

# “IT’S HARD TO CHANGE SOMETHING WHEN YOU DON’T KNOW WHERE TO START”: UNPACKING HIV VULNERABILITY WITH ABORIGINAL YOUTH IN CANADA<sup>1</sup>

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## ABSTRACT

### BACKGROUND

As a result of social and economic inequities, Indigenous youth globally are disproportionately vulnerable to HIV/AIDS. Canada's First Nations, Inuit, and Métis people are among them. In this paper, we discuss the collaborative community-based approach we adopted to uncover new possibilities for HIV prevention with Aboriginal youth that account for systemic inequities. This project is part of a larger Gendering Adolescent AIDS Prevention (GAAP) research agenda.

### METHODS

We conducted 6 focus groups with 61 Aboriginal youth in Quebec and Ontario. An inductive approach guided analyses. Data were coded using Nud\*ist qualitative data management software and collaboratively analyzed for main themes.

### FINDINGS

Youth discussed their divergent understandings of the links between colonialism, traditional knowledge(s), and HIV risk in relation to gender inequities, stigma, and involving multiple stakeholders in the HIV response.

### INTERPRETATION

New prevention approaches relating HIV risk to colonial legacies are necessary. Recommendations for future research and intervention development include: an analysis of systemic inequities in HIV prevention education, focusing on stigma reduction, building wide-spread community support, acknowledging diversity across Aboriginal peoples, and increasing active youth (peer) engagement.

## INTRODUCTION

Young people are at the centre of the global HIV/AIDS pandemic, with an estimated 11.8 million youth living with HIV/AIDS (UNAIDS, 2004). Each day nearly 6,000 people between the ages of 15 and 24 acquire HIV, accounting for half of all new infections (UNICEF, UNAIDS, and WHO, 2002). Globally, indigenous youth are disproportionately vulnerable to HIV/AIDS; this includes First Nations, Inuit, and Métis people in Canada.

Although the Canadian HIV infection rate (0.3 percent) is nowhere near the epidemic proportions of many areas of the world (Centre for Infectious Disease Prevention and Control [CIDPC], 2003; UNAIDS, 2004), an increase in youth infection rates, a recent surge in sexually transmitted infections (Maticka-Tyndale, 2001; Patrick, Wong, and Jordan, 2000; Public Health Agency of Canada, 2004), and a decline in youth knowledge about HIV (Boyce et al., 2003) indicate the potential for AIDS to spread among Canadian youth.

Aboriginal youth are particularly vulnerable and are overrepresented in Canadian HIV/AIDS statistics. Although indigenous peoples represent 3 percent of the Canadian population, they accounted for nearly 9 percent of all new HIV infections in 2005 (Public Health Agency of Canada, 2006). On average, Aboriginal people contract HIV approximately 10 years younger than their non-Aboriginal counterparts (Isaac-Mann, 2004). Currently, 30 percent of Aboriginal HIV infections are among youth 20–29 years old, compared to 20 percent in the non-Aboriginal population (Public Health Agency of Canada, 2006). Aboriginal women account for approximately 50 percent of all HIV-positive test reports among Aboriginal people, compared with 16 percent among their non-Aboriginal counterparts (DesMeules et al., 2003).

These statistics point to the need for a gender analysis of HIV risk, a task we have prioritized in our ongoing work with the Gendering Adolescent AIDS Prevention (GAAP) Project. But gender alone cannot fully account for the higher infection rates in young Aboriginal women (or young men): factors related to colonialism, racism, poverty, and geographical location (e.g., rural-urban) may be more salient. A response to the HIV/AIDS epidemic in Aboriginal communities must begin with an understanding of the unique social, cultural, and economic issues facing Aboriginal peoples. While Aboriginal youth are diverse in terms of culture, languages spoken, and social and geographical locations, they share the legacies of colonialism, the residential school system, and their ongoing harmful impacts. Coping with resulting hardships such as poverty, racism, and personal and structural violence contribute to youth risk (Canadian Aboriginal AIDS Network [CAAN], 2004). For instance, “common coping mechanisms that are detrimental for Aboriginal youth include migration to urban centres, street involvement, and injection drug use” (Prentice, 2004). 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). Aboriginal peo-

ple in Canada are also disproportionately affected by higher rates of sexually transmitted infections, histories of sexual and physical violence, and limited access to, or use of, health care services (Calzavara et al., 1998).

