Final Report

Gendering Adolescent AIDS Prevention (GAAP) CANFAR REPORT

HIV RISK, SYSTEMIC INEQUITIES AND ABORIGINAL YOUTH: WIDENING THE CIRCLE FOR PREVENTION PROGRAMMING

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SECTION ONE

INTRODUCTION

In this project we looked beyond individual factors of risk to explore some of the more systemic issues of HIV risk faced by Aboriginal youth. This research is a follow-up to our initial study with CANFAR in which we conducted four focus groups with urban Aboriginal youth in the Toronto area (Larkin, Mitchell, Flicker, Dagnino, Koleszar-Green, & Mintz, 2004) as part of a larger study that included rural youth in Ontario. The project was a sub-study of the Gendering Adolescent AIDS Prevention (GAAP) project which involves several studies with Canadian and South African youth (for details of our various projects see our website, www.utgaap.info).

Until recently, our work with GAAP has been focused on examining gender as a risk factor for HIV transmission among youth. The gendered patterns of infection rates in Aboriginal populations are evidence that such an approach is still warranted; Aboriginal women account for approximately 50% of all HIV-positive test reports among Aboriginal people, compared with 16% among their non-Aboriginal counterparts (DesMeules et al. 2003). Aboriginal women comprise nearly 25% of reported AIDS cases among Aboriginal people, while non-Aboriginal women account for only 8.2% among non-Aboriginal cases (Health Canada, 2003). Furthermore, there is a large increase in HIV infection among Aboriginal women between the ages of 15-29 years old. From 1985 to 1995 13% of HIV-positive test results were for women in this age group. However, this percentage has increased from 37% in 1998 to 45% in 2001 (Gatali & Archibald, 2003). Considering that almost 50% of the Aboriginal female population is under 25 years old, these are very frightening statistics (Dion-Stout et al., 2001).

Based on our work with Aboriginal youth and youth from other marginalized populations, we know that gender alone cannot fully account for the higher infection rates in young women (or young men): factors related to racism, poverty, and geographical location (e.g., rural-urban) are often more salient. For example, desperate economic conditions can convince women and girls to stay in relationships where condom use may be difficult to negotiate. Here gender intersects with poverty to create heightened conditions of risk.

Considering that Aboriginal youth are disproportionately affected by poverty and other systemic inequities (Health Canada, 2004), an intersectional analysis is key to understanding the forces that drive the disease. By intersectionality we mean an approach that "acknowledges that every person…exists in the framework of multiple identities" (Verma, 2003). This means considering factors related to race, class, gender and other social equity dimensions and "the ways in which these dimensions interact with each other (Anselmi & Law, 1998)" to increase HIV risk.

Given the multiple identities of youth "one-size-fits-all" approaches to HIV prevention are limited (Dowsett et al., 1998). While there are common issues that affect youth vulnerability to HIV infection (e.g., attitudes about condom use) our data show that the specificities of risk can be lost if youth are viewed as a homogeneous group. Considering the ways race, poverty, gender and other equity factors intersect to create conditions of risk is important to developing HIV prevention programs that address the situations of diverse
youth. For example, a key finding of our previous CANFAR study was the ways race/racism and a history of colonialism operate to create risk factors particular to Aboriginal youth. We have further explored these issues in this study.

1.1 Background

Although the Canadian HIV infection (0.3%) (Centre for Infectious Disease Prevention & Control, 2002; UNAIDS, 2004) rate is nowhere near the epidemic proportion of many areas of the world, an increase in youth infection rates, coupled with a recent surge in sexually transmitted diseases (STDs) are signs of the potential for the spread of AIDS in Canadian youth (Patrick, Wong, & Jordon, 2000).

Aboriginal youth are overrepresented in the HIV/AIDS statistics. Currently, 30% of Aboriginal HIV infections are among youth between 20-29 years old, compared to 20% in the non-Aboriginal population. Research indicates that the potential for the virus to spread among youth is enormous (CIDPC, 2003). A majority (70%) of Aboriginal youth are sexually active by the time they reach 15 years of age, but very few (less than 20%) use condoms consistently (Myers et al, 1993). This is evidenced by high rates of sexually transmitted diseases and teen pregnancies (OFIFC, 2002) which are often seen as predictors for HIV infection.

However, being Aboriginal is not what puts youth at risk of HIV infection. Unlike the majority of non-Aboriginal youth, Aboriginal youth must deal with a number of socioeconomic and systemic factors that increase their vulnerability to HIV. As Barlow (2003) states, as a result of colonization and the residential school system, violence, poverty and racism are commonplace in the lives of many Aboriginal youth. In general Aboriginal people experience lower educational levels, lower employment and income attainment, inadequate housing, unhealthy water supplies, health risks due to climate change and contaminants, lack of community control and self-determination, isolation, high youth suicide rates, high rates of alcohol and substance abuse and lack of health care access (CIHI, 2004). Each of these factors on their own can contribute to risk; taken together the effects of inequality contribute to the vulnerability of this population.

Common coping mechanisms that are detrimental for Aboriginal youth include the following: migration to urban centres, street involvement and injection drug use. All of these are associated with high risk behaviours such as trading sex for food, shelter or drugs; alcohol and substance abuse; inconsistent condom use; sex with more than one partner; and sharing needles or other drug use equipment (Miller et al, 2002; Neron and Roffey, 2000). To stop the spread of HIV among Aboriginal youth, HIV prevention and education is essential and it must address these socioeconomic issues that put Aboriginal youth at risk in the first place.
1.2 **Specific Research Objectives:**

The overall goals of this study were:

1) To further our work with Aboriginal youth on issues related to HIV risk and to use this data to suggest prevention strategies that may work for Aboriginal populations
2) To compare issues facing Aboriginal youth in regards to HIV in different geographical locations
3) To ensure the voices of Aboriginal youth in various contexts are considered in HIV prevention programming
4) To consider the relevance of our findings for HIV prevention programming for both Aboriginal and non-Aboriginal youth

1.3 **Report Focus**

We expanded on the research of our recently completed CANFAR project by conducting additional focus groups with Aboriginal youth in urban and on-reserve settings in two Canadian provinces: Ontario and Quebec. The focus group discussion guide developed for this project was revised based on the findings of our previous study and the issues identified by Aboriginal youth themselves.
SECTION TWO  

METHODS

2.1 Focus Group Locations

Contacts were made through Aboriginal members of the research team who have contacts in various Aboriginal communities. Individuals were contacted who work with Aboriginal youth in urban and on-reserve settings in Ontario and Quebec in schools, friendship centres, youth councils and other locations. One of the goals of the project was to have a balance of urban and on-reserve focus groups. In this project we went beyond our originally anticipated four focus groups and included two additional focus groups. Ultimately, we were able to conduct three focus groups in urban locations and three groups in on-reserve locations within Ontario and Quebec.

Please see Appendix A for a map showing the six focus group locations and Appendix B giving a detailed description of focus group locations.

2.2 Recruiting Youth Facilitators

Youth facilitators who had a strong connection with a school and/or community group were recruited. Facilitators were at least 16 years of age, and had some experience in working with youth and facilitating small group discussions. Generally, facilitators were responsible for recruiting youth participants in their community, finding an appropriate space, facilitating the group and subsequent follow-up.

Youth facilitators were provided with a facilitation guide, including all the appropriate forms, questions and protocol. Facilitators then had a one-on-one training session in person or over the phone with the GAAP Coordinator. The GAAP Coordinator attended each focus group to tape the focus group sessions, co-facilitate and provide support when necessary to youth facilitators.

2.3 Youth Participants

Overall, we trained 6 peer facilitators, held 6 focus groups and spoke with 61 Aboriginal youth (50% female and 50% male in the urban settings and 76% female and 24% male in the on-reserve locations). The Youth Participants (YPs) are young people (ages 14-27 years) who go to school/live in the schools/communities that the GAAP project had targeted for data collection. YPs participated in a 3 hour facilitated discussion on issues relating to their own communities in regard to HIV/AIDS. Youth were provided with an honorarium for their time, as well food and beverages. The demographic data were obtained from the forms the YPs filled out at the beginning of the focus groups.

Please see the following charts for tables describing groups and demographic data.
SECTION THREE  
FOCUS GROUP DESCRIPTIONS

<table>
<thead>
<tr>
<th>General Descriptor</th>
<th>Average Age</th>
<th>Age Range</th>
<th>Gender Ratio Female</th>
<th>Gender Ratio Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban Youth #</td>
<td>20 yrs</td>
<td>14-27</td>
<td>50%</td>
<td>50%</td>
</tr>
<tr>
<td>Ontario 1</td>
<td>16 yrs</td>
<td>15 – 17</td>
<td>60%</td>
<td>40%</td>
</tr>
<tr>
<td>Quebec 1</td>
<td>21 yrs</td>
<td>14 – 25</td>
<td>50%</td>
<td>50%</td>
</tr>
<tr>
<td>Quebec 2</td>
<td>23 yrs</td>
<td>20 - 27</td>
<td>30%</td>
<td>70%</td>
</tr>
<tr>
<td>On-Reserve Youth #</td>
<td>16 yrs</td>
<td>14-24</td>
<td>76%</td>
<td>24%</td>
</tr>
<tr>
<td>Ontario 2</td>
<td>18 yrs</td>
<td>17 – 20</td>
<td>70%</td>
<td>30%</td>
</tr>
<tr>
<td>Ontario 3</td>
<td>17 yrs</td>
<td>16 – 20</td>
<td>70%</td>
<td>30%</td>
</tr>
<tr>
<td>Quebec 3</td>
<td>16 yrs</td>
<td>14 - 24</td>
<td>86%</td>
<td>14%</td>
</tr>
</tbody>
</table>

This chart shows the breakdown of the six focus groups (3 urban and 3 on-reserve), the average ages of the youth participants, age range and gender ratio.

