Building research partnerships to strengthen sexual health of Aboriginal youth in Canada

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The article describes the process of building research partnerships between university researchers, community-based organizations, and Aboriginal communities to improve sexual health of Aboriginal youth in an urban Canadian centre. Sexual health of Indigenous youth is a high-priority research topic globally; however, sexual health of Aboriginal youth in Canada has seen little attention. The authors worked with a guiding Elder and eleven Aboriginal community-based organizations over a five-year period to define our research questions and to collect and analyze data that would be relevant for Aboriginal communities. Community Action Research describes our method; five principles for developing effective community research partnerships provide the framework for our discussion (Dalton, Elias & Wandersman, 2001). Several key lessons for partnership-building are highlighted including a developmental period devoted exclusively to collaboratively generating a research project; "power to name" in the hands of the community; and inclusion of Elders in the research process. We suggest that topics of study and research methods may differ, but reliance on the principles of partnership-building is fundamental to establishing and sustaining the collective action component of effective community-based research.

The purpose of this article is to describe the process of building research partnerships between university researchers, community-based organizations, and Aboriginal[1] communities. We united in our desire to strengthen sexual health among Aboriginal youth in our Canadian urban centre. The authors first came together as a team when the Executive Director of Planned Parenthood Regina (McWatters) approached university researchers to conduct a program evaluation of her agency. One aspect of this evaluation was a survey of Grade 10/12 high school students in our city (Hampton, Smith, Jeffery & McWatters, 2001). Following completion of our program evaluation, we presented findings based on analysis of youth surveys to various community groups, including school boards and health authorities; however, these groups were not interested in acting on some of our disturbing findings regarding the sexual health of youth in our city. We analyzed these data by ethnicity and discovered that Aboriginal youth in our community experience more sexual health risk factors than non-Aboriginal youth (Smith, Hampton, Jeffery & McWatters, 2001). For example, significantly more *Métis* (see Bourassa, McKay-McNabb & Hampton, 2004) students than other students reported being physically forced to have intercourse. We presented these findings to Aboriginal community-based agencies who were eager to learn what they could do to better meet the health needs of their youth. The authors embarked on a research journey to develop partnerships with community-based organizations and create knowledge that would assist them to meet their needs.

The Topic: Sexual Health of Aboriginal Youth

Sexual health of Indigenous youth is a high-priority research topic globally (Aguilera & Plasencia, 2005; Eng & Butler, 1997; Foley, et al., 2005). However, sexual health of Aboriginal youth in Canada has seen little attention. We include here an overview of research findings that suggest Aboriginal youth in Canada deserve improved sexual health care services. Researchers suggest that unplanned pregnancies are problematic for Aboriginal

youth and young adults (Anderson, 2002; Wadhera & Millar, 1997). The AIDS epidemic is leveling off in the general population, but rapidly increasing in Aboriginal populations (Marsden, Clement & Schneider, 2000; Vernon, 2001). As many as 20% of people infected with HIV/AIDS in Canada are Aboriginal; newly-infected Aboriginal individuals are considerably younger than non-Aboriginal individuals (Canadian Aboriginal AIDS Network). Aboriginal women, Aboriginal youth and two-spirited people are at increased risk due to high-risk sexual behavior and alcohol and drug use (Goldstone, et. al, 2000; LeDuigou, 2000; McKay-McNabb, 2006; Ship & Norton, 2000). Healthy pregnancies and births are identified as a high priority in the Royal Commission on Aboriginal Peoples consultation since, for example in Saskatchewan, the most common reason for hospitalization among Aboriginal Peoples is complications of pregnancy, childbirth and the puerperium (Regina Health District, 2000; RCAP, 1998). Cervical cancer is preventable when sexually active women receive regular PAPs and follow-up treatment, yet recent statistics show that mortality from cervical cancer is up to twice as high in North American Aboriginal women as non-Aboriginal women (Lanier & Kelly, 1999). These findings supplement information from the few studies that have included statistics on Aboriginal youth, and suggest that this group is in need of improved sexual health services (Anderson, 2002; Bertolli, McNaughton, Campsmith, Lee, et al., 2004; Foley, Duran, Morris, Lucero, Jiang, et al., 2005).