Nevertheless, opportunities abound: HIV remains 100 percent preventable. Aboriginal youth in Canada have many unique talents, skills, and assets that have yet to be fully harnessed towards prevention initiatives. National prevention campaigns targeted towards youth in countries as diverse as Thailand, Uganda, Zambia, and Brazil have successfully changed the course of their epidemics (UNICEF, UNAIDS and WHO, 2002). Working with youth to halt the spread of the epidemic is one of the most effective ways to confront rising infection rates. In our study, the use of participatory methods to investigate the particular social and historical determinants of HIV risk for Aboriginal youth uncovered new possibilities for prevention programming. In this paper, we discuss (1) how we became increasingly engaged in Aboriginal HIV prevention research, (2) our collaborative community-based approach, (3) key findings from our study, and (4) future research directions.

## OUR INCREASING ENGAGEMENT IN ABORIGINAL HIV PREVENTION

The Gendering Adolescent AIDS Prevention (GAAP) Project includes a team of researchers (faculty and students), educators, and youth activists in Canada and South Africa interested in participatory approaches to working with young people on HIV/AIDS prevention (Larkin and Mitchell, 2003). GAAP has used a variety of approaches to engage youth in Canada and South Africa in HIV activism, awareness, and curriculum development. Some of the innovative methods used include Photovoice (Larkin et al., forthcoming), performed ethnography (Ormandy et al., 2005; Punyarthi, Switzer, and Walsh, 2006), and participatory video making (Walsh and Mitchell, 2004). GAAP has also initiated studies that use more traditional methodologies, including surveys (Flicker et al., in press,<sup>a</sup>) and focus groups (Larkin, Andrews, and Mitchell, 2006; Larkin et al., 2005). In all of these approaches, GAAP is committed to a community-based participatory approach in building youth leadership and activism for HIV prevention (Israel et al., 1998). Partnering closely with youth and youth-serving agencies in all aspects of our research is both ethical (Flicker and Guta, 2008; Schnarch, 2004) and pragmatic: including communities most affected by HIV in the research process makes it more likely that results will be acted upon (Flicker et al., 2007; Travers et al., in press).

Until recently, our work with GAAP focused primarily on examining gender as a risk factor for HIV transmission among youth (for details of our various projects see our website, [www.utgaap.info](http://www.utgaap.info)). Increasingly, however, we have adopted an intersectional approach (Crenshaw, [1991] 2002) exploring how identities such as gender, sexual orientation, ethnicity, geography, and Aboriginal status are associated with each other and HIV vulnerability. This analysis highlights the interaction of discrimination with these multiple identities (Verma, 2003). An intersectional approach moves beyond a focus on the individual to an examination of the systemic inequities that increase HIV risk.

In the fall of 2003, we received funding for a study to understand how different groups of youth understand HIV risk. We conducted 11 focus groups with a broad cross-section of 139 Ontario youth in urban and rural settings. In keeping with our commitment to community-based, youth-oriented research, we put out a call for youth facilitators to convene focus groups on HIV risk and prevention possibilities in their own communities.

In most communities, this straightforward approach resulted in groups of 6–15 youth gathering for a two-to-three-hour discussion. Discussions were co-facilitated by the local facilitator and a GAAP coordinator. Generally, youth were lively, engaged, and very interested in sharing their thoughts and opinions. However, our experience in organizing focus groups with Aboriginal youth was different.

Originally, our goal was to conduct only one or two focus groups with urban Aboriginal youth. In the first case, we hired an Aboriginal facilitator, slightly older than the youth participants, who arranged for a session at a local Friendship centre. The facilitator laid the ground rules for the discussion and their regular group leader left the room. The youth were reminded that participation was voluntary, and asked for the signed parental consent forms that had been distributed the week before. At this point, one of the youth disclosed that he did not have parental/guardian consent; he was politely asked to leave the room for the duration of the conversation. From that point on, we experienced challenges. Youth were very hesitant about sharing; they were not interested in discussing the issues; and most remained fairly silent throughout. Many deferred to others in the group; when probed directly they would respond with “What she/he said.” Several attempts to draw the youth out were unsuccessful, and the focus group was wrapped up early.