3.1 Gender Division

<table>
<thead>
<tr>
<th>Focus Group Location</th>
<th># of Female Participants</th>
<th># of Male Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban Youth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ontario 1</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Quebec 1</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Quebec 2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>On-Reserve Youth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ontario 2</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Ontario 3</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Quebec 3</td>
<td>12</td>
<td>2</td>
</tr>
</tbody>
</table>

This chart shows the number of female and male youth participants in urban and on-reserve locations.
3.2 Race/Ethnicity of Focus Group Participants

<table>
<thead>
<tr>
<th>Location</th>
<th>First Nations</th>
<th>Métis</th>
<th>Inuit</th>
<th>Did not self-identify</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban Youth</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ontario 1</td>
<td>3</td>
<td>5</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Quebec 1</td>
<td>11</td>
<td>0</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Quebec 2</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>On-Reserve Youth</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ontario 2</td>
<td>9</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Ontario 3</td>
<td>10</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Quebec 3</td>
<td>14</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

This chart shows the ethnicity of focus group participants in each group.

3.3 Race/Ethnicity Summary Chart

<table>
<thead>
<tr>
<th>First Nations</th>
<th>Métis</th>
<th>Inuit</th>
<th>Did not self-identify</th>
</tr>
</thead>
<tbody>
<tr>
<td>N= 48</td>
<td>N=7</td>
<td>N= 5</td>
<td>N= 1</td>
</tr>
</tbody>
</table>

Please see footnote for a definition of Aboriginal peoples in Canada (First Nations, Métis and Inuit).

1 Canada's Constitution Act of 1982 recognizes three groups of Aboriginal Peoples:

First Nations, Inuit and Metis.

First Nations
A term that came into common usage in the 1970s to replace the word "Indian", which many people found offensive. Although the term First Nation is widely used, no legal definition of it exists. Among its uses, the term "First Nations peoples" refers to the Indian people in Canada, both Status and Non-status. Many Indian people have also adopted the word "band" in the name of their community.

Metis
People of mixed First Nation and European ancestry who identify themselves as Metis people, as distinct from First Nations people, Inuit or non-Aboriginal people. The Metis have a unique culture that draws on their diverse ancestral origins, such as Scottish, French, Ojibway and Cree.

Inuit
An Aboriginal people in northern Canada, who live above the tree line in Nunavut, the northwest Territories, Northern Quebec and Labrador. The word means "people" in the Inuit language - Inuktitut. The singular of Inuit is Inuk (NAHO, 2003).
The majority of the focus group participants were First Nations youth because the highest number of youth participants were in the rural areas, on reserves where First Nations youth reside. In the urban location (Montreal 1) more First Nations youth participated then Métis or Inuit because there was a larger number of First Nations youth who frequented the Friendship Centre at this time and heard about the focus group.

3.4 Procedures

Informed consent was sought from all participants. Parental consent was sought for those youth under the age of 18. At the beginning of each session, the consent form was read aloud and there was time for questions from group participants. All consent forms were collected prior to the beginning of the focus group. Youth were asked to fill out a survey which contained the seventeen questions used in the focus group to see what level of understanding they had in regards to HIV/AIDS before the focus group discussion. Using a scale of 1-5 (1 being strongly agree and 5 totally disagree) participants described how they felt about the questions. Focus groups lasted between 2 and 3 hours. All discussions were audio-taped and professionally transcribed verbatim.

Please see Appendix C for an outline of the discussion guide and Appendix D for the YP’s response to the survey questions before they were involved in the focus group.

3.5 Data Analysis

A community-based participatory research model was used to collect and analyze the data. A data analysis team of the Principal Investigator, two co-investigators, the Research Coordinator, one graduate student and an undergraduate student developed the coding framework and subsequent analysis. Two of the team members, the undergraduate student and the Research Coordinator, co-facilitated the focus groups. In addition, three of the data analysis team members were Aboriginal (50%).

A modified grounded theory interpretive approach guided the analysis. A sub-sample of transcripts was offered to the data analysis team from preliminary analysis. Based on emerging themes, commonalities and major differences, a preliminary coding framework was developed. Each transcript was coded separately by two team members for clarity and to avoid discrepancies. The coding scheme was revised to accommodate new themes as they emerged. After this step the codes were entered into Nud*ist qualitative data analysis software. Coded data were returned to the larger team for analysis. Weekly meetings were held to go over the coded data and discuss main themes, relevance and implications for each code. Collectively, the team’s notes were discussed and summary documents constructed to capture the most common themes, gaps and issues.
SECTION FOUR  

RESULTS

In this section we report on the six dominant themes that emerged from the data: (1) Colonialism (2) Attitudes toward traditions and Elders (3) Condoms (4) Othering (5) Stigma around HIV/AIDS (6) Prevention Strategies.

Our sample was by no means representative or random. Therefore, the results reported here are not meant to be generalized to all Aboriginal youth populations. That was never our intent: our goal was to work with diverse groups of Aboriginal youth to raise important themes that warrant further investigation.

4.1 Colonialism

_We didn’t have AIDS or HIV before. I guess it is the fact that they put us in a really bad position and they stuffed us on reserves and stole our land and told us that we don’t have the right to do this. And I guess that affected the community that there is no clean water and there are lots of drugs and alcohol. That makes the risk higher because when one person gets a sickness the whole community becomes unbalanced. But ultimately, it goes back to the individual. Some people are strong enough to stay clean._  (Female urban)

Youth who participated in the focus groups had varied reactions when asked if they thought that the high rates of HIV/AIDS in Aboriginal communities were related to colonialism. Some youth took a very individualized response when asked this question and did not think colonialism was a factor in the high rates of HIV/AIDS.

_I don’t think colonialism has anything to do with it, their coming here._  (Female urban)

_I think poverty has nothing to do with it. Personally, I think it depends on the individual._  (Male urban)

_We always had problems before the great confederacy; people will always have problems._  (Female on-reserve)

Other youth who participated in the focus groups referred to historical effects of colonialism and related how problems in their community and high HIV/AIDS rates are connected to it.

_It’s just like violence and all the other things you see, it’s just not surprising. It’s something I’ve always known. I guess the community doesn’t see and that really sucks because it’s so related to one another. It’s hard because we take on so much. We have to deal with all these problems and all those issues and there’s not a lot of help that we have. I think with our communities we have a lot of good programs but it doesn’t_
show how related everything is. We can go to a course for substance abuse or go to AA or things like that, but it’s good as far as that one subject. Knowing how many people are infected with almost everything in our community, you know, you can get past it but if you are still being abused...then you are still having emotional dysfunctions, then it’s not going to prevent anything. Everything adds up. I mean they need to show more, have information, because everything’s so related. (Female on-reserve)

Many youth felt isolated and felt the rest of Canadian society does not understand their situation. The youth also felt there was not enough support or respect from the government.

*We need Canadians to understand our issues. They are ignorant about our problems and our issues and they think we have it so easy. What about our land rights, and what they are doing to the earth, they don’t care. We need to educate ourselves first before we educate them. It’s white people’s fault for our problems. We can’t go back we have to go forward. It’s still happening to us today, everyone thinks it’s not. We’re left with all the problems from before to deal with.* (Male urban)

*Like our water, the government doesn’t care about that and all the other health problems we have in our communities, diabetes, suicide, alcoholism. The government doesn’t do enough to help our communities.* (Male on-reserve)

The following statements demonstrate how many Aboriginal youth feel mainstream society views them. Evident in their statements (that were accompanied by laughter when stated) is the underlining hurt and pain that accompanies them. Also in these quotes some of the stereotypes imposed on Aboriginal peoples are evident.

*Aboriginal people don’t exist. Where are they? Weren’t they all killed? I thought they killed them all. Didn’t they commit genocide...aren’t they all dead? No, they live in the forest... [laughter].* (Male urban)

*I’m telling you we should have left them [Europeans] all in the boat and let them die [laughter] I’m telling you they would have died, they didn’t even know what to eat.* (Female urban)

**How Colonialism Affects Aboriginal Youth**

Colonialism has had a devastating affect on Aboriginal peoples and how they see themselves in the world. The worldview of many Aboriginal people has been altered in negative ways. Visible cultural differences can be seen in literature, food, arts, language and dress. Less visible and more significant are what is known as 'deep culture' which include concepts of justice, approaches to problem-solving, notions of logic, ideals in
child rearing, gender roles, values, morality, and worldviews. Though invisible, worldviews can be seen as the foundation of healthy cultures. Political, economic and social institutions simultaneously reflect, reinforce, teach and legitimize a society's worldview (Scott, 1993; Ross, 1996).

Worldviews "fulfill the most general set of pre-understanding one has about reality (Nudler, 1990)". Oscar Nudler argues that worldviews are rooted in the most fundamental human need for meaning and are critical for human survival. He explains, "depriving people of their worlds and colonizing their minds for the sake of the expansion of one particular world…represents an extreme form of oppression, probably harder to face than pure economic exploitation (Nudler, 1990)". Consequently, the imposition of western ideologies and systems on Aboriginal peoples has threatened indigenous survival by eroding the very foundation of Indigenous culture, values, and worldview (Alfred, 1999; Nudler, 1990).

The effects on worldview are important because they affect how Aboriginal peoples see themselves and relate to the world around them. The Aboriginal youth who participated in the groups were very aware of the impact that colonization has had on their families and especially their parents. Unlike many youth, Aboriginal youth seemed to be more understanding and sympathetic to the issues their parents had to endure. They seemed to understand the hardships their parents had to deal with and why their judgments were sometimes distorted. Youth were also aware of the role self-esteem plays in taking care of oneself.

From my understanding, from seeing my mother's generation and being taken away from her mother and with her having children and not knowing how to be a mother, then raising children is hard, because she didn't know how to be a mother. They didn't know the teachings and the things about culture. They were taken away from them. I think the whole residential schools had a huge effect on self-esteem. Safe sex has a lot to do with self-esteem. Like saying the way you want to respect yourself and it has to do with social problems. (Female urban)

One of the most harmful consequences of colonialism is the internalization of the dominant worldview and values (Alfred, 1999). In most Aboriginal communities, everyday life is framed by two value systems that are fundamentally opposed. One still rooted in traditional teachings, structures, social and cultural relations; the other imposed by the colonial state, structures, and politics. This disunity is the fundamental cause of factionalism in Native communities, and it contributes significantly to the alienation that plagues them (Nudler, 1990).

