

INSTITUTIONAL ETHNOGRAPHY AS AN  
INSTRUMENT OF CHANGE:  
MAKING AN EMANCIPATORY METHOD OF INQUIRY VISIBLE

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## Abstract

Institutional ethnography's (IE) method of inquiry, itself, can be an emancipatory instrument of change. I make visible a new way of conducting IE, using the research process to advance knowledge utilization. More specifically, I illustrate how relational and accessible knowledge translation (KT) approaches facilitate transformative experiences for research stakeholders and researchers alike. My dissertation contributes a new and innovative direction to the growing fields of IE, KT, and decolonizing research.

My doctoral research used IE to examine how institutional supports and services were socially organized around children and youth diagnosed with a fetal alcohol spectrum disorder (FASD) diagnosis in two distinct communities: one rural Indigenous community and one urban, predominantly non-Indigenous, community. This community-based research was conducted in close partnership with community stakeholders and resulted in a number of KT initiatives based on research findings and recommendations. Instead of discussing research findings that critique communities or institutions that were—at the time of writing this dissertation—working to improve access to FASD-informed policies and programs, my dissertation makes visible the *process* and *value* of disseminating research findings to the community.

My dissertation is dedicated to advancing the use of IE as an emancipatory, decolonizing and community-based method of inquiry. I further argue that excellence in community-based applied health research is found in the relational *how* of research more so than *what* the research reveals. My dissertation is comprised of four manuscripts that reveal and discuss how I adapted IE to suit the needs of an Indigenous

community, struggled and dealt with unforeseen challenges, used visual graphics to facilitate research processes that are frequently text-based, and used IE to make discrepancies visible around an FASD diagnosis for children and youth in an urban community. Overall, this dissertation represents the thinking and learning produced from using IE as a method of inquiry in innovative and exciting ways, advancing the sociology of health research by making visible how IE can be used as a means to an emancipatory end.

## Acknowledgements

Not everyone I thank in this acknowledgement section will necessarily read my dissertation and I am okay with that. I am also haunted by the fact that this acknowledgement is inalterable by the time people read this and it may be missing someone important to the completion of my PhD. I hope you, the reader, are not someone I regretfully missed.

I *almost* feel guilty for having such a stellar PhD committee comprised of Drs. Fern Brunger, Diana Gustafson, and Blythe Shepard. Their solid mentorship, unwavering support, frank feedback, critical thinking, shared celebrations, and practical encouragement are traits that I hope to offer others down the road. Fern Brunger has the rare gift of delivering candid and critical feedback with assurances that I have what it takes to succeed. For this I am very grateful and inspired to go against my Japanese and Mennonite upbringing and be more frank. Fern was far more than I ever hoped for in a PhD supervisor. Diana instilled confidence in my ability to articulate myself in speech and in writing and generously shared many “lessons learned” anecdotes, pieces of advice, and home cooked soups-to-die-for. Blythe offered thoughtful and insightful reflections in areas that extended well beyond an area of expertise that attracted me to her in the first place.

My son has a t-shirt that reads “I avoid clichés like the plague.” While I want to avoid clichés, I do not know how else to say that my PhD was a team effort on the home front. Scott was an endlessly supportive spouse and insisted on “thesis staycations” that kept my mental health and writing deadlines intact. He also carried the heavier parenting load during the 4  $\frac{2}{3}$  years it took me to complete my PhD. I want



to thank my two oldest children for countless hours of looking after each other and their younger sibling while I was putting in long hours on the computer, traveling, or at meetings. All three children helped me feel grounded and frequently put my studies into perspective. I thank my family from the bottom of my heart for helping make my PhD be a labour of love instead of a labour of guilt. I want to dedicate this dissertation to my youngest child.

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I recall one of several conversations with Gloria Montano, my officemate while completing my M.Ed., where she told me that I needed to seriously consider doing a PhD. She told me it was one of her biggest regrets and she could see it being one of mine. One day Dr. Elizabeth Yeoman, my Masters co-supervisor at the time, visited our office and I followed her out of the office to awkwardly ask if she thought I had ‘what it took’ to do a PhD. She looked at me casually and said “Of course.” I doubt that she remembers this conversation but it was the moment I started imagining a future of completing a PhD and possibly working in academia. It was two years after that conversation that I applied to the PhD program at Memorial University.

In talking to other graduate students, I have come to appreciate many gems and unsung heroes in the Faculty of Medicine and parts of Memorial University. I would be remiss to not tell you how helpful and generous they are. I would like to make special mention of Dr. Shree Mulay, Associate Dean of Community Health and Humanities, for her constant and genuine interest in my progress; Shannon Steeves for her diligence and painful experiences of processing financial paperwork for my research; Darlene Tobin for filling in whenever I needed administrative help; Amy Carroll for maintaining a positive, patient, and compassionate perspective in the midst of chronic financial angst of many; Vicki Gill for being so responsive and thorough in responses to my various funding inquiries; Lori Fleming and Dion Fowlow for their ongoing interest in my studies and general life whenever I frequented the library (which was often); and Scott Howse-the-medicine-mac-IT-guy who I can imagine is mentioned in numerous thesis acknowledgements without his knowledge.

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### **List of Abbreviations**

CBR	community-based research
CBPR	community-based participatory research
FASD	fetal alcohol spectrum disorder
IE	institutional ethnography
KT	knowledge translation
NL	Newfoundland and Labrador
OCAP	ownership, control, access, and possession

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## Chapter 1

### Introduction

What makes research matter? The motives and purpose behind any research study can greatly vary and range from curious exploration to solving real-world problems. I chose to pursue an applied health and community-based research (CBR) study with clear intentions to make the research pragmatic—an agent of social change—while completing a doctoral degree in the process. It is my position that excellence in community-based applied health research is found in the relational *how* of research more so than *what* the research reveals. I used institutional ethnography (IE) both as a method of inquiry and as an emancipatory instrument of change. I argue that *how* researchers conduct their research—beyond methodology and technical analysis skills—will determine whether research findings are emancipatory, relevant, and/or valued by the community itself. I illustrate how relational and accessible knowledge translation (KT) approaches facilitate transformative experiences for research stakeholders and researchers alike.

My dissertation makes visible a new way of conducting IE, using the research process to advance knowledge utilization. This dissertation contains four stand alone manuscripts that collectively tell a story—a story that advances the field of IE, KT, and decolonizing research. The four manuscripts discuss how I used IE to uncover disjunctures between institutional supports and the needs of children diagnosed with fetal alcohol spectrum disorder (FASD) (*Chapter 5: Revealing disjunctures*); conducted decolonizing research using IE (*Chapter 2: A decolonizing method of inquiry*); navigated unforeseen challenges and dilemmas of doing doctoral research in an Indigenous community (*Chapter 3: Reframing challenges as opportunities for transformation*); and

developed and used visual graphics to make the research process and information accessible (*Chapter 4: More than words*).

Originally, the focus of this dissertation was to write about the experience of using IE as a community-based study solely as a subtext to my primary discussion, which was to be on the social organization of supports and services for children living with FASD in two very different communities in Newfoundland and Labrador (NL). However, this emphasis shifted radically.

While I was writing draft manuscripts, I was still in the midst of working closely with community and research stakeholders (including health directors, community leaders, FASD committee members, parents of children living with FASD, as well as policy and decision makers) to disseminate and discuss the implications of my research findings. Findings and recommendations were being shared in the form of reports, community presentations, and strategic meetings at the local, regional, and provincial levels (examples of these community dissemination documents are provided in Appendices D-G). Community members were engaged with research findings and several recommendations gained traction immediately after they were shared. The research results were more important to the community than they were for academia. After considerable reflection and conversations with my doctoral committee, I decided to focus on making the *process* of doing my research visible.

The shift from focusing on the organization of supports for children with FASD to how IE was used as an emancipatory method of inquiry was driven by my excitement to advance the sociology of health research. I assert that the most valuable contributions



from my doctoral research to the academic community are found in *how* I conducted IE, using the research process itself as an instrument of change.

I do, however, want readers to understand how I came to be interested in the topic of FASD, how I decided to conduct my research in particular communities, and how IE distinguishes itself from other methodologies. In the following sections, I share my personal connection to FASD, describe how my study came to be, and provide an orientation on the epistemology and ontology of IE, my chosen method of inquiry.

## **1.1 My Journey**

### **1.1.1 My connection to FASD.**

The following description is intended to provide readers with an understanding of what kind of work was involved for me, as parent to a child who was born with cascading health problems as well as social and medical interventions—work requiring institutional accountability. It is my own experience of raising a young child and pursuing an FASD diagnostic assessment that has, in part, led me to do my research in the area of FASD and from the standpoint of caregivers. While I did not include data on myself in this study, my experiences undoubtedly shaped my interview questions and social interactions with other caregivers who knew that I, too, was a parent to a child with an FASD diagnosis. My experiences also helped me to identify a research problematic.

Scott and I took the training required to become foster parents when we already had two young children of our own. The foster parent training was intended to be a mutual interview, with prospective foster parents learning about what is expected of them and child welfare social workers discerning if the prospective parents are suitable for the

children that frequently need families to help raise them. As part of this process, we were interviewed about what we felt we could take on and what we could not, among many other topics. I distinctly recall indicating that we did *not* feel equipped, at that time, to take on a child with extensive special needs. Immediately after the training was completed, we received a call from a social worker. He asked if we would meet a baby that was going to be discharged from the hospital in the next month. The first visit to meet this baby in the hospital was clearly expressed by the social worker as a “non-committal” visit.

We went. Prior to the call from the social worker, this baby had no consistent people caring for her. She was born at twenty-seven weeks, weighing a little over two pounds, and was not expected to live for any length of time. Hana (a pseudonym) had survived a major heart surgery when she was three months old, before we met her. The first five months of her life had been split between an intensive care unit and a medical ward. Nurses in the medical ward routinely set up a baby swing behind the nursing station counter and brought her into the staff room for meetings. We were asked by the social worker to visit Hana a few times a week, if possible. We discovered on the first night that our two young children were not allowed on the ward—there was a policy that prohibited non-admitted children on the medical ward. This meant that Scott and I needed to take turns visiting Hana in the evenings. One of us would go in each night, except on weekends, when one of us would visit her during the day.

We were unaware that nursing staff were growing concerned until we were called into a special meeting with the head nurse and the cardiologist (since Hana’s biggest underlying health issue was a cardiac one). It became clear during this meeting that we

were not meeting their expectations as future parents to Hana. Expectations included coming in more often, for longer periods of time, bringing in clothes for Hana, and washing them. No one had explained any of these expectations to us. When we had begun visiting her, she already had a full closet of clothes and a laundry hamper in her room. The only instructions we had received were suggestions from the social worker that we visit her as often as possible and that our two other children were not allowed on the ward. By the end of the special meeting, the medical staff learned why we were not visiting Hana more often and we took responsibility for Hana's clothing and laundry.

After a brief hospital orientation on administering medication, food, and oxygen, Hana was discharged into our care two weeks later, at approximately 6 months of age. We were approved for 40 hours of respite care a week because Hana required 24-hour care and we were not prepared to quit work to take on the level of care Hana needed. At the time of discharge, she had a liquid feeding schedule that involved mixing a formula and putting a specific amount into a bag connected to a pumping machine (which required batteries or electricity) that dispensed this liquid, at a programmed rate, through a nasogastric feeding tube. A single feeding took approximately 20 minutes. Hana was also attached to an oxygen machine or tank that released oxygen through nasal prongs taped onto her face. And, to monitor the level of oxygen, she was connected to a "sat monitor"—a machine that records oxygen saturation levels in the blood.

We quickly learned how to change the tape on her face, clean the oxygen prongs, and rotate the sat monitor sensor by taping it to a different toe each day. Relative to our lives before bringing Hana home, going places and scheduling appointments suddenly became much more complicated and time-consuming. My least favourite task was

replacing the nasogastric tube that required changing at least once a week. This process entailed wrapping Hana very tightly in a blanket (so she could not move her arms), using landmarks to measure the distance from her nose to her stomach, and marking the spot on the nasogastric tube that would tell us how far to push the tube down to reach her stomach. I would push the end of the tube to the back of her nose and she would start to cry. When she would inhale between screams, I would quickly push the rest of the tube down until the marked spot on the tube was in line with the tip of her nose. Occasionally, the tube would not go into her stomach but instead come out of her mouth—in those instances, I had to start again. Once the tube was in place, I would tape it to one side of her face and hope it would be a while before Scott or I had to do this again.

Fast forward two years. Hana was enrolled in the university campus daycare, off oxygen, and walking with the aid of a toddler walker. She had recovered from an eye surgery that resulted in no noticeable change in her eye alignment; had adjusted to her new gastro tube (a direct line to the stomach, that replaced her nasogastric feeding tube); and only needed medication in the early morning and before bed. Various members of a pediatric rehabilitation team monitored her progress on a weekly basis.

By the time Hana was in daycare, I was working on a number of different CBR projects. These projects included addressing urgent issues around release-planning for women leaving prison, emergency foster care placements of children under 12, and secure housing for several communities across NL. In each of these projects, the issue of FASD came up as a pressing concern. Not long after Hana had started daycare, and while I was immersed in contract research work, I attended an all-day provincial forum on FASD that included a wide range of people—from parents to policy makers and from community to

federal government representatives. At this forum, there were presentations from diverse perspectives, including a panel of FASD experts, youth and young adults living with FASD, a birth mother of a child with FASD, and government representatives from education, child welfare, justice, and health, among others. It was also at this forum that I met a pediatric geneticist that did diagnostic assessments for FASD and I obtained his contact information.

We had learned, when she was under a year old, that Hana was prenatally alcohol exposed but did not concern ourselves with this information at that time. We attributed many of her delays and challenges to a premature birth, medical interventions that limited physical movement, and attachment issues from not having consistent caregivers for the first six months of life. Remembering that Hana was prenatally exposed to alcohol, and having recently attended the forum on FASD, I started to read information on FASD online to see if there was a chance Hana was living with FASD. Many of the descriptions fit. I recall feeling surprised at first, then concerned with the long-term outcomes for people living with FASD, and eventually I relaxed because strategies that I was reading about were things we were already doing. We decided to contact the pediatric geneticist about an FASD assessment. Hana was seen by him and diagnosed with FASD by age three.

### **1.1.2 The start of identifying a problematic.**

In institutional ethnography (IE), the term *problematic* refers to an identifiable tension or contradiction that emerges from the standpoint of a person or group of people

when lived experiences are invisibly coordinated or regulated by institutions (Bisaillon, 2012a; Smith, 1993).

Once I understood that Hana was living with FASD, I realized that we were dealing with a diagnosis that is poorly understood. I was also experiencing new ways of interacting with strangers in public places who felt compelled to befriend Hana as she noisily shuffled along in her walker, wearing her ankle supports, wearing thick glasses, and saying “hi” to everyone who looked in her direction. She was visibly a child who required “more work” than my other two children and that attracted conversations about how “adorable and outgoing” she was. We decided to tell the daycare staff about her FASD diagnosis and suggested strategies we thought might be effective. The staff at that daycare already worked from a strengths-based practice model that enabled Hana to thrive, so incorporating new strategies was not unduly onerous for them.

It was not until Scott and I discussed Hana’s challenges and missed developmental milestones with various allied health professionals in the rehabilitation centre that we could see that sharing Hana’s diagnosis was inconsequential. By inconsequential, I mean that the centre’s rehabilitation programs, strategies, and tests for Hana followed standardized courses of treatment and assessment. The results of these standardized tests were consistently inconsistent. Programs that targeted certain skill sets seemed to show great success one week and not the next. The inconsistent and unpredictable results from treatments were mind-boggling to several allied health professionals. And even though I could see that some strategies being used were ineffective with Hana, I did not feel comfortable or knowledgeable enough to meaningfully engage in a conversation with these allied health professionals in the rehabilitation centre about other modes of

improving her cognitive and motor functions. While I was not intimately familiar with the assessment tools and treatment programs being used, I observed that Hana's ability to focus and comprehend instructions were sometimes misinterpreted as incompetence. I was concerned that suggesting ways to change their practices might jeopardizing my good relationship with the allied health professionals or, worse, might be misconstrued as me thinking that I knew more than they did in a specialized field of training. At that time, I was not able to find literature or materials that addressed how to treat children with FASD in physiotherapy, occupational therapy, or speech-language pathology. I remember thinking to myself, if *I* do not have the confidence to address the lack of FASD-informed practices, who would? My spouse and I are trained and experienced as a social worker and a teacher, respectively. Both of us are comfortable advocating for both our children and ourselves. Relative to the general population of parents, I think we would be among the first to address any perceived injustices but, at this stage in her life, we did not. Rather than challenge certain standardized programs and testing, we chose to be compliant parents by taking her to appointments and practicing exercises between appointments. This compliance was due to (a) our lack of "evidence based" material that might suggest alternative approaches to treatment; and (b) feeling privileged to have so much access to allied health professionals in a system that is a 2-3 year wait for some children.

When Hana was enrolled in school to start kindergarten, we decided to disclose her FASD diagnosis as a way to frame the kinds of strengths-based strategies and supports we wanted to put in place. We have since realized that disclosing her diagnosis is a double-edged sword. It gives us the platform to advocate for certain kinds of supports but it has

also lowered the expectations some educators have of her. We assumed that disclosing her FASD diagnosis—as an identified exceptionality by the provincial department of education—to the school, she would receive available supports and services in the classroom. In reality, while the diagnosis has the ability to activate supports and services, it is my experience that it is the work that we do, as parents, that informs what and how supports and services are negotiated.

### **1.1.3 How my research took shape.**

The impetus for doing research on FASD came from my experiences of raising a child with FASD and my pre-PhD CBR work. I was convinced that research in FASD could have something to offer people working in child welfare, corrections, education, and social services across NL. An initial scan of literature on the effects of FASD revealed that the overwhelming majority of literature is deficit-based. In other words, research is very much focused on the challenges, problems, and dysfunctions associated with people living with FASD and populations where it is suspected that there is a higher prevalence of FASD, such as children in care and repeat offenders in the criminal justice system (Boland, Chudley, & Grant, 2002; Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004; FASD Justice Committee, 2010; Fast & Conry, 2009). My research contributes to filling a gap in research in that is strengths-based, relevant to policy development, and practical to caregivers and institutions alike.

Retrospectively, the multi-stakeholder provincial forum in 2008—where I had met the pediatric geneticist—was a pivotal moment in my decision to pursue my doctoral studies. About one year following that forum, I inquired about any initiatives,



developments, or groups that may have formed as a result of the forum. When I understood that nothing formal had been put in place, I began to consider how I could do research that would move FASD-related work forward in NL. It was around this time that I decided to apply to a doctoral program at Memorial University.

After the forum and before I applied to my doctoral program, I created a simple and brief online survey to all forum attendees and those who were invited but did not attend the forum. This survey solicited information on what people felt were areas of research priority, potential research partners, and levels of interest in developing a research project. I also completed an environmental scan of FASD-related committees, programs, services, and staff across NL.

I created a list of contacts that included (a) individuals who chaired FASD committees in NL; (b) front line workers that worked closely with people who have FASD; (c) specialists involved with FASD screening and diagnoses; (d) current FASD researchers with recent publications; and (e) Memorial University faculty members who offered expertise relevant to my proposed research (e.g., gender, social justice, education, Aboriginal health issues and ethics, addictions, and mental health). After this preliminary fact-finding was complete, I applied to the doctoral program in the Division of Community Health and Humanities in the Faculty of Medicine.

#### **1.1.4 Aims of the study.**

The three research questions for my doctoral study were:

- 1) What are the pathways of communication and support between families with youth aged 9 to 14 diagnosed with FASD and the key systems with which they interact (e.g.,

health, education, corrections, child welfare, and social services)? How are these pathways organized?

- 2) How do health, corrections, child welfare, social services, and education institutions apply intervention, training, and policies to individuals and families with an FASD diagnosis?
- 3) How do institutional policies, procedures, and programs coordinate individuals and families who live with an FASD diagnosis?

My motivation, research study questions, and research methods were all rooted in the study's emancipatory possibilities. The aims of my doctoral study were to (a) document how communication between caregivers, community, and professionals is organized; (b) identify the range of interventions, supports, and services used and available to children with FASD and their caregivers; and (c) explicate how people interpret FASD diagnoses, information, and behaviours.

As part of my own interests and commitment to knowledge translation/sharing, I also had goals to (a) provide relevant and accessible research findings as the basis for recommendations to families, communities, and governments; (b) advocate for effective, collaborative, and organized systems of support for people living with FASD in NL; (c) build capacity and mobilize knowledge within and between institutional systems that are frequently in contact with people affected by FASD; and (d) advance theory, policies, and practices in the field of FASD.

## **1.2 About Institutional Ethnography (IE)**

### **1.2.1 My attraction to IE.**

I was attracted to IE for its theoretical foundations. For example, IE is based on the ideas that peoples' lives are shaped by access to resources and material conditions (e.g., health services, education, safe drinking water). People using IE subscribe to the idea that society is organized by access to knowledge and power; that is, certain kinds of institutional knowledge privilege some individuals and exclude others. A key tenet of IE is that institutions and organizational systems play an important role in the coordination of information, resource allocation, access to services, and everyday “doings” of people they aim to serve (Campbell & Gregor, 2008; Smith, 1999, 2005).

I was drawn to how IE could uncover and “make visible” the social relations that shape and influence the everyday lives of a certain group of people (Smith, 1990). IE has been well accepted and used to make important evidence-based policy and practice changes in the organization of health care, education, social work, employment and job training, international development, environmental policy, and community life. IE incorporates individuals, organizations/institutions, and relevant texts—including policies, procedures, manuals, and memos—as part of the analysis (Campbell & Manicom, 1995; Griffiths, 2005; Mykhalovskiy, et al., 2008; Mykhalovsky & McCoy, 2002; Sinding, 2010). IE does not aim to test or generate theory, but rather to produce evidence-based research that “maps” both human and textual/policy/institutional relations—in other words, to trace the relationships and kinds of communication that is facilitated between people, texts, and relevant institutions. Practically and materially speaking, I was drawn to a method of inquiry that was invested in multiple forms of data

collection, including interviews, environmental and cultural observations, and any relevant forms of text.

At the time of this study, there was no interdisciplinary diagnostic team in NL and very few supports available for individuals and families living with FASD; families and support systems do the best they can with the knowledge they have. In the absence of prevalence data to advocate for FASD-related resources, IE has the potential to be used in a way that provides comprehensive evidence that can be used to identify specific and clear recommendations for communities, service providers, and policy makers. Research conducted within the IE framework necessarily begins with individuals who are in relatively subordinate positions—in this case, families with an FASD-diagnosed youth—and then traces their relations with organizations, agencies, and institutions to identify and understand best practices and gaps in knowledge.

This research maps both human and policy relations between youth with FASD diagnoses, their families, their community, and relevant institutional systems (e.g., health, education, child welfare, corrections). This map provides the blueprint needed to help identify gaps and best practices, as well as prevent secondary disabilities<sup>1</sup>.

### **1.2.2 An IE ontology and epistemology.**

Crotty (1998) writes, “ontology is concerned with what is, with the nature of existence, with the structure of reality as such” and “epistemology is a way of understanding how we know what we know” (p. 3). I have invested considerable energy

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<sup>1</sup> Secondary disabilities refer to challenges that adults with FASD live (but not born) with, due to adverse childhood events and circumstances.

trying to understand what sets IE apart from other qualitative and applied research methodologies. I recall moments of confusion, more reading, and further reflections when I was told at various points throughout my doctoral studies:

- IE is not a methodology! It is a method of inquiry.
- IE is not limited to being qualitative research.
- IE is only new to sociology (suggesting IE is *not* novel); it's what many critical anthropologists do.
- IE is the antithesis of theory.
- IE does not produce theories but is informed by other theorists.
- The uniqueness of IE is in its attention to institutions.

