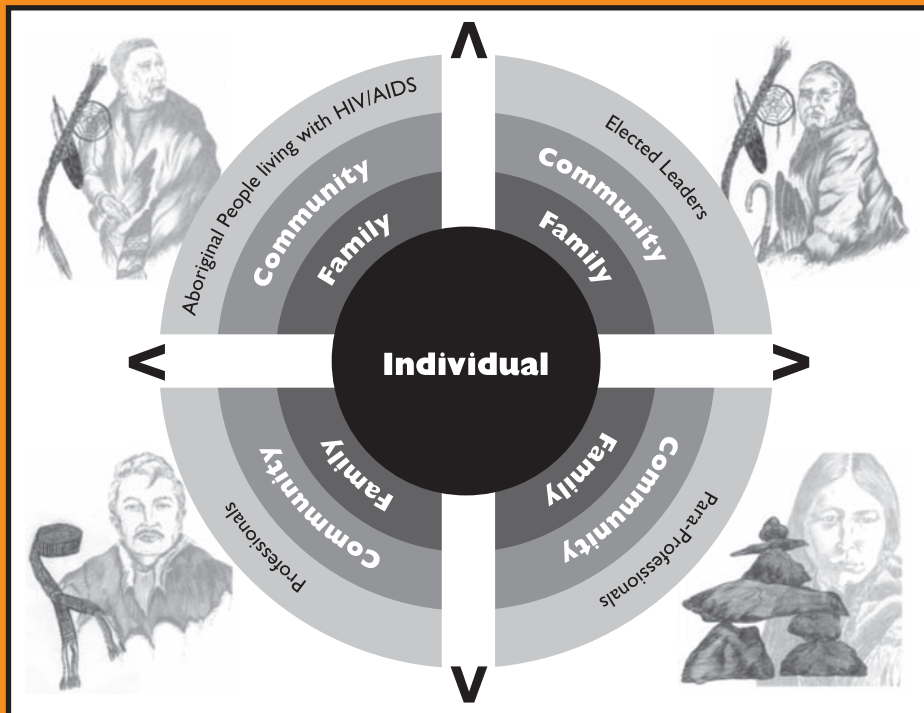




# MAKING IT OUR WAY

## A Community Mobilization Tool Kit



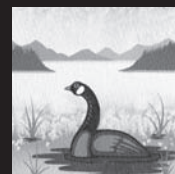
Written by:  
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## The Path That Led To Me

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A very good friend of mine, a leader in the Aboriginal HIV/AIDS movement, had always kept in touch with me. He heard I was just getting better after starting anti-retroviral medications for my HIV. He told me about the Annual General Meeting of the Canadian Aboriginal AIDS Network (CAAN) happening in Toronto in 1999. I applied for, and received a scholarship to attend. I was getting better physically but still so down and depressed.

The Toronto meeting included a two-day healing circle. All of us in that circle were Aboriginal People living with HIV/AIDS: mothers, aunties, medicine men, babies, 2-Spirited people, Elders, Métis, Inuit and First Nations. If I close my eyes now, I can still see them all because together, we went through some very special healing. Afterwards, I felt so much better.

A Haida woman from Vancouver Island caught up to me, just as I was being so thankful for the gift of healing I had just experienced. This person also offered me a gift. It was a bag of tobacco. She asked me to bring it back to an Elder in my community. She said that Haida people always give a gift of tobacco to acknowledge and honor the People whose territory they happen to be visiting. I am a member of the Mississaugas of the New Credit First Nation and Toronto is our territory. Wow, I thought!

The gift came with instructions. It started to make some sense. I saw the gift of tobacco as representing the gift of healing that I had received. And here was this woman telling me to go back to my community, to share it - give it back. So I went to my community within a week and gave tobacco to our Chief. I explained my experience of healing in Toronto to her. The Chief gave me a big hug and said to go see my cousin who was the Community Health Representative.

When I saw my cousin, I told her I was HIV-positive. I described my healing experience in Toronto and about how raw I was still feeling. She looked at me and asked "You have AIDS? Can you come and talk to the community at an AIDS workshop I am putting on?" I spoke at that workshop. Community and family members alike lined up to hug me (even the big, scary and tough looking ones). It felt so good to be home. I felt strong. I began to tell my story and share my experiences of living with HIV/AIDS to many of our communities. After awhile, Aboriginal HIV/AIDS working groups and committees began to ask me to help them get organized. I was learning more and more and helping a lot.

Two years had passed and my health greatly improved from the medications and healthier choices in my life. In 2001, I was elected to the Board of Directors of CAAN. I wasn't sure if this was really the right direction for my path to take. "I'll sleep on it", I laughed. That evening I went to an old friend's place for dinner. I hadn't seen her in ages. I don't like to visit people empty handed, so gave her a gift of Sweet Grass. She said she had something for me too and gave me a beautiful Eagle Feather. I was speechless. I am so sure that I am on the right path now. This is my role. This is my responsibility. I take Aboriginal HIV/AIDS advocacy seriously, because of what the movement has done for me.

Trevor Stratton  
Aboriginal HIV/AIDS Activist and Advocate



# 1. Introduction

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The Canadian Aboriginal AIDS Network (CAAN) managed this project because of a need to see how Aboriginal communities and organizations were addressing HIV/AIDS. As the HIV/AIDS epidemic continues to increase among the Aboriginal population, these questions were raised: Why is this happening? Do elected Aboriginal Leaders know how HIV/AIDS is affecting their communities and do they care? What more can be done?

Over a two-year period, some of these questions were answered. It is generally accepted that because many Aboriginal people experience higher levels of poverty, as well as childhood challenges such as being raised in residential schools, etc. that overall, we tend to experience poorer health. In terms of elected Aboriginal Leaders, this project conducted a short survey of mostly First Nations Chiefs. It found that many know about HIV/AIDS. A lot also knew someone living with HIV/AIDS and indicated that their communities had held educational HIV/AIDS workshops.

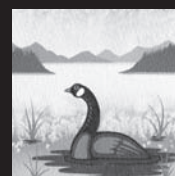
Earlier in this project, another survey was conducted. It surveyed organizations in what can be called the Aboriginal HIV/AIDS movement. CAAN is just one key player in this field. In that survey, we were able to determine how HIV/AIDS is being dealt with by the Aboriginal population.

The result is this **Community Mobilization Kit**. It is here to support First Nations, Inuit and Métis communities, organizations and others in order to take greater action around HIV/AIDS. It will present a model for mobilization and provide practical examples of how many Aboriginal communities and organizations do HIV/AIDS work; describe how effective or satisfied they are with the most common methods being used; and offer suggestions based on these findings to make it a lot easier to take up the challenge of trying to make a difference.

HIV/AIDS is entirely preventable. Yet many Aboriginal people are still becoming infected and may not be getting prevention messages, particularly where messages are not seen as culturally appropriate. All too often, once individuals find out they have HIV or AIDS, they experience backlash or negative reactions. Some fear for their safety or live in silence, which is not good for their health. Many do not know who to trust or where to go for support, especially from an agency or service that also understands their cultural needs. These are some of the reasons why Aboriginal communities need to mobilize around HIV/AIDS. Not only is it about preventing further cases of HIV, but also about changing the environments where we live, so that people who find themselves HIV-positive, can find the support they need.

## 1.1 Why should Aboriginal people be concerned about HIV/AIDS?

According to the Public Health Agency of Canada “Aboriginal peoples represent 23.4% of [HIV-positive test] reports with information on ethnicity.” Yet Aboriginal peoples are only 3.3% of the Canadian population. They go on to state: “Before 1993, 1.2% of reported AIDS cases were among Aboriginal peoples. This increased to 13.4% in 2003” (Public Health Agency of Canada. Understanding the HIV/AIDS Epidemic among Aboriginal Peoples in Canada: The Community at a Glance. 2005).



Clearly Aboriginal peoples are over-represented but more alarmingly the rate of growth is showing every year that increasing numbers of Aboriginal people are becoming infected with HIV/AIDS. It continues to affect Two-Spirited men, but also Aboriginal women who now make up almost half our cases. Aboriginal youth are also a major concern, with almost 4 to 1 odds of becoming HIV-positive. A recent CAAN/University of Alberta study, for example, shows Aboriginal youth may not always understand risk of infection and as a result are not being tested. Heterosexual (straight) contact and injecting drug use are also key factors in the spread of HIV.

## 1.2 What makes the Aboriginal Population different?

One of the first federal departments created after Canada became a country, was the Department of Indian Affairs. The Indian Act came into effect in 1876. Assimilation was always the goal, including the residential school system which is widely believed to be one of the most disruptive federal initiatives to date. These church-run and government sanctioned institutions led to physical and sexual abuse, among others, for all too many Aboriginal children.

It was this interaction between mainstream and Aboriginal societies, which sadly continued well into the 1960's, that builds the case and need for Aboriginal people to have control over their destiny. After all, it was outside sources that thought they knew what was best for Aboriginal people, and in the end contributed to disruptive changes that weakened many of the strengths that were once a key part of Aboriginal societies. While some non-Aboriginal people were well intentioned, the fact that Aboriginal people had little or no control over their lives and communities is in part why so many social and health issues are challenging Aboriginal communities today. It is because of this understanding of Aboriginal history, that this kit is developed by and for Aboriginal people. This Community Mobilization Kit will provide some answers to these situations. Before it does, we will offer some definitions to support this work.

## 1.3 What is Advocacy and Community Mobilization?

In the context of this project, advocacy is actively supporting and contributing to the empowerment of persons living with HIV/AIDS. It involves promoting respect for the rights, freedoms, autonomy, and dignity of these individuals, especially when some may not be able to find the courage to speak for themselves. To advocate is to speak up for, especially when someone is voiceless and does not have the means or support to face outside threats alone.

