7 Restorative research partnerships in Indigenous communities

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Nothing about us without us

Canada’s first peoples hold children’s well-being to be key to their social and economic development. The research thrust in Canada in turn is to understand what Indigenous people want for their children and how they can achieve these goals within the broader context of cultural revitalization and capacity building (Mussell et al. 2004). However, Indigenous scholars and political leaders in Canada, as in many countries, insist that relationships between researchers (be they Indigenous or not) and Indigenous people must be part of a wider process of decolonization and restorative social justice (Government of Canada 1996). Researchers engaging with Indigenous children are being challenged to rethink the ethics that guide their research, and to establish partnerships with Indigenous groups in order to negotiate the values, conceptual frameworks, methodologies, ownership issues and approaches to disseminating results (Interagency Advisory Panel of Research Ethics 2003). Nothing about us without us expresses the principle of participation around which considerations of ethics in research involving Indigenous people in Canada now pivot.

Indeed, the ethics of research involving Indigenous people is one of the most hotly debated issues in research in Canada. Although the number of Indigenous researchers is growing, most research about Indigenous people continues to be done by non-Indigenous researchers, some of whom may be poorly informed about the socio-historical conditions that nearly devastated Indigenous people in Canada (and the government policies that continue to oppress). Researchers may be ill-prepared to negotiate research agreements with Indigenous people, to follow cultural protocols and to respond knowledgeably to participants’ concerns.

Fortunately, more researchers are becoming aware of the special issues around research with Indigenous people, and their children.

Increasingly, Indigenous communities and organizations are articulating informal or formal written ethical codes of conduct. This is part of a groundswell of activity led primarily by Indigenous scholars to advance
new ethics in Indigenous research (Piquemal 2000; Castellano 2004). For example, the National Aboriginal Health Organization, representing First Nations, Metis and Inuit people in Canada, is promoting four criteria for Indigenous research. These are ownership, control, access, and possession at the level of the participating community (Schnarch 2004). The British Columbia Aboriginal Capacity and Research Development Environment programmes, established in many provinces in Canada, has proposed four Rs: respect, relevance, reciprocity and responsibility in research with Aboriginal peoples (BC ACADE 2004). At the University of Victoria (2004), the graduate programme on Indigenous governance deals with the evolving discourse on Indigenous research ethics and the three guiding principles for research: protection, participation and partnership. These principles raise ethical concerns, such as how to protect confidentiality when data are retained by a community. They also raise practical concerns, for example, the time needed to build relationships and negotiate community-level agreements, and the uncertainty about whether the researcher can count on being able to disseminate results after a project is completed.

One of the three large federal agencies to fund Canadian research, the Social Sciences and Humanities Research Council of Canada, facilitated an intensive online discussion throughout 2003 on Indigenous research ethics (Interagency Advisory Panel on Research Ethics 2003). This forum created an opportunity for Indigenous and non-Indigenous scholars and community leaders such as university-based research ethics board members to come (virtually) to one table to discuss various approaches and to formulate new understandings (Long and LaFrance forthcoming). There was a commitment to supporting self-determination on the part of Indigenous people. The fact that no unified statement or consensus on a specific set of guidelines has yet emerged can be seen as positive, given the current need to stimulate broad local, national and international debate and to bring more Indigenous groups and perspectives into the discussion.

This chapter offers some key learning points derived from ongoing discussions among scholars, as well as a decade of experience in research and training partnerships with Indigenous communities in Canada. The key ethical principle unifying all of the points is inclusion, an integral part of a post-colonial, restorative social justice agenda.

- **Learning point.** Non-Indigenous researchers need to acknowledge being members of the dominant culture and being researchers who are in positions of power. The potential to oppress and exploit Indigenous people is a matter of concern, and deliberate efforts should be made to level the playing field in negotiating research relationships.