There seems to be a layered understanding as to what is true to IE and what is not. I attempt here to summarize what I have come to understand about the ontology that informs how IE is defined. Smith (2005) has developed particular terms and “ways of seeing” the world around us. Examples of terms that are unique to IE are *ruling relations*, *trans-local* or *extra-local*, and *problematic* (see first manuscript entitled *A decolonizing method of inquiry*). These IE ways of seeing are rooted in an ontology of the social (Smith, 2005) that resists and rejects the idea that one can hypothesize or theorize before or after they conduct IE research. Smith (2005) writes:

The design of an ontology as a theory of the being of the social is intended to provide a guide to the aspects or dimensions of actual ongoing social processes, in time and in place, that institutional ethnography's project of inquiry can appropriate. It does make the claim, as an ontology, to provide a conceptual

framework for selective attention to actualities such that the project of inquiry can proceed as discovery of and learning from actualities. (p. 52)

Unlike mainstream sociology, IE takes a particular interest in peoples' *actualities* over any conceptual ideas that might explain what is happening. There is a commitment to discovering what people actually do and how their doings are connected to other discoverable practices, circumstances, and processes. Furthermore, the researcher/ethnographer is only able to explore and discover within the very world that is being researched. Ontologically, IE comes from an understanding that peoples' lives—their material conditions and particular experiences—can be traced to numerous constellations of social relations, including the organized concerting of people by institutions. In other words, being able to understand how things happen the way they do requires first exploring peoples' actual activities, and also understanding that these activities are socially organized by forces that are largely unknown to the people whose experiences are of interest. The focus is on *how*, not hypothesizing or theorizing *why*.

While Smith (2005) suggests that she is “not concerned with epistemological issues” (p. 52), she argues that IE studies must be particularly attentive to texts that coordinate or organize peoples' work. Texts that are *activated* by a reader can be powerful in their ability to transcend time and place. The word “activated” is used to highlight that texts are only relevant when they are used or referenced by people; in other words, texts cannot *do* anything on their own. Early IE studies were epistemologically informed by scholars who took an interest in people who were subject to ruling relations, experiencing some form(s) of oppression, and occupying spaces in social margins. In

most cases, scholars identified or worked closely with the people whose standpoint of oppression was the point of initial investigation. For example, Griffith and Smith (2005) studied the social organization of mothering children in the public school system; Diamond (1992) explored the social organization of nursing home care from the standpoint of nursing assistants; Pence (1997) evidenced the social organization of legal interventions for women in shelters who had experienced domestic violence. When IE was still considered a relatively new method of sociological inquiry, there were also scholars who used IE as political activists, allies, or simply as fellow citizens who saw the emancipatory relevance of an inquiry. Some of these pioneers include G. W. Smith (1990) on the social organization of policing the gay (male) community in Toronto and Devault (1991) on the work of women within their home.

In literature about IE, several authors talk about making an epistemological “shift.” By epistemological shift, I refer to the way IE can radically shift our understanding of how things are organized. An epistemological shift in the health field, for example, would be from focusing on an individual’s conditions to understanding how their lived experiences are coordinated through largely invisible trans-local processes. Deveau (2008) specifically writes about making the epistemological shift during her doctoral studies. She illustrates how peoples’ local experiences are located—much like maps that have an arrow that marks “You Are Here”—in a network of organized pathways connected to that very location (Campbell & Gregor, 2004). An IE project starts by identifying where someone’s experiential knowing (the local experience) is in contradiction with ideological knowledge (the taken-for-granted assumptions of what is happening). This contradiction is called a *disjuncture*, a fault line, or an epistemological

rupture, which then gets framed into an IE study's problematic (D. E. Smith, 1990; G. W. Smith, 1990).

Like Bisaillon (2012b), I saw analytic value in familiarizing myself with other methodologies before settling on IE. I wanted to ensure that I chose a methodology (or "method of inquiry") that had a compatible ontology and epistemology, was practical and feasible for a four-year doctoral program, and offered emancipatory possibilities embedded in or as part of the research dissemination at the end of the project.

Admittedly, there was a time between when I was certain that I wanted to use IE for my doctoral research and when I needed to make the commitment (as part of my ethics proposal) when I panicked. I remembered participating in the IE Working Group<sup>2</sup> (an online group of international scholars that meets monthly to discuss diverse topics on IE) and asking whose IE studies have produced results that were used to engage with stakeholders to change practices and policies. No members of the group had used their IE study to directly influence practices and policies. The only person that I knew who had conducted an IE study and then used the findings to advocate and implement change was Ellen Pence (1997). I was impressed with the content and organization of the *Making Care Visible* report (Bresalier et al., 2002) and could imagine the utility of such a report. After much reflection, I decided I would proceed with using IE for my doctoral study and

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<sup>2</sup> The IE Working Group is based out of the University of Calgary and lead by Dr. Janet Rankin, an established scholar in the IE literature. The group is primarily comprised of graduate students and university faculty. Depending on the group's interests, different IE experts will be invited to speak on a particular aspect of IE and field questions from the group.



marry it with what I knew about best practices around community engagement and knowledge sharing.

### 1.2.3 Mechanics of my IE analysis.

Rigor is not an area that is clearly addressed within IE literature, to date. In academic research, researchers are frequently expected to demonstrate trustworthiness and methodological rigor in funding applications and publications. Categories and tools used to measure rigor in quantitative and positivist research have been established and are largely uncontested. Lincoln and Guba (1985) established criteria for trustworthiness for qualitative research that are held as a standard by some, while criticized and problematized by others (see Table 1).

**Table 1.1 Assessing Trustworthiness and Rigor in Qualitative Research**

*Categories and Techniques to Demonstrate the Categories* (Lincoln & Guba, 1985)

Broad Category	Examples of techniques
Credibility	Confidence in the “truthful” nature <ul style="list-style-type: none"><li>• Prolonged engagement</li><li>• Persistent observation</li><li>• Triangulation</li><li>• Member checking</li></ul>
Transferability	Applicability to other settings and contexts <ul style="list-style-type: none"><li>• Thick descriptions</li></ul>
Dependability	If study were repeated, findings would be consistent <ul style="list-style-type: none"><li>• Inquiry audit</li></ul>

Confirmability	The unbiased—neutral—nature of the study <ul style="list-style-type: none"> <li>• Audit trail</li> <li>• Triangulation</li> <li>• Reflexivity</li> </ul>
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I am acutely aware of the subordination of qualitative health research, albeit subtle, relative to quantitative biomedical health research within health institutions, funding organizations, and in the public eye, such as news media (Green & Thorogood, 2009; Guba & Lincoln, 2004; Saludadez & Garcia, 2001). I see the utility of establishing standardized categories to adjudicate qualitative research for rigor as a way of demonstrating a sense of legitimacy and value within the positivist culture that continues to dominate the health field of research. However, I agree that “if there is no unified qualitative research paradigm, then it makes little sense to attempt to establish a set of generic criteria for making quality judgments about qualitative research studies” (Rolfe, 2006, p. 304). The diversity of ontological and epistemological stances among qualitative research methodologies makes it impossible to have a unified paradigm or categories to assess research rigor.

In Bisailon’s (2012b) dissertation on using IE to study the social organization of new immigrants to Canada who are living with human immunodeficiency virus (HIV), she suggests that rigor in an IE study is demonstrated when “the researcher clearly and convincingly shows *how* things are organized to happen in the material circumstances of people’s day-to-day lives; where an explication of the ruling relations that shape or coordinate people’s circumstances is produced” (p. 111). Smith asserted that IE analysis is arguably neither qualitative nor quantitative, but rather evidence-based and descriptive

in words and/or numbers of what is actually happening (personal communication, 2013). As such, I suggest that IE researchers can demonstrate credibility, dependability, and confirmability (as described in Table 1.1) by detailing how and what data were collected and analyzed. There is no standardized method or format for documenting data analyses in IE studies. Since I do not write extensively about my analysis in my dissertation manuscripts, I detail below how I conducted my analysis as a form of authenticity and transparency.

**Table 1.2 My Data Analysis Process**

*Tasks Accomplished at Each Phase of Data Analysis*

Phase	Data Type	Details
Organizing Data	Transcripts	Read and corrected transcripts by listening and reading transcripts, as transcripts were being completed. Started a list of categories for indexing all texts. Imported corrected transcripts into NVIVO. Noted documents such as acts, policies, manuals, and guidelines that were referenced in interviews.
	Forms/Documents	Imported documents into NVIVO. Linked parts of the transcript that were related to the document to the document itself. Read the documents and examined them for any links to other texts.
	Boss texts <sup>3</sup>	Located texts and imported them into NVIVO. Linked these texts to interview transcripts or other texts that referenced them.

<sup>3</sup> Boss texts refer to governing texts that organize other texts. In other words, boss texts are hierarchically positioned at or near the “top”, guiding other texts that carry out the work of an institution (Bisaillon, 2012).

Initial Analysis	All transcripts, texts, and maps	<p>Indexed all data within NVIVO using the following categories:</p> <ul style="list-style-type: none"> <li>▪ Caregiver work</li> <li>▪ Frontline worker work</li> <li>▪ Policy and decisions maker work</li> <li>▪ Ruling relation</li> <li>▪ Quotes for later consideration</li> <li>▪ Sources of FASD knowledge</li> <li>▪ FASD Diagnostic “knowledge framework”</li> <li>▪ Recommendations from participants</li> </ul> <p>With text documents, memos were made answering the following questions:</p> <ul style="list-style-type: none"> <li>▪ What categories of information are recorded?</li> <li>▪ Is an FASD diagnosis recorded? If so, to what end?</li> <li>▪ What information leads to more work?</li> <li>▪ How is this text connected to other texts?</li> </ul>
Collating Information	All transcripts, texts, and maps.	<p>Using a concept mapping software, a map was developed to document how people, texts, and processes were connected.</p> <p>A separate map was made of sources and resources that informed interviewees’ understanding of FASD.</p> <p>A third map of recommendations was developed.</p>
Checking back with interviewees	Maps	<p>All interviewees were invited (and most accepted) to review initial analysis results.</p> <p>Meetings were held with interviewees to review maps and make amendments and additions to maps.</p> <p>Several more texts were identified through this process and were added to NVIVO.</p> <p>Two additional people were identified and subsequently interviewed.</p>
Second round of analysis	All transcripts, texts, and maps.	<p>Created new memos within NVIVO.</p> <p>Amended maps in Mindnodes.</p> <p>Created several institution-specific maps because of the level of detail contained in the “master” map.</p>

Last round of analysis: community presentations and feedback	Maps	Created presentations using Power Point and large format maps to share with interviewees and other community stakeholders. Feedback was solicited. Very minor and nuanced notes on the data analysis were made as a result of the discussion.
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Using NVIVO qualitative analysis software allowed me to query terms, link transcripts to actual texts, make memos, as well as call up all references to particular indexed terms. More detail on the dissemination is found in the conclusion chapter of this dissertation.

### **1.3 Overview of Dissertation Manuscripts**

The following abstracts describe the four manuscripts that comprise the “filling” of my dissertation and are sandwiched by this introduction and a later conclusion. My IE study was conducted in two communities; one rural Indigenous community and one urban community. The first manuscript uses the findings from the urban community to illustrate how I used IE to identify and examine the utility of FASD diagnoses in ways that are highly varied and often invisible to caregivers and services providers alike. The second and third manuscripts are focused on aspects of doing research with a rural Indigenous community. The fourth manuscript applies to the research I did in both communities.

### **1.3.1 Revealing disjunctures: Using institutional ethnography (IE) to uncover disconnections between a fetal alcohol spectrum disorder diagnosis and institutional supports.**

In this chapter, I illustrate how the emancipatory value of IE can be found in identifying and examining *disjunctures*. Disjunctures refer to the discrepancies between what is assumed to be happening and what is actually going on. After providing a background on fetal alcohol spectrum disorder (FASD) and the role of caregivers in seeking an FASD diagnosis and supportive services for their children with FASD, I make visible four disjunctures from my doctoral IE study on the social organization of supports and services for children diagnosed with FASD. These four examples illustrate how IE produces empirical evidence by uncovering disjunctures and drawing attention to particular institutional policies and practices that are missing or require attention.

### **1.3.2 A decolonizing method of inquiry: using institutional ethnography to facilitate community-based research and knowledge translation.**

In this paper, I describe how I used IE as a decolonizing method of inquiry. By using IE with CBR and OCAP principles, following the four Rs, and incorporating an integrated knowledge translation (KT) approach, I argue that IE is well-positioned as a decolonizing way of conducting research and a means to a decolonizing end. I use examples from my IE study on fetal alcohol spectrum disorder (FASD) in a rural Indigenous community in eastern Canada to highlight new and exciting advances in the field of decolonizing research, IE, and Indigenous KT.

### **1.3.3 Reframing tensions as opportunities for transformation: Strategies to unforeseen obstacles as a doctoral student doing research with an Indigenous community.**

In this paper I highlight how, despite following best practice principles of doing community-based research with Indigenous people and communities, I encountered various forms of tension throughout my doctoral study. I draw on four examples of tensions that I experienced during my doctoral study to highlight that knowing principles is not always enough. For each example, I discuss the dilemma and how I dealt with it. I also suggest that it was my relational approach and investment in authentic relationships with community members that made it possible to transform the tensions into unforeseen opportunities. Part of the reason for writing this chapter is to advance the work of conducting decolonizing research with Indigenous communities by making my challenges and strategies transparent and visible.

### **1.3.4 More than words: Using visual graphics to help facilitate the research process.**

In this chapter, I argue that using visual graphics enhances and improves communication throughout all phases of research. I suggest that by improving communication and comprehension with diverse research stakeholders, the level of community engagement and trust is also greatly improved. I make visible, both literally and figuratively, how I used visual graphics to communicate concepts, ideas, and information from the development to the dissemination phases of research with a wide range of stakeholders, target audiences, and community informants.

The four manuscripts are not placed in any order of importance. They tell a story about how I used IE to make discrepancies—largely unchallenged and unnoticed—visible around an FASD diagnosis for children and youth in an urban community, conducted my research, adapted IE to suit the needs of an Indigenous community, struggled and dealt with unforeseen challenges, and used visual graphics to facilitate research processes that are frequently text-based.

The concluding chapter of my dissertation describes a range of KT activities I facilitated at various stages of my research. I give an example of how doing this research resulted in non-research initiatives that positively contributed to the advancement of FASD work in Newfoundland and Labrador. I reflect on several themes that weave my manuscripts together and suggest recommendations for further research. Overall, my dissertation offers new and exciting ways of approaching and practicing emancipatory, community-based, and decolonizing research using IE.



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### **Co-authorship Statement**

To the best of my knowledge, my dissertation does not infringe on anyone's copyright nor violate any proprietary rights. I am the sole author to all components, including the four manuscripts, of this dissertation. While my research was designed in consultation with community stakeholders, this thesis is focused on the *process* of my community-based doctoral research.

I declare that this is a final version of my dissertation, as approved by my thesis committee, key community stakeholders from my community-based research, and Memorial University's School of Graduate Studies.

## Chapter 2

### **Revealing disjunctures: Using institutional ethnography to uncover disconnections between a fetal alcohol spectrum disorder diagnosis and institutional supports**

#### **Abstract**

Institutional ethnography (IE) is a method of inquiry that offers emancipatory possibilities. This paper reveals how IE's emancipatory value is linked to identifying and examining *disjunctures*, which are discrepancies and disconnections between what is understood to be happening versus what is actually being experienced. Using examples from an IE study that examined the social organization of supports and services for children diagnosed with fetal alcohol spectrum disorder (FASD) in an urban community in eastern Canada, four specific disjunctures are revealed and discussed. These disjunctures make various disconnections between school-aged children living with FASD and institutional supports visible. Furthermore, I illustrate how the ambiguity of institutional policies and communication make it difficult for children living with FASD to thrive. This study also reveals how caregivers are required to be FASD experts while not being seen or treated as experts. By uncovering and making disjunctures visible, I argue that IE studies can draw evidence-based attention to specific institutional policies and practices that are missing or require change.

#### **Keywords**

institutional ethnography; IE; fetal alcohol spectrum disorder; FASD; evidence-based practice; early intervention

## 2.1 Introduction

In institutional ethnography (IE), one of the goals is to analyze *disjunctures*. Disjunctures refer to the discrepancies and disconnections between what is understood to be happening versus what is actually being experienced. This manuscript reveals how using IE is useful for identifying and examining disjunctures that occur when children are diagnosed with fetal alcohol spectrum disorder (FASD). To provide context, the first section of this paper reviews key aspects of FASD: what it is, how it is unique, why people seek early diagnostic assessments, how it affects the work of parenting, and its currency as a medical diagnosis. The methodology section details recruitment, data collection, and data analysis for an IE study on the social organization of supports and services for children diagnosed with fetal alcohol spectrum disorder (FASD).

Later, there is discussion on the disjunctures between (a) medical professionals' positions on the utility of an FASD diagnosis and the available supports; (b) eligibility criteria for supports and recognized exceptionalities; (c) requested support and the actual organization of the support; and (d) parenting work and the parental work that counts for institutions. By making the disconnections between living with FASD and the institutional supports visible, it becomes clear that ambiguity of institutional policies and communication make it difficult for children with FASD to thrive. It also becomes evident that caregivers<sup>1</sup> are required to be FASD experts while not being seen or treated as experts.

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<sup>1</sup> In this paper, the term caregiver refers to people who fill a parental role: it includes birth, foster, adoptive, and kinship parents.

## **2.2 Getting Acquainted with FASD**

### **2.2.1 What is FASD?**

FASD is an umbrella term coined in 2004 by medical professionals to represent a range of diagnoses related to prenatal alcohol exposure. From 1973 to 2004, people were diagnosed as having either fetal alcohol syndrome (FAS) or fetal alcohol effects (FAE). Since 2005, people are diagnosed with FAS, partial FAS (pFAS), alcohol related birth defects (ARBD), or alcohol related neurodevelopmental disorder (ARND) (Astley, 2013; Chudley et al., 2005). The etiology of FASD is often framed as maternal drinking of alcohol and, specifically, the effects of teratogens found in alcohol on a developing fetus. The teratogens can interfere with fetal development that is occurring around the time of consumption—making the central nervous system most vulnerable since it is in constant development in utero. While people may judge and blame women who give birth to children with FASD, some women drink before they know they are pregnant or as a coping mechanism to prevent further harm to themselves. Other women may lack the supportive environment to stop drinking (British Columbia Centre of Excellence in Women's Health, 2002, May; Poole, 2008; Public Health Agency of Canada: FASD Team, 2005; Rutman & Van Bibber, 2010).

Being diagnosed with an FASD is different than other developmental labels in that it draws a causal link between the person diagnosed with an FASD and their biological mother. It is also unique in that the diagnostic coding is based on severity rather than a pattern in neuropsychological functions (Price, 2014). Furthermore, pFAS, ARND, and ARBD require confirmation of prenatal alcohol exposure as the “causative agent” (Price, 2014, p. 41). Knowing a diagnosis does not determine a specific course of treatment or

intervention; however there is an inventory of approaches and strategies that have been documented as effective with children diagnosed with FASD. Child development and FASD literature agree that early interventions, birth to age 6-7 years, help mitigate potential challenges that children and youth living with FASD face as they move into adulthood (Abrams, 2010; Astley, Bailey, Talbot, & Clarren, 2000; Carmichael Olson, Rosalind, Gelo, & Beck, 2009). One current and major diagnostic challenge is that diagnostic testing is designed for children approximately age 7 and older, excluding adults, which is past the point of “early” intervention (Astley & Clarren, 2000; Benz, Rasmussen, & Andrew, 2009; Canadian Association of Paediatric Health Centres, 2010).

### **2.2.2 What is unique about FASD diagnoses?**

FASD is frequently cited as being the “leading preventable cause” (Bryanton et al., 2014, p. E121) or the “leading known cause of mental retardation” (Abel & Sokol, 1987, p. 51). It is unique in several ways. First, there is no other medical diagnosis for a developmental delay from birth that is considered both preventable and permanent. Mothers who give birth to children with FASD are often subjected to moral judgment to the extent that some pregnant women have been held against their will in custody such as prison or treatment centres for the sake of their fetus—sending the message that the state is more invested in the fetus’ well-being than that of the pregnant woman herself (*Winnipeg Child and Family Services (Northwest Area) v. G.(D.F.)*, 1997).

Second, it is a medical diagnosis that is not recognized by all health professionals as legitimate. The current diagnostic guidelines were last revised in 2005 (Chudley et al., 2005). The guidelines encourage a multi-disciplinary diagnostic team to ascertain four



domains of (a) growth, (b) facial phenotype, (c) central nervous system function, and (d) exposure to alcohol on a scale, and to determine the diagnosis depending on the combination of rankings. One of the most stigmatizing aspects of the diagnosis is that it requires doing a complete history that confirms maternal consumption of alcohol during pregnancy (Armstrong, 2003; Armstrong & Abel, 2000; May et al., 2009).

Third, the way FASD manifests in children living with FASD can greatly vary depending on a multitude of variables such as the volume, frequency, and timing of the alcohol consumption; living conditions and access to good prenatal care; early childhood environment; and co-existing mental health among other determinants of health (Abel, 1995; Chudley, 2008; Chudley et al., 2005). The implications of this variability are that the appropriate interventions and supports for people living with FASD are diverse and poorly understood (Carmichael Olson et al., 2009; Fast & Conry, 2011; Kalberg & Buckley, 2007; Lutke, n.d.).

### **2.2.3 Why get diagnosed?**

At the individual level, the impetus for caregivers pursuing an FASD diagnosis is often to gain access to supports and services as well as confirm or legitimize observed behavioural or developmental concerns (Carmichael Olson, Jirikowic, Kartin, & Astley, 2007; Gal I. Koren, Fantus, & Nulman, 2010; Streissguth et al., 2004). There are no studies that examine why caregivers do not pursue an FASD diagnostic assessment for children; however, scholars have made some conjectures about possible reasons (Badry, 2010; Carmichael Olson et al., 2007; May et al., 2009). Conjectures include the lack of FASD awareness and screening among health care professionals; lack of diagnostic

assessment services; misreading behaviours as symptomatic of other diagnoses such as attention deficit disorder (ADD), attention deficit hyperactivity disorder (ADHD), oppositional defiance disorder (ODD), or poor parenting skills; and the fear of stigma attached to the birth mother if an FASD diagnosis is made. Table 2.1 lists a range of possible reasons why caregivers may seek, or not seek, an FASD diagnostic assessment.