Community mobilization can include:

- Bringing together the talents, resources and skills of the community;
- Aiming for positive community participation and involvement;
- Providing a greater base of support for awareness and prevention; and
- Influencing opinion-leaders and decision-makers so that communities become more supportive and responsible for solutions.



## 1.4 How to use this Community Mobilization Kit

There are several ways to use this kit. First, it requires that at least one person in the community sees HIV/AIDS as an issue. As long as there is somebody who feels something must be done, then this kit can help. That person does not have to be a paid employee, simply someone who wants to make a difference. Consider this example:

*A mother on one reserve became aware that her sons were actively using drugs and alcohol. She also knew that they were using some hard drugs, the kind that needed to be injected through needles. She also knew that when people shared needles, they could increase their risk for HIV and/or Hepatitis C. Although she wanted her sons to not do drugs or alcohol, she knew that in her small, country community, there would never be a needle exchange program where addicts can get clean needles and bleach kits. Being a diabetic, she gave needles to her sons, because she did not want them to get infected with HIV or Hepatitis. Out of concern, she took action.*

This resource is not saying that this example is what every parent would do. It also recognizes that many people would disagree with her approach, and say things like she was keeping them in their addiction. What is important to recognize here is that someone saw an issue and took steps to make sure that at least those close to her might have less risk of becoming HIV-positive. Perhaps her efforts, simply as a mother, may one day allow her sons to make other choices and maybe set aside the hard drugs that can cause other harms. This is known as harm reduction.

Another example was a lady known as Condom Granny. Through her talks to schools and communities, she raised awareness and provided many people with the information and ammunition to make informed choices. Giving out a condom does not mean go ahead and have sex. It is about letting someone know that if they were to have sex, that certain harms can be avoided, such as HIV, other sexually transmitted infections, or even an unwanted pregnancy.

This kit offers one model of who in the community can be allies. It describes who else needs to be part of the solutions, in order to bring about awareness and ultimately change. The model is based on years of experience doing community HIV/AIDS work and looking at how Aboriginal people working in this field have gone about raising awareness and doing prevention.

To use this kit, we suggest reading it through and taking notes of some of the ideas. It may also be helpful to keep your community in mind and who or how you might go about doing the work that is outlined in this and other resources. The Aboriginal Strategy on HIV/AIDS in Canada (ASHAC) also offers ideas or areas to focus your attention on when designing HIV/AIDS programs. There is also the Young Eagles' Challenge developed by the Assembly of First Nations. This is a youth peer education model. The Canadian Inuit HIV/AIDS Network (under Pauktuutit Inuit Women's Association) also has an action plan for doing work in Inuit communities. The Métis National Council developed a HIV/AIDS booklet outlining basic facts on HIV/AIDS targeting Métis people. Keep these and other current resources in mind when you want to collect educational materials.

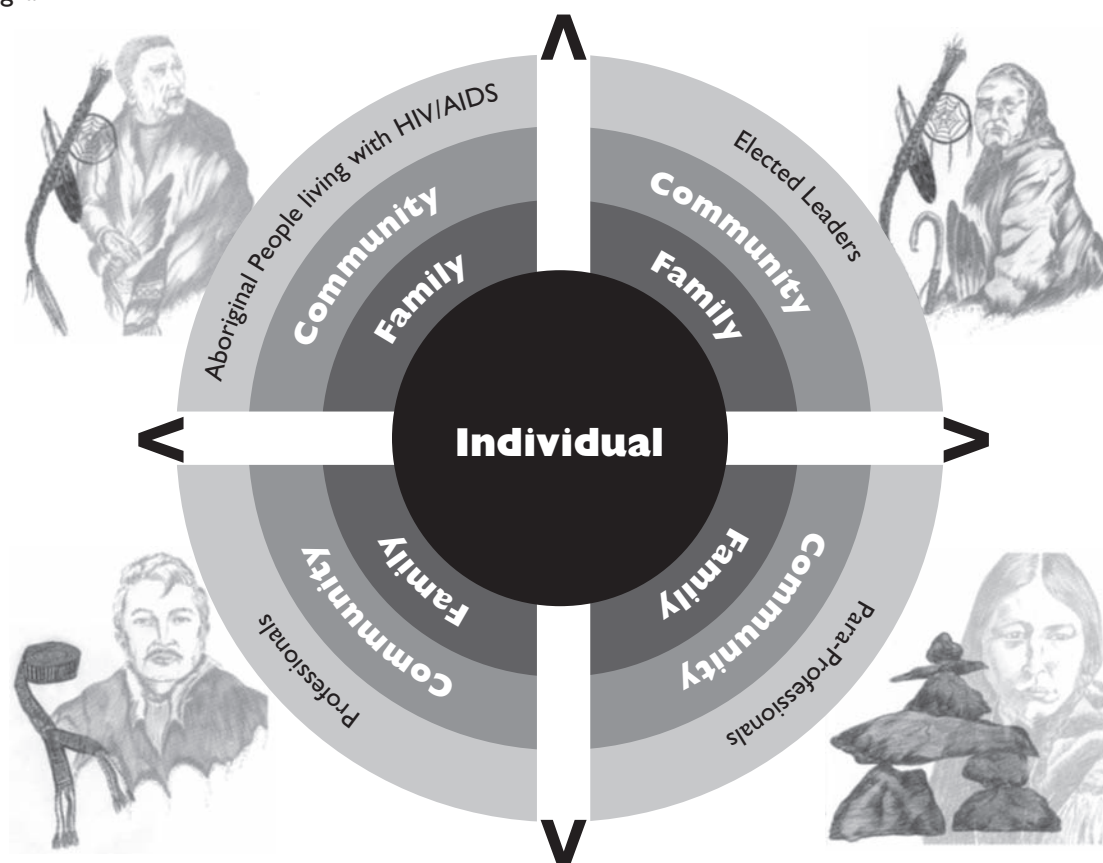
This kit is more about how to bring HIV/AIDS forward so that other key people in the community rally together to address a common cause. There is a resource section with organizations and websites, as well as a number of appendices that can help plan some of the activities, especially around Aboriginal AIDS Awareness Week. The next section will offer this model for taking action around HIV/AIDS.



## 2. Making It Our Way: One Model of Community Mobilization

The following model is based on many years working in numerous Aboriginal communities and organizations. One public speaker involved with this project, saw common needs and could also tell when a community was organized, or if it was struggling to put together the basics for a program. Some had their hearts in the right place but were not quite sure how to make it happen in a way that could result in good things for the community and reach those at an early age. The following model presents four sections or areas for who could be involved in mobilizing around HIV/AIDS or any other community issue. Following a description of each section, practical ideas will be presented for the roles of each involved in HIV mobilizing. It is important to recognize that not all communities are in the same place. Some may have more challenges to deal with, while others may have more resources.

Diagram 1



### The Four Sections of the Model are:

1. Aboriginal People living with HIV/AIDS (APHAs);
2. Elected leadership (Board of Directors, Chief & Council, National Leaders, etc.);
3. Professionals (school teachers/educators, Nurses, Doctors, etc.); and
4. Para-professionals (CHR, mental health workers, NNADAP, workshop facilitators, health directors, etc.).

## 2.1 Aboriginal People Living with HIV/AIDS (APHAs)

While prevention is important, the needs and issues of those living with HIV/AIDS must also have equal importance in any mobilization effort. When HIV/AIDS prevention and care/treatment/support efforts are delivered together, results are more successful than when done separately. It can be very powerful when an APHA shares their experience living with HIV/AIDS and this is tied to prevention. Both the community *and* the APHA can be enriched and empowered by the experience.

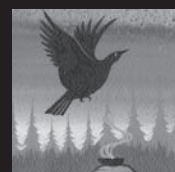
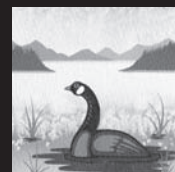
The freedom of choice is equally important. When treatment for HIV takes into account a person's beliefs in a holistic way, traditional healing and modern medicine can work together to result in healthier community members who feel truly supported within their community. Strong, confident APHAs who feel supported and useful in the community, in turn, means HIV awareness and prevention campaigns can be well informed by personal experience living with the disease.

Involving Aboriginal People living with HIV/AIDS (APHAs) in your community mobilization team makes sense, where possible. First, there is no better messenger than someone who knows exactly what it is like to be living with HIV/AIDS and is willing to share what risks they took that led to HIV/AIDS. Second, while HIV/AIDS is preventable, there are other benefits for why it is very useful to involve APHAs. This includes showing the community that **HIV/AIDS is not something to be afraid of, but something to be aware of.** It also shows that the community can support our own people when they are living with HIV/AIDS. In many people's minds HIV/AIDS has such a stigma and APHAs may not be willing to disclose their HIV-positive status. APHAs may see disclosure as an unsafe option and choose to keep their HIV status a closely guarded secret to protect themselves and in some cases, their children from negative stereotyping and discrimination that often occurs.

HIV/AIDS can be a scary disease but those who have HIV in their blood are just like anybody else. It is very important that fear is not the only reason to reduce risk-taking behaviors but rather that Aboriginal people reduce their risky behaviors out of a greater sense of self-love and self-esteem. Aboriginal people in the communities must be made to realize that anyone can get HIV. APHAs are people like you and me... with hopes, dreams, fears, happiness and sadness in their lives. Having HIV/AIDS education and awareness initiatives delivered by those who are living with the disease is a very powerful way to deliver the message. But APHAs cannot stand up there without support. They need the support of front line workers, elected Aboriginal Leaders and professionals such as teachers or nurses. This body of work intends to show how the workers in each of the four areas of the Community Mobilization Team support each other to create the "whole" team.

