine what has taken place as a result of the program. Of specific concern will be both the intended and unintended results attributed to the program. Specific attention will be concentrated on issues pertaining to the partnership aspect of the program.

### 3.3 Objective Achievement

*Objective Achievement* issues will determine the manner and the extent to which the program has achieved its stated objectives. In determining whether the program has attained its objectives, the impacts and effects will be investigated.

### 3.4 Alternatives

The final portion of the evaluation will involve the identification of *Alternatives*. The objectives may have been met with no negative impacts or effects, however, there may be more effective methods of achieving the program's stated goals and objectives. The identification of alternatives will serve to provide options available to stakeholders in regards to enhancing the delivery of the program.

## **4.0 The Program Objectives**

In the implementation of the project specific objectives were changed by the Aboriginal stakeholders invited to participate and oversee the implementation of the project. Although specific activities were changed, the spirit and intent of the project is consistent with the overall objectives originally described in the original agreement.

### 4.1 Contribution Agreement/Funding Proposal

The stated objectives for the program identified within the contribution agreement between Health Canada and CAAN include those identified within CAAN's original funding proposal.

The documents state the objectives of the program was;

- to provide a forum for Aboriginal people across Canada to express their needs and concerns regarding Aboriginal HIV/AIDS funding within the Canadian Strategy on HIV/AIDS (Health Canada);
- to gather information towards the design and development of administrative guidelines for urban, rural and non-reserve Aboriginal HIV/AIDS project funding.
- to work with Health Canada to develop a National Reference Group to act as a review board for all processes associated with the development of administrative guidelines;
- to provide administrative support to the National Reference Group and Cook Consulting;
- to coordinate the distribution and collection of the survey developed by Cook Consulting; and
- to coordinate five Council Circles across Canada.

### 5.2 Health Canada and Clarence Cook Consulting & Associates

The stated goals that guided the work between Health Canada and Clarence Cook Consulting & Associates were:

- to create the framework for a national Aboriginal public consultation regarding urban and other off-reserve funding for Aboriginal HIV/AIDS initiatives;
- to implement the national Aboriginal public consultation regarding urban and other off-reserve funding for Aboriginal HIV/AIDS initiatives including a survey and five council circles;
- to present the options generated by the public consultation, obtain focussed feedback and identify three national and five local and regional priorities; and
- to review the national consultation process and ensure that the issues identified by urban and other off-reserve Aboriginal stakeholders have provided direct input to the administrative guidelines that this process is intended to inform.

On November 16, 1998 the then National Aboriginal Reference Working Group on HIV/AIDS (NARGHA) rejected the national survey and the council circle processes developed by Health Canada and Cook Consulting. The council circle process was eventually replaced by the five National Round Tables that were intended to capture the information required for the development of the administrative guidelines.

Although the original processes designed to meet the project objectives were rejected by NARGHA and subsequently changed, the objective outlined will be used in measuring the success of the project.

## **5.0 The Evaluation Process**

### **5.1 Document Review**

A comprehensive review of documentation relevant to the program has been conducted to become familiar with every aspect of the process thus far. The following documents were reviewed:

- The Contribution Agreement;
- The Funding Proposal;
- The National Round Table Discussion Kit;
- The National Round Table Reports;
- Round Table Guiding Questions Response Matrix;
- The CAAN Policies and Procedures Manual and Constitution;
- National Aboriginal Reference Group on HIV/AIDS (NARGHA) Record of Decisions;
- NARGHA Terms of Reference;
- CAAN Board Minutes (where appropriate);
- Financial Reports and Records; and
- A Chronology of Events - Prepared by Daniel Paul Bork (Cook Consulting).

### **5.2 Review of Internal Mechanisms**

An overview of the tools available to the CAAN staff and their use in the administration of the program.

### 5.3 Survey Questionnaires

An examination of the perceptions and feedback from stakeholders involved in the program activities. The feedback examined will include those questionnaires completed at each Round Table and participant questionnaires and interviews conducted by Hunter-Courchene.

### 5.4 Data Consolidation, Analysis and Findings

A comprehensive examination and analysis of the information gathered with conclusions and recommendations.

## **6.0 Document Review Findings**

### 6.1 The Contribution Agreement

The Contribution Agreement sets out the goals and objectives of the program, the Terms and Conditions for the administration of the program and identifies the budget allocated to the program.

### 6.2 The National Round Table Discussion Kit

Each Round Table participant received a copy of The National Round Table Discussion Kit. The Kit included;

- an acknowledgement and welcome;
- an introduction to the NARGHA members and to NARGHA's role in the process;
- the Terms of Reference for the Round Tables;
- the Agenda;
- the Guiding Questions;
- Health Canada's Population Health explanation and terms;
- a draft outline for the funding guidelines;
- two presentation decks on the Canadian Strategy on HIV/AIDS;
- the Prevention and Community Action Programs (PCAP) Organizational Chart;
- a Round Table evaluation form; and
- Participant expense claim form with guidelines.

The Kit presented to the Round Table participants provides more than enough information to make informed decisions on administrative guidelines. The questions provided are designed to inform the participant by providing and brief background on the issue and asking discussion questions focussed on the development of administrative guidelines. The questions allowed for participants to share their knowledge on HIV/AIDS and Aboriginal people while gathering information relevant to guideline development.

### 6.3 National Roundtable Reports

The Round Table Reports were prepared by Clarence Cook Consulting & Associates for each of the five National Round Table Discussions.

The Reports were posted on the National Round Table Discussion web-site hosted by CAAN. The Reports summarize the Round Table discussion process and provided an overview of the discussions that took place on each of the subject areas. The Reports, do not include the specific responses to the guiding questions posed to the Round Table participants. The exclusion of the responses was deliberate to prevent participants prejudicing subsequent Round Tables.

The Reports are very informative and effectively describe the discussions that took place at each Round Table. At the time of conducting this evaluation the Reports were not available in French. Resources remain available to the project team to have the reports translated, distributed to the workshop participants and be posted on the CAAN web-site.

### Guiding Questions Response Matrix

The responses to the workshop questions for Edmonton, Quebec and Vancouver were provided to Hunter-Courchene. The type of information gathered should be sufficient in the development administrative guidelines relevant to the target population.

### National Aboriginal Reference Group on HIV/AIDS (NARGHA) Record of Decisions

A clear record of the decisions of the NARGHA was maintained throughout the project. The report provides the agenda item, the discussion, issues: action taken, follow-up, deadline and responsibility. The most important decision made by the NARGHA was the creation of the NARGHA Open Nomination Selection Committee, and the Round Table Discussion process. The NARGHA played a key role in overseeing the administration of the project. Although the record of decisions may be sufficient for the NARGHA participants, outside observers would have difficulty understanding the progress of work undertaken by the group.

The NARGHA may consider the development of a system to track specific tasks and attaching any relevant documentation to their reports. To avoid creating cumbersome reports we would suggest a brief background or chronology of the subject being discussed be included in the reports from NARGHA.

### 6.5 NARGHA Terms of Reference

The NARGHA Terms of Reference sets out the mandate, a description of the initial tasks and how decisions will be made by the group. The Mandate is to focus the Aboriginal component of the Canadian Strategy on HIV/AIDS within Health Canada.

The initial tasks set out by the group include the development of funding guidelines for urban and other non-reserve based projects and to further develop and define the tasks of the NARGHA.

The mandate and tasks set out by the group are consistent with the mandate of the project. The creation of the NARGHA itself is also consistent with the goals and objectives of the funding. Of concern with the development of NARGHA is the role of the CAAN in controlling the administration of the project resources.