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### Never again

#### Historical conditions of contemporary ethics

Indigenous people have withstood the near destruction of their populations, social structures and cultures. The most catastrophic impacts have occurred through direct physical assaults on Indigenous populations and their ways of life (e.g. germ warfare, raids on Indigenous settlements resulting in the death, capture and confinement of native children and adults, exposure to infectious diseases, and overhunting by traders resulting in widespread starvation). Further depletion of the Indigenous population, their capacity and their resources was effected by the imposition of a land reservation system, which created a system of apartheid and restricted movement of Indigenous people on and off reserves. Their participation in the labour force, education, social programmes, politics and Canadian society as a whole was thereby limited.

For the Indigenous population who survived, a final solution was sought through a government-sponsored programme to apprehend and forcibly confine native children in Indian residential schools (Assembly of First Nations 1994). By 1930, these institutions housed approximately 75 per cent of all First Nations children between 7 and 15 years of age. They were intended to Christianize and ‘civilize’ the Indigenous population by breaking the bonds between children and their parents, instilling shame about their cultural heritage, and indoctrinating children into Anglo-Canadian values, language, religion and ways of life (Barman 1996). During the 1960s and given the failure of residential schools to break the ties between children and their families, Indigenous cultures began to be acknowledged and governments in several provinces devised a new approach to interdicting the transmission of cultural knowledge and identity from parents to children. Commonly referred to as the ‘Sixties Scoop’, social workers in the dominant culture were encouraged to apprehend Indigenous children and arrange for their legal adoption into white families (Fournier and Crey 1997). Today, over 40 per cent of all children in government care in British Columbia are Indigenous. In turn, there is still seen to be widespread suspicion of outsider involvement in Indigenous communities (Cole 2002).

- **Learning point.** Researchers who wish to address issues pertaining to Indigenous children need to become familiar with the socio-political history of relationships between Indigenous and non-Indigenous people. The memory and contemporary sequela of this history continue to influence interactions between Indigenous and non-Indigenous people. Researchers need new forms of inter-
action to reinstate Indigenous self-determination, to restore power to Indigenous people in their dealings with authorities, and to recognize the rights of Indigenous people to make decisions about involvement in research.

- Learning point. Researchers wishing to engage with Indigenous people need to protect the rights of children and their parents or other guardians. Protection goes beyond merely obtaining informed consent. Research procedures should not require isolation of children from their caregivers; they should be fully informed of what will be done with their children and their refusal should be respected.

- Learning point. Researchers need to absorb the idea that relationships of trust are the foundation for ethical research practice, and these relationships require unprecedented amounts of time, self-disclosure and care before discussions about research can proceed.

Partnerships

Research is not only about the generation and application of new knowledge. It is also about politically significant social engagement with Indigenous people, based on trust and inclusion.

Some refer to the present as the beginning of a time of healing for Indigenous people (Long and Fox 1996). Researchers have conventionally tended to distance themselves from ‘that which is to be discovered’. They have positioned themselves as experts and focused attention unilaterally towards the research ‘subjects’. Among Indigenous people in Canada, this unidirectional gaze is no longer tolerated. Rather, researchers who hope to engage with Indigenous people need to be able to account for themselves, for example, by providing details of their ancestry, their family life, their scholarship, and their intentions, not only during initial introductions, but throughout a project.

- Learning point. Self-explanation is a first step in relationship-building in research. In order to establish trust, both parties need to define who they are, the scope and nature of their authority over knowledge sources and methodologies, their research purposes, plans and expectations. Cultural literacy is a prerequisite to establishing a partnership with an Indigenous organization or community. Researchers need to observe cultural protocols when approaching an Indigenous organization or community to explore their interest in a research project. Indigenous scholars and community-based agencies are often able to facilitate connections between prospective researchers and groups of interest.

