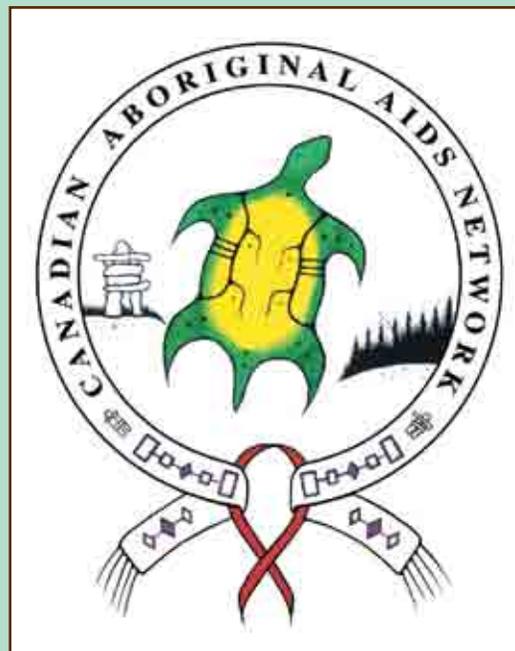
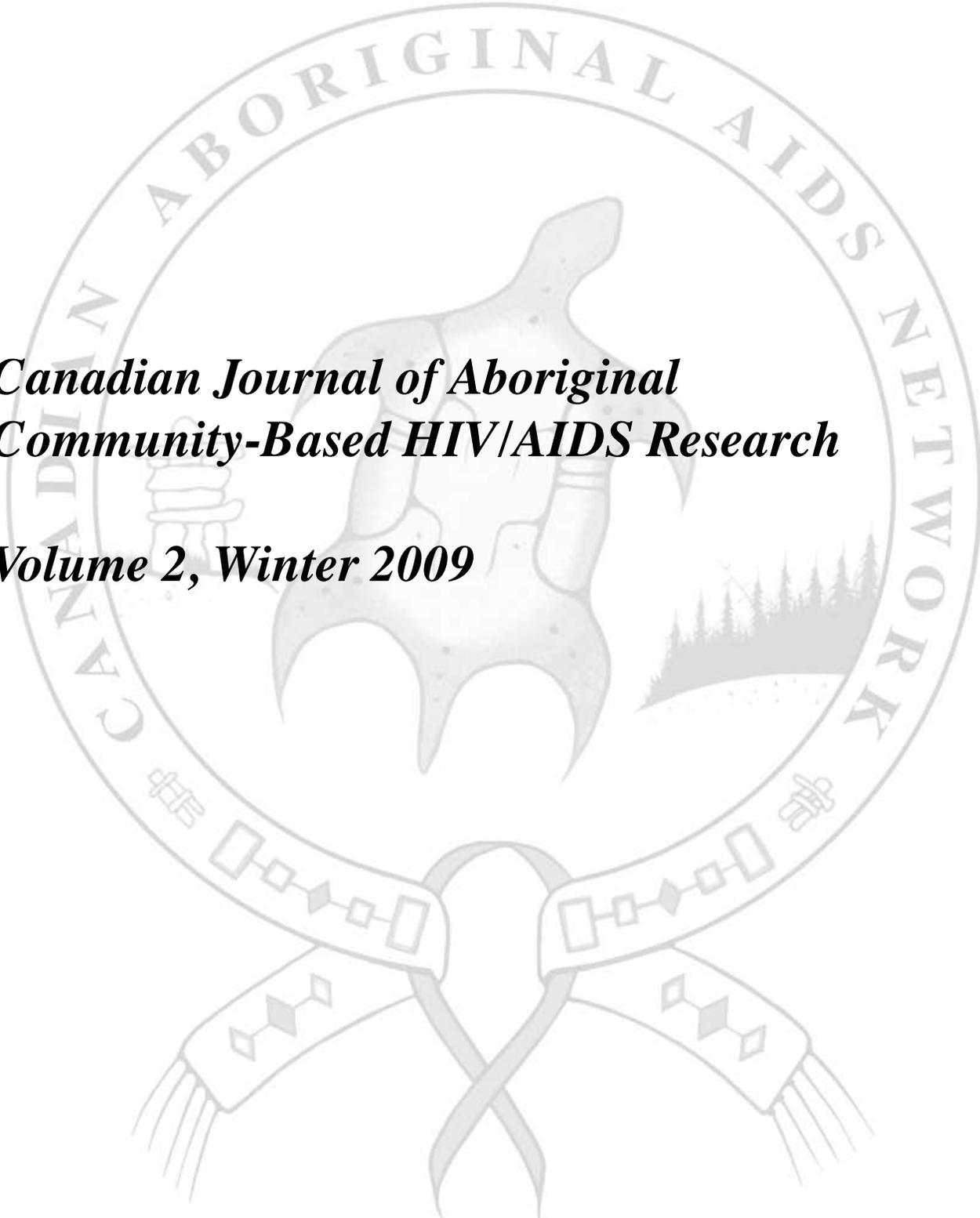


# CANADIAN JOURNAL OF ABORIGINAL COMMUNITY-BASED HIV/AIDS RESEARCH

VOLUME 2, WINTER 2009







***Canadian Journal of Aboriginal  
Community-Based HIV/AIDS Research***  
***Volume 2, Winter 2009***

## ***Brief Overview of the Canadian Aboriginal AIDS Network (CAAN)***

- Established in 1997
- Represents over 400 member organizations and individuals
- Governed by a national 13-member Board of Directors
- Has a four-member Executive Board of Directors
- Provides a national forum for members to express needs and concerns
- Ensures access to HIV/AIDS-related services through advocacy
- Provides relevant, accurate and up-to-date HIV/AIDS information

### ***Mission Statement***

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

### ***Acknowledgements***

CAAN is grateful for the participation of Aboriginal people living with HIV/AIDS and of the health care and support of professionals who shared their time and wisdom. CAAN also thanks the research team and members of the National Research Advisory Committee (NRAC).

### ***Funding Acknowledgement***

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**Canadian Journal of Aboriginal Community-Based HIV/AIDS Research (CJACBR)  
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***Editorial Policies: Purpose and Audience***

The CJACBR is an annual on-line and paper journal published by CAAN as a service to its members and anyone with an interest in Aboriginal Community-Based Research.

The CJACBR is a peer-reviewed journal which welcomes contributions from any author. Priority however, may be given to an author of Aboriginal ancestry/background, should manuscripts of comparable quality be available. First consideration will be given to innovative articles covering areas identified as HIV/AIDS research-intensive which demonstrates the use of Aboriginal Community-Based Research (ACBR) methods or philosophy.

Articles published in CJACBR are directed toward several audiences. The primary audience is Aboriginal HIV/AIDS service organizations and Aboriginal people living with HIV/AIDS (APHAs). The CJACBR secondary audiences include community leaders, policy and decision-makers, and anyone with an interest in HIV/AIDS, particularly within Aboriginal populations and communities.

***Acknowledgements***

CAAN would like to acknowledge the members of the Editorial Peer Review Board. Each member contributed to the development of review policies in addition to contributing to the peer review process.



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## ***Introduction***

Greetings Relatives!

It is with great pleasure that we present the second edition of the Canadian Journal of Aboriginal Community-Based HIV/AIDS Research (CJACBR). By this time, most of you know that CAAN is undergoing some major changes, mostly by relocating main offices to the Musqueam First Nation, at 6520 Salish Drive, Vancouver BC V6N 2C7. I asked for and received a role change, and now am serving as Chief Policy & Research Officer (CPRO).

The restructure, and the relocation to a lesser degree, is to strengthen CAAN's ability to lead in core areas. Research has taken on a greater role within CAAN, and under Randy Jackson's leadership, we have strengthened our capacity. As Randy works toward his PhD, we are continuing with this strategic investment, and linking research to policy, so that action is taken in a timely way.

CAAN has partnered with Dr. Charlotte Loppie Reading, now with the University of Victoria, to hopefully establish the Centre for Aboriginal Excellence in HIV Research (CAEHR). While we do not yet know word of funding, it is expected in May of 2009. This partnership and centre will increase CAAN's research leadership by supporting training, which is an approach CAAN has done well in. To date, we have held two Wise Practices Conferences, where we marry research and capacity building, and the Training Center will provide a more strategic response.

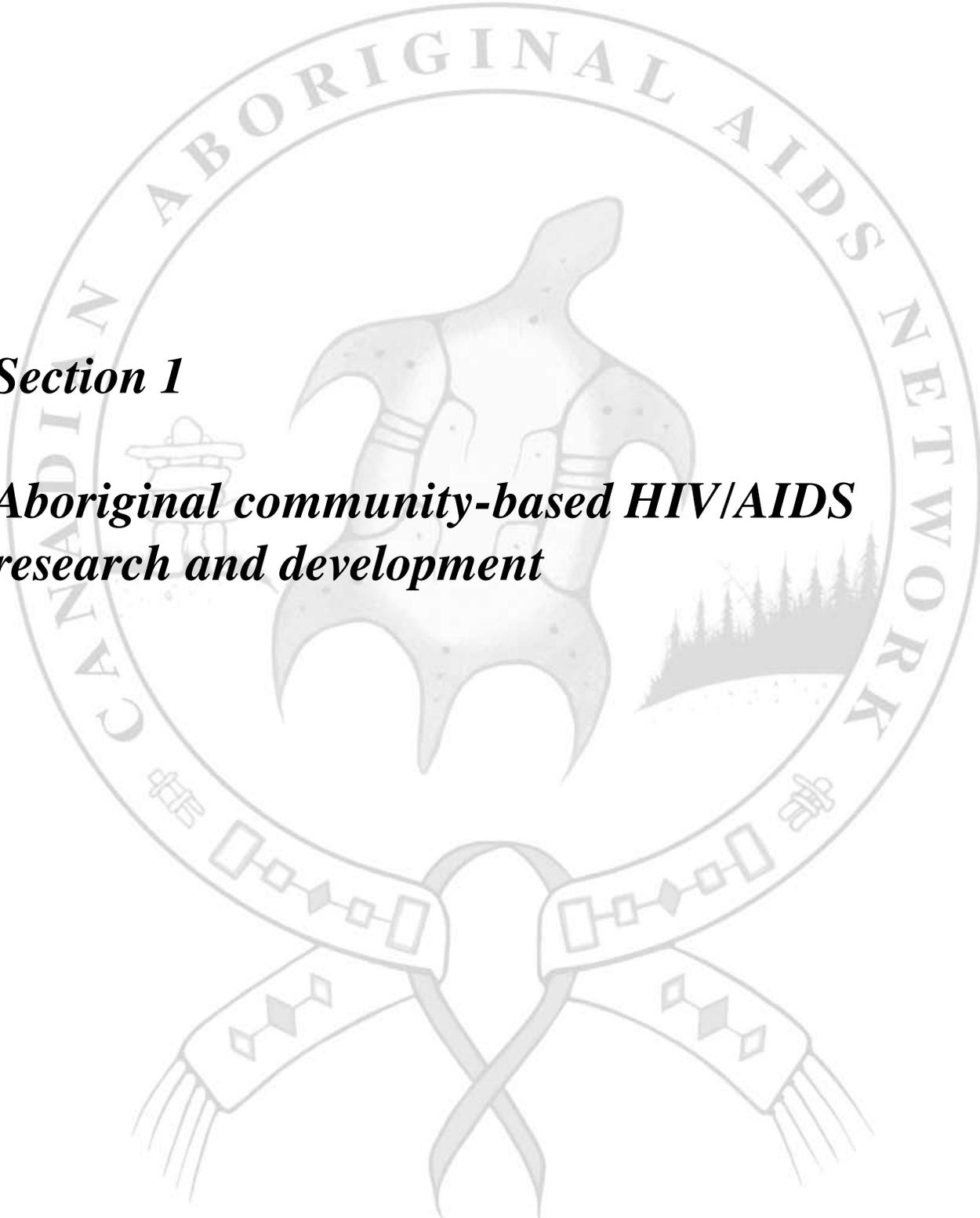
This edition of the CJACBR includes excellent articles addressing pressing and emerging issues related to youth, women and transgender/two spirit people. The links between housing and health outcomes and the implementation of a capacity building program further contribute to our understanding of the unique circumstances related to HIV/AIDS for Aboriginal Peoples in Canada. Our Editorial Peer Review Board members have again offered their insights and detailed feedback to contribute to the high standards for quality in the CJACBR. Through reviews of existing literature, program analysis, and original research the articles included in this edition assist us to ground our actions and recommendations in a solid evidence base.

In closing, I wish to thank the Research Technical Assistants (now Community-Based Research Facilitators), the National Research Advisory Committee of CAAN, the Board of Directors, research staff and our APHA Advocates for helping CAAN lead the way.

Welain, Thank you,

Kevin Barlow  
Chief Policy & Research Officer





***Section 1***

***Aboriginal community-based HIV/AIDS  
research and development***



# ***Capacity Building as a Component of Aboriginal Community-based HIV/AIDS Research***

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<sup>2</sup> Linda Archibald is an independent consultant who led three years of integrated evaluations of the Canadian Aboriginal AIDS Network.

<sup>3</sup> Randy Jackson is the Director of Research at the Canadian Aboriginal AIDS Network, an Ontario HIV Treatment Network Community Scholar and began doctoral work at McMaster University, Fall 2008.

## **ABSTRACT**

The Canadian Aboriginal AIDS Network has invested in Aboriginal community-based HIV/AIDS research capacity building for over eight years. CAAN's capacity building initiatives are designed to build and sustain community engagement in CBR. Evaluation of capacity building efforts indicates high levels of satisfaction from participants, successful outcomes and some ongoing challenges. This article discusses the process of capacity building grounded in the results of the evaluations of CAAN's efforts, the CAAN Research Unit's experiences and highlights ideas for future capacity building activities. This discussion contributes to the literature regarding the benefits of CBR as a response to community-based health issues.

## **INTRODUCTION**

Capacity building is one of the most important and challenging components of community-based research. The capacity building process includes attempts to increase confidence in local strengths to address HIV/AIDS, while fostering community agency premised on the recognition of these strengths (Campbell, Nair & Maimane, 2007). Saegert, Phillip Thompson, & Warren (2001) portray capacity building as "bonding social capital" – a sense of drawing from within community solidarity to address community identified issues. They present the analogy of a bridging process in which outside sources of help and support are brought in – conceptualized here as bridging Aboriginal Peoples engaged in a response to HIV/AIDS with academic partners. As a national Aboriginal organization, the Canadian Aboriginal AIDS Network (CAAN) has had experience on both sides of the capacity building process, as a recipient through its research partnerships with academics and institutions and as a builder in its work with community members, especially Aboriginal People Living With HIV/AIDS (APHAs) and community organizations. This article highlights some of the learning gained through this engagement in community-based research (CBR) capacity building.

CAAN began to formally integrate capacity building activities into research in 2000 with the understanding that there already existed a broad range of skills within the Aboriginal community and that all people have the ability to know the world around them. First steps included the formation of a National Aboriginal CBR Capacity Building Initiative that included the Summer Training Awards (STA) program. This initiative was designed in partnership with Health Canada to meet the needs of the Aboriginal community rooted in the understanding that "the full participation of the Aboriginal community was essential to ensure an effective response to the HIV/AIDS epidemic" (Canadian Aboriginal AIDS Network [CAAN], 2004b, p. 6; Downie with Crow Chief, 2003). Capacity building needs were identified through a National Environmental Scan (CAAN, 2004a) that informs the work of the CAAN Research Unit to this day. The STA evaluations and subsequent integrated evaluations<sup>1</sup> provide the first feedback regarding our capacity building efforts.

<sup>1</sup> In 2004, CAAN adopted an *integrated* approach to evaluation. The process involved developing a global framework in which outcomes and indicators were applied across the core program and the numerous special projects that had previously required separate evaluations.

A review of current literature regarding capacity building and CBR summarizes a climate of moving forward to a new era of independent Aboriginal research. Reflections from Research Unit staff assist in identifying next steps for the future of CAAN's capacity building efforts. Capacity building exercises are integrated throughout CAAN's research projects to assist team members to learn more about HIV/AIDS, CBR and working in partnership to enhance our ability to respond to HIV in our communities in a meaningful way. Within this context we are building on the lessons we've learned to continue to promote respectful capacity building initiatives.

## **A BRIEF LITERATURE REVIEW OF RESEARCH CAPACITY BUILDING**

Given rates of HIV infection in the Aboriginal population in Canada<sup>2</sup>, it is widely acknowledged that "to get ahead of the epidemic, we need research" (Canadian Public Health Association [CPHA], 2005, p. 17) that can potentially lead to an increase in effective evidence-based programs and services. Additionally, research can and should inform policy development and our response to specific factors that drive the epidemic in Aboriginal communities. To accomplish greater community involvement in research, an emerging trend in the literature emphasizes a shift to more participatory approaches where research capacity includes initiatives that support individuals, organizations and networks (Cooke, 2005). While there are many definitions and examples of research capacity building in the literature (for e.g. see Ontario Prevention Clearinghouse [OPC], 2002; Trostle, 1992), in May 2001, following a series of consultations with community stakeholders, CAAN adopted the following definition as one of several principles supporting Aboriginal community-based research:<sup>3</sup>

*To develop community capacity to conduct relevant community-based research, [and] provide guidance to the academic community regarding Aboriginal people/s and their research needs. Moreover, [it will strive ...] to include the principles of Aboriginal community ownership, control, [access and possession] within a community development framework while promoting an environment of mutual trust and benefit for all parties (CAAN, 2001, p. 4).*

This definition includes several objectives: (1) increasing the number of Aboriginal people conducting community-based research; (2) developing organizational and individual competencies in CBR; and (3) solidifying partnerships between community and academia. Research capacity building is conceptually a process that aims to reduce barriers to active and meaningful engagement in research activities at individual, organizational and community levels. CAAN's efforts have also included a focus on dissemination and the expectation that both the process and outcomes are evaluated.

Leung, Yen & Minkler (2004) expand upon the practical benefits of capacity building and CBR with regard to enhancing the work of epidemiology. They note the mutual responsibility that characterizes the reciprocal values that underpin CBR:

*Epidemiologists must be willing to build relationships with participants, learn from the community, and share both power and their own training and abilities for the good of the community. At the same time, the community must perceive a benefit in the project and the results, be willing to participate in the process and the tasks, and grapple with new concepts such as validity and reliability (p. 504).*

In addition, Stoecker (n.d.) has written extensively about the need for community engagement and capacity to engage in meaningful research outcomes that lead to real change in the lives of individuals and neighbourhoods/

<sup>2</sup> "A steady rise has been seen in the proportion of reported AIDS cases and positive HIV test reports among Aboriginal persons in Canada in recent years" (Public Health Agency of Canada [PHAC], 2007, p. 48). "Between 1998 and the end of December 2006, there were 21,435 positive HIV tests reported to CIDPC, 6,253 (29.2%) of which contained information on ethnicity. Of these 6,253 there were 1,458 positive tests reports identified as from Aboriginal persons (23.3%)" (ibid, p.49). "...evidence suggests that the HIV epidemic in the Aboriginal community shows no sign of abating. Injecting drug use is currently the most common mode of HIV transmission among Aboriginal persons, Aboriginal women make up a large part of the HIV epidemic in their community, and Aboriginal persons appear to be infected at a younger age than non-Aboriginals" (ibid, p. 57).

<sup>3</sup> CAAN defines "Aboriginal Community-Based Research [as] a form of research whereby Aboriginal community collaboration, direction, participation and commitment are essential. The goal is to develop culturally-appropriate and methodologically sound research, analysis, and dissemination strategies that are beneficial and empowering for the participating communities and other stakeholders in their preparation and implementation of an effective response to HIV/AIDS" (CAAN, 2001, p. 4).

communities. Minkler, Thompson, Bell, & Rose (2001) have published about the contribution that community involvement and capacity building make to organizational-level empowerment and the achievement of improved health outcomes through a case study analysis in the US.

Writing about decolonizing the research process when working within the Aboriginal community, Bartlett, Iwasaki, Gottlieb, Hall & Mannell (2007) emphasize reciprocity in capacity building. This notion builds on the agreement that “researchers who are not Aboriginal need to develop a capacity to bracket long held Western research paradigms and assumptions in order to become knowledgeable about and immersed within an Indigenous paradigm” (p. 2378). They stress that the “process of gaining research capacity from Aboriginal peoples, rather than providing it to them requires openness to diverse interpretations of life events” (p. 2379). In addition, there must be effort on behalf of Indigenous researchers to “constructively” challenge the academy to accept ways of knowing that are different from Western methodologies. Barlett et al. conclude in part, “this reciprocal capacity building means that discovery in research is bi-directional, which is an essential attribute of decolonizing research” (p. 2379). Opportunities for reciprocal exchanges occur through cultural events during CAAN gatherings that are open to Aboriginal and non-Aboriginal delegates and, more recently, research project activities have been specifically designed to directly involve non-Aboriginal researchers in cultural ceremonies. It is also noteworthy that the opportunity and the need for capacity building occurs when members of different First Nations work together and when First Nation, Métis and Inuit Peoples come together for a research project.

The literature identifies several areas of direction-setting for research capacity building. In a questionnaire designed to solicit information about capacity to participate in research, Ried, Farmer & Weston (2006) surveyed members of their health practitioners network (i.e., SARNet) in ten areas of specific research skills:

(1) Partnership building; (2) Finding relevant literature; (3) Critically review the literature; (4) Generating research ideas; (5) Writing a research protocol; (6) Applying for research funding; (7) Using quantitative/qualitative research methods (data collection); (8) Analysing and interpreting results; (9) Writing and presenting a research report; and (10) Publishing research findings.

Their findings indicate “a whole system approach more appropriately accommodates the capacity building needs of health care practitioners” (Ried et al., 2006, discussion section, para. 1). This provides a practical method for categorizing members and focusing planning of research capacity building initiatives. These findings are consistent with CAAN’s findings and lead the way forward with an informed understanding of the wisdom of investing in capacity building.

## **BACKGROUND**

When the “Canadian Strategy on HIV/AIDS” (CSHA) (PHAC, n.d.) was announced in 1998, a specific Aboriginal Research Program was initiated (Downie with Crow Chief, 2003). Aboriginal community stakeholders expressed concern regarding the launch of this CBR program citing the need for a more culturally relevant initiative (Yuzicapi-Fayant, 2001, p. 2). In response to these concerns, a partnership between CAAN and Health Canada was established to strive to ensure a high standard of excellence in CBR projects and to design the Aboriginal capacity building program (Yuzicapi-Fayant, 2001).

Although the formal partnership no longer exists, the value of capacity building to support the uptake of CBR continues to underpin the HIV/AIDS CBR program which, effective April 2004, is administered by the Canadian Institutes of Health Research (CIHR). An HIV/AIDS CBR Steering Committee, a strategic plan and the pan-Canadian policy response document the Federal Initiative to Address HIV/AIDS in Canada (PHAC, 2004) guide the CIHR. In addition to the STA program and various initiatives undertaken by CAAN through the National Aboriginal CBR Capacity Building Initiative between 2001 and 2004, scholarships were available to support HIV/AIDS CBR at the Masters and doctoral level, funds could be requested to assist in research proposal development, to host capacity building workshops and to support operating grants for full research projects. When the program transferred to the CIHR, the scholarships, development, operating and workshop grants were

maintained; however, the STAs were discontinued. While the current decision regarding the STA program is disappointing, the continuing commitment to learning and building capacity characterizes the AIDS movement overall, as people living with HIV/AIDS, their caregivers, medical practitioners, community organizations and researchers have all been confronted with learning about a virus that was identified only 25 years ago.

The CAAN Environmental Scan was undertaken to “explore the research capacity building needs of Aboriginal HIV/AIDS service organizations” (CAAN, 2004a, p. 1). The Scan proposed to:

Assess the research skill levels of CAAN member organizations and their willingness to conduct their own HIV/AIDS research [and to] discover and explore the needs of Aboriginal HIV/AIDS organizations or Aboriginal organizations with an AIDS program or services in terms of their ability to conduct research (ibid, p. 3).

Ultimately it was intended that the Environmental Scan would form the basis for finalizing and implementing a relevant national Aboriginal capacity building program.

Survey respondents were well educated<sup>4</sup> and had between 2 – 30 years experience related to HIV/AIDS community work. This was encouraging as a target group to work with. The overall barrier to engaging in CBR that emerged upon analysis was that: “HIV/AIDS service organizations are stretched to the limit and while they might see a need for community-based research, they do not presently have the human resources to conduct research” (ibid, p.9). Based upon a simple ranking of responses, three (3) main obstacles to CBR were identified:

- Lack of direct research experience within the organizations
- Limited funding for CBR projects
- Challenges of involving community members in research projects.
- This input defined the context for CAAN to begin to plan for capacity building regarding CBR within the Aboriginal HIV/AIDS movement.

The environmental scan (CAAN, 2004a) identified several specific areas of the research process where capacity might be required. The highest demands were in the areas of data analysis and research proposal development. Moderately high levels of interest were expressed regarding fund raising techniques, research question development, qualitative research methods, ethnographic research methods, and survey research methods followed closely by interest in quantitative research methods, focus groups, interviewing and report writing.

When asked how to deliver training about each of the areas above, workshops were most often cited as sources for learning followed by the internet. Areas where there was limited response — The North, East and Manitoba — indicated a 100% preference for working in person, with an average among all respondents of 78% for this preference. It is noteworthy that the preference was also to meet potential research partners in workshop or conference settings versus online. Written resources are viewed as useful tools to augment workshops and working in person. Formal contributions to academic literature regarding HIV/AIDS and Aboriginal people were also seen as useful. Time-saving resources such as lists of academics, sources of funding and assistance in filling out applications were also highly rated.

It is imperative when discussing academic research and Aboriginal peoples to be aware of the historically negative impact of research in the Aboriginal community. Too often, research was conducted ‘on’ rather than ‘with’ Aboriginal Peoples (Steenbeck, 2004). In the past, neither accumulated knowledge nor cultural contexts were routinely considered in the design and conduct of new research. Data were not shared for secondary analysis, findings were released with no regard for community impact or confirmation of an accurate interpretation, and communities were left with little or no ability to actively respond to recommendations set out in research reports. This has created a deeply rooted distrust of research and questions regarding the potential benefit of participating in research projects. Martin-Hill, Darnay & LaMouche (2008) write eloquently about the tension

<sup>4</sup> 82.4% of respondents had post secondary training ranging from “some college” through to a PhD (CAAN, 2004a).

of being an Indigenous [academic] and the need to rebuild community trust in the academic process while honouring community values and Indigenous ways of knowing the world.

It is also necessary to recognize that research has stifled the Indigenous voice through misrepresentation of Indigenous realities, the inappropriate privileging of mainstream forms of knowledge over Indigenous forms of knowledge, and the misappropriation of traditional Indigenous property, knowledge, and culture (Masching, 2006). These issues have shaped the Indigenous community's experience of research in Canada and abroad. Durie (2004), a Maori researcher, offered the following observations during the first meeting of the International Network for Indigenous Health Knowledge and Development:

*Indigenous knowledge cannot be verified by scientific criteria nor can science be adequately assessed according to the tenets of Indigenous knowledge. Each is built on distinctive philosophies, methodologies, and criteria. While there is considerable debate around their relative merits, contests about the validities of the two systems tend to serve as distractions from explorations of the interface, and the subsequent opportunities for creating new knowledge that reflects the dual persuasions (p. 1138).....*

*The challenge is to afford each belief system its own integrity, while developing approaches that can incorporate aspects of both and lead to innovation, greater relevance, and additional opportunities for the creation of new knowledge (p. 1143).*

Minkler & Jernigan (2008) address this legacy, through a commentary on the effectiveness of participatory CBR to respond to these concerns and move forward with a research agenda that honours rather than exploits the community of interest. The recent release of the CIHR Guidelines for Health Research Involving Aboriginal People (CIHR, 2007) also offer a direct response to this history and reinforce the approaches recommended by an UNESCO workshop (see Stephens, Porter, Nettleton & Willis, 2006) regarding engagement with Indigenous communities when pursuing research. This record impacts the learning curve for undertaking research today. CAAN's research takes place in a context that respects this history and sets out to 'reach around' historical barriers.

## **CAAN'S CAPACITY BUILDING ACTIVITIES**

CAAN has fully integrated capacity building in all aspects of the Research Unit's work. Taking a proactive approach, efforts reflect a combination of written resources with hands-on learning through engagement in the research process. This approach has resulted in a variety of capacity building activities including the STA program for undergraduate students; capacity building proposal development projects which engage APHAs, partners from Aboriginal community-based AIDS organizations and academics; the development of a series of workshops and written materials; and conference presentations. In addition, CAAN hosted two (2) regional Research Technical Assistants (RTA) between May 2005 and June 2007 and then one (1) National RTA from July 2007 to August 2009 to offer ongoing training and support regarding HIV/AIDS CBR. Details of each of these programs are attached as Appendix A.