## 6.6 CAAN Board Minutes

Upon review of the CAAN Board Minutes, it is undetermined if decision through motion was made specific to the “Going Forward Together”. The CAAN Board was provided with project updates on the activities taking place in the project and from time to time asked to ratify or approve the decisions regarding the project. Updates regarding the funding and the administration of the project were either done by CAAN’s NARGHA representative or by program administrators from CAAN.

It should be noted that the responsibility, and therefore any liability, for the funding resides with the CAAN Board of Directors. The funding agreement was signed between the Minister’s representative and the CAAN Board’s representative. The individuals on the Board must establish a mechanism to be informed of the decisions being made regarding any CAAN activities. The Board must be able to assure that the resources are being spent appropriately and are consistent with the organizations goals.

The CAAN Board should consider the adoption of a strategy to stay informed of all issues relevant to projects being administered through CAAN. We would suggest that a three part strategy be adopted. CAAN staff must:

- identify the decisions required by the Board;
- identify the issues surrounding the decision required; and
- present decision options to be considered by the CAAN Board.

Included within the options should be the status quo. The possible outcomes should the status-quo be chosen or if no decision can be made should be identified. The adoption of this policy would allow for the Board to remain informed of their responsibilities and allow for better decision making.

## 6.7 Financial Reports and Records

The financial reports and records provided to Hunter-Courchene provides unaudited costing of the project to date. According to the records provided, of the \$350, 000 dollars allocated for the project for fiscal year 1998/99, \$322,583.35 have been expended. This represents 92% of the total allocation for the project and is within respectable limits. According to the information maintained by the project officer, expenditure were consistent with the project goals and objectives.

## CAAN Policy and Procedures Manual and Constitution

The Policy and Procedures manual of CAAN is comprehensive in that it covers almost every circumstance that could occur in a national organization. It is our opinion, however, that some clarification is required with regards to project staff who are hired for a fixed term. The CAAN Board might consider the adoption of a policy that would clarify when and how project staff are considered within the policy and procedures manual.

## **7.0 Internal Mechanisms Review**

### **7.1 Communications Capacity**

The following communication mediums are presently being utilized by CAAN to administer the project:

Telephone;  
Fax Machine;  
Mail;  
Electronic E-Mail;  
CAAN Newsletter; and,  
CAAN Web-Site.

In examining the communications records maintained by the Project Coordinator, all methods of communication have been utilized. The most common methods employed are the telephone, the fax machine and electronic e-mail. The CAAN Newsletter has also been used to inform readers about the community consultations as well as the activities of NARGHA.

Feedback received from stakeholders involved in the consultation process were mostly pleased with the communications strategy employed by the CAAN office. The negative feedback received was with regards to the distribution of the Round Table kits in a manner that would have given the participant more time to review the materials.

Of concern to the evaluation team was the communications between the NARGHA and the CAAN Board of Directors. Although the NARGHA was set up to advise on the consultation process the responsibility and the liability for the delivery of the project remains with the CAAN Board. It is vital that should funding continue to flow through CAAN that a communications strategy or agreement be reached between the NARGHA and CAAN Board.

All the communications activities undertaken by CAAN are directly linked to the mandate and the objectives of the project.

## **8.0 The Survey Questionnaires**

Overall, participants were satisfied with the Round Table process and felt that the project has met its over all goal of sharing and networking and getting information that will aid in the development of administrative guidelines.

One issue raised by participants was regarding the timely-ness of the information provided. Most participants received the information upon registering for the Round Table discussions. Those identifying the issue stated that they did not have time to review the materials before the discussion took place. Methods of assuring the timely receipt of information should be explored. The quality of the information provided is compromised if individuals do not have the opportunity to discuss the issues with co-workers and friends.

Another concern expressed by the Round Table participants was with regards to the time frames associated with the Round Table. Many participants felt that two days was too short to discuss all the issues that were presented within the Round Table Kit. Many participants felt that should another such process take place, that the agenda be paired down to allow for a thorough discussion.

Participants opinions varied with regards to the talking circle. While many felt that it was a great opportunity to share issues and concerns. Others, however found that the circle was too long and sometimes got off the subject of HIV/AIDS.

Overall the participants were very pleased with the facilitators and the small group process. Many expressed how effective the small group process was as opposed to the plenary sessions.

Attached as Appendix A and B of this report are the response matrix and questionnaires for both the participant questionnaire provided within the Round Table Kit and the questionnaire developed by Hunter-Courchene. The responses to the questionnaires was not intended as a scientific process but was to get an overall sense of the participants towards the Round Table process.

We would recommend that the responses of the participant be reviewed as they provide some excellent feedback on the consultative process and how it could be utilized for possible future improvements.

## **9.0 The Program Rationale**

In examining the program, certain components remain relevant. The department has been successful in establishing the NARGHA to help guide them in future decisions regarding Aboriginal HIV/AIDS funding. Should the program continue the mandate and the objectives of the program will have to be changed to reflect the continued existence of the NARGHA, and how it would be administered and funded. The question to be addressed, is whether CAAN should continue to administer the program or should the NARGHA be incorporated as a separate entity. It is our opinion that the NARGHA should remain an advisory body with the administrative functions delivered through CAAN. This opinion was shared by many of the participants of the Round Table process. It should be noted, however, that should CAAN remain the administrative body, the CAAN Board will have to negotiate some kind of protocol with the NARGHA and Health Canada on their respective roles and responsibilities.

## **10.0 The Impacts and Effects of the Program**

As a result of the program the following intended and unintended outcomes have taken place:

- an increased awareness of the Canadian HIV/AIDS Strategy within the Aboriginal community;
- an increased understanding of the impacts of HIV/AIDS within the Aboriginal community;
- an increased awareness of the needs of Aboriginal people specific to HIV/AIDS;
- feedback from Aboriginal people on administrative guidelines for HIV/AIDS funding for Aboriginal people;
- increased networking between individuals working with people affected by HIV/AIDS;
- the establishment of the NARGHA;
- the organization of five National Round Tables;
- increased expectations within CAAN on their role in the area of Aboriginal HIV/AIDS;
- increase the capacity within CAAN to administer projects;
- expectations for guidelines that reflect an Aboriginal perspective;
- has established a working relationship between the Aboriginal organizations involved in HIV/AIDS; and
- has established a working relationship between CAAN and Health Canada.

The impacts and effects of the program whether intended or unintended are consistent with the provision of relevant HIV/AIDS programs and services to the Aboriginal population.

## **11.0 Objective Achievement**

The two main objectives of the program in the opinion of the evaluator have been met. The program has received feedback from Aboriginal people on the administrative guidelines, and has established an Aboriginal advisory body to assist Health Canada in the area of Aboriginal HIV/AIDS.

## **12.0 Alternatives**

The process undertaken to achieve the program goals was not the one originally envisioned by Health Canada and CAAN. Although there might be alternatives to the delivery of the program, the project followed the advice and direction provided to them from Aboriginal people through the national Aboriginal organizations. In order to continue to provide relevant services to the Aboriginal population, federal departments must continue to involve and invest in the Aboriginal infrastructure. A commitment to continue to involve Aboriginal people will only increase their capacity to provide effective feedback and deliver services that meet the needs of Aboriginal people.

## **13.0 Conclusion**

The evaluation team has concluded that the activities of the project are consistent with the stated goals and objectives originally intended by Health Canada and CAAN. We are, however, unable to make any conclusions with regards to the final administrative guidelines. At the time of writing this report, the administrative guidelines were in development. We are confident that the National Round Table process has provided the necessary information to develop administrative guidelines for the management of specific HIV/AIDS funding for urban, rural and non-reserve Aboriginal HIV/AIDS initiatives. We are confident that the working relationship developed between Health Canada, CAAN and NARGHA through this project will continue and that future activities will meet the requirements and aspirations of Aboriginal people at the community level.