Regaining and retaining control

In an effort to redress the loss of control over their children, social life, means of sustenance, traditional territories and social participation, Indigenous communities are asserting their rights to self-determination, especially in matters concerning their children, their land resources and their culture (Government of Canada 1996). Increasingly, communities that are receptive to research are prepared to articulate the conditions of their involvement in research (see Graham and McDonald 1998; Aurora Research Institute 2002; Akwesasne Research Advisory Committee 2004; Arctic Institute of North America 2004; Mi’kmaq 2004). Often, they seek a negotiated agreement with the lead researcher, as active partners with significant roles in all phases of the research.

To illustrate, a partner in a number of my community university research and training projects over the past several years has been Lil’wat Nation, a rural community of 1600 Salish-speaking, St’at’imc people on Canada’s west coast. Their senior administrator there, Sheldon Tetreault, has facilitated discussions with Band Councillors who govern this First Nation, leading to research agreements. Tetreault commented (and signed a consent form agreeing to be quoted):

We are working hard in Lil’wat Nation to develop our human resources and to create strong programmes for children, and I think that having the interest from the university in what we’re doing here is very positive. It holds a mirror up for everyone to see what we’re doing, and it amplifies the excitement. We want to retain the staff we have helped to develop and keep qualified people working in our community, and so for them to hear from researchers that other people are interested in what is going on here, and that we are doing things here that can be useful for others to learn from, that’s good ... developing long-term relationships, making sure everyone knows what they are agreeing to, and ensuring benefit to the community itself, and not just beyond the community – there is mutuality and respect that I think is exemplary.

- Learning point. Negotiated agreements to partner in research involve Indigenous representatives in most activities undertaken by researchers, including: adjudicating the purpose and plans for an investigation; the conduct of the research; accountability of all members of an investigative team; the nature and source of data; data ownership, possession, storage and access; and primary decision-making over research outputs.
Researchers are knowledge brokers with power to collect information and produce meanings which can support or undermine values, practices and people, and to construct legitimating arguments for or against ideas, theories, policies and/or practices. To date, Indigenous populations have been studied exhaustively and their faith in realizing positive returns has all but expired. A frequent comment in communities is: ‘Research is a four-letter word around here’.

At a recent conference of the National Aboriginal Health Organization, a First Nations colleague summed up a point made by many participants:

We are tired of researchers coming in and documenting all the things wrong with our communities: youth suicide, child neglect, alcohol abuse, family violence, poor nutrition, embezzlement. You would think people would want to figure out how we survived white people for so many hundreds of years. How we kept our children alive, kept our stories, kept our knowledge about how to live on the land, kept our ceremonies, kept our fires burning with hope for generations yet to come.

**Benefit**

Research should make a positive contribution to Indigenous goals. Involvement in research should clearly and directly benefit not only research participants but also members of their Indigenous community (Rheault 2000). Indirect benefits for the ‘greater good’ are insufficient. In a project on Indigenous fathers, a community member who supported the project for the benefits it could yield for his community asked: ‘Why should we contribute to knowledge in Canada? Why should Canadians know about us? I don’t call myself a Canadian and neither do lots of people in my community. We will do this [research] for us, but not for them.’ After generations of being research subjects while being subjected to racism, many Indigenous people are beyond an altruistic commitment as volunteers in research. One First Nations man introduced himself to me in this way: ‘I’m Alphonse, and I come from a long line of research subjects.’ He went on to explain that Indigenous people feel they have been ‘researched to death, with no benefit to us. Researchers come, they take our stories, take up our time, and leave. We never see any returns from what we gave.’

- **Learning point.** The researcher must be prepared to show specifically how the Indigenous people will benefit substantially within the foreseeable future. Demonstrations of benefit must be conveyed to research participants and possibly to their community as a whole, in terms that are readily understandable and can be directly experienced. A process must be made available for research participants to provide feedback and request changes to research outputs.