**Table 2.1 Rationale for Seeking or Not Seeking Diagnostic Assessment**

*Reasons for Pursuing versus not Pursuing an FASD Diagnostic Assessment*

Possible reasons to seek a diagnostic assessment (Carmichael Olson et al., 2007; Gal I. Koren et al., 2010; Streissguth et al., 2004)	Possible reasons to <i>not</i> seek a diagnosis (Badry, 2010; Carmichael Olson et al., 2007; Carmichael Olson et al., 2009; May et al., 2009)
<ul style="list-style-type: none"> <li>• clarity on the nature of the exhibited behaviours;</li> <li>• want to provide appropriate interventions, supports, and services;</li> <li>• proof of “disability” for access to resources or services;</li> <li>• rule out other possible explanations for challenges or behaviours; and</li> <li>• participate in a prevalence study that may lead to better services.</li> </ul>	<ul style="list-style-type: none"> <li>• caregivers and service providers alike are unfamiliar with FASD;</li> <li>• medical professionals are unfamiliar with FASD screening tools or other flags that may lead to a referral;</li> <li>• no local diagnostic team/capacity;</li> <li>• lack of trained interdisciplinary team (where assessments are possible but diagnoses are not);</li> <li>• women may not disclose prenatal alcohol consumption (e.g., fear of judgment, blame, stigma, uncertain of outcome etc.);</li> <li>• symptoms are diagnosed with other labels such as attention deficit disorder (ADD), attention deficit hyperactivity disorder (ADHD), oppositional defiance disorder (ODD); and</li> <li>• behaviours are interpreted as the effects of poor home environment or parenting skills.</li> </ul>

At the population health level, there is very little known about the prevalence of prenatal alcohol exposure in the general population. A recent population-based study in

eastern Canada reported the prevalence rate of prenatal alcohol-exposed newborns; however the number of alcohol-exposed newborns does not represent how many will experience alcohol-related neurodevelopmental delays or challenges (Bryanton et al., 2014). There are prevalence studies that focus on specific demographic groups that are also vulnerable and stigmatized, such as children in the child welfare system, Indigenous communities, and adults in the correctional system (Abel, 1995; Astley, Stachowiak, Clarren, & Clausen, 2002; Boland, Chudley, & Grant, 2002; May et al., 2009; Tait, 2001). Part of the drive behind studying the prevalence of FASD and the additional costs—that is, financial costs—of people living with FASD to Canadian taxpayers is to advocate for increased FASD prevention efforts and early interventions to mitigate secondary disabilities (May et al., 2014; Stade, Ungar, Stevens, Beyen, & Koren, 2007).

#### **2.2.4 Caregiver work of children with FASD.**

Literature on the work of caregivers has largely focused on foster parent experiences and retention of children with an FASD diagnosis, expressions and sources of caregiver stress, and the importance of early interventions which caregivers need to facilitate (Brown & Bednar, 2004; Brown, Bednar, & Sigvaldason, 2007; Caley, Winkelman, & Mariano, 2009; Carmichael Olson et al., 2009; Michaud & Temple, 2013; Pelech, Badry, & Daoust, 2013; Swart, Hall, McKee, & Ford, 2014). Caregivers are responsible for many aspects of supporting a child with FASD. In addition to the “usual” parenting responsibilities, they are subject to scrutiny of people who do not know about or understand FASD and how it is expressed in a child’s appearance, cognition, and behaviour (Brown & Bednar, 2004; Giunta & Streissguth, 1988).

Brown and Bednar (2004) conducted a study that used concept mapping to analyze caregiver answers to the open-ended question, “What are the challenges you face parenting a child with a fetal alcohol spectrum disorder?” (p. 4). The responses were grouped into the following eight categories: preventing setbacks, making time for self, keeping plans, home-school collaboration, keeping children involved, lack of support, social isolation, and behavioural problems. Michaud and Temple (2013) conducted a participatory action research study that asked, “What are the experiences of parents caring for children with FASD?” and “What do parents believe their families and children with FASD need to ensure good outcomes?” (p. 95). They found that general parenting skills do not (and should not) apply when caring for children with FASD; it is hard to figure out when it is safe to let their children make their own decisions and mistakes; there is guilt for asking their children to eventually move out when the behaviours become unmanageable; and concern for the future of their child with FASD is very stressful.

#### **2.2.5 The emphasis on early interventions.**

There has not been extensive research done in the field of early interventions for children with FASD, in part because most diagnoses do not occur until children are school-aged (Olson, Jirikowic, Kartin, & Astley, 2007; Streissguth et al., 2004). Early interventions refer to intentional efforts made to optimize the development of children ages zero to five that have developmental delays or challenges. The emphasis on early interventions grew when a book by Streissguth, Barr, Kogan, and Bookstein (1996) highlighted common *secondary disabilities* of adults living with FASD. Secondary disabilities refer to challenges that person was not born with but live with due to adverse

childhood events and circumstances. Literature suggests secondary disabilities include mental health issues, disrupted school experience, trouble with law, inappropriate sexual behaviour, alcohol and drug addictions, dependent living arrangements, and problems with employment (Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004; Gary Roberts and Associates, 2008; Streissguth et al., 1996). The main argument for early interventions is that if children had early interventions and appropriate supports throughout their childhood, secondary disabilities would be minimized or not exist.

There is not enough education, awareness, or use of screening tools in most schools to prompt an appropriate FASD assessment, or motivate teachers to have a conversation with parents about the possibility of alcohol exposure in utero (Gal I. Koren et al., 2010). Even for children that already have a diagnosis, their behaviours and academic performances are frequently mislabeled or mistaken for something other than FASD since children with FASD can present themselves as having a learning disability, attention deficit hyperactivity disorder, oppositional defiance disorder; or as simply being a non-compliant child (Carmichael Olson et al., 2009; Clark, 2012; Gal I. Koren et al., 2010). Few people spend more awake hours with school-aged children than teachers do. The education system is organized in a way that expects teachers to support children's development and academic progress and, in the case of students who have special needs, schools are expected to make adaptations to support individual children's development and academic success. However, teachers do not necessarily have familiarity, training, or access to supports to make appropriate adaptations for children with FASD.

Children with FASD have high rates of academic challenges as well as disruptive classroom behaviours and consequently disrupted school experiences, including

suspensions, dropping out, and expulsion (Burd, Klug, Martsolf, & Kerbeshian, 2003; Carmichael Olson et al., 1997; Streissguth et al., 2004; Streissguth & Kanton, 1997). Studies have repeatedly shown that caregivers are critical players in their child's educational trajectory. Caregivers are required to be persistent with school approaches, programs, and supports; they must advocate and educate school staff; and they must help with the transitioning from one school year to another and, eventually, transition to post-secondary or work programs after high school (Caley et al., 2009; Carpenter, 2011; Duquette, Stodel, Fullarton, & Hagglund, 2006; Job et al., 2013; Gal I. Koren et al., 2010; Paley & O'Connor, 2011).

#### **2.2.6 The power of medical diagnoses.**

Supposing all physicians and nurses are trained to screen and diagnose FASD, which they are not; supposing there were definitive ways to be 100% sure of the diagnosis, which there is not; supposing FASD was recognized in the Diagnostic and Statistical Manual (DSM) for mental health professionals to be able to reference and bill for, which it is not; and supposing there were interdisciplinary teams available in every Canadian province and territory, which there are not; there is no clear solution for how to avoid the social stigma attached to the diagnostic label. FASD can rarely escape from social stigma whether one gets a diagnosis or not. In short, FASD is a catch-22 situation. Having an FASD diagnosis can be stigmatizing to the person diagnosed as well as the birth mother; but *not* getting a diagnosis can prompt responses and reactions to troubling behaviour that over time, develops stigmatizing secondary disabilities.

Critics of medicalization have drawn attention to how medicine has played a role as an institution of social control in areas such as mental illness, delinquency, addictions, and hyperkinesis—referring to ADD and ADHD—areas which are all affiliated with FASD (Clarke, 2004; Conrad & Schneider, 1980). Parsons (1951) argued that the institution of medicine legitimizes deviant behaviours as illnesses through the work of medical diagnoses.

It seems that the FASD medical diagnostic guidelines are both a hindrance and a help. The term *fetal alcohol spectrum disorder* explicitly links a medical diagnosis with “preventable” prenatal and maternal alcohol consumption – which society has used to blame and control pregnant women who drink during pregnancy (Armstrong & Abel, 2000; *Winnipeg Child and Family Services (Northwest Area) v. G.(D.F.)*, 1997). On the other hand, a medical diagnosis is a form of currency that people such as caregivers are able to use to access or advocate for support since medical authority has been well established in contemporary society and is rarely questioned by people working in non-medical professions (Jutel, 2009).

## **2.3 Method of Inquiry**

### **2.3.1 About institutional ethnography (IE).**

This study used IE as a method of inquiry in an urban community in Eastern Canada. A growing number of studies are using IE to make visible how health-based institutions coordinate and organize the work of people within and outside of the institutions. One of the aims of IE is to make institutional relations explicit and visible—

explicating how institutions coordinate and organize a particular group's everyday experiences and activities.

The focus of IE studies is on *institutional* practices, with deliberate attention paid to relevant texts (e.g., forms, information brochures, training manuals, data management fields, and policies) that are activated by people that work within an institution. The *ethnographic* component reflects the way in which researchers start with exploring the everyday/every night experiences of a particular group of people, piecing how their social world is put together through a notion of work—defined as actions that take time, effort, and intent (Smith, 2006). In some ways, IE departs from the interest in generating theory, interpreting meaning, and conceptualizing; instead, it maps social relations to explain what is actually happening and how it happens as it does. IE has the capacity “to return knowledge to people...extend[ing] their ordinary knowledge of how things are put together” (Carroll, 2010, p. 24).

### **2.3.2 Ethics approval.**

The provincial Health Research Ethics Board approved this study (#12.110). The regional Education District and regional Health Authority gave permission to include school staff and hospital staff, respectively. Ethics approval was granted to include eligible and competent youth ages 11-14 with an FASD diagnosis to participate; however there were no eligible and interested youth informants in this study.



### **2.3.3 Informant recruitment, field work and data collection.**

Initially four caregivers, each from a different household, of five children ages 9-14 with an FASD diagnosis were recruited. Potential participants were approached by the physician that made the FASD diagnosis or by local FASD committee members and were given information about the study. The rationale for selecting caregivers of children ages 9-14 was three-fold: many children are not diagnosed until age seven or eight; information about what early interventions and services were accessed was of particular interest; and caregivers of children within this age group are key players in accessing various supports, services, and programs. None of the interviewed caregivers had children that fit the eligibility criteria<sup>2</sup> for participation by the youths themselves.

Data were collected over a 17-month period. The first round of semi-structured interviews was with caregivers. The second round of interviews was with 16 frontline workers including teachers, counsellors, medical, and allied health professionals connected to each child and youth living with an FASD diagnosis. During interviews with frontline workers, relevant texts such as forms, referrals, policies, and manuals that guide their work were both identified and discussed. The third round of interviews included 6 managers, regional administrators, and directors involved in relevant policy and program decision-making (see Table 2.2). All interviews were immediately transcribed and analyzed, institutional connections identified and mapped, and textual documents analyzed.

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<sup>2</sup> The eligibility criteria for youth in this study included being age 11-14, diagnosed with FASD, and deemed competent by their physician or social worker.

**Table 2.2** Informants by Institution

*Demographics of Institutional Informants*

	Health	Education	Child Welfare	Community
<b>Frontline Workers</b>	3	11	1	1
<b>Decision and Policy Makers</b>	1	3	1	1

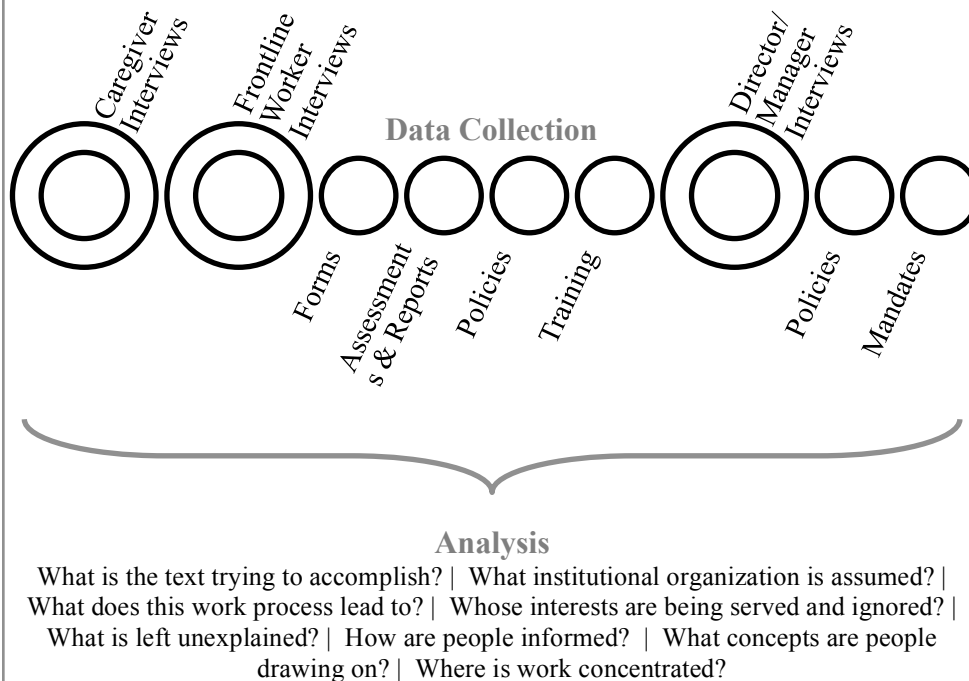
**2.3.4 Data analysis.**

Transcripts from 25 interviewees and 22 documents were indexed (not coding for themes but rather coding for references to texts, forms of work, transferring work from one location to another, and so forth) using qualitative analysis software. Analytical attention to the transcripts was paid to the following key areas: (a) examples and details of how informants' work was organized; (b) how work was connected to institutional processes and policies; (c) how people were educated or learn about FASD; and (d) reoccurring phrases or words. Documents were analyzed using questions inspired by Bisailon (2012), such as: Who authored this document? Who is the intended reader? What does this document intend to accomplish? What work does the document assume, refer to, or create? Who has access to this document and whose interests are being served? How is this document connected to other documents?

Throughout the data analysis phase of this study, I used concept mapping software to build a visual representation of people, institutions, texts, and processes that used texts – and the connections between them, as a map. After completing an initial analysis, all research informants were individually invited, though five informants declined because of

busy schedules, to review three documents: (a) a map-in-progress, (b) a summary of sources of FASD knowledge, and (c) recommendations for improved supports and services. I reviewed these three documents face-to-face with informants and in some cases informants identified additional documents that were not mentioned in their interviews. I let informants know that they would receive an invitation for a community presentation where findings would be shared and discussed. Figure 2.1 provides an overview of the data collection progression, analysis questions, and mapped content.

**Figure 2.1 Data Collection and Analysis Process**



Throughout the data collection and analysis phases, I added information to a “map” that made visible the connections between:

- Work of caregivers at home
- Work *between* caregivers and institutions
- Work *within* institutions
- Work *between* institutions
- Texts used
- Actions that result from texts used

*Figure 5.1* This diagram details, from left to right, research informants that were interviewed and the types of textual documents that were collected. It also lists the kinds of questions used to conduct the analysis. The information used to create a map is listed on the right hand panel.

## 2.4 Findings and Discussion

In this section, I describe four disjunctures—where what is understood to be going on is *not* what is experienced or accomplished. IE research is about interrogating the taken-for-granted, making invisible work visible, and tracing how the once invisible work is organized through institutional texts such as regulations, policies, or forms. This study reveals a number of disjunctures that are relevant to the discussion on the utility of an FASD diagnosis. I focus on the school as a key institution that provides supports to children ages 9-14 with FASD. I describe and illustrate how supports and services are organized in ways that go unnoticed or are largely invisible. Similarly, I explicate how differing epistemologies between caregivers, direct service workers such as teachers and social workers, and administrators such as principles and managers remain unresolved. By differing epistemologies, I suggest the ways in which caregivers, frontline workers, and administrators constitute their knowledge—that is how they know what they know—are not shared with each other.

Informants in this study identified a wide range of institutions such as primary health care, child welfare, and education that govern how and what resources they access for their children. Examples of other institutions include the following: provincial allied health care for occupational therapy, speech and language pathology, and counselling; Canadian federal government for non-insured health and child disability benefits; municipal departments or private companies for after school care and holiday camps; and community-based organizations for support groups. People from these various institutions were interviewed in this study; however the school features prominently since the focus is on supports for children ages 9-14. The school is a place where the children

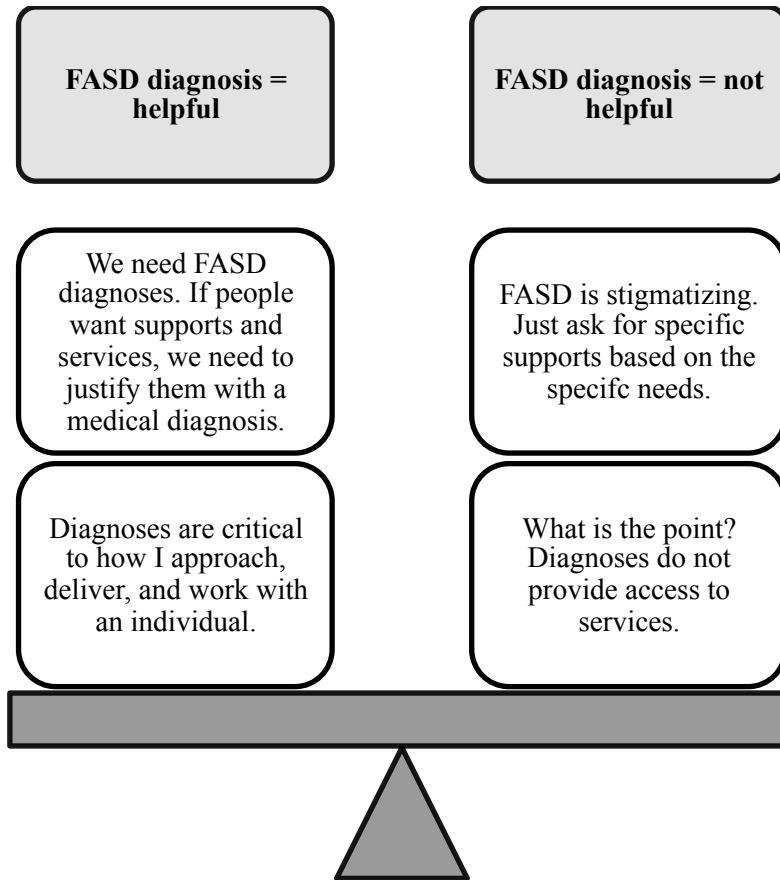
spend a lot of their childhood, parents rely on secondhand information from their child or school staff, and processes are often complex and non-transparent.

#### **2.4.1 Medical professionals' position on utility of diagnoses and credibility of medical diagnoses in other institutions.**

In the urban community where this study took place, the physician that conducted FASD diagnostic assessments requested supporting documents from institutions such as child welfare, schools, and allied health professionals that knew the child being referred for assessment. After the assessment was completed, a final report was sent to each of the institutions that provided supporting documentation for the FASD diagnostic assessment. In this study, all of the caregivers had pursued a diagnosis before their children started school and consequently caregivers had some control over where and when to share their child's diagnosis.

One challenge that caregivers struggled with was reconciling conflicting advice from various professionals and their family circles. Caregivers in this study shared varied and conflicting advice they received on whether or not an FASD diagnosis would benefit their child. Professionals that encouraged obtaining an FASD diagnostic assessment suggested that a diagnosis would provide leverage for services and direction for effective strategies. Reasons for why an FASD diagnosis was deemed to be not helpful included concerns about stigma, belief that needs—regardless of diagnoses—can be met at school, and skepticism about whether sharing a diagnosis would facilitate FASD-appropriate supports or services. Figure 2.2 identifies four commonly expressed epistemological positions of informants from this study on the utility of FASD as a medical diagnosis.

**Figure 2.2 Conflicting Messages on the Utility of an FASD Diagnosis.**



*Figure 5.2 This figure conveys the conflicting and varied messages that caregivers are confronted with as they consult and ascertain the pros and cons of getting an FASD diagnostic assessment for their child.*

In the caregiver accounts of contemplating getting their child or children assessed for FASD, three caregivers shared that they were encouraged by social workers and educator friends while being discouraged by medical professionals such as general practitioners and specialists. In one case, after the diagnosis was made, the caregivers were told by a medical professional that the diagnosis would not help them gain access to services but might help them in how they parent. A medical specialist who had been

providing care to children receiving classroom supports was interviewed in this study and suggested that a “...diagnosis itself does not bring anything. It's the level of deficit and impairment.” It is possible that some caregivers and parents do not pursue an FASD diagnostic assessment because they believe that a diagnosis will not facilitate better supports and services.

While disclosing an FASD diagnosis does not provide a roadmap for any service provider, not disclosing a diagnosis runs another risk—that people will label the child as a “bad kid” and/or as being raised by incompetent parents. One caregiver shared, “at least the child will get proper help if she got a diagnosis, but [until now] she's been labeled as just a bad kid.” For some educators and service providers who were not familiar with FASD, learning of the diagnosis prompted research and further inquiries. One teacher said, “a diagnosis is phenomenal because then you know you're doing the right thing and you know what to go and research and you know what accommodations may help. It helps, you know.” This sentiment and value placed on having a medical diagnosis was mentioned in all interviews with educators. In other words, none of the educators questioned the validity of an FASD diagnosis.

Caregivers including foster, adoptive, and birth parents in this study were not reluctant to share their child’s diagnosis if they thought it would benefit their child. As will be further discussed later in this paper, caregivers met with their child’s public school teacher(s) to request or establish classroom supports and services. Supports and services that incur additional costs to the institution—financial or human resources—require multiple layers of documentation, processes, and decision making by people who will never meet the child or their caregivers. A staff person in the educational system said,

“...and without the diagnosis sometimes their hands are tied...we can't provide services that we would like to because we have a pecking order of kids that do have a diagnosis that will have to receive those services before the ones without diagnosis.” This educator was referring to other students that she suspects may have FASD but have not had a diagnosis or the diagnosis has not been shared with the school. The disjuncture in this case is between the weight of a medical diagnosis for educators and the assumption of health professionals that needs-based classroom interventions are available without a diagnosis by medical professionals.

#### **2.4.2 “That's the list of accommodations that we would give a student who have a diagnosis or disability.”**

Until approximately three years before this research study began, the provincial educational department had an FASD consultant that would visit schools across the province where children with an FASD diagnosis were attending, consult with school staff, provide in-services, and advocate for FASD-informed classroom strategies. While this position no longer exists at the time of writing this paper, FASD is still recognized as an exceptionality that qualifies students for gaining access to available supports and services. At the time of data analysis, FASD was listed under “brain injury” in the provincial Department of Education Student Support Services’ definition of exceptionalities and in 2014, it changed to be listed under “neurodevelopmental and related disorders” (Government of Newfoundland and Labrador, 2014). Despite having FASD recognized as an exceptionality, there is a peculiar mismatch between categories of



behaviours/abilities that “count,” the kinds of accommodations that can be reported, and the kinds of behaviours/accommodations children with FASD in this study needed.

While there is great variability between children, there are some behaviours and challenges that are common among children living with FASD. For example, children with FASD frequently have trouble staying focused, remembering multi-step verbal instructions, regulating their eating, and understanding the concept of time (Burd, Cotsonas-Hassler, Martself, & Kerbeshian, 2003; Carpenter, 2011; Rasmussen, 2005). Research has shown that there are strategies to minimize the aforementioned challenges such as using visual reminders of tasks, repeating instructions, minimizing stimulation and modifying assignments that require abstract thinking (Carmichael Olson et al., 2007; Carpenter, 2011; Green, 2007; Streissguth et al., 2004). In schools where Student Assistants are available, behaviours or challenges children with FASD face do not match any of the eligibility criteria for having a Student Assistant. If students have a documented need for an accommodation, teachers are encouraged to select an accommodation from a list in a document called the *Record of Accommodations*. This list includes accommodations such as using calculator timetables, copies of notes, scribing, breaks, oral testing, transcribing, clarification on instructions, and extended time. How and which accommodations are facilitated by a classroom teacher can greatly vary. Table 2.2 lists some common issues and needs of children with FASD, eligibility criteria for students to have a Student Assistant, and possible classroom accommodations.