Sexual health of Aboriginal youth is also important because this is a growing population in Canada and a group that has culturally unique health care needs. Demographic profiles of Canadian population growth indicate that the Aboriginal population has been increasing at about twice the rate of the general Canadian population (Frideres, 1998; Tkach, 2003). The Aboriginal population also comprises a young population of childbearing age, with one-third younger than 15 and over half younger than 25 (Statistics Canada, 2001; 2002). These demographic trends combined with the long-term positive impact of early intervention suggest that sexual health care needs of Aboriginal youth should be a priority service delivery issue (Rew, 1997; Rotheram-Borus & Koopman, 1991; Rotheram-Borus & Futterman, 2000). Some researchers are attempting to understand the influence of "culture" when delivering appropriate sexual health care (Amaro & Raj, 2000; Amaro, Raj, & Reed, 2001; Jemmott & Jemmott, 2000; Reid, 2000; Rew, 2001). Examples of sexual health services for Aboriginal youth that draw on cultural strengths are rare (Foley, et al., 2005). Effective programs that are targeted at Aboriginal or Native youth have been shown to incorporate historical teachings, interventions that aid healing from intergenerational trauma, and offer traditional cultural activities to counteract the negative effect of colonization (Aguilera & Plascenia, 2005).

The impact of colonialism on Aboriginal Peoples is important to acknowledge in health care services and in health research (Tuhiwihai Smith, 1999). The health disparities between Aboriginal and non-Aboriginal Peoples in Canada can be directly traced back to colonization; access to culturally appropriate health care continues to disadvantage First Nations today (Foley, et al., 2005; Young, 1994; 1998). Examples of colonial policies such as residential schools not only interrupted and denigrated transmission of traditional Aboriginal knowledge, but also created a legacy of sexual and spiritual abuse which has had a negative impact on the generation of youth today (Aboriginal Healing Foundation; Anderson, 2000; Hanson & Hampton, 2000). We focused our research efforts on the sexual health care needs of Aboriginal youth as a high priority topic, but also as a response to the initial interest expressed by Aboriginal community-based agencies.

The Method: Community Action Research

Our overall research method is best described as Community Action Research, which includes and privileges voices of Aboriginal youth, community workers, and Elders (Senge & Scharmer, 2001). The Community Action Research method differs from traditional action research in that it "rests on a basic pattern of interdependency, the continuing cycle of linking research, capacity-building and practice: the ongoing creation of new theory, tools, & practical know-how" (Senge & Scharmer, 2001, p. 248).

This methodology focuses on fostering relationships and collaboration among diverse organizations and individuals, creating settings for collective reflection, and leveraging programs collectively to sustain transformative change. We worked with a guiding Elder and eleven community-based organizations that serve Aboriginal youth over a five-year period to define our initial research questions, and to collect and analyze data that would be relevant for Aboriginal communities. Community capacity-building has been generically defined as a community group's ability to define, analyze and act on health (or any other) concerns of importance to their members (Hawe, Noort, King & Jordens, 1997; Smith, Bagh-Littlejohns, & Thompson, 2001). Key elements of capacity building are: promoting problem-solving capability of organizations and communities; taking an asset rather than deficit-driven perspective; and nurturing collaborative community relationships (Hawe, et al., 1997; Kretzman & McKnight, 1993). Our continued research goal is to develop theory and interventions that link individuals with the community and build capacity of both to enhance sexual health of Aboriginal youth and young adults. The capacity-building framework may be particularly well suited for Aboriginal communities who are creating culturally distinct health care systems that are based on an Indigenous Knowledge paradigm rather than International Science paradigm (Grenier, 1998).

The Process: Community Research Partnership Building

We describe here our process of building partnerships and use as a framework the five principles of community research partnerships described by Dalton, Elias & Wandersman (2001). They suggest that research topics and methodologies differ, but principles that guide effective partnership building between academics and communities have remained consistent over decades of research in the field of community psychology (Heller, Price, Reinharz, Riger & Wandersman, 1984; Kelly, 1986; Price & Cherniss, 1977).

Principle 1: Community Research is Stimulated by Community Needs.

We had heard from members of Aboriginal community-based agencies that many of the youth they serve would not have been represented in the Grade 10/12 survey we conducted in high schools since their youth would not have been in school for three consecutive days or been likely to have returned parental consent forms. We wanted to include those agencies who expressed initial interest in our research partnership, but we also wanted to include others we had not yet heard from. In order to create a comprehensive research network, we engaged in a "developmental" phase that would help us identify existing assets in our community -- those agencies that were delivering effective services to this group of "invisible" Aboriginal youth. We conducted an assets inventory that identified community-based service agencies that are “providers of choice” for “invisible”/ marginalized Aboriginal youth with a goal of starting with what works rather than deficits in the community (Hampton, Jeffery & McWatters, 2001). The method for conducting an assets inventory is described by Kretzman & McKnight (1993) and generates a mapping of associations (Institute for Public Policy Research, 1997). The assets interviews were conducted by the second author (McKay-McNabb), an Aboriginal scholar who has extensive community ties and had established credibility and respect in our community. Based on her personal experience, she knew the devastating impact that colonialism has had on the sexual health of her People and she cared deeply about the topic. The authors identified eleven community-based agencies who we designated as "providers-of-choice" for marginalized Aboriginal youth and who expressed interested in a research collaboration. The community-based research partners identified in this developmental stage were not necessarily the agencies who are publicly recognized with awards or media attention. However, we learned, through talking with youth, community members, and service providers that they work effectively with Aboriginal youth who are "invisible -- that is, youth who are not historically represented in medical and psychological literature (Anderson, 2000; Kingsley & Mark, 2000; McKay, 2000). These are the ones the