Separation from one's heritage creates alienation, loss of identity and sense of self (Alfred, 1999). This profound loss of meaning and identity manifests in self-destructive behaviour and pervasive social dysfunctions (Alfred, 1999). Suicide rates are six to eight times the national average; domestic violence and sexual abuse plagues communities; unemployment rates on reserves average eighty to ninety percent; and incarceration rates
are twelve to seventy percent above the national average (Hamilton, 2001; Sinclair, 1997). Intergenerational trauma has left entire families and communities caught in a vicious cycle of abuse. Unfortunately, many youth feel this despair and shame imposed on them by the dominant culture.

*I think it goes back to being ashamed of all the things that we’ve gone through, we don’t feel we can be involved and our parents are alcoholics and don’t attend to problems, cause you carry that back to yourself.* (Male on-reserve)

### 4.2 Attitudes Toward Traditions & Elders

*The Elders don’t know enough about HIV/AIDS and they don’t want the community to have anything to do with them [people who are HIV positive]. In my community the Elders say they didn’t have HIV/AIDS when they were young and they are afraid if one person has it the whole community will get it.* (Male on-reserve)

In some Aboriginal communities it is possible to live with HIV with the full support of friends and family. In other Aboriginal communities, this environment is not possible because fear, lack of information and misinformation about HIV persist (Lambert, 1993; Red Road, 1999). Given the history of devastation by diseases in the past in Aboriginal communities\(^2\), as well as new chronic illnesses\(^3\), the difficulty of facing another potential killer by community members is understandable.

Many youth participants expressed their dismay at how people with HIV/AIDS are treated as outcasts when they return to their home communities. When examining this issue, it is helpful to look at how diseases were viewed by most Aboriginal communities traditionally. Aboriginal medical systems, like all such systems throughout the world are built on coherent, rational understandings of the universe and people’s place within it. ‘Rationality’ must be understood to be a culture-specific notion; one culture’s rational thought is not necessarily the same as another’s. Inherent in any group’s medical system are ideas about how disease is caused and what types of treatment are called for (Waldram et al, 2000).

**Traditional Views of Disease**

Traditionally, Aboriginal peoples in Canada saw/see disease as the product of either natural or supernatural occurrences. Within this worldview, minor illnesses such as colds, headaches and digestive disorders were not likely to arouse anxiety and were treated with herbal remedies. Serious illness, in contrast, was viewed as a penalty for a prior transgression of the moral order and a disruption in balance between the human world

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\(^2\) From the seventeenth century onwards, smallpox, measles, influenza, dysentery, diphtheria, typhus, yellow fever, whooping cough, tuberculosis, syphilis, and various unidentifiable ‘fevers’ caused illness and death as they spread from person to person and from village to village (Waldram et al, 2000).

\(^3\) Diabetes, heart disease, obesity, etc.
and ‘other-than-human’ entities and therefore required the assistance of a specialized healer (Waldram et al, 2000).

There were/are many types of healers among Aboriginal peoples of Canada. Basically, there are three types of healers: Herbalists, ‘Medicine men/women’, and Shamans. The herbalists employ various botanical substances, usually in combination with which they treat a wide variety of disorders. The ‘medicine man/woman’ denotes a healer who has supernatural sanction to make a person well and who follows supernatural dictates in his curing activities. The ‘shaman’ has the ability to fall into a deep trance and undertake spirit flight or summon spirits to council him/her (Waldram et al, 2000).

Between 1880 and the mid-twentieth century Aboriginal traditional medical systems were subjected to a variety of oppressive measures by Canadian government and the churches. Laws under The Indian Act prevented Aboriginal peoples from practising ceremonies; other restrictions imposed included leaving the reserve without a pass card and meeting in groups. Meanwhile, Christian celebrations were encouraged.

Although these laws existed, many Aboriginal people continued to practise the traditional ways in secret (Waldram et al, 2000). Despite this continued practise, significant amounts of traditional healing knowledge were lost and there were fewer healers than in the past. When these attempts to disrupt spiritual as well as political and economic infrastructures did not sufficiently assimilate "Indians," children became the next targets through the residential school system.

With the onslaught of European diseases and oppressive measures on traditional medical systems, traditional belief systems were unable to account for the new diseases, let alone counteract them. The legacy of these oppressive measures still exists today (Waldram et al, 2000). These factors play a role in why many Elders do not know how or do not want to learn how to deal with HIV/AIDS in their communities. As well, prejudice against drug users, those involved in the sex trade and issues of homophobia, all contribute to Aboriginal people who are HIV positive being stigmatized in their home communities.

_Yeh, the person who has HIV would be shunned because they’ ll be seen as dirty and bad. (Male on-reserve)_

As well, some reserve communities are in a state of denial with leaders who claim that HIV/AIDS is a ‘white man’s disease’, or that ‘we don’t have a gay problem on our reserve’, or that ‘It’s something that only happens in big cities’ (Vanderhoef, 1998). It does not help that in most Native languages there is no word for HIV or AIDS; the closest word to it in Ojibway is _akuusah_, or sick (Maxwell, 1999).

**Residential Schools**

Residential school legislation, which was in effect and implemented for over one hundred years (and ended in 1996), forced over 100,000 Aboriginal children out of their homes and communities into foreign educational systems (Sinclair, 1997). The ultimate aim of
these institutions was to assimilate Aboriginal peoples into Canadian society. The nature of the schools fostered various forms of abuse: physical, sexual, spiritual, cultural, and psychological. Nuns and priests were instructed to train the "Indian" out of the children and consequently cut their hair and changed their clothing into uniforms upon arrival.

Punishments were arbitrary and an everyday reality, especially for those students who dared speak in their Native languages (Llewellyn, 2002). Chronic under funding meant that many children were hungry, malnourished, and even forced into labour to support the costs of running the schools (Llewellyn, 2002). Many children upon return to their families could no longer relate to their parents. The disruption in family unity and child rearing practices has meant that survivors are often unable to care adequately for their children, and the cycle of abuse and neglect continues (Hamilton, 2001).

The legacy of residential schools has affected all Aboriginal peoples in Canada. These institutions have done severe damage and have left many with negative assumptions about sex and same-sex attraction. The widespread sexual abuse that occurred in residential schools makes it difficult for many to have a healthy view of sexuality. Instead, sexuality has become a source of shame and pain. (McLeod, 1997).

*It stems from the lack of culture when kids were away in residential schools and didn’t have their language and traditions. Drinking and all that stuff go way back and gets deeper and harder to deal with for generations. (Female on-reserve)*

Colonial ideology and Christian values of shame and guilt around sexuality have altered beliefs and customs and affected the way that some Aboriginal people are capable of talking about and practising sex. Early missionaries held a theocentric position, in which there was only ‘one truth’, and they harshly criticised Aboriginal peoples’ practises, and viewed customs related to sexuality as indecent. With the addition of forced assimilation through Christian residential schools, some Aboriginal peoples have maintained their conversion into Christian ideology and others may have simply adopted beliefs over time, sometimes on an unconscious level.

*A lot of people don’t talk about it [sex], my Godmother she won’t talk about it, only now she’s starting to talk to me about things but not really, her mom wouldn’t talk to her about it, she’s like it’s just not something they talk about, I guess they don’t feel comfortable with it. (Female urban)*

Some of the most obvious conservative beliefs of the Christian influence are sexual abstinence before marriage and discrimination of homosexuality. Even in today’s general society there is still a belief that sex education encourages youth to be sexually active. Historically, however, Aboriginal cultures openly taught about sexuality, even in ceremonial practices. Sexual intercourse was a sacred act which led to the procreation of life. Homosexual people of the community were accepted equally as anyone else, they were referred to as the ‘two-spirited people.’ There was no shame attached to the naked body or intercourse. It was a natural part of life, which followed the life passage of
puberty. Fear of stigma and discrimination from families, friends and community members is a powerful force against change. It discourages questions and honest conversations about sensitive topics and keeps people locked in unhealthy behaviours.

**Youth & Elders as Educators in HIV/AIDS Prevention**

During the focus groups the youth did not talk very much about how cultural traditions played a role in HIV/AIDS prevention (3 out of 6 groups did), but when they did discuss traditional cultural values they had positive things to say about their role in preventing the spread of the disease.

*That’s one of the strong things we have about our community [traditions], it’s still there and it’s still relevant too. (Female on-reserve)*

During the focus groups, it was evident that the majority of the youth had great respect for the Elders in their communities. Although both urban and on-reserve youth said they prefer peers who are living with HIV/AIDS to educate them about the disease, many youth (both urban and on-reserve) expressed how they would like to learn from the Elders about sexual education and diseases.

Many youth thought that it would be useful for the Elders in their community to learn more about HIV/AIDS so that they could influence the community to stop the shunning of individuals who are living with the disease. Some youth suggested a youth conference and an intergenerational connection where Elders and youth could learn together and then work together to fight this problem in their communities.

*I know that school is not the best way to learn because that’s not the traditional way. I think it should be through Elders. Some will talk about it but some wouldn’t. If they were informed than they might be really into it. (Male urban)*

**4.3 Condom Use**

The youth we spoke with were quite vocal about youth sexuality. They acknowledged that youth are sexually active, often at a very young age, but that many youth did not choose to use condoms. Many youth were not familiar with female condoms, or they were familiar but had never seen one up close. For this reason, in this report, we will be using the term ‘condom’ to refer to ‘male condoms’. All of the youth we spoke with – urban and on-reserve knew what male condoms were and were able to talk about them as both a form of birth control and STI prevention.

From what the youth said, it appears that females tend to take responsibility for condom use and males are somewhat reluctant to use condoms. During the focus groups, both urban and on-reserve youth said that condoms were readily available from youth drop-in centers, from the health nurse, school guidance office and the doctor’s office. Although free condoms are readily available, there is a lot of suspicion attached to using these
condoms by Aboriginal youth. This suspicion could be tied to the history of White settlers and the history of diseases such as smallpox that were imposed on Aboriginal communities.

