

Ethical Dilemmas in Community-Based Research: Working with Vulnerable Youth in Rural Communities

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Introduction

This paper focuses on the community-based research initiatives we have been involved with, both during our history of collaborating on projects together, and our more recent work within university settings. We will specifically focus our discussion on the impact of shifting social contexts and geographic spaces on the ethics of conducting research with Indigenous communities in BC. During this discussion of research ethics, we are assuming that researchers come from a diversity of backgrounds and may be members of the communities in which they work, bringing about unique ethical considerations. Central to our work has been the use of an intersectional framework, the development and process of working within an intersectional research team, and the decolonization of research through questioning dynamics of power in knowledge production.

This paper discusses the role and meaning of research in various community contexts (rural, with youth, Indigenous, academic, community), and the ways that researchers' accountability shifts and changes according to the contexts in which they are working. Additionally, we will introduce a “guiding principles” tool we have developed and adapted through various projects.

Intersectional Research Teams

The term *intersectional research team* was coined out of our early research work together to describe a project team made up of individuals occupying social locations which reflect a

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diversity of intersecting axes of power and oppression/privilege, as found in the communities in which the research is being conducted. The contextual nature of identity across geography, social and cultural contexts, and time is understood and is integral in the development of a team that is intersectional. We further developed the concept of an intersectional research team in response to concern that research projects were applying intersectional health frameworks to the participants in the research but were not reflecting on the location and position of themselves as academics or professionals conducting research with vulnerable populations. As we have defined it, an intersectional research team is committed to ongoing dialogue and deconstruction of each of our intersecting axis of identity and their influences on the project, which will be described throughout the paper (Clark and Hunt 2007, 2008, 2010; Clark et al. 2009)

Specifically, in our roles as researchers, we have had the privilege and honor of working with girls in rural communities across BC, and have heard their voices, in all their complexities. As researchers, practitioners, and educators, we locate ourselves and our shifting and fluid identities alongside the participants, and in many cases, we have held multiple roles, connecting with the girls as relatives, community members, and mentors.

An intersectional approach implies we not only consider the full complexity of the location of our co-researchers but first begin with who we are and the power, ethics, and diversity of who is involved in the research. This includes locating ourselves, as researchers, in relationship to systems of power and privilege, applying an intersectional lens to ourselves, our roles in the research, and our role in communities. It also involves seeing communities in all their fullness, rather than just along one axis of identity or social location: “social categories such as race, class, gender, sexualities, abilities, citizenship, and Aboriginality among others, operate relationally; these categories do not stand on their own, but rather gain meaning and power by reinforcing and referencing each other” (CRIA 2006). A key step in this process is grounding in your own experience, including investing time as a team to share your experiences/multiple locations, building a team that reflects the complexity of the community/issue you are entering and considering multiple locations from within and outside of various community locations, as all providing richness to the team. It is imperative to avoid essentializing any one member of a research team or expecting them to represent an assigned or static identity. Some of the questions we have developed to facilitate this process include:

- Who am I? (class, race, gender, other axis of socio-economic location) How does this change in the various contexts I move between? Who am I within my work? My research?
- What communities do I belong to? How do I define community? How does the community define me?
- How do I approach work in communities to which I belong—whether through geographic location, social location, gender or racial identity or otherwise?
- To whom am I accountable for my ethical conduct?
- How authentic am I in my relationships with co-researchers? With research participants? With others?
- What is my personal relationship to the issues in this research project? To other areas of work?
- How am I impacted by intersecting systems of domination and privilege?