Capacity building is incorporated into research projects through the inclusion of APHAs, Aboriginal community members, and representatives of regional Aboriginal AIDS Service Organizations (AASOs) drawn from across Canada on all national steering committees and research advisory committees. Community representatives participate with support from CAAN staff and the process provides them with numerous opportunities to become more familiar with the research process. In addition, the research team gains benefits from having access to the insights, knowledge, and experience that community members and regional representatives bring to the research process. CAAN staff members also participate in research teams that include academics and researchers in interdisciplinary collaboration and thus have opportunities to expand their own knowledge and expertise. In the latter case, it is the CAAN representatives that are viewed as the community representatives on the research team.

In 2006-2007, CAAN was involved in fourteen research projects funded by a variety of granting agencies. Topics included an exploration of culturally competent health care services, understanding and responding to depression among APHAs and issues of sexual violence among Aboriginal women living with HIV/AIDS. In all of the research projects, CAAN's role embodied both ends of the capacity building continuum: staff worked on research teams alongside academic researchers and the projects included APHAs and/or other community representatives on research teams, steering committees and advisory committees.

## **EVALUATING CAPACITY BUILDING**

CAAN has invested significant resources in seeking guidance and direction from Aboriginal communities and our membership through the environmental scan (CAAN, 2004a) and ongoing evaluation. In 2004, CAAN decided to pursue an integrated evaluation approach. The process involved developing a global framework in which outcomes and indicators were applied across the core program and the numerous special projects that had previously required separate evaluations. The integrated approach is consistent with the organization's mandate to "face the challenges created by HIV/AIDS in a spirit of wholeness" and it reveals the interconnectedness among diverse project goals and objectives. Details of our evaluation methodologies<sup>5</sup> for the Environmental Scan, Summer Training Awards and integrated CBR capacity building activities are included in Appendix B.

## **SUMMER TRAINING AWARDS**

The STA Program was an important vehicle for transmitting the philosophy of Aboriginal community-based research to undergraduate students, AASOs and academic advisors. This finding occurred consistently over three years (CAAN, 2004b, 2002b, 2001), leading to the recommendation that the Canadian Aboriginal AIDS Network, in partnership with Health Canada, look to extending the program beyond the summer of 2003 (CAAN, 2004b, p. 27).

The 2003 evaluation response rates for all groups involved were very high and ranged from 80% (academic advisors) to 100% (host Aboriginal organization representative and students); this is encouraging given the tight timelines for summer training activities. Evaluation results each year were used by CAAN staff to improve their interactions with projects; participation rates increased each year, in part due to this responsiveness. For example, it was learned in the first year that terms of reference for each of the participants, students, AASO staff and academic advisors would be helpful to clarify roles and expectations. Evaluation input was used to fine tune the terms of reference to suggest the inclusion of how relationships might work and to identify who is eligible to be an academic advisor (CAAN, 2004b, p. 36).

Ongoing Uptake of research – Of those responding in 2003, 66.6% of students rated continued involvement in Aboriginal CBR as either "Likely" or "Very Likely" (CAAN, 2004b, p. 32). As of the time of writing, two of the people involved in the STA program have continued their studies to the PhD level and have remained engaged in Aboriginal HIV/AIDS research. Several of the organizations that received STA funding have continued to pursue CBR initiatives and have undertaken new research projects. There was greater interest than ever before in working with the RTAs to apply for funds from the CIHR in the fall of 2006. In addition, several academic advisors have remained involved with CAAN as investigators, advisory committee members and editorial peer reviewers for the Canadian Journal of Aboriginal Community-based HIV/AIDS Research.

## **INTEGRATED EVALUATIONS**

CAAN's integrated evaluations addressed capacity building in various ways and to varying degrees over a three-year period (Archibald, 2007, 2006, 2005). In the first year, key informants were asked for their views

<sup>5</sup> The full documents, with data tables and further details regarding the evaluation processes, are available at [www.caan.ca](http://www.caan.ca) or by contacting the CAAN office.

on CAAN's success in influencing a range of outcomes. Over three-quarters (78.6%) agreed that CAAN had positively influenced an increase in skills and capacity at the community level (Archibald, 2005). One person noted in particular an increase in the number of Aboriginal people who have the skills and are interested in conducting community-based research (ibid). Also that year, ninety-one AGM participants and CAAN members involved in a telephone survey were asked about issues they would like the organization to address in the future. Advocating community-based research was a top priority (89.0%) along with advocating initiatives that involve capacity building and training (85.3%). The report notes that both of these areas were also recognized among the organization's strengths (ibid).

Evaluations have highlighted some of the benefits and the challenges associated with community participation on research committees. Participation grounds the research process in the knowledge and lived experience of the particular target group (depending on the project, this could be APHAs, youth, support workers or Aboriginal women). In turn, research questions, instruments and reports tend to be more relevant to the community and, therefore, more useful. In interviews, community members who participated on committees reported feeling that their contributions were valued, that they gained skills and confidence and learned something about the language, practice and practical value of research (ibid). Challenges included finding the time for meaningful participation and difficulties securing representation from all regions and cultural groups.

Each year CAAN holds a skills building forum in conjunction with its annual general meeting. Evaluation forms collected from individual workshop participants consistently rate the experience positively and individuals reported leaving workshops with greater knowledge and understanding than when they entered. This held true no matter how much knowledge participants had before attending the workshop. Similar results were reported in subsequent evaluations. Over a three-year period, evaluations indicated increasing internal capacity drawn from successful experiences regarding CBR capacity building across Canada. Specific highlights include:

- Research, especially CBR, is recognized as a real strength;
- CAAN's research processes are participatory; and
- All of CAAN projects include some degree of capacity building through the involvement of APHAs and AASOs on advisory and steering committees.

The 2005-2006 evaluation (Archibald, 2006) refined the data collection instrument that was used the previous year to rate CAAN's progress in influencing selected outcomes and it expanded the response group by including a short community survey in one of its newsletter mailouts. With respect to "increased skills and capacity at the community level," 35.3% of community respondents (n=51) and 44.5% of AGM participants (n=45) rated CAAN's progress as very good or excellent.<sup>6</sup> Table 1 compares response rates between these two groups. Higher ratings by AGM participants likely reflect their greater knowledge of the organization and its activities. In fact, community respondents saw less progress achieved and had higher levels of "Do Not Know" responses on all of the issues in the survey, especially providing a role for Elders and traditional teachings in HIV/AIDS prevention messages; increased support and advocacy among Aboriginal leaders, and; increased access to care, support and treatment for Aboriginal persons living with HIV/AIDS.

<sup>6</sup> The 2004-2005 question differed in that it asked key informants to reply only "yes" or "no" and 78.6% said yes. The 2006-2007 question provided a range of responses: poor, fair, good, very good, excellent, don't know.

**TABLE 1: Rating CAAN’s Progress: “Increased Skills and Capacity at the Community Level” as Reported by AGM Participants and Community Survey Respondents<sup>7</sup>**

RESPONDENTS	RATING						
	Poor	Fair	Good	Very Good	Excellent	dn/NA*	Total
2005 AGM (n=45)	0	11.1	37.8	26.7	17.8	6.6	100
AGM combined ratings	0	48.9		44.5		6.6	100
Community Survey (n=51)	7.8	19.6	15.7	21.6	13.7	21.6	100
Community Survey combined ratings	7.8	35.3		35.3		21.6	100

It was recommended that CAAN develop a strategy to increase its reach into First Nations, Inuit and Métis communities with a special emphasis on rural, northern and remote communities. The following year’s evaluation focused almost entirely on gathering information from the communities. A telephone survey was administered in the weeks following Aboriginal AIDS Awareness Week in December 2006. An Evaluation Committee comprised of staff and board members oversaw the design of the survey and a decision was made to attempt to reach every community on the general mailing list, in all, 727 First Nations communities, Friendship Centres and Métis organizations<sup>8</sup>. This decision resulted in the evaluation itself becoming a capacity building activity.

Interviewers were recruited from individuals known to CAAN living in the regions and social work students at Carleton University in Ottawa. An Interviewers’ Guide was distributed by e-mail and training sessions were held for those living in the Ottawa area. Out-of-town interviewers received detailed instructions by telephone after they had read the guide. In one case, a mock interview was set up at the request of the interviewer. Fourteen interviewers participated in the first round of calls and four were asked to return in January 2007. Wherever possible, interviewers were matched with the regions in which they lived or had lived and bilingual interviewers were assigned to the Quebec region.

Productivity varied greatly among the interviewers but the quality of the responses was consistent. The evaluation consultant remained in e-mail and sometimes telephone contact with the interviewers and any questions were quickly answered. Interviewers passed on requests for information and materials they received during the interview, such as: how to obtain a condom dispensing machine; printed material in Aboriginal languages; information about speakers’ lists; ideas for innovative ways to present to youth; and how to do an HIV/AIDS workshop. Interviewers reported learning a great deal about conducting a telephone survey as well as about HIV/AIDS and community issues. Some of the non-Aboriginal university students reported learning a lot about the geography and conditions of Aboriginal communities and about issues they had not previously thought much about. Aboriginal interviewers, especially those living in the regions, had knowledge of the communities and a way of interacting with people that likely contributed to an increased response rate. In the end, 530 communities were reached; the official response rate was 73.3%, but in reality it was much higher because a significant number of telephone numbers were out of service.<sup>9</sup>

<sup>7</sup> See Archibald 2006, p. 9-10. Table 1 is based on information extracted from Table 2 and Table 3 in the evaluation report.

<sup>8</sup> Inuit communities were not involved in this survey because the Inuktitut version of the AAW poster contained an error and required re-translating; it was not finished in time for the package to be distributed prior to AAW (December 1-5), and, therefore, parts of the survey would not have been relevant.

<sup>9</sup> Lack of infrastructure was noted as a problem, especially for many Métis organizations; for example, in Saskatchewan a large percentage of the telephone numbers were out of service. Also, many of the Métis contacts on the mailing list were members of an organization’s executive and where no office existed, the contact number was their home – as the executive changed, so did the contact and the mailing list too often contained out of date contacts.

The training and ongoing support provided to interviewers was essential to the success of the survey. Variations in productivity among interviewers was due to a variety of factors including the amount of time the individual could devote to calls, previous experience with similar types of work, and personality (e.g. shyness, difficulty making cold calls, etc.). It must also be recognized that when community members are involved in research, they cannot be expected to separate themselves from the issues. In some cases, their involvement in the research may trigger a strong emotional response. Planning included the possibility that some interviewers might not be able to complete the work and this in fact happened. A couple of individuals withdrew from the work and their call lists were passed to other interviewers. This was done in a supportive and non-judgemental manner.

## **OTHER INITIATIVES**

### **RESEARCH PARTNERSHIPS**

In partnerships involving academic researchers, CAAN's role in capacity building tends to focus on educating non-Aboriginal team members about Aboriginal cultures, values, and approaches to research. In 2002 CAAN developed a set of principles to formalize and guide participation in research with partner organizations, institutes and academics – essentially a model for building the research team's 'terms of reference'. The document, entitled "Principles of Research Collaboration" (CAAN, 2002a), works as a capacity building tool in that it challenges all of the players involved on a research team to talk openly and consider issues that might not otherwise have been discussed. The Principles document includes an authorship agreement, acknowledges the importance of incorporating cultural values and perspectives into the research process, and helps to make the principles of OCAP (ownership, control, access and possession of data) more concrete through articulation. The acceptance of the OCAP principles in the research field highlights the growing competence regarding research for and by Aboriginal Peoples.

### **NATIONAL RESEARCH ADVISORY COMMITTEE**

In 2006, CAAN established the National Research Advisory Committee (NRAC), composed of Aboriginal and non-Aboriginal researchers and community members with attention to geographic distribution, the inclusion of APHAs, women and Elders. CAAN staff and a representative from the CIHR contribute to the NRAC's activities in an ex-officio capacity. As previously noted, the engagement of CAAN's diverse stakeholders builds both internal capacity for the organization and leads to increased capacity for the individual participants. The specific involvement of an Elder helps to create a respectful environment of safety to air concerns in an honest way that can lead to actions being negotiated to the satisfaction of all partners involved.

Over several years of meetings (both in person and via conference call), research project presentations, consultations, proposal development discussions and review of dissemination materials, the NRAC has become a core resource for the CAAN research unit. The committee has assisted research coordinators to refine data collection efforts and tools, identified key resources across the country, helped to clarify cultural norms regarding specific topics of research interest and oversees all of CAAN's research endeavours. The capacity of this committee and the confidence demonstrated by research coordinators in the direction they are given are evidence of CAAN's growing sophistication in the research field while providing a space for dialogue about the many ethical and practical issues related to community-based research.

### **KNOWLEDGE BROKERING**

In 2006 CAAN launched the Canadian Journal of Aboriginal Community-Based HIV/AIDS Research (CJACBR). With CAAN staff as editors, this journal is a dissemination tool that enhances access to relevant Aboriginal HIV/AIDS research materials. Designed as a vehicle to engage both academic and community audiences, articles are reviewed annually by a volunteer Editorial Peer Review Board. The Peer Reviewers are individuals who bring a strong combination of academic training, community engagement and enthusiasm

to the review process. Individuals have indicated that the review process offers an opportunity to learn more about issues related to HIV/AIDS, to develop a deeper understanding of academic 'standards' for publications and, at times, the opportunity to mentor submitting authors in the development of high quality articles. As an open access document, the CJACBR is available at no charge on CAAN's website and in limited hard copies in both English and French. As a resource this journal contributes to the much needed 'evidence base' required to justify community initiatives and creates a resource for community members to begin to refer to research findings in their funding applications.

## **1ST ABORIGINAL CBR CAPACITY BUILDING CONFERENCE**

Capacity building was one of the key motivations for, and objectives of, CAAN's 2007 conference: *Walking a Path to Wise Practices: 1st Aboriginal HIV/AIDS CBR Capacity Building Conference*.<sup>10</sup> High profile keynote speakers from the Aboriginal research community opened and closed the conference and spoke at the traditional feast. Participants included more than two hundred delegates from across Canada representing First Nations, Métis and Inuit populations and reflecting cultural, gender and geographic diversity. Delegates included APHAs and at-risk groups alongside Aboriginal and non-Aboriginal researchers and academics. CAAN research projects were profiled in many of the sessions, some of which offered research teams opportunities to consult on and validate their findings with conference delegates.

Participants completed evaluation forms at the end of each of the 35 workshop and plenary sessions and a separate form for the overall conference. CAAN received a total of 383 workshop and conference evaluations. The information collected gave overall ratings and comments that were almost universally positive and for many, this was the best conference they had ever attended. Critiques most often related to the desire for more time, smaller groups and more handouts. Networking was also a key element of this event and participants offered suggestions to improve networking opportunities at future conferences. The evaluation report (Archibald, 2007) recommended that CAAN continue to place an emphasis on community-based research and CBR capacity building initiatives and that CAAN seek funding to convene a major CBR capacity building conference every two years.

### **“The Perspective of the Capacity Builders” Insights from the Research Unit Staff**

Reflections from CAAN staff highlight responding to the challenges of capacity building and how to engage with academic investigators, individual and organizational membership given cultural, structural, and geographic obstacles. In the 8 years that CAAN has invested in CBR capacity building, the research unit has ranged from 2 staff to a high of more than 8 research coordinators, research technical assistants, research assistants and a manager. Beyond those hired and housed at CAAN, the unit has benefited from the contributions of consultants and strong collegial relationships with other centres of research. There is a confidence that CAAN has set a strong example for undertaking research that is ethical, respectful and grounded in community need. This is reinforced by both the individual and organizational members of CAAN through consistent support as demonstrated in evaluations, resolutions during AGMs and a strong willingness to engage in research projects as resources and participants. As staff, a guiding principle is that research is undertaken for the purpose of assisting our membership directly through actions grounded in research findings and providing evidence that is useful for generating a local, provincial or regional response.

Following the review of CAAN's strategic plan for 2005- 2010, the 2006 document “Researching Ourselves to Life” outlined the following goal for the research unit:

<sup>10</sup> One of the stated conference objectives was “To increase the number of community-based researchers with knowledge of Aboriginal community-based research design and data analysis available to undertake HIV/ AIDS research in Aboriginal communities.”

*To expand capacity within CAAN and the community to create a solid base of Aboriginal researchers who will optimize culturally relevant community-based HIV/AIDS research related to Aboriginal Peoples and HIV/AIDS which will guide action in response to the epidemic (Masching, 2006).*

This goal is supported by several objectives with capacity building specifically identified in objective (1) to increase Aboriginal community engagement in community-based HIV/AIDS research with the secondary objective to support Aboriginal community-based capacity building initiatives (ibid). The paper goes on to identify strategies that CAAN will incorporate to meet this goal and objectives. Many are discussed in this paper already. Additional approaches that remain to be fully addressed include:

- Working with researchers to champion a pan-Aboriginal strategy for HIV/AIDS research that makes the best use of all skills and resources among Aboriginal peoples, both nationally and internationally; and
- Encourage Aboriginal leaders in HIV/AIDS research to help train and mentor new Aboriginal researchers, both at academic institutions and within Aboriginal communities.

Strong networks with leaders in both the Aboriginal and HIV/AIDS domains will facilitate ongoing efforts to pursue these ideas. These are areas where the results of capacity building within the Aboriginal community will be realized as new players step forward to participate in the development of a long term strategy and pursue ongoing training in CBR.

As a largely task-driven unit, questions arise about maintaining high output when all are engaged in existing projects with timelines which run from 1 to 5 years and include periods of intensive work mixed with periods of greater flexibility. Where is the time for new proposal development? Who is going to do the literature reviews necessary to ground a new proposal? How do we recruit the right person for each project when the topics we research can often include very personal issues? Is there a specific cadre of skills that we need to seek out in individuals and for the unit as a whole? How do we continually grow and improve our own capacity to understand the research process so that we can ensure that the principles of OCAP are respected – both through our own actions and to assist our membership should questions arise. Many of these issues begin to take on the challenge of ‘prioritizing the priorities’ and can inspire members of the research unit to reinvest in building internal and external capacity to undertake research.

In the community it is understood by research unit staff that there can be a lack of confidence to undertake research and that time is a significant barrier. It can be disheartening that many funding applications will require several months for development, followed by several months for review and then an announcement months after submission in an environment where access to resources is scarce. If a proposal is declined, the fact that funds will not be available again for a year can dissuade further pursuit of research initiatives in favour of more certain pursuits. Additional concerns revolve around how to find the ‘right’ academic partner and, once found, how to build trust given the destructive history of research involving Aboriginal peoples.

## **DISCUSSION AND NEXT/FUTURE STEPS**

Our activities, experiences and evaluations, with the focus here being on research capacity building, address a key concern with community-involved research; namely, that little has been offered to validate the impact of these efforts in community-based health initiatives (Steenbeek, 2004). Research capacity building can be viewed by some as contributing only in a very small way to building community capacity to address the larger issues brought to bear by HIV (i.e., crushing poverty, social inequality, etc). From CAAN’s perspective, capacity building has led to increased quality in HIV/AIDS community-based research regarding Aboriginal peoples. Much work remains to decolonize the research process and learn how to apply indigenous methodologies to HIV/AIDS research in Aboriginal communities in Canada. As Reading (2006) suggests; “the world requires a renewed exploration of Indigenous “ways of knowing,” with the integration of innovative ideas derived from ancient traditional practices of Aboriginal healers with the modern scientific methods of inquiry practiced by a new generation of researchers”. This view is consistent with community-based research. Thus our overriding

strategy in research capacity building involves building the necessary conditions for effective social action where Aboriginal communities develop agency to participate in this process.

Over the short term, it is always difficult to determine the impact of research on policy and practice. Nevertheless, it is clear that CAAN's community-based research initiatives are engaging the voices of Aboriginal people living with and affected by HIV/AIDS. The involvement of Aboriginal people, especially APHAs, as front-line researchers and members of research teams and advisory committees has influenced everything from: the topics under study; the ability of projects to recruit participants, and; the ways in which data are interpreted. This is in stark contrast to the manner in which research has historically dealt with Aboriginal peoples.

Today, research topics are emerging directly from the community. Research findings have been applied by stakeholders across Canada in the design and justification of new initiatives responding to the needs of APHAs. APHAs have been able to use their increased capacity to engage in the research process to advocate for themselves and assist their support networks to better understand the context of HIV/AIDS and Aboriginal Peoples in Canada. Aboriginal community-based AIDS organizations and programs have gained confidence in the research process through their formal roles with CAAN research projects and through the numerous presentations, workshops and resources developed by CAAN.

CAAN continues to be challenged by its relationship to study participants and the community to develop more creative approaches to disseminating the research results. For example, in addition to publishing reports, articles and fact sheets, knowledge transfer in future projects may include involving study participants in developing videos and plays and presenting community workshops based on the findings. Increased community involvement in disseminating the results of research and the use of more creative and diverse knowledge transfer strategies will inevitably involve CAAN in new areas of capacity building internally and with membership.

Future steps must identify more opportunities to incorporate CBR capacity building within existing programs. A renewal of the Environmental Scan, given the accomplishments achieved to date through capacity building, would be useful to continue to guide the Research Unit's endeavours. Future efforts must focus on how to use technology (e.g. Internet) to engage WITH the broad Aboriginal population in 'reaching around our challenges'. Creative approaches are required that address the diversity within the Aboriginal population, the often limited infrastructure within Aboriginal AIDS organizations and the broad geographic distribution of Aboriginal communities from sea to sea to sea. Staff members have identified responses such as:

- Development of step-by-step guidelines for the various components of proposal submissions to major funders;
- The development of online training modules; and
- Continuing to seek ways to incorporate CBR capacity building within existing programs.

As demonstrated throughout this article the results of capacity building initiatives to date have improved both CAAN's endeavours and increased community confidence in the research enterprise. This in itself is significant progress in the context of a once hostile relationship between Aboriginal peoples and research. Capacity building efforts which honour the talents of those involved and progress at a pace that participants find comfortable have led to great successes (see Masching, Ticknor, Archibald & Jackson, 2006).

## **CONCLUSION**

Community-based research is crucial in a refined response to the HIV epidemic within the Aboriginal population in Canada. It provides a framework for conducting solid, ethical research that embraces members of the community most impacted by the results of the study through a commitment to building capacity among community members. CAAN does this by including APHAs and community members on steering committees, advisory committees and research teams, by providing proposal development assistance to AASOs, by developing and distributing print and electronic resources on how to conduct community-based research and

by delivering training at annual general meetings and workshops. The participation of community members as interviewers in the community survey provided a model of capacity building that has been incorporated by other CAAN projects. Finally, CAAN's Research Unit promotes a vision for capacity building that has grown from the evolution of OUR internal capacity by engaging with community members and academics to conduct meaningful and timely research projects. New capacity building approaches using technology to bridge the challenges related to cross country work will build upon our successes to meet the diverse needs of Aboriginal communities in Canada.

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## APPENDIX A

### DETAILS OF CAAN CAPACITY BUILDING ACTIVITIES

#### **Environmental Scan**

CAAN undertook the Community-based HIV/AIDS Research Environmental Scan (CAAN, 2004a) and the final report details: (1) community-based research capacity building needs of Aboriginal HIV/AIDS organizations; (2) identifies barriers to participation in community-based research; and (3) recommends ways in which service delivery organizations can build their research capacities and participate in community-based research. Added to Ried et al.'s (2006) list of ten (10) areas, for Aboriginal community respondents to this survey, is the need for skills development related to ethical protocols and access to Research Ethics Boards (REB).

#### **Summer Training Award (STA) Program**

The STA Program operated between May and September in 2001, 2002 and 2003. AASOs partnered with local members of the Academy and undergraduate students and proposed a project that was peer reviewed by the CAAN Community-based Research Committee. A total of 19 projects were funded through this innovative capacity building approach. The overall goal of the program was to increase the number of Aboriginal people capable of undertaking community-based HIV/AIDS research with community partners. The logic of the STAs was to establish an intermediary phase of the scholarship component, administered by Health Canada for Masters and PhD students, to ensure qualified Aboriginal researchers would be available for future Aboriginal community-based HIV/AIDS research initiatives (CAAN, 2004b). Through host AASOs, student and academic advisors were provided opportunities to collaborate on HIV/AIDS community-based research activities of relevance to the local communities. A number of STA participants were also brought together to share the results of their research and to build more skills. Evaluation results indicated that the STA Program was an "important vehicle for transmitting the philosophy of Aboriginal community-based research to students, AASOs and academic advisors" (ibid, p. 27).

#### **Capacity building Proposal Development Projects**

CAAN has undertaken two research proposal development projects using a participatory development process. In general, the following objectives have been commonly identified: (1) Recruit members of Aboriginal communities to partner with CAAN and identified academic leads to develop a research application. The partnership structure enables successful research capacity building in the areas identified and responds to issues of community relevance. (2) To conduct a more thorough literature review to ground the development in current knowledge. (3) To draft, justify and submit a research application to an appropriate funding body (i.e., CIHR, etc.). (4) To involve the research technical assistants to work with community members in the development process. In short, the proposals are a logical extension of CAAN's research capacity building program, build partnerships between Aboriginal community partners and social science researchers, and build research capacity that may lead to addressing gaps in knowledge specific to Aboriginal peoples in the context of HIV/AIDS.

#### **Capacity building Workshops and Written Materials**

The Environmental Scan indicated a strong desire for working together in person whenever possible. CAAN embraces every opportunity to meet with our membership and interested Aboriginal community members to work with local stakeholders to build interest and capacity regarding community-based HIV/AIDS research. Workshops have been developed for our AGM and Skills Building gathering to offer capacity building opportunities related to the basics of CBR, Computer Assisted Qualitative Data Analysis Software (CAQDAS), understanding Knowledge Translation, and ethics. In addition to the workshops offered in conjunction with CAAN events, individual member organizations can request workshops.

Beyond workshops, CAAN produces a variety of written resources to support capacity building and a deeper understanding of the research process. A series of CBR Fact Sheets offer basic definitions, examples and additional resources regarding: the principles of OCAP, understanding CBR, conducting Literature Reviews, evaluating research reports, focus groups, formation of a research team, negotiating ethics agreements and selected readings on topics related to CBR and HIV/AIDS. These materials contribute to sustaining the skills discussed during workshops and offer a resource for participants to share upon returning to their organizations.

### **Conference Presentations**

CAAN understands capacity building as a holistic process where Aboriginal and non-Aboriginal participants involved in community-based HIV/AIDS research can come together to learn from each other to build partnerships and ultimately strengthen our response to the HIV/AIDS epidemic. In the spirit of this mutual learning, CAAN develops and delivers presentations at various conferences. The goal of these efforts is to build cross-cultural understanding and enhance the capacity of non-Aboriginal stakeholders to partner with Aboriginal stakeholders in research efforts. Presentations offer insights from current Research projects, highlight process when working with Aboriginal Peoples, identify ethical priorities and offer an opportunity for further discussion through questions and posting contact information.

### **Research Technical Assistants**

CAAN is committed to continue and expand its strategic approach to enhance community-based research capacity among Aboriginal peoples which will, in turn facilitate CBR projects designed to mitigate the effects of HIV/AIDS. From May 2005 to June 2007, two Research Technical Assistants (RTAs) became a significant addition to CAAN's passionately dedicated team. Each RTA was designated to cover half of the country (East/West). From July 2007 through to August 2009, one National RTA will carry on the RTA program which builds upon the CBR capacity building needs of Aboriginal community members. The RTA's objectives are:

- To build capacity as well as enhance cultural sensitivity for HIV/AIDS health care providers.
- To enhance dissemination of research.
- To address training in community-based research.

Key activities for the RTAs focus on mentoring for community-based HIV/AIDS research with Aboriginal Peoples. The RTAs help to create a foundation for community and academic partners through the research project development and grant writing process. When proposals are funded, the RTAs continue to offer technical assistance to implement the research design. If revisions are necessary, the RTAs also contribute to this process as needed. Included in these activities are opportunities for fact finding meetings with potential communities and researchers aimed to match community research interests with researchers. RTAs also take a leading role in the production of the Canadian Journal of Aboriginal Community-based HIV/AIDS Research and continually offer support to member organizations related to CBR.

## **APPENDIX B**

### **DETAILED EVALUATION METHODS**

As a foundation for CBR capacity building the Environmental Scan (CAAN, 2004a) used a survey developed by CAAN staff with guidance and supervision from the National Steering Committee of the Aboriginal HIV/AIDS Community Based Research Capacity Building Initiative in Canada. The survey “was constructed based on possible research capacity building needs ... focusing on research requirements, tools and barriers, and on best methods for building capacity at a local level” (CAAN, 2004a, p. 3). The survey was mailed (post and email) to CAAN member organizations and some Community Health Representatives (CHRs) in Quebec for a total of 130 targeted participants. The survey was also available on CAAN’s website (ibid, p. 4). Response rate was 39% of the targeted participants. Regional disparities occurred with limited responses from the North, Manitoba and the East. Analysis used SPSS and word processing software for content analysis (closed and open ended questions respectively) (ibid, p.4).