There is an estimated 3000-4000 Aboriginal people living with HIV/AIDS in Canada. While not all can be expected to be public speakers, many can be effective messengers with the proper support and resources. Just like the days of the Courier du Bois (runners) who ran the woods to the next village bringing news or warnings of things to come, this new Army of Messengers can be a key element in helping to mobilize a community. As one APHA leader recently said about APHA activists, *"We are like firefighters. While everyone is running away from the fire, APHA activists run towards the fire to help others."*

Although it has been done many times, no one can stand alone and deliver HIV/AIDS awareness initiatives with great success. It has to be a team effort. The other 3 sections of the Community Mobilization Team are essential to a holistic approach to the community's health.





This kit recognizes however, that a community may not know anyone in their community who is HIV-positive. Or, if there is someone, they may not be ready or able to be involved publicly. Each community needs to find a way that works for them, to provide support to any APHA willing to be open about their HIV-status, and to find ways to work with them, no matter where they are at, in a way that respects their valuable life experiences.

It is extremely important to not force anyone into a public role when they are not ready, and to move slowly to actively involve someone in community prevention efforts. There may be times when the person wants to be out of the spot light or is going through personal issues, where they do not have the time or energy to be vulnerable doing public talks. Establish a trusting relationship and much of this can be worked out as your community program grows. The following case studies are to be used in group discussions, to see how everyone sees the issues. They are intended to open dialogue.



## Case Study Scenario #1 :

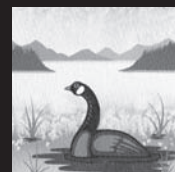
Picture your community. Now imagine a person, without naming them, in your community who has been involved in risky behaviors. This person thinks they may have HIV but are not sure. They worry that if they came forward to ask for help and ask for a HIV antibody test, that people might find out. They think they may be chased out of their community or physically harmed.

Questions to consider:

- Do you think this could happen in your community? Has it happened?
- If it did, do you think anyone else in your community who might be at risk, would ever consider stepping forward for help, after witnessing this type of community reaction?
- How would your community respond with what they know now? What would be the most holistic way to respond? Are they the same? Or does more awareness/education need to take place?
- Are there rumors about those with HIV/AIDS in your community? Does your community have any past experiences dealing with HIV/AIDS issues or APHAs? Do you think it's safe for a community member with HIV/AIDS or who wants to get tested to come forward for help?
- Does anyone in the community know enough about HIV/AIDS that they could help? Does anyone know where they would refer community members for more information or HIV/AIDS services?

This is the challenge that faces us! How we react as a community can either help create conditions or an environment where people feel safe to acknowledge their risks and get help, or they keep it hidden and live in silence and fear, never getting the help or support they may need. It is very important to look inward and challenge your own misconceptions, get informed, and then begin passing on that knowledge.

If there is stigma and fear of APHAs in the community, a HIV-positive community member is far less likely to seek care, treatment and support. Also, because people see how a community reacts, anyone else who thinks they may be at risk for HIV is not likely to come forward for testing especially if they know they will be discriminated against. There is often a lack of confidentiality where it may be a family member or close friend who works at the Community Health Centre. It is very important that APHAs, those at risk and *all* community members be educated on the issues of HIV/AIDS so that those infected and affected can have community support and that the community is educated around prevention. Prevention and care, treatment and support go hand in hand and are equal parts of the whole Aboriginal HIV/AIDS awareness effort.



## **Case Study Scenario #2 :**

A 45 year old Métis woman has been living with HIV for about three years. She has two young children, ages 5 and 7 and her husband left her after she tested HIV-positive. She lives in a rural community and has applied for low income housing. The landlord wrote on her rental application she is HIV-positive. She does not know if he was allowed to do this, but needs to find a place to live for her children and her. She does not know who to turn to.

Questions to consider:

- Does she have a right to privacy about who knows what about her health status?
- If you were someone in that community, what do you think she is going through and how would you help if she came to you?
- Who would you begin to talk to about making sure other people in similar situations did not experience the same kind of thing? How would you go about doing it while still respecting her privacy?

## **Case Study Scenario #3 :**

A 30 year old Inuk man who spent three years in prison, has now been released and is living in a large urban center. He considers himself gay, but finds few other Inuit who are open about being gay. He knows some First Nations people who use the term Two-Spirit but does not feel that really applies to his culture. He used to shoot up drugs using needles which resulted in him turning HIV-positive. He is depressed, and longs to go back up north, but feels there is nobody there to support him if he does. He knows of an Inuit group that does HIV work, but is scared to do public speaking. He speaks some English but his mother tongue is Inuktitut.

Questions to consider:

- What kind of support needs would he have?
- How would you work with him to help him along on his journey, and maybe one day help him to do public speaking?
- Where would you call to get information for his support?



## Case Study Scenario #4:

A First Nations youth of 18 who is straight just left his northern Saskatchewan reserve to move to a city to attend college. There, he makes friends from all over and begins to party a lot. He heard only a little about HIV but never really had any reason to listen to that kind of information. He is sexually active and never thinks to use condoms. In his third year of college, he feels sick, and the Doctor offers him a HIV antibody test. It comes back HIV-positive and he is lost and confused.

Questions to consider:

- What could have been done differently to get a message to youth, so that this young person might have found reason to listen?
- How would you handle him thinking that his life is over?
- What kinds of support would he need to deal with his diagnosis? Should he stay in college? How does he tell his parents who only speak Dene?

These case studies are only to open dialogue. As you can see, every situation is different, just as every person is. No one answer will work in all cases. What is needed in all of them though, is someone who is willing to listen and advocate when need be. The mobilization comes when you see that each case could have been prevented. If it happened to this person, it can happen to others. So the challenge is how to turn these life lessons into action so that fewer others go through the same thing.

In the resources section (appendix # 5), there is a check list for selecting APHA Speakers. This may help in understanding some of the unique needs that goes into this key piece. For example, many APHAs do not work as speakers. Some may even be on disability or fixed income. This means that they would need tickets for travel and meal allowances up front. If there is to be an honorarium, all this needs to be dealt with before booking the travel so that everyone knows what their obligations are. They also may not be able to cash a check without their bank freezing the amount for 3 to 5 days, so might need help.



## 2.2 Elected Aboriginal Leadership

Elected Aboriginal Leaders in many ways are a difficult group to reach. Their terms of office may be short term (2 years). There are many competing issues they have to be aware of and working on. Some Aboriginal HIV/AIDS Service Organizations (AASOs) have had some success in engaging elected Aboriginal Leaders but much more needs to be done. Elected Aboriginal leaders cannot advocate for Aboriginal HIV/AIDS issues without the support of the other 3 sections of the “Community Mobilization Team”. Our leaders must be convinced that HIV is an important issue within their respective jurisdictions. If no APHA has stood up to disclose their HIV-positive status in the Leader’s area, it may be difficult to convince that Leader that they exist and have needs.

It is important to know what it is we want from elected Aboriginal Leaders. Some successes that CAAN has had includes having National Chief Phil Fontaine of the Assembly of First Nations, President Clement Chartier of the Métis National Council and President Veronica Dewar of Pauktuutit Inuit Women’s Association address a press conference on Aboriginal AIDS Awareness Day December 1, 2003. Also, Member of Parliament Libby Davies asked a question in the House of Commons about a funding cut that CAAN experienced in 2003. These examples show how leadership can happen.

In addition, many support resolutions have come about, such as when Healing Our Nations in the Atlantic (formerly Atlantic First Nations AIDS Task Force) was formed. All the Chiefs in the Atlantic pooled their resources to create an agency that would address their HIV/AIDS education and training needs. Similar support has happened in other regions, such as with the Healing Our Spirit, BC Aboriginal HIV/AIDS Prevention Society and their annual conferences. The shortfall though, is resolutions get passed but there is no ongoing opportunity to feed information in a strategic way to elected Aboriginal Leaders.

One easy thing that an elected Aboriginal Leader can do is to attend and do the Opening/Welcome to the community’s HIV/AIDS workshops. When community members see their Leader taking an interest and talking about the importance of HIV/AIDS awareness, it means a lot. People remember.

Elected Aboriginal Leaders can bring an APHA activist/speaker to assemblies when they advocate for Aboriginal HIV/AIDS issues at these meetings. It gives a lot of credibility when a Leader has a community member who has experience ‘*living with the issues*’, particularly when HIV/AIDS is the subject. Other things Leaders can do:

- Be on a prevention/awareness poster shown supporting APHAs.
- Become involved in Public Service Announcements.
- Wear Aboriginal HIV/AIDS promotional material at political conferences and gatherings, like wearing the red ribbon.
- Sponsor or introduce a motion for HIV/AIDS governing resolutions in support of HIV/AIDS with help from the other 3 sections.
- Provide letters of support for APHA speakers.
- Attend/be vocal at CAAN AGMs or regional Aboriginal HIV/AIDS conferences/workshops.



It is important that elected Aboriginal Leaders become involved with mobilization efforts as they can provide increase community mobilization a lot by virtue of their role in the community. Their emotional response (whether positive or negative) to the mobilization effort will be noticed by community members, who may want to follow those attitudes and reactions.

By ensuring a supportive and compassionate community response to all medical and physical illnesses, the leadership of the community will be proactive to any liability issues which may occur relating to accessibility of various treatment and/or options. Why identify elected Aboriginal leaders as a key area in the community mobilization team? The answer is that Aboriginal leadership have the responsibility to ensure our communities are properly equipped with all the information and resources we need to live healthy and productive lives. It is hopefully why they sought elected office.

When HIV/AIDS first began to appear in Aboriginal communities, it followed what was being seen in mainstream society. That is, it began to infect Two-Spirit and gay/bisexual men in large urban centers. Sadly, this fact is believed to be a key reason why many people did not see it as a concern. That is, they saw it as a gay white disease affecting large urban centers and thought it would never affect them.