> The worry about free condoms is that someone has poked a hole in them and even if there’s a needle poke there’s still a risk with a little hole of contracting HIV/AIDS. (Female urban)

Although condoms were available, there were a number of concerns that prevented youth from accessing them, such as embarrassment, lack of confidentiality and worries about the quality of the condoms. When asked if they ever got condoms from the guidance office one youth stated:

> Yeh, but who’s gonna go ask, that makes you look stupid because you look like you’re gonna go fuck. (Male urban)

Two youth said the following about getting free condoms from the guidance office.

> In my school the nurse is smart because she just puts them outside her office. (Female urban)

> Yeh, but then you get the person who just walks by and puts them all in their pocket...[laughter] Yeh, I think it’s better to have them in school bathrooms in dispensers so it’s more discreet and have instructions so people know how to use them. (Male urban)

Other youth had the following to say about condoms that are available from dispensing machines in bathrooms:

> A lot of people don’t want the condoms from the machine because they are generic brands and really cheap and I don’t trust them I think I’ve seen one place where they had Lifestyles brand. (Male urban)

When youth tried to buy condoms in the city they said that they ran into situations where the sales people in the stores did not have enough knowledge about condoms to help them buy what they were looking for.

> Sometimes the people who work there [in the pharmacy] don’t know, you gotta be in a sex shop to ask a question like that...like I was at the pharmacy and I asked for a razor and the guy told me they don’t sell phones there...[laughter from group]...when they have helped me they give advice like this one is for his pleasure and this one is for you, and I’m like “ok”. (Female urban)

Youth also pointed out that it is embarrassing for some people to ask for condoms.
Just going in to buy condoms sometimes is embarrassing for some people, even nerve wracking. I think people don’t want to get the information, like asking the people in the pharmacy. But if they did ask, the people working there could tell them you can get condoms besides latex if [you’re] allergic. (Male urban)

Gender Relations and Condom Use

Prior to colonization, Aboriginal women enjoyed honour, equality and even political power in ways European women did not at the same time in history. The diminishing status of Aboriginal women began with the progression of colonialism. The majority of Aboriginal cultures in Canada were originally matriarchal or semi-matriarchal. European patriarchy was initially imposed upon Aboriginal societies in Canada through the fur trade, missionary Christianity and government policies. Because of white intrusion, the matriarchal character of Aboriginal spiritual, economic, kinship, and political institutions was drastically altered (LaRoque, 1994).

Colonization and racism go hand in hand. Racism has provided justification for the subjugation of Aboriginal peoples. While all Aboriginal people are subjected to racism, women further suffer from sexism. Racism breeds hatred of Aboriginal peoples; sexism breeds hatred of women. Aboriginal women often experience racism and sexism. Aboriginal women have been objectified not only as women but also as Indian women. (LaRoque, 1994).

White North American cultural myths, expressed in literature and popular culture, have perpetuated racist/sexist stereotypes about Aboriginal women. A direct relationship between racist/sexist stereotypes and violence can be seen, for example, in the dehumanizing portrayal of Aboriginal women as 'squaws', which renders all Aboriginal female persons vulnerable to physical, verbal and sexual violence. One of the many consequences of racism is that, over time, racial stereotypes and societal rejection may be internalized by the colonized group. The internalization process is one of the most problematic legacies of long-term colonization (LaRoque, 1994).

As a result of disintegrative processes inherent in colonization, many Aboriginal people have subconsciously judged themselves against the standards of white society. Part of this process entails 'internalizing' or believing — swallowing the standards, judgements, expectations and portrayals of the dominant white world. The result is often shame and rejection not only of the self but also of the similar other, i.e., other Aboriginal people. Due to this situation Aboriginal women often experience low self-esteem, physical violence from partners, racism, sexism, loss of traditional roles, discrimination by the government; the list goes on.

The youth who participated in the focus groups had the following to say about condom use and how it affects women in their communities:
Women may take risks they normally wouldn’t because they like a guy and want to keep him. (Female on-reserve)

Some girls have sex just to keep their man. (Female urban)

I find girls are more orientated with their own safety as opposed to guys. (Male on-reserve)

Yes, a lot of women feel they have to have sex. (Female urban)

Some will get abused if they don’t. (Female urban)

If the guy doesn’t want to use a condom the girl will agree. (Female urban)

Yes, if she’s weak... [laughter]. (Female urban)

Some women are afraid that a man won’t want them if they say they have to wear a condom or they’ll think they are easy. (Female urban)

If you have like low esteem, then you don’t care about things, so why use a condom. (Female urban)

I think it depends, I guess some girls are able to put pressure on the guy to wear it, I know some girls that are really assertive and insistent and I know some girls who don’t want to use a condom. (Male urban)

Following is what the youth in the focus groups had to say about Aboriginal males:

Some guys won’t wear condoms and force women to have sex anyway.  
(Female on-reserve)

Most men don’t want to use condoms, it just doesn’t feel as good.  
(Male on-reserve)

The youth who participated in the focus groups had a good understanding and awareness of sexual violence in their communities. The youth gave numerous examples of how women are often manipulated or choose not to wear condoms in their relationships due to low self esteem or in order to keep a man in their lives. Despite this the youth also indicated that it is often the women who decide whether condoms are used during sex most of the time, thus feminizing the role of condom use.

From what the youth said, there seems to be a double standard when it comes to condom use and gender. Youth talked about the sexual double standard that continues to operate
between young women’s and men’s sexuality. This is one area where there was little variance across groups: young men continue to be idolized for sexual prowess, whereas young women continue to be chastised for their sexual exploits.

If girls have lots of sex they’re sluts and guys are praised for it, it’s a double standard. If a woman has a lot of partners no one will know but if a man has a lot of partners you will know. Women are more secretive when it comes to their sexual activity. (Female on-reserve)

The youth also said that females were more likely to use condoms and are the ones who take responsibility when they are used.

I know girls who have sent guys ten blocks to get condoms. (Female urban)

Girls are more likely to use condoms because they don’t want to get pregnant, on my reserve we have so many 12 and 13 year olds who are getting pregnant. (Female on-reserve)

There are guys who purposely walk around without condoms knowing that they’re going to have sex. (Male on-reserve)

The youth also pointed out that it depends on the person’s self-esteem whether they use a condom or not.

I think it mostly depends on the guy or the girl and their attitude, if they don’t respect themselves, or have low self-esteem, ’cause a lot of guys think they’re good if they get a lot of pussy, it helps their self-esteem. If it is a girl she thinks “I wonder if this guy really likes me and if I do this with his maybe he will like me better.” (Female on-reserve)

Even if there are condoms available some people won’t use it because they’re drunk and they don’t care, and are ashamed of using it and letting everyone know they’re going to get laid tonight, takes away from the moment, hold on I have to put on this condom [laughter]. (Female on-reserve)

Some youth felt if they were in a relationship than it is safe to have unprotected sex, a stance that assumes both partners are monogamous and ignores the risk that may have come from previous partners.

I don’t think most youth care too much, they don’t think anything bad will happen, if the girl is on birth control and they are in a relationship, they won’t use a condom. (Female on-reserve)
Unfortunately, some on-reserve youth have a fatalistic attitude when it comes to using condoms and having sex, often brought on by isolation and boredom in reserve communities.

_Sometimes youth are too high, on my reserve they have like orgy parties [Laughter]...yeh, and they’re so drunk they don’t care who they’re with, some youth don’t care about their future. Yeh, there’s nothing else to do so they just do what feels good at the time._ (Male on-reserve)

### 4.4 Othering

Our research shows that youth ‘take up’ the notion of HIV as a disease of ‘the other’. Whether talking about “people in Africa”, “sex trade workers”, “poor people” or “urban” or “on-reserve” dwellers – it was clear that young people understood HIV as something that happened to other people ‘over there’. While AIDS is a disease that disproportionately affects such vulnerable groups, no one is immune from the risk factors associated with AIDS. A few Aboriginal youth identified HIV as a problem in Aboriginal communities, but generally, HIV was not understood as a problem in their specific community.

In general, urban and on-reserve youth, agreed that they thought women and men in the sex trade, were at the greatest risk for getting HIV/AIDS.

*A lot of women turn to prostitution to support drug habits._ (Female urban)

*Yes, prostitutes deal with a lot of people so their risk of getting AIDS and other STDs goes up._ (Female urban)

*Maybe they [prostitutes] can’t afford condoms._ (Female urban)

*Yes and sometimes getting the money is more important then being safe at the time._ (Female urban)

One young woman pointed out that although she was homeless she did not turn to prostitution to get money.

*I was homeless not even a month ago and I still didn’t sell myself for money._ (Female urban)

Although most youth agreed that women are more vulnerable to HIV/AIDS it was an urban male who had turned to prostitution when homeless. Male prostitution is seldom addressed in literature on HIV risk.
Other youth got their information from the media and thought women and children in Africa were the highest risk group.

*Women are more likely to have AIDS [laughter] I’m serious have you ever watched World Vision…women and kids are the ones who have it.*  
(Female on-reserve)

The majority of youth don’t believe HIV/AIDS is a gay disease. However, one youth talked about how people still have misconceptions about 2-spirited people, anal sex and HIV/AIDS.

*I don’t know, some people can be pretty ignorant and they’ll say “gay men can’t get AIDS, cause it’s anal sex”, I’m like “what are you talking about” I tell them it’s not true but I still hear a lot of people say that. Even with straight couples every now and then you hear you can’t get STIs if you have anal sex, a lot of people just think you can’t get infected that way.*  
(Female urban)

Some youth thought that poor people were at risk of catching HIV/AIDS. According to some youth, it was a person’s choice to be poor if they lived in Canada where poverty is less pervasive than in the developing world.

*Some are dirty, they don’t feel good about themselves so they go out and have sex, they don’t care about themselves, it’s their choice in this country anyway, in other countries people don’t have a choice if their poor or not, I mean people put themselves where they are at in this country anyway. If they are poor it is their choice to be poor because they chose to go to school. In other countries people don’t have a choice.*  
(Male on-reserve)

*People on the streets, etc. choose to be there.*  
(Female on-reserve)

*A lot of people experience negative things from people and it makes them think badly of the world and they try to cover their feelings with sex or drugs. They have never had the feeling that they are even worthwhile and that they have a choice about poverty so they choose to live their life in that way.*  
(Female on-reserve)

*Like alcoholics and drug users use that because they want to push their negative feelings aside and sex is the same; they have it to feel better and then they catch AIDS. That is why when you are poor you have a higher chance of getting AIDS because you are trying to cover the feeling of living in poverty.*  
(Female on-reserve)
Yes, that’s probably why AIDS is high in our community because a lot of our people feel this way. There are a lot of drugs in our community. (Female on-reserve)

During the focus group with urban youth, some youth talked about why they think on-reserve youth are at high risk of contracting HIV.