**Table 2.3** Categories of Behaviours and Needs versus Eligibility and Accommodations

*Comparing Common Behaviours and Needs of Children and Youth with FASD to Eligibility Criteria for Classroom Support and Possible Accommodations*

<b>Common Behaviours and Challenges</b> (Burd, Cotsonas-Hassler, et al., 2003; Carpenter, 2011; Rasmussen, 2005)	<b>Common Needs</b> (Carmichael Olson et al., 2007; Carpenter, 2011; Green, 2007; Streissguth et al., 2004)	<b>Student Profile for Student Assistant</b> (Government of Newfoundland and Labrador, 2011)	<b>List of Possible Accommodations</b> (Government of Newfoundland and Labrador, 2011)
Easily distracted	Visual reminders of tasks	Has few or no verbal skills	Calculator timetables
Cannot follow multi-step verbal instructions	Repeat instructions	Has severe mobility disability	Word processor and assistive technology
Cannot remember routine protocols	Repeat reminders to stay on task	Requires toileting assistance	Copy of notes
Unable to read social cues (such as non-physical bullying)	Minimize (noise and visual) stimulation and distraction in classroom	Has few or no self-help skills	Alternate setting
Cannot regulate their own eating (forget to eat)	Visual tools to illustrate time	Requires portering or lifting	Oral defense
Sudden emotional outbursts	Modify assignments that require analytic and/or abstract thinking.	Blind or deaf and on prescribed curriculum using Braille or American Sign Language	Scribing
Forgetful			Break
Leave classroom without warning or explanation		Date of last injury—specify if injury was to self or other	Reading of print
Lack concept of time			Organizational aids
			Oral testing
			Transcribing and chunking
			Clarification of instructions
			Extended time
			Visual schedule
			Adaptive aids
			Alternative format of materials

As one classroom teacher informant said, “There's a fine line between accommodations and good teaching practices.” There are accommodations that can be made for students that do not require additional resources (Table 2.2). In addition, if a child is disruptive in the classroom then implementing strategies or accommodations will help the whole class, including the teacher(s). The teacher informants in this study varied greatly in their positions and practices around implementing “good teaching practices” that did not require special meetings, permission, or resources. School staff in primary and elementary schools in this study were very responsive to implementing classroom strategies. One informant explained that “...when they leave this system and they go to a junior high or a high system, if they're not diagnosed, they don't receive the same accommodations, so the diagnosis is absolutely critical.”

The educational system is organized to respond to students who require specific in-school accommodations. The process of accessing and putting resources into place can greatly vary in the amount of time, documentation, cost, and levels of approval depending on a number of circumstances. For example, one child in this study had trouble following multiple instructions at one time, was easily distracted, and could not keep track of time. This student needed strategic placement in the classroom with minimal noise and visual distractions, reminders about tasks, and explanations on what questions meant on in-class assignments and tests. Her needs were not on the list of accommodations. She was not eligible for a student assistant because her needs did not match the criterion list. The year that I conducted the interviews, this student had staff that made accommodations that did not require approval or a student assistant. They put tennis balls on the bottoms of chairs to muffle the sound of contact on the floor, provided an exercise ball to sit on in class, and

provided simple sequential instructions on the board at the front of class that could be easily referenced. While this was a “successful” year for the student, these accommodations were entirely optional—similar efforts were not made in all previous years and there is no formal process or accountability for teachers in subsequent years.

#### **2.4.3 Accessing an institutional accommodation and what it actually accomplishes.**

In most urban Canadian communities, it is common for several elementary schools to feed into a large junior high school, and later into a senior high school. The environmental and routine structure of the day changes from being in one classroom for most of the school day in primary and elementary school, to junior high and high schools where students have different teachers for each subject area, have more same-aged peers on the school premises, and have unsupervised recess and lunch times (Cantin & Boivin, 2004). Students are required to take more ownership and control in recording and completing course work as well as in seeking extra help, if needed. Similarly, students must learn and adapt to differing classroom expectations with individual subject teachers. The work for caregivers is increased in junior high and high schools because of the increased number of teachers involved in the child’s everyday school experiences.

In this study, there was an unresolved issue whereby a high school student living with FASD named Clare (a pseudonym) repeatedly performed poorly on exams, scoring much lower than was expected based on her work leading up to exams. Interviews revealed that the high school administration heavily emphasized the importance of student independence, responsibility, and self-reliance. The only accommodation for

students who struggled with testing performance was to give students permission to take their tests in the school library. Clare's mother became concerned when Clare continued to score poorly on tests and realized that Clare was not taking her tests in the library, an accommodation the school said was available to Clare. When Clare's mother made an appointment to follow up with the school administrator to ask why accommodations were not made for her daughter, they were told that the school *did* offer accommodations but their daughter was not availing of the accommodation.

Policy stated that students were responsible for requesting this accommodation for *each* exam one week in advance by going to the front office to request this arrangement. Clare had trouble remembering to go to the office to request this accommodation and continued to test poorly. On occasion, a teacher would remind Clare but Clare would often get distracted and not make it to the office to submit the request. Moreover, two of her teachers felt that the library did not actually offer the distraction-free environment as intended, neither providing a staff person to ensure that Clare would stay on task nor an adult to clarify any questions that arose while Clare took her test. Furthermore, these same teachers felt that going to the library was detrimental to Clare's perceived need to fit in with her peers.

In this situation, a parent advocated for accommodations on account of their child's FASD-related attention challenges; the school offered an accommodation with a process that assumes students will remember multiple steps, a common challenge for people living with FASD; the accommodation did not actually offer the quiet environment it was intended to have; and teachers did not communicate their thoughts on the appropriateness of the library as an accommodation, in terms of it not being an improvement from testing

in class. Ironically, acquiring the accommodation required that Clare behave in a way that was the basis for the accommodation in the first place. In cases such as this, it is evident that not only is the accommodation inadequate but that there was no alternative process initiated to address Clare's testing performance—within the school or with Clare and her parents. While there are multiple aspects to this story that are problematic, it is the disjuncture between the intent of an accommodation, the process of accessing the accommodation, and actual environment for this accommodation that I want to highlight.

#### **2.4.4 Parental work for the child and parental work for institutional accountability.**

Researchers like Devault (1991) and Griffiths and Smith (2005) used IE to bring the work of mothers into view and illustrate how institutions socially organize mothers in ways that maintain forms of inequality. In the context of this study, institutions organize the work of caregivers in many subtle, invisible, and insidious ways. The everyday work of raising children can be demanding and at the very least, a serious responsibility. The everyday work of raising a child with FASD has the added dimension of discerning whether or not their child's behaviours and needs are related to FASD as well as whether or not their child's FASD diagnosis is relevant and needs to be disclosed or explained. As caregivers in this study described the everyday work of caring for their child, it became evident what "extra work" was involved—work that would not necessarily happen if their child did not live with FASD. The notion of *work* in IE refers to activities that require time, effort and intent. The caregiver work in this study was heavily organized by institutional expectations and surveillance by multiple institutions including

education, health care, child welfare, and various community-based programs. Table 2.3 lists examples of work that caregivers accomplished in order to meet the needs of their children, through institutional documentation and processes.

**Table 2.4** Caregiver Work of Children with an FASD Diagnosis

*Examples of Caregiver Work Under the Surveillance of Different Institutions*

<b>Institution</b>	<b>Examples of Work</b>
Education	<ul style="list-style-type: none"> <li>• Help complete homework.</li> <li>• Negotiate how much school work is possible.</li> <li>• Discern how to communicate academic concerns with teacher.</li> </ul>
Health	<ul style="list-style-type: none"> <li>• Administer medication(s).</li> <li>• Make and attend appointments with multiple health-related professionals (physician, counsellor, psychiatrist).</li> </ul>
Child Welfare	<ul style="list-style-type: none"> <li>• Explain how they are meeting the needs of their child during routine check-ins with social worker.</li> <li>• Discern how much to share with social worker during routine visits.</li> <li>• Justify and request respite care and/or babysitting.</li> </ul>
Other	<ul style="list-style-type: none"> <li>• Find after-school and day camps that will take children over age 12.</li> <li>• Attend parent support group.</li> <li>• Apply for funding to cover high costs of extra-curricular programs, medication.</li> <li>• Find babysitters that will be understanding and responsible.</li> <li>• Discern who needs to know about the FASD diagnosis and how to explain FASD to their child.</li> <li>• Defend parenting approaches and decisions to people who do not know about FASD or that their child lives with FASD.</li> </ul>

In addition to the work identified in Table 2.3, there is a more subtle form of caregiver work that also merits attention—the work of demonstrating “care” to institutions that have the power to report negligence or some form of unfit parenting. In most cases, caregivers spoke of the unusually high amount of energy that was spent getting their children to eat, where children would be easily distracted and required frequent reminders to keep eating at mealtimes; keeping track of their whereabouts including children that wandered off home properties without warning; and maintaining hygiene, not only requiring reminders but also reminding them of the process steps. If caregivers were not vigilant around mealtimes, unstructured play/free time at home, and hygiene, their children might be underweight, lost, look and smell unclean—all reportable forms of evidence of neglectful parenting.

Caregivers in this study did not articulate an urgent sense of fear that their children might be removed; however, in cases where the caregivers had their child(ren) removed in the past or had children placed in their care, that possibility is not forgotten. One informant had this to say about parents who had had their children removed by the child welfare system:

Like, I see people...they got their kids taken away. They could have their kids home. They ask for help and they come and they take their children. Here it is, I'm asking for help before they have to come and take my son and I'm not getting it, so it kind of makes me mad, you know, to see that people are asking for help and instead of getting help they're getting their children removed and put in foster



homes, when their parents are quite capable of taking care of their children with the right support system set up in place.

The point she makes here is that the child welfare system is not set up with the human or financial resources to support people who are struggling with caring for their own birth children. Instead, her observation and understanding is that the child welfare system is designed or organized to remove children and put supports in place with foster caregivers—supports that are not offered or available to the birth parents prior to removal.

The term *cascading vulnerabilities* is used in the engineering field to describe a large system failure when smaller parts of the system are disrupted. Badry (2009) borrowed the term cascading vulnerabilities to describe how children with FASD often end up being placed in foster care. Once children have been removed from parental care and the child welfare system is involved with a family, there is more attention drawn to how that child is cared for. The institutionalized processes used to evaluate parental competency is accomplished through passive observations by social workers that are looking for visible signs of negligence when meeting with caregivers (Braveman & Ramsey, 1997; de Montigny, 1995; Lietz, 2009). The implications are that parents who stop or pause in being vigilant in areas that might not be of concern with most other children may fear a possible cascading effect of events that start with a few missed meals to having their child welfare social workers visiting the home to question parental competency. There is a disjuncture between the mandate of “helping” institutions—including education, health, child welfare—to support children and how caregivers are held accountable for their child’s wellbeing by these same institutions.

## **2. 5 Failure to Thrive**

“Failure to thrive” is a medical term used for infants and toddlers whose weight is much lower than children of the same age and sex and for whom an underlying problem is unknown and unresolved (Marcovitch, 1994). Caregivers in this study all sought out an FASD diagnostic assessment in an attempt to address or mitigate their child’s failures at thriving. By making the disjunctures visible in this study, it becomes clear how the disjunctures impede the child/youth’s ability to thrive. In addition, some caregivers fear that their child’s failure to thrive will be constructed and documented by institutions as the caregiver’s failure to parent.

All caregivers in this study described a sense of relief and assurance when their child received an FASD diagnosis, in part, because it gave them hope: hope that a diagnosis might help secure services and hope that a confirmed diagnosis would provide a framework for how to parent differently. While caregivers did their own reading and researching on FASD, they expected the very institutions that are dedicated to helping children thrive—namely education, health care, child welfare, and recreational programs—to also have the knowledge for and commitment to understanding their child’s FASD. In many cases, caregiver’s expertise on effective strategies for their children remained untapped or ignored by institutions. Instead, the disjunctures in this study suggest that in order to receive FASD-informed supports and services for children with a diagnosis, caregivers must be experts in three areas: (a) FASD as it relates to their child; (b) institutional policies, procedures, and resources; and (c) best practices of FASD-informed institutional supports and services. However, caregiver expertise in all three

areas does not guarantee effective advocacy, since they may not be seen as being “professionally qualified” by institutions.

## **2.6 Conclusion**

An FASD diagnosis is not enough to make a difference to people living with FASD or their caregivers. Knowing that a child or youth has FASD can shift the gaze off the parents or shift assumptions that they are “a bad kid.” How FASD is taken up and interpreted by institutions is highly variable and largely invisible to caregivers. Similarly, differing opinions on the utility of an FASD diagnosis expressed by professionals that caregivers seek advice can be confusing and stressful. There is large amount of responsibility placed on caregivers to figure out and articulate how an FASD diagnosis is relevant to institutional work, understand how to navigate complex institutional processes, and challenge policies that do not meet the needs of children they are intended for. Caregivers are the common denominators in the coordination of care. As long as that is the case, caregivers need a road map for how to access services *or* an advocate that will do this work. Until then, caregivers are required to be experts on their children and institutions they rely on, while not being seen or treated as experts by institutions.

This study also illustrates how the ambiguity of institutional policies and lack of communication can render explanations for children’s failure to thrive invisible. By identifying disjunctures, IE offers emancipatory possibilities and practical insight for caregivers and institutional policy and decision makers alike. Assuming that institutions and caregivers want children and youth to thrive and succeed, despite challenges that are difficult to understand, IE offers an evidence-based lens that focuses on problems and not

on people. Making disjunctures visible creates an opportunity to correct or fill in gaps of understanding and pinpoint specific policies or procedures that require attention.

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## **Chapter 3**

### **A Decolonizing Method of Inquiry: Using Institutional Ethnography to Facilitate Community-Based Research and Knowledge Translation**

#### **Abstract**

This paper makes visible how I used institutional ethnography (IE) as a decolonizing method of inquiry. At the heart of decolonizing research is the task of shifting whose knowledge is privileged—from those with power (often researchers) to those who are being researched (those subject to the effects of colonization). I argue that when IE is used to facilitate community-based research and knowledge translation (KT), decolonizing research is made possible. I used IE to examine how supports and services are coordinated for children and youth medically diagnosed with fetal alcohol spectrum disorder in a rural Indigenous community in eastern Canada. This paper outlines principles for conducting research with Indigenous people and KT and further discusses how IE is well positioned to facilitate both decolonizing research and strategic KT. I suggest that IE can be a means to a decolonizing “end”. This study offers new and exciting advances to the field of decolonizing methods of inquiry and KT.

#### **Keywords**

institutional ethnography; decolonizing research; Indigenous health; knowledge translation; community-based research; decolonizing methodology



### 3.1 Introduction

Just as the effects of colonization continue to negatively affect Indigenous peoples' health in Canada, research practices have caused undue harm to numerous Indigenous people and communities (Adelson, 2005; Government of Canada, 1996). It is therefore urgent and critical that researchers doing research with Indigenous people think critically about how to practice decolonizing research. Decolonizing research is fundamentally about changing a power dynamic and Indigenous peoples' rights to self-determination. Kovach (2009) and Smylie (2011) argue that by privileging the knowledge of those who are being researched (people subject to the effects of colonization) over those whose knowledge has been privileged (researchers), decolonizing health research can reduce inequalities and improve health outcomes. In this paper, I describe how institutional ethnography (IE) as a research method of inquiry was adapted to fit the needs of a rural Indigenous community in Eastern Canada.

Knowledge translation (KT) is a term that refers to how research knowledge is shared. Widely accepted forms of mainstream qualitative and quantitative research and KT practices have been criticized for reifying colonialist ways of *doing* and *knowing* (Estey, Kmetz, & Reading, 2010; Smylie, 2011; Smylie, Olding, & Ziegler, 2014). Health research is primarily aimed at solving problems and in the context of solving "Indigenous problems", academic research in North America has largely been conducted and interpreted by non-Indigenous researchers who frequently benefit professionally, politically, or economically from their research (Bishop, 2003; L. T. Smith, 2012). In contrast, many Indigenous peoples and communities experience being misrepresented, passive objects of research, and excluded from discussions about research design or

findings (L. T. Smith, 2012). Concepts and language of mainstream research and KT practices are rooted in epistemologies that are often incongruent with Indigenous paradigms; paradigms where knowledge and action are intertwined and inseparable (Smylie et al., 2014).

IE is a method of inquiry that is born out of sociology and has been used to explicate the social organization of health work—through, by, and within health institutions. Rather than aim to test or generate theory, IE produces evidence-based research that maps how peoples’ activities are invisibly coordinated by institutional texts. To my knowledge, IE has been used explicitly with Indigenous people in three studies: a study by Pence and Wilson (2006) on legal interventions for Indigenous women living through domestic violence in the United States; a study by Restoule et al. (2013) on Indigenous students transition into post-secondary education; and an ongoing study by Ugarte (2014) on land use and planning for Indigenous people in Chile. In this paper I suggest and illustrate how IE can be used as decolonizing method of inquiry when paired with key community-based research (CBR) principles and appropriate Indigenous KT.

### **3.2 Understanding Context**

This research took place in a rural Indigenous community in eastern Canada. This particular community, like many other Indigenous communities across Canada, has participated in countless research studies over the years. In the early stages of exploring the idea of doing research related to fetal alcohol spectrum disorder<sup>1</sup> (FASD), three points

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<sup>1</sup> Fetal alcohol spectrum disorder (FASD) is an umbrella term for a range of medical diagnoses for neurodevelopmental disabilities that result from alcohol consumption in

were made clear to me: (a) some Indigenous community leaders were keen to talk about FASD and how research might address FASD-related concerns, (b) some Indigenous community members and leaders were skeptical of research, and (c) there was an unofficial research moratorium in this community. I learned that the skepticism and moratorium were the result of past research studies that offered little (or no) benefit to the community, research fatigue, and harm done to the community through research. People shared personal experiences and historical accounts of harm done by well-intentioned academic researchers who were disseminating research findings. The concern about personal and community stigma associated with FASD was also clearly expressed in the early stages of consultations, before it was decided that the study would happen.

As a researcher, I was concerned about reifying colonialist ways of conducting research. In particular, I had approached community members that were connected to or concerned about people living with FASD—as opposed to being approached *by* the community to conduct research. There was no formal process for community approval on proposed research studies so I began by talking to people I knew in the community. People I knew recommended others that I talked to and the number of people I spoke with grew.

The decision to conduct the study was made after many conversations that happened over approximately one and a half years. These conversations included discussing how the community would benefit from research on FASD, how research on FASD could be done without stigmatizing individuals or the community, and who would

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uterus. The term fetal alcohol spectrum disorder clearly links the disability with the birth mother, leading to mother-blame and stigma for drinking during pregnancy, regardless of circumstances.

be involved in the study. People spoke from past experiences where “external agencies and academics [analyzed] data [and had] the power to interpret the data and to construct an image of Aboriginal communities as desperate, disorganized, and depressed environments” (O’Neil, 1993, p. 34). I was well aware that public media have portrayed FASD as an “Aboriginal problem” and that this media coverage was in part due to research studies that took place in Indigenous communities. Tait (2003) highlights in her doctoral dissertation how FASD in Canadian Indigenous communities exacerbates a particularly gendered portrait of “sick, disorganized communities” (p. 186).

I needed to convey that my research would not make the community look sick or disorganized and further, explain how I planned to report on findings that, if not careful, could potentially be misinterpreted by the public in ways that harm or disserve the community. My energies at this stage were heavily invested in relationship building through listening, engaging with people of diverse perspectives, acknowledging concerns, and suggesting how I could address the concerns.

I would be remiss if I did not disclose a nuanced yet relevant detail about myself as a researcher in this study. I am a foster mother to a child who shares the same Indigenous identity as the research community—though not from the research community itself; I am a mother to a child living with FASD; and I am frequently and incorrectly assumed to be Indigenous, based on my Japanese-white blended facial features.

### **3.3 What is Decolonizing Health Research and (Indigenous) Knowledge Translation?**

Decolonizing health research is a relatively new and growing field. Most examples

of explicit decolonizing research in the health field have used participatory action research (Jacklin & Kinoshameg, 2008; Pyett, 2002; Wallerstein & Duran, 2006); Indigenous medicine wheel teachings (Mundel & Chapman, 2010), and iterative qualitative research methods using an Indigenous knowledge framework (Bartlett, Iwasaki, Gottlieb, Hall, & Mannell, 2007). Research findings are often made to represent “the truth” (L. T. Smith, 2012, p. 35). If researchers do not think critically about the ontology and epistemology underpinning research methodologies and methods, we risk oppressing Indigenous people in unintentional and insidious forms of oppression. L. T. Smith (2012) points out that behind all research is theory. Research theories have not been developed out of Indigenous worldviews, and Indigenous and mainstream forms of research are sometimes at odds with each other.

### **3.3.1 Key tenets of decolonizing research.**

There are a number of principles for researchers to carefully think about before starting a research study with and for Indigenous people. The principles encourage researchers to ensure Indigenous control, practice responsibility through reciprocity, honour what is shared without judgment, be attentive to how one communicates and what they represent, and use research methodologies that serve and benefit the Indigenous community (Hart, 2010; Kovach, 2009; L. T. Smith, 2012; Weber-Pillwax, 2001; Wilson, 2008). These principles are also well articulated by Schnarch (2004) in the Ownership, Control, Access, and Possession (OCAP) principles and Kirkness and Barnhardt (2001) in the four R’s—respect, reciprocity, relevance, and responsibility.

The health of Indigenous people in Canada is profoundly and negatively linked to

past and present colonial approaches, ideologies, and systems of governance (Nelson, 2012; Reading & Wien, 2009). Just as decolonizing research and self-determination are two sides of the same coin, decolonizing research is possible when those who have been colonized are in a position to determine how and what research is practiced.

### **3.3.2 Knowledge translation (KT) in health research.**

Currently, there is increasingly more attention and funding for research KT. Knowledge translation, mobilization, transfer and exchange, uptake, sharing and dissemination all share similar meanings and carry different currencies depending on the discipline. These terms are nuanced and intend to reflect the nature of relationship and processes between the researcher and intended audiences, such as decision-makers and community stakeholders (Estabrooks, Thompson, Lovely, & Hofmeyer, 2006). Critics of the KT movement suggest that it began with a political and economic agenda between universities and industry as well as between universities and government (Bercovitz & Feldman, 2006; Guston, 1999). KT models for health research are intertwined with concepts of “evidence-based” medical practices and “evidence-informed” decision-making (Graham et al., 2006; Greenhalgh & Wieringa, 2011). How much one prioritizes KT greatly varies depending on the nature and aims of a research study.

Concepts, practices, and models for KT in health research have changed over time. For example, Weiss (1979) observed and categorized “research utilization” practices into six distinct models of which the *knowledge-driven model* is no longer an endorsed model in academic health research. He observed that research was most often in one of the

following categories: the knowledge-driven model, problem solving model, interactive model, political model, tactical model, and the enlightenment model.

Almost two decades later, Lomas (1997) wrote about “research dissemination and uptake” models out of concern and an observation that researchers tended to write for and present to other researchers while decision makers were expected to make informed decisions, based on evidence-based research. Lomas was invested in having research play a stronger and more meaningful role in improving the Canadian health care system. He observed that researchers, depending on their location within or outside of a university, would fall into one of four models: the academic subordination model, quarantine model, academic freedom model, or the hybrid model.

Today, the Canadian Institutes for Health Research (CIHR), Canada’s federal funding agency for health research, couches its KT priorities in the language of “evidence informed” practices and “health system improvement” (CIHR, 2012). As such, CIHR offers two generous categories of KT: integrated KT and end-of-grant KT. Health researchers who are invested in the work and support of CIHR *and* Indigenous research have articulated how to conduct appropriate KT with Indigenous populations. Table 1 provides snapshots of how KT has been categorized and encouraged between 1979 and 2014 in Canada, including how Indigenous KT is framed using decolonizing principles for health research funded by CIHR.