Grounding in our own Experiences

Sarah:

As an Indigenous woman working in community, government and academic context, I aim to make my skills and social location of use to those members of my community who do have access to modes of knowledge production within mainstream institutions. I have developed this sense of myself in my role with girls in rural communities: as someone who can offer a set of tools, bridge differences, and bring their voices forward to decision-makers. In my work with rural Indigenous girls, I have found myself connecting across many points of difference, which have intersected with points of similarity. Although I may share similar cultural and gender identities with the girls with whom I've worked, I have never assumed that these points would instantly provide a sense of sameness or equality. For me, locating myself in all of my multiplicity has been a central part of loosening the boundaries of identity to see the richness of experience that we all bring to our lives. Having worked with sexually exploited youth, having listened to many stories of extreme violence, trauma and abuse, I believe that it was my compassion and understanding of processes of colonialism that allowed the girls to connect with me, rather than my Indigenous identity. We must look beyond our fixed notions of identity to those of shared spaces where all of our selves meet. These spaces of grief, anger, despair, repair, healing...they are beyond identity, and require a lens of intersectionality in order to comprehend their fullness. As academics, practitioners, and allies to the youth we work with, we must not attempt to fix the lives of girls into boxes, but stand back and witness the richness of their experiences emerge.

An intersectional lens has been important for my own self-awareness, and the shifting nature of my identity. Having grown up as a member of the Kwakwaka'wakw First Nation, away from my Indigenous community, with my Ukrainian-English single mom, I knew the complexities of identity at an early age. As a girl, I moved between rural and urban areas of BC, and knew the isolation of being the only Indigenous person on my street, as well as the joy of being on a rural reserve with my Kwakwaka'wakw relatives. I believe that by focusing on the connections, intersections and interwoven nature of our lived experiences, we are moving beyond identity politics (which forces us into boxes according to race, gender, etc.) to one of building coalitions toward a common goal. While situating ourselves in our lived experiences—with an analysis of the positions of power and oppression that we occupy—is important, it is equally important to strive to make collective change with a framework of decolonization. “The knowledge that we are in symbiotic relationship to all that exists and co-creators of ideologies—attitudes, beliefs, and cultural values—motivates us to act collaboratively” (Anzaldúa 2002). I believe that by exposing intersecting axes of power at work in our experiences and analytical frameworks, we are ultimately contributing to the goal of decolonizing these same power systems.

Natalie

My previous and ongoing work with young women and communities has always called me to answer the question “who are you and why do you care?” I have had to continuously engage in the process of locating myself and of role modeling for young women the multiple locations and identity moments in ones' life. I have shared my

own intersecting identities of oppression and privilege: growing up an Anglo-European Canadian rural girl with strong connections to the Secwepmec community in Chase; growing up with a single parent, living in poverty, in a rural community where we were “other”; growing up fighting sexism; growing up understanding the privilege in my white body while fighting racism as an ally to my friends and lovers. As an adult I learned of my own Aboriginal heritage something that as a child and adolescent I had often questioned my mother and grandmother about. My maternal grandmother denied her own Aboriginal heritage, with her father and her mother both being of mixed Aboriginal descent, and her response to my questions would only speak to the shame of growing up “mixed”. This has shifted my own identity understanding and experience, and through sharing my own experience of this, I often connect with youth and students at the university who are just coming to know and understand their own Métis or First Nations heritage.

The youth and communities that I work with continue to ask me “who are you and why do you care?” and as my answer to this questions shifts over time and space and geography, so too does my relationship with the girls and communities I work with. For example, in my move to the Interior of BC to work at the university, my identity shifted from that of a community-based researcher to a university-based researcher and this implied shifting ethics and power to account for. In addition, as my children include a mixed-race girl, and twin boys who are from the Secwepmec First Nation, I now am living in the community where my research is happening, and at times, have been both insider through family relationships, and outsider through my role at the university, within the same research project. I am aware that how I answer the question “who am I and why do I care?”, keeps me ethically grounded and allows me to build and maintain relationships across time and shifting locations

Decolonizing Knowledge Production

Decolonizing research and the role of academics, particularly in Indigenous communities, includes recognizing the role that research has had in colonialism. As Indigenous writers such as Linda Tuhawi Smith have noted, research ethics and methods call for an understanding that the “pursuit of knowledge is deeply embedded in the multiple layers of imperial and colonial practices” (Smith 1999).

Central to our approach to research is the role that ethics play in decolonizing research and the history of research within Aboriginal communities.

Sarah: As an Aboriginal researcher, I have a desire to ensure I am not reproducing the same power relations embedded in traditional academic research.