#### **CAAN approaches evaluation from two perspectives**

- To assist CAAN in better meeting its mandate to provide leadership, support advocacy for Aboriginal people living with and affected by HIV/AIDS by identifying factors contributing to or hindering the successful implementation of individual projects and of CAAN’s operations as a whole; and
- To foster learning about how CAAN, as a national Aboriginal organization can optimize its operations, including the management and implementation of projects.

#### **Summer Training Award Program evaluation methods**

The STA program was evaluated each year to identify trends and patterns regarding the impact of the program for the student, the Aboriginal organization, and the academic advisor. Exit evaluations were conducted with the student researchers, academic advisors and host organization representatives. A standard questionnaire was constructed based on the year’s indicators of success and previous recommendations for the purpose of a telephone interview (CAAN, 2004b). A copy of the questionnaire was sent to all participants prior to the interview, providing an opportunity to reflect on experiences. The focus on previous years’ recommendations was important to see whether implemented changes had the intended effect. All responses were tabulated and frequencies calculated using the computer programs, Excel and SPSS. Recommendations were formed from the results to assist program staff to make improvements, draw conclusions about the program’s operation and to meet goals and objectives.

#### **Integrated Evaluation**

The integrated evaluation approach involved developing a global framework in which outcomes and indicators were applied across the core program and the numerous special projects that had previously required separate evaluations. The integrated approach reveals the interconnectedness among diverse project goals and objectives. For example, the integrated approach lead to an interview question asking respondents what they learned through their involvement in CAAN. The 2004-2005 evaluation concluded that the inclusion of community representatives on project advisory and steering committees brought a capacity building component to every project.

In the first year of the integrated evaluation (2004-2005), the focus was on generating an overview of the organization and beginning the process of gathering baseline data. Findings were based on the following information sources: 43 AGM participant evaluation forms; 108 evaluation forms from participants in 16 workshops in the Skills Building Forum held prior to the AGM; a telephone survey of 27 individual and 21 organizational members of CAAN; 45 key informant interviews with members of CAAN’s Board of Directors,

project advisory/steering committees, staff and external partners; document review and; observations of research team meetings, capacity building workshops and media events.

Elements of the 2004-2005 integrated evaluation were repeated the following year by standardizing a number of instruments, including AGM and workshop evaluation forms. Sources of information in 2005-2006 included 45 completed AGM evaluation forms; 226 completed workshop evaluation forms (AGM) plus 5 evaluation forms from a software training program held in December; 51 completed community surveys; a focus group of individuals involved in a Toronto AAW event; focus groups involving 28 students in Wagmatcook, NS; document review and; observation of media events, research team and advisory committee meetings. Both qualitative and quantitative methods were used. The analysis included an in-depth exploration of the data collected. Qualitative content analysis identified key themes, patterns, differences and unique circumstances or events and quantitative methods where appropriate, included analysing closed-ended questions in surveys, interview schedules and evaluation forms.

The integrated evaluation for 2006-2007 engaged community members across the country based upon CAAN's mailing list and the dissemination of Aboriginal AIDS Awareness Week (AAAW) materials. Five hundred and thirty people (530) from First Nations communities, Métis organizations and friendship centres participated in telephone interviews in December 2006 and January 2007. The interviewers were recruited from individuals known to CAAN living in the regions and social work students at Carleton University. Bilingual interviewers made the Quebec calls. The survey was posted on a website with an online survey engine and interviewers entered responses directly onto the on-line form. The overall response rate was 73.3%. No sampling strategy was involved because attempts were made to contact every community and organization on CAAN's general mailing list of 727 contacts. Inuit communities were not involved in this year's survey because the Inuktitut version of the AAW poster required re-translating and was not finished in time for distribution. Data were cleaned online and the standard reports generated included frequency tables for closed-ended questions and text of responses to open-ended questions. Content analysis of open-ended questions proceeded inductively by reading through responses and organizing data according to identified themes. Evaluation data also included evaluation forms completed at the Walking a Path to Wise Practices: 1st Aboriginal HIV/AIDS CBR Capacity Building Conference, February 13-16 in Vancouver. The evaluation consultant also observed some AAW activities, a focus group and national steering committee meeting for the Harm Reduction project.

### **Limitations for the 2006-2007 Integrated Evaluation**

Interviewers asked to speak to the person responsible for HIV/AIDS and other health issues. As such, interviewees were viewed as key informants and representatives of their communities. Results should not be interpreted as being representative of all First Nation community members, friendship centres or Métis organizations.



# ***HIV Prevention with Aboriginal Youth: A Global Scoping Review***

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## **ABSTRACT**

HIV infection is a serious and ongoing health concern among young people in Aboriginal communities, both locally and globally. This paper summarizes lessons learned from a global scoping review of both peer-reviewed literature (n=38) and community reports (n=14) on 'wise' practices in HIV prevention with Indigenous youth. Results include the importance of (a) reaching youth at a younger age; (b) adopting peer education approaches; (c) leveraging partnerships; (d) addressing colonial impacts in HIV prevention efforts; (d) attending to diversity; (e) addressing stigma; (f) revising current educational practices; (g) adopting a harm reduction approach; (h) identifying testing as a potential point of prevention intervention; (i) incorporating arts-based approaches into prevention initiatives; (j) adopting culturally sensitive/decolonizing approaches to research conducted in partnership with Indigenous communities. The discussion focuses on what has been learned from this collective body of knowledge and makes recommendations/suggestions for future research and practice directions.

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## **INTRODUCTION**

In the third decade of the HIV epidemic, there is a wide body of globally available evidence that has contributed to our in-depth understandings of the possibilities for HIV prevention. There is also a growing body of work specific to Indigenous/Aboriginal youth, but there have been few efforts to synthesize this knowledge in an integrated way. This lack of attention has implications with respect to both future research directions and applied decision-making. In order to assist with policy and practice planning, it is important that findings from discrete studies are presented in accessible and useable formats <sup>1</sup>. The goal of this paper is to systematically review the published literature focused on HIV prevention with Aboriginal/Indigenous youth and to synthesize findings into an integrated whole by drawing out dominant themes and suggesting future directions.

This review came out of our desire to build on what was already working in the field of HIV prevention with Aboriginal youth in Canada. Consistent with CAAN's Aboriginal Strategy on HIV/AIDS in Canada (2003), the term 'Aboriginal' is used to include Inuit, Métis, and First Nations (Status and Non-Status) peoples. Furthermore, we wanted to learn from other parts of the world where Indigenous peoples are considered 'minority' populations. We recognize that there is tremendous diversity in terms of language, culture, lifestyles and perspectives between and within these groups. "While this diversity makes lumping people together under generic terms like 'Aboriginal' or Indigenous' profoundly misleading, most groups nevertheless share a common social, economic, and political predicament that is the legacy of colonization" <sup>2, p607,3</sup>. As argued below, it is precisely this common encounter with colonialism that puts Aboriginal/Indigenous communities at elevated risk for HIV.

## **HIV/AIDS AMONG YOUTH IN INDIGENOUS/ABORIGINAL COMMUNITIES**

Young people are at the center of the global HIV pandemic with an estimated 11.8 million youth living with HIV/AIDS <sup>4</sup>. Each day nearly 6 000 young people between the ages of fifteen and twenty-four acquire HIV, accounting for half of all new infections <sup>5</sup>. Globally, Indigenous youth are also disproportionately affected by HIV/AIDS and available epidemiological evidence suggests that Canada's Aboriginal First Nations, Inuit and Métis youth are among them.

Presently, there are roughly one million Aboriginal peoples living in Canada, accounting for approximately 3.3% of the total population. However, the Public Health Agency of Canada estimates that "[Aboriginal peoples] are estimated to account for 7.5% of persons living with HIV in Canada at the end of 2005 and 9% of all new HIV infections in 2005. This shows an estimated overall infection rate in Aboriginal persons that is nearly 3 times higher than among non-Aboriginals."<sup>6</sup> In addition, the profile of Aboriginal AIDS diagnoses differ from non-Aboriginal diagnoses in three important ways: gender, age and exposure category: women, youth and injection drug users. Available epidemiological data shows that Aboriginal youth are at increased risk for HIV infection with the shift in median age at onset of HIV infection from 32 years to 23 years of age <sup>7</sup>. The increasing Aboriginal youth infection rates coupled with a recent surge in sexually transmitted infections <sup>8</sup> and a decline in youth knowledge about HIV<sup>9</sup> are signs of the potential for the further spread of HIV amongst youth in Canada.

### **Accounting for rates of HIV Infection in Aboriginal Communities**

Indigenous peoples are vulnerable to a number of socioeconomic and systemic factors that increase vulnerability to HIV infection. While there is diversity among Indigenous groups, there are a number of structural similarities. Local, as well as global research indicates that HIV follows patterns of inequity <sup>10, 11</sup>, with marginalized groups most at risk. Globally, Indigenous peoples are more likely to be economically disadvantaged, displaced from their lands or live in rural locations, have lower educational attainment and have poorer health outcomes than their non-Indigenous counterparts <sup>12</sup>. Locally, these outcomes can be linked directly to historical and ongoing systemic oppression. Specific factors facing Aboriginal peoples in Canada include racism, assimilation, the legacy of residential schools, persistent economic inequality and cultural and social isolation <sup>13-20</sup>. As a result, Aboriginal peoples are disproportionately affected by many social and behavioural factors that increase their

vulnerability to HIV infection, including higher rates of substance abuse, (sexual and physical) violence, sexually transmitted infections, and limited access to, or use of, health care services <sup>21</sup>.

Learning to cope with hardships such as poverty, violence and racism as a result of colonialism may put youth at risk <sup>22</sup>. Common coping mechanisms are associated with high risk behaviours such as trading sex for food, shelter or drugs, alcohol and substance abuse, inconsistent condom use, sex with multiple partners and sharing needles or other drug equipment <sup>22</sup>. While most HIV prevention approaches tend to focus on individual behaviors, an active engagement with the social, political and historical determinants of health (e.g. colonialism) that shape these behaviors may be crucial to reaching Aboriginal youth <sup>23</sup>. In order to address HIV prevention and education, strategies need to consider the socioeconomic and systemic factors that put youth at risk in the first place <sup>23-26</sup>. This shift in focus moves away from pathologizing individuals and it emphasizes the social and structural factors that shape risk.

### **What can be done about this situation?**

Despite this daunting portrait, the good news remains that HIV is 100% preventable. National prevention campaigns targeted towards youth in countries as diverse as Thailand, Uganda, Zambia and Brazil have managed to successfully change the course of their epidemics <sup>5</sup>. It is recognized that the National prevention campaigns which have been successful in the above-mentioned countries, may not work in Canada. Aboriginal youth in Canada have many unique talents, skills and assets that have yet to be fully harnessed towards prevention initiatives <sup>27</sup>. An important step in moving forward is reviewing the scholarly and community-based literature to see what has been done, which approaches have worked and which have not. Given the unique ways in which Indigenous/Aboriginal youth experience the epidemic, <sup>28</sup> there is an urgent need to develop and document preventative initiatives that attend to these vulnerabilities.

As such, this paper summarizes lessons learned from a global scoping review of both peer-reviewed literature and community reports on 'wise' practices in HIV prevention with Indigenous/Aboriginal youth. The discussion focuses on what has been learned from this collective body of knowledge and makes recommendations and suggestions for future research and practice directions.

### **Methodology & Search Strategy**

Using a collaborative approach, a team of graduate students, Aboriginal scholars and a university-based researcher conducted a systematic scoping review of 'wise' practices in HIV prevention with Indigenous youth.

Scoping reviews are specifically designed to identify gaps in the evidence base where little research has been conducted. A scoping review enables researchers to map out a field and examine the extent, range and nature of research activity <sup>29</sup>. What makes a scoping review different from other kinds of systematic reviews is that it is welcoming of all relevant literature regardless of study design, which may be particularly important in an Indigenous research context <sup>30</sup>. Furthermore, scoping reviews are specifically designed to identify gaps in the evidence base where little research has been conducted. They differ from other types of reviews in that they follow a strict protocol and ensure that as much relevant research as possible has been considered and that studies are synthesized in a valid way. For reviews to be reliable they need to be carried out vigorously and the process should be documented in sufficient detail to enable the study to be replicated by others.

Included in this systematic scoping review are peer reviewed articles on HIV prevention with Indigenous youth. Fifteen databases were systematically searched<sup>^</sup>. After mapping out key words, search terms included (a) adolescent or adolesc\* or teen\* or youth; (b) HIV or AIDS or sexual health or sexually transmitted disease

<sup>^</sup> Medline, Web of Science, Applied Social Sciences Index and Abstracts, CSA Social Services Abstracts, CSA Sociological Abstracts, CSA Worldwide Political Science Abstracts, Digital Dissertations @ Scholars Portal, Education: A SAGE Full-Text Collection, Health Sciences: A SAGE Full-Text Collection, PsycINFO, Science Citation Index Expanded (1982-1993), Science Citation Index Expanded (1994-1999), Science Citation Index Expanded (2000-2004) and Science Citation Index Expanded (2005-current).

or sexually transmitted infection; (c) Indigenous or Native and First Nation\* or Aborig\* or Indian<sup>B</sup>. Articles included were limited to those published in English. Due to the limited number of relevant articles that matched our key words search, all papers regardless of the year of publication were included.

After systematically combing each database and removing duplicate copies, 539 abstracts were retrieved. Using specific exclusion/inclusion criteria, all of the abstracts were reviewed in order to determine which articles were relevant. Abstracts were excluded if they: (a) did not relate to HIV, STI, STD or sexual health, (b) did not relate to adolescents, teens or youth (ages 12-25), and (c) did not relate to Indigenous peoples. Two reviewers independently screened studies that met inclusion criteria, checking disagreements with a third reviewer. After reviewing 539 abstracts, a total of 140 abstracts met the inclusion criteria.

All 140 articles were located and reviewed. Detailed information was extracted (when available) and entered into a summary table. After reading the articles, only 34 studies met the search criteria. An additional 4 peer reviewed papers were identified by community contacts. Once the summary tables were complete, the research team reviewed the tables and relevant papers and met for a day long intensive session, to critique and discuss the findings. The 38 relevant studies were further broken down according to methodology: (a) cross-sectional (n=16), (b) mixed methods (n=7), (c) longitudinal (n=5), and (d) interventions, descriptions and evaluations (n=10).

Knowing that some of the most promising programs are rarely disseminated through peer review channels, the research team contacted experts in the field in hopes that they might be able to refer us to other kinds of documents -- specifically program reports, helpful website links, agency evaluations and other kinds of community-based or government reports that would help us learn more about effective strategies and approaches for HIV prevention with Indigenous youth. After systematically searching literature through peer review channels, the research team contacted 133 individuals representing over 100 different organizations with a mandate to work with Indigenous communities both locally and globally. There was an immediate positive response from organizations that worked directly with Indigenous youth and deliver HIV education and prevention programs. Many individuals that we contacted were happy to hear that more research was being conducted on HIV prevention with youth. If the organization did not have any material to share, they gladly forwarded contacts they thought could assist us in our search. Those that had materials sent us documents or directed us to appropriate web links.

The methodology used for collecting grey material was similar to that of snowball sampling technique. Snowball sampling is a technique for developing a research sample where existing study subjects recruit future subjects from among their acquaintances, thus the sample group appears to grow like a rolling snowball<sup>31</sup>. Our contact list grew by process of referral. Another useful technique was contacting individuals and community organizations from a mailing list that was obtained from a conference whose focus was on community based research and Aboriginal health.

Similar to the review of the peer reviewed abstracts, two reviewers independently screened each website link and document to ensure they pertained to HIV prevention among Indigenous youth. The team reviewed 20 website links and 40 papers, manuals or reports. After reviewing the material, 10 reports met the search criteria. The most common reason why material was excluded was because it did not focus on Aboriginal/Indigenous youth or HIV/AIDS. Detailed information was extracted (when available) and entered into a summary table. The 10 relevant documents were further broken down according to document type: (a) program evaluation (n=3), (b) prevention messages based on research findings (n=3), and (c) manuals and activities for HIV education and prevention (n=4).

Summary tables were created for each paper reviewed (see attached). Various members of the team then met on several occasions to draw out lessons learned from the literature and map out main areas of research findings, policy and practice.

<sup>B</sup> Denotes variations of the term i.e. adolesc\* or adolescents or teen\* or teens

## RESULTS

Key findings from this scoping review<sup>32</sup> point to a number of emerging ‘wise’ practices. These include:

### Reaching youth at a younger age

Prevention messages need to reach youth before the age of 15. There is a documented gap for appropriate programming for children ages 7-12<sup>22,23,25</sup>. Education that addresses risks, consequences and prevention needs to begin by sixth grade. Continued education and information on “safe” sex practices i.e. condom use is necessary throughout middle and high-school to reinforce the messaging<sup>33-35</sup>.

### Adopting Peer education approaches

Peer education is an effective choice for HIV prevention with Indigenous youth<sup>13, 16, 17, 22, 25, 36, 37</sup>. Using peer educators as part of an intervention strategy can have both positive impacts on the peer educators and the youth they are targeting<sup>13, 26, 34, 36, 38, 39</sup>. It is important to honor youth (participation) publicly<sup>34,39</sup>. Involving members of the target population will not only build capacity among youth, but it will increase the likelihood that initiatives are maintained<sup>22</sup>. In addition, when youth can see the results of their efforts every day and share pride in learning, their skills improve quickly<sup>38</sup>. Even though it can be challenging, the rewards and educational benefits to youth are even greater. Empowering youth to make decisions in the area of their own sexuality, can increase self-esteem and self-confidence.

### Leveraging Partnerships

All members of the community need to be a part of the solution. Collaboration with various members of the community including, youth, Elders, front-line workers, community members, nurses and community organization is necessary<sup>7, 14, 17, 18, 22, 25, 35-37, 40-43</sup>. Involving leaders in the community builds awareness in the community<sup>22</sup>. The importance of adult role models (both familial and otherwise) was highlighted<sup>44,45</sup>. Having counselors available on-site, effective debriefing and consistent support was crucial to the success of some groups<sup>26,38</sup>. Nurses can also act as advocates for sexual abuse awareness and HIV prevention programs in high schools and high-risk communities<sup>17,18,35</sup>. It was recommended that all service delivery requires Aboriginal involvement to validate and provide culturally appropriate assessments of the services offered<sup>15</sup>. Recommendations include: networking with schools and mainstream health providers serving Aboriginal youth; provide training to Aboriginal frontline workers on how to conduct sensitivity and awareness training for mainstream service providers; training should allow workers to convey the context of urban Aboriginal youth issues<sup>22,25</sup>.

### Addressing colonial impacts in HIV prevention efforts

Historical and current systemic factors facing Aboriginal youth include racism, assimilation, residential school system legacies and isolation.<sup>13, 14, 16-19, 46</sup> In order to address HIV with Indigenous youth, prevention and education strategies need to consider the socioeconomic and systematic factors that put youth at risk in the first place.<sup>22, 23, 25, 26, 38</sup> Young people may adopt a fatalistic outlook and may be less able to negotiate with partners about safe behaviours, or they may be seeking consolation or affirmation through risky behaviour after dealing with stressful situations.<sup>47</sup> Culturally based HIV education/outreach that speaks directly to the root cause of why Aboriginal people are at high risk is important<sup>26</sup>.

### Attending to diversity

Culturally attuned HIV prevention services and education are needed.<sup>7, 13, 15-17, 19, 21, 40, 41, 46, 48-50</sup> Taking a pan-Aboriginal approach to HIV prevention will likely be unsuccessful. Youth are not a homogenous group and they represent diverse and distinct cultures that need to be addressed and respected.<sup>22, 23</sup> Messages need to be

sensitive to the environment youth live in. As such, urban, on-reserve, rural and Northern youth may respond quite differently to similar messages.<sup>22, 51</sup> Furthermore, many Aboriginal youth are seeking services from non-Aboriginal organizations or migrating to urban centres due to the lack of youth-specific or youth-friendly AIDS prevention programs<sup>22</sup>. Therefore, attention needs to be paid both to building the capacities of Aboriginal-specific agencies as well as mainstream organizations. As such, providing clear messages is more effective than blanket messages targeting all Aboriginal youth.

## **Addressing stigma**

Despite public education, stigma still exists and more efforts are needed to dispel myths and clarify confusion about HIV/AIDS. Stigma and negative attitudes towards people living with HIV is present and stereotypes about who can become infected are prevalent<sup>13, 50, 52</sup>. Breaking the silence and shame that surrounds HIV/AIDS is important. It is both a human rights imperative as well as a key prevention opportunity. Addressing the ways in which stigma intersects with HIV risk is key<sup>22, 50, 53</sup>. As such, anti-fear, stigma and discrimination campaigns are needed<sup>22</sup>.

## **Current educational practices**

Youth reported not being happy with what they were taught in school. Youth report that education needs to illuminate the fact that HIV/AIDS can happen to anyone<sup>23</sup>. Providing youth with life skills education such as negotiation and conflict resolution, self respect, job skills and self-confidence are effective ways to reduce risky behaviour<sup>22</sup>, and speak to the importance of the situation of HIV within a social determinants of health framework. Taking a collaborative approach and involving key members of the society is important to the success of an HIV/AIDS intervention<sup>16</sup>. Guest speakers and or counselors have the most impact when they participate in group activities alongside group members<sup>38</sup>. The use of traditional knowledge in sex education and curriculum works better in some communities than others<sup>22, 25</sup>. Some communities/individuals no longer practice their traditional cultures. HIV prevention strategies do not necessarily have to be traditional to succeed<sup>39</sup>.

## **Adopting a harm reduction approach**

It is important to address the links between substance use and HIV risk factors<sup>22, 25, 26, 38, 47, 49, 54-58</sup> and the ways that histories of physical and sexual violence exacerbate HIV risk<sup>14, 25, 26, 35, 38, 47, 57, 59-61</sup>. Harm reduction programs are needed to address existing or exacerbated vulnerabilities<sup>15, 47, 58</sup>. Many youth IDUs are not accessing methadone maintenance therapy and are not benefiting from education and needle exchange<sup>46</sup>. Culture and skill-based information on HIV risk/harm reduction activities is a highly effective way of drawing high-risk community members into HIV education and prevention<sup>38</sup>. It is important to situate condom use in the context of youth lives, and address issues of access<sup>21-23, 25, 47, 62</sup>. Embarrassment in obtaining condoms was a deterrent to condom use; condoms should be available anonymously and confidentially in reserve<sup>21</sup> and urban communities.

## **Identifying HIV testing as a potential point of prevention intervention**

There is a need to improve services to reduce access barriers to public health or primary care, HIV testing and HIV treatment. Many youth are seeking services from non-Aboriginal organizations or migrating to urban centres. As such, HIV prevention, testing and counseling and new treatment options need to be made more relevant for Aboriginal youth<sup>22, 23, 42, 48, 63</sup>. Current HIV testing services are inadequate for a variety of reasons including remoteness of some communities, cultural differences and a failure on the part of the health care system to address needs of Aboriginal communities. Youth reported concerns regarding confidentiality, establishing trust, client-health care provider relationships, improving services to reduce access barriers to testing and treatment<sup>23</sup>. There is a lack of appropriate HIV testing services on reserves; given the shortage of physician services in rural communities, public health units need to increase the rate of HIV testing and greater access to primary care is needed<sup>48, 64</sup>.

## **Arts-based approaches**

Incorporating arts-based approaches into prevention initiatives may be particularly effective ways of working with Aboriginal youth. Arts-based approaches to HIV prevention have been successfully employed in a variety of contexts with Aboriginal youth.<sup>26, 38, 39</sup> Disseminating HIV information in creative ways has been shown to engage and mobilize Aboriginal communities in strategies for prevention in other contexts.<sup>36</sup> Arts-based strategies helped young people remain engaged and enthusiastic about the program<sup>36</sup>. Disseminating HIV information in creative ways engaged and mobilized Aboriginal communities in strategies for prevention.

## **Adopting culturally sensitive and decolonizing methodologies**

Adopting culturally sensitive research approaches and ‘decolonizing’ methodologies<sup>30</sup> is an imperative for research conducted in partnership with Indigenous communities. Many projects reported extensively collaborating with the local community and designing culturally appropriate methods for collecting data improved research outcomes.<sup>14, 21, 48, 58, 65</sup>. The importance of adhering to Indigenous ethical guidelines and protocols was highlighted repeatedly.<sup>14, 42, 58, 66</sup> Taking a collaborative approach and involving key members of the society is important to the success of an HIV/AIDS intervention<sup>16</sup>. Success in recruitment and retention of participants was attributed to using Indigenous project staff<sup>36</sup>.

## **Limitations**

There were several specific issues that may have contributed to the limited number of studies located for this review. In our search, studies were limited to those that were written in English and those that were publicly available. This may have been problematic for cultures that might resist ‘writing down’ or sharing Indigenous knowledge basis. Furthermore, the nature of the term ‘research’ is inextricably linked to European imperialism and colonialism<sup>30</sup>. Given the history of researcher/community relations with many Indigenous communities, there may be resistance to disseminating through traditional ‘peer review’ networks. Also, it is likely that many HIV interventions and prevention strategies are conducted by and for Indigenous peoples, without the assistance of researchers. As such, results may not be evaluated or publicly disseminated.

In addition, the term Indigenous is a complex term and no universally agreed upon definition exists. This created some difficulty in our search because it was not always clear whether a particular group was a minority or an Indigenous people when searching for articles globally. Finally, North American studies were over-represented here. This is likely due to a number of factors including (1) publishing bias, (2) greater resources available for dissemination, and (3) better local community contacts on our end. Care should be taken in generalizing the research globally.

It is our hope, that by documenting the wise practices in HIV prevention, we can move forward and provide meaningful direction for future work in this area. One of the most promising ways that this can be achieved is through community-based research, coupled with a decolonizing methodological framework that uses the guiding principles of ownership, control, access and possession (OCAP)<sup>30, 67, 68</sup>. This approach has been shown to foster collaboration amongst diverse organizations, individuals and researchers that builds on reciprocal relationships<sup>69, 70</sup>. As such, taking a CBR approach may itself become a community development strategy<sup>69, 71</sup>.

## **CONCLUSION**

This scoping review took a systematic approach to understanding the kinds of research and work being done in the area of HIV prevention with Indigenous youth. Very few studies in the peer-reviewed literature addressed HIV prevention with Indigenous youth. This is a pressing issue that deserves attention and the message is clear that Indigenous youth experience heightened vulnerability to HIV. In order to stop the spread of HIV, prevention and education strategies that address the socioeconomic and systemic factors that put youth at risk are necessary.

Working with youth is an essential part of confronting the HIV/AIDS epidemic and is one of the most promising approaches to prevention.

The academic and Indigenous community has provided some excellent recommendations for future work in HIV prevention. Nevertheless, several questions remain unanswered: What are the similarities and differences across groups of Indigenous youth in terms of resilience, assets and risks to HIV? In what ways do gender, class and sexuality intersect with cultural identity to shape or constrain risk and choice? What intervention models are, or have proven, effective for putting the power into the hands of Indigenous community to address HIV prevention? How is healthy sexual practice negotiated and experienced? Culturally, how is sexual identity constructed? How are cultures within cultures and competing identities shaped? What are the prime motivators for protective behaviours? What are effective condom distribution and uptake strategies? What are the links between structural, social, psychological and behavioural patterns? There are many other questions and suggestions for future work in this area. In laying out these questions, we hope to put a call to those in the research community to continue work in their area, and hope that many will adopt a CBR approach that attends to the principles of OCAP. A new approach and research direction is necessary and Indigenous communities need to have their voices heard as they have many intelligent suggestions in regards to HIV prevention in their own communities.

As we undertook this scoping review we attempted to put these principles into practice. Aboriginal scholars were key members of the research team. We also sought to expand the idea of what is ‘relevant’ evidence by explicitly seeking community reports and experience for inclusion.

Nevertheless, this scoping review pointed us towards developing further participatory research in the area. Over the next few years, we will be engaged in a research project that will further explore how Aboriginal youth in Canada link structural inequalities with individual risk, HIV and Aboriginal culture(s) using art-based methodologies. We will be involving youth, adopting a community-based research approach and adhering to the principles of OCAP<sup>67, 68, 72</sup>. Through this project entitled, *Taking Action: Using Arts-Based Approaches to Develop Aboriginal Youth Leadership in HIV Prevention*<sup>73</sup>, recently funded by the Canadian Institutes of Health Research, we hope to fill some of these gaps and we look forward to following the work of others in this area.