**Table 3.1 Knowledge Translation between 1979-2014**

*Examples of Knowledge Translation Models and Definitions for Health Research*

<b>Literature Review of Research Utilization</b> (Weiss, 1979)	<b>Working Paper for Centre for Health Economics and Policy Analysis</b> (Lomas, 1997)	<b>Guide to Knowledge Translation Planning at CIHR</b> (CIHR, 2012)	<b>Institute for Aboriginal Peoples' Health</b> (E. Estey, J. Smylie, & A. Macaulay, 2009)
<p><b>Knowledge-Driven Model</b> “Push” model of “if you build it, they will come”</p> <p><b>Problem Solving Model</b> Identified problem becomes a research study to fill a particular knowledge gap</p> <p><b>Interactive Model</b> Linkage and exchange concept where researchers collaborate with end-users at multiple points of research study</p> <p><b>Political Model</b> Research study for political needs or agendas</p> <p><b>Tactical Model</b> Content of the research findings</p>	<p><b>Academic Subordination Model</b> Research completed under direct control of decision makers within an organization</p> <p><b>Quarantine Model</b> Research that is completed outside of academic institutions and government</p> <p><b>Academic Freedom Model</b> Research completed within academia with access to various university resources</p> <p><b>Hybrid Model</b> Research centres (e.g. manage health</p>	<p><b>Integrated KT (iKT)</b> Researchers and research users collaborate throughout research – from development to dissemination</p> <p><b>End-of-Grant KT</b> Research findings get disseminated to “knowledge users”; range from publications, tailored messages for target audiences, and commercialization</p>	<p><b>Indigenous KT</b> Draw and build on Indigenous practices, knowledge sharing, and concepts of health and well-being</p> <p>Practice the 4 R’s of research (respect, reciprocity, relevance, and responsibility)</p> <p>Follow ownership, control, access, and possession (OCAP) principals</p> <p>When doing <i>integrated KT</i>, utilize the multiple types of knowledge and ways of knowing</p> <p>When doing <i>end-of-grant KT</i>, consider how to get messages out in partnership with community members, Aboriginal/Indigenous community-based organizations, and Aboriginal/Indigenous leaders/elders</p>



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is <i>less</i> important than the fact that research is being done	information for geographical populations) that support investigator-initiated studies as well as client-based research
<b>Enlightenment Model</b>	
Research that develops concepts or theories that “seep out” over time, diffusing into dominant discourses; more common in social science research	

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Despite the emphasis on health research KT, numerous scholars who work in Indigenous research contexts have drawn attention to how aspects of mainstream concepts and language around KT are inadequate and inappropriate for research with Indigenous communities. It has also been argued that KT strategies with Indigenous peoples must be re-conceptualized, further developed, and evaluated (Estey, Kmetz, & Reading, 2008; E. A. Estey, J. K. Smylie, & A. Macaulay, 2009; Hanson & Smylie, 2006; Ranford & Warry, 2006; Smylie, 2011; Smylie et al., 2004; Smylie et al., 2014). In this paper I used the term *knowledge translation (KT)* because of its current currency in the health research field however, I prefer the term *knowledge sharing*. To me, the term *knowledge sharing* implies a relational and multi-directional form of communication rather than *translation*, which implies one-way communication from researcher to “knowledge users”.

### **3.3.3 Indigenous KT.**

The concepts, language, and history of KT are rooted in particular epistemologies; epistemologies that are born out of bench science and other quantitative research methodologies. The idea that knowledge and actions are separable often does not agree with Indigenous paradigms, where knowledge and action frequently are intertwined and inseparable (Smylie et al., 2014). In other words, knowledge is gained through “doing” something that is visible, tangible, or can be felt. It is for Indigenous communities to have “the right to make decisions about what, why, how, and by whom information is collected, as well as how it will be used and shared” (First Nations Centre, 2007, p. 4).

Estey et al. (2010) draw attention to four important activities for researchers when planning KT with Indigenous people: (a) clarify what KT means to both researchers and Indigenous communities; (b) acknowledge and work through any history of negative experiences between Indigenous research participants and past researchers; (c) reach consensus on what “doing KT” will look like in a particular project; and (d) discuss and decide on roles and responsibilities of various people invested in KT.

## **3.4 Institutional Ethnography (IE)**

### **3.4.1 What is IE?**

The concept of an *institution* in institutional ethnography refers to any organization that coordinates and concerts peoples’ activities and experiences from a distance, often removed or invisible to the people being coordinated (D. E. Smith, 1999). The word *organization* in the context of IE refers to any nexus whose function involves coordinating or organizing peoples’ activities. *Ethnography* refers to detailing particular

everyday experiences of people through descriptions of their surroundings, circumstances, and activities. IE studies aim to uncover and “make visible” the social relations that shape and influence the everyday lives of a certain group of people (Smith, 1990). IE specifically investigates how institutions organize work that takes place within and outside of institutions (Smith, 2004). Smith encourages the researcher to consider how when “[Y]ou get out of bed, turn on the tap, make coffee, read the newspaper you collected from your front step....you are participating in [social] relations (municipal water systems, international trade, the mass media)” D. E. Smith (2006, p. 111).

IE has been well accepted and used to make evidence-based policy and practice changes in the organization of health care, education, social work, employment and job training, environmental policy, and community life (de Montigny, 1995; Diamond, 1992; Eastwood, 2002; Mykhalovskiy, 2001; Nichols & Griffith, 2009; Townsend, Langille, & Ripley, 2003; Turner, 2001). Dorothy Smith, a sociologist who developed IE as it is practiced today, argues that many qualitative research methodologies are used within a theory or framework that often strips contexts, removes people, and renders them invisible—a disappearing act. Fundamentally, she claims that it is not until we see differences in how social relations are expressed that we even think about how social relations shape our experiences. IE assumes that the everyday world is comprised of social relations that can be explored and that it is the job of researchers to make what is taken for granted visible.

The entry point of an IE research study is called a *problematic*. A problematic is formulated when a particular standpoint (that of the researcher or a research participant) of everyday lived experiences is profoundly connected to social relations that are far

removed (invisibly so) from their actual experiences. The researcher is then tasked with uncovering the ways in which particular experiences are “hooked into” ruling relations; relations that coordinate the things that go on in a particular setting. Often the ruling relations are embedded in policies, forms, procedures, and other institutional regulations that are activated by the people that are employed by/in an institution. When possible and deemed relevant, IE researchers may explore the history behind how particular regulatory tools came into being. It is the job of the researcher to make visible the unseen ruling relations that coordinate the activities or people in a particular location—socially, geographically, or organizationally. Researchers must:

- document the standpoint of original informants;
- learn about particular contexts and environments in which the standpoint informants live or work;
- uncover how people make use of relevant texts in their practices;
- describe what practices are shaped by texts that people rely on; and
- detect how informant practices are coordinated by texts that are invisible to them (Bisaillon, 2012).

IE has been used in a variety of health research studies. Ng et al. (2013) highlight the “disjunctures between policy and practice and identify opportunities for change” (p. 1) in the work of special education for children with chronic health conditions or disabilities. Rankin and Campbell (2009) make visible the ways in which “nurses play an active part in the subordination of their own professional judgment to the objectified knowledge and knowledge-based practices that externalize decision making...” (p. 1).

Sinding (2010) illustrates the work of marginalized patients as they navigate cancer care, resulting in cancer treatment disparities. Bresalier et al. (2002) conducted an extensive IE research study on the work of people living with HIV/AIDS accessing the health care system, AIDS service organization and social service agencies.

### **3.4.2 Decolonizing aspects of IE.**

IE makes institutional work visible. It is a method of inquiry that can locate taken-for-granted (and colonial) assumptions within institutional organizations and make them visible. In the context of the effects of colonization on the health of Indigenous peoples in Canada, IE is particularly fitting because of its attention to *ruling relations*. Ruling relations describe the use of policies, forms, procedures, or other regulatory texts that coordinate peoples' activities—usually invisibly so. IE can begin make visible how health, economic, environmental, and other policies are clearly linked to large health disparities between Indigenous and non-Indigenous populations (Frohlich, Ross, & Richmond, 2006; Richmond & Ross, 2009).

IE studies begin from the standpoint of people whose everyday lived experiences are profoundly connected to social relations that are not visible in their actual experiences. When an IE study begins with the everyday lives of Indigenous people, researchers can uncover how particular experiences are “hooked into” ruling relations that are embedded in texts that are activated by people that work within an institution. In IE, researchers will also explore the history behind how relevant regulatory tools came into being. Understanding how and why institutional texts were developed can elucidate how

they are connected to other texts; texts with political agendas, outdated texts, or influential texts that few people know about.

Researchers using IE do not aim to hypothesize or point blame at individuals. IE researchers explicate. Data analysis is focused on piecing together how actual texts organize people's lives through institutional work rather than peoples' attitudes or behaviours. IE is similar to the conflict resolution motto, "focus on the problem, not the person." By taking the focus off individuals, I suggest that people are more likely to participate in interviews, engage in discussions about findings, and get involved in recommendations stemming from IE research. Focusing on texts rather than individuals creates more fertile ground for institutions with (overt or subtle) colonialist practices and policy to be engaged in the research study and its KT activities.

### **3.5 Commitment to Decolonizing Health Research: Adaptations Made in an IE Study**

I suggest that IE has the methodological flexibility that allows researchers and communities to conduct a community-based study with KT activities using decolonizing principles. I used IE to examine how supports and services are coordinated for children and youth medically diagnosed with FASD in a rural Indigenous community in eastern Canada. Beginning from the caregivers' and parents' standpoint, I documented peoples' everyday lived experiences, analyzed a wide range of texts (e.g., intake forms, policies, and training manuals), and observed community and institutional settings to illustrate and explain how everyday lives are (un)intentionally coordinated by institutions and by staff that do the work of the institutions.

The attraction of using IE was both its methodological flexibility and comprehensiveness in making explicit how relevant supports and services are organized in an Indigenous community that has complex and unique jurisdictional arrangements between federal, provincial, regional, and local governments. Just as Thorne (2013) urged qualitative health researchers to “take a break” from particular methodological dogmatisms and instead creatively adapt useful and insightful research methods of inquiry to answer relevant health research questions, I used IE to meet the interests of an Indigenous community.

The rural Indigenous community involved in my IE research study is currently working through a complex transition to self-governance, a transition that is sometimes referred to as *devolution*. Educational, child welfare, primary health care, social health, justice, and other systems tied to this community remain tied to historically colonial institutions. Despite mutually good intentions, there are still tensions and assumptions made about the roles and responsibilities of non-Indigenous government institutions as they continue to be involved in this Indigenous community. My study sought to make the work of caregivers, community resources, *and* institutions visible. People within most institutions are predominantly non-Indigenous and unaware of how their work is tied to other institutional processes, documents, and in particular—the everyday lives of people the institution aims to serve.

### **3.5.1 A community-based research (CBR) approach.**

The term *community-based research* is ambiguous and broadly used. Many researchers, across disciplines, have used CBR to describe their projects and studies.

There is great variation in the level of community involvement throughout all stages of any given study, from the development of research questions to disseminating results. A non-contentious definition for CBR is a research study that is: (a) situated physically in and being of practical relevance to a community, (b) collaborative with shared control between community members and researchers throughout the research phases, and (c) action-oriented in ways that help facilitate and promote social change and equity (Centre for Community Based Research, 2013). Based on community-based health research (CBHR) guidelines developed by Israel, Schulz, Parker, and Becker (1998), guidelines for Indigenous health research were further developed to suggest CBHR must:

- acknowledge historical experience with research and with health issues and work to overcome the negative image of research;
- recognize tribal sovereignty;
- differentiate between tribal and community membership;
- understand tribal diversity and its implications;
- plan for extended timelines;
- recognize key gatekeepers;
- prepare for leadership turnover;
- interpret data within the cultural context; and
- utilize Indigenous ways of knowing (LaVeaux & Christopher, 2009).

Very few researchers have developed CBR studies using IE. Bresalier et al. (2002) explored the work people living with HIV/AIDS managing their health; Pence (2001) studied how the criminal justice system is organized around women who are seeking



safety from domestic abuse; Campbell, Copeland, and Tate (1998) focused on how service provision was organized for people living with disabilities. In my IE study, the impetus for using a CBR approach came from an interest and commitment in doing research that would be relevant, valuable, and practical to a community.

There are CBR elements in my study that are not necessarily common practices in IE studies. First, preliminary discussions heavily involved community members and leaders in establishing the research questions, the research design, which community members would be involved, and the timeline. Community members and leaders helped me both identify and connect with key informants (including directors of health, education, child welfare). Throughout the data collection and analysis stage, I consulted with community members and leaders as well as additional community stakeholders that were identified during the study. Ongoing and informal consultations helped secure interviews that would otherwise be difficult to secure, provide political and historical contexts and explanations for preliminary findings, and articulate recommendations (based on findings) that would benefit the community. In short, this study fit the three basic tenets of CBR as identified earlier and Indigenous CBHR guidelines as outlined by LaVeaux and Christopher (2009).

### **3.5.2 Integrated and Indigenous KT.**

Before the research study began, a community-researcher agreement was created and signed between a community leader and me. This agreement outlined how the study would adhere to the OCAP principles. The OCAP principles (2007) were written, in part, to reclaim how research is conducted with Indigenous peoples based on three core points:

(a) historical research relations were “colonial, oppressive and exploitative” (p. 4); (b) capacity building in research skills must be prioritized for research within Indigenous populations; and (c) Indigenous people have the right to self-determination, including what and how research is done.

Understanding the three core points and the four principles of OCAP—ownership, control, access, and possession—the community leader and I discussed how following the principles would actually work in this community, with an IE study, and with me as researcher. We discussed limited human resources as it related to capacity building in research skills, community members that would be consulted throughout the study, infrastructure—or lack thereof—for secure storage of research data within the community, and protocols for disseminating research findings outside of the community such as academic conferences and papers. We also discussed how research on FASD and the community could easily stigmatize the community and therefore must be presented with a strengths-based lens. As a researcher, I agreed that I would do the following:

- conduct and analyze interviews with translators, if necessary;
- manage and store the research data;
- provide the community with a copy of all research findings and dissemination materials;
- seek community permission before presenting or submitting writing about research that may identify the community;
- consult key community members throughout the research study;
- use a strengths-based lens when presenting findings on the research; and

- translate findings in ways that are both accessible and useful to the community.

My approach to fulfilling the aforementioned commitments was a relational one. I suggest that a relational approach is one where researchers invest in relationships, give and share of themselves, and recognize personal and community strengths—both in and outside of formal research contexts. Building authentic relationships takes time. It begins with the first conversation about a potential research study, continues throughout all phases of a research study, and ideally continues after the research study is complete. The time between my first conversation, exploring the possibility of conducting research with community stakeholders, until I started data collection was approximately three years. Similarly, as I write this paper, I continue to be involved in several KT initiatives that began over one year ago, when key findings from the research on FASD were first publicly shared in the community.

An integrated KT approach is aimed at engaging key stakeholders and target audiences throughout all stages of research. IE is well positioned for an integrated KT approach that aims to build interest and investment in the research results, maximizing the potential uptake of research findings and recommendation. In IE there is often a progression of documenting *local* accounts of everyday lived experiences (standpoint informants); documenting how institutions are implicated in the coordination of the standpoint of informants' relevant activities; and documenting institutional work by *extra-local* informants that are far removed and unfamiliar with the standpoint informants but play an important role in creating, deciding on, or enforcing governing texts.

In my case, interviews with local and extra-local informants helped identify target audiences and champions that would be instrumental in addressing research

recommendations at the end of the study. KT literature suggests that effective strategies often include identifying and building relationships with strategic target audiences and particularly with policy and decision makers (CHSRF, n.d.; CPHI, 2001; Organizing Committee for Knowledge Transfer: Looking Beyond Health, 2000; Ross, Lavis, Rodriguez, Woodside, & Denis, 2003). In Indigenous health research, having champions and influential people is critical to making the research findings and recommendations have traction—for a decolonizing agenda (Ranford & Warry, 2006; L. T. Smith, 2012; Smylie, 2011).

Undocumented historical and political contexts were shared through formal and informal conversations, meetings, and interviews. Gatekeepers and influential people within the community and organizations were identified. Research deadlines were moving targets because of changes in leadership and staffed positions, community events planned at the last minute, community priorities that shifted, tragic deaths in a small community, and the reality that organizational leaders required frequent air travel to other city centres, often without much notice. However when research plans required changes or postponement, opportunities to participate in community life would often arise and as a researcher, I learned more about how this particular Indigenous community shared information and planned events. For example, I learned that the local radio was a common and easy way to communicate—in the local Indigenous dialect—with community members; community planning in areas such as education or health would not draw a large crowd; door-to-door delivery of invitations or informational brochures were done regularly by organizations; and despite being a small community, people did not know everyone in their community.

In addition to face-to-face conversations, I incorporated many visual diagrams and illustrations to convey research concepts, design, and findings. Using visual aids helped make information both accessible and engaging for a broad range of people—from the stay-at-home foster parents to medical specialist and from Indigenous elders to non-Indigenous government directors. The use of visual graphics leveled the playing field, demanded less time of the research participant, and engaged people in more conversational ways than any text-heavy document that I could have been produced instead.

### **3.6 Examples of How Adaptations Were Made at Different Stages of Research**

#### **3.6.1 Research development stage.**

In the research development stage, I travelled to the rural Indigenous community to meet with two community contacts and others to ask what kind of research on FASD they wanted to see happen. The responses I got were tentative and unsure. However when I asked what they wanted to see happen in the community, not necessarily in a research context, people comfortably articulated that they wanted information or “proof” that they needed more supports and resources for people living with FASD, in order to create a community where people with FASD could live without stigma, and to improve the quality of services for families living with FASD. After much reflection and discussions with others who had done community-based work with this community, I decided to take a different approach for a meeting that was scheduled for a later time in this same visit. By different, I mean that I would not ask such broad questions. Instead, I proposed an IE research study design with research questions as a place to start dialogue—explicitly

stating that my proposal was up for negotiation, discussion, and that I was not married to the proposed design. People in the room were both curious and supportive of the ideas I presented on what IE was, how it might look, and what it could possibly accomplish.

I felt conflicted about proposing a research study as a PhD researcher rather than have the study be conceptualized by community members. I wondered how much community ownership there might be when I have approached a community to ask if they wanted to do research together rather than the other way around. At the time, I was plagued with questions like: How much do I request of peoples' time to have a process that feels better for me, as a researcher—such as having a brainstorming session to develop a research project dreamed up by the community? Is it fair to ask community members to help develop a research project when they have never been part of such a discussion before? Is it problematic to propose a preliminary design based on my own discernment of what a study may have to offer the community, from talking to interested and invested community members?

### **3.6.2 Data collection stage.**

Part way through the data collection stage and because of the nature of an IE study, I could identify most key people and institutions that were responsible for supports and services associated with families that had a youth with an FASD diagnosis. Having met many people that worked with children or families living with FASD in the design and data collection stages of my research, I was able to help connect people to each other as issues or questions came up both inside and outside of interview contexts. I was also involved as a committee member on various regional, provincial, and national FASD-

related organizations in addition to networking at international FASD conferences where I became familiar with many current and best practice approaches, material resources, and successful initiatives related to FASD prevention and support. As a researcher, the benefit and luxury of being able to travel and participate in special events and conferences outside of the province allowed me to connect people with other people and helpful information.

At the end of an interview with a director and after the recorder was turned off, he asked: *What does the FASD liaison do? Are there any models for working with youth with FASD in other jurisdictions like mine? Are there any good resources you'd recommend for my staff? If I have questions about ---, who should I talk to for a referral?* There were several interviews and many conversations where similar lines of questions were asked. On a separate occasion, I learned that one community had contracted an FASD educator to deliver training in their community and not long afterwards learned that someone in a relatively nearby community was struggling to find funding for FASD training, so I connected people in both communities. As a result, the training contract was modified to affordably include both communities and, since the training, to collaborate on other initiatives. In both the aforementioned examples, my research-related relationships helped initiate connections for others—connections that resulted in consultations, planning meetings, working groups, and FASD training. I share these examples to illustrate how researchers can facilitate KT in ways that extend beyond the research study itself and provide tangible benefits to a community.

During informant interviews, I used my own discretion about when it was appropriate and relevant to share my identity as a mother of young children, including a

child with an FASD diagnosis, and/or a foster mother to a child whose Indigenous family may be known to the informant. The significance of this point is that in IE, there is a term called *institutional capture* that refers to a phenomenon that often occurs when a researcher and informant share a common identity. The concern is that informants may use jargon or spend less time explaining details while researchers “fill in the blanks”, without thinking critically and interrogating the discursive organization of what informants are sharing. In the end, I decided to be very mindful of institutional capture *and* disclose my identity as a mother to a child with FASD whenever I interviewed caregivers of children with an FASD diagnosis, in particular. I felt that this detail mattered to caregiver informants and my integrity as a researcher on this topic. I was motivated to accomplish two things: (a) create a sense of honesty, whereby I would share something about myself before asking others to share honestly about their own experiences and (b) establish that I have a long term and vested interest in the topic of FASD.

### **3.6.3 End-of-project KT stage.**

In an IE study, there is no expectation that researchers will ask informants for their recommendations on how to improve an issue or problem; however I did. My reason for asking informants for recommendations was informed by CBR and the ownership, control, access, and possession (OCAP) principles that value different ways of knowing and community strengths. After my analysis was complete, I compared my recommendations based on research findings with recommendations from interviewees, and found that there was a lot of overlap. Community stakeholders were particularly



interested in what recommendations would emerge from my research. I shared key findings and facilitated discussion on proposed recommendations at two public community presentations. For the community presentations, I created and used contrasting maps to provide evidence of the range of services available versus services that were being used. Illustrations were also used to show eligibility criteria for available supports and (the lack of) coordination between institutions that share the same “clients.” The use of visual maps, diagrams, and illustrations meant that people with diverse backgrounds, education, and connection to the topic were able to make meaning of the research findings to both comment on and suggest recommendations based on the research. I was then invited to serve on an FASD Working Group that included stakeholders from two Indigenous communities. My research report was used to inform the FASD Working Group’s work plan and several recommendations stemming from this research have been incorporated into the community’s health strategy—a health strategy led by Indigenous leaders in the community.

### **3.7 Conclusion**

One challenge that researchers using IE for decolonizing research may encounter is presenting or writing critically about the research findings and its implications. IE as a method of inquiry is fundamentally intended to uncover and make visible the ruling relations – a concept that is tied to (a) how power is built into the way institutions are organized to accomplish particular goals, as opposed to the individuals who *do* the organizational work (Foucault, 1979) and (b) material conditions that inform how and

what people can produce<sup>2</sup> (Marx & Engels, 1976). While this IE study produced evidence of colonialist practices and policies that need attention, presenting this evidence in a public arena—such as academic publications—did not lend itself well to using a strengths-based lens that I agreed to in the community-researcher agreement. In this study, the findings were presented and discussed in meetings with people involved in the research and people implicated in the recommendations. A research report briefly outlining the study, key findings, and recommendations was submitted to community leaders to be used to inform a community health strategy. And since one of the key findings was the lack of awareness and coordination of services and supports available to the community, one of the strengths-based KT activities involved creating community asset maps that were later delivered to each household in the community in conjunction with a community-wide event to celebrate existing health and healing services.

I suggest that IE as a decolonizing method of inquiry could be in line with Indigenous values, demonstrate community accountability, give back and benefit the community. Ethical research with and for Indigenous people also requires authentic relationships and open discussions about differing epistemologies—that is, how we know what we know (Bull, 2010; Kovach, 2009). Just as researchers and Indigenous people involved in research should discuss differing epistemologies, researchers must also continue to facilitate dialogue with other researchers on how we know what we know about conducting decolonizing research.