# **HIV/AIDS and Aboriginal People in Canada:**

## **A Discussion Paper on the Capacity of the Community to Respond**

Prepared by Albert McLeod

for the

**Canadian Aboriginal AIDS Network Inc.**

#409-396 Cooper Street

Ottawa, Ontario

K2P 2H7

March 1999

Funding for this paper was provided by Health Canada.



## ACRONYMS GLOSSARY

Aboriginal Person Living with HIV/AIDS	APHAs
AIDS Service Organizations	ASO
Aboriginal AIDS Service Organization	AASO
Canadian Aboriginal AIDS Network	CAAN
Canadian AIDS Society	CAS
Canadian Strategy on HIV/AIDS	CSHA
Injection Drug User	IDU
Laboratory Centre for Disease Control (Health Canada)	LCDC
Manitoba Aboriginal AIDS Task Force	MAATF
Medical Services Branch (Health Canada)	MSB

Prepared under contract by Albert McLeod for the Canadian Aboriginal AIDS Network  
Through the Canadian Strategy on HIV/AIDS, March 1999

The views expressed herein are solely those of the author and do not  
necessarily reflect the official policy of the Minister of Health of Canada



## Introduction

The Canadian Strategy on HIV/AIDS (CSHA) released on June 1998 identifies Aboriginal people as one of its priorities because the number of AIDS cases among Aboriginal Canadians has risen steadily since 1984, particularly among women and those under 30. There has been no decrease in the number of HIV infections in Canada and Aboriginal people are disproportionately over-represented among those being newly diagnosed. In addition, Aboriginal people continue to be over-represented in groups at *high* risk such as injection drug users, gay youth, and socially and economically vulnerable women.

Two decades into the epidemic, Aboriginal leaders, community AIDS activists, and the federal and provincial governments are just beginning to address the threat that urban HIV epidemics pose to Aboriginal people. Epidemiologists are concerned that the high degree of movement of Aboriginal people between inner cities and rural areas may bring the risk of HIV to even the most remote Aboriginal community. We are beginning to understand the important role that marginalization and poverty play in increasing the spread of HIV among vulnerable populations. For Aboriginal people apartheid, racism, cultural genocide and attempted assimilation are issues factors that continue to hamper have to . These issues have created cultural, social and economic inequality and poverty for Aboriginal people in Canada. While Aboriginal people are aware of this, many non-Aboriginal people in the AIDS work movement have no understanding about it at all.

The strategy document states that, *for Aboriginal people the key to prevention and treatment is knowledge*. Many vulnerable Aboriginal people have the knowledge but because of feelings of hopelessness they may not be able to prevent themselves from becoming infected or be able to seek proper treatment when they are HIV positive. There is now a growing force within the Aboriginal AIDS movement that says, in order to assist in empowering those most vulnerable, we need to create safe, stable, and culturally appropriate environments in which to deliver our services. The objectives of this paper are to:

- to provide an overview of how HIV/AIDS has affected Aboriginal people
- to explore the capacity of Aboriginal people and communities to respond
- to make recommendations to CAAN and Health Canada for future action

The sources for this paper includes government data, community-based research documents, anecdotal information and the lived experience of front-line Aboriginal workers in the HIV/AIDS field.



## SECTION ONE

### A History of Epidemic Viral Migrations

Aboriginal people in Canada have a unique history with non-indigenous diseases that began after European contact in 1492. First introduced in South America, they were spread broadly along trade routes by European and Aboriginal traders. Large and small populations experienced high fatality rates because they had no natural immunity to the bacteria and viruses that caused these diseases. Today academics and scientists understand a great deal about these organisms, and how the diseases they cause can be prevented and treated. Through the work of researchers and universities who study this period, we are also beginning to understand more about the impacts they have had on indigenous populations. This knowledge is important, not only to academics, but also to Aboriginal people who are in the process of responding to new infectious diseases like HIV.

It is only recently that some Aboriginal researchers and communities have had the opportunity to explore this era for themselves. The Sto':lo Nation of British Columbia recently published, First Contact: Smallpox, Sto':lo Curriculum Consortium, 1996, an essay that documents the way in which "smallpox" affected their people. It wasn't until 1782, almost three hundred years after Columbus reached South America, that this nation was first exposed to the smallpox virus. The essay reports the virus was spread to this region through Aboriginal trade networks that had been in existence for thousands of years. In this instance, smallpox was first introduced by Europeans in Mexico, and then passed on by Aboriginal traders from community to community until it arrived in the Fraser Valley. The resulting epidemic among the Sto':lo happened despite the fact that Euroamericans were never closer than 3,600 kilometers from the Fraser Valley. This example of early "epidemic viral migrations" gives us a unique perspective. It shows that diseases were not only spread by "face-to-face" or "active" contact with Europeans, they were also spread through passive contact. <sup>1</sup>

Smallpox is caused by a parasitic virus that is spread by "droplet infection". A minimum of one third, or 33% of all people exposed to smallpox, die from the disease. It is also considered a "crowd disease" because it only spreads between humans, and requires a large densely populated community in order for it to survive. Like other crowd diseases, smallpox spreads from urban centres outwards into non-immune populations until it eventually reaches areas where the population is too thin to allow it to spread further. Most of the lethal crowd diseases originated from domestic animals. Because large scale animal domestication never occurred in North and South America, this region escaped such viruses until they were introduced by Europeans. <sup>2</sup>

Once introduced smallpox spread quickly among the Sto':lo people and scholars estimate that 62% of the population died. The surviving population was in mourning, depressed and fearful about what had occurred. Euroamericans were unaware of the epidemic until a decade later and the Sto':lo did not immediately associate the disease with its Euroamerican source. The loss of so many people devastated the population and brought starvation. Because many of the elders were killed by the virus it is believed the next greatest loss was the community's cultural knowledge. Despite these losses, the essay concludes that Sto':lo society has survived with an amazing degree of cultural continuity that is a testimony to the strength and endurance to their cultural traditions. <sup>3</sup>

The essay also provides a perspective on "Aboriginal medicine" used to treat diseases that were indigenous and non-indigenous to North America. Sto':lo traditional healing practices involved

community members gathering around the sick person’s bed to provide spiritual support. Other medical practices included cleansing “sweats” and cold morning baths in rivers or lakes. These medical practices may have also compounded the smallpox death rate. While appropriate for many pre-contact illnesses, such techniques did not work against smallpox, simply because they were not designed to deal with a non-indigenous, introduced, parasitic crowd disease. Oral traditions also speak of traditional medicine being used to cure smallpox during later epidemics. The stories describe someone acquiring “spirit power”, which makes them strong enough to withstand the disease. 4

---

Indigenous North/South American Diseases

Non-Ventral Syphilis + Pina	Salmonella
American Leishmaniasis (Forest Yaws)	Tuberculosis
American Trypanosomiasis (Chagas)	Dysentery
Localized Rickettsial Diseases (Rocky Mountain Spotted Fever)	Viral Pneumonia
Streptococcus + Staphylococcus (Strep Throat, Rheumatic Fever, etc.)	Trachoma (chlamydial) ?

Diseases Introduced to North/South America

Smallpox	Typhus	Bubonic Plague	Malaria
Viral Influenza	Yellow Fever	Measles	Typhoid Fever
Cholera	Whooping Cough	Polio	Diphtheria
Scarlet Fever	Cold ?	Venereal Syphilis ?	Herpes Zoster ?