youth trust. We also looked for agencies and service providers who exhibited an attitude of sharing, synergy and collaboration during the assets interview rather than a sense of competition for scarce resources.

We invited representatives from these eleven agencies to participate in our research project; the goal of this developmental phase was to design a research project that would have relevance for their work. About half of the community agencies/service providers who became our research partners are Aboriginal; most of those who attended our gatherings were directors of the agencies who brought with them a youth service worker or youth client. Regular community meetings offered opportunities to accomplish the goals articulated in community action research (Senge & Scharmer, 2001). We asked an Aboriginal Elder to join our team to guide us in the research process and to open and close every meeting with prayer. Appropriate protocol was followed each time we asked for Elder assistance. The authors facilitated the meetings and took "process notes" that were immediately shared with the group as a research project took shape. As we moved toward defining our research questions, several versions of the questions were edited and discussed in the meetings until we arrived at a consensus. For choice of research method, the large research team (approximately 30 people at each meeting) decided that "numbers are helpful", so we agreed to adapt our Grade 10/12 youth survey for culturally appropriateness and add items that were relevant for the community. A task force consisting of Aboriginal and non-Aboriginal academic and community representatives was appointed for this task. This team met regularly over the next year to adapt our survey instrument for cultural appropriateness and relevance. Some of the most productive discussions we had during these meetings were defining "Aboriginal" for our objective survey as well as defining such terms as "two-spirited" and deconstructing the colonial legacy of these terms that have defined Aboriginal membership. We designed a survey instrument that consisted of 64 items and 6 standardized scales (Shercliffe, Hampton, McKay-McNabb & Jeffer, in press). The research team wished to combine these objective data with focus group data collected with Aboriginal youth, Elders, and service providers to generate a model which would guide effective service delivery for this group.

While developing the research questions, a key moment occurred during two team meetings: this was "naming" the project. By consensus (and partly by democratic vote), the entire group had a voice in naming our project "Strengthening and Building Sexual Health of Aboriginal Youth and Young Adults." Discussions around "naming" emerged as an important aspect of the capacity-building, empowerment, and owning the research by the community (Tuhiwai Smith, 1999). One of our research assistants (McNabb) designed a beautiful logo depicting an Aboriginal individual and eagle within a braid of sweet grass that conveys inspiration and cultural relevance for our project. This logo ties together all of our work.

Principle 2: Community Research is an Exchange of Resources.

All research partners attended regular team meetings, collaborated in approving the re-design of our sexual health youth survey for culture appropriateness, facilitated recruitment of youth participants, and assisted with data analysis. The collective experience of each individual was essential. Academics combined knowledge of research design with service providers' direct experience with youth and Elders' knowledge of history and protocol. Youth partners were particularly helpful giving feedback on appropriate youth terminology for questionnaires. The meetings were lively affairs, held with a lunch, that offered research partners an opportunity to reflect on the issues with others who are doing similar work, to share resources and information, and generally benefit from a synergy that continued during our collaboration (Senge & Scharmer, 2001). Data collection at the site where our research partners work as well as collaborative analysis and interpretation of data are key aspects of our research strategy.

Data collection would have been impossible without the full participation of members of the research team. The participants

we wanted to include are hard-to-reach and marginalized youth. Service providers described our participants as those youth who are "invisible". To them this meant that, although society saw them as problematic, the larger community does not see the beauty and potential in this group of youth and therefore chooses to "not see" their needs. Review of the literature suggested that this was indeed an important group to include in our knowledge of sexual health of youth. In a review of recent trends in sexual health research, Wellings and Cleland (2001) stated that "socially stigmatized groups" are missing from existing sexual health databases making general population surveys inappropriate and misleading. McKay (2000) describes the importance of sexual health research with hard-to-reach, vulnerable populations in Canada such as street youth. These recommendations are similar to consensus in our community meetings (Hampton, et al., 2001) that "invisible" Aboriginal youth should be the focus of study.