I heard that Aboriginal youth who are very sexual are not big on condoms, especially people who don’t live within the city. (Male urban)

I had an experience with my ex-girlfriend and she actually lives up North, in a small community and the way I felt was for her to use a condom over there...I guess they have a kind of immaturity, I guess because in their schools that they don’t teach that or support that about how important it is. I guess to them they’re not comfortable with that. (Male urban)

On-reserve youth described activities in their community that would suggest many youth have a lack of awareness or concern for situations that put them at risk for HIV/AIDS.

Promiscuous youth are at risk, the one’s who sleep around a lot and don’t protect themselves because they don’t care. (Female on-reserve)

Drug addicts who shoot drugs [are at risk]. (Male on-reserve)

People on reserve drink a lot and have group sex. (Female on-reserve)

Sometimes youth are too high, on my reserve they have like orgies . (Male on-reserve)

[Laughter]...yeh, mine too and they’re so drunk they don’t care who they’re with. (Male on-reserve)

After prostitutes and those who are promiscuous, youth thought drug addicts were at risk of catching HIV/AIDS. Some youth had some pretty strong feelings towards how they thought some people who are addicts with HIV/AIDS would interact with others when it came to safe sex practices. This comment illustrates the internal turmoil that may lead to drug abuse and other risk behaviour that leads to HIV/AIDS infection.

When you are an addict, you don’t care about yourself, so why would you care about HIV, or giving it to somebody else?...so if you know you have it you don’t care about how many people you give it to cause all you want to do is take other people down with you. No one is helping, you know you may be surrounded by people, but you feel isolated and you don’t have the self esteem or the drive to go on so what does it matter if you hurt others along the way. Like your hurting someone else to make yourself feel a bit
better, maybe it’s not the worst situation, so some people have that
attitude like I’m hurting, so I’m gonna make other people hurt, make you
feel what I’m feeling and they just don’t care sometimes and if you are an
addict...like the world is pretty bleak sometimes...so you know, why
should you care if you’re hurting people on the way. And sometimes you
find solace in knowing that the other person is going to get what you have,
maybe for five minutes, it’s like it’s nothing, you get that comfort for that
brief period of time, it’s just like any other addiction, instant gratification.
(Female urban)

Both on-reserve youth and urban youth felt like they were considered “others” by
mainstream society. Urban youth had the following to say about how non-Aboriginal
people see them in the cities. The following quotes illustrate issues connected with
assimilation. It seems from the comments by the YPs that urban youth deal more with
racism and on-reserve youth deal with issues of isolation and its consequences.

There are so many misconceptions, because nobody understands, nobody
knows. So people think “Oh you are Indian,” well maybe you don’t pay
taxes, or this, that, or I thought Indians are gone. (Male urban)

I get that people refuse to believe that I’m Aboriginal. It’s either that or
it’s oh God, she’s Aboriginal. They always go do you drink a lot? One of
my names growing up was Pocahontas because the movie had just come
out and they’re like “hey Native girl.” And they’re like “Oh, it’s her, it’s
Pocahontas”. (Female urban)

People used to think I was Chinese [Laughter]. (Male urban)

I’m Chinese and black, Filipino and black, Spanish and black, Japanese
and black or Ethiopian. (Female urban)

I’m not an Indian. I’m Aboriginal. (Female urban)

On-reserve youth felt that they were considered “the others” by mainstream society and
had strong feelings about how things needed to change to bridge the relationship between
Aboriginal peoples and the rest of Canada. These quotes show how isolation on reserves
can make Aboriginal youth feel disconnected from the rest of society.

We need Canadians to understand our issues, they are ignorant about our
problems and our issues and they think we have it so good. (Female on-
reserve)

What about our land rights, and what they are doing to mother earth, they
don’t care. (Female on–reserve)
We can’t go back we have to go forward. It’s still all happening to us today, everyone thinks it’s over but it’s not. (Female on-reserve)

Most Canadians think that we don’t pay taxes or that we get free education, and they think we should be equal citizens. (Female on-reserve)

4.5 Stigma About HIV/AIDS in Aboriginal Communities

Aboriginal people living with or affected by HIV/AIDS experience discrimination in many ways. Discrimination may come from band administrators and community members, health practitioners and the general public. Discrimination is often associated with misunderstandings or lack of knowledge about HIV/AIDS (Matiation, 2000).

Many Aboriginal people feel they could not return to their home communities because of the stigma of HIV/AIDS. Often people want to return home but feel they cannot because of the shame they would bring to themselves and their families or they feel they wouldn’t be accepted by the community (Report of the Royal Commission on Aboriginal Peoples, 1996). When fear and stigma are what people feel when they hear about HIV/AIDS in Aboriginal communities, it prevents the community from dealing effectively and openly with the disease. As a consequence, the virus has a better chance of spreading.

Youth in the focus groups were very understanding of how community members felt towards people who had HIV/AIDS.

_They know, that the infections or HIV is something bad that kills you and can be transmitted and they take that information and they go further with that. So yeah they are afraid to get it too so they call that person who has it unclean._ (Male urban)

_I guess they are just afraid of getting it. For them, those kinds of sicknesses are a death sentence. So it is like “Oh I got this disease, I can’t go on anymore”, and people are just afraid of it._ (Male urban)

_There is no problem asking for help about tonsillitis because it’s not dealing with an area that most people feel kinda private about. Like cancer, like to say I have cancer you get sympathy and support but HIV you are getting really personal and the person is afraid they’ll be shunned._ (Female urban)

_That’s true, but I think people are more open to talk about cancer because it is not something that you can pass on to another person and HIV/AIDS you can, so I think that is what makes people afraid._ (Male urban)
The youth who lived on-reserve talked about how it was not safe to let other people know your business because then it would be spread throughout the community for everyone else to know.

*And the people are ashamed and they keep it quiet. And it’s not a safe environment.* (Female on-reserve)

*You can’t come out [telling you have HIV/AIDS] in a small community. You can’t do anything without everyone knowing what you are doing.* (Male on-reserve)

*The girls that I used to have lunch with at the Aboriginal lunches at the school they just sat there and gossiped the whole time, they knew everybody’s business. It’s pretty scary and it limits what you are going to do if everybody is going to know about it.* (Female on-reserve)

The youth also talked about how people with HIV/AIDS were treated when people found out they had the disease.

*If someone looked like they had AIDS in my community they would be kicked out.* (Male on-reserve)

*Yeh, mine too.* (Male on-reserve)

*I agree, no one would tell because even their family would be like outcasts.* (Female on-reserve)

*Most people wouldn’t go back to their community if they had it.* (Female on-reserve)

*And they’d blame the person who had it, no compassion just judgment and punishment.* (Female on-reserve)

*There is a stigma that goes with it. There is also a lot of fear associated with it. It is something that once you have it, you have it. And there is a sense that it could only get worse.* (Female urban)

*People are afraid when they have the disease to tell other people about it because they are afraid to be rejected.* (Male urban)

One youth told the focus group about a very painful experience he encountered when he returned home. He was not HIV positive but his family thought because he had lived in the city and had resorted to prostitution in order to provide himself with shelter, that he was dirty and should not use the same dishes and utensils as the other family members.
This is a real true story, when I left home, I told my mom I was on the street and I was pushed into a short-term period of prostitution until I found a homeless shelter, my mom had a separate set of cups and dishes for me. My dishes were not allowed to mix with their stuff and all of my things had to be in the washroom and theirs in the kitchen. (Male urban)

Youth also pointed out how many people, especially older people don’t want to talk about HIV/AIDS.

When you live in society when everything’s taboo and you don’t talk about things, then there’s a different reaction. In an open society like this, nothing is hidden and it’s all okay. And there are still societies similar to where I came from, those societies where they think it’s weird, it’s not normal. It’s something you don’t really hear a lot, but I think it is a big problem... It’s almost like It’s forbidden. (Male on-reserve)

Because sexual abuse and drug abuse are very rampant they stay quiet because they don’t want to be punished for it, banished, be pointed out, singled out, they just continue to keep quiet. (Female urban)

It’s better not to talk about it like if you get raped on the reserve you’re the talk of the town for months and you feel like an outcast, you got your family against you the cops don’t care so it’s better to say nothing so no one talks about it and it’s like AIDS no one wants to talk. (Female on-reserve)

Like you just don’t go and talk about HIV if you know nothing about sex, the parents don’t talk to their kids because they think the school should do it and the school thinks the parents should do it and there are those people who think nobody should talk about it. (Female urban)

One youth said that on their reserve a woman went around to the schools in the community and talked to the youth about the disease. The youth saw this as a very positive situation for their community.

Where I used to live, they talked about it a lot cause a lot people down there got it. And there’s this one lady that goes around to all the schools and talks about it. I don’t know if she’s got it, but she talks about it, and she goes around and tells everybody about it. (Female on-reserve)

4.6 Strategies for Preventing HIV/AIDS in Aboriginal Communities

The HIV epidemic among Aboriginal peoples shows no signs of slowing down. Evidence suggests that injecting drug use is the most common mode of HIV transmission (64%) and that Aboriginal women make up a large part of the HIV epidemic in their
communities (50%). Aboriginal AIDS cases are younger than non-Aboriginal cases. 28.6% of Aboriginal people who are infected are under the age of 30, compared to 17.6% in the non-Aboriginal population. Developing prevention messages that are effective in Aboriginal communities is crucial to stopping this epidemic (CAAN, 2002). A first step is identifying the factors that contribute to HIV risk.