Fast forward more than a decade, and what we are seeing is that HIV/AIDS is affecting just about every segment of the Aboriginal population. Aboriginal women make up almost half our HIV/AIDS cases. Aboriginal youth are at very high risk under the age of 20, and high risk up to age of 29. Straight (heterosexual) men are also being infected, and when sharing needles while using injecting drugs, may infect others including their sexual partners. Aboriginal inmates are also being infected. Residential School survivors, especially when using negative coping behaviors, such as alcohol and drug use, have also been shown to be among the HIV-positive cases in the Aboriginal population. Aboriginal women make up almost half our cases.

Support from elected Aboriginal leaders is in some cases non-existent or slow to materialize. In some cases though, assemblies have passed resolutions calling for increased funding or to support Aboriginal HIV/AIDS service organizations to secure the resources needed to do the work. But resolutions alone are not enough.

### ***Suggested Action Items:***

- A) Community staff can write one page briefs giving statistics about how HIV/AIDS is affecting the Aboriginal community.
- B) Elected Aboriginal leaders can be invited to speak at HIV/AIDS conferences and to publicly support HIV/AIDS work. This helps to normalize or make HIV/AIDS a common day to day part of our discussions so that people hear about it and know that something is being done.
- C) Elected Aboriginal leaders can direct community-based agencies and services to work more closely together. HIV/AIDS work cannot just be left to health staff, it belongs also to education, social services, community policing, youth workers, and many others.
- D) Develop a strategy to engage leadership, which can include briefs and training sessions.



## 2.3 Para-Professionals

Para-professionals and front-line community workers such as Community Health Representatives (CHR's), outreach and support, addiction, and mental health workers, workshop facilitators, health directors, etc., serve a very important role. More often than not these workers are the people with the responsibility mandated in their work-plans to address HIV/AIDS issues. These workers need support as well. Particularly, they need the support of elected Aboriginal leaders in order to address controversial and difficult to discuss HIV-related issues such as substance use, men who have sex with men (2-Spirit issues), self-esteem, healthy sexuality, physical abuse, family violence and many others.

Assisting in maximizing the effectiveness of 'health and wellness programs,' should be facilitated by the various programs in the community. Family crisis intervention for the care, support and assistance related to HIV/AIDS issues should be readily available in the community.

A key segment of the mobilization model relates to those workers who support overall health efforts within the community. These can include, but not limited to:

- National Native Alcohol and Drug Abuse Program (NNADAP), both field workers and treatment center staff.
- Community Health Representatives (CHRs).
- Brighter Futures Initiative (BFI) or Building Healthy Communities (BHC).
- Outreach Workers.
- Guidance Counselors.
- Recreation, Coaches or Team Leaders.
- Scout Masters.
- Project Coordinators.
- HIV/AIDS Educators.
- Police Community Liaison Workers.
- Family Violence Coordinators; and,
- Youth Workers, etc.

In a youth peer education manual called *Young Eagles' Challenge*, developed by the Assembly of First Nations, a community team was presented as a resource to establish a group of concerned individuals who could support youth as they offer peer education and support to other youth around HIV/AIDS and related issues such as sex, healthy sexuality, sexually transmitted infections, alcohol and drug use, teenage pregnancy, etc. Para-professionals can play a key part in supporting this work, and sitting on a community mobilization team.

Two areas of work outlined in this manual can be: 1) Structured activities, which are community workshops, class presentations, guest speakers, role model programs, etc. 2) Un-structured activities, such as talking one-on-one with youth or others about HIV/AIDS; listening to someone who may be worried if they took risky behaviors; driving them to go get a HIV anti-body test, etc.

Para-professionals can reach into different groups within a community based on where they work and who they see. Because not all community members use the same services, for example, some youth may not be attending school, then it is important to plan events and awareness programs for those in and out of school. This is how para-professionals can open doors and use structured or un-structured



ways of getting the message out. Before doing so, para-professionals may need to be informed of why there is a concern and how they can play a role. Whoever has the lead responsibility to plan HIV/AIDS work, may need to gather information and build a plan on who to get on side to help deliver different activities.

Often, when communities begin to address HIV/AIDS awareness and education, the whole community is invited to a HIV/AIDS workshop. This is a good start as it introduces the concepts and issues to a wide audience of community members. However, different community members take in the information differently. For example, the way one delivers a workshop to highschool-aged youth likely would not be the way it was presented to Elders. Frontline workers such as CHRs and addiction workers may need a different approach than presenting to Elected Aboriginal Leaders.

There is a need to design workshops with gender-specific, age-appropriate approaches to selected target groups. Even within the high school-aged groups, HIV/AIDS awareness education approaches are more effective when tailored specifically for these target groups or diverse groups with specific information needs. One example is that of sexual health education. Young girls and boys at certain ages may not feel comfortable talking about their bodies or feelings in front of members of the opposite sex.

Often, they will talk and share more freely when in the safety of their own group. After working with boys and girls separately, they can come together and share what they have learned with the other group. Splitting up the youth group according to age can be helpful too. Preteens need different messages about risk-reduction than do teenagers experiencing puberty. Mixing the two age groups can create confusion in messaging. Teens typically want more direct answers to sexual questions and risk reduction rather than preteens who often just want to understand how their bodies work and how to keep healthy.

### ***Suggested Action Items:***

- A) Identify a list of workers in your community who can become part of a community mobilization team. Do a little research to find out how HIV/AIDS work can fit within their mandates. Next, see what kind of activities they each hold and brainstorm how HIV/AIDS information can be worked in, like giving out pamphlets, condoms, etc.
- B) Form a team, which includes key players. The team can start small and be expanded later if some key people are missing.
- C) Plan regular meetings to see how work can begin or get expanded.
- D) Identify key community players, like an Auntie or sports athlete who is popular, and begin to create allies to make HIV/AIDS a topic of discussion. Create your own role models in the community who counter risk behaviors with positive role modeling.





## 2.4 Professionals

APHAs also need support from professionals such as nurses, doctors, etc. who are the 'experts' in the facts. Likewise, teachers and schools can join prevention and awareness efforts by openly discussing and making it appropriate to discuss HIV/AIDS in Aboriginal communities.

### *The Role of Teachers*

Teachers and school principals know how to communicate with young students and can determine appropriate ways, time and place to teach kids about HIV/AIDS awareness within a formal school setting. This is important because during HIV/AIDS workshops put on for the whole community, youth rarely attend. When part of the school day, it is just a natural part of learning. And this is the overall goal; that HIV/AIDS education and learning ultimately becomes a topic people talk about in their daily lives.

Most Aboriginal communities have some key professionals that are either based in the community or visit on a regular basis. Some communities also either have their own school or have their children attend a nearby school. Teachers and other educators who provide workshops/awareness campaigns on HIV/AIDS in the school systems must endeavour to recognize the different levels of knowledge/awareness required for each of the different age groups in the school system (elementary, junior high and high school).

By always keeping in mind the age groups, the teachers and educators can gear their workshops to provide age appropriate information (i.e. children at the elementary age group are not usually sexually active, so the emphasis will be more on general HIV transmission issues with less emphasis on the sexually transmitted aspects as opposed to junior high or high schools students, who would require enhanced emphasis or focus on the sexually transmitted aspect or drug related aspects of HIV transmission along with the general version).

One school wellness curriculum developed by the Province of Saskatchewan under the Instructional Learning Unit provided this outline for how to deliver age-appropriate HIV/AIDS education:

#### **Grade One:**

Apply a concept of infectious diseases that attack the body. Be explicit that HIV is an enemy stronger than the immune system. AIDS is caused by HIV and the focus is on how HIV **cannot** be transmitted.

#### **Grade Two:**

Instruct about providing the emotional support for someone who is ill. Demonstrate the compassion needed. Focus again is on how HIV is **not** spread.



### **Grade Three:**

Safety issues, such as finding a needle. Discuss HIV transmission, within this kind of scenario. Focus becomes managing or controlling HIV/AIDS and introduce it as a potential school research project.

### **Grade Four:**

Discuss role of medical advancements in treating HIV. Speak of advantages and limitations to these. Speak also to progress made in treatments.

### **Grade Five:**

Focus grows to be more on facts and misconceptions around HIV/AIDS. Discuss ways HIV is spread, including needles and sexual activity.

### **Grade Six:**

Focus is on transmission modes and safety in emergency situations (universal type precautions).

### **Grade Seven:**

Focus is on non-risk taking behaviours; stages of HIV infection; signs and symptoms; the immune system and HIV.

### **Grade Eight:**

Discussion can be on sensitive issues, such as the effects of HIV/AIDS on families (and individuals) and communication strategies with parents and caregivers.

### **Grade Nine:**

Focus is on physical, social and emotional needs. Overcoming stigma. Risky behaviours. Community response, present and projected to HIV/AIDS.

### **Grade Ten:**

Focus on HIV antibody testing. Options for testing. Understanding positive, negative and indeterminate (inconclusive) test results. Describe how HIV/AIDS is diagnosed.



## Suggested Action Items:

- A) Use national or regional events, like Aboriginal AIDS Awareness Week, as opportunities to provide learning experiences for students to discuss how HIV/AIDS affects Aboriginal communities. Several examples of learning opportunities are provided below.
- B) Connect with a local Aboriginal AIDS service organization to identify a HIV-positive Aboriginal speaker to come speak to the class. In setting up a public speaker, take this opportunity to begin a discussion with students. Ask them what they don't know about HIV and what they would like to know. Sometimes it is better to provide another option as well - have students prepare and submit their questions anonymously. For older students, particularly, this may reduce their level of discomfort. Share questions with the public speaker before s/he arrives so that they can prepare themselves.
- C) One suggested activity that can be adapted across all youth age groups is a written and/or public speaking exercise. This can help students understand the facts and issues surrounding HIV/AIDS in Aboriginal communities. Open a discussion by beginning with what students feel they already know or have heard about HIV/AIDS. Next, ask students what they would like to know about the disease. Organize students into groups and tell them they are newspaper reporters. Provide students with suggested topics including, for example, how HIV is transmitted, exploring the role culture can play in HIV transmission and mortality or how historical circumstances can influence present day reality in the context of HIV/AIDS, etc. Provide students with appropriate information, such as copies of *Young Eagles' Challenge* (available from the Assembly of First Nations) or have them use the internet where they are to research and prepare a written draft. When complete, work with students to edit and then critique written work. Once a final draft is complete, student groups can present before their classmates for group discussion. Other student exercises can be found in *Young Eagles' Challenge*.
- D) Provide written resources to students, such as fact sheets or information brochures. This can be done on ongoing basis. For older students, a school may wish to consider providing free and anonymous access to condoms, etc.