The term "invisible" is used informally in Aboriginal communities to describe those youth and young adults who live on the margins of mainstream society; therefore, their needs are not "seen" and they do not receive the benefits given by dominant society to mainstream youth. For purposes of our research, "invisible" Aboriginal youth are operationally-defined as youth and young adults who: are not attending public or private schools; are homeless or live on the street (Dematteo, et al., 1999; Rew, 2001; Walters, 1999); are in foster care or group homes (Noel, et al., 2001); are in correctional centres; are sex trade workers (Kingsley & Mark, 2001); are lesbian, gay, bisexual or transgendered (Travers & Paoletti, 1999); are segregated in ways that leave them unconnected to any services; are in alternative educational programs; or use needle exchange programs due to drug addiction (Lawless, et al., 1996). These parameters helped us articulate our sampling strategy to look for youth who are at high risk and typically underserved. Two Aboriginal research assistants visited research partner sites where our partners recruited appropriate youth participants for our study. These youth would not have volunteered for such a study if it were not for the trust that the service providers (our research partners) had earned from them.

Principle 3: Community Research is a Tool for Social Action.

One specific example of social action resulting from our research partnerships is the focus group with Elders that led to a dialogue between Elders and youth (Hampton, McKay-McNabb, Farrell Racette & Byrd, in press). Our guiding elder (who has developed relationships of care with other Elders in our community) verbally invited the network of Elders in our area who are active in healing work to a focus group. We used the definition of "Elder" provided by Steckley (2001): those individuals who have significant wisdom in areas of traditional Aboriginal knowledge; are recognized as having that wisdom by their community and Nation; and have the capacity to transmit this knowledge to others. Their communities, Aboriginal organizations, and their nations have recognized all seven Elders who participated in our research as meeting these criteria. Our research team reserved space for the focus group at a local Aboriginal gathering place and generated a hard copy invitation to these Elders. The guiding Elder for our research delivered these invitations to each individual Elder and asked them to participate if they were interested. It was through the respect given our guiding Elder and the trust that exists between this community of Elders that our research team was able to be a part of this gathering of Elders. The Elders asked for a second focus group with youth, which we facilitated. During this dialogue, youth came to understand the power of these Elders and asked their schools to invite them to be part of the school community. These schools now have Elders-in-residence to guide students.

Principle 4: Evaluation of Social Action is an Ethical Imperative.

Throughout our research process, we attempted to open the "ethical space" described by Ermine, Sinclair, & Jeffery (2004). We attempted to create environments in our gatherings that demonstrate respect and commitment that moves people to share their hearts. The continued presence over five years

of our research partners at meetings and during data collection and analysis, suggests to us that we made progress in this regard. We also learned things along the way that caused us to re-evaluate our strategies, our definitions, and our actions. For example, we learned from the youth that they do not see themselves as "invisible" and do not like that term. As researchers we learned from the stories told by youth in focus groups and have adjusted the term from "invisible" youth to "community" youth. We also gave feedback to our funding agency that their funding initiatives may have to change from "Increasing Access to Appropriate Services for Marginalized Groups" to something more active. We learned that we cannot open our doors and wait until these youth find their way to us. We need to go to the youth, where they are, when they are accessible. Many of our research partners are using this strategy through street van services in the middle of the night; we validated the effectiveness of this approach through our findings. Another on-going learning presented itself to three of the authors who are non-Aboriginal researchers. The listening and learning demanded of us was considerable, yet enjoyable (Bishop, Vicary, Andrews & Pearson, 2006; Gerrett-Magee, 2006). We most likely fell short many times and thank our Aboriginal partners for their tolerance and respect.

Principle 5: Community Research Yields Products Useful to the Community.

Following completion of the developmental, partnership-building phase, we received funding to conduct our study and generated usable findings for our partners. Results of our survey generated a profile of the health care needs of Aboriginal youth in our city; our research partners have used these findings to validate their current services, to improve services, and to apply for funding for targetted programs. They asked that statistics be presented in "user-friendly" fact sheets. We created nineteen colorful Fact Sheets (including a "How to Use These Fact Sheets" fact sheet), bound and distributed booklets to our partners, and downloaded them onto our Community Psychology Research Team website (http://uregina.ca/hamptoma/).