Colonial concepts and power relationships are built into research processes. We must ask ourselves what it means to bring Indigenous knowledge in to institutions such as universities, both as Indigenous and non-Indigenous researchers. What does it mean when there is a huge gap between the power of the research participants (ie. rural Aboriginal youth) and the university? This is often done without second thought by non-Indigenous researchers, but Indigenous researchers, and those closely connected to the community on a personal level, have more at stake in doing so. It is important to recognize that research happens within institutions, embedded with hierarchies of privilege and that researchers attached to the university hold power in the research process. Our goal is to expose those

power dynamics, and ethically work with them in mind in order to challenge and shift and undermine them as much as possible.

Some key questions to consider in approaching research with Indigenous communities include:

- Who has initiated this research? Who has defined the research question?
- How has research historically been seen within these communities? Has research had any harmful effects on the community members?
- How have marginalized groups been left out of processes of knowledge creation and mobilization?
- How can Indigenous and non-Indigenous researchers actively decolonize research? (methodology, partnerships, ethics...)
- How can research be a tool for the community?
- What role do ethics play in this decolonization process?

There is a danger in developing the language of decolonizing knowledge production without developing methods and actions to shift power in a meaningful way. Just because researchers say they are interested in shifting power does not mean it is happening. We are continually asking ourselves where the “action” is in action research, and where the “collaboration” is within the academy. Challenge is inherent in community-institution partnerships, and researchers must be willing to be held accountable for each step in the research process, including processes of decision-making, and framing and naming research material.

Insider, Outsider, Border Crosser

Our work conducting research in various vulnerable communities throughout British Columbia have included examples of us entering communities from which we belong and others to which we are outsiders in some ways. In addition, we have each had experiences of being considered an outsider by our role as a researcher, even though we were in a community to which we are a part.

Some of the challenges that we have encountered with traditional Research Ethics Boards (REB) in the communities we work with include: the research participants are your relatives; the participants may be labeled if their participation is discovered so parental consent is a problem (ie. for youth who are truth-telling about abuse or exploitation); confidentiality is problematic because co-researchers may know the participants in other contexts; traditional knowledge from Indigenous communities may have community ownership and may require unique ethical considerations; at university, Indigenous students are part of an Indigenous community, but there is no natural body for signing off on research ethics (no First Nations band council, etc.). Additionally, in rural areas, there are few resources for conducting research and supporting community-based researchers, while research projects change a lot over time making the need for flexibility is imperative.

Within institutional contexts and urban settings, research with a focus on Indigenous issues or participants have different design and ethical considerations than those in rural or on-reserve contexts. Within an academic setting, for example, research projects with Indigenous students must acknowledge that the students are bound up in the power dynamics of the university. If Indigenous students are participating in university-based research projects, how will their confidentiality be maintained so that their standing at the university is not impacted? A focus on research outcomes is essential in this context, as the institution has much to gain from conducting research with Indigenous people (financial gain, in particular) while the students

may gain very little. Participatory and outcome-focused research initiatives have the potential to greatly benefit Indigenous student participants, such as in the case of research projects where programs are being evaluated by the students themselves. In this way, students are given an opportunity to participate in programs, while the research framework is being used as an evaluative tool to impact future programming.

Trevor

I am from the Snuneymuxw Nation. I was a participant in the LE,NONET Project at UVic from 2008 to 2009. The programs that were part of the research project created a safe space for Indigenous students, and being involved helped me on many different levels. The project office was a safe space where I could hang out on campus, connect with the staff and fill up my water bottle. It was also a place that helped me out financially and emotionally. I can remember a period in time where I was experiencing personal issues and a staff member sat and listened to me when I needed it the most. According to her job description she did not have to help me the way she did. In Indigenous communities we wear different hats, and this helps to create relationships rather than staying fixed in our roles as “students”, “researcher”, “faculty” or “staff”. I saw the LE,NONET Project as a multi-layered project that enabled me to feel free to be myself in a Western-dominated space. I also was gifted with excellent opportunities for networking on the UVic campus and, more importantly, in other Indigenous communities. The key here was that the students were able to participate in programs that were being evaluated for best practices and were part of a larger research project. As a student, the programs were a great success because they were the priority and the research participation was optional and was not intrusive.