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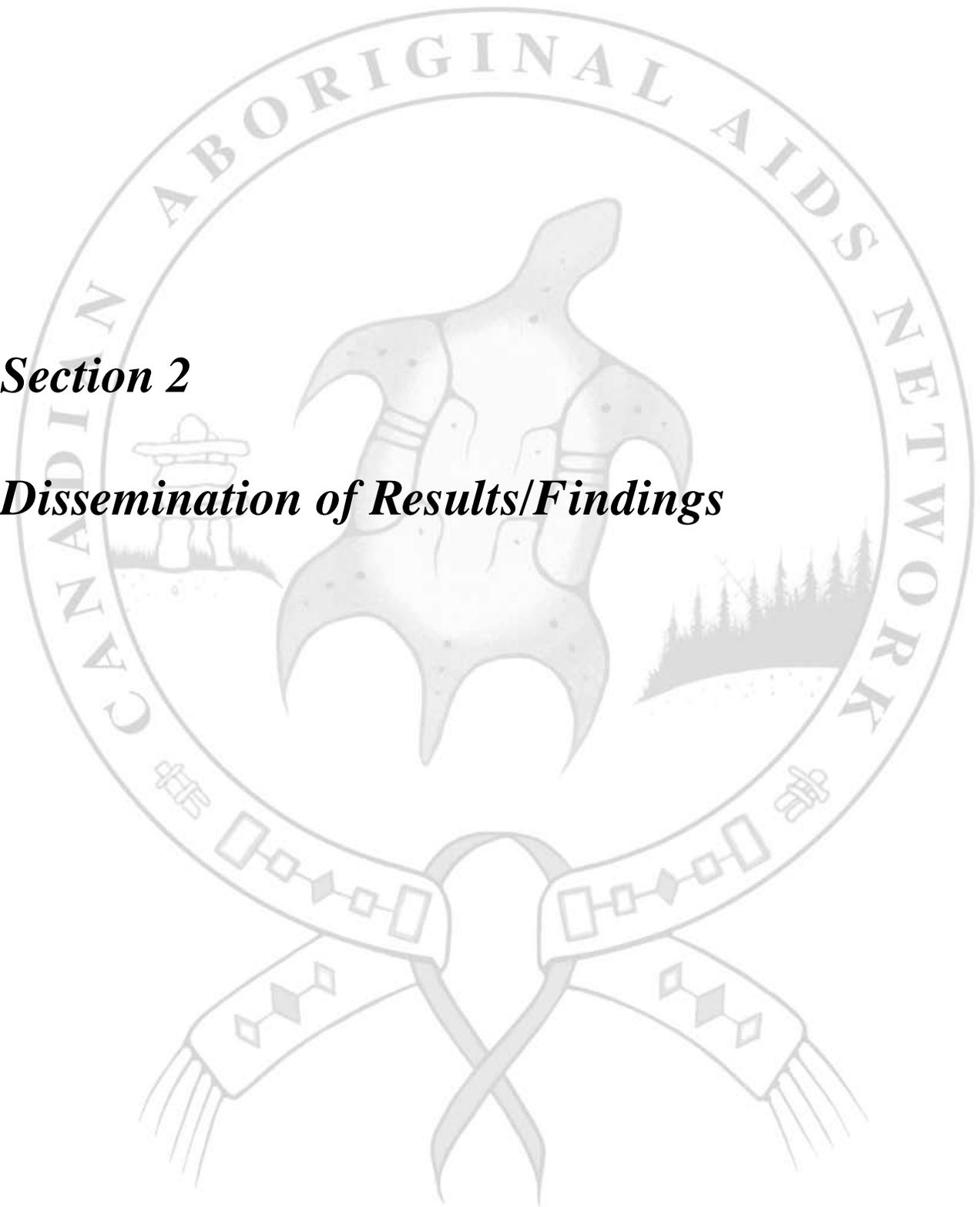
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***Section 2***

***Dissemination of Results/Findings***





# ***Housing Status and Health Outcomes in Aboriginal People Living with HIV/AIDS in Ontario: The Positive Spaces, Healthy Places Study***

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## **ABSTRACT**

Aboriginal people are vastly overrepresented in the HIV epidemic in Canada, but little is known about whether some Aboriginal groups are more at risk than others. The purpose of this paper is to highlight the differences in health and social determinants between First Nations, Métis and Inuit Aboriginal people living with HIV/AIDS in Ontario. Eighty Aboriginal people living with HIV/AIDS living off of reserve were recruited and interviewed by trained peer research assistants to collect information on socio-demographics, health status, housing, health care access, homelessness, discrimination, and health-related quality of life. Fifty (63%) participants were First Nations who would have lived at least part of their lives in reserve communities and 30 (37%) were Métis and Inuit who have lived most of their lives off of reserve settings.

Our findings indicate that all Aboriginal people are coping with severe health and social stresses that threaten their health. However, First Nations people were less likely than Métis and Inuit people to have completed high school, and they were more likely to have been incarcerated, to have been homeless, to not feel at home in their neighbourhood, to have harmful alcohol use, and to have experienced significant depression. First Nations people were also less likely than Métis and Inuit to be on antiretroviral treatment or to have seen an HIV specialist.

More research is required to determine to what extent conditions on reserve (e.g., little access to health care, AIDSphobia) and/or the loss of social support from leaving the reserve community contribute to the difference in health and social determinants between First Nations, Métis and Inuit people with HIV living off of reserve in order to develop more appropriate services in both reserve and non-reserve settings that will improve health of all Aboriginal peoples.

## INTRODUCTION

Aboriginal peoples face particular challenges related to housing and its impact on their physical and mental health. While Aboriginal communities face the same common determinants of health as other Canadian communities, their history of colonization, along with its social, economic and political effects, add to the significance of access to appropriate and stable housing as a determinant of health (Walters & Simoni, 2002, cited in: Cedar Project Partnership, et al, 2008; Bailie & Wayte, 2006).

Canadian Aboriginal Peoples (First Nations, Inuit, Métis), who make up 3.8% of the total national population (Statistics Canada, 2006) and constitute a vibrant, growing segment of the population, are vastly overrepresented in the HIV epidemic in Canada. At the end of 2005, between 3,600 and 5,100 Aboriginal people were living with HIV (Boulos et al, 2006). In 1998, 18.8% of positive HIV test reports were estimated to be among Aboriginal peoples. This increased to 27.3% in 2006 (PHAC, HIV/AIDS Epi-Update, Nov. 2007).

The need for safe, affordable and appropriate housing is urgent among Aboriginal peoples in Canada and is critical for Aboriginal people living with HIV or AIDS. Aboriginal peoples, who share a common legacy of oppression and resilience, experience some of the worst housing conditions in Canada, and have an exceedingly difficult time locating affordable housing (Deschamps & Thoms, 1995).

Globally, Indigenous communities are forming a larger part of urban societies; in Canada, over 57% of Aboriginal peoples now live off reserve and approximately 50% live in large urban centres (Statistics Canada, 2003, cited in Walker, 2008; Cardinal, 2006; Statistics Canada, 2005; Siggner & Costa, 2005). In spite of the size of the First Nations off-reserve and Inuit and Métis population in Canada and the high rates of reciprocal movement among First Nations peoples between on- and off-reserve (urban-rural) locales, public policy discussions concerning Aboriginal peoples and housing tend to focus on on-reserve communities, perhaps because “the concepts of ‘urban’ and ‘Indigenous’ still seem an uneasy fit in policy and public consciousness.” (Walker, 2008, 185; Callaghan, 2007; Hanselmann, 2001) As Hanselmann (2001) points out, “this oversight is problematic as it ignores the urban realities of Canada’s Aboriginal population. An acute public policy need therefore exists for a broadening of perspectives to include not just on-reserve Aboriginal communities but also urban [and other off-reserve] Aboriginal communities.”

For First Nations peoples living on Canadian First Nations reserves, there exists an immediate housing and infrastructure crisis: shortages that lead to severe overcrowding, lack of plumbing, no electricity, poor insulation, toxic mould, and substandard construction (First Nations Housing Action Plan, 2005). The situation for First Nations peoples living off-reserve and Inuit and Métis peoples is not much better.

While there is a lack of data on the actual lived experiences of off-reserve First Nations and Inuit and Métis peoples, the information that is available indicates that the poor quality of life experienced by First Nations communities on-reserve is also present among Aboriginal peoples living in other areas (off reserves) (Cardinal, 2006). According to the Canada Mortgage and Housing Corporation (2001), in Ontario 35% of Aboriginal peoples living outside of reserves were unable to access or were not living in “acceptable” housing (Housing Conditions of Aboriginal Households Living outside Reserves, 2001). For example, Walker (2008) notes that “racial discrimination continues to be a complicating factor in [Aboriginal peoples’] search for adequate and affordable housing in Canada.” In 1992, fewer than 20% of the Aboriginal peoples living in urban centres in Canada were home-owners, lower than any other ethnocultural group (Balakrishnan & Wu, 1992). More recently, according to the BC Office of Housing and Construction Standards (2007), fewer than half of all Aboriginal peoples in Canada are home owners, with Métis peoples being the most likely to own a home (56%) and Inuit peoples being the least likely. Among the non-Aboriginal population, in Canada, nearly 66% are homeowners. (CMHC 2005 Housing Observer, cited in Palmer, et al, 2007)

A large part of the housing stock that is occupied by Aboriginal peoples is substandard and inappropriate—particularly for people living with HIV or AIDS (PHA)—because it is in poor condition, lacks basic amenities or is overcrowded (Palmer, et al, 2007; Deschamps & Thoms, 1995). There is no housing facility in Ontario that is designated specifically for Aboriginal people living with HIV or AIDS. Any such housing facility would need to be in adequate condition, encompass Aboriginal cultures and traditions, be integrated with Aboriginal health care services and practices, and be sensitive to the needs of Aboriginal people living with HIV/AIDS. The housing needs for Aboriginal people living with HIV have been recognized by the Royal Commission on Aboriginal Peoples in Urban Centres (1993), the Assembly of First Nations' First Nations Health Commission National Roundtable on HIV/AIDS (1994), the Canadian Aboriginal AIDS Network, and the Ontario Aboriginal HIV/AIDS Strategy (2008).

In any attempt to reconcile the historical lack of attention to the housing and health needs of Aboriginal peoples, it is important to first acknowledge the inappropriateness of much of the inquiry related to Aboriginal groups in Canada to date (Smylie, 2004; Stout & Kipling, 1998). While Aboriginal communities are, in general, a highly researched group, much of the work that has been done has effectively reproduced the colonial relations experienced between Aboriginal peoples and other peoples living in Canada (Castellano, 2004; Cardinal, 2006; Schnarch, 2004). Aboriginal communities have been over-researched in inappropriate ways. Researchers have: gathered data on Aboriginal communities without their consent; selected academic subjects that are often not relevant to Aboriginal community needs; viewed Aboriginal persons as “subjects” only rather than as agents of power; pressured individuals and communities to participate in research; and excluded Aboriginal peoples from all but tokenistic decision-making (McPherson, Nelson & Rabb, 2004). Aboriginal self-determination has historically been unrecognized in research related to Aboriginal communities.

In response to this historical legacy, the Principles of Ownership, Control, Access and Possession (OCAP) were developed, and the methodology of community-based, peer-driven research (CBR) began to take hold within communities excluded from research-decision making. The OCAP Principles and CBR methodology operationalize the concept of Aboriginal self-determination in the context of research. Given the heightened awareness of physical and mental health issues facing Aboriginal communities, there has recently been increased interest in CBR about and for Aboriginal peoples in Canada (McPherson, Nelson & Rabb, 2004). A growing body of literature has started to focus on exploring Aboriginal lives and communities as a means of addressing these complex challenges (Stout & Kipling, 1998).

The Positive Spaces, Healthy Places (PSHP) team emerged within this context. PSHP, which was established to investigate the effects of housing on the health of all people living with HIV or AIDS in Ontario, recognized the importance of highlighting the unique needs of Aboriginal people living with HIV or AIDS off reserves in Ontario, within the framework and principles of CBR research and OCAP principles.

An annual retreat in 2002 of the Ontario AIDS Network Executive Directors was a key turning point in the development of the housing and health work in Ontario. At this meeting, housing was identified as one of the most urgent unmet needs of people living with HIV in Ontario. Without any research data for the Canadian context, a provincial sub-committee was formed to look at the issues facing people living with HIV directly related to housing. Through this work, Aboriginal and non-Aboriginal people living with HIV or AIDS, Executive Directors from AIDS service organizations (ASOs) in Ontario, and researchers from York and McMaster Universities began to develop a partnership to study the housing and related health needs of people living with HIV.

The collaborative efforts of the partnership resulted in a pilot, cross-sectional study<sup>1</sup> that examined the housing and health needs of people living with HIV and AIDS in Ontario. Shortly after the initiation of this study, the Canadian Institutes of Health Research (CIHR) launched its CBR program for HIV/AIDS. In the fall of 2004, the Ontario HIV Treatment Network (OHTN) provided support to the initial team to build a mixed method

<sup>1</sup> With project funding from the Ontario HIV Treatment Network (OHTN), the AIDS Bureau (MOHLTC), the Ontario AIDS Network and the Wellesley Institute.

prospective research study (i.e., with quantitative and qualitative components) and establish a larger team with more research breadth and experience to take advantage of this emerging opportunity. In April 2005, CIHR awarded three years of funding for this mixed method study and, with the bridging of the initial pilot study, the Positive Spaces, Healthy Places Study was formed<sup>2</sup>.

The goals of Positive Spaces, Healthy Places are to: (1) Increase understanding and awareness about the housing needs and experiences of people living with HIV and to highlight the ways in which current social policy may impact the housing circumstance and stability of people living with HIV in Ontario; (2) Investigate the relationship of housing quality and security to the physical and mental health of people with HIV; (3) Investigate the relationship between housing quality and security to access to health care, treatment and social service utilization; and (4) Examine how housing characteristics may change for people with HIV from diagnosis through their life course, and identify possible areas for intervention. A major focus of PSHP has also been to determine possible variations in the housing and/or homelessness experiences of people living with HIV/AIDS from specific communities: Aboriginal communities, ethnocultural communities, women, families, sexual minorities, youth and ex-prisoners.

The principal aim of this report is to explore the housing status and experiences of Aboriginal people living with HIV/AIDS off reserves in Ontario and, more specifically, how the social determinants of health (i.e., socio-demographics, housing situation and geography, medical markers of HIV disease, social and psychological factors, health-related quality of life) and access to health and social services may vary between: 1) off-reserve First Nations people living with HIV/AIDS who have lived at least part of their lives on-reserve, and 2) Métis and Inuit people living with HIV and AIDS in Ontario.

## **METHODS**

We recruited a sample of 605 people living in Ontario, who were principally affiliated with or connected to a community-based AIDS service organization in Ontario. This included youth, women, Aboriginal people, and people with HIV from endemic countries. To capture the full range of housing experiences, the team made specific efforts to include harder-to-reach populations such as those with HIV who engage in drug use and those who live in and out of hostels and homeless shelters. All participants were screened for eligibility, and informed consent was obtained prior to administering the questionnaire.<sup>3</sup> For participants to be eligible for the PSHP study, they had to be HIV-positive, able to provide informed consent, and live in Ontario. To ensure a representative cross-section of people in Ontario, participants were sampled based on regional epidemiological data and through a range of access points, including: shelters and agencies serving women, families, and youth; Aboriginal organizations; transitional housing providers; and supportive housing agencies.

The PSHP study was conducted in three phases. Phase I involved the development of a 90-minute semi-structured quantitative questionnaire (with standardized survey instruments) by the PSHP Team, selection and training of research staff (Project Coordinator and peer research assistants), establishment of data-collection sites, and baseline data collection. To reflect the Principles of Ownership, Control, Access and Possession (OCAP), peer research assistants were trained by Aboriginal organizations on culturally appropriate ways to interview Aboriginal participants. Phase II involved the development of a short (15-20 minute) 6-month survey instrument, and qualitative questions and survey approach. Phase III involved the review and finalization of a 90-minute semi-structured quantitative one-year questionnaire (with survey instruments) similar to baseline.

The baseline questionnaire,<sup>4</sup> developed in consultation with the entire PSHP team and pilot-tested with a sample

<sup>2</sup> As of May 2008, data collection for the one year study has been completed and the final analyses are underway; dissemination of research findings and action-outcome activities have also begun and are directed towards establishing relationships with relevant policy makers, community leaders and program providers in the areas of housing and supportive care.

<sup>3</sup> Research ethics approval was obtained from McMaster University.

<sup>4</sup> Complete survey instrument is available upon request.

of participants, was administered face-to-face by peer research assistants in approximately 60 to 90 minutes. A comprehensive spectrum of issues related to the housing experiences and health status of people living with HIV and AIDS was explored, including information on socio-demographics, markers of HIV disease, social and psychological factors such as presence of depression and harmful use of alcohol or other drugs, housing status, stability and experiences, health care access, experiences of discrimination, health outcomes and health-related quality of life. We made every attempt to design the survey in a way that would be engaging to the multiple cultural and racial groups we were recruiting. This included a few specific culturally-appropriate questions for Aboriginal communities (e.g., with respect to treatment options and modalities).

The qualitative interviews complemented the quantitative research methodology by capturing the health and housing experiences of people living with HIV in Ontario; our approach was based on the view that it is important to include the 'voices' of people with HIV through in-depth interviews with a sub-sample of the research participants. These interviews provide additional knowledge about the connection between the health and housing experiences of people with HIV. Including excerpts of personal narratives and an analysis of the interviews in conjunction with statistical analyses will make the research accessible to all stakeholders.

A selected sub-group of 50 of the 605 participants participated (14% of whom were Aboriginal) in in-depth, semi-structured interviews (Phase II). As a main aim of this study is to explore subjective meanings, experiences, and interpretations and to facilitate the understanding of the essence of experience, a phenomenological orientation was incorporated (Creswell, 1998). Potential interview participants were identified based on an illustrative purposive sampling methodology, using specified sample stratification criteria relating to housing status, time between diagnosis and base line survey, gender, race, and risk category (MSM, heterosexual, IVDU), as well as the study's sampling strategy of ensuring the relevant and appropriate representation of Aboriginal communities and families affected by HIV/AIDS<sup>5</sup> and the interviewer assessment of the face-to-face baseline questionnaire. To be eligible for the qualitative research, participants had to have completed the baseline survey in phase I and provided informed consent at the follow-up assessment. Peer research assistants were trained to conduct the qualitative interviews, and they recruited participants for the qualitative interviews when conducting the 6-month follow-up phone call.

In addition to our semi-structured interview with participants, we also administered several standardized psychometric instruments to capture key determinants of health that we expected would be related to housing status and stability and also included measures to capture health outcomes.

The primary outcome of the PSHP study was health-related quality of life (HRQOL) as measured by the Medical Outcomes Study HIV Health Survey (MOS-HIV) (Wu, 1996). The MOS-HIV is the most commonly used health-related quality of life measure in HIV research (Wu, 1997a). It is routinely incorporated as a secondary outcome measure in clinical trials and is increasingly being used as a primary outcome in observational studies (Wu, 1997a; Wu, 1997b). The psychometric properties of this instrument have been evaluated extensively, showing adequate content and construct validity (Wu, 1997a; Wu, 1997b), high internal consistency (Cronback's values above 0.75 across studies) (Wu, 1997b; Badia, 1999) and adequate test-retest reliability (Intraclass correlation coefficient of 0.72 for PHS and 0.53 for MHS over 4 months) (Revicki, 1998). The MOS-HIV is a 35-item instrument addressing 11 dimensions of health: General health perceptions, Physical functioning, Role functioning, Social functioning, Cognitive functioning, Pain, Mental health, Energy/fatigue, Health distress, Quality of life, and Health transition. To reduce the 11 dimensions into a smaller set of factors, the developers created through factor analysis two summary scores (Revicki, 1998): A physical health summary score (PHS) and a mental health summary score (MHS). Since these summary scores are recognized to be different components of health-related quality of life, separate analyses will be conducted on each.

We administered validated screening instruments for both alcohol and drug use: The Alcohol Use Disorders Identification Test (AUDIT) was developed by the World Health Organization (WHO) as a simple method

<sup>5</sup> Families affected by HIV/AIDS include either couples or adults with children where at least one person in the family is infected with HIV, thereby affecting the whole family.

of screening for excessive drinking (i.e., identify persons with hazardous and harmful patterns of alcohol consumption) and to assist in brief assessment. It can help in identifying excessive drinking as the cause of the presenting illness. The first edition of this manual was published in 1989 (Document No. WHO/MNH/DAT/89.4) and was subsequently updated in 1992 (WHO/PSA/92.4). The Drug Abuse Screening Test (DAST-20) is a 20-item instrument that may be given in either a self-report or in a structured interview format; a “yes” or “no” response is requested from each of 20 questions. The purpose of the DAST is 1) to provide a brief, simple, practical, but valid method for identifying individuals who are abusing psychoactive drugs; and 2) to yield a quantitative index score of the degree of problems related to drug use and misuse. It obtains no information on the various types of drugs used, or on the frequency or duration of the drug use. An internal consistency coefficient of .92 was obtained for a sample of 256 drug/alcohol abuse clients. To assess depression and mental health status, we used the Center for Epidemiologic Studies Depression Scale - Revised (CESD-R); the CESD-R is a 20-item scale that evaluates symptoms of depression over the previous 2 weeks, including depressed affect, somatic complaints and suicidal ideation (Eaton, 2004; Gallo, 1999). The response options range from “Not at all or less than 1 day” to “Nearly everyday for 2 weeks”. The final scores range from 0-80, with higher scores indicating greater impairment. The scale is commonly used as a screening for depression with a cut-off of 16 or above as indicative of possible depression. The psychometric properties of the original CESD are well established with internal consistency values above 0.8 and test-retest reliability between 0.4 and 0.7 (Radloff, 1977; Devins, 1988), adequate concurrent and discriminant validity (Weissman, 1977) and high sensitivity and specificity for the cut-off score of 16 or above for depression (Devins, 1988). The CESD-R has not received the same psychometric attention as the original CESD, but a high correlation ( $r = 0.88$ ) between both versions suggests similar psychometric properties (Eaton 2004).

## COMMITMENT TO OCAP

To reflect the OCAP Principles, one of the study co-investigators is an Aboriginal person with long involvement in the HIV/AIDS movement, who was involved early in the research design and reviewed all aspects of the study related to Aboriginal peoples, including classifications (i.e., First Nations, Métis, Inuit) and developing strategies to recruit Aboriginal participants. Recruitment of Aboriginal participants was both general (i.e., through advertising, community-based AIDS organizations) and directed (i.e., through elders, traditional medicine people). The project tried unsuccessfully to recruit an Aboriginal peer research assistant who would conduct the interviews with the Aboriginal participants. To compensate for the lack of an Aboriginal peer research assistant, the Aboriginal co-investigator trained other peer research assistants on Aboriginal issues and how to interview Aboriginal people respectfully. Aboriginal workers from the Ontario Aboriginal HIV/AIDS Strategy worked with peer research assistants to schedule interviews, and were available before, during and after interviews to provide support. As a result, there was not a single complaint about the conduct of the interviews. The Aboriginal co-investigator was also involved in all analyses and conclusions, and presented the first outcomes to an Aboriginal audience at the first CAAN CBR Conference in Vancouver. Some of the individuals attending the CAAN conference had participated in the study, so they received the first report on research outcomes. The Aboriginal co-investigator also presented the research findings at the CAHR conference, and there is an ongoing commitment from the study to have the Aboriginal co-investigator present the Aboriginal findings at all conferences and events. All data, consent forms and confidential information from the PSHP study is stored in a locked cabinet in a locked office, and only the Project Coordinator and investigators from the study have access to this data. All PSHP study information and data will be retained for at least 10 years after the study is completed.

For the purposes of this paper, we are focusing exclusively on the baseline data for the 80 Aboriginal participants who were enrolled.<sup>6</sup> Other manuscripts in development will address findings from the larger PSHP study, including the qualitative analyses.

<sup>6</sup> The target enrolment of Aboriginal participants for the study was 10% of sample, and we were able to recruit 13%.

## RESULTS

All three phases of the PSHP research study are now complete. Data from Phase I have been analyzed and are the focus of this report.

### I. SOCIO-DEMOGRAPHIC CHARACTERISTICS

Of the 605 participants enrolled in PSHP across Ontario, a convenience sample of 80 participants (13% of total sample) identified as being from an Aboriginal group.<sup>7</sup> 63% of whom identified as being First Nations, 29% as Métis, and 4% as Inuit<sup>8</sup> [5% of sample did not specify that they belong to a specific Aboriginal group, and 3% reported belonging to an African ethnic and cultural group].

While all participants were living off-reserve at the time of the study, First Nations peoples who are also defined as “status Indians” under the Indian Act<sup>9</sup> are the only Aboriginal peoples who are legally entitled to live on reserves, and 100% of First Nations participants had lived on-reserve at some point in their lives. Our PSHP research team hypothesized that Aboriginal people who had lived on-reserve where they would be among the majority and have a strong sense of belonging might be less comfortable or familiar with urban housing and support services than those who had never lived on-reserve – and therefore feel less supported when they leave their home communities. To assess whether the health and housing experience might be different for those who had lived at least part of their lives on-reserve, our research team analyzed the data on the 50 First Nations participants (“First Nations”) separately from the 30 participants who identified themselves as Métis and Inuit or did not specify an Aboriginal group (“Métis and Inuit”). See Table 1 below for the breakdown of these participants by their Aboriginal group, gender, age, sexual orientation, and geographical region.

**Gender and Sexual Orientation:** As indicated in Table 1, about 65% of the participants were male, 29% female and 6% identified as Transgender. All five Transgender participants were First Nations; they accounted for 71% of the total Transgender sample in the PSHP study. In terms of sexual orientation, 46% identified as being heterosexual (23 First Nations, and 14 Métis and Inuit), and 38% identified themselves as Gay, Lesbian, or Bisexual (22 First Nations, and 16 Métis and Inuit). Five per cent identified their sexual orientation as “other” (4 First Nations), while one person refused to answer this question.

**Age:** The average age<sup>10</sup> of participants was 41.8 years, with a range of 26 to 65 years. Almost 63% were 40 years or older and 10% were younger than 30 years at the time of the interview. First Nations participants were somewhat younger (average age 40.3 years) than the Métis and Inuit participants (average age 44.2 years). There was a significantly higher proportion of First Nations participants who were younger than 40 years than Métis and Inuit participants in that age group (42% versus 20%, respectively).

**Geography:** 50% of the Aboriginal sample lived in the Greater Toronto Area, while one-fourth lived in Eastern Ontario (Ottawa and Kingston areas), 16% in Northern areas (Thunder Bay, Sudbury, and Kenora areas) and 9% in Southwestern Ontario (Hamilton, Guelph, Kitchener, and Windsor areas). The distribution of First Nations and Métis and Inuit participants is similar in GTA and Eastern Ontario; 75% of First Nations and Métis and Inuit participants live in these two regions. A relatively higher proportion (20% versus 10%) and lower proportion (4% versus 17%) of First Nations participants than Métis and Inuit participants reside in Northern Ontario and Southwestern Ontario, respectively.

<sup>7</sup> Of the 80 enrolled, 19 were lost to follow-up at one year (24%) – this will be part of our 1-year analysis.

<sup>8</sup> Despite our efforts and direct recruitment, we were able to recruit only a small number of Inuit participants. As the study was conducted with a small number of Aboriginal people, it represents a convenience and exploratory sample of Aboriginal people living with HIV/AIDS.