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<sup>2</sup> The word “produce” is language that Marx and Engels (1976) used to talk about how one’s activities and productivity is directly linked to the material conditions that one lives under.

There is a frequently referenced sentiment that Indigenous communities in Canada have been ‘researched to death;’ however, some communities have clarified that their fatigue is tied to being part of research that they have not requested, benefited from, or had control over how they were represented. Bull (2010) suggests that meaningful community engagement in research can research them “back to life” (p. 17). While literature on CBR strongly encourages community members to be highly involved in all stages of research, I suggest that it is not always possible or desirable to expect that a community, particularly a rural Indigenous community, have that level of human and time resources to dedicate to research. I argue that researchers need to continue thinking creatively about using methodologies from other fields—such as sociology, as is the case with IE—and adapt them to expand the possibilities for conducting decolonizing health research.

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## **Chapter 4**

### **Reframing tensions as opportunities for transformation:**

#### **Strategies to unforeseen obstacles as a doctoral student doing research with an Indigenous community**

##### **Abstract**

In this paper, I illustrate how a relational approach in a research study facilitated transformative experiences for research stakeholders and researchers alike. When conducting research with Indigenous peoples and communities, there are numerous principles and practices that must be taken into consideration. As a doctoral student conducting community-based research in a rural and remote Indigenous community in eastern Canada, I aimed to follow best practice guidelines such as the four R's of research—respect, reciprocity, relevance, and responsibility—and the Ownership, Control, Access, and Possession (OCAP) principles. I reveal four unforeseen tensions and challenges that arose during my applied health research study and discuss the strategies and rationale for how I dealt with them. The four tensions I describe include: (1) finding out that an independent consultant was hired to conduct research that overlapped with mine; (2) reconciling university requirements of producing a thesis that uses inaccessible terminology and concepts to many community members; (3) being asked to name the community in publications without compromising confidentiality of individuals involved in the study; and (4) discerning how much energy from community members was fair to spend discussing academic dilemmas.

While some of the issues I encountered may be relevant to any researcher based in an academic institution, I argue that there are some unique aspects to being a graduate student. Indigenous scholars have acknowledged the importance of researchers creating authentic relationships with Indigenous people involved in research. Using examples from my doctoral study, I illustrate how I built authentic relationships with community members by being transparent about my positionality. Furthermore, I suggest that researchers must write about their tensions and strategies to further the work of conducting decolonizing research with Indigenous communities.

**Keywords**

community-based research; Indigenous population; Aboriginal community; Indigenous community; graduate research; institutional ethnography; OCAP principles

### **3.1 Introduction**

In this paper, I reveal and discusses tensions found at the nexus of conducting applied health research with an Indigenous community and completing a doctoral study. I encountered a number of unforeseen obstacles that required pauses, personal critical reflections, and uncomfortable conversations at different points of my doctoral research study with a rural Indigenous community in eastern Canada. Horowitz, Robinson, and Seifer (2009) suggest that the field of community-based research (CBR) has moved from the margins to the mainstream of research practices. After several years of conducting CBR as a non-academic researcher, I felt that I had reasonable expectations around common challenges of doing CBR and translating research into formats that benefit the community. Having now completed my doctoral research, I suggest that graduate students conducting community-based research with Indigenous people are differently positioned than other experienced and established researchers. While there is a growing body of literature on guidelines, principles, and general approaches for conducting research with Indigenous people in Canada, there is a dearth of literature on considerations and challenges for graduate students doing CBR and even less so in Indigenous research contexts. While some of the issues I encountered may be relevant to any researcher based in an academic institution, I argue that there are some unique aspects to being a graduate student.

## 4.2 A Doctoral Student Perspective

### 4.2.1 Situating and positioning myself.

Bakhtin (1981) writes that dialogue between two people is “half someone else’s” (p. 293). When researchers and community partners, informants, or stakeholders engage in dialogue, we are co-creating knowledge (Kovach, 2009). If researchers are serious about engaging in authentic relationships with an Indigenous community, we must be honest about how we are *situated* (England, 1994). By *situated*, I am referring to being transparent about our positions when they may be relevant and relative to those we are engaged with. Lowan-Trudeau (2012) points out that positioning ourselves as researchers is particularly important for research with Indigenous people and is vitally important to building relationships in many Indigenous cultures (Broad & Reyes, 2008; Lowan-Trudeau, 2012). In sum, researchers need to (a) critically reflect on how their positionality affects how research is interpreted and presented and (b) consider how being transparent with community partners and research participants may enhance social interactions.

My doctoral research study examined the social organization of supports and services provided to children and youth diagnosed with fetal alcohol spectrum disorder (FASD), a medical term to represent a range of diagnoses related to prenatal alcohol exposure. I interviewed caregivers of children with a medical diagnosis of FASD; school staff; social workers; community workers; provincial managers; physicians; medical specialists; FASD program coordinators; and directors of education, health, and child welfare. I also met with other community stakeholders to discuss the research design, get permission to conduct research in the community, discuss preliminary findings, and



collaborate on dissemination and recommendations. In short, I interacted with a diverse group of informants.

My doctoral research took place in a rural and remote Indigenous community, an Innu First Nations community. I look Indigenous to many people, including some Innu who thought I was Innu, though in reality I have a mixed heritage of white Mennonite and Japanese descent. One of my children is Innu with biological family ties to another rural and remote Innu community in the same province. This meant several people involved in my research knew—or knew of—my daughter’s family; and by extension, I have Innu familial ties. One key informant said he was happy to know that I would not reify the “one night stand” and since I have a Innu daughter, I was “practically married to the community” (Penashue, 2014). There were other aspects of who I am that I disclosed upfront to people, aspects that people frequently asked about, and some that I would only share if it seemed relevant or helpful in building rapport. For example, depending on the context, I shared that I am a parent to a child diagnosed with FASD; began my working career as a high school teacher; am an experienced community-based researcher; serve on local, regional, and national FASD committees; and am in a Faculty of Medicine doctoral program.

When meeting with people in the Indigenous community, I would always disclose that while I may appear to be Indigenous (or Innu), I was not. I would usually call myself a student rather than use PhD or doctorate or graduate student at the risk of being seen as trying to demonstrate some kind of “smartness hierarchy” and in some cases, people may not know what I meant by graduate student. I would tell people who my Innu daughter was because there was a high chance they would know her family; and with caregivers, I

would share that I am raising a child living with FASD. The purpose of sharing my “situated-ness” is to provide a backdrop to the next section where I discuss specific tensions I encountered and how I either overcame them or was left with more questions.

#### **4.2.2 Background on the Indigenous community.**

The community of Sheshatshiu is one of two Innu communities in Newfoundland and Labrador, the most eastern province of Canada, and has a population of approximately 1300. While the community is rural, it is approximately 40 kilometers by paved road from Happy Valley-Goose Bay (HVGB), a community of over 7500 people and a hub for many health-related services for people living in Labrador. Residents of Sheshatshiu are almost exclusively Innu and Innu-aimun remains their first language. Like many other Indigenous people across Canada, the Sheshatshiu Innu have experienced colonization through schools, relocation, and loss of traditional ways of living off the land. In 2001, the Labrador Innu Comprehensive Healing Strategy (LICHS) was established for both Innu communities in Labrador. The intent of the Healing Strategy was to address core issues through holistic approaches that would restore a vision of healthy communities. The Healing Strategy included registering the Labrador Innu as status Indians, recognizing the two communities as bands under the Indian Act, as well as developing and implementing community-based health programming (Aboriginal Affairs and Northern Development Canada, 2007). The timing of my research coincided with the ending of the LICHS funding. My relationship with community members, developed through our research study partnership, has led to integrating the research recommendations into a Labrador Innu Healing Strategy (Innu Round Table, 2014).

A sentiment that was expressed by community members before my doctoral research started was that many university-affiliated researchers have come and gone over the years – with little investment in long-term relationships, meaningful results that the community can relate to, or public engagement at any stage of a research project. As a result, several community leaders had announced that the community was on a research moratorium. In reality, there were a few research projects in progress and they were almost exclusively projects that community organizations had initiated to address a particular priority issue. The frequent reference of Indigenous people being “researched to death” was not lost on me when I was at the early stages of planning my research. One informant during an interview shared,

If you want to be part of the research, you have to be part of the research. Don’t just go in there and fly in and parachute and just take off and run with it and be gone because we know people...we’ve been there; we’ve done that.

#### **4.3 Knowing Principles May Not Be Enough.**

The work of conducting a doctoral CBR study with an Indigenous community was, in part, informed by several key principles and policies. I familiarized myself with CBR and community-based participatory research principles in Indigenous contexts (B.A. Israel et al., 2003; LaVeaux & Christopher, 2009); the Tri-Council Policy Statement on Research Involving the First Nations, Inuit and Métis People of Canada (Canadian Institutes of Health Research, 2014); the four R’s of research—respect, reciprocity, relevance, and responsibility (Kirkness & Barnhardt, 2001); and the Ownership, Control, Access, and Possession (OCAP) principles for research with First Nations peoples of

Canada (First Nations Centre, 2007). A summary of the principles and policies are found in Table 4.1.

**Table 4.1 Principles and Policies for Research with Indigenous People**

*Various Articulations of Principles and Policies by Different Authors and Institutions*

<b>Contextualized CBPR for Indigenous Research</b> (LaVeaux & Christopher, 2009, p. 7)	<b>Canadian Tri-Council Policy Statements</b> (Canadian Institutes of Health Research, 2014)	<b>The Four R's</b> (Kirkness & Barnhardt, 2001)	<b>OCAP</b> (First Nations Centre, 2007; Schnarch, 2004)
Acknowledge past negative experience with research and the effects of colonization on health issues.	Engage with community when on Indigenous land, recruitment includes Indigenous identity, research interprets Indigenous history, artifacts, and/or identity.	<b>Respect</b> for cultural integrity: cultural knowledge, traditions, and core values must be recognized.	<b>Ownership:</b> the community owns the information collected during research in the same way people own their personal information.
Work to change the experiences of research.	Determine nature and extent of community engagement with community members; get permission from formal Indigenous community leaders; recognize and engage with Indigenous organizations and communities – rural and urban.	<b>Relevance</b> to Indigenous perspectives and experience: appreciate traditional knowledge, understanding, and representation as a way to view the world around us.	<b>Control:</b> the community has a right to control all aspects of research processes that impact them (such as data management, review process, conceptual frameworks)
Recognize Indigenous governance.	Understand research approval process for a community; pass institutional research ethics review; articulate engagement with community to the ethics board; make an agreement when a community has agreed to participate.	<b>Reciprocal</b> relationships: research is an opportunity for all partners to be producers and	<b>Access:</b> communities have a right to
Differentiate between Indigenous and community membership.	Take diverse interests into consideration within Indigenous community; make		
Understand Indigenous diversity and its implications.			
Plan for extended timelines.			

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Recognize key gatekeepers.	research relevant to community needs and priorities; support capacity building.	consumers of knowledge.	access data about themselves, regardless of where the data is held.
Prepare for leadership turnover.	May conduct research that is critical of Indigenous governments and governments that exercise authority over Indigenous peoples.	<b>Responsibility</b> through participation: people in positions of power/authority must make the process of research hospitable and critically examine their socially constructed power.	
Interpret data within the cultural context.	Respect community customs and codes of research practice; consider collaborative and participatory approaches; engage, include and recognize Elders and other knowledge holders.		<b>Possession:</b> is a literal directive to have the data stored where they can self-determine and self-govern their information.
Utilize Indigenous ways of knowing.	Community representatives should collaborate on data interpretation and review findings before public dissemination.		

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The principles and policies found in Table 4.1 are congruent with each other and with a body of literature on decolonizing research. Literature on decolonizing and Indigenous research is largely focused on conducting research that does not reify the colonial relationship between knowledge institutions that are predominantly non-Indigenous and Indigenous people being researched. Metaphorically speaking, decolonizing research literature suggests that Indigenous communities should be in the driver's seat (Atalay, Rains Clauss, McGuire, & Welch, 2014). In the context of my doctoral research experience of working with an Indigenous community, the vehicle metaphor would be one where I was the driver with Indigenous passengers navigating the

way on a long road trip. While I have experience driving a vehicle and following road signs, others in the vehicle are familiar with the roads and the lay of the land.

Knowing and practicing principles and policies are two different areas of competency. I argue that while researchers may be familiar with principles and policies, discerning *how* to put the principle and policies into practice can be challenging. My experiences have taught me that there are occasionally principles that community partners may not embrace and/or agree with. The next section briefly outlines common challenges, tensions, and experiences documented by other researchers who have conducted CBR and research with Indigenous peoples.

#### **4.4 Common Tensions, Challenges, and Experiences of Other Researchers.**

There are common tensions researchers may face when conducting CBR research with Indigenous people or communities while conducting graduate research. Anticipating or knowing common tensions or realities experienced by others can help prepare graduate students and other researchers. In addition to providing reality checks, literature on the tensions of CBR in Indigenous contexts may serve to minimize tensions, provide assurance that particular experiences are common, suggest strategies to overcome possible obstacles, and highlight key competencies and skills that are not necessarily emphasized in research methodology courses.

Examples of competencies and skills that are valuable when conducting research that may not be explicitly taught or emphasized in university research methods or methodologies courses include nuanced aspects of communication and conflict resolution skills. There is not much literature on effective qualities and competencies needed as a

community-based researcher; however, looking at the list of expectations for conducting research with and for Indigenous people, one cannot take for granted that researchers know how to *be* relational. What are the basic skills one needs to either possess or practice to build relationships of trust, respect, collaboration, and effective communication? Dobbins et al. (2009) offer that the personality traits of an skilled knowledge broker, a person who builds rapport between researchers producers and users, is one who has very skilled mediation, team building, flexible, diplomatic, and communication skills. I partially attribute the successes of my relational approach in this study to a background in conflict resolution and CBR, as mentioned earlier as part of my situated-ness.

Several researchers have written about tensions faced by academic researchers conducting CBR in Indigenous and non-Indigenous communities. Examples include sharing the cost of research expenses, discerning who represents the community, agreeing on a concept of scientific rigour in research, and finding funds to support relationship and research development work before a research project is established. Table 4.2 below outlines issues that have been identified by other researchers or studies doing community-based participatory research (CBPR) and research with Indigenous people.

**Table 4.2 Common Tensions and Experiences**

*Tensions and Experiences faced in CBPR and in Research with Indigenous People and Communities*

CBPR [taken from Horowitz et al. (2009) and Israel, Schulz, Parker, and Becker (1998)]	Research with Indigenous People/Communities
Research timeframes are often longer than non-CBR studies.	If researchers must be approached by Indigenous communities, junior researchers may not get experience because communities may only ask people they know (Castleden et al., 2012).
Mistrust of researchers; researchers must understand historical events and build trust through authentic relationships.	Funders rarely provide adequate funding for the development of a project or for building necessary relationships (Bull, 2010).
Gaps in culture and social class between researcher(s) and community can cause conflict.	How researchers get community consent greatly varies and may not be clear (Bull, 2010).
Different objectives for research and perspective on research process can cause disagreement.	Indigenous researchers may be viewed as betraying Indigenous ways of knowing (Kovach, 2009; Smith, 2012).
Cost of the research (researchers and community partners) may feel inequitable.	Academic institutions do not always know how to support, build capacity, or mentor Indigenous graduate students in Indigenous research (Kirkness & Barnhardt, 2001; Kovach, 2009; Wilson, 2008).
Authentically sharing of power through resources and decision-making.	Relational work between research institutions and Indigenous communities may not have been done yet (Kovach, 2009).
Conflicts are inevitable – how they are addressed is what matters.	Research ethics boards may not be familiar with best practices and principles for conducting research with Indigenous people (Ball & Janyst, 2008).
Decisions on who represents the community and how is the community defined.	Researchers may not know how to create <i>ethical spaces</i> (when two or more
Questions (from academic community) about scientific rigour of research.	
Research design cannot always be known in advance of securing ethics and funding approval.	
Demands of university and funders can be difficult to justify.	
Unforeseen politics and social dynamics in the community.	



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disparate worldviews come together to engage in meaningful dialogue) (Ermine, Sinclair, & Jeffery, 2004).

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#### **4.5 Emergent Issues from My Doctoral Research Experience**

In the following section, I describe four issues that arose while I was a graduate student conducting research in Sheshatshiu. I then share and discuss strategies used to address or resolve each issue.

##### **4.5.1 Issue #1: Someone else is doing similar work in the community?!**

I was in the process of finishing an initial data analysis and had plans to soon return to the community when I found out about a consultant who had just been contracted to do research on FASD in the community. The purpose of my next trip was to meet with research informants and key stakeholders in the community to discuss the preliminary findings. I found out, through one of my informants, that a consultant who was known to the community, though not from the community, was hired to do work that clearly overlapped with my research. The person sharing this information with me was not involved in the decision to hire the consultant and did not have any context or insight into the process that went into that decision. I came to understand that this consultant was hired in a process that I was not privy to. As part of the Labrador Healing Strategy development, a leadership committee made a decision to hire consultants to provide assessment reports for each of their newly formed working groups—of which an FASD Working Group was one. The people who made the decision were not close to my

doctoral research at that time and I had no reason to believe that people were intentionally withholding information from the consultant or me.

I decided to get in touch with the consultant and we scheduled a time to meet. In our first meeting, I discovered three important details: (a) we shared similar views and commitments to working collaboratively with invested community members, (b) the consultant was hired to do an assessment and submit a report within the upcoming few months, and (c) the consultant needed to gather information I had already collected. This meeting flagged three practical issues for me. First, I was concerned about research fatigue and confusion in the community about being interviewed twice by two separate people about the same general information. Second, I was concerned about the timing of the request for her report since it was earlier than I planned to share the results from my study. Third, I was unclear how the community “ownership” of the ownership, control, access, and possession (OCAP) principles applied to my initial data analysis and recommendations versus later iterations of data analyses and recommendations, based on community stakeholder reflections and input that the community was not privy to yet.

Regarding my first concern about research fatigue, in my meeting with the consultant I learned what kind of information was of interest. The consultant was tasked with conducting research in both Innu communities, whereas my study was only in Sheshatshiu; and her research was not as in-depth as mine. However, some of the information they wanted was information I already had—information that belonged to the community, and the same community that hired her. It was not really *my* information to share and yet my initial thought was that informants had shared that information with me for the purpose of the study I was working on. In other words, the informants were

entrusting the information to *me*—not *me and anyone else* that I thought ought to have access to data.

My second concern was about the content and timing of the assessment report from the consultant. The community stakeholders and I had not finalized a plan for how results from my study would be shared, represented, and documented. The tension between following the OCAP principles and fulfilling my academic requirements of writing manuscripts for my dissertation was not one I had anticipated. I had decided to write a manuscript-style dissertation, a thesis that is comprised of several manuscripts for submission or already published. While I was open and prepared to co-author papers with community members, one limitation to manuscripts that are part of a dissertation was the requirement that I “[make] a major intellectual and practical contribution to all work that is reported in his/her thesis” (Memorial University of Newfoundland, 2014, p. 4). I was concerned that research findings from my doctoral research versus that of the consultants would be blurred and my contribution and authorship in a future manuscript may be put into question since her report may be easily accessible to the public. Or worse, that my doctoral study findings would be seen as irrelevant to the community after the consultant’s report was completed.

My third concern is related to my first point about sharing data that belonged to the community. Both the contracted consultant research and me were committed to producing work for and with Sheshatshiu Innu First Nations. The OCAP principles are clear that research data must be owned and information must be controlled and managed by the community. However, I was unclear about how much ownership or control I had over how the data was analyzed. The Vancouver Protocol (Clever & Colaianni, 1997), an

international standard that outlines authorship on publications, explains that sharing data alone does not justify authorship. It was highly unlikely that community members or the consultant would write any academic publication submissions; however, any form of content that has been published in a public document or report needs to be declared when submitting an article to peer-reviewed journals. This was my concern. What if the most important findings from my research were published in a public report, or by someone else prior to my own academic publishing?

I was initially torn and wondered: (a) What am I risking by sharing research results with the consultant? (b) What information can I share without breaching confidentiality? (c) Does my contribution get acknowledged? If so, how? (d) If a community-based committee wants this consultant's report on a tight timeline, do I owe it to them to—ethically and in accordance with the OCAP principles—share my information? (e) What if someone requests that I hand over my information to the consultant? (f) What about research participant exhaustion? Will research participants from my study be wondering why someone else is asking them similar questions after I have already interviewed them? and (g) What is my role and responsibility in connecting with the committee that hired the consultant?

#### ***4.5.1.1 Strategies for Issue #1: Someone else is doing similar work in the community?!***

The consultant and I met to understand the nature of her contract, share the scope of my research, establish areas where our work overlapped, and brainstorm a plan for moving forward with the community's interests in mind. This meeting took place before

I met with my supervisor for our monthly meetings. When I shared this update with my supervisor, she was concerned about authorship and compromising my chance of publishing my doctoral research results—results that would be made public in a report that I had no say in. We talked through my options and, in the end, I drafted an memorandum of understanding (MOU) between the consultant and me.

The issue of academic publishing can be uncomfortable and awkward for academic researchers doing CBR and/or research with Indigenous communities. Publications are one form for academic researchers to advance in their careers and are historically one way researchers exploited Indigenous peoples and communities (Glass & Kaufert, 2007). On one hand, academic freedom is about being able to publish research findings without interference of governments, funders, or commercial entities; yet when doing Indigenous research using the OCAP principles, Glass and Kaufert (2007) ask “if a community requires that it review and approve a paper before publication...who should have the last word regarding publishing?” (p. 36). Castleden, Morgan, and Lamb (2012) write about the need for memorandums of understanding (MOU) that outline publication expectations to avoid tensions between pressures to publish academically versus community needs.

I shared the overall findings and names of people I had interviewed with the consultant. I also drafted an MOU that the consultant would: (a) cite data received from me in the report, (b) refrain from publishing any academic papers that included data from my research study without consulting me at the conception/development stage, and (c) provide me with an opportunity to review and discuss public documents that included aspects of my research before being made public. The consultant understood my

predicament and was willing to sign the MOU. I agreed to discuss this MOU with key community stakeholders I had connected with in my research. This MOU was then shared and approved by my supervisor and community stakeholders before being signed. The conversations stemming from the MOU did lead to a better mutual understanding of interests being served between the committee that hired the consultant, the newly established FASD Working Group, and community stakeholders close to my research. The consultant and I agreed to collaborate and produce material that would be valuable to the community.

After discussions with the people who had contracted the consultant, I understood that the consultant's report was intended to inform the work of the FASD Working Group and the Innu Health Strategy. It was agreed that I would submit a report alongside the consultant's so that the reports could be reviewed together and provide a comprehensive picture of what was happening in the communities as well as to compare recommendations. As I continued working with community stakeholders, my commitment to making my doctoral research meet the needs of the community was becoming more evident to community stakeholders. I was invited to participate regularly on the FASD Working Group, lead a committee on creating community asset maps, a recommendation in my report, and present the community asset maps at the Labrador Innu Healing Forum.