In our debriefing discussions about why the session had not worked, there was consensus that youth involved in programming at that centre did

not always respond well to outsiders. Even though an Aboriginal youth facilitator had been retained, participants did not connect with her as “one of them.” Efforts by the Caucasian GAAP coordinator (experienced in working with diverse groups) to draw them out were especially unsuccessful. Staff also suggested that perhaps youth were reticent because we had asked a group participant to leave; they recommended that we rethink our parental consent policies, hire group members as facilitators, and consider allowing staff to remain in the room to assist with facilitation. We heeded many of their suggestions and tried again.

A new Aboriginal youth facilitator was hired who was younger and more actively engaged in the community. A focus group was scheduled at a local alternative school. When the GAAP team arrived, we were overwhelmed. Over 30 youth came and they were keen to participate. Rather than turn any away, the decision was made on the spot to split up. The coordinator and a member of the agency staff facilitated one group and the youth facilitator and another staff member facilitated a simultaneous group. Because we still could not accommodate everyone who was interested, we scheduled a subsequent session (for a total of three focus groups at the school). Our youth facilitator began each session by welcoming the group, identifying her cultural heritage, and situating herself in the research. This time, youth were engaged, enthusiastic, and heartily (often with great humour) offered their insights and opinions.

Success was attributed to good prior working relationships with the host agency, co-facilitating with staff, hiring a youth facilitator with strong community organizing skills, and well-developed group dynamics. The groups were so successful that we hired the facilitator to join the analysis team and become a community investigator on subsequent grants. This aligned with a key goal of GAAP — to develop youth capacity for HIV/AIDS research and education from the communities in which we work. Both agencies asked us to continue working in this area and were enthusiastic about partnering with us in the future.

As we analyzed the data, we realized that the focus groups with Aboriginal youth stood apart from the other data gathered. While the issues facing Aboriginal youth were similar in many respects (e.g., the persistence of the slut/stud dichotomy, the woefully inadequate state of sex education), the experience of Aboriginal youth was distinct or heightened in ways that warranted a more in-depth examination. Aboriginal youth were more aware of HIV/AIDS and the structural inequities that contribute to risk than their non-

Aboriginal counterparts. In addition, they were the only groups to talk about colonialism in the context of HIV in their community. Aboriginal youth were, however, more likely to hold a fatalistic view of their future and to blame their own community for high infection rates (Larkin et al., 2007a; Larkin et al., 2007b).

Three prime motivators encouraged further exploration of our findings: 1) the disproportionate burden of HIV borne by the Aboriginal community; 2) a request by Aboriginal community workers for further data to guide their prevention work; and 3) the unique issues and links raised by Aboriginal youth offered important insights for understanding risk and prevention from the perspective of historic and systemic inequities. We decided to partner more explicitly with Aboriginal organizations from the outset and expanded our team to include more Aboriginal scholars.

The Canadian Aboriginal AIDS Network (CAAN) became a key partner. CAAN's mission is to provide leadership, support, and advocacy for Aboriginal people living with and affected by HIV/AIDS regardless of where they live. CAAN believes strongly in community-based research approaches and the principles of OCAP (ownership, control, access and possession) (see Barlow et al., 2005; Schnarch, 2004). Careful attention to these principles means including Aboriginal community and academic scholars as full partners in the research process. We successfully leveraged a grant to conduct further focus groups with both urban and rural Aboriginal youth in Quebec and Ontario. We began by hiring a skilled Aboriginal research coordinator with extensive community contacts and experience in adolescent health promotion research and obtaining an ethical review of our protocol through the University of Toronto.

