

Canadian Journal of Aboriginal Community-based HIV/AIDS Research

Volume 3 • Winter 2010



Table of Contents

Introduction	1
Section 1 – Dissemination of Results / Findings.....	3
Suit the Situation: Comparing Urban and On-Reserve Aboriginal youth preferences for Effective HIV Prevention Messaging.....	5
<i>Jean-Paul Restoule, Amy Campbell McGee, Sarah Flicker, June Larkin, Christine Smillie-Adjarkwa</i>	
Strengthening Community-Based Approaches to HIV/AIDS & STI Screening, Treatment & Prevention among Atlantic First Nations People.....	17
<i>Audrey Steenbeek; Marni Amirault; Gabe Saulnier; Cheryl Morris</i>	
Section 2 – Stories.....	29
Watching the Tide come in: An Aboriginal participant reflects on participating in the HIV Research field and the University Without Walls Program.....	31
<i>Doris O'Brien-Teengs</i>	
Section 3 – Student Work.....	33
Addressing HIV/AIDS among Aboriginal People using a Health Status, Health Determinants and Health Care Framework: A Literature Review and Conceptual Analysis.....	35
<i>Earl Nowgesic, RN, BScN, MHSc</i>	
Call for Papers.....	47

Suit the Situation: Comparing Urban and On-Reserve Aboriginal youth preferences for Effective HIV Prevention Messaging

Jean-Paul Restoule¹, Amy Campbell McGee², Sarah Flicker³, June Larkin⁴, Christine Smillie-Adjarkwa⁵

¹ Jean-Paul Restoule is Anishinaabe from Dokis First Nation in Ontario and has lived in or near Toronto for over 25 years. He is assistant professor of Aboriginal education at OISE/University of Toronto.

² Amy Campbell McGee is a researcher and recent graduate of OISE/University of Toronto. Her research interests are HIV, street involved youth, pregnancy and birth.

³ Sarah Flicker is an assistant professor in the Faculty of Environmental Studies at York University. Her research interests are in the areas of urban health, youth health, HIV, health promotion, ethics, the social determinants of health, and community-based participatory research.

⁴ June Larkin is undergraduate coordinator and lecturer in the Women and Gender Studies Institute, University of Toronto. Her research interests include sexual harassment, violence against women, gender equity and schooling, body image and eating disorders, and gender and HIV/AIDS.

⁵ Christine Smillie is a doctoral candidate in the Aboriginal Education & Community Development Program at the Ontario Institute for Studies in Education, University of Toronto. Christine is a member of the Métis Nation of Ontario and she is the proud mother of three beautiful children and the *Nookomis* (grandmother) of one.

Contact: Jean-Paul Restoule
Adult Education and Counselling Psychology
Ontario Institute for Studies in Education/University of Toronto
252 Bloor St. West, Toronto Ontario M5S 1V6

Phone: 416-978-0806

Fax: 416-926-4749

Email: jeanpaul.restoule@utoronto.ca

ABSTRACT

The researchers set out to determine whether one's location on a reserve or in an urban setting makes a difference in Aboriginal youth preferences for effective HIV prevention messaging. Locally recruited facilitators used community based participatory research methodology to convene focus groups with a total of 61 participants in 6 communities in central Canada. Three of the communities could be characterized as rural reserves. Three of the communities were large urban settings. Data were analyzed using a modified grounded theory interpretive approach. According to our small sample, having HIV prevention programs designed specifically for particular Aboriginal communities, whether they are on reserve or off reserve, is more likely to increase their effectiveness than a universal message approach. We find agreement across the groups that HIV prevention messaging and strategies must be captivating innovative and flexible to adapt to the diverse and distinct characteristics of each community. Furthermore, first person and peer-based approaches will find greater reception in urban contexts than on reserve while rural strategies should be fun and involve the whole community in some way. All agreed that because Aboriginal communities are diverse and distinctive, HIV prevention should be designed specifically for each separate context. Both groups demonstrated an awareness of, and interest in colonialism and intergenerational impacts.

ACKNOWLEDGEMENTS

The authors would like to thank the Canadian Foundation for AIDS Research for funding the research presented in this article. We would like to acknowledge the contributions and support of the many members and contributors to the Gendering Adolescent AIDS Prevention Project research and administration. Finally, our thanks to the youth participants in the Aboriginal communities who shared their knowledge with us. Chi Miigwec and Nia:wen Kowa!