---

Source: Sto:lo Curriculum Consortium, 1996

Smallpox was only the first in a series of devastating European diseases that impacted Aboriginal people. Diseases like measles, tuberculosis, mumps, influenza, and gonorrhea and syphilis came in waves, eventually depopulating many communities. These losses weakened the ability of Aboriginal people to resist the colonization process that began shortly after.

## SECTION TWO

### Impacts of Colonization

In colonizing North and South America, the goal of competing European countries was to take control of as much land and natural resources as possible. Powerful European “corporations” required their business ventures in North America to return an enormous amount of wealth. Aristocratic families, immigrants, convicts, trading companies, military men, institutions of learning and religious orders were enlisted to be the front edge of the colonization process. In order for them to gain “unlimited” access to the wealth, they attempted to erase or alter the identities of Aboriginal people so they no longer had any historical connections or inherent rights to the land. In some cases, the entire Aboriginal population of a region was erased through genocide.

The Euroamericans fought wars with Aboriginal nations to force them to surrender their ancestral lands. They also began a process of “cultural genocide” which involved the devaluing and outlawing of Aboriginal traditional belief systems, hereditary and spiritual leaders, healing knowledge, ceremonies, and languages. Many of these actions were first accomplished through the use of intimidation, violence, fraud, displacement, imprisonment, terror, murder, slavery, abduction, rape, starvation, the breaking of treaties, and the destruction of sacred items, sites and traditional food sources.

Later on, these corporations developed more sophisticated approaches to colonization and continued its implementation through democratically sanctioned processes which included legislating new laws and policies designed specifically to achieve this purpose. Governments controlled by white Anglo Saxon males were then in a position to assimilate Aboriginal children into Euroamerican society by “legally” removing them from their parents and culture to be indoctrinated into Eurochristian beliefs. This was attempted by forcing Aboriginal children into residential schools. The schools were run by religious orders and existed for over a hundred years in both in Canada and the United States.

The inter-generational impacts of disease epidemics and colonization are important factors to consider when discussing Aboriginal responses to HIV. Because diseases like smallpox and influenza were previously unknown and so lethal to Aboriginal people, there was no time for their leaders to incorporate these “new entities” into their world view.

The world views of Aboriginal people evolved over thousands of years as each generation passed their knowledge on to the next one. They explored and studied the world around them, incorporating the facets of their experience and environments into this world view. For example, when we look at post-contact indigenous languages, we find new meanings for ancient words or phrases pop up to explain new entities. In the Cree language, the word “mista-atim” is used to describe a horse. It translates to mean “big dog”, which tells us that when horses were first introduced to the Cree by the Sioux, they decided that it resembled a dog. Similarly, the Sioux describe a horse as a “mystery dog”, which tells us that when the first horses from Spain were seen on the plains, their sudden appearance could not be explained.

Unfortunately, because of the epidemics, this process of analysis was greatly diminished as Aboriginal people were overwhelmed by the magnitude of the death, starvation, grief and fear around them. The following generations found themselves separated from the stable and healthy pre-contact lives of their ancestors. Those who were not killed were forced to sever important links to thousands of years of artistic, intellectual and spiritual expression to begin a struggle to survive. Aboriginal people are still

living in the “survival mode” because they continue to experience chaotic epidemics of violence, diabetes, cancer, heart disease, sexual abuse, alcoholism, sexually transmitted infections, and suicide.

One of the most important influences that has hampered the ability of Aboriginal people to recover from centuries of cultural genocide is the residential school syndrome. In relating his personal perspective at the Keesaywatissiwini (In A Caring Way): Aboriginal AIDS Conference in 1992, Tomson Highway spoke about how Catholic priests at the residential school he was in began a process of brainwashing him when he was six years old. He was taught to believe that the Aboriginal race was inferior and that God was white God. Mr. Highway also put forward the position that in order for Aboriginal people to be indoctrinated into the patriarchal Catholic religion, their Mother Earth (female centred world view) had to be killed. This metaphor clearly illustrates the degree of physical and emotional violence experienced in such institutions. It also shows how the traditional roles and status of women were destroyed as well. He believes this experience has resulted in Aboriginal men being placed into non-traditional hierarchical roles that continue to this day to perpetuate violence against women and children.

The children, who were separated from their parents for years, experienced psychological, mental and physical abuse designed to break their spirit and will to resist. Mr. Highway reports that they also experienced sexual abuse at the hands of the same priests who presented themselves as servants of their superior God. His account describes one of the most degraded forms of cultural genocide supported by governments. Mr. Highway believes this experience greatly affected his younger brother and ultimately led to his death from AIDS. One important point he makes is that he is now in a position to speak out about these experiences, not only so that other Canadians become aware of the crimes that were perpetrated against them, but also to inform the rest of the world of how Aboriginal people have been treated in Canada.

“before the healing can take place, the poison must first be exposed . . .” *Lyle Longclaws*

Source: Dry Lips Oughta Move Kapuskasing, Tomson Highway, 1989

This point is crucial to understanding how Aboriginal people respond to misfortune and chaos. Normally, “negative” forces or elements would be rationalized, recorded and integrated into the oral tradition of story telling and ceremonial practice. The intent is to counter the negative influences with positive ones so that a spiritual and harmonious balance could be maintained among all forces. Unfortunately, before the effects brought by the chaos of disease and colonization could be incorporated into the collective memory, residential schools began to attack the languages which were the vehicles used to transport this “state of recovery” to the next generation. Speaking an Aboriginal language in the residential schools was forbidden and punishable in various ways. Punishment was delivered through public humiliation, either through being strapped on the hands, slapped in the face or being forced to kneel for hours. Practices like these were meant to cause the extinction of Aboriginal languages.

What effect has this attack had on indigenous language speakers? The experience devalued the language in a very profound way for some people to the point where they rarely spoke it and chose not to teach it to their children. This may have been seen by them, consciously or sub-consciously, as a way to “protect” their children from abuse or the discrimination that came with being identified as Aboriginal. Another effect, which is not so apparent, is the silencing of Aboriginal voices. When a person who thinks and speaks in their first language does not easily understand, speak or read English they can be

intimidated and fear humiliation. If their language is unrecognized by mainstream society and has a history of being devalued, they will also not readily articulate what is in their mind and heart.

Even though a person may want desperately to express their opinions, emotions or pain, they can feel powerless to the point where they become silent. With nowhere to direct these negative feelings they are soon turned inward. Without a voice to ask for validation or express feelings of rage and compounded grief, the only remaining option is to use whatever you have left. For disenfranchised Aboriginal people living in extreme poverty, the only part of their lives they may they have any control over is their body. Eventually, a life of struggle, violence, addictions and hopelessness becomes expressed in a physical way. For some, the only choice they feel that is left for them is suicide, which can also be seen as a demonstration of political and social resistance.

Because many marginalized people are street involved and homeless they are seen often in public. The media promotes negative stereotypes of them as being poor, homeless, addicted and powerless. The result is that the general public has become desensitized to their situation to the point where these stereotypes become accepted as a norm. The reality is that their situation is abnormal and is a result of having their lives interfered with.

Non-Aboriginal people continue to have a deep-seated fear of Aboriginal people, namely because the lives and careers of their families have been built on Aboriginal land and resources. This fear is rooted in the fact that the Europeans who came to this continent were attempting to escape from poverty, oppression and religious intolerance themselves. This historic fear of being without a country or landless can be hidden so deep within societal groups that it is barely perceptible, yet its effects can be powerful and far reaching. Normally, most Aboriginal people would be close to the land living in productive healthy communities. Instead, they are refugees within their own country. While most non-Aboriginal people may see their lives as being tragic, we need to recognize the “resistance to oppression” that exists beneath the surface of this stereotype. Although their voices may be silenced, they still speak “at” us about the exploitation, oppression and indifference that has brought them to this point.