## OUR CBPR APPROACH

Since GAAP adopts a community-based participatory research approach (Minkler and Wallerstein, 2003), we consider youth to be vital partners in the HIV response. We recognize that youth, and the community organizations that serve them, have important assets, talents, skills, and ways of seeing and understanding their world that can provide an effective response. Drawing on feminist, critical, and post-modern theory to blur the distinctions between objectivity and subjectivity (Gaventa, 1993; Wallerstein and Duran, 2003), participatory approaches acknowledge that a community's local knowledge is crucial to understanding and addressing their own social problems. GAAP partners with local communities in all aspects of knowledge

creation and social change (Cornwall and Jewkes, 1995; Hall, 1993; Maguire, 1987), breaking down the rigid distinctions between researcher and researched (Gaventa, 1993). CBPR is particularly effective in health research with young people (Grossman et al., 2004; Smyth, 2001; Society for Adolescent Medicine, 2003).

Opportunities for youth participation are hampered by stigmatizing attitudes and social discouragement from their communities and peers (Vailaitis, 2002; Watt, Higgins, and Kendrick, 2000). Young people's skills and talents are regularly underestimated by both the mainstream public and the academic research community (Checkoway et al., 2003). Often, youth internalize "adultist" notions that they have nothing to offer (Checkoway and Richards-Schuster, 2001). Only a small fraction of youth are aware of research as a form of participation and fewer still have the resources to take action of this type (Checkoway, Dobbie, and Richards-Schuster, 2003).

Involving youth in research is often complicated by greater barriers to participation such as parental consent (Flicker and Guta, 2008), and a perception of young people as "problematic" research subjects — because of their alleged "unreliability" and "lack of cognitive, emotional, or intellectual maturity." Time constraints imposed by school and/or work, lack of drivers' licenses, unsafe public transit systems, and living in suburban and rural communities may also affect meeting attendance during regular work hours (McCormack-Brown et al., 2001). Marginalized young people who are homeless, gay or lesbian, inject drugs, and/or live with HIV are even less likely to be invited to the table (Flicker et al., 2005).

Nevertheless, this commitment to investing in and building the capacities of young people as active research partners is a cornerstone value of our approach. Active community participation in research often provides results more accessible, accountable, and relevant to people's lives (Israel et al., 1998), and an increased likelihood of program and/or policy change (Flicker et al., 2007). Finally, given the historical human right violations in the name of "research on indigenous communities" we believe it vitally important to do research "with" Aboriginal youth that is respectful of the diversity and talents of young people (Smith, 1999).

## METHODS

The research coordinator took the lead in identifying and training peer facilitators from each of the six participating communities. Training youth facilitators in local communities builds the capacities of young people to

engage in research and promote dialogue about HIV prevention, with multiple benefits. Partnering with young people on research projects and community initiatives improves their confidence and skills, and often results in new and beneficial long-term opportunities (Flicker, 2006; Jarrett, Sullivan, and Watkins, 2005). It also builds communal social capital, keeping skills and resources in the community to address future health issues long after the project is completed (Hawe et al., 1997). Youth facilitators gain valuable job experience, and the project benefits because young people engage more freely with a known facilitator.

Youth facilitators worked with the research coordinator to co-facilitate focus groups in their own communities. Youth participated in a three-hour guided discussion on issues relating to their own communities in regard to HIV/AIDS. The goals of the focus groups were to further explore the links between systemic and individual risk. Youth were provided with an honorarium for their time (\$20) and a meal. 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, a consent form was read aloud and there was time for questions from group participants. All forms were collected prior to the beginning of the focus group. Youth were then asked to fill out a short quiz that helped them reflect on how they understood HIV risk. The questions were designed as a warm-up and a starting point for discussion. After the participants completed the exercise individually, the facilitator took the responses and, through a semi-structured facilitation process, probed for further understandings of the issues raised. The conversations were focused on discovering notions of HIV vulnerability and new, culturally appropriate HIV responses. The discussions generated through this process were rich and nuanced. Focus groups lasted between two and three hours. All discussions were audio-taped and professionally transcribed verbatim.

A data analysis team of the principal investigator, two co-investigators, the research coordinator, one graduate student, and an undergraduate youth facilitator developed the coding framework and subsequent analysis. Three of the data analysis team members (50 percent) were Aboriginal.