Shifting the Power: Community Ethics First

Institutional ethics reviews are not necessarily informed by community or Indigenous frameworks. It is sometimes up to us as researchers and project managers to ensure the accountability is there, beyond just the official ethics protocols. How can we respect both the community and institutional ethics processes? What do we do if there is a discrepancy between the two?

The ethics process we are involved in and have conducted in various research projects is a relational ethics which begins with community, and through established community advisories is guided by the community at all stages of the research process. Ethics is not something that we obtain from our funder or university REB and then proceed to the research. Rather, we centralize the power of the community stakeholders by first engaging in a meaningful dialogue about the research ethics at a community level, and then move on to obtaining institutional approval. Through this process, we can better account for community-institutional power dynamics and consider ethical dilemmas that are apparent to community members but may be invisible within the institutional ethics process. Some important steps in this process are shifting decision-making power and defining ethics as a process. In our research with the Justice Institute of BC (JIBC 2002, 2006) we developed an ethics checklist and principles which are developed with participants and stakeholders and which reflect a number of ethics frameworks including human rights, Indigenous OCAP principles and culturally determined ethics. Further, we recognize the intersection of geography with ethics and have established community advisory processes to guide the

ethics process with an understanding of rural community needs, the ethics of research with youth; and working with First Nations band councils.

Intersections: Youth and Girls: “Not my 14 Year Old Daughter”

Particularly sensitive ethical concerns emerge when conducting research with youth. Some of the questions that have emerged through our research in rural communities have centred around issues of protection versus exclusion. Paternalistic stances by research ethics boards often exclude youth from being involved in research without parental consent, without an understanding that this consent in and of itself could put the youth at risk. For example, for research that includes lesbian, gay, bisexual, transgender, two-spirit and questioning (LGBTQT) youth, the question of parental consent must be sensitive to the reality that many youth are not yet out to their family and communities. While LGBTQT youth have the right to participate in research which may inform recommendations about policies or programs affecting their health and wellness, they must be able to do so without jeopardizing their family relationships or personal safety, particularly within small city and rural contexts. In addressing issues of consent we have advocated within our research applications and to the research ethics boards the imperative of including youth in research. However, the Tri-Council guidelines are silent on the competence of youth as research participants—we see this as a complex and dynamic dimension of the ethics field.

The liberatory nature of community-based social action research has challenged the nature, roles and boundaries of researcher and subject, who drive the research agenda. Essentially, it attempts to address the intersecting power differences in research projects (Denzin and Lincoln 2000; Lincoln and Guba 2000; Wallerstein and Duran 2003). Additionally, community based social action researchers have enhanced the responsibility of this research to bring the voice of marginalized persons to the centre. This project has the distinct opportunity to engage youth ethically and centre their voice as paramount to revealing what their needs are.

As we have stated, one of the outstanding barriers to youth participation in research is the issue of parental consent. This requirement is a barrier to many youth who have parental/guardian relationships that are strained, non existent or abusive and exploitive. These are some of the very youth we most need to hear from and whose voices are further marginalized by a requirement that acts oppressively. The over confidence that chronological age determines competence is a major concern stemming from one of the fundamental principles of research: respect for people’s autonomy (Leadbeater et al. 2006). A number of Canadian universities have been at the forefront of change in this area, including the University of Waterloo, University of Toronto, University of Victoria and University of Saskatchewan. They have all made specific recommendations in regards to addressing the age of consent. They are suggesting that the autonomy to make the informed decision to participate in research should be based on the youth’s cognitive capacity to participate and not on chronological age (Leadbeater et al. 2006).

Additionally, if we draw upon the social service, health and legal systems that engage with youth for some insight we discover young people under the age of 16 are in positions of making significant sole decisions about their health and well being. For example, at the age of 12 youth are allowed to voice in court their preference for parental guardianship. At the age of 13 youth are allowed to consent to their own medical treatment including medical services such as an abortion, addiction treatment or

commit to counselling (http://www.cba.org/BC/public_media/rights/238.aspx). Often in these circumstances the practitioner deems consent given by a youth at the age of 13, if they are assessed as competent in the understanding of what they are consenting to and are also assessed at being developmentally 13 years of age. Ultimately, the ethical engagement of young people in research and organizations requires that we review our practices, standards, and ways of conducting research (Alderman et al. 2006).