#### **4.5.2 Issue #2: Accessibility and academic publications.**

"...particularly in an Aboriginal context, community relevance and community usefulness may be the most telling measures of the worth of a study. The question

of quality is subordinate. The next point is that a community-driven, community-controlled project is more likely, although not guaranteed, to score highly on those measures.” (Schnarch, 2004, p. 89)

Personal experiences suggest that the notion of accessibility is an important ingredient for emancipatory CBR. By accessibility, I am referring to the importance of making oneself socially approachable and easy-to-reach by phone, by e-mail, or in person. I am also referring to the importance of using a language including actual language, terminology, visual tools that are understandable to the audience or target group I am appealing to. There is little emphasis in CBR, research with Indigenous communities, and knowledge translation (KT) on *how* researchers practice accessibility. My way of making myself accessible was to spend time in the community, attend community events, accept invitations to walks/tea/meals, share my connection to the community and to the topic of FASD, use familiar language and terms, and in some cases downplay my education by calling myself a “student doing a research project on FASD.” The advantage I had in the context of this research study was my “credibility” as a mother—of young children, to a child with FASD, and a foster mother. My situated-ness, as I described earlier, undoubtedly made me more approachable than someone who did not have a personal connection with the research topic or with the Indigenous community members informing the research study.

When it came time to share initial research findings and recommendations, I was challenged to produce materials that would convey information effectively and accessibly for a diverse group of research informants and community stakeholders. In the end, I

used a lot of visual diagrams and illustrations to convey key findings. Through many face-to-face meetings, presentations, and conversations, I drew attention to the relevance and implications of the research findings to the community. However as a doctoral student, there is an overt pressure and expectation to derive critical and intellectual insight from my research—findings, abstractions, and discussion that extend beyond the relevant findings that are important to the community.

The level of analysis and complexity that the community was interested in versus what I needed to produce to fulfill my academic requirements were incongruent. Herein lay my dilemma. How could I explain that I needed to produce “more intellectual” material from the study? Technically, the community owns the data, but how much of the intellectual property from analysis do they own? How can I ethically review my academic writing with a community representative when I am using language and concepts that are inaccessible and potentially irrelevant to the community, not to mention the time-consuming nature of participating in this task?

#### ***4.5.2.1 Strategies for Issue #2: Accessibility and academic publications.***

To make research findings accessible to community informants and stakeholders, I used multiple visual diagrams and illustrations to convey information and concepts. The rationale was to minimize the gap between those who are highly literate and familiar with content-specific language and those who may not speak English as their first language and are less comfortable asking questions. When speaking I used language that was part of everyday vernacular; when meeting with people one-on-one, I used terminology and explanations to mirror the level of content-specific language of the other person. In some



Innu social contexts I related to people by sharing some of my own experiences of navigating the education or child welfare systems as well as parenting a child living with FASD.

The research process and findings from the study in Sheshatshiu have resulted in multiple community presentations and discussion forums, a report that is informing the work of the FASD Working Group, and my role in leading the Innu Health and Healing Community Asset Mapping committee work. I realize that writing an academic journal article will not benefit the community. Since the community is explicitly named in my manuscripts, community members reviewed my draft manuscripts for my dissertation and academic publication as did people who are identified or are identifiable in the manuscripts. I believe that the relationships formed throughout the research study are built on a foundation of honesty and trust. I trust that the people who reviewed my academic manuscripts were frank about what they liked, disagreed with, or did not understand.

#### **4.5.3 Issue #3: Community acknowledgement after signing confidentiality forms.**

The default standard when conducting research is to keep the identity of research informants confidential. The assumption is that people are not supposed to be identifiable, especially in small communities where providing minimal information can reveal who said or did something. In Canada, there is a Tri-Council Policy Statement (TCPS) (Canadian Institutes of Health Research, 2014) that outlines how researchers, particularly university-based researchers, must adhere to policies on the ethics of

conducting research that involves people. The TCPS emphasized the importance of safeguarding peoples' identities; however also acknowledges that there may be instances where research participants may be comfortable being identifiable or even wish to be identified.

When researchers want to use a quote from a participant or informant, confidentiality is usually paramount and pseudonyms are used. Schnarch (2004) highlights that "at the heart of OCAP is self-determination, including recognition of First Nations jurisdiction over research in their communities" (p. 89). As I was discussing my hopes to write about aspects of this research for publications, a key stakeholder in this research who is also a community leader requested at the end of the project that I publicly name the community so that the community is acknowledged for their contribution and involvement in this research study. At that request, I reflected on the consent process I had used with research informants where I had explicitly indicated that their words would be kept confidential. I wondered how I could write about the research with clear examples and disclose the community *without* identifying individuals. In that moment, I replied that it seemed like a reasonable request but that I would need to think about how that might be done without betraying anyone's trust. I promptly met with my academic supervisor who helped me to understand that this request was not a problem. That is, that despite my assumption that participants can never be identifiable, in some cases it may be ethical to name an individual or a community if this is what they request. In the case of naming the community (at the request of the community leader), where individual quotes may then potentially identify an individual despite the use of a pseudonym, it would be necessary to seek explicit informed consent from the individual whose identity might be

inadvertently revealed, to ensure that they were comfortable having their identity revealed and having those particular words identified as being theirs (Canadian Institutes of Health Research, 2014).

A community-researcher agreement (see Appendix A) outlined the efforts I would make to keep information confidential. At the time of writing and signing the agreement, there was an understanding and assumption that any research on FASD may be polarizing or, at the very least, a sensitive matter. Two years after the agreement was signed, the research findings were being shared with interested research participants, community members, and other stakeholders. It was during this time that the community representative that signed the community-researcher agreement requested that the community be both named and fully acknowledged as a partner in any written documents on the FASD research study. This request was in direct conflict with the community-researcher agreement and with my approved provincial ethics proposal – but not in conflict with the OCAP principles. The community representative and I discussed this request. I shared my understanding of needing to keep information confidential and anonymous but also wanted to respect the desire to fully acknowledge the communities commitment, interest, investment, and role in the research study. Our first conversation was left unresolved and we agreed to have a follow-up conversation.

I wondered if this is a common situation in CBR. How could I write about study results that acknowledge a small community without identifying individual participants? Which community members decide whether or not the community is identified? How much and what kind of input and feedback from a community member who reviews my manuscripts merits being named a co-author?

***4.5.3.1 Strategies for Issue #3: Community acknowledgement after signing confidentiality forms.***

A study by Castleden, Morgan, and Neimanis (2010) involved interviewing researchers on their perspectives and practices around authorship in “scholarly dissemination of their community-based participatory Indigenous research” (p. 23). They found a very wide range of practices on how people and communities were acknowledged and concluded that there needs to be more attention given to how Indigenous contributions are recognized.

The issue of co-authorship is particularly relevant in cases where a doctoral student needs to produce a thesis. Even if a doctoral student like me wants to co-author parts of a thesis, there are university restrictions and regulations that limit how much the second author can contribute. In the context of writing up research that takes place in an Indigenous community, a particular power dynamic that favours researchers around whose knowledge counts and is recognized is reified. Ahmed (2000) writes about how academic researchers using traditional ethnography are praised for giving up aspects of their authorship; however, the same cannot be said about the reverse, that is, community giving up aspects of their authorship. I do not want to put community members involved in my research in a position where they are left unmentioned in publications, for my convenience or gain. Therefore, I have agreed with community representatives involved in my doctoral research that I will acknowledge contributions of time, energy, investment, and support in manuscripts related to my research with Sheshatshiu Innu First Nation.

#### **4.5.4 Issue #4: How much energy (from community members) is reasonable to spend discussing academic dilemmas?**

This question is one that spans across all of the issues I discuss in this paper. If I were a consultant or an independent researcher that had no pressure to produce scholarly writing, I would not be agonizing over such issues. In other words, my dilemmas are directly tied to the fact that I am trying to juggle the priorities of an Indigenous community and academia. The term *two-eyed seeing* is found in contemporary literature to describe simultaneous seeing the strengths of Indigenous and “Euro-Western” ways of knowing (Hatcher, Bartlett, Marshall, & Marshall, 2009; Iwama, Marshall, Marshall, & Bartlett, 2009; Vukic et al., 2012). Two-eyed seeing is a “weaving back and forth” of ontologies, epistemologies, methodologies, and research goals and emphasizes the importance of “co-existence, interrelativeness, interconnectiveness, and community spirit....and with Mother Earth” (Institute for Integrative Science & Health, n.d.; Marshall, Marshall, & Bartlett, 2010). Each of our eyes actually sees a different perspective and the brain is able to reconcile them into one unified picture that is deeper, richer, and more accurate as a result of having those two perspectives. I suggest that two-eyed seeing, like the OCAP principles, sometimes feels elusive and open to interpretation—and that putting two-eyed seeing into practice is challenging even if one can appreciate the value of its principles.

I struggled to justify, let alone ask for, the time of community members that were already stretched to sort out practicalities of a well-intentioned doctoral student conducting research with an Indigenous community. Occasionally, I got the sense that there was enormous faith and trust placed in me by community members to make the

“right” decisions. In some ways, I felt as if I had two bosses: (a) relatively “hands off” community leaders and stakeholders that were involved in my research and (b) the “hands on” academic world full of rules and regulations that were often blind to the idea of two-eyed seeing.

As explained earlier in this paper, the majority of community involvement was in defining the research questions, providing feedback and making connections throughout the data collection and analysis stages, and in using the findings and recommendations to inform significant documents like the Labrador Innu Healing Strategy. The community members I worked with trusted that I knew how to properly interview community members, and analyze transcripts and documents appropriately, and that I would let them know what I needed, and spend my research funds appropriately.

In contrast, institutional policies and processes around financial eligibility criteria, approval, and accountability are not written for CBR. For example, paying for refreshments for presentations and meetings required written justification, quotes for anticipated quantities, and an agenda for the meeting—to be submitted at least two weeks in advance of the event, for approval consideration. Often my plans for a trip were a moving target and I did not necessarily know the details in advance; so I applied for what I expected would happen and erred on the side of more people than less since I could underspend, but overspending would have resulted in time-consuming scrutiny and justification. Initially, I needed to consult with community members about what was reasonable and appropriate for food and drinks at meetings, whom I should buy them from, find out if receipts were possible, and receive an estimated quote. There was a community Elder who made Innu donuts that did not run an official business but was

fundraising for a traditional winter walk. In this case, I created a receipt that she signed so that the expense would be recognized as a legitimate.

When applying for grant funding as the principal investigator or principal applicant, I needed to submit a detailed budget that itemized all in-kind contributions. For this, I needed a letter or written confirmation from a community representative that they would provide the listed resources. Whenever I used university funds to produce materials for or with the community, I was required to use the university printing press and the university logo had to be displayed. This detail was one that required consulting and discussing with community members about why we were not going use a local (to Sheshatshiu) printing business and whether having the university logo alongside the Sheshatshiu Innu First Nation logo felt appropriate.

#### ***4.5.4.1 Solutions to Issue #4: How much energy is reasonable to spend discussing academic dilemmas?***

I shared and discussed this article and its contents with an individual who is both a community representative and a key stakeholder in this research. In his multiple community roles, he is extremely busy. The irony of having to find time to discuss this paper and talk about what is a reasonable amount of energy to spend on academic papers that do not necessarily benefit the community was noted and found humorous. I, however, believe that it was the spirit in which I asked that resulted in a meaningful conversation that led to a better understanding of each other. I learned that he was interested in reading my writing, irritated with academic writing that felt like a riddle with a main point that was hard to find, and appreciative that I had thought about challenges

that faced community members in tandem with my own challenges. He learned more about the expectations placed on me as a doctoral student to publish, follow particular health research ethics protocols, and be held accountable to university-affiliated institutions (e.g., the academic department, the office of finance, my funders, and the health research ethics board). He also learned more about how I value relationships, invest in processes, and think critically about the effects and demands of doing research with community members.

I have no solutions to university bureaucratic processes except to suggest that as I became more and more familiar with the policies as I needed to access research allowances and grant funding. After several letters of apology, persuasive requests, and special meetings with people in the finance department, I learned how to work within the system that likes specificity and certainty with a community that makes tentative plans and is comfortable with uncertainty.

#### **4.6 Conclusion**

My rich experience of doing doctoral CBR with people in Sheshatshiu Innu First Nations has given me insight and experience using principles and policies important to conducting research in Indigenous communities. My desires to be both a contributing member to the world of academia and to the community of Sheshatshiu were possible but not without several bumps in the road. I attribute several of the tensions I experienced and described in this paper to the realities—sometimes constraints—of being a doctoral student researcher.



I suggest that much of the success experienced in my doctoral research experience was due to the nature of personal connections and investments in authentic relationship building. Penashue (2014), a community leader and key informant, shared with me as we discussed how he felt about doing research in his community,

[recounting an earlier conversation with another researcher] I said, “you know, the best thing to do is actually – you have to marry your clients,” and she said, “What do you mean marry your clients?”; and I said, “Well, if you look at the value in terms of what marriage is...you have to be part of the method or part of the process....people are having one-night stands, and then leaving, and that’s it. They don’t ever see that person again but once you start developing a relationship,” I said, “and if want to have a really good relationship you have to start having a relationship with the Innu people, and that means being part of the marriage...and right now you’re married into the Innu ‘cause you have [an Innu] child.

As more researchers and community partners write frankly about their positionality, tensions, and solutions to the lived realities of putting Indigenous community-based research concepts and principles into place, the more we will further the work of decolonizing and community-based research.

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## **Chapter 5**

### **More than words: Using visual graphics for community-based health research**

#### **Abstract**

I argue that making research concepts and process visual enhances the level of comprehension, engagement, and knowledge utilization. Moreover, community-based researchers who engage with diverse community partners and stakeholders can improve communication of information by using visual graphics throughout all research phases. Visual graphics such as graphs, charts, figures, and photographs are common in scientific research dissemination; however, they are less common as a communication tool in research. Using visual graphic examples of drawings, diagram, and maps from my community-based health research, I describe how my visual graphics were created and used. I discuss how visual graphics helped facilitate dialogue and communication at different phases of research and more importantly, made research content both accessible and engaging to diverse research informants and stakeholders. While I suggest visual graphics enhance communication and build relationships, I also argue that researchers must carefully consider how visual graphics are used and what they represent to the target audience, minimizing the risk of misunderstanding. This paper literally makes visible new ways to advance community research engagement and knowledge utilization throughout all phases of a research study.

#### **Keywords**

visual aids; translational research; knowledge translation; community-based research

## 5.1 Introduction

In this paper I suggest that researchers can improve communication of information by using visual graphics throughout all research phases. Visual graphics such as graphs, charts, figures, and photographs are common in scientific research, especially as part of dissemination; however, they are less common as a communication tool in research. Visual graphics are well positioned to reach and include people outside of the academic field during the process of conducting research and can be used in two very different ways: (a) to communicate information and (b) as a methodological tool for gathering or analyzing data (Frith, Riley, Archer, & Gleeson, 2005). This paper focuses on using visual graphics as a communication tool.

Literature on visual graphics does not suggest that verbal or written techniques are unnecessary, but rather that writing and speaking combined with graphics is *better* (Miller & Barnett, 2010). Umoquit, Tso, Burchett, and Dobrow (2011) conducted a systematic review on the use of diagrams at the data collection phase of research and found that only half of the studies described the details of how research participants engaged with diagrams. In other words, little is written in academic literature about how and why researchers use diagrams. There is also increased attention to knowledge translation (KT) and community engagement in the applied health research field for which visual graphics can be highly effective at all stages of research and influential when engaging with policy and decision makers (Frith et al., 2005; Yonas, Burke, & Miller, 2013).

KT refers to “the process(es) through which knowledge is transformed into action” (Estey, Kmetz, & Reading, 2008, p. 25). The language of KT has been adopted, promoted, and prioritized by government funding agencies and research institutions as a



way of making research visibly relevant and valuable (CIHR, 2012). In the context of conducting community-based research with an Indigenous community, as is the case with the examples provided in this paper, I assert that self-determination is possible when knowledge is made transparent and accessible, allowing people to make informed decisions. Despite the growing support for diverse KT strategies and activities, there is not a lot of emphasis or training on the foundational *how to*'s of developing or creating materials.

I suggest that academic researchers must be taught the art of making information accessible and engaging without losing a sense of academic integrity. By accessible, I am referring to the value of communicating information in a language that can be understood by the target audience: it also makes the communication or conversation more of a level playing field and increases the likelihood that target audiences will engage with the information since it is intelligible. It is both fundamental and necessary for researchers to use accessible language—spoken, written, or visual—in community-based research and research that involves non-academics at any stage of the research study. Nesbit and Adesope (2006) found that graphic representations enhance memory and recall in comparison to spoken and written language. I argue that visual graphics can be a valuable and effective way of making information both accessible and engaging.

## **5.2 Terms to Know**

There are different terms used to describe types and uses of visual graphics. Some terms like *infographics* have been adopted from other fields such as marketing. I have asked or been asked: is the incorporation of visual graphics in research considered arts-

based? Who and what disciplines are the masters at developing concept maps? How can expertise in one field be translated or used in another? Is an infographic anything that is graphic that is trying to convey information? Are people in different fields calling the same thing by different names? Arts-based research methods describes a broad range of art media used in research. Concept mapping, drawing, and graphic elicitation usually refer to a method of engaging research participants at the data gathering stages.

Diagrams, flowcharts, and infographics are most often used as part of the data analysis or research dissemination stages. Visual graphics is the term I most prefer because it can be used to describe any visual representation of information. The following table identifies some common terms used in the research literature of various academic disciplines to describe visual graphics.

**Table 5.1 Common Terms for Visual Representation in Research**

*Definitions and Descriptions for Visual Representations Terminology*

Term	Description
arts-based research methods	Includes various forms of art (such as fine art, music, performance, photography, poetry) as the primary mode of research inquiry; found in qualitative research; and allows for different and creative forms of knowledge, expression, and representation in research (Bagnoli, 2009; Leavy, 2009; McNiff, 2008; Parsons & Boydell, 2012).  Similar term: arts-based inquiry
concept mapping	Can be used to brainstorm or represent ideas, concepts, or relationships; can link people, ideas, concepts, or feelings to each other; frequently requires reflection, creativity, and critical thinking in its creation (Harrison & Gibbons, 2013); has been used in community-based participatory research (CBPR); can be used to structure a process and as a way to incorporate both individual and shared views (Kane & Trochim, 2007; Windsor, 2013); and translates complex data into an image that draws connections between ideas, knowledge, and other forms of data (Windsor, 2013).

	Similar terms: concept diagraming, information mapping, mind mapping
diagrams	<p>Any visual representation that is comprised of texts and images that cannot be adequately expressed alone as text or as images (Blackwell, 2002); can be used at any phase of research (Copeland &amp; Agosto, 2012); sometimes used in contexts where there may be language or literacy barriers between research participants and researchers (Crilly, Blackwell, &amp; Clarkson, 2006); and can range from physical and literal information to conceptual abstractions (Crilly et al., 2006).</p> <p>Similar terms: models, graphic representations, visual graphics, frameworks, relational maps</p>
drawing	<p>Drawing combined with interviews serves to elicit richer, emotional, and more complex data as well as triangulate information better than if everything were done verbally (Copeland &amp; Agosto, 2012); can be used to explore how people understand a topic or experience; and offers richness and insight on how people experience and understand the world, in forms that can complement or replace words (Guillemin, 2004).</p> <p>Similar terms: visual method, sketching, painting, illustrating</p>
flowcharts	<p>Graphically illustrates process(es) with a clear sequence of events or functions; describes how an organization or process is structured or organized; frequently illustrates a sequence of steps to solve a problem, arrive at an answer, build something, or solve a problem; and commonly used to describe systematic review processes in academic journals articles.</p> <p>Similar terms: organizational chart, process diagram, map, process flow chart, process flow diagram</p>
graphic elicitation	<p>Visual methods to elicit information; often used in a research interview context; includes a broad understanding of graphics such as drawings, maps, diagrams, photography, videos, objects, and life stories (Bagnoli, 2009; Banks, 2001; Chase, Medina, &amp; Mignone, 2012; Copeland &amp; Agosto, 2012; Johnson &amp; Weller, 2001) – all of which convey information which is more difficult to expressed with words (Copeland &amp; Agosto, 2012); and can help interviewee participation that might be difficult to get through dialogue alone (Crilly et al., 2006).</p> <p>Similar terms: visual methods, photo elicitation, visual elicitation, diagrammatic elicitation</p>

infographic	<p>Conveys complex information in a clear and quick way; frequently used to represent quantitative data in a qualitative way; may include text as labels, highlights, brief explanations to accompany imagery; often in the form of diagrams, maps, graphs, illustrations, timelines; and images, sizes, shapes, colour, and placement play a key role in presenting information (Lankow, 2012; Smiciklas, 2012).</p> <p>Similar terms: data visualization, information architecture, information design, infoposters (Smiciklas, 2012).</p>
visual graphics	Any illustration that conveys more than words; what I use in this paper to describe a wide range of visual representations including infographics, diagrams, drawings and maps.

### 5.3 How I used visual graphics

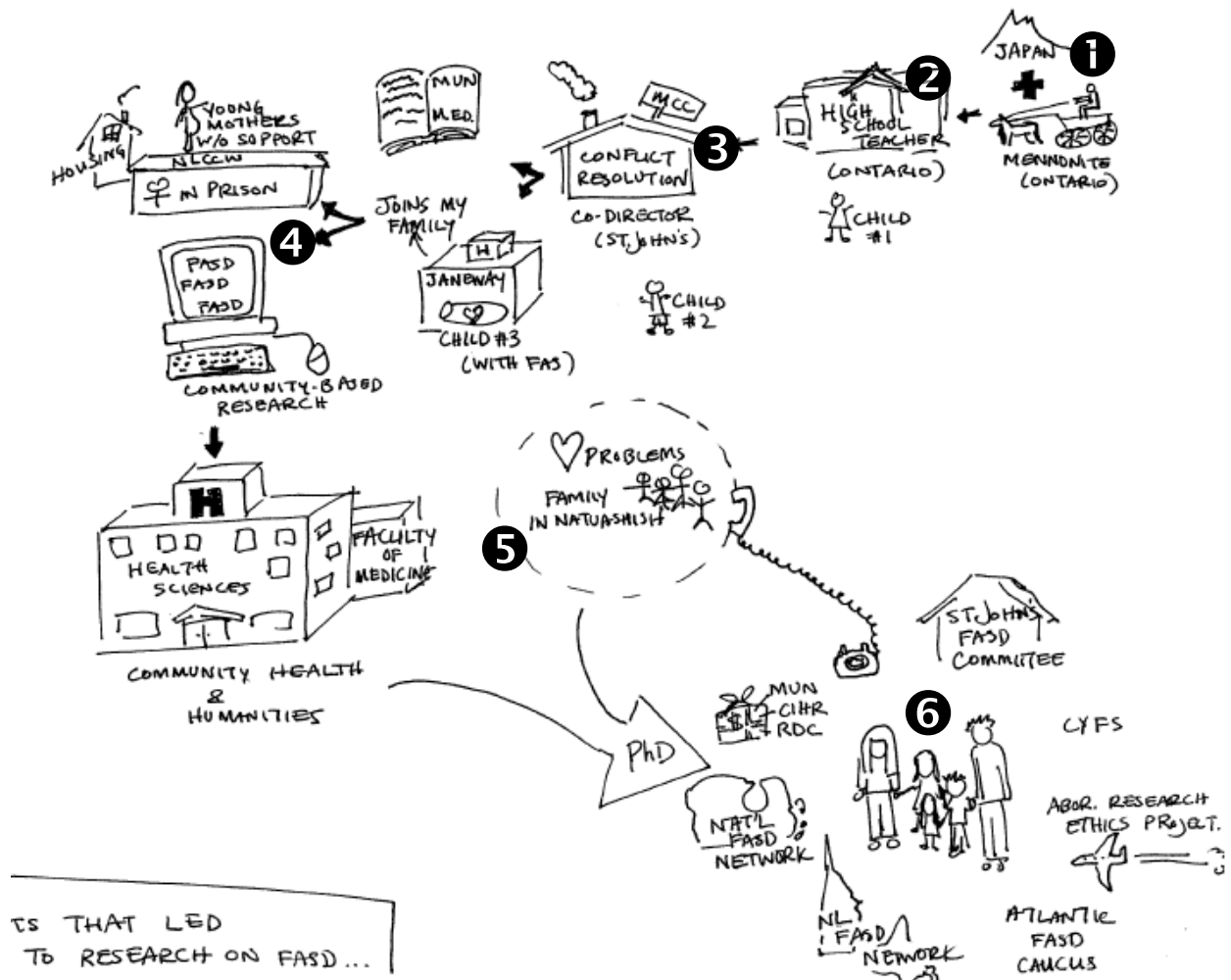
As someone who enjoys and values visual art, I incorporated visual graphics throughout an applied health research study that was developed, conducted, and disseminated with community partners. Rather than use arts-based methods to elicit information during interviews, I used visual graphics to improve understanding of a complex process, provide information in a concise and time-effective way, and overcome potential language and terminology barriers. The use of visual graphics in this study ranged from informal sketches to posters designed with a graphic designer. In the following sections I provide examples of visual graphics, describe how I developed them, explain how and why they were used, and reflect on their use during different research stages in a community-based research study.