Despite the process of colonization, Aboriginal people have survived because their diverse cultural traditions have an inherent capacity to support a lifestyle that is healthy and productive. Credit must be given to the Aboriginal leaders, elders and traditional teachers who have sacrificed much to safe-guard this knowledge so it can be passed on to future generations.



## SECTION THREE

### Changing Trends of HIV Infection Among Aboriginals

The human immunodeficiency virus (HIV) is a virus that can be spread through epidemic viral migrations and also originates in a host animal that lives close to humans. We know that people around the world first began to be infected two decades ago. HIV is different from the smallpox virus because it can only be contracted through, 1) exposure to infected sex fluids during sexual contact, 2) blood to blood exposure through sharing drug equipment and 3) infected mother to child through breast milk. HIV is a fragile virus that cannot exist outside the body for long and a large enough concentrations of virus need to be present before infection can occur.

Smallpox, on the other hand was a hardy virus that could live up to a year in moist conditions, for example in a blanket. Smallpox was eradicated from the earth in the 1970's by a coordinated international effort. It is the only virus that has ever been defeated by modern medicine. It was easier to contract because it was spread through inhaling or touching droplets or fluids infected with the virus. Although these viruses are very different from each other they can both result in death of the infected person. Even though smallpox had a high fatality rate, between 35-100%, a proportion of the people infected could recover and develop immunity. People who contract HIV may live for up to fourteen years or more, but scientists expect that 100% of them will eventually die from the infection.

Estimates by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO) indicate that by the beginning of 1998 over 30 million people were infected with HIV, and that 11.7 million people around the world had already lost their lives to the disease. The virus continues to spread, causing nearly 16,000 new infections a day.<sup>5</sup> In Canada, since the beginning of the epidemic to December 31, 1998, a total of 43,347 positive test and 16,236 AIDS cases have been reported. Approximately half of the estimated 4,200 new HIV infections which occurred in Canada in 1996 were among injection drug users (IDUs).<sup>6</sup>

Aboriginal people are not immune to becoming infected with HIV even though communities may believe they are isolated from the current epidemics. In the first decade of the epidemic in Canada, HIV/AIDS was closely associated with being gay because the virus spread quickly in this population. By the mid-nineties it was evident that people who inject drugs were also becoming infected. Because Aboriginal people have been segregated from society and each other by race, ethnicity, religion and jurisdiction, and lack adequate information systems, it has been easier for them to believe in misconceptions about HIV/AIDS. The Aboriginal world view can be very narrow at times and have an individual, family or community focus that is directed primarily inward. The attitude promoted by leaders at the time, which is still prevalent, was that their communities were immune to AIDS because it was a "gay white man's disease" and because there are no gay Aboriginals there was no real risk.

This is indicative of three things, the first being that Aboriginal people do not fully understand the potential of HIV migrating to their isolated communities the same way past epidemics of smallpox and tuberculosis have. (There does seem to be a collective memory, record, oral history or research that tells us what the impact was or what was learned from the experience.)

Secondly, this attitude or belief says a lot about how Aboriginal communities have been re-structured to adopt Euroamerican views of sexuality. There is a lot of historical evidence that shows in pre-contact

times there were other socially accepted sexual and genders roles beyond ultra male and female. These included social and ceremonial roles for gays and lesbians. Same sex activities were openly or discreetly tolerated at one time but because of the rigid beliefs of Eurochristian churches, many of these roles were seen as sinful and became unacceptable. Today, rarely does an Aboriginal person who is gay, lesbian, bisexual or transgender identify their orientation because there is no place for them to fit into Aboriginal society. This has resulted in a misconception that there are no Aboriginal gays, hence the ability of the community to distance themselves from the epidemic.

Thirdly, the lack of access to appropriate information and education may have lead to another misconception that is very telling. This relates to fact that a majority of Aboriginal people believe being gay, lesbian, bisexual and transgender is abnormal. The Ontario First Nations AIDS and Healthy Lifestyle Survey of 651 individuals reported that between 80-90% of respondents felt that homosexuality was an unacceptable lifestyle. <sup>7</sup> Another belief that may have formed is that HIV is exclusively a gay disease. This would mean that risk is not only associated with same sex activities but also to the misconception that gay men are also biologically different and prone to HIV infection. In essence, HIV becomes distanced by the following three degrees of separation, a false belief in immunity because of isolation from city diseases; the non-existence of Aboriginal gay people; and the belief that HIV can only infect gay men.

Despite misguided attempts to distance the Aboriginal community from the HIV epidemic, there is evidence that gay/bisexual Aboriginal men and transgender people been affected by HIV since the very beginning of the epidemic. During the early 1980's, Aboriginal men who have sex with men (MSMs) were among the first Aboriginal people who became infected with HIV as it spread among gay populations in larger Canadian cities. These men were living in urban centres like Vancouver, Toronto and Montreal at the time or migrated there later from rural towns and First Nations, Metis and Inuit communities. A majority of these Two Spirit (gay, bisexual and transgender) people had left their families to seek a better life and to escape intolerance and homophobia.

Epidemiological data from the Laboratory Centre for Disease Control shows that exposure categories among the 213 male Aboriginal AIDS cases were 59.2% for MSM, and 13.6% for MSM/IDU. <sup>8</sup> Aboriginal females make up 16.5% of Aboriginal AIDS with IDU being the exposure category for 47.6% of the 42 female cases. Research shows these trends have changed over time. From 1983-87, MSMs made up 86.7% of AIDS cases, and there were no female cases. Data collected between 1993-97 shows that the number of MSM cases reported decreased to 43.7%, while MSM/IDU increased from 6.7% to 16.8%, and that in the heterosexual IDU exposure category there was an increase from 0 to 30.2%. <sup>9</sup>

Data (1993-98) from BC, Alberta, and Saskatchewan show that Aboriginal people account for 15%, 26%, and 30% of newly diagnosed HIV-positive cases respectively, and that IDU and heterosexual behaviours were the most significant risk factors. <sup>10</sup>

### **Characteristics of Aboriginal Injection Drug Users**

Available research shows that HIV infections among Aboriginal MSMs are different, although they happened at the same time or shortly after those among other gay and bisexual men in North America. While the majority of non-Aboriginal men became infected through having unprotected sex with infected partners, there is evidence that drug use was a significant factor in HIV infections among Aboriginal MSMs. The proportion of Aboriginal MSM AIDS cases in the MSM/IDU exposure category is 32.7%

compared with 8.1% for all other AIDS cases in the same category.<sup>11</sup> This data indicates that substance use and sharing injection drug equipment with HIV infected people has been a major risk factor. There is also evidence that a series of smaller urban epidemics are shifting to the heterosexual population, especially affecting women who are IDUs or whose partners are IDUs.

In 1997, CAAN conducted a survey among 126 Aboriginal IDUs in various Canadian cities and prisons. The survey reveals a group of Aboriginal people who are severely economically depressed, with low levels of formal education and who live in unstable housing or on the streets.