Natalie Clark

In one of the first ethics review processes I engaged in at my university, the ethics application took 17 weeks for approval, but I refused to compromise on the importance of including youth under the age of 16 without parental consent. I spoke to an ally on the research ethics board who indicated that one member of the board had said “not my 14 year old daughter” when considering approval for youth to consent to research without parental consent. This was when I researched the many contexts and spaces that her daughter and others were already moving in and freely consenting to without parental knowledge, in addition to the precedence set by other universities that had already considered this question.

Key questions to consider include:

- Which risks might youth face in getting consent from a parent?
- Are the research team members trained in responding to trauma (if this is something that may emerge, depending on the research topic)?
- What action outcomes are being envisioned for the youth participants in this project?
- Do any youth representatives sit on the research project advisory?

Relational Ethics

Relationships are central to any type of community work, including research. Conducting research as an “outsider” or an “unknown” is much more difficult than as a trusted friend or adult ally. How, then, do we build relationships without creating problems of being in a position of trust or authority with participants?

What we must focus our attention on is the quality of relations with the people we seek to represent in our texts: are they viewed as mere fodder for professionally self-serving statements about a generalized Other, or are they accepted as subjects with voices, views and dilemmas—people to whom we are bonded through ties of reciprocity and who may even be critical of our professional enterprise? (Narayan 1997)

Youth and other community members continually keep us accountable, asking “Who are you and why do you care?” Researchers who are connected to the community are therefore accountable to the community for the ethics, practice and outcomes/action of the research. The findings are more than data, but are stories and actions in relationship with people and communities. Research courses at university do not address these issues. They generally do not teach students how to conduct research in their own communities, or communities in which they have multiple roles, beyond that of “academic”. For example, most courses assume that researchers working in Indigenous communities are coming in as “outsiders”. Ethics take different meaning when you are a member of the community with which you are working.

Georgia: I have been the keynote youth speaker at several conferences, like the youth health conferences, presenting the research I was part of as a youth researcher. All I have done as helped me become who I am. I am a confident woman, who strives to be the best I could be. I have done my Basic Infantry Qualifications to become a trained soldier. I sat on the AYIAA (Aboriginal Youth in Action Alliance) and the Centre for Community-Based Youth Health Research, youth advisory. All of these activities have benefitted my high school by keeping me active and staying out of trouble in my teen years. They also pushed me to have goals and dreams. I desire to expand my community and to open young minds to go to school and inspiring other youth to search for knowledge kindles my own quest to understand the world and people around me.... I

Tools and Process–Intersectionality in Action

Through our research projects in community we have developed a number of tools to assist in applying intersectional frameworks in research with vulnerable communities. These tools are attached in the appendix as examples of frameworks that can guide your work. The ethics checklist was developed together with a community advisory for a previous research project, and is intended to be adapted to reflected the complexity of the community/issue with which you are engaging. In addition, we recommend that you utilize and build on existing research principles developed by stakeholder groups. For example, in one research project with street-involved youth, the youth-serving organization had their own ethics processes that all research projects went through before approval. As well, some stakeholder groups, such as Indigenous communities, may have developed guidelines for outside researchers to use (ie. First Nations bands or Indigenous organizations).

Questions for Reflection

Some of the questions to consider in research across various social and geographic spaces include the following:

- How do the ethical procedures at your university take in to account Indigenous community protocols?
- How do they account for diverse community needs and processes?
- How do youth factor in to ethics processes at your university or within your own research projects?
- How can ethics processes within university institutions change in recognition of the power imbalances, particularly when conducting research with traditionally marginalized groups?
- Can you think of a time when you were challenged to consider the complexity of your own interlocking, intersectional identity as a researcher? (how did you see yourself, how were you seen?)
- How do researchers negotiate the complex power relations stemming from institutional authority which does not account for intersectional identities of belonging?
- What are some of the daily practices that inform and guide community based research utilizing this framework?

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