Within many funding agencies, Indigenous people serve on review and selection committees and some funding agencies prioritize partnership approaches. For example, the Social Sciences and Humanities Research Council of Canada has a new Community-University Research Alliances programme. The Canadian Institute of Health Institute Research has an Aboriginal Peoples’ Health Institute that supports partnership research involving academic institutions and Indigenous communities in Canada, Australia and New Zealand. At the community level as well, leaders often play a major role in vetting research proposals. In general, Indigenous people are demanding assurances of specific and immediate ways in which they will benefit from proposed research.

There is a clear preference among Indigenous groups for research that focuses on strengths of their children and families. Many communities have made enormous strides in their cultural recovery, social organization, and development of infrastructure to support child and family well-being, including health, social and education services, Elder care and cultural centres.

**What’s ours is still ours, even after we’ve shared it with researchers**

**Intellectual property**

When Europeans arrived in North America, they claimed to ‘discover’ new lands. They soon positioned themselves as sovereign over the land and its original inhabitants, casting Indigenous people as subjects. Research involving Indigenous children and families has involved countless replications of this colonialisit pattern, including claims to discovery and ownership of knowledge which, in fact, has been passed down through generations. Social scientists have also asserted their singular authority to interpret and represent Indigenous children and families. Indigenous people in Canada have joined global efforts by Indigenous peoples to institute laws governing of ownership, possession and control of Indigenous intellectual property (Couture 1998; Smith 2002). The principles of ownership, control, access and possession asserted by the Canadian National Aboriginal Health Organization are one example (Schnarch 2004).
Ownership

Indigenous knowledge has traditionally been handed down orally across generations through clan and community ceremonies such as the potlatch, pow-wow and puberty rites. Colonial prohibition of traditional ceremonies has meant that much Indigenous knowledge has not been transmitted to younger generations (Couture 1996). Thus, the focus of research is heavily on recording and organizing existing, often ancestral, knowledge, more than on the creation of new knowledge. As holders of traditional knowledge, Elders have a right to ownership of that knowledge, as well as to how and by whom it is transmitted. The source of traditional knowledge must be acknowledged, and permission must be obtained from Elders and their representatives regarding what knowledge can be conveyed to others and in what form.

- **Learning point.** Sources of knowledge (Elders, artefacts, oral histories, etc.) must be acknowledged. Researchers should not assume that participants prefer to remain anonymous. Many Indigenous participants in research prefer to be named, and communities and organizations prefer to be named and credited for contributions to the work.

Possession and access

In Canada, as elsewhere, researchers as well as documentarians (e.g., photographers, journal writers, art historians, and museum archivists) have been keenly interested in dissecting and depicting the lives of Indigenous peoples. Indigenous people are now attempting to reclaim ‘artefacts’ needed to restore and revitalize living cultures, from collections in universities, municipal, provincial, national and international galleries and storerooms. Most Indigenous communities today are adamant not only about ownership (i.e. clear understanding about who owns the knowledge or the material objects collected – the data) but also about retaining or regaining possession of knowledge or objects of study (i.e. retaining rights to location for storage and distribution). They are equally adamant about retaining decision-making authority over conditions of access.

- **Learning point.** Extreme caution should be taken regarding removal of objects of study from their place in families and communities. This extends to the taking of photographs, removal of test scores, testimonials, stories, children’s artwork and so on. Consultation with the Indigenous partner(s) should be sought if removal of information or things belonging to the community is needed for research.

Data retention and storage

Concerns about possession and access extend to data storage. A standard item in ethics protocols at many universities is a declared intention to ‘destroy data a specified number of years following the end of the project funding period’. Indigenous community leaders have been distressed at the prospect that valuable information, such as Elders’ testimonials, might be treated as so trivial as to be discarded: Elders would be expending precious time and energy in their final years to transmit their knowledge for the research project. A community may request that interview transcripts are stored in the community, for example in a cultural centre, rather than at the research institution, with the intention that these data would never be destroyed. Further, with interviewees’ permission, they may wish to attach names of all interviewees to interview transcripts. These data may be of value to the community for their own purposes. Also, many Indigenous people are suffering from ‘interview fatigue’. Interviews collected for one project might be useful to provide to a later research project, rather than exhausting people – especially Elders – by asking them to be interviewed yet again. Collection and retention of Indigenous knowledge for continued community use is one way that a research project can ‘give back’ to the community.