## The Role of Nurses/Doctors and other Health Professionals

When considering physical health it goes without saying that the role of nurses, doctors and other health professionals (e.g., dentists, psychologists, social workers, etc.) is extremely important to APHAs. In many ways, health professionals will play a key role assisting APHAs to achieve a quality of life and live longer. To do this effectively, all health professionals need to be aware of, if not knowledgeable around, a number of important features that impact how Aboriginal people experience health care. Research shows that a number of important factors need to be considered when providing care to APHAs. They are:

- Many APHAs live not only with HIV, but experience a *layering of stigma*. This layering is thought to be the result of overlapping factors, including how they became infected (e.g., sexual practices or injecting drug use, etc.), that their Aboriginal culture, mental health (e.g., depression or addiction, etc.) or social class (i.e., poor). Research has demonstrated that is particularly true when a health professional, either knowingly or not, takes these factors into account when providing care. Although many feel HIV stigma has been significantly reduced, its important to realize that stigma continues to be an important feature that APHAs must deal with when using health services.
- Although there is incredible diversity within the Aboriginal community in terms of culture, language and traditional practices, it is important to also recognize that Aboriginal people have generally shared similar historical experiences. The experience in the residential school system, for example, cannot be underestimated. For many APHAs this can lead to a lack of trust in any non-Aboriginal, including health care services.
- For many Aboriginal people living with HIV, the importance of traditional health and wellness practices, beliefs and values cannot be underestimated. When Aboriginal people are supported and encouraged to use traditional practices when dealing with HIV, generally they experience a stronger resolve and are better able to deal with negative life experiences, such as living with HIV. It is important to understand that although there is much diversity in practices, beliefs and values, generally the Aboriginal belief system is built around the concept of balance and is an approach to living that is holistic in nature that considers emotional, physical, mental and spiritual aspects of self. Aboriginal people also tend to be family-based cultures.

Probably the most important thing health professionals can be aware of is that when features important to Aboriginal people are not addressed in health care it can lead to limited use of or avoidance of health services all together. The question for health professionals is how best to account for these factors in providing services.

### Suggested Action Items:

- A) One study recognizes the importance of providing not only an awareness of culture, but increasing the cultural content in health programs. Traditional Healers and Elders on staff with resources for traditional practices can make a huge difference to APHAs. Where



funding does not allow Traditional Healers and Elders on staff, health professionals can refer APHAs to an individual in their area. They can also work with Elders and Traditional healers to make them more knowledgeable around HIV/AIDS issues. It is important to always assist with access to traditional services use in dealing with HIV/AIDS.

- B) Health professionals can be mindful of the ways in which a layering of stigma can contribute to negative experience accessing and using health services. Health care professionals can be mindful of practices that (e.g., double gloving, not supporting the use of traditional practices, etc.) lead to negative experiences. Of central importance is to be particularly mindful of issues of privacy and confidentiality at several key points including, at point of diagnosis, entering buildings, dealing with reception, waiting rooms, etc.
- C) Health care organizations can hire Aboriginal front-line staff. Aboriginal front-line staff can help to reduce the lack of trust in a predominantly non-Aboriginal health care system.
- D) Health professionals must engage in a constant process of self-reflection. Questions that can be asked include, “Do I have any attitudes or beliefs about Aboriginal people that may influence my interaction with them?” Only by engaging in a process of self-reflection can health professionals hope to be effective in providing health care to APHAs. Health care professionals who have more awareness, knowledge, are informed and educated around HIV/AIDS issues can contribute to improved experiences for APHAs.



## 3. Making It Happen: Into Action

The following survey showed the top six ways that Aboriginal communities mobilize around HIV/AIDS. A solid majority in each area feel the methods are either good or adequate. Most areas add up to between 80% to 95% who say their methods are effective.

### 3.1 Aboriginal HIV/AIDS Mobilization Methods

|    | <i>% who use</i> | <i>Top 6 Choices of Aboriginal Mobilization</i>                                       | <i>User-Rated Effectiveness</i>   |
|----|------------------|---|---|
| 1) | 96%              | Holding events: AIDS walk, Aboriginal AIDS Awareness Day (now week), AIDS fairs, etc. | 66% said these were good methods, 26% said adequate   |
| 2) | 90%              | Subscribing to HIV/AIDS publications, email lists and mail groups                     | 49% said good, 43% said adequate  |
| 3) | 88%              | Holding HIV/AIDS workshops and conferences  | 74% said good, 22% said adequate  |
| 4) | 87%              | Joining or starting up AIDS groups and/or organizations                               | 69% said good, 15% equally also said either adequate or poor  |
| 5) | 79%              | Ordering HIV/AIDS materials / Offering HIV/AIDS services.                             | 64% said good, 29% adequate for ordering materials. 51% said good, 37% adequate for offering services |
| 6) | 75%              | Implementing Training   | 64% said good, 23% adequate   |

The lowest rating was “joining or starting HIV/AIDS groups or organizations”. While the survey did not ask individuals to explain their answers, there may be a number of reasons why people who replied to the survey do not feel this is as strong an area as they would like. Still, this area added up to about two-thirds who feel it was a good method for mobilizing. This may be speculation, however it is also based on what has been raised in different forums. One may be that the existing Aboriginal HIV/AIDS service organizations need to be supported more to provide a greater effective role within their regions. Most regions have at least one key Aboriginal organization that is addressing HIV/AIDS issues. However, many are fairly new compared to non-Aboriginal HIV/AIDS organizations, some of



which have been around 20 or more years. Also, many of the Aboriginal organizations are short staffed, having maybe two to three staff to serve an entire region.

One other example that did not make the top six, yet a significant number supported the method was to hold forums, talking circles, or committees of Aboriginal People living with HIV/AIDS. Sixty-seven (67%) per cent of the survey respondents used this method, and of this number, sixty (60%) per cent felt it was good method of mobilizing. This was followed by sixty-five (65%) per cent who said having contests (art, competitive projects/presentations, etc.) was a method they used and sixty-two (62%) per cent felt it was good.

These methods can be seen as ways a community can mobilize when starting up a HIV/AIDS program. The resource section and appendices in this report has new templates or tools that can be used to support these types of action. For example, December 1 used to be Aboriginal AIDS Awareness Day and also World AIDS Day. This allowed for a lot of media coverage on a day where HIV/AIDS became the focus of the country with help from the media. In 2004, the Canadian Aboriginal AIDS Network expanded this awareness campaign to be a five day event. Now, December 1 to 5 each year is Aboriginal AIDS Awareness Week. Appendix # 2 offers a list of suggested activities that a community can use to plan and hold a series of events that will help mobilize the community.

There are also other national events that are not Aboriginal-specific, yet could also serve to keep HIV/AIDS in the forefront. The Canadian AIDS Society holds the AIDS Walk, which generally falls in late September. The date varies depending on the region or community. It is a fundraiser and awareness type event to help bring attention to HIV/AIDS and support HIV/AIDS service organizations to offer services to those living with HIV/AIDS. This same organization also oversees a mainstream National AIDS Awareness Week which runs the last week of November and ends on December 1<sup>st</sup>. The Aboriginal AIDS Awareness Week kicks off on December 1<sup>st</sup>, allowing HIV/AIDS to become a steady way of providing messages around awareness and prevention. Materials can be ordered for free from the Canadian Aboriginal AIDS Network or the Canadian HIV/AIDS Information Centre.

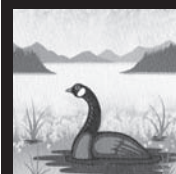
After you mobilize or begin to take action, a natural step is to do advocacy work. Advocacy is about speaking up for the rights of those who may not have a voice. In this case, APHAs, who for whatever reason, may be living in fear and silence. A good approach is to involve APHAs, even if they are not from your community to try and find out what their needs are. Then, find ways to get them involved and do advocacy work in partnership. The next section shows how Aboriginal groups do advocacy work around HIV/AIDS issues.



### 3.2 Aboriginal HIV/AIDS Advocacy Methods

|    | <i>% who used</i> | <i>Top 9 Choices of Aboriginal Advocacy</i>   | <i>User-rated effectiveness</i>                          |
|----|-------------------|---|--|
| 1) | 96%               | Committees, boards, working groups, etc.  | 54% said good, 34% adequate                              |
| 2) | 94%               | Awareness/education campaigns (AAAD, posters, etc.)   | 67% said good, 27% said adequate                         |
| 3) | 75%               | HIV/AIDS strategies, action plans, protocols / media events (press release, news interview, etc.) | 53% adequate, 38% good                                   |
| 4) | 60%               | Governing resolutions (band/hamlet council, B.O.D, etc)   | 56% said good, 41% said adequate                         |
| 5) | 54%               | Letter-writing/email campaigns, petitions   | 42% good, 29% said adequate or poor                      |
| 6) | 52%               | Professional associations (NIICHRO, Abor. Nurses Assoc. etc.)                                     | 52% said good, 30% said adequate                         |
| 7) | 50%               | Parliamentary Politicians (MP, MLA, MNA, MPP)   | 46% said this method was good, 27% said adequate or poor |
| 8) | 46%               | Political Assemblies/Forums   | 38% said poor, 33% adequate, only 29% said good.         |
| 9) | 46%               | Federal/Provincial/Territorial Governments  | 42% said adequate, 33% said poor, only 25% said good.    |

Interestingly, HIV/AIDS protocols or strategies were seen by slightly more than half (53%) the survey respondents as being adequate, followed by 38% saying they were good. This may suggest a need for more resources to train community groups and agencies to establish protocols and strategies. A further interesting observation is very few felt mainstream political players, assemblies or governments were advocates around HIV/AIDS issues. All three in the last table were under half the respondents used these methods, with very low ratings of effectiveness.