Many have ended up on the streets as a partial result of abuse and neglect during their childhood. The majority (87%) have spent time in jail and 71% of the women are involved in prostitution. According to all the means by which we can predict HIV infection, these people are at great risk of acquiring HIV. The respondents indicate that they do not want to contact HIV and where Harm Reduction services are made available, most have changed their risk behaviours in order to reduce their chances of HIV infection.<sup>12</sup>

Jurisdictional segregation of Aboriginal people has resulted in the development of inner city “ghettoes” where large numbers of Aboriginal people live in extreme poverty. Many of them are First Nations people (treaty status) who have migrated there from reserve communities. Without appropriate access to employment and training opportunities, many urban Aboriginal people survive on an annual income of between 6-9,000 dollars and families live on annual incomes of between 11-14,000 dollars. Single individuals living on a reserve can receive as little as \$156. a month for social assistance. In comparison the average annual income for a Canadian family is \$50,000.<sup>13</sup>

Aboriginal people living in urban centres are vulnerable targets for exploitation by people who sell substances like Chinese wine, Lysol, solvents, prescription drugs, cocaine, heroin and tobacco. Children and young adults are also vulnerable to being exploited in the sex trade and by gangs.

In 1997, Manitoba Health and the Laboratory Centre for Disease Control collaborated to undertake a research project among IDUs. The results of the Winnipeg Injection Drug Epidemiology (WIDE) Study were released in February 1999. Interviews and saliva HIV tests were conducted with 609 consenting ever-IDU. The median age of ever-IDU was 33 years; 50% were male, 49% female and 1% transgender. Cocaine was the drug injected most frequently by 63% of the sample, and was associated with high rates of binge use (57% cocaine users) and injection with used needles in the last year (44%). The overall HIV infection prevalence estimate from the saliva samples was 12.6%. The study showed that 65.8% of IDUs in the study were Aboriginal.<sup>14</sup>

### **Aboriginal Youth at Increased Risk**

According to the 1996 Census, the total population of North American Indian, Metis or Inuit people was 779,010, which is approximately 4% of the Canadian population.<sup>15</sup> Since younger people are

increasingly at risk, it is important to understand what proportion of the Aboriginal population is in this age group. The census shows that of the total Aboriginal population:

- 
- 35% are between the age range 0 to 14
  - 53% are under age 24

- 35% are between the age range 15 to 34
- 70% are under age 34
- 8.25% are 55 years and over

---

Source: Statistics Canada, 1996

Almost half of the Aboriginal population is near the of age 23, which is the median age of HIV infection in Canada <sup>16</sup>. According to Health Canada this means that half of the people who become infected with HIV are under age 24. When this degree of risk is combined with other factors like poverty, systemic discrimination, and the lack of safer sex role models, there is a cause for concern. The First Nations HIV/AIDS Resilience study of 289 youth shows that over one-half felt they had some chance of getting HIV/AIDS. No less than 18% felt they probably would get it and one claimed already to be infected <sup>17</sup>.

The disproportionately low number of older Aboriginal adults also increases vulnerability because single parent families are left with fewer supports which extended families are able to provide. When youth move away from their communities they may loose contact with their family and become involved in substance use, street crime or the sex trade in order to survive.

## SECTION FOUR

### A Culturally Based Response to HIV/AIDS

Aboriginal front-line workers have been active in the AIDS movement since the late 1980s. They have collaborated with government programs in order to provide information on prevention, care, treatment and support. Along the way, these workers have been instrumental in integrating HIV information into the Aboriginal community by using traditional teachings. The rationale for using a blend of western and traditional approaches can be found in the following experience I had with a First Nations community.

In the early 1970s laws that forbade traditional and healing ceremonies were repealed. This *cultural knowledge* has now become a strong foundation for improving the health of Aboriginal people. These teachings have a holistic philosophy that addresses the emotion, mental, physical and spiritual aspects of life and acknowledges an important relationship with the *earth* (environment).

---

In 1995, I was invited to a small First Nations community in Manitoba to present an AIDS 101 workshop to a variety of groups in the community. Gabe Kakeeway, who was an HIV/AIDS educator from the Treaty #3 Area in Northwestern Ontario at the time, accompanied me to assist in translating the information into Ojibway. We were invited by the Nurse in Charge from the Nursing Station to present to the students in the school and to have separate workshops for young men and women and the Chief and Council. After we had presented in the school, our activities in the community were cancelled because an elder had died.

However, the Chief and several of the band councillors did attend a workshop arranged specifically for them. I used the AIDS 101 posters (visual teaching tools) to explain the stages of HIV disease as well as information about prevention and treatment. As he repeated the process, Gabe translated the information into Ojibway. Afterward, the participants had a long discussion with him. When the workshop was over Gabe told me they had understood the information and that they had given him their perspective on why illnesses like HIV are now afflicting Aboriginal people.

They believed Aboriginal people are suffering from many diseases today because they had lost an important connection to the earth. This lost connection revolved around the fact that Aboriginal people no longer eat the traditional foods that were once a part of their everyday diets. At one time their food consisted of land and water animals like ducks, muskrats, beavers, deer, moose and fish. Their ancestors believed the Creator placed "good medicine" in the water plants the animals ate. The medicine was then transferred to humans when they ate the animals and this was how Aboriginal people were meant to stay strong and healthy.

They also said, "At one time we had a drum and a shaking tent. The shaking tent would tell us a person was sick or how long they had to live. We were also were given remedies and ceremonies to treat the sickness. Some of us remember being apart of these ceremonies but it was a long time ago and we are Christians now."

---

Over the years, staff, clients and board members of Aboriginal AIDS service organizations (AASOs) have worked with traditional healers, teachers, elders, and other Aboriginal organizations in Canada and the United States to gain this knowledge. Culture-based HIV prevention models and service delivery approaches have now been developed using traditional values, medicine wheel teachings, the HIV/AIDS Wheel and the HIV/AIDS Teaching Turtle. 18

*CULTURE refers to “the integrated patterns of human knowledge, belief and behaviour that depend upon one’s capacity for learning and transmitting knowledge to succeeding generations.” (Webster’s New Collegiate Dictionary) 19*

Aboriginal youth are learning these cultural practices and will soon expect them be integrated into their education, health, social, and community services. Some components of Aboriginal belief systems, values, and practices that can be used in developing and providing culturally based services are:

Seven Teachings	Child Centered	Sharing Circles
Respect for all Nations	Elders	Traditional Medicines
Circle Teachings	Extended Families	Healing Ceremonies
Medicine Wheel Teachings	Non-interference	Sweatlodge Ceremonies
Four Directions Teachings	Non-hierarchical	Naming Ceremonies
Heritage/Identity/Clan	Non-verbal communication	Feasting and Fasting
First Languages	Self-determination	Sundance Ceremonies
Oral Traditions	Humour	Traditional Healers/Teachers
Two Spirit People	Open Door Philosophy	Pow-wows

In October 1996, an APHA consultation was held in Vancouver. It was part of a project, Aboriginal Communities and HIV/AIDS, on inter-jurisdictional issues sponsored jointly by the Canadian AIDS Society (CAS) and CAAN. Some of their stated needs were:

- *to be informed of their rights and the policies of government and NGOs which affects them*
- *a blend of conventional and traditional services to choose from*
- *trained Aboriginal and APHA HIV/AIDS trainers, educators and advocates*
- *to be educated on how to “learn to live with HIV”*
- *to receive non-judgmental support whether they are using substances or not*
- *local, medical, staff and Band Council policies in place to ensure integration, care treatment and support in the community*

APHAs were asked what kinds of services they would expect to have in place in their communities of origin and in urban settings. The following is an ideal scenario of a continuum of service on and off reserve recommended by them.