Risk factors for Aboriginal youth (First Nations, Metis and Inuit) associated with contracting HIV/AIDS include:

- Young people are likely to experiment with activities that put them at higher risk like alcohol and drug use, and various forms of sex;
- Young people often believe they are invincible, and that it won't happen to them, coupled with mind altering substances, this combination can be very dangerous;
- Young people are also more likely to traffic between high and low risk areas, for example, it is not uncommon for First Nations young people to leave their reserve and move to a larger city like Toronto, where the risk of HIV infection is higher, then return and pass the virus on to youth in lower risk areas;
- Sex education provided in schools is sometimes not culturally appropriate to reach Aboriginal youth. A lot of the time, HIV is identified as a gay disease, and straight or bi-sexual youth believe they will not be affected by it (CAAN, 2002; Health Canada, 2000).

Although the following risk factors for contracting HIV/AIDS are not particular to Aboriginal communities, they are compounded by the kind of challenges facing Aboriginal youth, such as the affects of colonialisms including racism, poverty, substance abuse, etc.

- Low rates of safer sex practices (indicated by high rates of teenage pregnancy and high rates of sexually transmitted diseases),
- sexual and physical violence,
- low self-esteem,
- alcohol and drug abuse,
- poor health in general,
- high mobility among the Aboriginal population,
- reluctance to get HIV testing (Ontario Aboriginal HIV/AIDS Strategy, 2002).
As this graph shows, there are notable differences between Aboriginal and non-Aboriginal peoples with respect to exposure category for both reported AIDS cases and positive HIV test reports. For reported AIDS cases, includes data from 1979 to December 31, 2003. For positive HIV test reports, includes data from 1998 to December 31, 2003 (Public Health Agency).

**Prevention Strategies:**

Key findings from the Canadian Aboriginal Aids Network (CAAN) report, *HIV Prevention Messages For Aboriginal Youth*, state that there are not enough Aboriginal (First Nations, Métis and Inuit) specific messages for youth; messages need to target youth before they become sexually active (under the age of 15); messages need to target injection drug users; on-reserve, rural and isolated areas need more attention; and that a coordinated, national strategy for Aboriginal youth HIV prevention should be developed (CAAN, 2004).

In our findings with urban and on-reserve Aboriginal youth we learned that both groups would like to see ‘scare tactics’ (i.e., messages that instil fear) when it comes to effective prevention messages. Contrary to what the literature says about scare tactics not working with youth (Vergani & Frank, 1998) we have to keep in mind that Aboriginal youth may prefer to learn in different ways than mainstream youth, and so different strategies need to be used to reach them.

On-reserve youth, particularly in the fly-in communities, thought video conferencing would be beneficial so that all the fly-in communities, and all the people who live there, (Elders, parents and youth), could get the same information. The youth came to the conclusion that if everyone got the same information about HIV/AIDS and understood
the facts, that this knowledge could potentially break the cycle of banishment of those with HIV/AIDS in their communities.

*I think video conferencing would be good then you could connect all the communities together and everyone would be getting the same information and then the Elders and other people could watch and find out the truth and stop banishing people with HIV/AIDS.* (Male on-reserve)

Urban youth pointed out that the messages need to address the environment the youth live in: urban messages for urban youth and relevant messages for on-reserve youth, Inuit youth and those who live in rural areas.

Below is a chart showing a summary of the suggestions from urban and on-reserve Aboriginal youth in Ontario and Quebec who participated in our focus groups, when asked about what strategies they thought would and would not work when developing prevention strategies and methods of delivery for Aboriginal youth.

**Suggestions for Effective Methods of Delivery for HIV/AIDS Prevention:**

<table>
<thead>
<tr>
<th>Urban Aboriginal Youth Methods of Delivery</th>
<th>On-Reserve Aboriginal Youth</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female: I think the youth council could inform other youth</td>
<td>Female: Have people with AIDS tell their story and what they go through daily</td>
</tr>
<tr>
<td>Female: Maybe youth mentors</td>
<td>Female: Peer groups are really important</td>
</tr>
<tr>
<td>Female: Pamphlets aren’t going to work</td>
<td>Female: Education programs, programs to stop binge drinking</td>
</tr>
<tr>
<td>Female: Commercials work</td>
<td>Female: We grow up watching media, they can put messages through the media</td>
</tr>
<tr>
<td>Male: TV shows like Degrassi High, if we had an Aboriginal version that tackles issues Aboriginal youth face then maybe that would get the youths interested</td>
<td>Male: Bribery works, like us here today we’re getting $20</td>
</tr>
<tr>
<td>Female: Let them know how it is spread, that it is not just sex but bodily fluids from blood and mother’s milk</td>
<td>Female: I don’t think anyone has ever talked within a discussion group beyond the one subject, like how all our problems are related and how they all started, it’s just about the present issues, it’s hard to change something when you don’t know where to start</td>
</tr>
<tr>
<td>Female: A role model is a good idea, they know and we’d listen because we can see they have it and they can tell us what they’ve been through and how they are</td>
<td>Female: We learn in a different way than mainstream kids, we need to be scared of what could happen, need graphic details, pictures, people talking about it</td>
</tr>
<tr>
<td>Male: In my community we had people come and talk about HIV and that didn’t work</td>
<td>Female: Need pictures of people all disfigured or something, or their internal organs and how they are affected compared to a normal person, or a picture of the number of medications they have to take</td>
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</tr>
<tr>
<td>Male: I think it needs to be put out there more and it needs to grab the people and really educate them because the information that we get now is so bland</td>
<td>Female: There was a program called “Try Hugs Not Drugs” and when they first started it, the lady who co-ordinates it honestly thought that there would only be 2 or 3 kids who would show up. But when it started there was a lot more people who showed up because they provided a lot of fun things to do. If you do something like that about AIDS and have different stations were you can go and do something fun with lots of activities about AIDS, then a lot of people would come</td>
</tr>
<tr>
<td>Male: Going to high schools once a year and telling people about things. They have to go out and do it. People are going to have sex whether you like it or not, but it is best that they be reminded of the dangers</td>
<td>Female: There was this event that talked about alcohol, and they had glasses you could wear to see what a drunk sees, something interesting like that, things like that</td>
</tr>
<tr>
<td>Female: In the street art festival they made a game out of it. There was a spinning wheel, I remember that. It was like snakes and ladders and you had to answer questions Male: They made it into a game, asking sex questions to see how much you know about sex Female: You felt pretty cool if you won Male: It means you know a lot Female: If you didn’t win you were so surprised</td>
<td>Female: But you can’t always have all these fun things all the time because that is not educating. You have to show them that it is a crippling illness</td>
</tr>
<tr>
<td>Male: We have a lot of organizations don’t we? We have APHA and all kinds of organizations whose entire being is because of the disease. So they should be informing people</td>
<td>Female: You can have something fun and attractive but you also have to have some scary stuff. It has to be educational. Tell them that if you look at someone with AIDS you wouldn’t know, they have a physical illness, things like that</td>
</tr>
<tr>
<td>Male: It is mostly information, information</td>
<td>Female: I think in order to stop AIDS in</td>
</tr>
</tbody>
</table>
has to be out there and you have to force feed this information because nobody is going to ask you “Can you tell me about this?”

our community I think that people that have AIDS or know about it should tell kids that they can have a better lifestyle if they know about AIDS because we really do live by example

Female: The hardcore reality is effective. Somebody who is living in a city is not going to really relate to someone who lives in the country. You need to suit the situation

Female: A comic book would be good

Male: There was a girl last year who was going from school to school talking about her experience with HIV/AIDS, that was a good way

Female: I think there should be a black and white poster with a HIV positive person’s organs and the organ would be all you see because it would be in colour and then say “this person has AIDS” and put them around the school

Male: Well they should be out with more media and staking out the bars and making sure that people are getting protection

Male: I think video conferencing would be good then you could connect all the communities together and everyone would be getting the same information and then the Elders and other people could watch and find out the truth and stop banishing people with HIV/AIDS

I think a youth conference would be good then youth can get involved and learn more about it

Pamphlets are useless, we need real people connecting to the communities

**Sex Education:**

When it came to sex education, across the board, youth said they were not happy with what they were taught in school. Below are some statements about what urban and on-reserve youth thought about sex education in their schools and what they thought should be included in sex education classes.

**Experiences with Sex Education Classes in Schools:**

<table>
<thead>
<tr>
<th>Urban Aboriginal Youth</th>
<th>On-Reserve Aboriginal Youth</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female: Our Sex Ed teacher didn’t know much about sex. He was telling us that a douche was a form of contraceptive and I’m like “no it’s not, what are you talking</td>
<td>Female: You learn basics… very basics, what STDS are…and the boys go in the other room</td>
</tr>
</tbody>
</table>
about?” then he had to go home and ask his girlfriend. Then he came back and said “Oh I’m sorry. I was wrong yesterday.” He’s like just practice abstinence

<table>
<thead>
<tr>
<th>Male: Health class, for one week we learned about it, not much just the basics</th>
<th>Female: I have to take it like third year of high school. You’re like forced</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male: They taught me about sex in grade 8 or 9 and I was like “you guys are kind of late because most people have had sex already, good time to tell us</td>
<td></td>
</tr>
<tr>
<td>Male: They tell us the forms of contraception, abstinence, HIV and all they tell us is that they are bad. Like if you have sex you’ll contract gonorrhoea</td>
<td></td>
</tr>
</tbody>
</table>

What Aboriginal Youth Would Like To See In Sex Education Classes:

<table>
<thead>
<tr>
<th><strong>Urban Aboriginal Youth</strong></th>
<th><strong>On-Reserve Aboriginal Youth</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Female: Give them condoms, show them how to use them properly</td>
<td>Female: The teacher can say here is the topic, ask me about what you want to know about and I’ll explain them to you</td>
</tr>
<tr>
<td>Male: Talking and demonstrating condom use</td>
<td></td>
</tr>
<tr>
<td>Female: If you’re close with your family you learn more from them because half the time the school doesn’t even know what they are talking about</td>
<td>Female: Peer educators and they should separate women from men because the way they talk about sex is completely different and to have someone 50 years older than you, even 20 years older, is screwed up and you’re not going to listen, it’s like thinking about your parents having sex</td>
</tr>
<tr>
<td>Female: Sit them down and talk seriously about it</td>
<td>Female: Talk in the school about it and promise paintball afterwards and all the kids would come</td>
</tr>
<tr>
<td>Male: I don’t think there is anything they can do that will work they need to find out on their own</td>
<td>Female: Yeh, and the whole community needs to be informed to understand so they don’t make anyone an outcast who has it and so people understand the risks better</td>
</tr>
<tr>
<td>Female: Making sex fun and enjoyable</td>
<td>Female: You have to make it fun too</td>
</tr>
</tbody>
</table>
Testing:

HIV testing among Aboriginal people must address broader issues in the communities in order to be effective. There is no single solution to testing and confidentiality is a big issue in Aboriginal communities. The situation in each community is different: remote reserves, reserves closer to built-up areas, rural communities, urban communities, and groups such as two-spirited people, women, men, and drug users may each require a different approach.