We met our objective to gain a better understanding of sexual health knowledge, behaviors, health service utilization, and service needs of 201 "invisible" (Community) Aboriginal youth who are not adequately represented in existing databases (Amaro, et al., 2001; Jemmott & Jemmott, 2000; Rew, 2001). These data were compared with results from a previous sample of 1875 non-Aboriginal and 241 Aboriginal Grade 10 and 12 high school students in Regina. Our findings indicate that Community Aboriginal youth in our urban setting are more at risk for sexual health problems than non-Aboriginal youth or Aboriginal youth who are regularly attending high school. Behavioral risk factors include early sexual debut with older partners as well as multiple lifetime sexual partners. Community Aboriginal youth are more likely to use no method of contraception at first intercourse and are less knowledgeable about effectiveness of various methods of contraception. We found that this group is also at increased risk for long-term health problems (i.e., no PAP or STI testing). Environmental risk factors for Aboriginal youth include higher levels of sexual violence than non-Aboriginal youth, lower awareness of health services, reliance on community-based service providers for access to health care, as well as multi-dimensional barriers to accessing health care such as poverty, racism, and dysfunctional families due to residential school legacy. We generated a model of culturally competent sexual health care for this group that is guiding service delivery by our partners.

Lessons Learned

We conclude that a developmental period devoted exclusively to partnership-building that follows the principles of effective community research partnerships described over decades of community psychology is essential for research that results in transformative community action. The process described here occurred over an 18-month period -- from beginning our assets inventory, holding team meetings where we defined our research questions, naming the project, adapting the survey instrument, to receipt of funding. Our submission to the national funding body resulted in a successful

application that was ranked number one in its competition; the research project generated products that are useful to the community. Our conclusions are that this developmental, partnership-building process is fundamental to laying the groundwork for successful community-based research. We have developed a program of research that has resulted in several iterations of funding from the Canadian Institutes of Health Research. Our research partnerships continue to result in innovative research projects. Many of our community partners are aware that Aboriginal peoples have been "researched to death" and often deny access to researchers who will use them for their own personal advancement. However, this experience demystified research for many of our partners who have gone on to secure research funding for their agencies and conduct research that is under their control. We have successfully used our method of developing partnerships and defining research questions for other research projects (Baydala, Placsko, Hampton, Bourassa & McKay-McNabb, 2006).

One important process finding that we wish to highlight is the "power to name". Indigenous Peoples across the world have been labeled as a method of control; most have been restricted to use of land on reservations after being labeled. It is imperative that Indigenous Peoples have the power to control all aspects of the research process, particularly when it comes to generating categories of response (i.e., who is "Aboriginal"; where did the term "two-spirited" come from; what is the title of this project). This imperative has been institutionalized in many ethical guidelines across our country in the form of OCAP principles: ownership, control, access, and possession (Schnarch, 2004). Another unique lesson is the importance of including Elders throughout. Elders teach a world-view based on the knowledge that all things are governed by natural law and are related in a sacred manner. This teaching comprises "wisdom," which is the realm of Elders. Traditionally, Elders maintain Tribal memories of the stories and social structures that ensured the "good life" of the community, through the spirit (Cajete, 1994). Elders' roles are to share their wisdom, to offer a spiritual dialogue that informs proper behavior (Stiegelbauer, 1996). In other words, they can guide researchers and community members to a place of respect.

There are also areas for improvement in our research process. One area in which we failed was developing a youth advisory group. While we conducted focus groups with youth and included youth representation at our team meetings, our formal attempts to create an advisory group of Community Aboriginal youth did not get off the ground. We have also been criticized for bounding our research to one Canadian urban centre and questioned about the generalizability of our findings. Our response is that our research findings corroborate results found in international research suggesting Indigenous youth are at higher risk of sexual health problems than non-Indigenous youth. But we have added an "action" component through our method that ensures improved service delivery informed by evidence. The research partners are members of the community who are utilizing results of this research in sustainable, health-promoting ways. The literature indicates that local community and cultural norms about sexual health practices differ, so a solid understanding of these norms in one geographical area must be collected prior to planning any intervention (McKay, 2000). This may be particularly important when working with the diversity that exists among First Nations, Metis, and Inuit Peoples. Saskatchewan has the second highest proportion of Aboriginal people in Canada at 13.52%, so interventions occurring in our province will make a difference (Tkach, 2003) Saskatchewan's median age for population reporting North American Indian identity is the youngest in Canada suggesting that youth in our province are in need of immediate attention (Statistics Canada, 2001). The slogan, "think globally, act locally" makes sense to us. We believe that the content of our findings may not be generalizable, but the process is. The five principle for building effective community research partnerships continue to hold up (Dalton, Elias & Wandersman, 2001).

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Notes

[1] Aboriginal is defined in the Constitution of Canada and refers to all Peoples of Indian, Inuit and Metis heritage, including non-status Indians. Other terms such as "Indigenous" or "Native" are also used to refer to First Peoples or Original Residents of a Land.

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