An inductive approach guided the data analysis. A subsample of transcripts was given a preliminary analysis. Based on emerging themes, commonalities, and major differences, a coding framework was developed. Each transcript was coded independently by two team members. The coding scheme was revised to accommodate new themes as they emerged. The codes were then entered into Nud\*ist qualitative data management software. Coded data were

returned to the larger team for analysis. Weekly meetings were held to review the coded data and discuss main themes, relevance, and implications for each code, and compare and contrast findings. The team's notes were discussed collectively, and summary documents were constructed to capture the most common themes, gaps, and issues. This collaborative analysis created an environment of mutual learning where the skills and knowledge of various team members were exchanged and built upon. Including youth facilitators on the data analysis team also ensured that contextual factors that might not have surfaced in transcripts were included in analysis. The transparent sharing and discussion provided nuanced analyses, in line with the OCAP principles that are central to research in partnership with Aboriginal peoples.

## RESULTS

We held six focus groups and spoke with 61 Aboriginal youth in Ontario and Quebec (50 percent female and 50 percent male in the urban settings; 76 percent female and 24 percent male in the on-reserve locations). Participants were young people (ages 14–27 years) who go to school or live in the communities targeted by the GAAP facilitators for data collection. The majority of the focus group participants identified as First Nations (see Table 1).

**Table 1: Sample Demographics**

<i>General Descriptor</i>		<i>Average Age</i>	<i>Age Range</i>	<i>Gender Ratio % Female</i>	<i>Ethnicity*</i>
<b>Urban Youth</b>	<b>#</b>	20 yrs	14–27	50% Female	45% FN
Ontario 1	8	16 yrs	15–17	60%	3 FN, 5 M
Quebec 1	14	21 yrs	14–25	50%	11 FN, 3 I
Quebec 2	6	23 yrs	20–27	30%	1 FN, 2 M, 2 I, 1 U
<b>On-Reserve Youth</b>	<b>#</b>	16 yrs	14–24	76% Female	100% FN
Ontario 2	9	18 yrs	17–20	70%	9 FN
Ontario 3	10	17 yrs	16–20	70%	10 FN
Quebec 3	14	16 yrs	14–24	86%	14 FN

\* Where FN= First Nations; M=Métis; I=Inuit and U=Unknown.

Several themes that emerged from the data were similar to our findings with youth across Ontario (Larkin et al., 2005). For example, there was little variance across groups for gender and sexuality: young men continue to be idolized for sexual prowess, young women continue to be chastised for their sexual exploits. The participating youth in the Aboriginal focus groups had a good understanding and awareness of sexual violence in their communities. They 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. Several also talked about rape as an ongoing issue in their community. Despite this, it is the women who decide whether condoms are used during sex most of the time, thus feminizing the role of condom use.

Our primary focus in this paper is on issues unique to Aboriginal youth, most particularly, how youth understood colonialism and traditional knowledge in relation to HIV risk, and their ideas for addressing these issues in HIV prevention strategies. Youth participating 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 systemic issues (see Table 2). Some youth saw no link between structural inequalities and individual risk, but understood HIV risk to be a problem related to self-management. They associated contracting HIV with poor (and/or unlucky) decision making and resisted the idea that social processes had any bearing on the construction of individual risk. For these youth, the notion of individual choice provided them with a sense of control over their own destiny. Some felt that linking risk to social structures was an attempt to shirk personal responsibility. Self-determination was something to be proud of and showed character and strength.

Other youth saw links between colonialism and HIV risk; they described individual risks as socially mediated. For these youth, situating HIV within a framework of systemic risk helped them to challenge dominant stereotypes of self-blame and resist prevailing stigma about being Aboriginal experienced in everyday life. Some youth talked about HIV in the context of a variety of health and social disparities, making HIV both a cause of and a contributor to inequality. This was the idea that “everything is related” and so when “one part of the community is sick,” it affects the entire community. In other groups, the links were explained through the violence and oppression that followed European contact.