INTRODUCTION

In this paper we report on the findings of a project with urban and on-reserve Aboriginal youth designed to explore their understanding of HIV risk and uncover new possibilities for prevention. As a group, young people are experiencing a growth in rates of Human Immunodeficiency Virus (HIV) with half of all new infections worldwide in youth between the ages of 15 to 24 (Flicker, Larkin, Smilie-Adjarkwa, Restoule, Barlow, Dagnino, et al., 2007; UNAIDS, 2004; UNICEF, UNAIDS, & WHO, 2002). Aboriginal youth are particularly vulnerable and are overrepresented in Canadian HIV/AIDS statistics. In 2006, 28% of people with positive HIV tests were First Nations, Inuit or Métis (Public Health Agency of Canada, 2007) even though Aboriginal people represent only 3.8% of Canada's population (Statistics Canada, 2006). We know that the pattern of HIV infection in Aboriginal populations is different. Forty-eight percent of Aboriginal people who test positive are women (Ontario HIV Treatment Network & Ontario Aboriginal HIV/AIDS Strategy, 2008). Further, Aboriginal youth are more likely to have a late diagnosis, more likely to become acutely ill earlier, less likely to receive optimal medical treatment, and have shorter survival rates (Mill, Jackson, Worthington, Archibald, Wong, Myers, et al., 2008). Because of the distinctive nature of HIV infection in the Aboriginal population, the Gendering Adolescent AIDS Prevention Program (GAAP), University of Toronto, specifically organized engagements with Aboriginal participants. The GAAP brings together youth, community based service providers, policy makers, students and researchers on projects that use participatory approaches to working with young people in relation to sexuality, HIV prevention and AIDS awareness.

The GAAP initially sought to analyze gender as a risk factor in youth HIV transmission in South Africa and Canada, using a community based participatory approach (Minkler & Wallerstein, 2003). In the initial GAAP focus groups, Aboriginal participants conveyed markedly different responses from other participants. Intrigued by these findings, and curious whether these responses were commonly held among Aboriginal youth, the GAAP team embarked on a more targeted study.

The new research team was composed of June Larkin and Jean-Paul Restoule from the University of Toronto; Sarah Flicker, York University; Kevin Barlow, Canadian Aboriginal AIDS Network; Claudia Mitchell, McGill University; project coordinators Christine Smilie-Adjarkwa, and Michelle Dagnino; and student researchers Ruth Koleszar-Green and Christina Ricci. The overall goals of the 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 with 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.

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 (See Figure 1).

The team held focus groups with Aboriginal youth seeking their views on effective HIV prevention. Half of the 61 participants were residing on reserves and the other half in urban areas (Larkin, Flicker, Restoule,

Barlow, Mitchell, & Smillie-Adjarkwa, 2007). The Aboriginal participants in these focus groups suggested that HIV prevention strategies should be designed specifically to address urban or on-reserve populations, as well as specific cultural groups. The research team examined the data to better reveal differences and similarities between urban and rural youth preferences.

METHODS

GAAP adopts a community-based participatory research approach (Minkler & Wallerstein, 2003). This means that we understand 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 need to be leveraged for an effective response. Drawing on feminist, critical and post-modern theory to blur the distinctions between objectivity and subjectivity (Gaventa, 1993; Wallerstein & Duran, 2003), participatory approaches acknowledge that communities often already have local knowledge that is crucial to understanding and addressing their own social problems. As such, GAAP partners with local communities in all aspects of knowledge creation and social change (Cornwall & Jewkes, 1995; Hall, 1993; Maguire, 1987), and attempts to break down the rigid distinctions between the researcher and the researched (Gaventa, 1993). Using a CBPR approach has been highlighted as particularly effective for health research with young people. (Grossman, Agarwal, Biggs, & Brennehan, 2004; Smyth, 2001; Society for Adolescent Medicine, 2003).