On Reserve Services

*To live with dignity: HIV/AIDS trained health care workers; policy development for all levels of service and responsibility; independent living; inherited assets (family); travel-pre-arranged agreements; mobile care team*

Urban Services

*To live with dignity: Aboriginal ASO direct services in – counselling, home support, self-empowerment, education (formal/informal), job/career training, advocacy; housing program; emergency housing: subsidy, women with children, single parents; drop-in centre; mobile care team*

*The APHAs also described urban drop-in centres as safe places to develop supports for themselves. They discussed the pros and cons of this concept.*

#### *APHA Drop-In Centre*

*Pros: safety, non-judgmental, information, accessible, fundraising for APHAs, holistic approach, alternative medicines and therapies, resources already exist, after hours service, cable television*

*Cons: loss of confidentiality, limited to PHAs, funding for staff, rent, rules/policies 20*

In Winnipeg, The Village Clinic's Living Room (LR) evaluation report findings and recommendations specific to Aboriginal people are:

*Aboriginal Staff: Some clients felt Aboriginal staff was needed. Others stated Indian medicine could be "bad medicine" and were somewhat apprehensive about including Aboriginal workers.*

*Counselling: Counsellors should be people who have "lived experience" with the type of problems clients have; not middle class people who do not understand". Aboriginal counsellors could be an option.*

*Areas of Growth: While beginning links were made with Aboriginal agencies, a stronger connection between Aboriginal agencies and Village and the LR was desirable. Aboriginal staff and culturally appropriate care are needed. These connections are vital. Traditional sweats could be helpful for some people. Inner city people with HIV need to get away from the city sometimes; programming could help them reduce their stress in this way*

*Service providers can learn from the clients. There is a learning curve for both the client and the care provider. If you threaten the survival techniques that are in place too quickly, you may not be able to develop trust with clients. When people are mobile, they often feel isolated. There are many Aboriginal women and children who are mobile and in need of services. Some service providers need to meet clients half way. Health promotion opportunities are there and could be more fully developed 21.*

In 1997, the CAAN conducted a needs assessment among Aboriginal people who use injection drugs. The respondents addressed the importance of culture and Aboriginal-driven services.

*The principle for Aboriginal-driven AIDS education and service provision is that culturally appropriate HIV/AIDS services will be more effective. The responses of the sample of 126 Aboriginal IDUs confirms a higher likelihood of success for HIV/AIDS services which are Aboriginal-driven and culturally appropriate. When asked, "do you think culture is important when dealing with this illness [HIV/AIDS]?", 84% of the respondents answered yes. Some reasons were: "because it gives you strength and hope" and "because it helps bring community together". 79% of the sample claim they would utilize and Aboriginal-specific service for HIV testing and HIV/AIDS information if one was available. The reason is clearly about being "more comfortable with my own people."*

*One respondent explains all the silent and intangible reasons why services for Aboriginal people should be provided by Aboriginal people: "To have someone who shares the same social background and similar experiences and belief systems means some unsaid communication can begin healing the spiritual hurt that is part of HIV."*

*In terms of traditional cultural activities (i.e., sweats, healing circles, teachings), the respondents generally think that these activities are important. Eighty percent (80%) of the respondents would find an Elder helpful and 78% would use the services of an Elder. Issues of internalized shame and fear about approaching an Elder will have to be addressed first. Most respondents feel that these traditional cultural services should be blended with western addiction and Harm Reduction services. Many members of the sample group were careful to state that*

*culture should not be forced on anybody. Others stated that the priorities in services should be on housing and skill development, before spiritual programming.*

*“I feel a traditional addictions program should first and foremost deal with the person in the most critical areas, i.e. health issues, clothing, nutrition, and housing. I feel spirituality has a place for everyone, but in different ways and at different times and should not be imposed on any one. Compassion and to be non-judgmental are critical to dealing with addictions issues. It should deal with addiction, somewhere to live, and life skills and then culture.” 22*

In the spring of 1997, the Manitoba Aboriginal AIDS Task Force (MAATF) in Winnipeg, changed its annual strategic planning retreat to an open community forum on Aboriginal people and HIV/AIDS. Other ASOs and stakeholders were invited to provide their input. The meeting was held as a lead in to Phase I of the Joint ASO Strategic Planning Process. One of its purposes was to determine if the MAATF should fold into the process and become a program of a larger model. The final outcome was that the MAATF must retain its autonomy and identity as an Aboriginal ASO. This direction was reiterated in Phase I by the MAATF board in the joint ASO statement of September 15, 1997.

During Phase II of the process, which took place from April to September 1998, a needs analysis identified a need for a strong presence of Aboriginal services. The final report's *Nine Circles* framework identifies several areas for Aboriginal involvement.

*Circle Two – Cultural Environment: The cultural environment surrounding the client is of primary consideration in service delivery. Each individual, family or community incorporates a distinct profile of cultural traditions (“identity”) based on ethnicity, gender, age, social position, language and sexuality.*

*Circle Six - Aboriginal Direction: Due to the large representation of Aboriginal people among PHAs (people living with HIV/AIDS) and at-risk groups, it is important that mechanisms be developed which are practically integrated at every level of the model, including Mission, and Definition, Governance, Human Resources, care, treatment and prevention, community collaboration and facilities.*

*Aboriginal Representation - Involvement of Aboriginal communities at every level of the agency is desirable and necessary, including governance, policy development, administration and service delivery. Partnerships with Aboriginal organizations and individuals will help ensure culturally-based accessibility for Aboriginal clients and APHAs. A commitment has been demonstrated to integrating Aboriginal-led service delivery throughout the organization, including specific as well as integrated Aboriginal services in outreach, education, advocacy, support and care. Recognizing the need for specialized expertise, the MAATF will lead the coordination of this initiative. 23*

Components of culturally based Aboriginal services and governance described in the model include advocacy, harm reduction, staffing, holistic approaches, first languages, interpretation, self-determination, sweat lodges, healing circles, traditional teachings, elders, traditional healers, committees and community liaison.

There is compelling epidemiological evidence and consistent community based research outcomes which support the development of Aboriginal culturally based HIV/AIDS service delivery across Canada.

### **Barriers to the Development of Aboriginal Culturally Based Services**

Since 1991, AASOs have been involved in a number of projects designed to engage Aboriginal, First

Nations and Metis organizations, leaders and APHAs in HIV/AIDS social action. These initiatives have had limited success because social, political and jurisdictional divisions remain. These divisions continue to create barriers that hamper a collective response to Aboriginal HIV/AIDS issues.

*BARRIERS refers to limitations on people having access to services, including: inadequate staff resources and insufficient service provision, lack of language skills and interpreter services, lack of awareness of services available, physical location of services, administrative practices, inappropriate and/or culturally insensitive attitudes of service providers, etc. 24*

Some of the key barriers that need to be addressed are:

- Systemic racism and discrimination against people of Aboriginal descent
- Resistance within the AIDS community to address the needs of newly affected populations
- Lack of appropriate representation of Aboriginal people in planning, delivery and evaluation of services
- AIDS service organizations have little or no understanding of Aboriginal history, culture, beliefs, language, diversity, traditions, healing ceremonies, identity, self-government, and social and political structures
- AIDS service organizations have little or no experience in providing culturally based services to Aboriginal people
- Some Aboriginal and non-Aboriginal service providers discriminate against people who may be: poor, HIV+, substance users, injection drugs users, street involved, Two Spirit, gay, lesbian, bisexual, transgender, homeless, mentally ill, terminally ill, have FAS/FAE, illiterate, involved in the sex trade, in prison or an ex-inmate
- A majority of the Aboriginal population is AIDSphobic, homophobic, and IDUphobic
- Provincial governments and other stakeholders perceive that Aboriginal people are a Federal responsibility
- Aboriginal people are disadvantaged in participating in community development and advocacy because the majority of the population is very young
- First Nations HIV/AIDS initiatives are directed primarily to on-reserve populations

The creation of a culturally based model of HIV/AIDS service delivery in Winnipeg is an indication of how services can be changed to meet the needs of Aboriginal people. However, there can be resistance to changing the status quo to meet the needs of people who are stigmatized and marginalized. In the first wave of the epidemic, most of the HIV infections were among gay white males, who were educated, employed and had resources to fall back on. The shift of the epidemic to IDUs, inmates, Aboriginal people, and women, requires that the AIDS movement change from a gay centred approach to one that

can address a diversity of issues and needs.