Following are some issues raised in the literature related to HIV testing. According to the literature the issues that need to be addressed are vast, for example:

- Discrimination is experienced by Aboriginal people living with or affected by HIV/AIDS in cities and in rural and reserve communities,
- Many people have concerns about confidentiality, especially in small communities,
- Some people do not trust Western medicine and Practitioners,
- Some people are not comfortable using mainstream testing facilities. In some cases this reflects cultural difference rather than direct racism,
- Differences between Aboriginal and non-Aboriginal values, attitudes and experiences respecting sexuality, relationships and other issues that can have a bearing on HIV testing,
- Culturally based differences in communication styles and differences in language,
- Culturally based differences can make mainstream facilities and services less accessible to Aboriginal people,
- Low self-esteem affects the number of people being tested. In some subgroups, especially street drug users and other street-involved people, there is a fatalistic and/or defeatist attitude about HIV,
- Aboriginal people are a highly mobile population in Canada. As people move across jurisdictional boundaries from reserves to cities, from cities to reserves and from province to province, they often fall into a policy and service vacuum or have difficulty finding appropriate services,
- It is not uncommon for Aboriginal people to experience racism in health care (CAAN, 2002).

The HIV testing currently available to Aboriginal people is inadequate for a variety of reasons, including: the remoteness of some communities, cultural differences, and a failure on the part of the health-care system to address the specific needs of the
Aboriginal community with respect to HIV testing. As a result, despite rising numbers of HIV and AIDS cases in their community, many Aboriginal people are reluctant to get tested for HIV (CAAN, 2002).

Currently, Aboriginal people can receive HIV testing off reserve from any provincial or territorial institution or clinic that can conduct the test, including hospitals, doctors offices, and anonymous testing clinics, where available. In addition, a small number of testing clinics or programs specifically designed for Aboriginal people are available in a few Canadian cities such as Vancouver and Toronto. Many of these organizations, however, are under severe demands for their services and lack sufficient funding to respond to the needs of all those who approach them (CAAN, 2002).

A factor that stops Aboriginal people from testing for HIV/AIDS in remote communities is the cost of accessing testing facilities from distant locations. In some parts of the country an Aboriginal person may have to travel long distances at great expense to take advantage of an anonymous testing facility, or even to get tested at a local health centre. The period between taking a test and getting the result is generally much longer in rural and reserve communities than in major cities and may require two expensive trips, one for the test and one for the result. Further, many communities are visited by a health nurse only sporadically. In these circumstances, the chance that a person will get tested or, having been tested, return to the health centre to get the result, is reduced.

On reserves, Aboriginal people can generally be tested for HIV at the community health centre by a community health nurse (CHN). Most reserve communities have a CHN and health centre, although in some smaller communities the CHN may divide time between a number of communities. Aboriginal people may not feel comfortable using mainstream testing facilities; others might prefer to see a non-Aboriginal practitioner or testing site in order to increase the sense of anonymity.

There are barriers to testing in facilities within a small community. People may be reluctant to use the local health centre due to confidentiality concerns. In some communities, a health centre capable of performing the test may not be available and a person may be referred to a larger centre. Many people in smaller Aboriginal communities lack the resources to get to a testing facility in a larger centre. As a result, few Aboriginal people living in rural areas are being tested (CAAN, 2002).

The majority of youth in the focus groups, both urban and on-reserve knew where to go to get an HIV test. However, youth who lived on-reserve said they would not go and be tested in their communities because they felt scared or embarrassed. The reasoning behind this was that they would know someone at the clinic who would tell other people about their coming in to be tested. As one youth said:

She’ll tell my grandma…guess who’s at the clinic getting condoms and an HIV test. (Female, on-reserve)

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4 Vancouver Native Health and Anishnawbe Health in Toronto are two examples.
Yes, people are embarrassed; they’d be an outcast if everybody knew they had it. (Female on-reserve)

Youth living on-reserve said that in order to get an HIV test they would go out of their community so that they could keep the test confidential.

I’d go out of my community. (Male on-reserve)

One youth pointed out that some youth don’t know where to go to get tested where their test results will remain confidential.

The thing is, a lot of people don’t know where the facilities are and how to go about it, a lot of people are like “I’m not going to go” it’s like not having the knowledge of where to get tested where no one will know who you are. (Male on-reserve)

Urban youth said they believed some young women and men get tested when they go for check ups or a pap test at the doctors.

They might get tested when they go for a check-up at the doctor’s. (Female urban)

Yes, maybe once a year when they get a check-up. (Female urban)

Or when they go for a pap test. (Female urban)

Maybe when he goes for a check-up. (Male urban)

Other youth thought it was good to ask for an AIDS test when you are getting other blood tests.

It’s not embarrassing if you get it with other blood tests. (Female on-reserve)

Youth in the focus groups said that they know very few of their peers who had been tested. Youth who were tested or who would consider going for testing gave the following conditions they thought would be ideal:

It was at the centre and they were giving out HIV tests. They said “why don’t you go get tested” and they gave you money, they gave me like $20.00. It was like ‘wow’, sure I’ll get tested, I get money and get to know my status, why wouldn’t I go do it. (Female urban)
Maybe if they are in the doctor’s office and the doctor asks them if they want to have an HIV test while they are there, then they’ll say “yes”, but they won’t just walk in and ask for a HIV test. (Female on-reserve)

You have to go to Toronto to get an anonymous test [at the free clinic] they don’t take your name or health card they just give you a number that matches your blood. (Female on-reserve)

Some youth agreed that youth would only go for an AIDS test if they felt they were at risk of contracting the disease.

I don’t think most youth would go for a test. (Male on-reserve)

Only if their partner had it and was showing signs, maybe then. (Male on-reserve)

Maybe then, if they had sex and then felt sick. (Male on-reserve)

Reasons youth gave for not going for AIDS testing include the following:

They don’t think about it, it’s not something like you go get your pap and you think I’m clean I don’t have to get a test. (Female urban)

Especially, like some people will have steady partners for a long time so they don’t play the game anymore, so they can relax and people who play around they don’t think of it too much either. (Male urban)

And you don’t want to think that everyone has HIV, you hope that they are going to be honest with you and if you ask them and they tell you “no”, you wanna believe them. (Female urban)

They don’t test much, they test for pap and everything else you have to ask for individually and they don’t ask you if you want to do it, they don’t want to work that hard. (Female urban)

And you go to a clinic and you say “I want to have an HIV/AIDS test” and they’re like “ok come back in four months”. (Female urban)

And you’re afraid of the test because it might come out positive and you just don’t want to know, it’s like you’re in denial. (Female urban)

Get tested at the clinic, if you are positive they will call your partners so people won’t go and be tested. (Female on-reserve)

Most youth thought that women were more likely to be tested than men.
Women are more likely to get tested than men because when they get a pap, they sometimes get tested for STIs and the doctor asks if they want an AIDS test. (Female on-reserve)

A lot of men are scared of the different tests and won’t be tested. Men won’t even test or check their urethra because they don’t want anyone touching them there. (Female on-reserve)
SECTION FIVE  IMPLICATIONS AND RECOMMENDATIONS

This study took a community-based participatory approach to studying and understanding systemic issues of HIV risk faced by Aboriginal youth in on-reserve and urban communities in Ontario and Quebec. In this study we also examined factors related to colonialism, racism, poverty, and geographical location (e.g., rural-urban).

It is important to note that Aboriginal youth are not a homogenous group and that providing messages that have a pan-Aboriginal approach will not work. First Nations, Métis and Inuit youth all come from diverse, distinct cultures and each culture’s values and beliefs need to be addressed and respected. Aboriginal youth live on-reserve and in urban settings and these factors also need to be addressed when talking to youth about HIV/AIDS, as each environment needs a different approach to be effective.

All of the youth who participated in the focus groups, both on-reserve and in urban areas, were very outspoken and clear about how they felt about HIV/AIDS whether positive or negative. Many are determined to see things change in their communities in regards to HIV/AIDS. This a promising for the future.

While it is beyond the scope of this study and report to offer a full analysis of how best to address the issues of HIV/AIDS amongst Aboriginal youth, there are several key recommendations that come out of this study:

5.1  Prevention

HIV prevention strategies should engage explicitly with connections to colonialism, racist histories, and the impacts of residential schools. It may be productive to situate HIV prevention within large discussions of the social determinants of health and connect to the issues affecting Aboriginal communities and individuals. Being aware of the issues that Aboriginal people and communities face historically, on a daily basis and in regards to HIV/AIDS is crucial not only for Aboriginal peoples but for front-line health care workers and anyone else dealing with HIV/AIDS.

Specific actions that health care workers can do to increase Aboriginal populations participation in testing and prevention measures include:

- Acknowledging the layered stigma that exists for Aboriginal peoples when accessing the health care system (e.g. avoiding mixed population support groups, where often non-Aboriginal people are insensitive to Aboriginal people’s concerns; instead have available culturally relevant talking and sharing circles with Aboriginal facilitators, so that Aboriginal people feel comfortable talking about HIV/AIDS)

- Improving services to reduce access barriers to testing and treatment (e.g. confidentiality, camouflaging services, etc.)
- Establishing trusting client-health care provider relationships (e.g. health care workers can be more welcoming to Aboriginal clients and non-judgemental towards 2-spirited clients, etc.)

- Recognizing the importance of culture (e.g. establishing services that are culturally competent (e.g. hiring Aboriginal staff, Elders, etc.)) (R. Jackson et al, 2006).