Research methods

In building trust, methods that are readily understandable and transparent are likely to gain more support from partners and prospective participants. Research designs should be short-term or, if carried out over a long period, should include tangible outcomes or reports to partners at regular intervals. Community-based research partners and assistants can advise how individuals can decline to participate or to have their children participate. Indigenous people are less likely to decline to participate if the research has been introduced to them first through a series of events. This might entail announcements in a community newsletter, followed by a community dinner to introduce the research team members and the project, flyers, group forums, and a letter of invitation to individuals. Parents need several opportunities to meet the research team members who will interact with their children, ask questions, and discuss among themselves whether to participate and on what terms.

Participatory research methods, such as participatory action research and community action research, are strongly preferred (Jackson 1993; Reitsma-Street and Brown 2002). Several First Nations organizations have interdicted or disrupted research on children involving certain standardized assessment tools. A few studies are underway to explore the value and feasibility of creating developmental monitoring and screening tools specifically for Indigenous children.
Research methods require active collaboration with Indigenous people who understand their own people and are better positioned to advise on strategies that are informed, respectful and protective. They will be more able than visiting ('outside') researchers to respond helpfully if extra support is needed for participants who are distressed as a result of research participation.

**Interpretation**

Another lesson learned by Indigenous people is the risk of being misrepresented in research. Nearly every Indigenous community has stories about anthropologists from colonial universities, and before them Indian agents representing the colonial government, leaving their communities and representing their lives inappropriately. Many of these depictions have been steeped in racism and focused only on the negative, helping to justify government-sponsored interventions (Deloria 1995).

Research needs to document strengths fostered within communities, for example: fluency in the heritage language of the community as well as in English; cultural literacy; spiritual values; attention to and memory for oral teachings and observational learning; performance skills for participation in cultural ceremonies; knowledge of the natural environment; and survival skills.

**Dissemination**

Research outcomes and products must be accepted as indeterminate, with the Indigenous partner making final decisions about what results will be shared within and beyond their community organization, by whom, and in what ways.

- **Learning point.** Reports of results and other products of research to which Indigenous groups have contributed should be presented to them in draft form for editing before any form of distribution and Indigenous partners have the right of veto or censure over research products.

While some might argue that true partnerships do not prejudice the interest of any one partner, it can be argued that, within these collaborative partnerships, the interests of the Indigenous partner organization or community, or of Indigenous peoples as an entity, take precedence over the interests of the researcher and her/his sponsoring organization. An example occurred in one study where findings about the perceptions of Indigenous youth conflicted sharply with findings about the perceptions of Elders in the same community. It was decided to postpone disclosure of the research results until a dialogue within the community could be facilitated by community leaders to explore the intergenerational divergences found. The ethical principle guiding the decision was to seek meaning in the results that would contribute to, rather than disrupt, social cohesion and healing.

- **Learning point.** Researchers must ensure protection of Indigenous participants and communities, including protection from any negative impact that might result from the findings of the project being made public. This may include placing a moratorium on the research for an agreed period of time or keeping data confidential. Co-presenting and co-authoring research reports are widely accepted approaches for disseminating findings. An Indigenous collaborator can discuss the significance and applications of research findings with reference to their intimate personal knowledge of the contexts of culture, community, governance and politics of the subject matter.