Several young people blamed colonial processes such as the residential school system as key contributors to HIV risk. This practice of attempted cultural genocide left a generation of children bereft of their social and cultural traditions, disrupted community and family unity, decimated self-esteem, and seeded cycles of sexual and physical violence (Hamilton, 2001; Llewellyn, 2002; McLeod, 1997). The residential school system failed to teach their parents and grandparents how to parent, and in turn their parents recreated cycles of violence and substance use that shaped HIV risk. Nevertheless, many of the youth felt that they had the fortitude to break these cycles and looked

**Table 2: Individual and Systemic Risk**

Individual Responsibility	<p>I don't think colonialism has anything to do with it, their coming here. (Female urban)</p> <p>I think poverty has nothing to do with it. Personally, I think it depends on the individual. (Male urban)</p> <p>We always had problems before the great confederacy; people will always have problems. (Female on-reserve)</p>
Colonialism	<p>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)</p>
Competing Explanations	<p>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)</p>
All Problems are Related	<p>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 ... if you are still being abused ... then you are still having emotional dysfunctions, then it's not going to prevent anything. (Female on-reserve)</p> <p>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)</p>
Residential Schools → Social and Cultural Dislocation or Alienation	<p>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)</p> <p>It stems from the lack of culture when kids were away in residential schools and came back 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)</p>
Role of Stigma and Silence	<p>If someone looked like they had AIDS in my community they would be kicked out. (Male on-reserve)</p> <p>I agree, no one would tell because even their family would be like outcasts. (Female on-reserve)</p> <p>Most people wouldn't go back to their community if they had it. (Female on-reserve)</p> <p>And they'd blame the person who had it, no compassion just judgment and punishment. (Female on-reserve)</p>
Relation to Canadians	<p>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. (Male urban)</p>
Intergenerational Approaches	<p>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)</p> <p>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)</p> <p>Yeah, the person who has HIV would be shunned because they'll be seen as dirty and bad. (Male on-reserve)</p>
Gender	<p>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)</p> <p>Some girls have sex just to keep their man. (Female urban)</p> <p>I find girls are more orientated with their own safety as opposed to guys. (Male on-reserve)</p> <p>Yes, a lot of women feel they have to have sex. (Female urban)</p> <p>Some will get abused if they don't. (Female urban)</p>

forward to a future where they might parent differently in a new narrative of hope.

Most youth, however, stood somewhere in-between. While they connected structural violence to individual risk, they also felt that they could challenge and break these cycles:

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)

This young woman is clearly wrestling with a variety of dominant ideologies. On the one hand, she argues strongly for the links between colonialism and a variety of health outcomes (alcoholism, water-borne disease, HIV). On the other, she draws on traditional notions of communal balance and interdependent health. However, at the end of her thoughts, she goes back to the idea that risk is really about individualism. She was not alone. In many of the groups, young people drew on multiple (and occasionally conflicting) narratives to describe the ways in which HIV intersects with individual choice, traditional ways of knowing, and colonial cultural violence.

Many youth also described the effect of isolation, from the rest of Canadian society, on the construction of risk, stigma, and difference. Racism is an ongoing issue and youth talked about people discriminating against Aboriginal people or relying on stereotypes. In one of our urban groups, youth joked about the isolation and lack of awareness of cultural issues:

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)

Youth living on reserve also discussed how this othering operated in their daily lives and, on a state level, in government social policy and responsibility. They connected recent water scandals to the same practices that fuel HIV risk. These forms of interpersonal and social discrimination fuel the perpetuation of conditions that create poverty. Constant exposure to these racist ideologies can diminish youths' sense of self-worth and self-efficacy.

Many youth also talked about the powerful contribution of intracommunity stigma to HIV risk and silence. For instance, several youth expressed their dismay at the treatment of people with HIV/AIDS as outcasts when they return to their home communities. Nevertheless, some understood 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)

The youth who lived on reserve said 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. Others talked about how the stigma is "contagious" and sometimes whole families get treated as outcasts.

One youth told the focus group about a very painful experience 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 for 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 street 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.

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)

During the focus groups, youth did not say much about the role cultural traditions in HIV/AIDS prevention, but when they did discuss traditional cul-

tural values they had positive things to say about their values 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)

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) said they would like to learn from the Elders about sexual education and other diseases. Many youth felt that it was important for Elders in their communities to learn more about HIV/AIDS so that they could take a leadership role in alleviating stigma. 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.