## Suggested Action Items:

- A) Committees, Boards and Working groups are most commonly used but only about half say they are effective. In order to increase effectiveness, try smaller teams with some key allies. Have one strong team leader and set realistic goals. It may be also very useful to evaluate these approaches to find out how to make them work better for you.
- B) Awareness Campaigns were listed next as most commonly used, and close to 70% of people said they were effective. Order materials early to do proper planning. Get local businesses on side to donate prizes for most popular or creative school project. Use the time to reach different groups in the community, even those outside of school. Awareness is the first step, anyone can be aware that a service or health issue is available. Education comes next, once you have someone's attention, then you can get more information to them to educate them. Prevention comes from these two efforts, after someone is aware of an issue, and get the facts - then they may make changes to prevent it from happening. Do your own community-based research to see how messages can be tailored to your own community.
- C) Most groups said they used strategies, protocols or action plans to guide their work. But again, only about half said they were effective. Follow the example of the Aboriginal Strategy on HIV/AIDS in Canada (ASHAC) or the Canadian Inuit HIV/AIDS Action Plan. The ASHAC was made easier to read which showed the goals, objectives and the pay off or expected outcome when you did the work outlined in each strategic area. The Inuit Action Plan was developed from community up, and is a good example of how a community not yet hit hard with HIV/AIDS took steps to prevent future cases. Any community can be proactive like that, they do not have to wait until there is HIV in the community to take action. Professional development using these various documents and resources can help increase dialogue and interest in applying them. Attend the annual skills building forum of the Canadian Aboriginal AIDS Network.
- D) Sixty percent said they used resolutions but only half said they were effective. We need to be clear about what we need from elected Leaders. Passing a support resolution can be easy, simply introduce it just before lunch when everybody is hungry and they will vote quickly and pass it. What really is needed, is the passing on of accurate information to Leaders, so they understand the impact and can call for action. So find ways to feed information to your Leadership, and when it comes time to get them on side, they will be more knowledgeable. In many cases, the Leaders who show the most support are those who know someone in their family who has HIV/AIDS. We need to make the message hit home with them, and get them to speak openly about why we must pull together on this issue.



### 3.3 Building Support with elected Aboriginal Leaders

As stated earlier, in developing this kit, two surveys were conducted, with key HIV/AIDS organizations and a number of elected Aboriginal Leaders, mostly First Nations Chiefs.

The data from elected Leaders will be presented next. Because it was a Chief’s meeting, it stands to reason that the majority of those reached are First Nations. The survey was also done by phone and reached two Métis individuals. Efforts were made to reach both Inuit and Métis people and agencies, but were not as successful, in part because the attempt was made leading up to the First Minister’s Meeting in Kelowna BC, which involved Aboriginal leaders in the late fall of 2005.

According to the Métis National Council, generally speaking, Métis Leadership are not directly approached or surveyed. This is left to their lead staff to convey information on behalf of their leader. The Métis respondents in this survey were a senior Health staff or key advisor.

The Inuit community is also in need of better data to reflect how Inuit Leadership can be engaged properly. Attempts were made through an Inuk living in Iqaluit to do phone surveying, but did not produce any results. Thus, while there are some common informational needs of elected Aboriginal leaders, the data about to be presented has a bias toward First Nations.

Sixty-four (64) individuals were reached. Six of these were French speaking First Nations communities, all in Quebec. One of these were an Innu community. Fifty-eight were English speaking. There were two Métis respondents. None were Inuit.

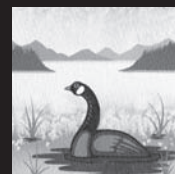
#### Demographics:

| NWT | YK | NU | BC | AB | SK | MB | ON | QC | NB | NS | PE | NF |
|-----|----|----|----|----|----|----|----|----|----|----|----|----|
| 2   | 0  | 0  | 10 | 1  | 2  | 10 | 26 | 10 | 1  | 2  | 0  | 0  |

#### Respondent Titles/Positions

| Chief | Grand/Vice Chief | Councillor | Health Director | Other** |
|-------|------------------|------------|-----------------|---------|
| 40    | 4                | 15         | 1               | 4       |

(\*\* Chair/ Special Advisor/ Chief Negotiator/ Proxy)



**Q.1. How do you rate your knowledge of HIV/AIDS?**

|                |                  |                |               |                    |                 |
|----------------|------------------|----------------|---------------|--------------------|-----------------|
| 0<br>No answer | 1<br>very little | 2<br>know some | 3<br>fair bit | 4<br>major details | 5<br>know a lot |
| 2              | 3                | <b>22</b>      | 18            | 15                 | 4               |

- 19 out of 64 felt they knew very good knowledge.
- 18 out of 64 felt they knew a fair bit.
- 27, the majority, did not answer or said they had very little or some knowledge.

**Q.2 What per cent of HIV-positive test reports are Aboriginal?**

|              |        |                                     |
|--------------|--------|-------------------------------------|
| Less than 5% | 10-15% | <b>15% or more</b> (correct answer) |
| 6            | 23     | <b>34</b>                           |

Approximately **50%** had the correct answer. One person did not answer this question.

**Q.3 What per cent of HIV-positive test reports are Aboriginal women?**

|               |           |                                     |
|---------------|-----------|-------------------------------------|
| Less than 20% | 20 to 30% | <b>40% or more</b> (correct answer) |
| 14            | <b>40</b> | 10                                  |

Approximately **16%** had the correct response. About 63% felt the situation was worse. Close to 21% thought the situation among Aboriginal women was much lower, which is incorrect.

**Q.4 What per cent of HIV-positive test reports are Aboriginal youth?**

|              |           |                                     |
|--------------|-----------|-------------------------------------|
| Less than 5% | 20 to 25% | <b>25% or more</b> (correct answer) |
| 16           | <b>29</b> | 19                                  |

Approximately **30%** had the right response. Approximately 45% thought it was worse. Approximately 26%, felt it was not as serious as it is.



**Q.5 What per cent of HIV-positive test reports are due to injecting drug use (IDU)?**

| Less than 30% | 40 to 50% | 60% or more<br>(correct answer) |
|---------------|-----------|---------------------------------|
| 20            | 34        | 10                              |

Approximately 16% chose the right answer. The majority, 55% felt the situation was about half of our cases. About 30% thought IDU was not as serious an issue.

In addition, 43 of the 64 people surveyed said they knew someone who was living with HIV/AIDS. The vast majority (58 of 64, over 90%) said their community had held an HIV/AIDS workshop. A really good sign was that an overwhelming majority (almost 90%) wanted to know more about HIV/AIDS. About two-thirds said they knew where to call for more information or help.

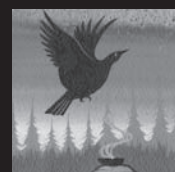
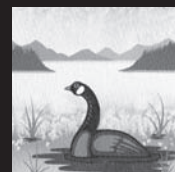
While this information is a very small sampling, it does give some insight into what some elected Aboriginal Leaders know about HIV/AIDS. For those who thought the situation was higher than the current numbers, this can be seen as a good thing, in that they may be saying it needs more attention and concern. For those that thought the situation was not as bad, obviously need more accurate information to help them understand that the HIV/AIDS epidemic is an area of concern for many groups, such as women and youth, to name two. The next section will speak to one barrier that at times, can prevent HIV/AIDS work from happening in a community.

**3.4 What are Community Gatekeepers and how do they fit in?**

In each of our communities and organizations, there is always at least one person who is a 'key' player who is instrumental in making things happen. This could be an Elder or other community member who is knowledgeable about the relevant issues in the community or the community worker who is always involved in different committees. Ensuring the inclusion of committed and knowledgeable community members will further enhance the mobilization effort.

**3.5 Building the Team**

The community mobilization team should include the people from each of the areas that were outlined in section two. This will ensure that the voices of the APHAs will be heard and included and the inclusion of people who are committed to change for the betterment of the community will provide further access and enhanced influence on the funding aspect related to the mobilization effort. But why involve other groups not involved in health? To better explain the need and value, consider this real example of a First Nation community in New Brunswick.



In the early 1990s, a First Nation community of about two-thousand people was struggling with suicides. In 1993, the number peaked, which brought the community to a major realization: something different had to be done. By looking inward, they realized that for every suicide and for every attempted suicide, each community agency would get triggered with crisis management needs. Staff were burning out, the community was hurting. How they handled this challenge was to form a community wellness team, made up of every agency in the community, like the local police, the school, the alcohol and drug workers, nurses, teachers, etc. They also involved the local RCMP. A smaller management team had the responsibility of getting this team working. They secured funding for a crisis line. They set up training. They had a plan and each time a suicide occurred, they acted swiftly. This approach helped to do two things: 1) it got people talking where they found solutions together; and 2) they did more than just crisis management and began to invest in their workers to avoid burnout but also were able to do long term, healing plans with those community members in need.

Although the community still experiences suicides, they are no longer feeling out of control and continue to work together to find solutions. The team has been in place for quite awhile and has been able to take advantage of this organized approach to deal with other issues, including HIV/AIDS when they realized there were community members who were HIV-positive. They struck their own task force to get additional training to prepare for the situation.