**Capacity building**

Capacity building is a top priority for Indigenous people across Canada. Through partnerships, there is much that non-Indigenous people can learn about themselves as well as about Indigenous ways of knowing, living and communicating. Partnership in research can be an opportunity to learn new skills, explore topics of interest, and network with other individuals and organizations. In my own programme of research, when funding is obtained for research with Indigenous children, Indigenous research personnel are hired at the university and in the partnering communities. Their participation in customized training workshops for the project, attendance at conferences, and opportunities to enrol in post-secondary coursework are a budgeted part of the research plan. In this way, the research aims to contribute to the confidence and capacity of Indigenous partners to offer direction and, ultimately, to assume control of aspects of the project.

- **Learning point.** As part of the collaborative process, the researcher should take responsibility for learning and co-developing research skills with members of the partnering community or organization.

An important aspect of ethical research practice is the choice of values, assumptions and concepts that underlie research questions and methods. Indigenous scholars have been vocal about the need for researchers to consult with Indigenous people about whether the research questions hold meaning, whether plans for carrying out data collection follow cultural protocols and resonate with Indigenous ways of knowing, whether the meas-
urement tools are culturally fair and transparent, and what frames of reference will be used to interpret and communicate results.

- **Learning point.** Indigenous values must be acknowledged by incorporation within the research questions, design, methods, and outputs of the project.

Notwithstanding their diversity, Indigenous cultures in Canada have some commonalities. They tend to be collectivist societies which conceive of individuals as sharing spiritually in the lives of others, both living and deceased. Human life is understood to be an interconnected web of living things and as dependent upon and responsible for the physical environment. Children are experienced as gifts of a Creator, and their lives are understood as spiritual. Children’s well-being is seen as embedded in family and community health and wellness across generations. The family, or sometimes the community, is a more culturally fitting unit of analysis than the child alone.

To illustrate, a First Nations Elder explained, in the context of a research study about child-care practices in her community, how concepts that distinguish children according to age, stage or abilities are not meaningful and not wanted in her community:

The idea of early childhood and ideas like disabled children, or that some children have special needs and some children are gifted—these ideas don’t come from us. They are not Aboriginal ideas. They come from white people, and from cities. All children have gifts and are gifts from the Creator. We don’t like to box people up and separate them out. We’ve seen how that can be used as a way of getting rid of people, of boxing them up and shipping them out, out of the community to special schools, or what have you. Until we were forced to send our children away to school, we always kept all our children with us, and all together, in families, and we want that again.

Importing research questions, methods, and interpretative frameworks that are predicated on non-Indigenous agendas must be recognized as an intervention that may run counter to the overarching goal of cultural recovery and rebuilding Indigenous ways of family and community life (Stairs and Bernhard with Aboriginal Colleagues 2002).

**Summary**

This chapter has discussed the ethical principles of respect, inclusion, reciprocity and relevance, contributing towards the realization of a post-colonial research era in Canada. Rather than a unidirectional gaze by non-Indigenous researchers upon native children, a two-way process of mutual learning, sharing and production is considered. It is suggested that negotiated partnership agreements can structure research projects so that Indigenous people are assured of ownership, possession, control and access to data. Partnerships can help to ensure that topics under investigation are priorities for Indigenous people, that they reinforce Indigenous values, are understood using Indigenous frames of reference, and are beneficial to Indigenous people.

**Further reading**

For further discussion of research in Indigenous communities, see Kirkness and Barnhardt (1991), Letendre and Caine (2004) and Wihak (2004).

**Questions for reflection**

1. What steps can we take to ensure ethical conduct by researchers and research participants?
2. In cases where we use research methods that evolve over time as a result of extensive collaborative participation, should we offer a continuous process of consent rather than one-off consent at the start of the project? If so, what steps do we take to do so?
3. Does collaboration mean that everyone on a project should share the same goals, values and preferred modes of conducting the project, and agree with the outcomes?
4. Is there a place in Indigenous social research this has been conceptualized in Euro-western academe?
5. How do we acknowledge diversity within Indigenous communities, so that both individual choice and collective choice to participate are respected?

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