However, opportunities for youth to participate can be hampered by stigmatizing attitudes and social discouragement from their communities and peers (Vailaitis, 2002; Watt, Higgins, & Kendrick, 2000). Young people's skills and talents are regularly underestimated by both the mainstream public and the academic research community (Checkoway, Richards-Schuster et al., 2003). Often youth internalize "adultist" notions that they have nothing to offer (Checkoway & 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, & Richards-Schuster, 2003).

Involving youth in research is often complicated by greater barriers to participation such as having to navigate parental consent (Flicker & Guta, 2008), and the fact that young people are often seen as "problematic" research subjects because of their alleged "unreliability" and "lack of cognitive, emotional or intellectual maturity." Time constraints often due to school and/or work, lack of drivers licenses, unsafe public transit systems, and living in suburban and rural communities may also be a barrier for meeting attendance during regular work hours (McCormack-Brown et al., 2001). Marginalized young people who may be homeless, gay or lesbian, inject drugs, and/or living 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 to become active research partners is a cornerstone value of our approach. Active community participation in research often renders results more accessible, accountable and relevant to people's lives (Israel et al., 1998), with the added value of an increased likelihood of program and/or policy change (Flicker et al., 2007). Finally, given the historical human right violations that have happened in the name of "research on Indigenous communities" we believed it to be vitally important to do research "with" Aboriginal youth that was respectful of the diversity and talents of young people (Smith, 1999).

In 2007, sixty-one Aboriginal youth, from six communities, participated in three-hour facilitated discussions on issues relating to their own communities with regard to HIV/AIDS. Consistent with our commitment to community based participatory research, the project put out a call for youth facilitators to convene the focus groups that were to be held in their community. Training youth in local communities builds the capacities of young people to engage in research and promotes dialogue about HIV prevention, with multiple benefits: the youth acquire confidence and skills that can lead to long-term opportunities (Flicker, 2006; Jarrett, Sullivan, & Watkins, 2005) and the communal social capital is strengthened by keeping knowledge and resources in the community after the project is completed (Hawe, Noort, King, & Jordens, 1997). Youth facilitators gain valuable job experience and the project benefits because young people engage more freely with a known facilitator.

Youth facilitators who had a strong connection with a school and/or community group were selected. Facilitators were at least 16 years of age and had some experience 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. The youth facilitator and participants of each focus group were paid an honorarium for their time. The focus groups began by discussing an agree/disagree exercise on issues related to HIV. The discussion was recorded and transcribed. The facilitator offered input when participants had questions about the study or requested further information on matters related to HIV/AIDS. In each focus group location, a contact person (e.g., teacher, community worker) acted as a liaison between the youth facilitator, the focus group participants and project coordinator. The liaison person advertised the project, collected consent forms, distributed the ad for the facilitator position, and carried out other minor administrative tasks associated with the project.

Youth participated in three-hour guided discussions on issues relating to their own communities with regard to HIV/AIDS. The goals of the focus groups were to further explore the links between systemic and individual risk. Youth facilitators worked with the research coordinator to co-facilitate focus groups in their own communities. 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 to provide a starting point for discussion (see Figure 1 below). After the participants completed the exercise individually, the facilitator took up the responses and probed for further understandings of the issues raised through a semi-structured facilitation process. The conversations were focused on unpacking notions of HIV vulnerability and uncovering new possibilities for culturally appropriate HIV responses. The discussions generated through this process were rich and nuanced. All discussions were audio-taped and professionally transcribed verbatim.

Figure 1: Modified Agree/Disagree Exercise for GAAP Focus Group Discussion

Question	Agree/Disagree?	
Men's biological make-up makes their chances of HIV infection higher than women.	Agree	Disagree
When someone has an STD, they are more at risk for HIV infection.	Agree	Disagree
Globally, women and girls are more at risk of HIV infection than men and boys.	Agree	Disagree
Being poor puts people more at risk for HIV infection.	Agree	Disagree
HIV is a gay disease.	Agree	Disagree
Condom use is now a regular practice in the sexual activities of gay and straight youth	Agree	Disagree
Young women and young men are equally willing to use condoms.	Agree	Disagree
Getting an HIV test is a common practice for sexually active youth.	Agree	Disagree
Young people worry about contracting HIV/AIDS.	Agree	Disagree
Some youth are more at risk for contracting HIV than others.	Agree	Disagree
There are still many myths and stereotypes about HIV/AIDS.	Agree	Disagree
I had a good sex education that included information about HIV/AIDS.	Agree	Disagree
I know people who have been affected by HIV/AIDS.	Agree	Disagree
HIV/AIDS is a problem for people in my community.	Agree	Disagree

*This activity is used as a spring board for discussion. Once the youth participants had completed the form individually, the facilitator takes up their responses in the larger group.