<sup>9</sup> The Indian Act, R.S., 1985 C. 1-5

<sup>10</sup> Data on age were available for 77 of the 80 participants

**Table 1. Gender, Sexual Orientation, Age, Place of Residence, Education, Employment, Income, and Incarceration**

Demographic Characteristics	First Nations (N=50)	Métis and Inuit (N=30)	Total Sample (N=80)
	%	%	%
<b>Gender</b>			
Female	28	30	29
Male	62	70	65
Transgender	10	0	6
<b>Sexual Orientation</b>			
Heterosexual	46	47	46
Gay, Lesbian, Bisexual	44	53	48
Other	8	0	5
<b>Age</b>			
Mean (SD)	40.3 (7.4)	44.2 (8.0)	41.8 (7.8)
<b>Age Categories</b>			
20-29 years	6	10	8
30-39 years	36	10	26
40-49 years	42	60	49
50 years or older	12	17	14
<b>Region of residence</b>			
Greater Toronto Area-GTA	56	40	50
Eastern Ontario	20	33	25
South Western Ontario	4	17	9
Northern Ontario	20	10	16
<b>Highest level of education</b>			
Less than Grade 12	46	30	40
Completed high school	18	17	18
Trades/technical/college	22	40	29
University	14	13	14
<b>Employment</b>			
Working for pay	12	10	11
<b>Gross Monthly Income *</b>			
Mean (\$)	\$ 1,094	\$ 1,271	\$ 1,129
Median (\$)	\$ 1,006	\$ 1,170	\$ 1,100
<b>Incarceration †</b>			
Have been in Jail or Prison	56	47	53

\*Data is missing for 3 participants. †Data is missing for 21 participants

**Table 2. HIV Disease, Addiction and Depression, Housing, Mobility, Homelessness, and Discrimination**

Health-related characteristics	First Nations (N=50)	Métis and Inuit (N=30)	Total Sample (N=80)
	%	%	%
<b>Time of HIV Diagnosis</b>			
1978-1990	20	23	21
1990-2000	54	57	55
2001-2006	26	20	24
<b>Highest CD4 count (last 6 months)*</b>			
<200	28	0	16
200-499	32	37	34
>=500	40	63	50
<b>AIDS defining illnesses &amp; HCV co-infection</b>			
Diagnosed with AIDS	46	50	48
Diagnosed with Hepatitis C †	35	30	33
On ARV treatment	60	70	64
<b>Prevalence of Addiction and Depression</b>			
Harmful Alcohol Use ‡	60	17	46
Harmful Substance use §	74	63	70
Depressed ¶	58	37	49
<b>Housing Situation</b>			
Housed with supportive services	22	23	22
Housed without supportive services	66	77	70
Unstable housing	12	0	8
<b>Number of times moved</b>			
Moved 3 or more times since HIV Diagnosis	70	70	70
Moved in the last 12 months	36	23	31
<b>Homelessness</b>			
At least once	64	57	61
Three to five times	16	13	15
More than 5 times	20	13	18
<b>Discrimination accessing housing services</b>			
Experienced discrimination	52	43	49
<b>Basis of discrimination (Top 6)</b>			
Source of Income	24	30	26
Race	20	28	25
Employment status	18	26	21
Sexual orientation	12	13	13
HIV Status	12	10	11
Gender	6	10	8

\*Data is available for 44 participants; † Data was collected 12 months later from 61 participants; ‡ Data is available for 55 participants; § Data is available for 50 participants; ¶ Data is available for 75 participants.

## II. SOCIOECONOMIC CHARACTERISTICS

Aboriginal participants' socioeconomic characteristics such as level of education, rate of employment, monthly income, and history of incarceration are presented in Table 1.

**Education:** Overall, 40% of Aboriginal participants in our sample reported not completing high school; this proportion is higher among First Nations groups (46%) than Métis and Inuit groups (30%). Métis and Inuit participants were twice as likely to have received Trade, Technical or College level training compared to First Nations participants (40% versus 22%, respectively), while 14% (similar to the proportion among First Nations participants) had University level training.

**Employment and Income:** At the time of the baseline interview, only 11% of Aboriginal participants were working for pay or employment; the employment rate was the lowest among Aboriginal women living with HIV (employment rate of 4%). A slightly higher proportion of First Nations participants reported being employed than Métis and Inuit participants (12% vs. 10%, respectively). Employment rate varied by region, with the highest rate in Southwestern Ontario (33%) and the lowest in Eastern Ontario (33% and 5%, respectively). Despite the slightly higher employment rate, the average monthly income for First Nations participants was 14% lower than that of Métis and Inuit participants (\$1,094 and \$1,271, respectively). Aboriginal transgender participants earned an average of \$800, 29% less than the average income. For the entire sample, those participants in Southwestern Ontario reported the highest average monthly income (\$1,666), while people living in Eastern Ontario reported the lowest monthly income (\$1,085).

**Incarceration:** Overall, 74% of participants provided information on their history of incarceration. Of those who provided information, 48% reported a history of being in prison or jail at least once. Of those who reported being incarcerated in the past, 61% lived in the Greater Toronto Area and Eastern Ontario. A slightly higher percent of First Nations participants (56%) than Métis and Inuit participants (47%) were incarcerated.

## III. HEALTH STATUS OF ABORIGINAL PARTICIPANTS

Selected measures indicating the health status of Aboriginal participants is presented in Table 2.

**Time of HIV Diagnosis:** Approximately 55% of the 80 Aboriginal participants were diagnosed between 1991 and 2000, 21% were diagnosed before 1991, and the remaining 24% were diagnosed between 2001 and 2006. The time of diagnosis is similar for both First Nations and Métis and Inuit, with a slightly higher proportion of HIV diagnosis among First Nations since 2001 than among Métis and Inuit (26% vs. 20%, respectively).

**CD4 T Lymphocyte Cell Counts:** CD4 (T-cell) count is used to assess the status and progression of HIV infection into AIDS and to determine treatment types required. Information on participants' highest level of CD4 (T-cell) count in the 6 months prior to the baseline interview was collected. A lower CD4 (T-cell) count indicates higher susceptibility of an HIV-infected person for opportunistic infections. Approximately 55% of participants provided information on their highest CD4 count in the 6 months period prior to the baseline interview. Approximately 50% of participants had a CD4 count of 500/mm<sup>3</sup> or higher, while 34% reported that their highest CD4 count was between 200 and 499. The remaining 16% of participants had a CD4 count of less than 200/mm<sup>3</sup> and all of them were First Nations participants. Overall, about 63% of Métis and Inuit participants reported having a CD4 count greater than or equal to 500 while only 40% of First Nations participants had a similar level of CD4 count.

**AIDS-defining Illnesses:** Nearly half (48%) were diagnosed with AIDS-defining illnesses. The gender breakdown indicates that 50% of female, 48% of male, and 40% of transgender Aboriginal participants were diagnosed with at least one AIDS-defining condition. A slightly higher percent of First Nations (50%) than Métis and Inuit (46%) – and Gay, Lesbian, and Bisexuals (50%) than Heterosexuals (44%) – are diagnosed with AIDS.

**Antiretroviral Treatment:** About 64% of participants reported receiving antiretroviral treatment at the time of the baseline interview. A higher proportion of Métis and Inuit participants than First Nations participants (70% versus 60%) were represented in this group. Seventy percent of all gay, lesbian, and bisexual participants were receiving treatment, compared to 60% of heterosexuals, and a higher percentages of males than females reported being on antiretroviral treatment at baseline (70% versus 61%, respectively).

**Addiction and Mental Health (Depression):** Standardized population measures were administered to determine the level of harmful alcohol and substance use and depression among the participants. Of the 80 Aboriginal participants, 69% provided information on their alcohol use while 63% and 94% provided information on substance use and status of their mental health, respectively. With respect to alcohol use, nearly half of the 50 Aboriginal participants reported use above an established threshold considered “harmful use” of alcohol, while 70% reported harmful substance use. Half (49%) of the 75 Aboriginal participants who provided information on their mental health had a level of depression consistent with a clinically significant level of depression. A significantly higher proportion of First Nations participants reported harmful alcohol use than Métis and Inuit participants (60% vs. 17%). First Nations participants also reported a higher prevalence of harmful substance use (74% versus 63%) and depression (58% versus 37%) than Métis and Inuit participants.

**Co-Infection with Hepatitis C:** During our follow-up interview conducted at one year, 76% of Aboriginal participants (61) were able to be re-interviewed and were asked if they had ever been diagnosed with Hepatitis C. Of the 61 interviewed, 57 provided a response: 33% reported being diagnosed with Hepatitis C virus infection. Higher proportions of participants who were First Nations than Métis and Inuit (35% versus 30%) and females than males (41% versus 28%) were diagnosed with HIV-HCV. The prevalence among those participants identified as being heterosexual was 2.5 times higher than those participants who identified as being gay, lesbian, or bisexuals (54% versus 21%).

**Access to Health Services:** More than 70% of Aboriginal participants (77% of Métis and Inuit versus 74% of First Nations) reported receiving services of a family doctor at least once; 79% and 25% (respectively) reported receiving services of HIV specialists and other specialists (excluding mental health specialists). A higher percentage of Métis and Inuit than First Nations participants (87% versus 76%) reported accessing HIV specialists, while a slightly higher proportion of First Nations participants (26% versus 23%) received services of other specialists. A higher proportion of First Nations participants accessed culturally appropriate services than Métis and Inuit participants (50% versus 23%).

#### **IV. HOUSING CHARACTERISTICS, MOBILITY, HOMELESSNESS, AND DISCRIMINATION**

Our semi-structured interview included questions on type of housing, experience of homelessness, number of times people moved, experience of discrimination in accessing housing services, and perceived basis of discrimination. Results are presented in Table 2.

A total of 22% of Aboriginal participants were housed with support services to assist with their physical or mental health, physical ability and rehabilitation on site. The vast majority of Aboriginal participants (70%) were living in apartments or houses with no on-site supportive services. The remaining 8% of the Aboriginal sample were living in unstable housing conditions including shelters, outdoors, streets, and parks. Equal proportions of First Nations and Métis and Inuit participants were housed with supportive services, while all those with unstable housing conditions were First Nations participants. Higher proportions of Métis and Inuit than First Nations participants (77% versus 66%); gay, lesbian, and bisexual than heterosexuals (29% versus 16%); and male participants than female / transgender participants (25% versus 18%) were receiving on-site supportive services.

**Homelessness:** There were 61% of participants who reported experiencing homelessness at least once, with

a higher percentage among First Nations compared to Métis and Inuit participants (64% versus 57%), among females compared to males (70% versus 54%), and among those participants who identified as heterosexual compared to those who identified as gay, lesbian, or bisexuals (68% versus 53%). There is a high prevalence of homelessness in the overall sample of participants: 65% in the greater Toronto area (GTA) area, followed by 60% in Eastern Ontario, 57% in Southwest Ontario, and 54% in Northern Ontario.

Twenty-two per cent of those who experienced homelessness had been homeless 3 to 5 times, and another 30% reported being homeless more than 5 times. A higher percentage of female participants compared to male participants (39% versus 29%) and those who identified as heterosexuals compared to those who identified as gay, lesbian, or bisexuals (38% versus 26%) reported experiencing frequent homelessness (i.e., being homeless 3 or more times). Aboriginal participants reported that inability to pay rent; eviction; release from jail, prison or hospital; social issues due to HIV; and concern for personal safety were the five (5) most common factors for their recent past episode of homelessness.

**Participant Mobility:** People move frequently in search of better health care or a living environment that minimizes social and psychological stressors associated with HIV infection. Participants of the study were asked if they had moved since they were diagnosed with HIV and the number of times they had moved. Almost all Aboriginal participants (96%) had moved at least once and 70% had moved 3 or more times since they were diagnosed with HIV. The number of times moved is similar between First Nations and Métis and Inuit participants. However, a higher percentage of participants who identified as gay, lesbian, or bisexual (84%) had moved frequently (i.e. 3 or more times) than those who identified as heterosexual. About 30% reported moving in the 12 months prior to the time of the interview. A significantly higher proportion of First Nations participants reported moving during this period than Métis and Inuit participants. (36% versus 23%).

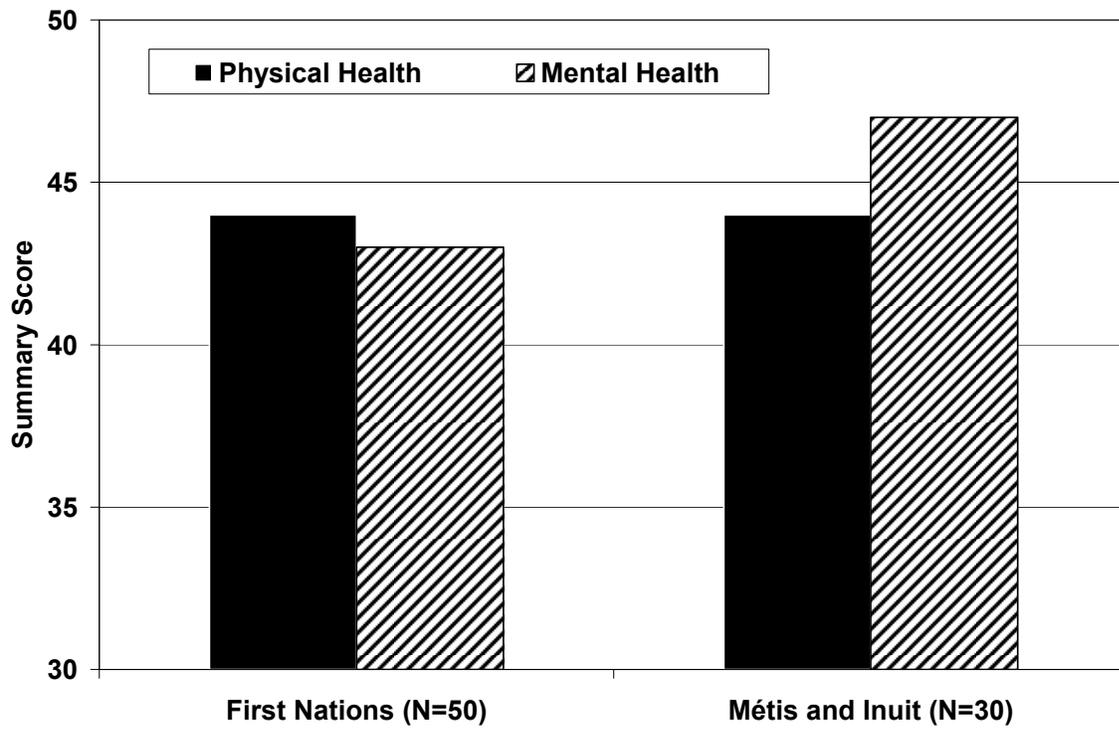
**Experiences of Discrimination Accessing Housing Services:** Overall, half (49%) of the 80 Aboriginal participants reported experiencing discrimination when trying to get housing services, with a higher percentage of First Nations participants reporting discrimination than Métis and Inuit participants (52% versus 43%). A higher proportion of female and transgender participants than male participants (60% versus 42%) and those who identified as heterosexual rather than gay, lesbian, or bisexual (54% versus 39%) reported experiencing discrimination when trying to get housing. Aboriginal participants reported their source of income, race, employment status, sexual orientation, HIV status, and gender as the most common reasons for discrimination when trying to access housing services. These reasons were similar among both First Nations and Métis and Inuit participants.

**Feeling of Belonging in Their Neighbourhood:** First Nations participants were much less likely than Métis and Inuit participants to feel they belonged in their neighbourhood (54% compared to 77%) or to report that their home provided a good location for them (56% compared to 70%).

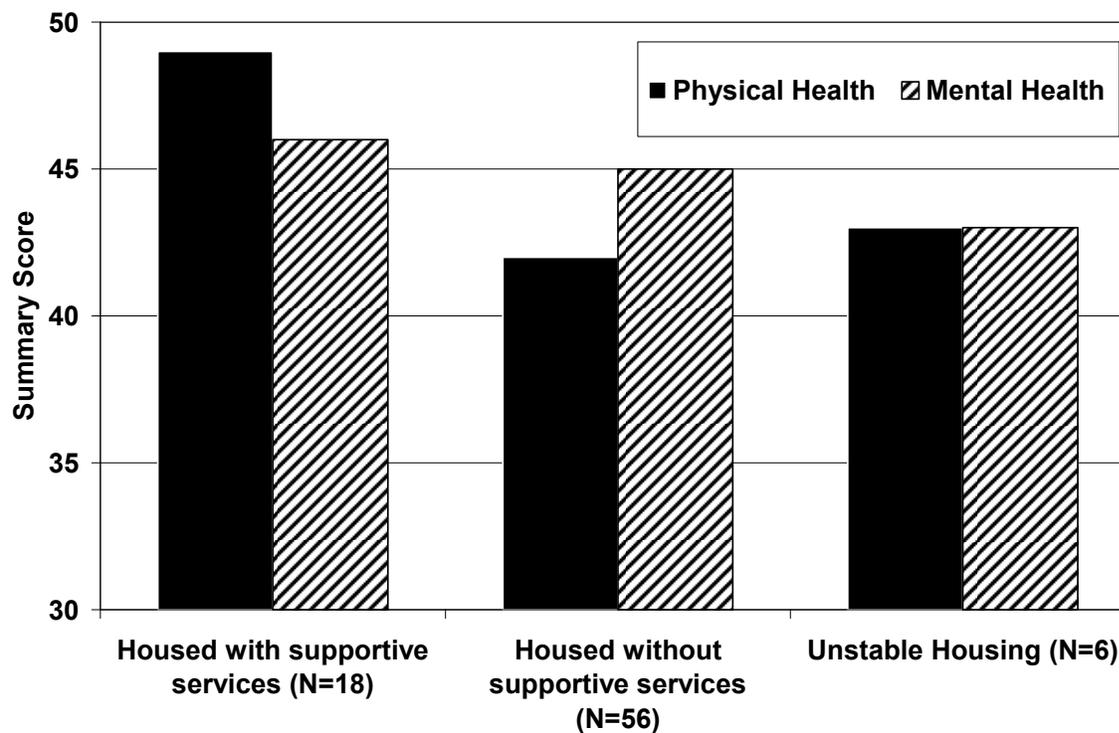
## **V. HEALTH OUTCOMES: HEALTH-RELATED QUALITY OF LIFE**

MOS-HIV health outcome measures: Health-related quality of life among Aboriginal participants was assessed with the Medical Outcomes Study (MOS)-HIV instrument. The items of this instrument (n=35) can be scored and summarized into 10 dimensions: General Health Perceptions, Physical Functioning, Pain, Role Functioning, Social Functioning, Cognitive Functioning, Mental Health, Energy, Health Distress, and Quality of Life, and 2 summary measures: Physical Health and Mental Health (summary scores range from 0 to 100 with an average of 50, lower scores indicating poor health status and higher scores indicating better health status). Results of these two summary measures (Physical Health and Mental Health) are presented in Figures 1-3 below to illustrate the health-related quality of life outcomes of participants.

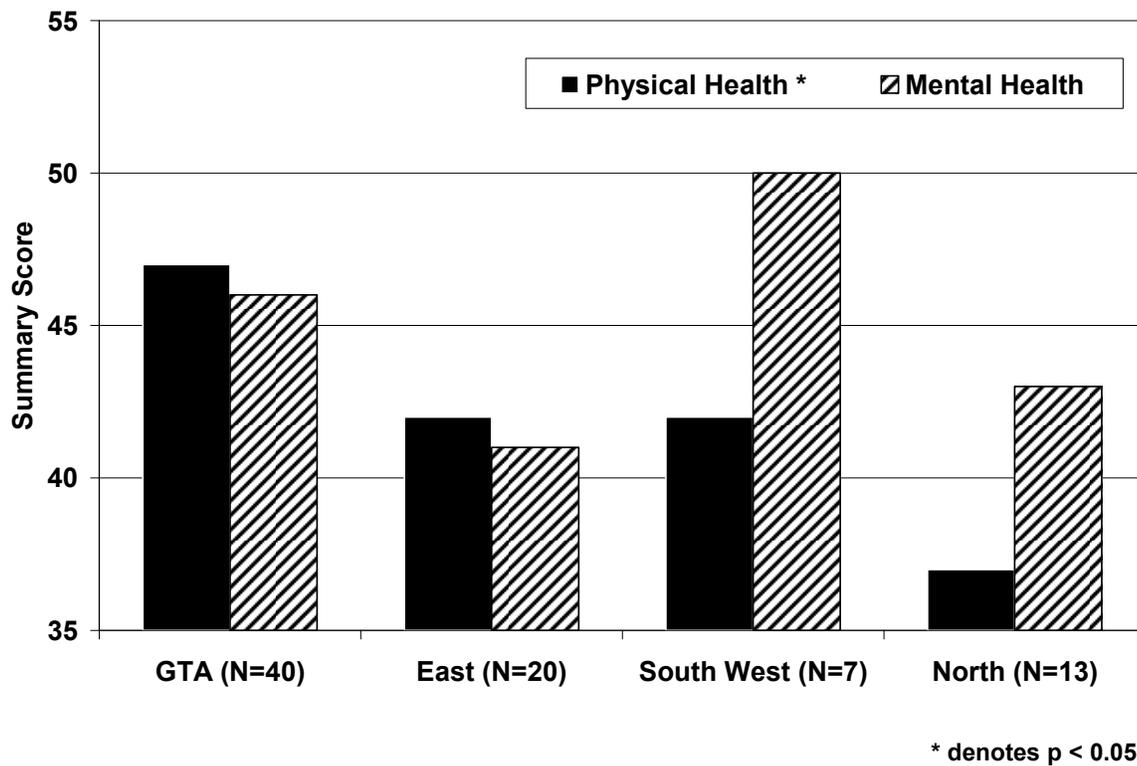
**Figure 1: Physical and Mental Health Status by Aboriginal Group**



**Figure 2: Physical and Mental Health Status by Housing Situation**



**Figure 3: Physical and Mental Health Status by Region**



## HEALTH OUTCOMES

**By Gender:** Overall, Aboriginal participants had below-average physical and mental health scores (average score is 50), indicating that their health status is worse than that of a person living with HIV with average health. While First Nations participants had a similar physical health status to that of Métis and Inuit participants, they had a poorer mental health status compared to that of Métis and Inuit participants<sup>11</sup>.

**By Housing Situation:** As can be seen in Figure 2, health-related quality of life outcomes also varied by housing situation of Aboriginal participants, with those housed in places with supportive services having better physical and mental health than those housed without supportive services or with an unstable housing situation.

**By Gender and Sexual Orientation:** A considerable variation of health-related quality of life outcomes by gender was reported<sup>12</sup>. Overall, Aboriginal male participants reported having better physical and mental health than female and transgender Aboriginal people. Transgender participants had the highest physical health, but the lowest mental health score. However, this result should be interpreted cautiously, as only 8% of participants identified as being transgendered. Gay, lesbian, and bisexual participants had better health-related quality of life at the time of the interview than participants who reported their sexual orientation as heterosexual or “other”.

**By Age:** An age-associated mental health gradient was observed<sup>13</sup>. Participants in the 20-29 years of age category had the lowest level of mental health, and a significant increase in mental health outcomes was observed with an increase in age. A different pattern was observed for physical health-related quality of life: Younger participants (20-29 years old) had the highest level of physical health, followed by those 50 years or older. Participants between the ages of 30 to 39 years had the lowest level of physical health outcomes score.

**By Geography:** Health-related quality of life also varied by geography (see Figure 3). Overall, Aboriginal participants in the Greater Toronto Area reported having the best physical and mental health outcomes, followed by those in Southwestern Ontario and Eastern Ontario. Participants in Northern Ontario had the lowest level of physical health outcomes.

## DISCUSSION

The innovative community-based research study Positive Spaces, Healthy Places has broken new ground in its ability to engage Aboriginal peoples living off reserve in a longitudinal study in Ontario. The success of the study is due to a number of factors. The research team identified an issue that was highly relevant to Aboriginal peoples, included an Aboriginal researcher on the team, and engaged the Aboriginal community early in the design of the study, in decisions about survey instruments, in the training of peer research assistants, and in the recruitment of Aboriginal participants. The Aboriginal community has also been directly involved in the analysis and interpretation of the data, in presenting findings, and in knowledge translation strategies. Aboriginal self-determination was essential to build trust with participants. The study has effectively used CBR methodology, OCAP principles and best practices in knowledge translation and exchange (KTE) to engage a traditionally hard-to-reach and under-represented population in research. It has also managed to complete a culturally sensitive survey of Aboriginal peoples within the context of a larger study of people living with HIV. The advantages to Aboriginal peoples living with HIV are the opportunity both to understand their own lived experience with housing and health, and to compare their experience to other populations and ethnoracial groups living with HIV. The Aboriginal participants living with HIV can assist in resulting advocacy and community development efforts to improve the programs and services available to them.

Our current findings provide interesting insights into the different experiences of those who have likely lived at least part of their lives on-reserve (First Nations), compared to those who will have lived mainly in non-

<sup>11</sup> Figure not shown – available from authors

<sup>12</sup> Figure not shown – available from authors

<sup>13</sup> Figure not shown – available from authors

reserve settings (Métis and Inuit). On average, Aboriginal persons living with HIV in our study have poor health outcomes. However, compared to Métis and Inuit peoples, First Nations people living with HIV are younger, less educated, have lower incomes and are more likely to have harmful substance use and suffer depression. They are more likely to have been incarcerated and to have experienced discrimination when trying to get housing. They are also more likely to be homeless or unstably housed, to feel not-at-home in their neighbourhoods, to be dissatisfied with their housing situation, and to feel that they do not belong. They have lower CD4 counts (a marker of more advanced HIV disease), are more likely to be co-infected with hepatitis C, and are less likely to be on treatment or to have seen an HIV specialist.

The Aboriginal front-line workers and researchers involved in this study believe that the experience of First Nations people with HIV is related to having lived for at least some time on-reserve, where there is little access to adequate health care – particularly specialized HIV care and treatment. This view is supported by evidence that variation in health status and risk-taking behaviour within/among First Nations communities may be related to varying colonial histories. (Jacklin, 2009). Although First Nations people with HIV living on-reserve are likely to have better family support and a social support network, many also experience either homophobia or AIDS-phobia, which drives them away from the reserve and their support networks. This loss of community can be associated with depression, mental health issues and substance use. Once in urban settings, these people may not know how to access supports such as social assistance, community-based AIDS organizations, or housing. Many will not have the health card they need to access services. Because First Nations people living with HIV off-reserve are younger, they will have less schooling and be less employable, which will affect their ability to find housing and may lead them into survival sex or sex work – which, in turn, is associated with high rates of substance use, depression, incarceration and housing loss.

These findings have implications for both policy and services. To meet the needs of all Aboriginal people with HIV who live off-reserve, it will be important to develop and enhance culturally sensitive services that will improve housing and access to health services in urban centres, as well as help these people cope with a wide range of other health and social issues – including the need for social support networks that will help build a sense of community, particularly for First Nations people with HIV. However, action off-reserve will not be enough. Many of the experiences that affect the housing and health of First Nations people with HIV – such as substance use, depression, lack of access to adequate or HIV-specific health care and lack of adequate or appropriate education – were experienced in their home communities, and First Nations communities must be part of the solution. It will be important to provide more information and education for First Nations communities about the quality of life issues faced by First Nations people living with HIV who leave their home communities to obtain specialized care and other services, including housing. More attention should also be given to combating homophobia/AIDS-phobia in all Aboriginal communities and to improving the health and social services available to First Nations Aboriginal peoples living with HIV who are living on-reserve.

This paper looks at the differences between two distinct groups of off-reserve Aboriginal peoples: those who have lived at least part of their lives on-reserve (First Nations) and those who have not lived on-reserve (Métis and Inuit). When reviewing these findings, readers should be aware that the proportion of all people living with HIV who are experiencing housing and related health problems is extremely high. However, the situation for all Aboriginal peoples – First Nations, Métis and Inuit – is much worse than for others living with HIV. Other work underway by our group will help to quantify the magnitude of differences in health outcomes in key vulnerable populations affected by HIV.