## 4. Moving Forward

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There are many issues that Aboriginal communities are facing. It is also not an easy task to be an elected Leader. Housing, suicide, family violence, retaining language and culture, employment, safe water, and many other needs all compete for attention and action. As we see in the previous example, some communities do meet the challenges directly.

Our cultural and traditional strengths remind us that we are family-based cultures with extended family systems. This kit is about using what strengths and knowledge your community has to deal with HIV/AIDS. Underlying this health issue are many related ones, including self-esteem, sex and sexuality, alcohol and drug misuse, and lack of support and feelings of not belonging, etc.

The more we look at different health issues within the realities of what is causing these challenges, we stand a better chance of changing the direction we are going. Our people and communities deserve a better way of life. We are worth investing in our health and well being. This kit is just one tool to help take action on HIV/AIDS and related issues. Elected Aboriginal Leaders are part of the solution and only together can we hope to challenge HIV/AIDS in our communities. We hope you become part of the solution and join in the fight to **stop the spread of HIV/AIDS AND to support our people who are now living with it.**



# Resource List

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## HIV/AIDS Organizations

Canadian Aboriginal AIDS Network (CAAN) – [www.caan.ca](http://www.caan.ca)

Canadian Inuit HIV/AIDS Network (CIHAN) – <http://www.pauktuutit.ca>

Canadian AIDS Treatment Information Exchange (CATIE) – [www.catie.ca](http://www.catie.ca)

Canadian AIDS Society (CAS) – [www.cdnaids.ca](http://www.cdnaids.ca)

Canadian HIV/AIDS Legal Network (Legal Network) – [www.aidslaw.ca](http://www.aidslaw.ca)

Canadian HIV/AIDS Information Center (formerly Clearinghouse) – [www.clearinghouse.cpha.ca](http://www.clearinghouse.cpha.ca)

Canadian Working Group on HIV and Rehabilitation – [www.hivandrehab.ca](http://www.hivandrehab.ca)

Prisoners AIDS Support Action Network – [www.pasan.org](http://www.pasan.org)

Canadian Rainbow Health Coalition – [www.rainbowhealth.ca](http://www.rainbowhealth.ca)

Planned Parenthood of Canada – [www.plannedparenthood.com](http://www.plannedparenthood.com)

Canadian Treatment Advocates Council – [www.ctac.ca](http://www.ctac.ca)

Inter-agency Coalition on AIDS and Development – [www.icad-cisd.com](http://www.icad-cisd.com)

Canadian Association for HIV Research – [www.cahr-acrv.ca](http://www.cahr-acrv.ca)

Clinical Trials Network – [www.hivnet.ubc.ca/e/home](http://www.hivnet.ubc.ca/e/home)

BC Centre for Disease Control - Chee Mamuk – [www.bccdc.org](http://www.bccdc.org)

Healing Our Spirit, BC Aboriginal HIV/AIDS Society – [www.healingourspirit.org](http://www.healingourspirit.org)

All Nations Hope AIDS Network – [www.allnationshope.ca](http://www.allnationshope.ca)

2-Spirited People of the 1<sup>ST</sup> Nations – [www.2spirits.com](http://www.2spirits.com)

Healing Our Nations AIDS Network – [www.healingournations.ca](http://www.healingournations.ca)

BC Red Road HIV/AIDS Network – [www.red-road.org](http://www.red-road.org)



First Nations of Quebec and Labrador Health & Social Services Commission – [www.cssspnql.com](http://www.cssspnql.com)

Nishnawbe Aski Nation AIDS & Healthy Lifestyles Program (Thunder Bay, ON) –  
<http://aids.nan.on.ca>

Wabano Centre for Aboriginal Health (Ottawa, ON) – <http://www.wabano.com/healing.html>





# Appendices

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## Appendix 1

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### Aboriginal AIDS Awareness Week

#### *Sample Proclamation*

WHEREAS, AIDS and HIV impact the globe with an estimated 40 million people living with AIDS or HIV infection worldwide; and

WHEREAS, Canada has a estimated 58,000 people living with HIV and AIDS; and

WHEREAS, Aboriginal peoples are over-represented in the epidemic in Canada with an estimate of 4000 cases; and

WHEREAS, at least one out of every twelve persons are HIV infected in Canada daily is an Aboriginal person.

WHEREAS, Aboriginal people make up 3% of the Canadian population and account for approximately 23% of HIV infections nationally; and

WHEREAS, the epidemic of HIV infection and AIDS requires a nationwide effort to stop the spread of HIV and AIDS; and

WHEREAS, Aboriginal AIDS Awareness Week offers an opportunity to increase community awareness and dialogue about the risk factors for HIV/AIDS, to commemorate those lost, and to bring leaders together to fight the epidemic.

THEREFORE, I, (insert name), serving as (insert title) of (insert city/prov), do hereby proclaim December 1 – 5 Aboriginal AIDS Awareness Week

Signed this \_\_\_\_\_ day of \_\_\_\_\_, 200\_



# Appendix 2

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## Aboriginal AIDS Awareness Week (AAAW) - Suggested Activities :

**Task:** Come up with different types of AAAW activities to run December 1 to 5.

**Purpose:** Looking for any kind of activity where people are

- (1) raising awareness
- (2) coming together
- (3) distributing information

**Audience:** Could be activities targeting youth, addictions, health care professionals, Aboriginal leadership, students, etc.

### Categories:

- (1) Social Events;
- (2) Traditional Activities;
- (3) Media-Related Events;
- (4) Youth and School-Related Activities;
- (5) Sports Events;
- (6) Memorial and Recognition;
- (7) Other Possibilities.

## (1) Social Events

Aboriginal communities can plan gatherings for raising awareness of HIV/AIDS issues and as a place where information and resources are distributed. These Events may include the following:

- Dances
- Women's event (including performance and entertainment)
- Multicultural group function
- Red ribbon sales
- Information stall
- Morning tea and gathering
- Awareness raising information fair
- Community BBQ
- Education session
- Trivia night
- Creation and display of quilt
- Youth talk
- HIV resource displays



- Art competition exhibition
- Newsletters
- HIV-positive speakers
- Community breakfast
- Bake fair
- Bonfire party
- Talent show
- Fashion show
- Concert headlining Aboriginal performers
- A local celebrity invited to participate in various events
- A local AIDS service organization asked to host an open house with various partners
- Snow sculpture competition
- Parade with representation from First Nations, Inuit, Métis, as well as Non-Aboriginal Communities
- Presentation of HIV/AIDS-related films and plays
- A walk on a historical trail
- A panel discussion on Aboriginal HIV/AIDS issues
- Charity casino
- Bingo
- Drag competition
- Pie eating contest
- Auction
- Gift bag promotion
- Flea market

## (2) Traditional Activities

You can integrate both traditional and contemporary Aboriginal activities into your agenda and involve an Aboriginal Elder. Activities could include:

- Talking circles
- Mini powwows
- Drum groups
- Throat singers
- Opening and closing prayers
- Presentation on holistic healing
- Community feast
- Traditional dancers
- Traditional games
- Storytelling
- Arts and crafts display or workshop (i.e. create innovative artworks dealing with HIV/AIDS and sexually transmitted infection, education and prevention)
- Bannock and other Aboriginal food-making demonstrations
- Construction of a traditional dwelling or structure
- Presentation/demonstration on traditional hunting, fishing and gathering techniques



- Workshops on medicinal plants
- Traditional sweats
- Drum making

### **(3) Media-Related Events**

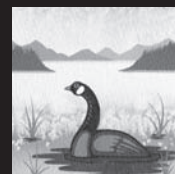
Local media, including print, radio, and television are excellent forums for event announcements, advertising and for awareness-building.

- Write a story about an APHA to be printed in your local newspaper
- Invite the local cable television station to cover events
- Send public service announcement to various Aboriginal media and send invitations for them to attend local events
- Host a workshop on Aboriginal HIV/AIDS issues or post stories of APHAs the Internet

### **(4) Youth and School-Related Activities**

National Aboriginal Day (June 21) can be recognized in schools and by students in a variety of ways. For example:

- Aboriginal guest speakers
- School paper submissions (stories, poems etc)
- Arts and crafts display or workshop
- Traditional or contemporary games
- Storytelling
- Dancers and singers
- Essay and artwork contest
- Give a quiz on HIV
- Field trips to local ASOs and friendship centres
- Research the Aboriginal HIV/AIDS epidemic
- Aboriginal food preparation
- Childrens' colouring contests
- Contests with prizes (talent, poetry, art)
- Camp out
- School plays
- Battle of the bands
- Dinner and a movie night
- 40-hour famine
- Pajama party



## **(5) Sports Events**

Sports events could be organized in schools, communities and businesses, involving both children and adults, in order to raise awareness for HIV/AIDS issues. Activities may include:

- Hockey tournament
- Cross-country skiing race
- Northern and Arctic games
- Snow shoe race
- Group hike
- Snowmobile/dogsled rides
- Day camps

## **(6) Memorial and Recognition**

AIDS Awareness Week is also a time to remember our friends, family and community members who have lost their lives to HIV/AIDS. You can light a candle, show solidarity in silent meditation, read or write a prayer or make an AIDS ribbon. Other options:

- Candle light procession
- Service of remembrance
- Lunchtime vigil
- Memorial ceremony
- Honorary/symbolic tree planting
- Balloon release

## **(7) Other Possibilities**

Special displays of prevention techniques and testing information could take place in libraries, museums, city halls, schools and other public places. Professional gatherings could also be organized. Some ideas:

- Banners on highway
- Honour Aboriginal HIV/AIDS front-line workers and support organizations
- Hold meetings with mayor/city councils and Chief/band councils to share best practices
- Invite institutions that promote Native Studies programs, (e.g., First Nations University of Canada, University of Lethbridge, Trent University) to participate in Aboriginal AIDS Awareness Day activities
- Posters and flyer displayed around the community
- Mobile testing clinics
- Give-aways: prevention (eg. condoms, dental dams, diaphragms, jelly) or awareness (eg. frisbees, calendars, treats)
- Collect a toy (collecting toys or perishable goods and donate to HIV/AIDS organisations)



# Appendix 3

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## Sample Resolution Template

### RESOLUTION # 000/00

#### Issue: HIV/AIDS

Whereas the Human Immuno-deficiency Virus (HIV) causing Acquired Immune Deficiency Syndrome (AIDS) has been identified as having pandemic potential in Aboriginal people; and

Whereas (Aboriginal) (First Nation) (Inuit) (Metis) people have been identified as a high risk group within the Canadian population; and

Whereas since the emergence of this illness, Aboriginal HIV/AIDS Service Organizations (AASO), Aboriginal people living with HIV/AIDS (APHA) and community health care workers have remained committed to the care, treatment and support of our citizens dealing with this life threatening disease; and

Whereas current statistics demonstrate the immediate need for action by elected leadership.