Participants were aware that meeting in a group setting provided limits to the degree of anonymity or confidentiality that researchers could meaningfully promise. The duty to report suspicions of abuse was communicated but there was no disclosure of this sort in the circles. Accounts of high-risk behaviour and infection were second-hand. The youth facilitator had been trained in HIV prevention and used the discussion guide as a tool for providing accurate information, and provided further resources for individuals to access after the focus group. While confidentiality could not be completely controlled by the research team, pseudonyms were used for participants and no personally identifying names or characteristics, other than gender and urban/rural status, have been reported in subsequent publications.

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%) were Aboriginal. An inductive approach guided analysis. A sub-sample of transcripts was offered to the data analysis team for 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. 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 go over the coded data and discuss main themes, relevance and implications for each code and compare and contrast findings. Collectively, the team’s notes were discussed and summary documents were constructed to capture the most common themes, gaps and issues. This method of 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 may not have surfaced in transcripts were attended to in analyses. Furthermore, this method of transparent sharing and discussion assisted with nuanced analyses that are in line with the principles of OCAP that are central to research in partnership with Aboriginal peoples.

Contacts were made through Aboriginal members of the research team who had connections to various Aboriginal communities. Individuals were contacted who work with Aboriginal youth in schools, friendship centres, youth councils and other locations. One of the goals of the project was to have a balance of urban and rural focus groups. Ultimately, we were able to conduct three focus groups in urban locations and three groups in rural reserve communities.

Table 1 shows the composition of the six focus groups.

Table 1: Focus Group Demographics

General Descriptor	Average Age	Age Range	Gender Ratio Female	Gender Ratio Male
Urban Youth	20 yrs	14-27	50% Female	50% Male
#				
Ontario 1	8	16 yrs	15 – 17	60%
Quebec 1	14	21 yrs	14 – 25	50%
Quebec 2	6	23 yrs	20 - 27	30%
On-Reserve Youth	16 yrs	14-24	76% Female	24% Male
#				
Ontario 2	9	18 yrs	17 – 20	70%
Ontario 3	10	17 yrs	16 – 20	70%
Quebec 3	14	16 yrs	14 - 24	86%

Table 2 shows the number of female and male youth participants in urban and on-reserve locations.

Table 2: Focus Group Gender Distribution

Focus Group Location	# of Female Participants	# of Male Participants
Urban Youth		
Ontario 1	5	3
Quebec 1	7	7
Quebec 2	2	4
On-Reserve Youth		
Ontario 2	6	3
Ontario 3	7	3
Quebec 3	12	2

RESULTS

The results from this comparison of rural and urban focus groups are preliminary. While the overall suggestions made in urban and rural groups intersected, there were some ideas more strongly represented in each group.

Both rural and urban groups spoke more about prevention with regard to safer sex, and better sex education, than safer injecting practices, although injection drug use is the most common route of transmission for Aboriginal people in Canada (Public Health Agency of Canada, 2004). There was agreement that sex education was inadequate.

You learn basics... very basics, what STDs are...and the boys go in the other room (Female, on-reserve).

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!” (Male, urban).

Prentice (2004) argues that Aboriginal youth under the age of 15, and injection drug users, are the people most in need of HIV prevention. While our participants rarely discussed injection drug use, there were some comments on the risky behaviours associated with using drugs generally. When asked about risk factors, one participant noted that “there are many drugs in my community,” while another participant shared: “Sometimes youth are 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 all the time.” (Male, on-reserve). Harm reduction has been used in Canada as a way of addressing the risks of injection drug use in urban contexts. The Canadian Aboriginal AIDS Network (2004) and others such as Landau (1996) criticize abstinence based programs and suggest the use of harm reduction programs for Aboriginal people. Australian and New Zealand scholars in response to Landau’s article raise challenges to this approach arguing that a harm reduction approach can be culturally unsuitable, where many Aboriginal community members hold a view that alcohol and drugs are alien to Aboriginal cultures, and as such promote the use of both abstinence and harm reduction programs (Kahn & Fua, 1997; Sellman & Huriwai, 1997).