## MOVING FORWARD: ADDRESSING HIV

Youth we spoke with were generally frustrated by the state of sexual health education they were (sometimes) being offered through school and community networks. Some complained about receiving inaccurate information from teachers (e.g., douching is an effective contraceptive). Others talked about feeling bored, uncomfortable, or unengaged with traditional sex education approaches. Both urban and Aboriginal youth (unprompted) felt that traditional media such as pamphlets were ineffective. As one youth stated, "Pamphlets are useless, we need real people connecting to the communities" (Female on-reserve).

By contrast, they had a number of suggestions for improving HIV prevention (see Table 3 for a summary of suggestions). Both urban and on-reserve youth stressed the importance of involving youth in the delivery of HIV prevention messages; many youth were adamant about the importance of leveraging youth peer networks. They wanted to hear from other youth about sexual health and felt that they might be able to relate better to people of their own age and ethnicities. That being said, participants (especially those living on reserve) felt that involving the whole community in HIV prevention was essential to combating the spread of the virus and related stigma. Youth recommended that parents and Elders also need HIV education, and many suggested the need for intergenerational programming. Some also mentioned the importance of incorporating traditional knowledge.

**Table 3: Youth Suggestions for Improving HIV Prevention**

<p><b>Peer Approach</b></p>	<p>I think the youth council could inform other youth. (Female urban)                  Maybe youth mentors! (Female urban)                  Peer groups are really important. (Female on-reserve)                  I think a youth conference would be good then youth can get involved and learn more about it. (Male on-reserve)                  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. (Female on-reserve)</p>
<p><b>Levering Youth Media</b></p>	<p>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. (Male urban)                  We grow up watching media — they can put messages through the media. (Female on-reserve)                  A comic book would be good. (Female on-reserve)                  Well, they should be out with more media and staking out the bars and making sure that people are getting protection. (Male on-reserve)</p>
<p><b>Incorporating GIPA (Greater Involvement of People with HIV) Principles</b></p>	<p>Have people with AIDS tell their story and what they go through daily. (Female on-reserve)                  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 suffering from it. (Female urban)                  Pamphlets are useless. We need real people connecting with the communities. (Female on-reserve)</p>
<p><b>Integrated Programming</b></p>	<p>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. (Female on-reserve)</p>
<p><b>Make it Fun</b></p>	<p>There was a program ... and when they first started it, they 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 fun with lots of activities about AIDS, then a lot of people would come. (Female on-reserve)                  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. (Male urban)</p>
<p><b>Intergenerational Approaches</b></p>	<p>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. (Gender not noted, on-reserve)                  Yeah, 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. (Female reserve female)</p>
<p><b>Condom Accessibility</b></p>	<p>Give them condoms, show them how to use them properly. (Female urban)                  Talking and demonstrating condom use. (Male on-reserve)</p>

In keeping with the Denver GIPA principles<sup>2</sup> (Advisory Committee of People with AIDS, 1983; Travers et al., in press), participants felt that people living with HIV needed to be an important part of the prevention effort. Youth in almost every focus group talked about the importance of hearing from people actually experiencing the challenges of living with the virus. They suggested that this might also go a long way towards reducing stigma. In addition, many youth felt that HIV prevention messages should be incorporated into other youth programming.

Finally, youth suggested that HIV prevention messages should be delivered in fun, innovative formats. They recommended leveraging youth media and integrating messages with condom availability.

## LIMITATIONS

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.

## CONCLUSION AND RECOMMENDATIONS

This study took a community-based participatory approach to understanding systemic issues of HIV risk faced by Aboriginal youth in Ontario and Quebec on-reserve and urban communities. All of the participating youth felt that things needed to change and many are determined to be a part of transformation. This is promising for the future.