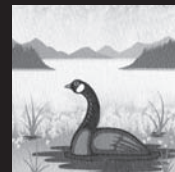
**THEREFORE BE IT RESOLVED** that the \_\_\_\_\_:

- a. Recognise and honour the work of ASO's, APHAs and community health workers for their ongoing commitment in the treatment and prevention of HIV/AIDS;
- b. Mandate the \_\_\_\_\_ Committee to develop a community action plan to deal with \_\_\_\_\_.

Moved by: \_\_\_\_\_

Seconded by: \_\_\_\_\_

**ADOPTED**



# Appendix 4

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## Policy and Procedures Protocol Template

### Policy:

- framework to guide decision making;
- may be general statements about priorities, guidelines, procedures or standards to be achieved, written regulations and may also be informal or unwritten but widely recognized practices.

### Purpose:

to educate our community on the prevention and spread of the Human Immuno-deficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS); protect the rights and privileges of individuals infected with HIV/AIDS; and provide safe environments.

## HIV/AIDS POLICY

### Definitions

AIDS stands for Acquired Immune Deficiency Syndrome

HIV stands for Human Immuno-deficiency Virus or any other causative agent of AIDS.

### Community Responsibility

Our community leadership, council & health departments and staff are committed to programs and policies that protect our community members' confidentiality and

Our community leadership, staff and departments are committed to providing HIV/AIDS awareness and education in order to ensure the health and welfare of all community members



# Appendix 5

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## Points to Consider when choosing APHAs as Guest Speakers:

(Special thanks to 2-Spirited People of the IST Nations and the Gaagiigidok Ogokwek trainees for creating this list.)

- Listen to how well the voice projection is of the APHA when contacting on the phone, if possible.
- HIV+ and Aboriginal speakers are best.
- Education and experience, knowledgeable about HIV/AIDS with experience giving workshops, self research, vast professional network established, graduate from an APHA Speakers Bureau, experience working in Aboriginal communities.
- Ask for and check references from Elders, AASO's or other Aboriginal leaders.
- Speaker should have confidence.
- Ability to tailor "speak" to fit a community or event theme.
- Cultural sensitivity or awareness.
- Contact by phone and listen to voice projection and speaking style - do you feel the charisma?
- Speakers should be able to provide a short personal biography that could be included in the community's HIV/AIDS Workshop flyer or advert.
- Does the speaker promptly return attempts to contact her/him; phone, email, etc.
- Check the APHAs reputation or track record. Traits to look for: punctuality, how good at speaking?, how informed are they?, health status (are they well enough to travel?), theme/ tone of past "speaks", culturally appropriate.
- The best way to get a speaker is by asking other workers who they know and who has given "speaks" in the past. Ask about how the "speak" went. Ask to see the evaluation forms (if there are any) from past workshops where they've spoken.





# Appendix 6

## Statement on Meaningful Engagement of Aboriginal People

This statement is intended to act as a guidepost for how partnerships can better be facilitated between Aboriginal and non-Aboriginal players. It is in response to requests from CAAN members on how best to frame issues of importance when pursuing partnership agreements. It recognizes that there are different levels of engagement, and at times, political issues may arise. While we are aware and respect the choices of individual Aboriginal people living with HIV/AIDS (APHAs) to sit on various committees or Boards, this level of representation does not abdicate the rights of other APHAs to have access to culturally controlled programs and services.

CAAN originated in 1992, as a group of concerned Aboriginal people, some living with HIV/AIDS saw a need. The group incorporated as the National Aboriginal People with HIV/AIDS Network (NAPHAN), however the group was not able to fully mobilize, in large part because dollars were not available to the Aboriginal community in the first two phases of Canada's National AIDS Strategy.

When the second phase of the National AIDS Strategy (NAS-II) ended in 1997, CAAN became incorporated as it secured project dollars through the then Medical Services Branch (now First Nations & Inuit Health Branch) of Health Canada and established an office in Ottawa. Shortly after, many Aboriginal HIV/AIDS groups who belonged to other national HIV/AIDS organizations withdraw their memberships and became members of CAAN. CAAN is a lead voice on Aboriginal HIV/AIDS issues, and for Aboriginal People Living with HIV/AIDS (APHAs) and Aboriginal HIV/AIDS Service Organizations (AASOs) because it has a primary mandate to address HIV/AIDS.

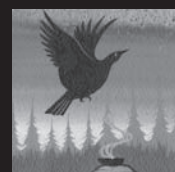
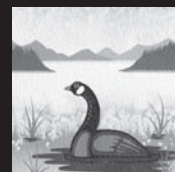
CAAN is one of the National Partners that works with the federal government to ensure a comprehensive response to HIV/AIDS is available in Canada. In addition to CAAN, the National Aboriginal Council on HIV/AIDS (NACHA) provides policy advice to the federal government on Aboriginal HIV/AIDS issues. Both work closely together and have common members to ensure issues have streamlined and cohesive actions with clear roles and relationships.

This statement is to clarify that while CAAN respects the decisions of its members (individual and organizational) to make alignments wherever they see necessary, that Aboriginal groups continue to be in need of critical elements in any partnership negotiations that may be formed with the non-Aboriginal community. These are:

- Recognition and acceptance that Aboriginal people possess Treaty and Aboriginal Rights, and are not classified as a visible minority. The right to self-determination is key to addressing negative impacts of government sanctioned assimilation policies (Residential Schools, etc). Aboriginal people have parallel systems which must be recognized.
- Aboriginal people require adequate resources (not based on per capita formulas) to design, deliver and control culturally appropriate and relevant programs and services.



- Individual Aboriginal people have all the rights and freedoms available to anyone to choose which programs and services they access. This right to choose does not diminish the right to have Aboriginal-specific programs/services also available. As some Aboriginal people become involved with non-Aboriginal service providers, they do so as individuals and not as an official representative of the Aboriginal population.
- Aboriginal people come from diverse backgrounds and are not one homogenous group. This diversity is found within First Nations; between First Nations, Inuit and Métis. Some are based on risk behavior, gender imbalances, sexual orientation, social status, historical issues and often result in minorities within a minority, some of which are compounded by environmental factors, e.g. Correctional Institutions.
- There can be competing interests when considering partnerships. This can include perceptions that a larger organization may want to absorb the smaller group, or, that the larger group may see loss of funding as a threat. Both are valid that need to be openly discussed in order to better understand how to work together. It must be clear that what has contributed to many social challenges for Aboriginal people are based on non-Aboriginal society in general, backed by government policy, which sought to define both the problem and the solution for Aboriginal people, not in partnership with.
- Aboriginal peoples have distinct worldviews that govern how our societies are structured. Cross-cultural efforts are but one way of helping to bridge this divide.
- Aboriginal people often face many challenges which result in inequities that are not easily overcome. These “lived experiences” must be treated as the common ground which binds Aboriginal people together and who are the experts in their own communities and affairs. True and lasting solutions will only come from within the Aboriginal population.
- Aboriginal people must be full and equal partners in any relationship, and have the right to insist that community/cultural protocols and codes of conduct are respected. Skills transfer in some cases must be considered between Aboriginal and non-Aboriginal partnerships so that Aboriginal people can advance the work themselves.
- Partnerships are oftentimes necessary and need to be negotiated with respect and a true willingness to realize mutual objectives without dictating the process or outcomes.
- Non-Aboriginal organizations do provide services to Aboriginal people. These need to be fairly assessed to determine: 1) whether these services are better delivered by an Aboriginal organization and if so, under what conditions; or 2) how best to collaborate with Aboriginal groups so that services provided by non-Aboriginal groups have proper referral systems, Aboriginal staffing, Aboriginal involvement and autonomy.
- A cornerstone of community development is the meaningful involvement, at all stages, of the community being targeted. •









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### **About the Canadian Aboriginal AIDS Network (CAAN):**

- ▶ A National, not-for-profit organization established in 1997;
- ▶ Represents approximately 200 member organizations and individuals;
- ▶ Provides relevant, accurate and up-to-date information on issues facing Aboriginal people living and affected by HIV/AIDS in Canada; and
- ▶ CAAN is governed by a thirteen member Board of Directors.

### ***CAAN Mission Statement:***

As a key national voice of a collection of individuals, organizations and provincial/territorial associations, CAAN provides leadership, support and advocacy for Aboriginal people living with and affected by HIV/AIDS. CAAN faces the challenges created by HIV/AIDS in a spirit of wholeness and healing that promotes empowerment, inclusion and honors the cultural traditions, uniqueness and diversity of First Nations, Inuit and Métis people regardless of where they reside.

### ***CAAN Vision Statement:***

A Canada where First Nations, Inuit and Métis people, families and communities achieve and maintain strong, healthy and fulfilling lives free of HIV/AIDS and related issues where Aboriginal cultures, traditions, values and Indigenous knowledge are vibrant, alive, respected, valued and integrated into day-to-day life.

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