Our PSHP study is the first systematic community-based study in Canada to explore how housing status and stability affect the health and well-being of people living with HIV in Ontario. The results presented in this paper represent only a first cross-sectional examination of how the social determinants of health are having a negative impact on the health and well-being of Aboriginal people living with HIV and AIDS. While we had a broad and engaging recruitment strategy that was developed and supported by the Ontario Aboriginal HIV/AIDS Strategy, our findings are limited by the fact that we had a relatively small and “convenient” sample which may not be not representative of all Aboriginal people living with HIV in Ontario, especially for those who

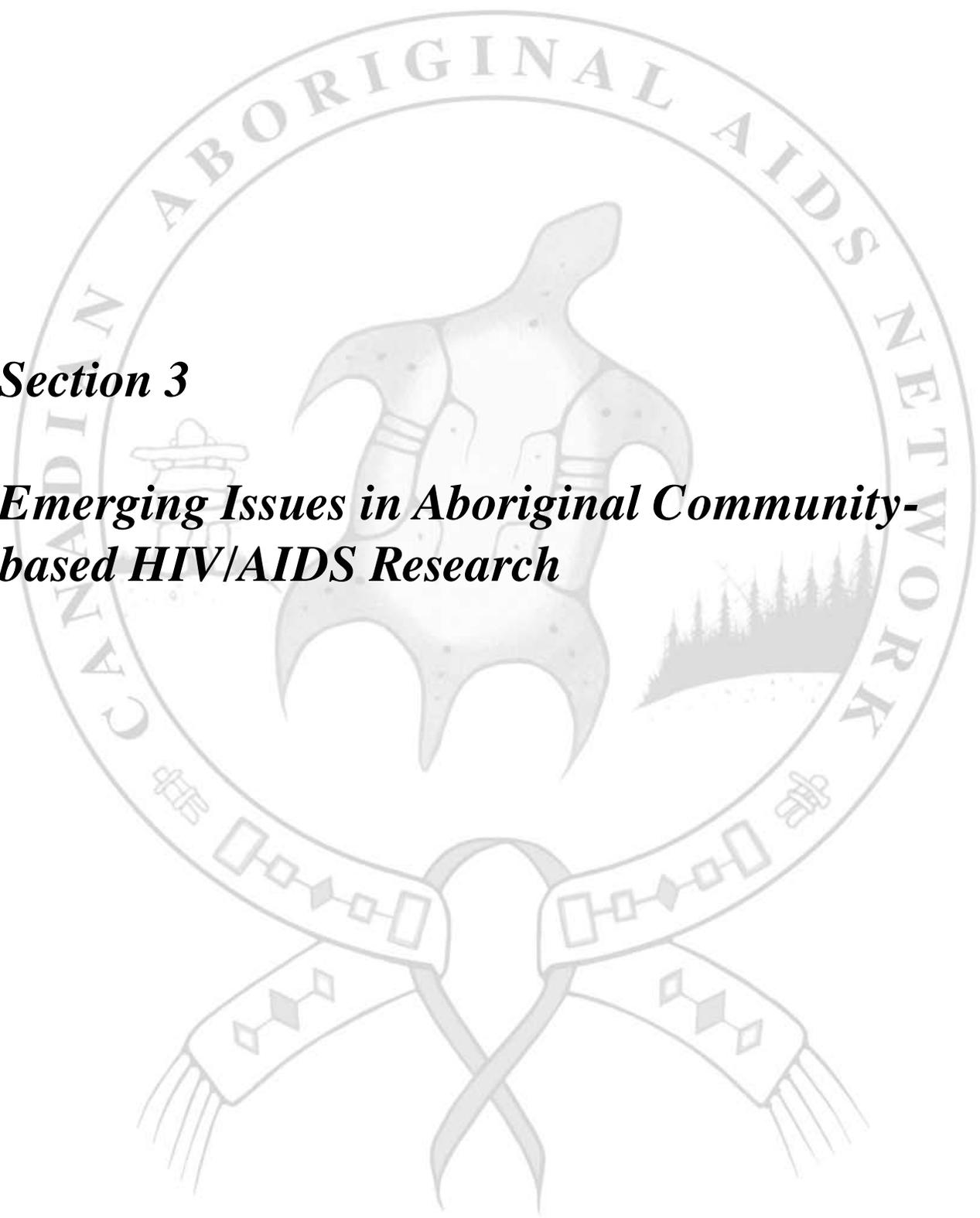
identify as Inuit. These limitations notwithstanding, with our prospective analyses underway, we will be able to begin to explore and understand how housing instability and other social determinants of health are more tightly linked to health outcomes and health-related quality of life for our current sample of Aboriginal people living with HIV/AIDS in Ontario. Through these explorations, we will begin to shed light on the types of interventions and strategies that may be helpful to explore and evaluate, to influence better housing and health policy and care decisions that will improve the health of all Aboriginal people living with HIV and AIDS.

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***Section 3***

***Emerging Issues in Aboriginal Community-based HIV/AIDS Research***



# ***Health and Safety Issues for Aboriginal Transgender/Two Spirit People in Manitoba***

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## **ABSTRACT**

A community-based needs assessment funded by Public Safety and Emergency Preparedness Canada was conducted following OCAP principles in order to gain specific knowledge of the safety and security concerns, the service and support experiences, and the service and support needs of the transgender and Two Spirit people of Manitoba and Northwestern Ontario. Participants provided quantitative and qualitative data by completing questionnaires. Data was analyzed using Epi Info and content analysis. Twenty-seven of our 75 participants identified as Aboriginal. The assessment shows that participants are at high risk for serious threats to health, quite apart from the need for access to sex reassignment procedures. Many live in poverty or near-poverty, experience high levels of emotional distress, and high exposure to hostility and violence from a variety of sources in everyday life. Findings were similar in Aboriginal and non-Aboriginal participants in many respects, with the Aboriginal participants having higher levels of poverty and correspondingly higher levels of concerns, experiences and needs associated with living in poverty. Levels of known STI and HIV infections are much higher among participants than in the general population, and especially among male-born Aboriginal participants. Key recommendations include establishing a Centre of Excellence in trans care; an information campaign for trans people throughout the region, distribution of care and referral protocol throughout the health system, trans-competence training for first responders in emergency and police services.

This article reports on information provided by Aboriginal participants in a needs assessment that was conducted in 2006 in order to gain specific knowledge of the safety and security concerns, service and support experiences, and service and support needs of the transgender and Two Spirit people of Manitoba and Northwestern Ontario.

We know from previous North American needs assessments that transgender people encounter threats to their health, safety, education, family relations, job security, housing, and employment in their daily lives, and that those who need sex reassignment procedures typically confront a health care system that has not developed the resources to provide them (Bockting & Avery, 2005). Dangers to trans wellbeing could be expected to be even more the case for Aboriginal transgender people, who encounter the interlocking effects of both racism and “transphobia,” which can be thought of as negative attitudes to people who cross the conventional gender lines of masculine men and feminine women. Nine Circles Community Health Centre in Winnipeg was funded for this study with a \$50,000 grant from the Crime Prevention Branch of Public Safety and Emergency Preparedness Canada.

## WORKING DEFINITIONS

The transgender rights movement has just emerged in the last few decades and people define basic terms differently, sometimes with serious implications for matters ranging from political alliances to medical rights and needs. Below are definitions of terms as we used them:

**Sex** is one's biological sex at birth: usually "male" or "female," and more rarely intersex.

**Gender** is one's sense of being a man or woman, masculine or feminine.

**Female to Male (FtM)** refers to a person who is born female but feels male (like a man) at heart.

**Male to Female (MtF)** refers to a person who is born male but feels female (like a woman) at heart.

**Trans** or **Transgender** is an umbrella term that includes some Two Spirit people, transsexuals, cross-dressers, and others whose identification falls outside the social conventions of male/man and female/woman. Transgender people may be heterosexual, homosexual or bisexual in relation to their birth sex or chosen gender.

**Transsexual** is a specific term for people whose gender conflicts so completely with their biological sex that they take (or given the means, would take) medical measures to permanently change their physical sex.

**Two Spirit** is a sacred term meaning an Aboriginal person who identifies as having been blessed at birth with both masculine and feminine spirits, a modern usage that is in keeping with the historical traditions of many First Nations (Wilson, 1996). We recognize that the historical authenticity of the term is under debate (Medicine, 2002), that many transgender Aboriginal people do not identify as Two Spirit, and that some Aboriginal lesbians, gays, and bisexuals who are not transgender do identify as Two Spirit. However, we used the term "transgender and Two Spirit" in all our project communications rather than just "transgender" to signal our desire to reach out to Aboriginal transgender people and our commitment to respecting the rights and perspectives of Aboriginal people.

## PROJECT TEAM

The project team included project coordinator Jennifer Davis and principal investigator Catherine Taylor. Both women are lesbians and community activists with longstanding involvements in the lesbian/gay/bisexual/transgender/Two Spirit (LGBTT) and Aboriginal communities, but not transgender or Aboriginal ourselves. Three of the five members of the Advisory Committee identify as MtF and two as FtM. Three have experienced accessing sex-reassignment medical care and have fully transitioned. Two identify as lesbian, two as straight, and one as queer. They ranged from early 20s to early 50s, white collar to working class to student, and include Aboriginal and White people. Our committee meetings were hosted by Circle of Life Thunderbird House and Kelly Houle in her capacity as Oshkitwaawin Outreach Worker to Women, Youth, and Two Spirit people.

## METHODOLOGY

### Supporting Institutions

We received ongoing support from many community organizations and service agencies including the Transgender Café, Rainbow Resource Centre, Women's Health Clinic, Sage House/Mount Carmel Clinic, the Health Sciences Centre, Club 200, New Directions for Children, Youth, Adults and Families, Winnipeg Transgender Group, and Kali Shiva AIDS Services.

### Ethical Review Process

#### Aboriginal Community Approval

We were committed to fulfilling the OCAP principles of community-based research (Schnarch, 2004). We sought and received approval and full support for our project in general and in detail from Linda Blomme, Resident Elder of Circle of Life Thunderbird House. She was consulted throughout the project to ensure that our research plans were culturally appropriate and would protect participants from harm, ensure confidentiality, and

provide them with real benefits. We had First Nations representation on our advisory committee and involved Aboriginal stakeholders at every stage of the research from identifying research questions to collecting and interpreting data to reporting results. Because our survey was anonymous it was not possible to report back directly to each participant, but the Advisory Committee and other participants reviewed a draft of the project report and provided feedback on the recommendations that were incorporated into the final project report (Taylor, 2006) on which this article is based.

## **Other Approvals**

The Senate Committee for Ethics in Human Research at the University of Winnipeg approved two key departures from standard procedures to safeguard participants: (1) Participants would give “performative” consent rather than signed consent by checking a box indicating they had read our consent terms and agreed them. (2) Minors could self-consent if they lacked a guardian who supported their transgender identity, so as avoid the emotional and physical risks documented in scholarly studies of family reactions to disclosure of LGBTTT identity (Taylor, 2008).

The Winnipeg Regional Health Authority (WRHA) approved the same conditions, allowing us to tap into their “Street Connections” program.

## **Design of the Study**

Data were collected through two questionnaires developed in consultation with Canadian researchers who had conducted similar needs assessments. We also reviewed 15 questionnaires developed for needs assessments of the transgender or LGBTTT community in Canada and the U.S including those found or described in Bockting and Avery (2005), GLBT Wellness Project of Ottawa-Carleton (2000), Goldberg (2003), Kenagy (2005), Lombardi (2001), Moran and Sharpe (2004), and Walters (2001).

We offered a short version (4 pages) and a long version (19 pages) that included open-ended questions. We asked for standard demographic information (age, ethnicity, location, birth sex), and trans-specific information (gender identity, transition status, sexual orientation). The questionnaires covered indicators of mental and physical health and asked people to identify their experiences of safety, acceptance, and competent service in various aspects of their lives on five-point scales. The questionnaires were reviewed, pre-tested with the Advisory Committee and several members of trans groups, and revised for clarity, neutrality, relevance, and completeness.

Participants were recruited by snowball sampling. Questionnaires were made available in a local LGBTTT newspaper, at related agencies, centres, and events, and on websites in Manitoba and across Canada. We publicized the project on university radio and in student newspapers and the Advisory Committee used personal connections. Kelly Houle facilitated survey filling-in sessions for Aboriginal participants. Of the 75 people who completed a questionnaire (34 long, 41 short), 27 self-identified as Aboriginal (8 long, 19 short).

Data were analyzed using qualitative and quantitative methods. Content analysis identified trends and counter-patterns in responses to open-ended questions. Excerpts are provided here to illustrate the range of responses that fit the trend under discussion. Forced-choice responses were analyzed in Epi Info, a freeware statistics package developed by the U.S. Centre for Disease Control (<http://www.cdc.gov/epiinfo/>). Percentages and frequencies provided here are based on the number of participants (n) who answered a question (e.g., if n = 25, and 5 answered “always,” the figures are given as “5 / 20%”). In cases where all Aboriginal participants answered a “check one” question, the frequencies add up to 27. Where one or more did not answer a question, frequencies add up to less than 27. Where people were instructed to “check off as many as apply,” frequencies may add up to more than 27. All numbers refer to Aboriginal participants unless otherwise stated.

## **PARTICIPANTS**

### **Demographic Profiles of the Participants**

The 75 participants were largely urban, with 90% of respondents living in Winnipeg, although over half were born in a smaller community. Over one-third (27) were Aboriginal, with most others identifying as White, and small numbers identifying as Black, Asian, biracial, or other visible minority. Anyone who self-identified as Aboriginal, Métis, Cree, Two Spirit, or as having grown up on a reserve in answer to any survey question is counted as Aboriginal in this analysis, resulting in a higher number than in our original project report (20). All but one of the 27 Aboriginal participants live in Winnipeg.

**Table 1: Demographic Characteristics of Aboriginal and non-Aboriginal Participants (frequencies/percentages)**

	Aboriginal Participants (n = 27)	Non-Aboriginal Participants (n = 48)	All Participants (n = 75)
<b>Birth Sex</b>			
• male	21 / 77.8%	30 / 62.5%	51 / 68%
• female	6 / 22.2%	15 / 31.3%	21 / 28%
• intersex	0	3 / 6.3%	3 / 4%
<b>Gender Identity (check all that apply)</b>			
• female	10 / 37%	24 / 50%	34 / 45.3%
• male	9 / 33.3%	14 / 29.2%	23 / 30.7%
• Two Spirit	9 / 33.3%	0	9 / 18.6%
• transgender	6 / 22.2%	9 / 18.8%	15 / 20%
• intersex	0	2 / 4.2%	2 / 2.7%
• other	1 / 3.7%	4 / 8.3%	5 / 6.7%
<b>Transition Status</b>			
• considering transition	2 / 7.4%	4 / 8.3%	6 / 8%
• currently transitioning	7 / 25.9%	11 / 22.9%	18 / 24%
• fully transitioned	1 / 3.7%	9 / 18.8%	10 / 13.3%
• no plans to transition	15 / 55.6%	19 / 39.6%	34 / 45.3%
• no answer	2 / 7.4%	3 / 6.3%	5 / 6.7%
<b>Living in Chosen Gender Role</b>			
• full-time	21 / 77.8%	30 / 62.5%	51 / 68%
• part-time	3 / 8.1%	15 / 31.3%	18 / 24%
• never	2	0	2 / 2.7%
• No answer	1 / 3.7%	3 / 6.3%	4 / 5.3%
<b>Sexual Orientation</b>			
• Gay	13 / 48.1%	10 / 20.8%	23 / 30.7%
• Lesbian	2 / 7.4%	11 / 22.9%	13 / 17.3%
• Bisexual	5 / 18.5%	8 / 16.7%	13 / 17.3%
• Straight	3 / 8.1%	9 / 18.8%	12 / 16%
• other	3 / 8.1%	10 / 20.8%	13 / 17.3%
• no answer	1 / 3.7%	1 / 2.1%	2 / 2.7%
<b>Age</b>			
• 18-25	3 / 8.1%	12 / 25%	15 / 20%
• 26-40	14 / 51.9%	5 / 10.4%	19 / 25.3%
• 41-60	10 / 37%	27 / 56.3%	37 / 49.3%
• 60+	0	2 / 4.2%	2 / 2.7%
<b>Ethnicity</b>			
• Aboriginal	27 / 100%	0	27 / 36%
• Black			2 / 2.7%
• Asian			2 / 2.7%
• Jewish			2 / 2.7%
• Visible minority			1 / 1.3%
• White			39 / 52%
• Interracial/bi-racial			2 / 2.7%

	Aboriginal Participants (n = 27)	Non-Aboriginal Participants (n = 48)	All Participants (n = 75)
<b>Place of Residence</b>			
• Winnipeg	26 / 96.3%	42 / 87.5%	68 / 90.7%
• small city	1 / 3.7%	1 / 2.1%	2 / 2.7%
• town or small community	0	3 / 6.3%	3 / 4%
• reserve	0	0	0
• other	0	2 / 4.2%	2 / 2.7%
<b>Average Annual Income Before Taxes</b>			
• Under \$10,000	13 / 48.1%	12 / 25%	25 / 33.3%
• \$10,000 - \$24,999	6 / 22.2%	11 / 22.9%	17 / 22.7%
• \$25,000 - \$39,999	3 / 8.1%	8 / 16.7%	11 / 14.7%
• \$40,000 - \$74,999	3 / 8.1%	4 / 8.3%	7 / 9.3%
• over \$75,000	0	8 / 16.7%	8 / 10.7%
• not sure/no answer	2 / 7.4%	5 / 10.4%	7 / 9.3%
<b>Education (highest level completed)</b>			
• completed college or university	5 / 18.5%	27 / 56.3%	32 / 42.7%
• completed high school	15 / 55.6%	12 / 25%	27 / 36%
• completed grade school.	6 / 22.2%	4 / 8.3%	10 / 13.3%
• did not complete grade school	1 / 3.7%	5 / 10.4%	6 / 8%
• completed other training	3 / 8.1%	10 / 20.8%	13 / 17.3%
• dropped out or underperformed	16 / 59.3%	6 / 12.5%	22 / 29.3%

## DEMOGRAPHIC NOTES

### Gender Identity

Respondents were asked to identify how they feel at heart: Female, Male, Trans, Two Spirit, or Other. Many checked more than one. A minority of Aboriginal respondents (2 of 6 born female and 6 of 21 born male) identified with their birth sex. Some described having disguised their true gender identity to fit in:

*I hide most of the time. I don't want to be turned away*

*In earlier years, YES, I played a male role to the tee as to not get abused and self-denial. Now accept myself I don't think so*

Most (21; 18 of 21 MtF and 3 of 6 FtM) described themselves as now living in their true gender full-time. We asked respondents to explain what it meant for them to do this:

*Its who I am mentally, spiritually, emotionally*

*maybe sometimes dangerous, but it's who I really am*

### Transition Status

Participants occupy the full range of transition status (physically changing from one sex to another through hormone therapy and surgery), with 9 of 21 MtF and 1 of 6 FtM considering transition, currently transitioning, or fully transitioned, and the rest having no plans to transition. Fewer Aboriginal participants were going through

or had gone through transition, which could reflect financial barriers to SRS for people living in poverty. Some who answered that they had no plans to transition expressed satisfaction with their birth sex:

*I like my naked body the way it is*

*I think I am beautiful enough the way I am and I think you shouldn't try to fix what's not broken*

## **Sexual Orientation or Identity**

Because they were developed by 19th century European sexologists thinking within a framework that did not include the possibility of transgender people, sexual orientation categories are a poor fit for people who might be biologically one sex but another gender at heart, people who are in transition from one sex to another, and people who are intersex. For example, people who are attracted to women might identify as “lesbian” because they are biologically female or because they feel female at heart. However, most participants identified as LGBTTT or queer, with only a few identifying as straight, even if they have transitioned and are attracted to people of their birth sex.

## **RESULTS**

Transgender and Two Spirit people are not unique in experiencing hostility based on their identities. However, some studies suggest that trans people encounter more hostility even than other LGBTTT people, in part because they are less likely to “pass,” especially those in mid-transition. Forms range from ridicule and assault to being denied health care (Cochran, Stewart, Ginzler & Cauce, 2002; Lombardi, Wilchins, Priesing, & Malouf, 2001; Moran & Sharpe, 2004). Further, unlike most other identity groups, trans people (and LGBTTT people generally) are unlikely to have parents who share their identity, and therefore do not have an understanding family in which to find support. From the time that they first become aware of their sex/gender difference as children, trans people therefore encounter hostility in every aspect of their lives, compounded, for Aboriginal trans people, by racism and poverty.

### **Family, Home and Housing**

Participants (n = 8) saw the reactions of family members to their trans identity as ranging from “honouring who I am” and “acceptance” to “discomfort” and verbal and physical abuse. Some explained that they had few reactions of any kind to report because only a very few trusted people knew they were trans. Only one Aboriginal participant (n = 8) lived with a partner, and one other was guardian to a child. Being unpartnered makes people more likely to live in substandard housing and more vulnerable to losing their home.

Of the 8 participants who reported on their living arrangements, 6 rented, 1 owned, and 1 lived in a rooming house. Three had had to move because of their trans identity because of verbal abuse, fear of discovery and the repercussions, and desire to access care, services, and a supportive community. One had been evicted because of their trans identity.

### **Employment and Income**

Almost half (48%) of Aboriginal participants reported pre-tax incomes under \$10,000 (including those who reported “welfare” or “social assistance” income). If we can assume that most people who are unsure of their income are also low income earners, up to 56% of Aboriginal participants live on less than \$10,000 a year income, and up to 78% on less than \$25,000 (compared to 35% and 58%, respectively, for non-Aboriginal participants). Two answered that their transgender status had led them to work in the sex trade.

## Education

While the percentage of Aboriginal participants with low incomes is higher than average, 56% have completed high school and 18.5% some form of post-secondary education. Still, 59% answered “Yes” to our question, “Was your education interrupted because of your sex/gender identity?” (compared to 12.5% of non-Aboriginal participants). Most had negative experiences of schooling, whether their schools were church-led or secular, and described school life as characterized by bullying and depression that led them to under-perform, skip classes, or drop out altogether.

## SUPPORT NETWORKS

### Ethnic community

Aboriginal participants expressed mixed experiences of support in Aboriginal communities. Five of 8 said that they felt supported within their ethnic community with regards to their sex/gender identity, and 2 did not (1 no answer):

*the reserve of mine goes by Christianity*

*the indigenous culture (very few) are knowledgeable with two-spirit history*

*two-spirit community strong support for me*

*in the aboriginal I feel total acceptance for sex/gender identity*

*whenever I do return to my reserve people who do know me are pretty much happy to see me and always say hello*

### Religious Community

Very few participants named any religious group they identify with, which perhaps reflects the negative experiences of organized religion common to LGBTT people generally (see, for example, Buchanan, Dzelme, Harris, & Hecker, 2001; Schuck & Liddle, 2001; Sherkat, 2002) and to Aboriginal people in particular. All 8 Aboriginal respondents who answered the long questionnaire had left Christianity behind for Aboriginal, Wiccan, or New Age spirituality.

### Services and Organizations

Although our goal was to include as many trans people as possible who were not already well connected, most of our participants had participated in a support group where people not only get the benefit of social acceptance but exchange crucial practical information about how to meet medical and other needs. Many made regular use of the trans services and organizations available (a support group, a website, a Two Spirit support group, an LGBTT phone line, counselling, and the LGBTT bar scene). People who were not connected reported feeling isolated.

### Acceptance in the Larger LGBTT Community

Participants (n = 8) were divided on whether they feel accepted by the larger LGBTT community (3 yes, 3 sometimes, 1 no, 1 no answer). One noted, though, that being bi can be a challenge sometimes. Some lesbians can be very negative and even sometimes downright nasty about someone who is bi, and another the effects of having a known reputation (put behind me) that involves drug use and prostitution.

## Acceptance in the Transgender and Two Spirit Community

Most participants (n = 8) felt accepted in the transgender or Two Spirit community (4 yes, 2 sometimes, 1 no), and explained why they felt this way:

*all my girls are there*

*I'm involved and recognized as transgender in transition programs (transition programs that focus on drug addiction and prostitution)*

*two-spirit community can also be somewhat neg about bisexuality*

Some non-Aboriginal respondents said the issue of acceptance was not applicable to them because they are not in touch with the trans community (I've never been interested; I've moved on; No contact with them. Do they exist?). None of the Aboriginal respondents expressed these sentiments.

## Emotional Care and Mental Health

Anyone who realizes they cannot be themselves in their own bodies is in danger of overwhelming isolation, anxiety and depression. Aboriginal people face additional stress from racism, and those who are noticeably transgender undergo an extreme version of the "insidious trauma" affecting marginalized populations (Burstow, 2003) as they face discrimination, harassment and the threat of assault in their daily lives. Transsexual people experience further stress trying to access sex reassignment procedures, pay for them, and deal with sometimes severe emotional reaction to hormonal changes. Participants described a range of reactions to these stresses:

*SHAME - is "10" w guilt. It's like roller coaster ride.*

*chronic depression, panic attacks, post-traumatic stress disorder, generalized anxiety, ADD*

*I hate having a body part that is not me.*

We adapted a list of emotional and mental health problems from scales used to measure post-traumatic stress disorder (PTSD) arising from the experiences of bullying, harassment and discrimination. (See Bully Online [2005] and the entry for PTSD in the Diagnostic and Statistical Manual (DSM) of the American Psychiatric Association [2000].) Participants were asked how often they experience the feelings listed, where 1 equals "Never" and 5 equals "Always." The results are presented in Table 2.

**Table 2: Indicators of Mental Health**

Aboriginal (n = 27)	1 Never	2	3	4	5 Always	Ever
Depression (25)	6 / 22.2%	7 / 25.9%	5 / 18.5%	4 / 14.8%	5 / 18.5%	19 / 87.8%
Loneliness (27)	3 / 11.1%	6 / 22.2%	8 / 29.6%	3 / 11.1%	7 / 25.9%	24 / 88.9%
Irritability (27)	3 / 11.1%	7 / 25.9%	6 / 22.2%	9 / 33.3	2 / 7.4%	24 / 88.9%
Nervousness, anxiety (27)	5 / 18.5%	4 / 14.8%	8 / 26.9%	3 / 11.1%	7 / 25.9%	22 / 81.5%
Body image concerns (27)	3 / 11.1%	7 / 25.9%	4 / 14.8%	9 / 33.3%	4 / 14.8%	24 / 88.9%
Sleep disturbances (26)	2 / 7.7%	4 / 15.4%	8 / 30.8%	2 / 7.7%	10 / 38.5%	24 / 92.3%
Sudden angry or violent outbursts (26)	8 / 30.8%	11 / 42.3%	5 / 19.2%	1 / 3.8%	1 / 3.8%	18 / 69.2%
Exhaustion and chronic fatigue (26)	6 / 23.1%	4 / 15.4%	7 / 26.9%	3 / 11.5%	6 / 23.1%	20 / 76.9%
Guilt (26)	3 / 11.5%	7 / 26.9%	9 / 34.6%	1 / 3.8%	6 / 23.1%	23 / 88.5%
Feelings of detachment (26)	4 / 15.4%	4 / 15.4%	9 / 34.6%	5 / 19.2%	4 / 15.4%	17 / 84.6%
loss of interest (25)	2 / 8.0%	9 / 36.0%	5 / 20.0%	2 / 8.0%	7 / 28.0%	23 / 92%
loss of ambition (25)	4 / 16.0%	4 / 16.0%	9 / 36.0%	2 / 8.0%	6 / 24.0%	21 / 84%
Poor concentration (24)	2 / 8.3%	8 / 33.3%	5 / 20.8%	4 / 16.7%	5 / 20.8%	22 / 91.7%
impaired memory (25)	5 / 20%	7 / 28%	6 / 24%	2 / 8%	5 / 20%	20 / 80%
joint pains, muscle pains (27)	8 / 29.6%	7 / 25.9%	3 / 11.1%	6 / 22.2%	3 / 11.1%	19 / 70.4%
Emotional numbness (26)	5 / 19.2%	7 / 26.9%	2 / 7.7%	4 / 15.4%	8 / 30.8%	21 / 80.8%
physical numbness (26)	9 / 34.6%	6 / 23.1%	5 / 19.2%	2 / 7.7%	4 / 15.4%	17 / 65.4%
low self-esteem (26)	4 / 15.4%	7 / 26.9%	6 / 23.1%	4 / 15.4%	5 / 19.2%	22 / 84.6%
Overwhelming sense of injustice and a strong desire to do something about it (23)	2 / 8.7%	2 / 8.7%	5 / 21.7	8 / 34.8%	6 / 26.1%	21 / 91.3%

As can be seen, the vast majority have experienced all of the specified symptoms of mental distress at some point, with the rates of physical numbness and sudden anger being slightly lower. If a ranking of 3 to 5 is considered “often,” at least half experience all these symptoms often, except for sudden anger and physical numbness. Only a few in the case of each symptom “never” experience it.

## **Suicidality and Self-Harm**

Because people can experience distress for a great range of reasons unconnected with their identities, we also asked if participants had “ever felt like or tried to hurt or kill yourself because of the way you are treated with regards to your sex/gender identity.” Granted that only 8 Aboriginal participants filled out the long survey that addressed suicidality, and that it can be difficult to self-assess which factor led to suicidality, the answers show a very high level of self-harm feelings, plans and attempts and suicidal feeling, plans and attempts – only 3 of the 8 had never felt like hurting themselves, 4 had hurt themselves, and 3 had felt like killing themselves. These findings are consistent with studies of suicidality in the transgender community and in the larger LGBTTT community (D’Augelli, Grossman, Salter, Vasey, Starks & Sinclair, 2005).

Several participants made the point that their distress was caused by the experience of being transgender in a transphobic society, rather than by being transgender itself; transgender people having long been pathologized in both mainstream culture and the medical/psychiatric world as “sick.” One participant reported what a huge difference it made to hear otherwise from an endocrinologist (a specialist who manages hormone replacement therapy for sexual reassignment purposes):

*the endo. Saying that being trans is noting to be ashamed of. Just words. Support It makes a world of difference to know that the DSM - is just a way of doing things and not be all of end all. So I am not psychotic (for being different)*

One of the ironies of transgender existence is that in order to be accepted for sex-reassignment surgery, transsexual people must have written indication from a psychologist that they have a mental illness (Gender Identity Dysphoria or “GID” in the DSM).

## **Addictions and Substance Use**

Aboriginal participants’ (n = 27) use of drugs is consistent with the reported levels of severe mental distress: 18 (66.7%) use alcohol, 8 (29.6%) use over-the-counter drugs such as sleep aids, 16 (59.3%) use prescription drugs such as anti-depressants, and 12 (44%) use street drugs such as marijuana and crack cocaine. (The numbers are similar for non-Aboriginal participants except in the category of street drugs, which only 6 of the 48 [12.5%] report using.) Eighteen (66.7%) indicated that their drug and alcohol use had ever been “a problem,” compared to 31.3% of non-Aboriginal participants.