While it is beyond the scope of this study to offer a full analysis of how best to address the issues of HIV/AIDS among Aboriginal youth, there are several key recommendations that may be explored in future prevention work:

1. The Legacy of Colonialism: HIV prevention strategies should engage explicitly with connections to colonialism, racist histories, and the impacts

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2. The 1994 Paris AIDS Summit marked a turning point for the HIV/AIDS movement, with international recognition of the importance of the Greater Involvement of People Living with HIV/AIDS (GIPA) principle. GIPA emphasizes the “obligation to act with compassion for, and in solidarity with, those with HIV or at risk of becoming infected, both within our societies and internationally,” and “to ensure that all persons living with HIV/AIDS are able to realize the full and equal enjoyment of their fundamental rights and freedoms without distinction and under all circumstances.” Since its inception, GIPA has evolved into a broad philosophy meant to underpin all forms of intervention (prevention, treatment, support, policy, and research) with persons living with HIV/AIDS.

of residential schools. It may be productive to situate HIV prevention within larger discussions of the social determinants of health and connect HIV to other issues affecting Aboriginal communities and individuals.

2. **Stigma Reduction:** Stigma around HIV/AIDS is profound in Aboriginal communities. Many people are banished when it is discovered they are HIV positive. Stigma reduction through education; teaching of traditional values around sex, disease, and homosexuality; and finding a role for people living with HIV in prevention work may help reduce the discrimination against people with HIV and ultimately be a prevention strategy.
3. **Community Support:** In the focus groups, with both urban and on-reserve Aboriginal youth, the issue of community support for HIV/AIDS prevention arose repeatedly. Community acceptance is an important issue for these youth, something we didn't hear to the same extent from other youth groups (Larkin et al., 2005). 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 so might resonate as a culturally relevant approach.
4. **Diverse, Distinct Cultures:** It is important to note that Aboriginal youth are not a homogenous group and that providing messages intended to be pan-Aboriginal will not necessarily be effective. First Nations, Métis, and Inuit youth all come from diverse, distinct cultures and the values and beliefs of each culture must be addressed and respected. Furthermore, different approaches may be necessary in urban and reserve environments.
5. **Youth Engagement:** New, culturally appropriate, participatory approaches that engage youth, peers, parents, and Elders in HIV prevention are necessary to create holistic approaches to prevention.

Our partnership is currently developing proposals for this work. We hope to work directly with Aboriginal youth to identify contextual community-based approaches using the strengths, talents, and assets of young people. Arts-based methods (photography, video, dance, mural-making) will explore the links between individual and systemic risk and create culturally meaningful prevention media (by youth for youth) addressing a range of prevention needs. Building community capacity in the areas of research and HIV prevention is just one way we ensure the sustainability of our work.

More than anything, this kind of work calls for new methodologies that are culturally appropriate and feed into what might be described as a "youth

as knowledge producers” framework (Mitchell, 2006; Mitchell, Walsh, and Moletsane, 2006). This is supported by a growing body of literature (Mitchell and Smith, 2001; Norris, 2000; Ridgley, Maley, and Skinner, 2004; Strack, Magill, and McDonagh, 2004) that is interested in the links between “youth media” — a framework incorporating a wide range of communication tools (e.g., the Internet, photography, video, and music production software) to promote community development, critical literacy, artistic expression, civic engagement, and social activism. By this, we mean ways not only of engaging young people through arts-based participatory approaches which respect their work as cultural producers, but also ways that respect the fact that young people are themselves producers of knowledge, and indeed resources to themselves and to each other. This approach builds a type of self-efficacy and confidence that is often lacking in more conventional approaches to addressing youth and sexuality.

At the crux of this approach is an understanding that our world is indeed transformable, and youth can play active roles as change agents (Flicker et al., in press,b). Despite centuries of colonization, Aboriginal peoples continue to value their cultural traditions (Jackson et al., 2006a; Jackson et al., 2006b; Jackson and Reimer, 2005). Research and its colonizing effects have failed to eradicate underlying cultural values, beliefs, and perspectives. New approaches will let Aboriginal people tell their own stories through their own frameworks and adopt Aboriginal-centred responses to the epidemic. By encouraging and facilitating youth to choose the media with which they will create their own data (e.g., music, video, photography), we can challenge dominant constructions of knowledge and who has the power to produce and shape it.

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