Rural and urban youth agreed that HIV prevention needs to be captivating, using pop culture such as television and comic books that entertain and emotionally engage.

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).

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).

On-reserve youth suggested that fear would engage their interest. They believed their peers could be motivated by fear to make better decisions.

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 (Female, on-reserve).

(We) 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 (Female, on-reserve).

Rural youth on reserve had confidence that young people would attend HIV prevention which was paired with fun activities, and that generally young people in their communities are eager to show up and see what's going on.

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 where you can go and do something fun with lots of activities about AIDS, then a lot of people would come (Female, on-reserve).

In a recent workshop organized as part of an extension of this current study, our community coordinator from the reserve believed that the reason for the high turnout of youth to the workshop was that 'it gave them something to do.' For on-reserve youth, HIV prevention workshops could be popular because they provide a place to go and an activity to be involved in.

Urban youth highlighted how fun also needed to be "cool," to know about sex is "cool."

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 (Urban).

Both on-reserve youth and urban youth felt like they were considered "others" by mainstream society. The urban youth were more likely to name racism as a problem while on-reserve youth showed concern with being or feeling isolated and its consequences. The following quotes illustrate issues connected with assimilation. It seems from the comments by the youth participants 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)

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)

The connection between HIV vulnerability and intergenerational trauma has been well documented (Pearce, Christian, Patterson, Norris, Moniruzzaman, Craib, et al., 2008) and the young people in our study demonstrated awareness of this association. Both groups suggested HIV prevention in Aboriginal communities should explicitly recognize the role of colonialism and its intergenerational impacts. As Chansonneuve (2002) noted, the heightened need for HIV prevention in Aboriginal communities may be usefully situated within the disproportionate representation of Aboriginal people with HIV as well as other preventable social, economic and legal problems in Canada. This seemed very important to both groups.

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).

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).

Aboriginal youth are from diverse and distinctive cultural groups. HIV prevention must be designed for specific cultural contexts. While both groups were interested in first person accounts and peer-based approaches, the urban groups stressed these approaches to greater degrees and also emphasized the importance of messaging that specifically targeted people from similar cultural and geographical contexts.

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, urban).

The heightened stigma associated with positive HIV status in on-reserve communities may render first person and peer based approaches less pragmatic. In Mill et al., (2008) some Aboriginal youth commented on the lack of openness about HIV and AIDS on reserves:

It's just a different way of life. I mean we look at it as a Southerner, as someone who's been used to a different culture, one where in school, I was taught about AIDS and HIV and not having sex before a certain age, and not getting pregnant, and stuff like that. Then I came up here and pretty much everyone I met - like young, old, whatever ... I mean everything seems to be different here. Just the way children are raised and what they're taught, it's kind of like they're left to fend for themselves. (Female, urban).

If it is important for young people to learn from people who intimately understand their community, and if it is unsafe for a young person to disclose a positive HIV/AIDS status, it would be unreasonable to suggest a first person approach. On-reserve youth were less likely to suggest peer-based approaches than their urban counterparts, and more likely to suggest approaches that involved their whole community, particularly Elders. They were more interested in their communities connecting with other communities, and learning from each other.

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).

CONCLUSION

While more research is needed, important findings have emerged from this study. To increase the success of HIV prevention programs, messages must be targeted to their specific audience. Having HIV prevention programs designed specifically for particular Aboriginal communities – on reserve and off reserve – is likely to increase their effectiveness. That is, as one young person in the research stated, efforts to message HIV prevention must “suit the situation.” In rural reserve contexts, this means engaging the whole community, not just the youth; including activities that are fun; and using messages that provoke using fear or scare tactics. To a greater degree than rural youth, the urban youth suggested that peer-based approaches and first person accounts would be an effective means for HIV prevention education. Involving young people as collaborators in designing the HIV prevention they require may be a very successful strategy. As well, the youth stated that the messages should be distinct for First Nations, Métis and Inuit Nations and should represent each group individually and in a culturally relevant manner. These comments are an important reminder that Aboriginal youth are not a homogenous group; 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.