## **Mental Health Self-Assessment**

Most people who addressed their present state of mental health described themselves as doing much better than in the past, often because they had been able to get the help they needed:

*however I feel that it is just keeping me afloat - support group, friend, spiritual counsellor, jungian psychologist*

*Able to deal with emotional and mental issues through good counsellor.*

*great, lots of improvement after receiving help*

Others seemed to be putting on a brave face in the situation, describing their mental health as good but disclosing significant distress as they elaborated:

*fairly well & positive with huge large problems*

*It's a full time job to stay on top of the game let alone get ahead of it*

Although the level of distress reported is high enough to be of great concern, the literature on self-report of negative characteristics (mental distress, harmful habits, disease symptoms) gives reason for concern that participants may have underreported or repressed their level of distress in a determined effort not to be seen as “sick” or to see their lives as intolerable, and that the actual levels of distress may be even higher (Breetvelt & Van Dam, 1991; Eisenberg, 1992). Further, participants were generally making use of support services and therefore might be in the upper range of resilience among people in the trans community.

## **HEALTH AND CARE SERVICES - GENERAL**

### **Mental Health Care**

Participants were very specific when asked, “What kinds of services would be helpful in supporting your mental health?” They wanted accessible, affordable, non-judgmental support from counsellors who are informed about trans/Two Spirit issues and can help with practical concerns:

*more access to affordable mental health workers*

*people who understand tgs with mental health problems*

*we need Two Spirits specific programs in Wpg.*

Participants also identified the need for better access to the psychological assessment process required before undertaking funded sex reassignment. However, many participants expressed frustration that counsellors assume all trans people want to pursue sex reassignment, when some have no desire to undergo physical alterations, just the freedom to express their preferred gender.

### **Physical Health**

Some trans people have medical concerns that are specific to being transgender, such as hormone therapy and SRS. Some are at higher risk for the health problems associated with poverty or the sex trade. Trans people generally, of course, also need to access care for the full range of medical concerns affecting the population as a whole, but may have trouble finding providers who are respectful of their sex/gender identity.

Whether Aboriginal or not, most participants rated their health as excellent or good (78% and 75% respectively). However, 21.3% of our 75 participants have to their knowledge had a sexually transmitted infection (STI), and 8.2% are HIV positive, with another 8.2% unsure of their HIV status. The figures are much higher among Aboriginal participants (15.4% HIV+, 7.7% unsure) than among non-Aboriginal participants (4% HIV+, 8.5% unsure) and among MtF than among FtM for all participants. See Table 3.

**Table 3: HIV and STIs**

	n	HIV + yes	HIV + Don't know	STI ever yes	STI ever Don't know
Aboriginal b.Male	21	4 / 20%	1 / 4.8%	8 / 38.1%	1 / 4.8%
Aboriginal b.Female	6	0	1 / 16.7%	1 / 16.7%	0
All Aboriginal	27	4 / 15.4%	2 / 7.7%	9 / 33.3%	1 / 3.7%
Non-Aboriginal b.Male	30	2 / 6.9%	3 / 10.3%	6 / 20%	1 / 3.3%
Non-Aboriginal b.Female	15	0	1 / 6.7%		
Intersex	3	0	0	0	0
All Non-Aboriginal	48	2 / 4.3%	4 / 8.5%	7 / 14.6%	1 / 2.1%
All participants	75	6 / 8.2%	6 / 8.2%	16 / 21.3%	2 / 2.7%

### Trans-acceptance and Trans-competence of Health Care Providers

Participants stressed in many ways that they want access to medical care providers who are comfortable with and respectful of trans people. We asked, “How trans-competent is the person who provides most of your medical care?”

Most participants who ranked the trans-competence of their health-care providers as “4” or “5” (where 5 is “best”) indicated that they were clients of providers who served trans and LGBTT, Aboriginal, and HIV positive people. Other participants gave various reasons for not having their health needs met:

*lack of good general practice doctors in Mb*

*nobody is networked, get help is like a jigsaw puzzle or Easter egg hunt*

*money is the problem with getting what I need in personal care fields*

We asked, “If you have had positive experiences with a health or helping professional related to your sex/gender identity, please describe one or more examples.” The answers stressed simple respect and listening:

*my own doctor listens to and answers any questions I have. She has even read up on health issues regarding gay community*

*[Jane Doe] is great listener and understand what tg people go through. She always listens to what I say and understand what I go through.*

*eye contact – welcoming facial expression*

In answer to the question, “What could a caregiver say or do to create a safe environment for you to speak completely freely about your sex/gender identity?” the answers ranged from having signs/posters up that talk

about sex and gender identity issues to simply saying,

*be yourself and don't be too concerned about what other people think. After all it is your life*

## **HEALTH AND SAFETY IN DAILY LIFE**

As they go about their daily lives, transgender people have to navigate barriers presented by every minor event in order to avoid provoking a society that seems obsessed with enforcing a rigid sex/gender system into which they do not fit. Even boarding a bus can be an anxiety-fraught event met with stares, laughter, and rude comments, and getting off the bus can be accompanied by fears of being followed and assaulted.

Many of our participants report having been harassed for using, or were not allowed to use, washrooms or change rooms, especially at school, in restaurants, and at health clubs and gyms, but also at workplaces, government offices, and social services. Many who have not fully transitioned avoid using public washrooms (even in nominally trans-inclusive LGBTTT bars) and change rooms in order to avoid unpleasant confrontations. A situation that prevents one from using washrooms at school or work obviously interferes with daily life.

### **Identification Papers**

A wide array of official documents in everyday use identifies one's sex/gender and name (also usually sex/gender specific) including birth certificates, passports, bank records and credit cards, driver's licenses, social insurance records, employment records, and educational records. People who have begun to transition need to change these sex/gender markers on the documents in order to avoid problems when they use them. For people living in poverty, the cost is prohibitive. One person responded this way to our question, "would you like to add anything": - yes, add to survey questions, this - do you think \$147 is too much money to get your name change from male to female?

### **Safety in Everyday Places**

We asked participants to estimate how unsafe they had ever felt in various places in their daily lives when expressing their preferred sex/gender identity, and the level of safety they feel now, where 1 is Completely Unsafe and 5 is Very Safe. See Table 4.

**Table 4: Safety in Everyday Places**

Aboriginal	Most unsafe ever felt					Safety felt now				
	n = ever, now	1 Un- safe #/%	2	3	4	5 Safe	1 Un- safe #/%	2	3	4
Home (19 ever, 24 now)	3 / 15.8%	2 / 10.5%	5 / 26.3%	4 / 21.1%	5 / 26.3%	1 / 4.2%	0	3 / 12.5%	7 / 29.2%	13 / 54.2%
Work (18 ever, 14 now)	3 / 16.7%	4 / 22.2%	4 / 22.2%	3 / 16.7%	4 / 22.2%	1 / 7.1%	0	3 / 21.4%	3 / 21.4%	7 / 50%
School (20 ever, 19 now)	7 / 35%	0	3 / 15%	7 / 35%	3 / 15%	1 / 5.3%	2 / 10.5%	2 / 10.5%	5 / 26.3%	9 / 47.4%
Doctor's (20 ever, 23 now)	2 / 10%	1 / 5%	8 / 40%	3 / 15%	6 / 30%	1 / 4.3%	0	3 / 13%	6 / 26.1%	13 / 56.5%
Social services (17 ever, 18 now)	5 / 29.4%	2 / 11.8%	6 / 35.3%	2 / 11.8%	2 / 11.8%	1 / 5.6%	0	4 / 22.2%	6 / 33.3%	7 / 38.9%
Worship (14 ever, 15 now)	5 / 35.7%	4 / 28.6%	1 / 7.1%	0	4 / 28.6%	2 / 13.3%	0	2 / 13.3%	4 / 26.7%	7 / 46.7%
LGBTT space (17 ever, 20 now)	3 / 17.6%	2 / 11.8%	4 / 23.5%	3 / 17.6%	5 / 29.4%	1 / 5%	1 / 5%	1 / 5%	4 / 20%	13 / 65%
Public places (20 / 21)	4 / 20%	2 / 10%	6 / 30%	4 / 20%	4 / 20%	1 / 4.8%	1 / 4.8%	7 / 33.3%	7 / 33.3%	5 / 23.8%
Traveling (19 / 19)	3 / 15.8%	2 / 10.5%	7 / 36.8%	4 / 21.1%	3 / 15.8%	1 / 5.3%	2 / 10.5%	4 / 21.1%	7 / 36.8%	5 / 26.3%

As can be seen on the left side of the table, school, social services, and places of worship are the places where participants are most likely to have felt completely unsafe, and home, a doctor's office, and LGBTT space as the places where they had felt safest. The right side shows that fewer participants "now" feel very unsafe and more now feel very safe in these places. For example, if we consider an answer of 4 or 5 to mean "quite safe," over half (57.1%) who answered the question for public spaces feel quite safe there compared to just 40% at some earlier point in their lives. 85% now feel quite safe in LGBTT spaces, compared to 46% earlier, which could reflect the increased visibility and social integration of the larger LGBTT community over the last twenty years. 73.7% now feel quite safe in school, compared to 50% earlier, which might reflect improved atmosphere at school, or perhaps more likely, less transphobia in adult learning environments (none of our respondents is younger than 18) than in their younger school experiences. 73.4% of those who answered the place of worship question feel safe there, compared to 28.6% earlier, which could be attributable to their having switched to an LGBTT-positive congregation. 83.4% feel quite safe at home, compared to 47.4% earlier, which again could reflect the difference between their adult living situation and their situation in childhood or youth, when trans people are first confronting hostile family reactions.

Overall, these improvements could be evidence of a reduction in societal homophobia and transphobia, a difference between younger and older experiences, or an increase in our participants' resilience over time (24 of the 27 are over 25), or all three. It should also be noted that our participants are those who have managed to survive, to persist in their determination to be true to their sex/gender identity, and in most cases, to get access to the limited trans services available in Winnipeg. Those who have given up and resigned themselves to pretending to be conventionally gendered, and those who have committed suicide or been murdered, are not represented in these numbers. Still, improvements notwithstanding, daily life involves a significant degree of danger-avoidance for transgender and Two Spirit people, and many participants still feel unsafe in many everyday places that they need to go.

We also asked people to identify how often they had experienced various forms of attack which they reasonably believe were related to their sex/gender identity. See Table 5.

**Table 5: Experiences of Assault**

<b>Aboriginal participants (n = 27)</b>	Never	Not sure	Once	2-3	Often
Refused service (27)	13 / 48.1%	7 / 25.9%	4 / 14.8%	3 / 11.1%	2 / 8%
Refused access to bathrooms (25)	18 / 72%	1 / 4%	2 / 8%	2 / 8%	7 / 35%
Verbal insults (25)	7 / 28%	1 / 4%	2 / 8%	9 / 36%	6 / 24%
Received phone threats (26)	15 / 57.7%	2 / 7.7%	5 / 19.2%	4 / 15.4%	0
Personal property damaged/stolen (25)	15 / 60%	4 / 16%	3 / 12%	1 / 4%	2 / 8%
Threat with physical violence (26)	11 / 42.3%	0	4 / 15.4%	7 / 26.9%	4 / 15.4%
Attempted physical violence (26)	14 / 53.8%	1 / 3.8%	2 / 7.7%	6 / 23.1%	3 / 11.5%
Had objects thrown at you (26)	11 / 42.3%	1 / 3.8%	5 / 19.2%	5 / 19.2%	4 / 15.4%
Been chased or followed (26)	9 / 34.6%	2 / 7.7%	5 / 19.2%	5 / 19.2%	5 / 19.2%
Punched, hit, kicked or beaten (26)	12 / 46.2%	0 / 0	6 / 23.1%	6 / 23.1%	2 / 7.7%
Attempted rape or sexual assault (26)	20 / 76.9%	3 / 11.5%	3 / 11.5%	0	0
Raped or sexually assaulted (26)	17 / 65.4%	0	3 / 11.5%	5 / 19.2%	1 / 3.8%
Threatened with a weapon (26)	14 / 53.8%	0	7 / 26.9%	5 / 19.2%	0
Assaulted with a weapon (26)	15 / 57.7%	2 / 7.7%	6 / 23.1%	3 / 11.5%	0
Attempted murder (22)	22 / 100%	0	0	0	0
A friend was killed or assaulted (26)	9 / 34.6%	2 / 7.7%	1 / 3.8%	7 / 26.9%	7 / 26.9%

All of these rates of experience of insult, threat, and violence are high, but several stand out, especially when compared to non-Aboriginal participants' experience: 53.8% of respondents to the "Had objects thrown at you" question answered "once" or more (compared to 18.6% of non-Aboriginal). 34.6% of respondents to the "Assaulted with a weapon" question answered "once" or more (7% of non-Aboriginal). 57.6% reported that a friend had been killed or assaulted at least once (28.6% of non-Aboriginal). Further, Aboriginal participants

were less likely to know if they or their friends had been threatened or assaulted in various ways because of their sex/gender identity, presumably because being Aboriginal and living in poverty also elevate the risk of assault. One person annotated her “often” response to the last item,

*A lot of sex trade workers were killed. (my friends)*

## **DISCUSSION**

### **Health Trends**

The key issue identified in our needs assessment was that effective access is needed to trans-competent health care of every kind: counselling, general health care, and transition-related health care. Many participants emphasized the extreme difficulty of working their way through the medical system to access the general and trans-specific services they need. Some resort to the dangerous practice of procuring hormones over the internet and monitoring their own treatment (a finding consistent with other studies: Kenagy & Bostwick, 2005; Nemoto et al., 2005; Sperber et al., 2005; Xavier et al., 2005). For trans people who do not need or want sex reassignment procedures, the lack of a trans-competent personal physician might be assessed as no more problematic than for others in the general population. However, the assessment showed that our participants are at high risk for serious threats to health, quite apart from the need for access to sex reassignment procedures. As serious as the situation is for our participants in general, it is especially grave for Aboriginal participants.

### **STIs and HIV Infections**

The levels of known STI and HIV infections are much higher among Aboriginal participants than in the general population: 33.3% known STI and 15.4% known HIV, with another 7.7% unsure of HIV status. The rates are highest for Aboriginal participants born male: 38.1% known STI and 20% known HIV, with another 7.7% unsure. The known HIV rate is much higher the national average in Canada, where it is estimated that fewer than 0.2% (0.17) of the general population is HIV positive (including clear diagnosis figures as well as an estimated portion of the population who are not aware of their HIV+ status). It is estimated that approximately 1.5% of the general Aboriginal population are HIV+. (Public Health, 2005) Herbst et al.’s (2008) work also found that rates of HIV+ status are much higher in sero-tested than in self-reporting study participants, which suggests that rates of HIV infection among our participants might be higher than they know.

There are no official estimates of the HIV status of the trans population in Canada or the United States but the finding is consistent with Herbst et al.’s estimate of 27.7% HIV+ in the general male-born transgender population (a figure derived from their meta-analysis of 34 previous studies of HIV prevalence among different transgender populations). Further, Bockting, Huang, King, Robinson, & Simon Rosser (2005) found that transgender people are much less likely than other members of the LBTT community to have been tested for HIV. Herbst et al. (2008) point out that estimated infection rates are highest among male-born African-American transgender people. Among the factors involved are not only engaging in risky behaviors such as intravenous drug use, unprotected anal sex, and sex trade work, but the contextual factors that give rise to risky behaviors, such as mental health concerns, physical abuse, social isolation, economic marginalization, and unmet transgender-specific healthcare needs. Other risk factors related to poverty and racism include intravenous drug use (Public Health Agency, 2007) and imprisonment, where rates of IDU and unprotected anal sex are known to be high.

### **Mental Health Problems**

Deep and often suicidal levels of depression are much more common among the participants than in the general population, as people lose hope of ever living a viable life where they feel at home in their bodies. Many described themselves as suffering from loneliness, and many participants expressed deep frustration and anxiety about inability to access transition services and other vital health services as life goes by. Aboriginal participants live with the additional mental stressors of poverty and elevated risk of assaults of various kinds.

## **Consistency with Findings of Other Trans Needs Assessments**

The results of this assessment are consistent with those of other needs assessments elsewhere in Canada and the U.S. (Bockting & Avery, 2005; GLBT Wellness Project, 2000; Goldberg, 2003; Kenagy, 2005; Kenagy & Bostwick, 2005; Lombardi, 2001; Moran, 2004; Morrison & L'Heareux, 2001; Walters, 2001; Ware, 2004). Trans and transition-related health care is chronically under-resourced even in large cities that have gender clinics because they tend to have correspondingly larger trans populations (who have left smaller communities) who need services. Self-procurement and self-administration of hormones is common. Employment, housing and job training are needed. Levels of depression and suicidal ideation are high. Lack of knowledge, insensitivity, and discrimination are the norm among mainstream service providers, especially if participants are not only trans but poor or people of colour.

## **Limitations**

While the 27 Aboriginal participants in our study provided a wealth of information, our non-random sample cannot provide statistical generalizability. It is likely that our participants are among the best-connected to medical and other support services and that their needs are being better met than are those of less connected people who did not hear of or participate in our study. We were not successful in recruiting minors or residents of smaller and remote communities.

## **RECOMMENDATIONS**

What Aboriginal transgender and Two Spirit people told us they need is what we all need: the dignity of an everyday life not dominated by anxieties about health and safety. Trans people try to get their general and transitioning-related health needs met in a system that has not tried to develop trans competence or provide funding for SR procedures. They suffer a crushing degree of stress brought on simply by being who they are in a transphobic society, and when trying to get their mental health needs met they encounter more barriers. In an ideal world (the one non-LGBT people inhabit with reference to their sex/gender identities), all health care providers would be knowledgeable about the health needs of transgender people and respectful of their decisions, whether they be to pursue sex reassignment or to live with their bodies as they were sexed at birth. They would make appropriate referrals through a well-funded health care system to specialists with a high level of competence in sex reassignment procedures. The health care system would treat those procedures as a medical necessity and fund them accordingly. In a more just society, people would not be living in poverty, targeted by racism, and suffering the consequences to their mental and physical health. In an even slightly improved society, the needs of people fighting these odds would be the top priority of our health care system.

In the absence of that transformed society, we concluded that the needs of the region's transgender community in general and the Aboriginal trans community in particular will remain acute and should be regarded as a state of emergency that demands attention. We made many recommendations for the development of policies and procedures to improve the situation in health care, schools, workplaces, social services, police and security systems, and in public places. The recommendations were made in the larger context of general transgender needs, but are all the more relevant to Aboriginal trans people, since so many needs are intensified by poverty and prejudice. A network of community health agencies and Manitoba Health's Primary Care program have committed to collaborating to implement recommendations from the report. The recommendations most relevant to the HIV/health community are described below. Additional recommendations addressed policy and program gaps in workplaces and schools. Interested readers are invited to contact me for the full report (Taylor, 2006).

1. That the health care system work towards the development of a centre of excellence in trans health care that would offer coordinated counselling, psychiatric, general health, endocrinological and surgical services that fulfil or exceed such best-practices guidelines as the sixth version of the Harry Benjamin (2005) "Standards of Care for Gender Identity Disorders," the Kopala Report (2003) "Recommendations for a Transgender

Health Care Program,” and the recently completely comprehensive set of clinical guidelines developed by the Vancouver-based Transgender Health Program’s (2006) “Trans Care Project.” The Centre would offer medical and counselling care onsite and work in close connection with off-site psychiatrists, psychologists, endocrinologists, and surgeons. The Centre could be a one-stop centralized clinic, or else a well-coordinated multisite centre of excellence that would involve the main agencies that now serve the trans community. Either model would need to be complemented by an effort to achieve basic trans-competent care among other medical service providers in the region for the benefit of people who do not have access to the Centre of Excellence.

2. That an effort be undertaken to reach agreement with two additional psychiatrists to commit to make themselves available for assessment purposes and develop the knowledge base necessary to do so.
3. That the trans-competency of counsellors and crisis workers be further developed through workshops to be designed by experienced counsellors, health care providers and clients.
4. That information be distributed to trans people including youth and people in remote communities and reserves via (1) a trans-positive public service announcement campaign about the availability of medical support and counselling, (2) an information pamphlet on transgender/Two Spirit identity and services, (3) a video about the medical/psychiatric processes involved in transitioning, and (4) an LGBTTT-positive health care providers list updated to include a separate focus on transgender and Two Spirit concerns.
5. That information be distributed throughout the regional health system including family physicians and clinics via (1) a trans-care and referral protocol and (2) an office poster modelled on the successful “lgbt-positive space” campaign used in universities. The protocol would cover key aspects of trans-competent health care and include contact information for clinics and specialists offering transition-related medical services. It would not be an attempt to educate all physicians on all related mental and physical health issues, but rather to ensure that all physicians are in a position to treat transgender clients respectfully and to make appropriate referrals.
6. That allies of transsexual people encourage Manitoba Health to provide the necessary funding for sex reassignment procedures, including out-of-province surgeries where an adequate level of expertise is not available in the region.
7. That trans-competence training be offered to Law Enforcement and Emergency Response personnel. Such training is especially important in the context of Aboriginal people’s understandable lack of confidence in the Winnipeg police service as examined by the landmark Aboriginal Justice Inquiry (Hamilton & Sinclair, 1991), a context compounded by historically widespread police mistreatment of gender-variant people. Unnecessary additional stress would be reduced in crisis situations involving police officers, paramedics, and “biz-district” personnel if they knew ahead of time of the existence of transgender people and why there might be differences between a person’s gender presentation and their sex designation on identification papers.

Beyond these, there is a need for further research into the situation of Aboriginal transgender/Two Spirit people in other parts of Canada, including minors and residents of small and remote communities, in order to build an evidence-based case for an adequate response to the health and safety needs of this very oppressed and underserved population. Among the most urgent research needs are larger scale studies of the health needs including the HIV status of Aboriginal transgender/Two Spirit people, the levels and types of violence they experience in their daily lives, and best practices for combating the racism and transphobia endemic in our institutions and communities.

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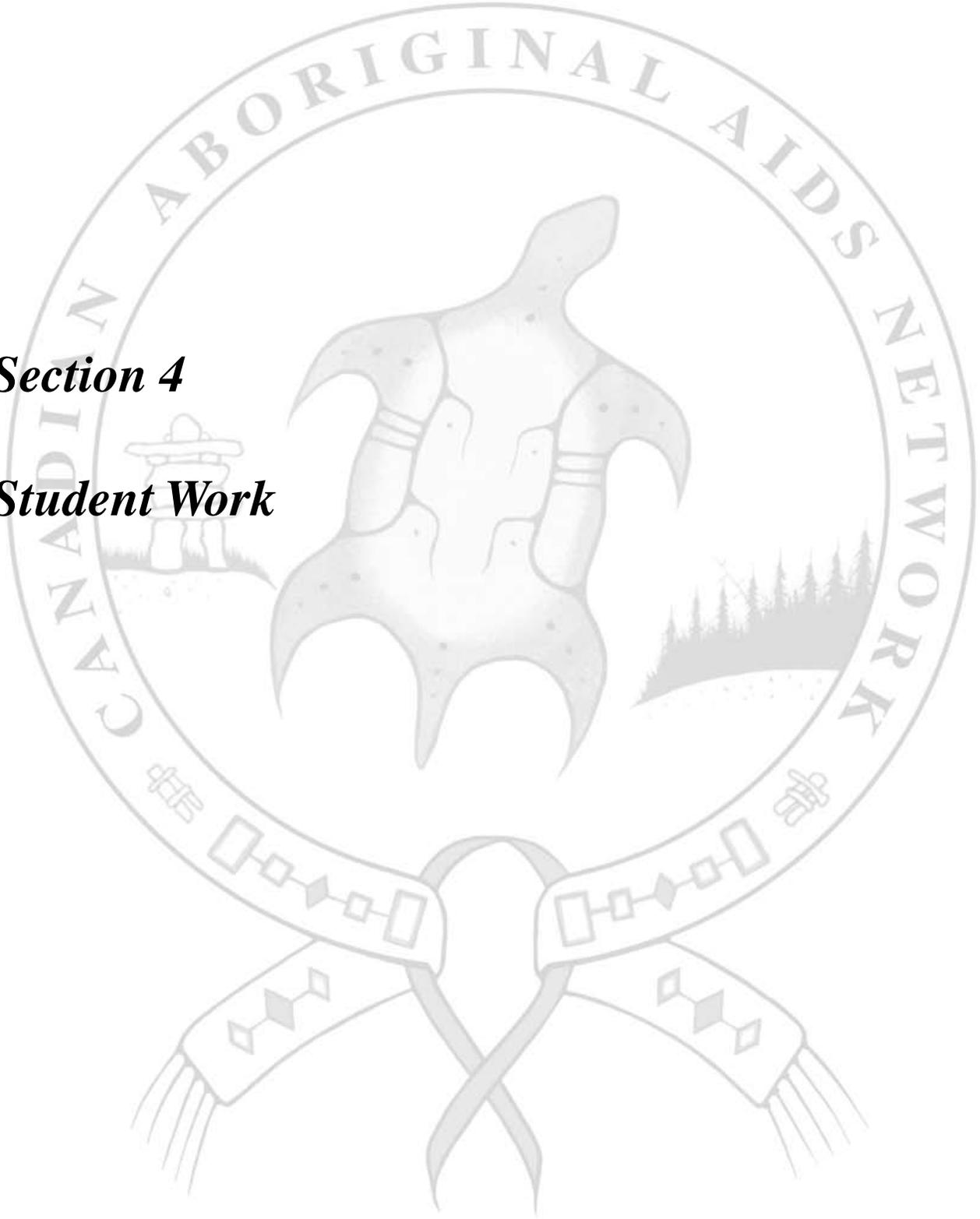
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***Section 4***

***Student Work***





# ***HIV/AIDS Impact on Aboriginal Women's Lives: A Meta-Analysis Review***

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## **ABSTRACT**

Worldwide, the rate of women living with HIV/AIDS continues to be on the rise. While a burgeoning of research into the experience of these women has occurred in the last decade, a paucity of understanding exists on Aboriginal women living with HIV/AIDS. Meta-analysis findings from extant literature will be provided in this article. Overall, positive experiences and impacts for women living with HIV/AIDS include: (a) connection to spirituality, (b) increased positive relationships, and (c) self-change. Negative experiences and impacts involve: (a) stigma, (b) depression and suicide, and (c) affected identities of mothers. Studies focusing on Aboriginal women living with HIV/AIDS confirm these general experiences and highlight additional impacts. Positive aspects for Aboriginal women also include: (i) connection to spirituality and culture, (ii) increased identity as mother, and (iii) personal growth. Negative aspects include: (i) historical factors of colonization, (ii) addictions, and (iii) isolations and stigma. Recognition of these impacts of HIV/AIDS on Aboriginal women will help shape future HIV/AIDS interventions and prevention programs. Recommendations for future research and HIV/AIDS program development will be discussed.

Women are quickly becoming the leading group infected with HIV (UNAIDS, 2006). In Canada, HIV is infecting Aboriginal women at an alarming rate (Public Health Agency of Canada [PHAC], 2006). The Aboriginal population comprises only 3.8% of the total population of Canada as of the 2006 census (Statistics Canada, 2008). Yet, the number of Aboriginal people testing positive for HIV represents 22% of the total number of people testing positive (PHAC, 2006). This may not be a complete representation of the HIV statistics in the Aboriginal community because not all provinces collect information on race when testing HIV. Until 2005 only 29% of tests for HIV had information related to ethnicity (PHAC). Consequently, there remains a lack of clear statistics of Aboriginal women living with HIV. What is evident is that Aboriginal women comprise up to 47.3% of the Aboriginal HIV epidemic (PHAC). This mimics global populations of women from resource poor countries, such as Sub-Saharan Africa, Caribbean, and Ukraine. There is an apparent pattern of women who are socio-economically disadvantaged being infected with HIV at a higher percentage. A key difference in the rates of HIV for women in Sub-Saharan Africa and the rates of HIV in Aboriginal women is that the majority of women in Africa contract HIV through heterosexual intercourse (UNAIDS). Aboriginal women's risk category, on the other hand, is predominately IDU (Intravenous Drug Use) and heterosexual intercourse comes in as the second mode of HIV transmission (PHAC).

HIV is a virus that ultimately leads to AIDS, which is presently a terminal illness. Given the fatal nature of this disease, women invariably experience a cycle of grief and develop strategies for coping following a diagnosis. Prior to highly retroactive antiretroviral therapy (HAART), the research on HIV/AIDS was quite bleak, given short life expectancy. Since HAART, people living with HIV who have access to medications are living longer and productive lives. The impact of HIV has had many effects on the lives of women globally. In the last decade, there has been a burgeoning of HIV research focusing on women. While researchers have outlined some aspects of the trajectory in living with this illness for women in general, no synthesis of the research has been published. Likewise, the unique experience of living with HIV/AIDS as an Aboriginal woman has not been systematically detailed from existing research. It is imperative that health professionals, counsellors, public health educators, and policymakers understand the experience of women living with HIV/AIDS and the ways in which a diagnosis impacts women's lives.