As the epidemic evolves and changes, so do the communities affected and infected by HIV. Gay men, who took on the struggle to educate and care for their communities in the early 1980s, are now faced with the challenge of transferring knowledge and sharing resources to address HIV epidemics in other communities, with the result that a shrinking block of resources is being divided among more and more people in need. <sup>25</sup>

## SECTION FIVE

### Capacity of Aboriginal People to Respond

In 1997, CAAN was one of the national stakeholders that worked with Health Canada to development the Canadian Strategy on HIV/AIDS (CSHA), that was launched in May 1998. CAAN conducted a national consultation among Aboriginal people to seek direction for the renewed strategy. The recommendations from the Report of the Aboriginal Consultation of the National AIDS Strategy Phase I and II <sup>26</sup> were:

#### General Recommendations:

- Eighty percent (80%) of respondents replied that research would be useful and assist in the designing of HIV information that would have a greater impact on Aboriginal populations (*Being Worked On*)
- Need for a standardized “Aboriginal Community HIV/AIDS Intervention Model” (*Not Done*)
- 55% supported a national Aboriginal HIV/AIDS program at Health Canada (*Done*)
- Eighty-seven percent (87%) of people supported the development of national Aboriginal HIV/AIDS organization (*Done*)
- Priorities are better access to care, access to information, access to home communities (*Not Done*)

#### Key Recommendations:

1. That CAAN receive operation funding (*Done*)
2. That more AASOs be funded (*Not done*)
3. That Health Canada improve and increase internal collaboration and information sharing (*Being Worked On*)
4. That a national Aboriginal HIV/AIDS strategy be developed (*Not Done*)
5. That national Aboriginal HIV/AIDS conferences focus on skills development (*Being Worked On*)

In reviewing the status of these recommendations it becomes evident that the capacity of Aboriginal people to respond to the complexity of issues around HIV/AIDS and the reality of growing epidemics in urban areas is very limited. Many of the staff that work in the AASOs that at the regional level are also required to work at the national level to support the development of the national Aboriginal HIV/AIDS organization (CAAN) and advise non-Aboriginal HIV/AIDS organizations, Health Canada and other government programs. Aboriginal front-line workers are extremely over-extended and will soon begin to experience burn out unless more people are involved in doing the work.

Another serious limitation is the uneven support of the work of the AASOs by Provincial governments, non-governmental organizations. The vision of the CSHA is to move towards a nationally shared Strategy with improved collaboration among all levels of governments, among communities, non-governmental organizations, professional groups, institutions and with the private sector.<sup>27</sup> There is a clear direction of collaboration in the Strategy, yet it has not been demonstrated in concrete relationships that are designed to improve services for Aboriginal people. Epidemiological data and social research shows Aboriginal people are over-represented in all the newly emerged groups affected by HIV, women, IDUs, inmates, and gay youth, yet few Aboriginal people are hired to develop culturally based programs.

In addition, there has been no evaluation of the education and prevention work that has been delivered in Aboriginal urban, rural and on-reserve communities over the last ten years. Despite the fact that the majority of Aboriginal AIDS cases are among MSMs, we have not seen appropriate education and prevention initiatives developed. In fact, we have seen a generalizing of Aboriginal HIV information and prevention information to the point that it becomes meaningless. This is an indication of the internal resistance that has occurred within the Aboriginal community, that prevents open discussion of sexual issues of gender, orientation and abuse.

## **SECTION SIX**

### **Recommendations**

1. Health Canada: Improved communication, collaboration and accountability across jurisdictions. There needs to be concrete agreements that establish communication and collaboration mechanisms between the regional stakeholders of ACAP, MSB, and Provincial Health Departments and ASOs. The Aboriginal community should be able to know at the regional level how they work together to address HIV/AIDS.
2. Health Canada: To develop another level expertise to improve the capacity of CAAN and AASOs to respond to HIV/AIDS. Support for another level of expertise related to Aboriginal HIV/AIDS issues is required to fill the gap between the national and regional levels. A mechanism is required to pool this expertise to make it available to Aboriginal and non-Aboriginal stakeholders. This will relieve the demands placed on front-line workers.
3. CAAN: To improve partnerships and collaboration at the national level with Aboriginal and non-Aboriginal NGOs. Consultations should be undertaken to negotiate agreements and actions plans on how these national groups will work together over the next three years of the Strategy. The focus must be the development of a national Aboriginal HIV/AIDS strategy.
4. CAAN: To advocate for the development and funding for Aboriginal culturally based programs and services at the regional level. It is apparent that this is the direction supported by service users and providers. This initiative will require support from Provincial governments.
5. CAAN: To direct research that increases knowledge of cultural traditions and builds on the capacity to survive diseases and colonization. In the Aboriginal community, we are trying to use a non-Aboriginal approach to preventing and treating disease without validating historical experience or knowledge. This must eventually result in the reform of current health and social service systems to be more culturally competent to meet the needs of Aboriginal people.



## REFERENCES

1. First Contact: Smallpox, Keith Thor Carlson, Sto'lo Curriculum Consortium, 1996
2. Ibid.
3. Ibid.
4. Ibid.
5. Report on the global HIV/AIDS epidemic, UNAIDS, June 1998
6. HIV/AIDS Epi Update, LCDC, Health Canada, April 1998
7. Ontario First Nations AIDS and Healthy Lifestyle Survey, Myers T., Calzavara LM, 1993
5. HIV/AIDS Epi Update, LCDC, Health Canada, April 1998
6. Ibid.
7. Ibid.
8. Ibid.
9. Joining the Circle: An Aboriginal Harm Reduction Model, CAAN, June 1998
6. Statistics Canada, Canadian Census 1996
7. Winnipeg Injection Drug Epidemiology Study, Blanchard J., Elliott L., Dinner K., February 1999
8. Statistics Canada, Canadian Census 1996
8. HIV/AIDS Epi Update, LCDC, Health Canada, 1995
9. AFN First Nations HIV/AIDS Resilience Project, June 1998
18. Manitoba Aboriginal AIDS Task Force Policy & Procedures Manual, November 1997
19. Action Access Diversity!, United Way of Greater Toronto, December 1991
20. Aboriginal Communities and HIV/AIDS, A joint project of with CAS and CAAN, March 1997
21. The Living Room Evaluative Report, Village Clinic, July 1998
22. Joining the Circle: An Aboriginal Harm Reduction Model, CAAN, June 1998
23. An Integrated Model of HIV/AIDS Service Delivery, Winnipeg AIDS Services Planning Committee, 1998
24. Action Access Diversity!, United Way of Greater Toronto, December 1991
25. An Integrated Model of HIV/AIDS Service Delivery, Winnipeg AIDS Services Planning Committee, 1998.
26. CAAN Report of the Aboriginal Consultation of the National AIDS Strategy Phase I-II, October 1997
27. The Canadian Strategy on HIV/AIDS, Moving Forward Together, Health Canada, 1998