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. The youth who participated in the focus groups had many interesting ideas for prevention messages and programs. 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 and people with HIV. Participants 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 have 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. 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 risky behaviours. Aboriginal youth have many creative and relevant suggestions with regards to preventing HIV/AIDS in their communities. Putting the power and resources in the hands of Aboriginal youth and community members is an important first step in stopping the epidemic of HIV/AIDS in Aboriginal communities.

REFERENCES

- Canadian Aboriginal AIDS Network. (2004). *Joining the Circle: Aboriginal Harm Reduction*. Ottawa: Canadian Aboriginal AIDS Network.
- Chansonneuve, D. (2002). *Reclaiming Connections: Facilitating Recovery from the Trauma of Residential School Abuse and its Intergenerational Impacts*. Ottawa, ON: Wabano Centre.
- Checkoway, B., D. Dobbie, and K. Richards-Schuster. (2003). "Involving young people in community evaluation research." *Community Youth Development Journal* 4(1).
<http://www.cydjournal.org/2003Spring/checkoway.html>.
- Checkoway, B. and K. Richards-Schuster. (2001). "Lifting new voices for socially just communities." *Community Youth Development Journal* 2, 32–37.
- Checkoway, B., K. Richards-Schuster, S. Abdullah, M. Aragon, E. Facio, L. Figueroa, E. Reddy, M. Welsh, and A. White. (2003). "Young people as competent citizens." *Community Development Journal* 38(4), 298–309.
- Cornwall, A. and R. Jewkes. (1995). "What is participatory research?" *Social Science and Medicine* 41(12), 1667–1676.
- Flicker, S. (2006). Who benefits from community based participatory research? *Health Education and Behaviour* (May 31).
- Flicker, S. and A. Guta. (2008). "Ethical approaches to adolescent participation in sexual health research." *Journal of Adolescent Health* 42(1), 3–10.
- Flicker, S., Larkin, J., Smilie-Adjarkwa, C., Restoule, J.-P., Barlow, K., Dagnino, M., Ricci, C., Koleszar-Green, R., & Mitchell, C. (2007). "It's hard to change something when you don't know where to start": Unpacking HIV Vulnerability with Aboriginal Youth in Canada. *Pimatisiwin: A Journal of Indigenous and Aboriginal Community Health*, 5_(2), 175-200, December 2007.
- Flicker, S., B. Savan, M. Mildenerger, and B. Kolenda. (2007). "A snapshot of community based research in Canada: Who? What? Why? How?" *Health Education Research*, doi: 10.1093/her/cym007.
- Flicker, S., H. Skinner, T. Veinot, A. McClelland, P. Saulnier, S.R. Read, and E. Goldberg. (2005). "Falling through the cracks of the big cities: Who is meeting the needs of young people with HIV?" *Canadian Journal of Public Health* 96(4), 308–312.
- Gaventa, J. (1993). "The powerful, the powerless, and the experts: Knowledge struggles in an information age." pp. 21–40 in P. Park, M. Brydon-Miller, B. Hall and T. Jackson, eds., *Voices of Change: Participatory Research in the United States and Canada*.
- Grossman, D.C., I. Agarwal, V.M. Biggs, and G. Brennenman. (2004). "Ethical considerations in research with socially identifiable populations." *Pediatrics* 113(1).
- Hall, B. (1993). "Introduction." In P. Park, M. Brydon-Miller, B. Hall and T. Jackson, eds., *Voices of Change: Participatory Research in the United States and Canada*. Toronto: OISE Press.
- Hawe, P., Noort, M., King, L., & Jordens, C. (1997). Multiplying health gains: the critical role of capacity building within health promotion programs. *Health Policy*, 39, 29-42.