The central purpose of this paper is to shed light on the experiences of Aboriginal women living with HIV/AIDS. Given the paucity of research on this population of Canadian women, we anchor the discussion more broadly in the experience for women in general and draw some references from research on women living with HIV/AIDS in resource poor countries. By reviewing, amalgamating, and summarizing the extant research we glean a meta-analysis understanding to further our own lives and work. Furthermore, we hope to contribute to shaping future interventions, prevention programming, and support services for these women.

## **METHODS**

### **SEARCH STRATEGY**

The strategy used for this meta-analysis review followed general steps put forth by Leedy and Ormrod (2005). First, a search of Academic Search Premier, PsycINFO, and Social Work Abstracts databases was conducted. Next, a search of the University of Calgary library catalogue followed by various search engines on the World Wide Web identified further relevant research. Several government and larger organizational websites were accessed. The key words used were HIV and women, HIV impact and women, HIV and Aboriginal women, HIV and coping, and HIV diagnosis. By using these terms an initial set of articles and research papers were identified. A further search was conducted using the ancestry approach. While searching for relevant Aboriginal research, an attempt was made to honor research conducted by Aboriginal people themselves; however, very limited studies of this nature have been published.

## **DEFINITIONS**

For the purpose of this paper, 'Aboriginal' is defined as "indigenous peoples in Canada, including Inuit, Métis, and First Nations who are Status or Non-Status, On or Off- reserves" (Canadian Aboriginal AIDS Network [CAAN], 2003, p. iii). We respect and celebrate that each group of Aboriginal people is as diverse as the regions they come from and that within the communities, there is further uniqueness and diversity. Nevertheless, for the purpose of this article, we use the term Aboriginal more generally to facilitate our discussion.

## **BACKGROUND**

### **WOMEN AND HIV GLOBALLY**

Globally, women have been greatly affected by HIV/AIDS. Almost half of those living with HIV/AIDS are women: 17.3 million women ages 15 and over according to UNAIDS (2006). Sub-Saharan Africa suffers the greatest devastation of the HIV/AIDS epidemic. That is, of those infected with HIV in Sub-Saharan Africa, 59% are women; 51% of those infected with HIV in the Caribbean are women; 46% in the Ukraine. In Canada, the rates of HIV infection among women increased from 12% in 1988-1995 to 25.4% in 2005 (PHAC, 2006). Although Canada's rates for women are not as high as other countries, there is an obvious increase in HIV incidence. This increase echoes the need for more research and programming for women in Canada.

The gender inequalities of resource poor nations have made the fight against HIV/AIDS particularly challenging (UNAIDS, 2006). Not uncommonly, survival for women of these resource poor countries includes prostitution for food, stable living conditions, and other basic necessities. Women in these countries are often subjected to violence in intimate relationships and have little control of their partner's use of condoms or whether they have been monogamous. Furthermore, in relation to HIV/AIDS, there is often fear of violence in being labeled HIV positive. Stigma of this diagnosis precludes women from getting tested, accessing treatment, care, and necessary support. Although Aboriginal women live in a resource rich country, their situation is akin to women in resource poor countries (Aboriginal Nurses Association of Canada, 1996).

### **WOMEN LIVING WITH HIV/AIDS**

### **POSITIVE COPING**

Several researchers have focused on the positive ways of coping with the diagnosis of HIV for women in general (DeMarco, Miller, Patsdaughter, Chilsholm, & Grindel, 1998; Doyal & Anderson, 2005; Dunbar, Mueller, Medina, & Wolf, 1998; Goggin et al., 2001; Jenkins & Guarnaccia, 2003; Moneyham et al., 1998; Siegel & Schrimshaw, 2000; Siegel, Scrimshaw, & Pretter, 2005; Turner-Cobb et al., 2002; Updegraff, Taylor, Kemeny, Wyatt, 2002). Eight of these studies focused specifically on minority women or economically disadvantaged women or had participant samples that were 70% or greater that met those two criteria (see DeMarco et al.; Doyal & Anderson; Dunbar et al.; Goggin et al.; Moneyham et al.; Siegel & Schrimshaw; Siegel et al.; Updegraff et al.). All eight studies used structured or semi-structured interviews to gather information that was then coded for themes. The participation ranged from 34 women to 184 women interviewed. From these eight research studies, several themes emerged relative to the positive impact that HIV/AIDS had in women's lives. The following section explores the predominant themes: connection to spirituality, increased positive relationships, and self-change.

### **CONNECTION TO SPIRITUALITY**

Dunbar and colleagues (1998) and Siegel and Schrimshaw (2000) found positive growth in spirituality after HIV diagnosis. Women were able to redefine their lives, deal with death, and create meaning for their lives. Similar results were obtained by Goggin and associates (2001) who revealed an enhanced closeness to God.

Researchers also found that spirituality was an effective coping strategy in distressful times (Doyal & Anderson, 2005; Goggin et al.; Moneyham et al., 1998; Siegel & Schrimshaw). Women turned towards spirituality when coping with emotional distress and physical illness and this was evident despite the extent of religiosity in the communities that women resided.

## **INCREASED POSITIVE RELATIONSHIPS**

It was evident from the research that women experienced positive changes in their relationships. Women identified that living with HIV gave them the strength to improve their relationships with their children, family members, and friends (Dunbar et al., 1998; Goggin et al., 2001; Siegel & Schrimshaw, 2000; Updegraff et al., 2002). Wong-Wylie, Doherty-Poirier, and Kieren (1999) confirmed this experience for both men and women living with HIV/AIDS. Goggin et al. also reported that women became closer to their families and relied on them for support. Sixteen percent of the women they interviewed became closer to their family, regained custody of their children, and established new romantic relationships. They were also able to create new support networks. Although there were positive changes in relationships, researchers have suggested that program development should not discount that a large percentage of women identified no known family or friend support. Dunbar and associates also noted that an HIV diagnosis empowered women to end various relationships that were not meeting their needs.

## **SELF-CHANGE**

One of the most noted positive changes for women living with HIV/AIDS was change in their selves. The voices of women from various studies revealed that despite the initial hopelessness upon diagnosis, HIV prompted them to make personal changes in their lives (DeMarco et al., 1998; Doyal & Anderson, 2005; Dunbar et al., 1998; Siegel & Schrimshaw, 2000; Updegraff et al., 2002). Many women developed a more positive sense of self and felt that the diagnosis made them stronger and more caring. Furthermore, Goggin and colleagues (2001) and DeMarco and colleagues found that women living with HIV/AIDS not only developed a positive sense of self but also felt empowered to advocate for themselves. They reported that many women found strength in the face of adversity to rise above the situation, improve their sense of self, and lobby for their needs.

Another notable change in self was dealing with drug addictions-- not necessarily abstaining from drugs completely, but reducing the amount of harm they did to themselves (Goggin et al., 2001; Siegel & Schrimshaw, 2000). Goggin and associates found that 25% of the women they interviewed entered recovery for substance abuse. These women specifically conveyed that the diagnosis of HIV forced them to reevaluate their lives and cease the drug abuse. Consistent with these reports, Siegel and Schrimshaw found that women who had substance abuse histories reported the most profound changes and growth. These results may be encouraging for the link with Aboriginal women who are becoming infected with HIV predominately by IDU. With increased research on the factors involved in these women's reduction or cessation of drug use there could be positive implications in working with Aboriginal women living with HIV and dealing with substance abuse.

## **NEGATIVE IMPACT**

Just as there are positive impacts and ways women have coped with the diagnosis of HIV/AIDS, there are also negative aspects. This section focuses on the negative impacts women have experienced with their HIV diagnosis. More general research on minority and economically disadvantaged women are included given the similarities to Aboriginal women's oppressive circumstance. Three predominant negative themes gleaned across the research on negative impacts of HIV/AIDS on women's lives included: stigma, depression and suicide, and the identity of motherhood.

## **STIGMA**

Along with the epidemic of HIV/AIDS comes the epidemic of stigma and discrimination. Since the first days of HIV, the general population has put the blame of the spread of HIV on those that are infected. First, it was a “gay disease”, then a “prostitute’s disease”, and a “druggies disease”. These are all marginalized people from society that often bear the burden of others’ discriminatory behaviours. The result of a fear or stigma is lack of disclosure among those who are infected. They then may live in isolation and limit efforts to seek out support.

Several studies reported on stigma as a source of negative impact for women (Abel, 2007; Doyal & Anderson, 2005; Goggin et al., 2001; Walker, 2002; Wilson, 2007). Walker investigated a small group of rural women with HIV. As mentioned, the fear of stigma left many of the women in isolation and kept them from accessing services. Smaller communities leave women with HIV exposed to rejection in many areas of life: dentist, restaurants, and schools. The fear of stigma can also create a barrier to treatment for women. Women are less likely to go for counselling or medical attention if they believe their HIV status will be discovered. In rural communities there is a perception of a lack of confidentiality; therefore, women living with HIV/AIDS are reluctant to seek services. Goggin and associates also discovered that stigma impacted these women’s ability to disclose their HIV status to their families. The link between rural women to Aboriginal women is important, especially for those Aboriginal women living in First Nation and Inuit communities that are small and often isolating. That is, information about rural women living with HIV informs researchers and program planners about obstacles many Aboriginal women living with HIV may encounter if living or returning to First Nations and Inuit communities, which are often similar to a rural setting.

## **DEPRESSION AND SUICIDE**

An HIV/AIDS diagnosis is devastating to most people even to the point of wanting to end their lives (Cooperman & Simoni, 2005). There are obvious reasons why many may feel this way: along with the stigma, HIV is a virus that will ultimately lead to AIDS, which is fatal. Even in the era of HAART, many people still feel a sense of hopelessness and despair with their diagnosis (Wong-Wylie & Jevne, 1997). Depression in women who are diagnosed with HIV/AIDS is not uncommon. Catz and colleagues (2002) found that 56% of the women they interviewed reported significant depressive symptoms. Nevertheless, the women in this study were all economically disadvantaged. The question arises as to whether these women are depressed because of the HIV diagnosis or because of living in poverty. However, other studies corroborate the increased rate of depression and suicidal attempts. Stevens and Hildebrandt (2006) examined depression in women with HIV and found that 20% were suicidal in the first year of diagnosis. Furthermore, 33% of women were depressed even 10 years after initial diagnosis. Cooperman and Simoni (2005) further underscored the significance of depression and suicide in the lives of women living with HIV/AIDS. Their study involved 207 HIV positive women: 78% of women reported suicidal thoughts since their diagnosis.

## **AFFECTED IDENTITIES OF MOTHERS**

Women may evolve through various roles and identities over the course of their lives: daughter, sister, friend, lover, worker, and mother. The research indicates that a diagnosis of HIV for women threatens their identities, particularly that of ‘mother’. In exchange, many women feel that they become a face of HIV/AIDS: promiscuous, vile, dirty, and shamed. These labels may be internalized and invariably affect women’s ability to cope with their diagnosis.

Women living with HIV/AIDS are “[s]ocially marginalized women in particular, [who] frequently report both the stress of motherhood but also its importance as a ‘normalising’ activity” (Doyal & Anderson, 2005, p. 1732). Although being a mother gave women something positive to focus on, not all mothers felt this way. Cooperman and Simoni (2005) found that women with children were more likely to have suicidal ideation and attempts. Mothers receiving an HIV diagnosis explicitly voiced their experiences of fear in having their children

discriminated against (Cooperman & Simoni; Doyal & Anderson; Wilson, 2007). In particular, Wilson revealed that mothers were very concerned about the stigma and discrimination their children would likely encounter due to their association with HIV. Mothers also experienced anxiety in being deemed a bad mother as a result of their HIV status. The illness threatens the motherhood identity at once in that they will either be judged as a bad mother for contracting the virus and/or they will get sick and someone else will assume the role of mother in their children's lives. Motherhood, although a reason for some women to strive to continue life normally, is a demanding role that can compound the stress of living with HIV/AIDS.

## **ABORIGINAL WOMEN AND HIV/AIDS**

Turning to the research conducted specifically with Aboriginal women living with HIV/AIDS, our analysis revealed only seven articles related to the topic (see Aboriginal Nurses Association of Canada, 1996; CAAN, 2005; McKay-McNabb, 2006; Mill, 2000; Romanow, 2003; Ship & Norton, 2000, 2001). Of those seven, only four articles fit the parameters of this analysis. The three excluded were for the following reasons: Aboriginal Nurses Association of Canada did not research HIV positive women; Ship and Norton (2001) was not a research paper but a discussion of previous research; CAAN focused on recommendations for overcoming barriers in programming for Aboriginal women living with HIV/AIDS.

The four studies remaining that centered on the lived experiences of Aboriginal women with HIV/AIDS included: McKay-McNabb, 2006; Mill, 2000; Romanow, 2003; and Ship and Norton, 2000. Each of these studies involved a small group of women and one study also included women that were Hepatitis C positive only or co-infected with HIV and Hepatitis C. Participants were recruited utilizing a convenience sample from local health clinics or AIDS service organizations. These qualitative studies employed face to face interviews with Aboriginal women. Overall, these studies confirmed the aforementioned themes derived in the experience of women living with HIV/AIDS and highlight additional impacts. Without these four studies, the in-depth and unique experiences and challenges for Aboriginal women would be lost. Positive aspects and impacts for Aboriginal women with HIV included: connection to spirituality and culture, increased identity as mother, and personal growth. Negative aspects included: historical factors of colonization, addictions, and isolations and stigma. The following is a discussion of the themes that were consistent in the research.

## **POSITIVE IMPACT**

### **CONNECTION TO SPIRITUALITY AND CULTURE**

Mill (2000) revealed that many women found a cultural connection after HIV diagnosis. The diagnosis led them to want to connect with their traditions and traditional healing practices. Even when it came time for treatment, some women chose a combination of traditional healing ways and modern medicine. The reconnection to a higher power and traditional way of life was how Aboriginal women were trying to cope positively with their illness.

### **INCREASED IDENTITY AS MOTHER**

Another positive impact that helped these women cope with their HIV illness and their addictions was their children. Although the burden of stigma and related discrimination hindered their own perceptions of themselves as mothers, these women took the love for their children as a way to turn their lives around (Mill, 2000; Ship & Norton, 2000). Mill highlighted that Aboriginal women felt motivated to regain custody of their children and to raise their children differently than they were raised.

### **PERSONAL GROWTH**

Mill (2000) conveyed other positive consequences that HIV/AIDS had on Aboriginal women's lives. Most of

the women “experienced personal growth, felt more honest with themselves, developed greater self-respect, and viewed their lives from a more positive perspective” (p. 49). In turn, this prompted women to have better respect for others and to become more involved in their community. Despite experiencing past traumas and the initial crisis that the HIV diagnosis triggered, the majority of the women were able to forge ahead and cope positively and productively with HIV/AIDS in their lives. Likewise, McKay-McNabb (2006) underscored that “[s]ome of the Aboriginal women have embraced their new identities as Aboriginal women living with HIV/AIDS” (p. 13). These women found pride in who they are and how they overcame obstacles in their life. This newfound appreciation facilitated a holistic healing journey including mind, body, and spirit, which reflects the medicine wheel and the emphasis in the Aboriginal culture on illness as holistic.

## **NEGATIVE IMPACT**

### **HISTORICAL FACTORS OF COLONIZATION**

A central theme in three of the studies was the impact of colonization, residential schools, and the subsequent abuse Aboriginal women encountered. The women themselves reported that either they or their parents were in residential schools (Romanow, 2003; Ship & Norton, 2000). Furthermore, Ship and Norton found that eight out of the eleven women interviewed had been sexually abused as children. Romanow reported that 95% of the women interviewed experienced some form of abuse: physical, emotional, or sexual. Many linked their experiences with residential schools or non-Aboriginal foster homes. They also spoke of abuse in their homes from their own family members. As a result of this abuse, women often escaped to the streets and engaged in high risk behaviours that included prostitution, IDU, and often crime. For example, in Romanow’s study 73% of the women reported prostitution as their form of occupation. The past abuse these women experienced has been linked to the legacy of abuse from residential schools and cultural stressors on Aboriginal peoples’ lives.

In turn, this link to the past and factors of colonization has been shown to lead Aboriginal women to engage in high risk behaviours that ultimately exposed them to HIV. Many women commented on the need to heal from past abuse and that the inability to heal was thwarting their ability to cope with HIV. In order for them to become substance free or reduce their harm of certain substances, those wounds of the past needed healing. Aboriginal women in these studies voiced their need to find the strength to start on their healing journey.

### **ADDICTIONS**

There were many similarities in the four studies in terms of alcohol and drug use by Aboriginal women living with HIV/AIDS. All the women in both Romanow (2003) and Ship and Norton’s (2000) research had used or were still using alcohol. Nine of the eleven women interviewed by Ship and Norton used injection drugs as did the majority of women in Romanow’s and McKay-McNabb’s (2006) studies. The overwhelming use of drugs for these women prior to knowing they were HIV infected led them to continue or increase their drug use to cope with their diagnosis. One woman’s response to drug use was as follows: “Usually when I get sick, I cope with it by doing heroin, morphine. It helps me cope with the pain” (McKay-McNabb, p. 12). Aboriginal women were identified in the research as using drugs to cope with the diagnosis, sickness, and pain of HIV.

### **ISOLATION AND STIGMA**

Ship and Norton (2000) conveyed that many of the Aboriginal women living with HIV/AIDS believed that isolation thwarted their ability to heal from the past and from the impact of HIV. Women described the experience of isolation from a lack of community and family closeness. Further impeding their access to support, the isolation also impinged on effectively coping with HIV/AIDS (McKay-McNabb, 2006; Romanow, 2003; Ship & Norton). These women reported feeling isolated because the services they sought were not gender friendly or Aboriginal friendly. If the organization was culturally sensitive, Romanow found that many women still felt judged by the staff because they were deemed as bad mothers who used drugs and had HIV. Moreover, many

Aboriginal women were fearful of returning to their home communities because of the HIV stigma.

HIV brings stigma regardless of one's age, gender, sexual orientation, and cultural background. The fear of stigma-related discrimination can often paralyze people living with HIV/AIDS. One of the respondents in Ship and Norton's (2000) study explained the stigma-related impact of HIV/AIDS as follows:

*It's the stigma that goes with it. It's not the death part. It's how you got it. You must be homosexual. You must have used IV drugs. You must have done something wrong. That's the fear for me, the rejection because of stigma. (p. 82)*

The related stigma and secrecy of their infection is paramount to many women, especially Aboriginal women with children. Mothers also want to protect their children from being stigmatized. Once again because of the stigma related fear, women are less likely to seek support and services to help them cope more effectively with their illness and the related emotional issues, as well as coping with their lifestyles.

## **LIMITATIONS OF RESEARCH**

The area of HIV/AIDS is a sensitive topic and many people, men and women, are (not surprisingly) not outspoken about their condition. The fear of stigma and discrimination highlighted throughout the research forces many people to live in shame and to be less forthcoming in participating in research. For this reason, the information gleaned from the research may not be representative of women living with HIV. That is, most of the samples of Aboriginal participants were recruited utilizing convenience sampling and often yielded a small number of participants. Those women too afraid to participate in research that highlights the experience of living with HIV/AIDS may have different experiences not captured by the research. Convenience sampling impedes accurate representation; nevertheless, the research captured the voices and lived experiences of those who participated, which is fundamental and lends invaluable insight.

Another limitation to the existing research is the methodology. All of the studies on Aboriginal women were qualitative in nature, which can be criticized for being too open to interpretation. For example, researchers focusing on positive coping asked questions about the positive ways that HIV impacted their lives. Likewise, researchers who looked predominately at distress asked questions that focused on negative impacts. The results could be criticized as being suggested by the questions asked. While we acknowledge this limitation of the research, it is important to note the advantages of qualitative studies in generating rich, in-depth, and thick descriptions of lived experiences. Given the focus of the research on the experience of living with HIV, qualitative research was a most fitting research paradigm (Leedy & Ormrod, 2005)

Additional limits to the research include an assumption and reliance on the participants to disclose all involvement in high risk behaviours or attempts of suicide and other topics. In fact, shame and/or social desirability may compel women with HIV/AIDS to not completely disclose. It is important to bear in mind that participants may not have been totally forthright with involvement in certain activities. Finally, the dearth of research on women, and in particular Aboriginal women living with HIV/AIDS, thwarts our ability to fully understand the multifarious experience. These initial studies can provide a glimpse of the broader picture for Aboriginal women.

## **CALL FOR FUTURE RESEARCH**

There is an urgent need for research on the experiences of Aboriginal women living with HIV/AIDS, given the high rate of infection in this population. A wide-range of research foci is needed to inform appropriate HIV/AIDS Aboriginal intervention and prevention programs and service delivery. Specific research directions emerging from our review include recognition that women in different regions of the world have different access to support and treatment. In Canada, treaty First Nations and Inuit people have access to free medications. As

such, Aboriginal people that do not qualify for free medication may encounter more stressors in their lives. Not one research study addressed the subject of access to medication and its impact on Aboriginal women coping with HIV/AIDS. It is an important area of focus for future research. While not discounting the critical importance of HIV/AIDS research on Aboriginal women as a whole, it is important to note that Inuit, Métis, and First Nations women who are Status or Non-Status, and living on or off reserves have many varied experiences. Consistent with the perspective that group differences exist with Aboriginal people, it is imperative for future researchers to capture the nuances of these groups distinctly. Furthermore, giving voice to Métis women, for example, would be empowering and legitimizing; and facilitate specific areas needed for advocacy and potential enhanced HIV/AIDS program planning.

There are ethical considerations in researching this population of women, which is considered greater than minimal risk by the Tri-Council Policy Statement (TCPS) (Canadian Institutes of Health Research, 1998). The TCPS was developed by the Interagency Advisory Panel on Research Ethics in Canada for ethical conduct and contains Section 6 for research involving Aboriginal peoples and articulates good practices, ethical principles, standards, and procedures. For example, it is suggested that ethics review of research should be proportionate to the risks of potential harm. That is, if there is any potential for participants' identity to be revealed due to involvement in the research, the research protocol should not be approved by the ethics board and a representative from the Aboriginal community should be involved in the review.

Informed consent as well as the utmost protection of anonymity and confidentiality of women participating in research would need to be thoroughly considered prior to inviting participants to the study. Patterson, Jackson, and Edwards (2008) have noted that work with the Aboriginal communities and researchers need to engage in a "reflexive process of negotiation, and build community capacity for research" (p.49). Therefore active engagement with Inuit, First Nations, and Métis women living with HIV in the research process would be key; especially in developing research questions and cultural perspectives.

## **PROGRAM RECOMMENDATIONS**

This meta-analysis review of the extant literature and research sheds light towards needed program development strategies that would benefit the lives of Aboriginal women. Based on the scant research available, it is evident that historical impacts of colonization and residential school need to be addressed when working with Aboriginal women diagnosed with HIV. Culturally responsive and holistically delivered programming within a non-judgmental environment is essential. Inclusive of this would be addressing addictions, especially providing this non-judgmental support at the onset of diagnosis so future women diagnosed with HIV receive support in a much more timely way.

Researchers have indicated the strength in the identity of motherhood for creating a positive outcome for Aboriginal women. As such, programs incorporating an emphasis on the resiliency and empowering nature of the motherhood identity may prove beneficial. Likewise, programming that is responsive to the cultural, traditional, and artistic healing of mind, body, and spirit provided in nurturing and supportive environment accessible to all women, regardless of drug use would be beneficial. Finally, it is of critical importance to have continued education, awareness, and advocacy about HIV/AIDS in efforts to remove the barrier of HIV stigma in our society. In turn, these efforts would enhance Aboriginal women's lives so that treatment, support, and care are accessed when living or returning to their HIV discrimination-free communities.

## **SUMMARY AND DISCUSSION**

Many themes emerged from this meta-analysis review of women living with HIV/AIDS. Overall, researchers identified fear of stigma, depression and suicide, and isolation-- which were themes apparent in the studies. Similarly, there was convergence on the experience of positive coping such as turning to spirituality and culture and finding something positive that came out of the HIV diagnosis. These positive impacts and aspects are

necessary for front line healthcare professionals and mental health counsellors to be aware of as they may aid in providing hope to other women. Addressing the negative impacts is also crucial in facilitating women to live better with HIV/AIDS.

One of the major distinctions in the research between the more general population of women living with HIV and Aboriginal women was the emphasis on the past. In the Aboriginal-specific research, there was emphasis on how colonization, residential schooling, and past abuse have impacted their experience of living with HIV. Other studies on women and HIV/AIDS rarely acknowledged past issues as a contributing factor, or did so briefly in terms of impact of their current ability to cope. This is a key difference that also warrants attention for further research in the area.

Another difference between the two bodies of research was identity. Studies involving general groups of women living with HIV/AIDS predominantly focused on motherhood as exacerbating the inability to cope with the diagnosis. On the other hand, the limited research on Aboriginal women with HIV/AIDS underscored motherhood as a positive identity that motivated women to change their lives. More research is needed in the area to draw any further conclusions.

Finally, the major difference in the two bodies of research included in this analysis was in the area of addictions. The research revealed that drug abuse is a common method of coping for the participants who were Aboriginal women with HIV/AIDS. The same could not be reported from the research involving other groups of women. Drug abuse, as a way of contracting HIV and dealing with HIV, needs to be further explored in research involving Aboriginal women. A focus on addictions is also imperative in HIV intervention, prevention, and programming for Aboriginal women in light of this finding.

## **CONCLUSION**

The rates of HIV in the Aboriginal community are increasing, especially for women. There is an urgent need for more programming and support for these women. Aboriginal women living with HIV/AIDS face many obstacles and require specialized programming to help them cope and live healthier with HIV/AIDS. The scant research on this topic points to other disparities such as culturally relevant programming with input from women who would be utilizing their services (CAAN, 2005). Through more financial support, research and theory-driven program development, and a relevant evaluation framework, programs can be made available that will address pertinent issues and foster healthier lives for the Canadian Aboriginal female population living with HIV/AIDS. It is hoped that reviews such as ours can be used by community-based organizations, AIDS service organizations, and Tribal Council health services to apply for community based research grants to help address these gaps in knowledge and programming.

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## Canadian Journal of Aboriginal Community-Based HIV/AIDS Research (CJACBR)

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### *Call for Papers*

The Canadian Aboriginal AIDS Network (CAAN) is calling for papers to be considered for the second issue of the *Canadian Journal of Aboriginal Community-Based HIV/AIDS Research* (CJACBR). The CJACBR is a peer-reviewed journal, published by CAAN, which welcomes contributions from any author. Priority will be given to an author of Aboriginal ancestry/background, should manuscripts of comparable quality be available. First consideration will be given to innovative articles covering areas identified as HIV/AIDS research- which demonstrate the use of Aboriginal Community-Based Research (ACBR) methods or philosophy.

Articles should be submitted related to the following themes:

- **Aboriginal community-based HIV/AIDS research and development:** These are articles using either quantitative/qualitative research methods that are community-based in design and process and prepared in a language and manner appropriate to the audience.
- **Commentary:** These are opinion pieces. They speak to trends in communication or other issues of importance to professional communicators.
- **Dissemination of Results/Findings:** These articles focus on results or recent findings related to Aboriginal Community Based HIV/AIDS Research.
- **Emerging Issues in Aboriginal Community-based HIV/AIDS Research (ACBR):** These articles focus on ground-breaking issues, findings and/or reports grounded in ACBR.
- **International work that includes an Aboriginal Canadian component:** Articles written for or by an international audience about Indigenous peoples, HIV/AIDS and/or related issues. Articles must include a Canadian component.
- **Ownership, Control, Access, and Possession:** Articles that focus on or enhance the use of the Ownership, Control, Access and Possession principle.
- **Professional/Personal Development:** These articles are based upon the author(s) particular expertise on a subject that will benefit service design/delivery and/or the career development of Aboriginal peoples involved in the HIV/AIDS movement.
- **Review:** These are critiques of new books, journal articles or anything else that would be appropriate for the audience of the CJACBR.
- **Stories:** These are personal accounts of experiences related to HIV/AIDS. Service providers can also submit an account of very successful and innovative approaches to address HIV/AIDS in Aboriginal communities.
- **Student work:** Students at the MA or PhD levels can submit articles (term papers, thesis, etc) that focus on HIV/AIDS in Aboriginal communities.

**Submission Deadline:** Friday, October 30, 2009. Please submit manuscripts via email to the Canadian Journal of Aboriginal Community-Based HIV/AIDS Research at [cjacbr@caan.ca](mailto:cjacbr@caan.ca). All submissions are peer-reviewed (blind).

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