Offering some level of traditional health and wellness programs within conventional health care services can help ensure that Aboriginal people will feel more comfortable accessing testing services as well future interventions. Many youth in our study said they would like Elders to teach them about sex education and HIV/AIDS. If health care workers collaborate with Elders and offer supports such as sharing circles, traditional ceremonies, Elders as advisors, availability of traditional medicines, traditional gatherings, etc. within their programs where there are large Aboriginal populations this may help increase Aboriginal participation in HIV/AIDS prevention and treatment.

5.2 Limitations of Existing Programs

Attitudes towards relationships, condoms and HIV prevention are gendered and prevention approaches need to take into account the gendered realities of youth relations. From our research it is evident that there are many strong young Aboriginal women and men who are protecting themselves from HIV infection. Unfortunately, there are still some young women who do not have the confidence to insist on protection during sex or who feel pressured into having unsafe sex with their partner. Likewise, there are still too many young men who either do not care to protect themselves during sex or do not know how to use condoms effectively. These issues regarding relationships, condoms and HIV prevention, need to be addressed in prevention programs.

Sexual risk taking and substance use are interconnected and serve to multiply issues for youth – this heightened situation of risk needs to be addressed in all prevention programs. During our focus groups, many on-reserve youth talked about their communities where boredom and isolation often lead to substance abuse and unsafe sexual practices. This is a barrier to health care services in HIV prevention that needs to be addressed.

A critical factor that is not currently being addressed is that of confidentiality in regards to HIV/AIDS testing. In order for more people to access testing services more anonymity in services is needed. Many youth stated that they would not go for testing in or near their own communities because of the lack of confidentiality and the stigma that would be directed at them if anyone found out they were HIV positive.

As well as the issues of confidentiality in regards to testing, access to condoms is also a problem for youth in urban and on-reserve communities. Youth stated in the focus groups that they did not trust free condoms or felt embarrassed asking for them. Unfortunately, youth in the focus groups did not give specific examples of how condoms should be made
available, beyond being available in dispensers in washrooms. Therefore, alternative measures of delivery developed with the input of the youth in regards to accessing condoms, is needed.

Stigma around HIV/AIDS and those who have the disease is very profound in Aboriginal communities. Many people are banished from their communities when it is discovered they are HIV positive. Stigma reduction through education, teaching of traditional values around sex, disease and homosexuality, may help reduce the discrimination of people with HIV and ultimately operate as a prevention strategy.

5.3 Community Involvement

During the focus groups with both urban and on-reserve Aboriginal youth it came up repeatedly how more community support is needed in regards to HIV/AIDS prevention. It was quite evident that community acceptance is an important issue for these youth, something we didn’t hear to the same extent in focus groups with other youth groups (Larkin et al., 2004). This community approach is important because focus on the community as opposed to the individual is a part of the worldview of many Aboriginal peoples and communities and so would be a culturally relevant approach.

The youth also emphasized how it is important that everyone get the same information about HIV/AIDS and understand the facts. Youth also saw the importance of having this kind of education available to community members at a much younger age, such as in elementary school. Education also needs to address the problem of seeing HIV/AIDS as a disease of the ‘other’, such as sex trade workers and poor people. Education programs need to illuminate the fact that HIV/AIDS can happen to anyone. The youth came to the conclusion that this knowledge could potentially break the cycle of banishment of those with HIV/AIDS in their communities.

Many youth pointed out that they would like to learn the traditional values around sex, homosexuality and disease. The youth noted that too many older people in their communities would not even talk about sex and felt ashamed of sex due to Residential Schools and Christianity. By learning about the traditional values around these topics they could ultimately break the cycle of shame and stigma around sex and disease that currently exists in their communities.

5.4 Delivery of Prevention Messages and Programs

The youth who participated in the focus groups had many interesting ideas for prevention messages and programs (please see pp. 29-31 for specific suggestions). The comment that came up the most often is that programs should be interactive and fun. Most youth agreed that face to face and peer programming may be effective, as well as initiatives that have a connection with real people such as HIV/AIDS workers, people with HIV. Youth also pointed out that youth would be interested in media as a form of communication, such as video conferencing which could also be utilized by other members of the community such as Elders, parents and smaller children.
Other youth suggested a youth conference and an intergenerational connection where Elders and youth can learn together and then work together to fight this problem in their communities. Following a youth conference it was suggested that follow up studies be done that include Aboriginal youth engagement.

Perhaps the current generation of Aboriginal youth can break the cycle of shame and stigma around sexual practices and HIV/AIDS in Aboriginal communities by talking openly about sexual education and learning from Elders about traditional ways. By involving the whole community whether it be in an urban or on-reserve setting, and providing support through culturally relevant prevention and treatment programs the statistics in regards to HIV in Aboriginal communities is sure to decrease. Aboriginal youth have many creative and intelligent suggestions in regards to preventing HIV/AIDS in their communities. Putting the power and resources in the hands of these youth and others in their communities to stop this epidemic of HIV/AIDS in Aboriginal communities is the key to prevention.
Appendix A

HIV Risk, Systemic Inequities and Aboriginal Youth: Widening the Circle for Prevention Programming

Focus Group Locations in Ontario and Quebec (Urban and On-Reserve)
Appendix B

Focus Group Locations

In total, six focus groups took place for this project. All focus groups were conducted by an Aboriginal member of the research team. An extra group was held in Quebec (Quebec 2) due to interest from youth participants. Following is a detailed description of each focus group location.

Ontario 1:

The Ontario 1 focus group, consisted of youth participants (YPs), who lived in the East end of Scarborough, ON. The area where the youth reside is an area where youth are significantly disconnected, alienated and gang involved. Many initiatives are offered by Aboriginal agencies so the youth can avoid gang involvement and reclaim lost ties and revitalize their Aboriginal roots.

Three males and five females participated in the group. The age of the participants ranged from 15 to 17 years old, with the average age being 16 years old. The majority of the participants were Métis. Most youth knew each other well and felt comfortable with each other, although many did not feel comfortable talking about sex with their peers in a group setting.

Ontario 2:

The Ontario 2 focus group took place at a First Nations High School on land where a former Residential school was located. Being a private First Nation controlled and operated school, the High School offers a very unique and culturally relevant educational experience to 24 First Nation communities in Northern Ontario.

The First Nations youth who attended the focus group on November 9, 2006 were in grades 9 through 12 and were of various ages. All the youth who attended the focus group were very articulate and talked favourably about their school environment. It was clear by the youth’s mannerism and speech that they were a very tight knit community even though they were originally from different communities. This closeness was further enhanced from the students living and attending school in the same location and interacting with each other on a daily basis.

Quebec 1 & 2

The focus groups for Quebec 1 & 2 took place in the same organization: a non-profit, non-sectarian, autonomous community development agency whose principal mission is to promote, develop and enhance the quality of life in the urban Aboriginal community. The agency serves the Aboriginal population of eleven nations of Quebec. These nations include the Inuit, Cree, Mi’gmaq, Naskapi, Algonquin, Montagnais, Abenaki, Mohawk, Attikamekw,
Huron and Malecite. The centre also works with other nations throughout Canada and the United States.

In the focus group for Quebec 1, fourteen Youth participated, seven females and seven males. The youth who participated in this focus group were older with an average age of 21. The majority of YPs in this group were First Nations and 3 YPs were Inuit.

On the day of the focus group for Montreal 2, 12 youth were signed up for the group but only 6 were able to attend. This shortage of participants was due to it being a Friday and because there was a terrible snow/freezing rain storm on that day. The six participants who attended the group consisted of four males and two females. The youth ranged in age from 20 to 27 with the average age being 19 years old. The majority of the YPs in this group were Inuit.

**Ontario 3**

This focus group took place in the library of a southern Ontario First Nations community. This group was pretty close knit. Many of the youth were related, which allowed the youth to be more open and honest. Ten youth participated in the focus group, seven females and three males. The ages of the youth ranged from 16 to 20 years old, with the average age being 17 years old.

**Quebec 3**

The Quebec 3 focus group took place at a First Nations community situated by the Ontario/Quebec boarder in Canada and the Upper New York State border. This group was very challenging at first as there was a large number of young youth. The youth seemed to be really hesitant at first to speak and needed a lot of probing. Many of these youth were either siblings or first cousins. Four-teen YPs, all First Nations youth, attended the focus group, and the average age was 16 years old.
Appendix C

Discussion Guide

After the youth participants had filled out the following form individually, the youth facilitator guided a discussion through the questions.

GAAP Focus Group Discussion

Gender: __________

Age: __________

Location: ______________________________________

First Nation ___  Métis ___  Inuit ___  Non-Status ___

On a scale of 1 to 5 describe how you feel about the following questions

1) I strongly agree
2) I somewhat agree
3) No feeling
4) I somewhat disagree
5) I totally disagree

1) Men have a higher chance of getting HIV because of biology.

2) When someone has a Sexually Transmitted Infection (e.g. Chlamydia, Herpes, Gonorrhoea or Syphilis) they are more at risk for HIV infection.

3) Globally, women and girls are more at risk of HIV infection than men and boys.

4) Being poor puts people more at risk for HIV infection.

5) HIV is a gay disease.
6) Most youth (two-spirited and straight) use condoms when that are having sex.

7) Young women and young men are equally willing to use condoms.

8) Most sexually active youth get HIV tests every time they change sex partners.

9) Young people worry about contracting HIV/AIDS.

10) Some youth are more at risk for contracting HIV than others.

11) You can tell by looking at someone whether they are HIV positive.

12) Sex education in schools is where most youth get information about HIV/AIDS.

13) HIV/AIDS is a problem for people in my community.

14) Aboriginal communities are more at risk for HIV than other Canadians.

15) There are things that Aboriginal communities can do to help protect youth from HIV.

16) Youth from Aboriginal communities are well informed about HIV risk.

17) Youth in my community know where to go to get an HIV test.
Appendix D

Urban Youth: Answers To Survey
Questions 1-9

Urban Youth: Answers To Survey
Questions 10-17

Number of survey questions
On-reserve Youth: Answers To Survey Questions 1-9

On-reserve Youth: Answers To Survey Questions 10-17
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