- Israel, B., A. Schulz, E. Parker, and A. Becker. (1998). "Review of community-based research: Assessing partnership approaches to improve public health." *Annual Reviews Public Health* 19(1), 173–194.
- Jarrett, R. L., Sullivan, P. J., & Watkins, N. D. (2005). Developing social capital through participation in organized youth programs: Qualitative insights from three programs. *Journal of Community Psychology*, 6(3), 207-221.
- Kahn, M., & Fua, C. (1997). Harm reduction method and the alcohol treatment for Aboriginal people. *Drug and Alcohol Review*, 16, 85-90.
- Landau, T. (1996). The prospects of a harm reduction approach among Indigenous people in Canada. *Drug and Alcohol Review*, 15, 393-401.
- Larkin, J., Flicker, S., Restoule, J., Barlow, K., Mitchell, C., Smillie-Adjarkwa, C. (2007). *HIV Risk, Systemic Inequities and Aboriginal Youth: Widening the Circle for Prevention Programming*. Canadian Foundation for AIDS Research.
- Maguire, P. (1987). *Doing Participatory Research: A Feminist Approach*. Amherst: University of Massachusetts, Center for International Education.
- McCormack-Brown, K., M.S. Forthofer, C.A. Bryant, D.K. Eaton, T. Merritt, D.C. Landis, and R.J. McDermott. (2001). "Developing youth capacity for community-based research: The Sarasota County demonstration project." *Journal of Public Health Management & Practice* 7:2.
- Mill, J., Jackson, R., Worthington, C., Archibald, C., Wong, T., Myers, T., et al. (2008). HIV Testing and Care in Aboriginal Youth: A community based mixed methods study. *BMC Infectious Diseases*, 8, 132-145.
- Minkler, M., & Wallerstein, N. (2003). *Community Based Participatory Research for Health*. San Francisco: Jossey-Bass.
- Ontario HIV Treatment Network, & Ontario Aboriginal HIV/AIDS Strategy. (2008). *Fact Sheet: The HIV Crisis in Aboriginal Peoples in Canada*. Toronto: OHTN.
- Pearce, M., Christian, W., Patterson, K., Norris, K., Moniruzzaman, A., Craib, K., et al. (2008). The Cedar Project: Historical trauma, sexual abuse and HIV risk among young Aboriginal people who use injection and non-injection drug in two Canadian cities. *Social Science and Medicine*, 66, 2185-2194.
- Prentice, T. (2004). *HIV Prevention Messages for Canadian Aboriginal Youth*. Ottawa: Canadian Aboriginal AIDS Network.
- Public Health Agency of Canada. (2004). *HIV/AIDS Epi Update*. Ottawa: Public Health Agency of Canada.
- Public Health Agency of Canada. (2007). *HIV/AIDS Epi Updates*, November 2007: Ottawa: Public Health Agency of Canada.
- Sellman, D., & Huriwai, T. T. (1997). Comments on Landau's "The prospects of a harm reduction approach among Indigenous people in Canada. *Drug and Alcohol Review*, 16.

- Smith, L.T. (1999). *Decolonizing Methodologies: Research and Indigenous Peoples*. London: Zed.
- Smyth, R. (2001). "Research with children: Paediatric practice needs better evidence — gained in collaboration with parents and children." *British Medical Journal* 322, 1378–1379.
- Society for Adolescent Medicine. (2003). "Guidelines for adolescent health research: A position paper of the Society for Adolescent Medicine." *Journal of Adolescent Health*, 33(Nov), 396–409.
- Statistics Canada. (2006). *Aboriginal Peoples in Canada in 2006: Inuit, Métis and First Nations*. Retrieved April 15, 2008. from <http://www.statcan.ca/Daily/English/080115/d080115a.htm>.
- UNAIDS. (2004). *2004 Report on the Global HIV/AIDS Epidemic: 4th Global Report*. Geneva: UNAIDS.
- UNICEF, UNAIDS, & WHO. (2002). *Young People and HIV/AIDS: Opportunity in Crisis*. New York, Geneva: UNICEF.
- Vailaitis, R. (2002). "'They don't trust us; We're just kids.' Views about community from predominantly female inner city youth." *Health Care for Women International*, 23, 248–266.
- Wallerstein, N. and B. Duran. (2003). "Chapter 2: The conceptual, historical and practice roots of community based participatory research and related participatory traditions." pp. 27–52 in M. Minkler and N. Wallerstein, eds., *Community Based Participatory Research for Health*. San Francisco: Jossey-Bass.
- Watt, S., C. Higgins, and A. Kendrick. (2000). "Community participation in the development of services: a move towards community empowerment." *Community Development Journal* 35(2), 120–132.