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

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## **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.

## REFERENCES

- Archibald, Linda. (2007). *Canadian Aboriginal AIDS Network 2006-2007 integrated evaluation report: Focus on communities*. [Unpublished]. Ottawa: CAAN.
- Archibald, Linda. (2006). *Canadian Aboriginal AIDS Network: 2005-2006 integrated evaluation report*. [Unpublished]. Ottawa: CAAN.
- Archibald, Linda. (2005). *Canadian Aboriginal AIDS Network's programs and activities: An integrated evaluation 2004-2005*. [Unpublished]. Ottawa: CAAN.
- Bartlett, J. G., Iwasaki, Y., Gottlieb, B., Hall, D., Mannell, R. (2007). Framework for Aboriginal-guided decolonizing research involving Métis and First Nations persons with diabetes. *Social Science & Medicine*, 65, 2371–2382.
- Campbell, C., Nair, Y., & Maimane, S. (2007). Building contexts that support effective community responses to HIV/AIDS: A South African case study. *American Journal of Community Psychology*, 39, 347-363.
- Canadian Aboriginal AIDS Network (2004a). *Final report: The community based HIV/AIDS research environmental scan*. Ottawa: Author.
- Canadian Aboriginal AIDS Network. (2004b). *Summer training awards: Final report 2003-2004*. Ottawa: Author.
- Canadian Aboriginal AIDS Network. (2002a). *Principles of Research Collaboration*. Ottawa: Author. (retrievable from <http://www.link-up-connexion.ca>).
- Canadian Aboriginal AIDS Network. (2002b). *Summer training awards: The applicants and the evaluation, final report*. [Unpublished]. Ottawa: Author.
- Canadian Aboriginal AIDS Network. (2001). *Summer training awards: Final program evaluation*. [Unpublished]. Ottawa: Author.
- Canadian Institutes of Health Research. (2007). *CIHR guidelines for health research involving Aboriginal people*. Ottawa: Author.
- Canadian Public Health Association. (2005). *Leading together: Canada takes action on HIV/AIDS (2005 – 2010)*. Ottawa: Author.
- Cooke, J. (2005). A Framework to Evaluate Research Capacity Building in Health Care. *BMC Family Practice*, 6(44). Retrieved October 10, 2006 from <http://www.biomedcentral.com/1471-2296/6/44>.
- Downie, R. with Crow Chief, R. (2003). *Aboriginal community-based research capacity-building program on HIV/AIDS: Interim Evaluation*. Ottawa: Health Canada.
- Durie, M. (2004). Understanding health and illness: Research at the interface between science and Indigenous knowledge. *International Journal of Epidemiology*, 33, 1138-1143.
- Leung, M.W., Yen, I.H., & Minkler, M. (2004). Community-based participatory research: a promising approach for increasing epidemiology's relevance in the 21st century. *International Journal of Epidemiology*, 33, 499-506.

- Martin-Hill, D., Darnay, A., & Lamouche, J. (2008). Jidwá:doáh “Let’s Become Again”. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, 5(2), i–viii.
- Masching, R. (2006). *Researching ourselves to life: Strategic research priorities, the CBR process & knowledge translation*. [Internal document]. Ottawa: CAAN.
- Masching, R., Ticknor, J., Archibald, L., & Jackson, R. (2006, November 27). *Capacity building as a component of Aboriginal community-based HIV/AIDS research*. Oral presentation at the 2006 Ontario HIV Treatment Network Conference. Toronto, Ontario.
- Minkler, M., & Jernigan, V. (2008). Forward. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, 5(2), i–viii.
- Minkler, M., Thompson, M., Bell, J., & Rose, K. (2001). Contributions of Community Involvement to Organizational-Level Empowerment: The Federal Healthy Start Experience. *Health Education & Behavior*, 28(6), 783-807.
- Ontario Prevention Clearinghouse. (2002). *Capacity building for health promotion: More than bricks and mortar. [Tip Sheet]*. Toronto, Ontario: Author.
- Public Health Agency of Canada. (2007). *HIV/AIDS Epi Updates, November 2007*. Ottawa: Surveillance and Risk Assessment Division, Centre for Infectious Disease Prevention and Control.
- Public Health Agency of Canada. (2004). *Federal initiative to address HIV/AIDS in Canada: Strengthening federal action in the Canadian response to HIV/AIDS*. Ottawa: Government of Canada.
- Public Health Agency of Canada. (n.d.). *Canadian strategy on HIV/AIDS: Moving forward together*. Retrieved June 2, 2008 from [http://www.phac-aspc.gc.ca/aids-sida/fi-if/monitoring/can\\_strat\\_e.html#top](http://www.phac-aspc.gc.ca/aids-sida/fi-if/monitoring/can_strat_e.html#top).
- Reading, J. (2006). Guest editorial: The quest to improve Aboriginal health. *Canadian Medical Association Journal*, 174(9), 1233.
- Ried, K., Farmer, E., & Weston, K. (2006). Setting Direction for Capacity-Building in Primary Health Care: A Survey of a Research Network. *BMC Family Practice*, 7(8). Retrieved October 11, 2006 from <http://www.biomedcentral.com/1471-2296/7/8>.
- Saegert, A., Phillip Thompson, J., & Warren, M. (2001). *Social capital in poor communities*. New York: Russell Sage Foundation.
- Steenbeek, A. (2004). A holistic approach in preventing sexually transmitted infections among First Nations and Inuit adolescents in Canada. *Journal of Holistic Nursing*, 22(3), 254-266.
- Stephens, C., Porter, J., Nettleton, C., and Willis, R. (2006). Disappearing, displaced, and undervalued: a call to action for Indigenous health worldwide. *The Lancet*, 367, 2019-2028.
- Stoecker, R. (n.d.). *Welcome to the e-Folio of Randy Stoecker*. Retrieved May 21, 2008 from <http://comm-org.wisc.edu/stoeckerfolio/stoeckerefolio.htm>.
- Tostle, J. (1992). Research Capacity-Building and International Health: Definitions, Evaluations and Strategies for Success. *Social Science and Medicine*, 35(11), 1321-1324.
- Yuzicapi-Fayant, A. (2001). *Aboriginal capacity-building program for Aboriginal community-based research: Report of the working group on capacity-building for CBR, A partnership initiative between the Canadian Aboriginal AIDS Network Inc. and Health Canada*. Ottawa: Canadian Aboriginal AIDS Network.



## 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.