#### 5.3.1 Research development phase.

In the early stages of discussion with community partners in a First Nations community about the *idea* of doing research on fetal alcohol spectrum disorder (FASD)

supports and services, it was agreed that I would facilitate a meeting to discuss what a potential research study would look like. For this, I prepared a drawing—a paper handout—that gave people a simple overview of what I bring as a researcher, to accompany my introduction for new acquaintances around the table (see Figure 5.1).

**Figure 5.1** My Introduction Using a Life Sketch



*Figure 5.1* This sketch depicts significant and relevant events of my life from childhood until the present. Starting in the top right hand corner, illustrations and captions served as a guide for introducing my background and connections to the research topic. This illustration was used at a community stakeholders meeting at the research development stage.

The numbers in Figure 5.1 correspond with the following details I shared with community stakeholders as part of my introduction:

1. While I am often mistaken or assumed to be Indigenous, I did not want to give false impressions of being Indigenous; I am part Japanese and white-Mennonite as indicated in the top right hand corner of the drawing.
2. I have experience as a high school teacher and have worked with school aged youth.
3. I have experience working in the field of conflict resolution and mediation.
4. Community-based research led to my desire to do a PhD dedicated to the topic of FASD.
5. I am a parent of a child with an FASD diagnosis.
6. I am involved in FASD committees and networks.

I facilitated the particular meeting where the visual graphic in Figure 5.1 was used. The meeting was comprised of various community stakeholders, some of whom I had never met and some of whom had not formally met each other. After everyone introduced themselves, I provided everyone with a handout that included this sketch of my background to give community partners a particular view of my background, general skill set, commitment to doing research on FASD, and my life outside the context of doing research. As an outsider to this community, my aim was to be transparent and forthcoming about my background as well as share what skills and experience I brought to the proposed research. In this case, I knew that the people attending this meeting might wonder—but not ask—about details that I included in Figure 5.1. I am also someone who does not like to talk about myself at great length; using this illustration, I was able to keep

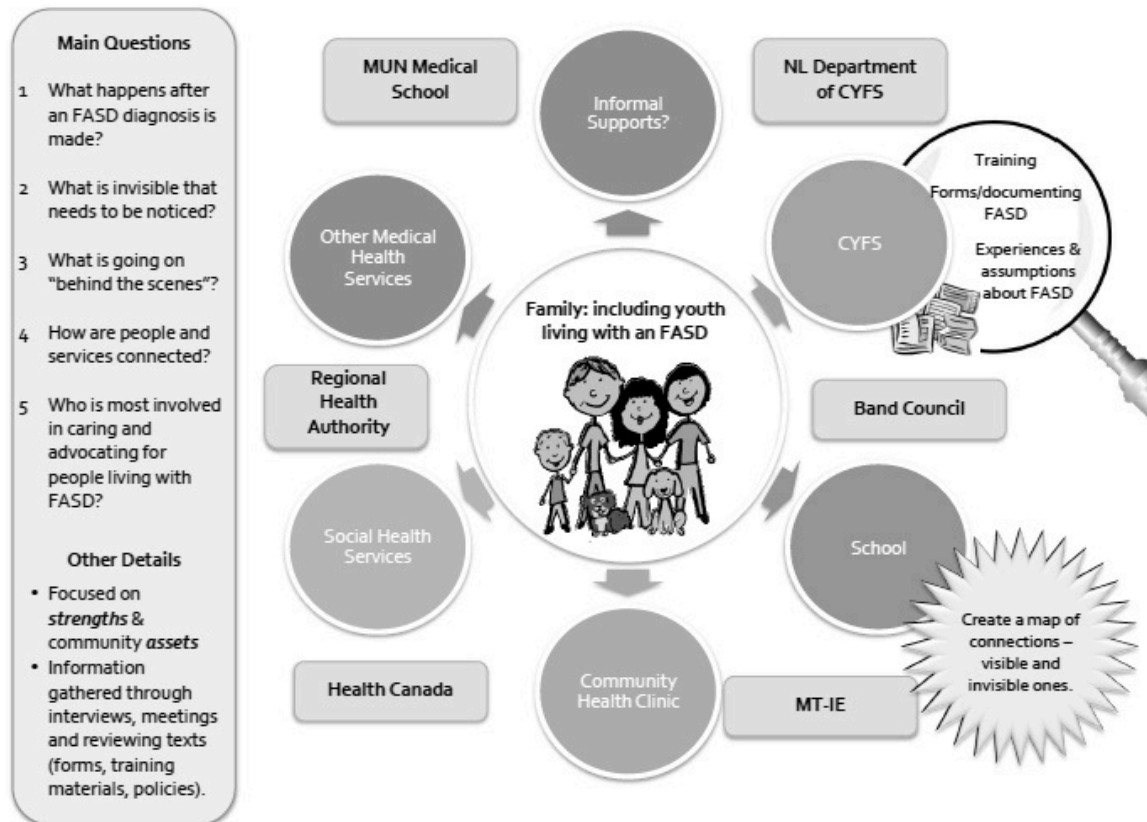
to my key points and people were able to ask me questions about specific current and past involvements.

I did not spend a great deal of time on this illustration. I recall contemplating creating something digital; however, at the time I was concerned that it would be perceived as a narcissistic investment of time. Retrospectively, this simple drawing not only provided information about me as a researcher but also subtly conveyed my abilities in being accessible and building rapport. In this same meeting, I also included visual graphics in a draft project proposal summary to illustrate a possible research design, research questions, a sample four-year timeline, researcher commitments, and potential community benefits.

### **5.3.2 Data collection stage.**

As I met with research informants and as part of the consent form process, I showed them a visual graphic that illustrated how the study would be conducted (see Figure 5.2). Health research consent forms that required approval from a research ethics board had to meet very specific criteria that are typically conveyed through text or verbal communication in some community-based research studies. Knowing that some informants may struggle to read through a consent form and may not disclose what they did not understand, I minimized text, used diagrams, and explained the information verbally.

**Figure 5.2.** Conceptual Map For A Study Design



*Figure 5.2.* This visual graphic outlines the conceptual idea around the study on supports and services accessed by children and youth diagnosed with fetal alcohol spectrum disorder (FASD), using institutional ethnography as a method of inquiry. The magnifying glass represents the attention paid to textual documents in one institution. The text box down the left hand side lists the kinds of research questions that the proposed research would answer.

The visual graphic in Figure 5.2 was used in addition to an informed consent form. Due to the comprehensive and potentially complex research design, I thought it was prudent to not only illustrate how the research was to *begin* by interviewing caregivers of children diagnosed with FASD, but to also suggest possible institutions that would be part



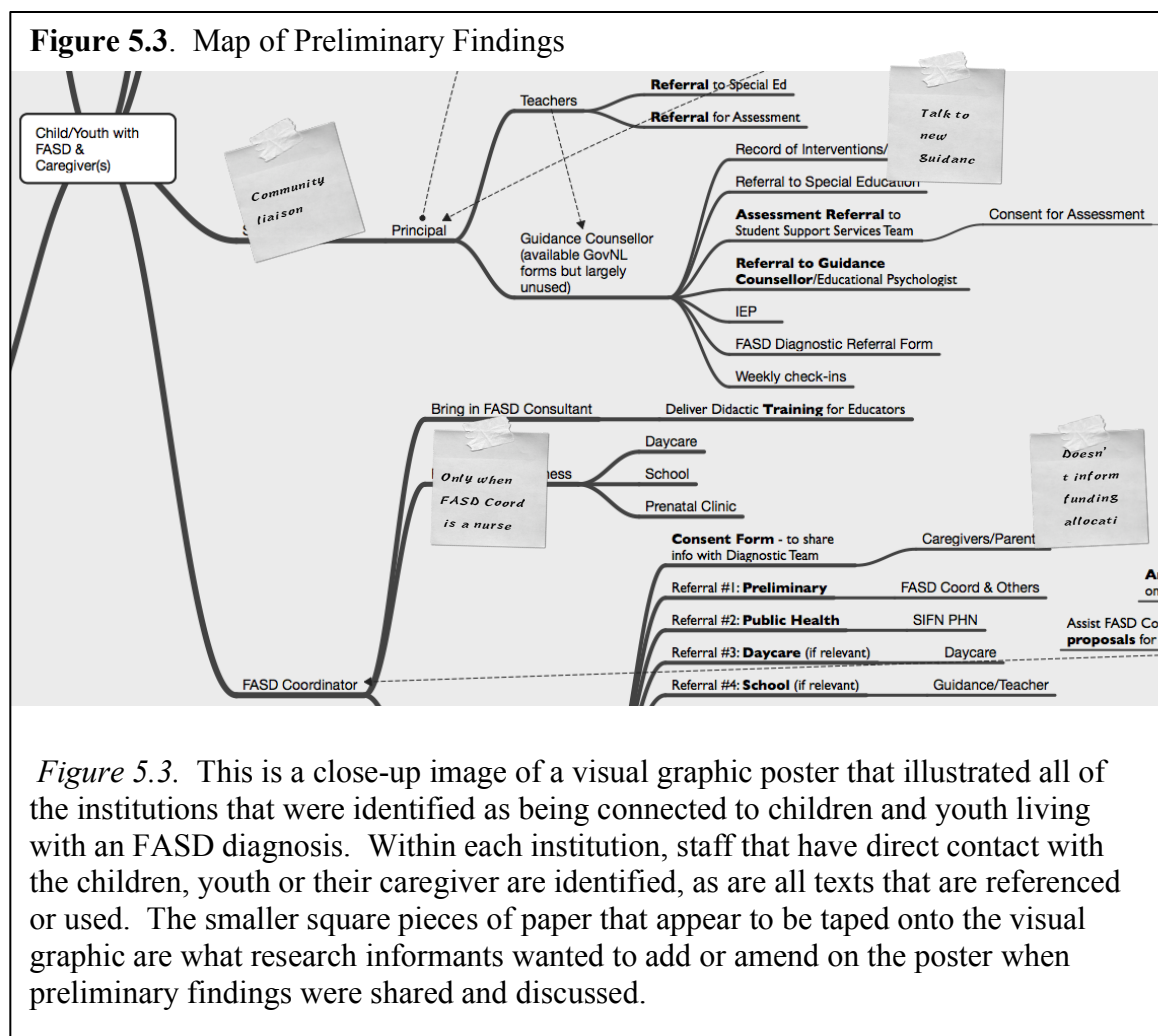
of the next round of interviews. I also used the magnifying glass to symbolize how I would be paying close attention to textual documents that institutions use to organize their work; the jagged circle was to remind people that one goal for this research was to map how people and textual documents were linked to each other; and the text box on the left were paraphrased research questions to explain what the research might answer. Research informants responded with questions and comments that told me that they understood how they fit into the bigger picture of the study and how their contributions would help answer the research questions.

### **5.3.3 Data analysis stage.**

The data analysis was an iterative process. The analysis stage involved creating documents that described my initial findings, meeting with each research informant to discuss and amend any of the findings, and presenting a revised overview of the community's findings to informants for feedback. A central focus of my research was the social organization of institutional supports and services. I was particularly keen to show which institutions were involved in the lives of people living with FASD, how institutions and people were connected, what textual documents played a role in how people and their work was organized, and connections between institutions. I had collected a lot of information. In this one community, I had interviewed over thirty people and examined over forty documents.

I reviewed software programs that would have built-in templates that would be easy for me to input information. There was no exact match but I did use a simple concept mapping program that provided an easy interface to input basic information without

having to design or create a functional layout. I created a “map” of all of various institutional connections attached to youth diagnosed with FASD (see Appendix C). I shared this map with research informants for their feedback and input. I brought along adhesive paper so that I could add notes and amendments when I met with research informants for the second and third time. Figure 5.3 illustrates what the poster looked like after people had provided feedback.



There were several benefits to using the same comprehensive map with research informants and key stakeholders. At a glance, people observed and appreciated the amount of information that was collected. It provided a bird's eye view of the sheer number of institutions involved in the care of a youth; the amount of work that is required of caregivers to navigate the system, both figuratively and literally, in the interest of their child; the number of forms, assessments, and policies that need to be completed or followed; and a sense of the invisibility to caregivers of institutions as to how services are organized and funded. While I wanted to produce a map that conveyed both institutional connections *and* temporal sequences of events, I was unable to do so without compromising its comprehensibility.

I included infographics in the other documents during the data analysis stage. For example I included prints of select portions of the overall map where I collapsed “branches” of detailed information and left only the relevant portions of the map for stakeholders who had a particular interest in discussing or examining only one or two institutions. Research informants also received a list of training and educational (re)sources that people cited, which is not necessarily a part of the IE study but was a question that was important to community research partners. For this, I created a two-page infographic summary of sources that people shared during their interviews. I also created an infographic handout that summarized recommendations from research informants since community research partners were interested in those recommendations as well.

#### **5.3.4 End-of-project dissemination stage.**

The findings from this research were translated into numerous formats including community presentations with digital slides projected on a large screen (see Appendix E), a 10-page summary report (see Appendix D), oral presentations in several meetings, posters (see Appendix C and I), and web-based summaries of research findings and recommendations. All of the aforementioned dissemination materials and formats included visual graphics that required considerable amounts of time and energy to make concise, clear, consistent, and with minimal yet adequate text.

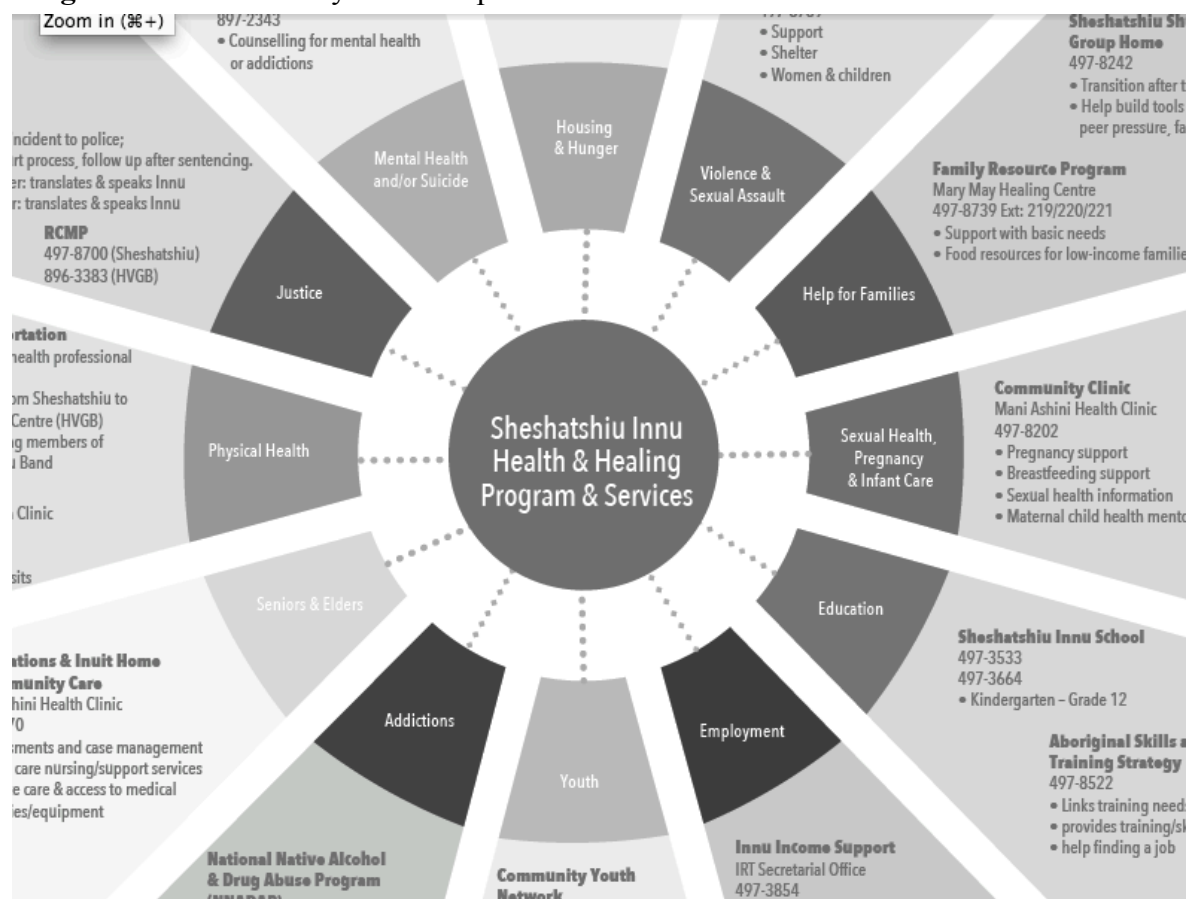
My strategy for creating each visual graphic typically followed a process like this:

1. Identify target audiences and intent of a visual graphic.
2. Take inventory of the most relevant and appropriate information.
3. Scan and critique what others have created to present similar types of information using internet searches.
4. Create a draft visual graphic and get trusted colleagues to give feedback on clarity, language accessibility, and aesthetics.
5. Consult a graphic designer before creating a final version.

When there was funding to pay a graphic designer, I hired a professional graphic designer to be involved after the first two steps of the process I just described. Visual graphics intended for dissemination *without* verbal explanation took considerably longer to develop than visual graphics that I could verbally elaborate on. Without verbal explanation, there is increased possibility that people will misinterpret the information or get confused with unclear or incomplete information.

One of the recommendations from this study became part of a knowledge sharing initiative. The initiative was to create two community asset maps that identified all of services and programs that people in the two communities could avail of—for distribution to every household in each community. These community asset maps were intended to be a stand-alone document that would be easy to navigate, understand, and use (see Figure 5.4). The creation of the maps was an iterative process that required establishing and revising content, colours, configuration, categories, overall shape, font size, locations of certain contacts relative to other contacts, specific language, size of the poster, and formatting for a website version.

**Figure 5.4. Community Asset Map**



*Figure 5.4.* This visual graphic is close-up of the centre of a community asset map. The community asset map helps community members identify what health and healing services are available to them as well as contact information. The committee members that helped inform the design of this map preferred to use a circular image to avoid any perceived hierarchies in services.

## 5.4 Discussion

Combining visual graphics with words can be a very effective tool for communication. Communication is key to building authentic relationships in research and authentic relationships in research are critical in community-based research and applied health research, among others. I suggest that when researchers make concepts and language of research accessible to research participants, informants, and other

stakeholders alike, relationships are strengthened. I also suggest that it is the researcher's responsibility to ensure that theoretical, conceptual, and study designs be made accessible to people involved and invested in their studies. By not making research designs easily understood, there is a risk that key stakeholders may lose interest in the research due to a lack of understanding or misunderstanding. Lack of clarity and understanding can also create distrust in the researcher(s) and offer little to no knowledge uptake at the end of a research study.

Sheridan (1980) writes that the use of diagrams is closely tied to Foucault's concepts of discipline and control. He suggests that technologies of representation use signs and systems that impose power structures, based on certain kinds of knowledge and experience. In other words, when using visual graphics, one needs to carefully consider the origin of the image, its uses over time, whose knowledge it privileges, and what assumptions people may make about it. Visual graphics are meant to be intelligible in ways that expect readers to both translate and interpret the images appropriately but caution and awareness is warranted.

#### **5.4.1 Questions researchers need to ask when using visual graphics.**

Academic researchers are trained to use particular research methodologies, write project and funding proposals, and produce manuscripts. Academic researchers may turn to literature on knowledge translation, mobilization, transfer, uptake, and sharing to find tips and examples of how to effectively engage and communicate with people outside of a researcher's field. I argue that researchers must pay attention to what information is most relevant and engaging to their target audience; critically analyze how visual graphics may

be interpreted; and educate themselves on strategies and cautions of using visual graphics. Without careful attention, critical analysis, and education on visual graphics researchers risk using ineffective or misleading visual graphics.

Researchers can learn from the field of marketing and communications about what visual graphics can convey, how they target certain audiences, how complex information can and cannot be expressed, and what kinds of artistic/technical knowledge is required to produce graphics. Frith et al. (2005) ask, are we skilled enough to use visual images artfully? Today, there are software programs and graphic designers that researchers can work with. My experience with numerous software programs with built-in templates is that they often have limited layout options with epistemological assumptions build into the templates, such as infographics that only accommodate quantitative data representation.

If a research study prioritizes engaging people, researchers need to ask a number of questions—some reflexive and contemplative and others that are curious in nature and require homework. Researchers must consider the preferred modes and purpose of communication when engaging with people that the visual graphics may be aimed to reach. For example, what method of communication is most comfortable for the target audience? Is the environment in which a target audience is reviewing your information conducive to engaging with your content? What relevant concepts and content are they familiar with? How much time do you have to convey what you want? What impressions or assumptions might target audience members have of researchers and of participating in research?



More specifically, when focused on the visual graphics themselves, researchers must consider additional questions such as: What are my key messages? Can they be captured or summarized in an infographic? How can I convey the most with the least amount of text? Do I have the technology and knowledge to produce the visual graphics I want? What genre will I use and what might that genre represent to the reader? Where and when do I want readers to see it? How will readers relate to my material? Is my messaging consistent and clear? Is the information broken into understandable pieces? What do the colours and shapes suggest about the data? Whose knowledge is being represented and whose is missing? How will my information be circulated (Rose, 2001)? What knowledge is required to interpret the images (Weber, 2008)?

Asking critical questions about what visual graphics aim to convey, how they are represented, and how they are received minimizes miscommunication. In the conflict resolution field, there is often reference made to the intent-action-effect model (Mediation Skills, 2012). This concept is based on the idea that we have intentions that lead to an action (e.g., verbal and non-verbal) that then leads to an effect (e.g., on another person). The only thing that is observable is the action and the point where conflicts tend to arise. Borrowing from that, I suggest that researchers need to prioritize being transparent, clear about their intentions, and attentive to how they use visual graphics (i.e., the action).

## **5.5 Conclusion**

Without describing how visual graphics were developed, how they were used, and why they were included, researchers are missing opportunities to improve communication tools that are further developed in other professions such as graphic design, marketing,

and education. My community-based health research prioritized KT activities with community partners. When I realized there was a dearth of literature that described or highlighted the use or importance of visual graphics and accessible language in research, I incorporated aspects of graphic design, communication, and conflict resolution strategies to guide my use of visual graphics. In the context of using institutional ethnography as a method of inquiry, there were many uses for visual graphics since IE encourages mapping the invisible ways in which identifiable groups of people are social organized by institutions. Similarly, any CBR and KT initiatives must consider using means that are accessible and effective communication tools for the people they want to engage with—including visual graphics.

I do not suggest that visual graphics entirely replace much of what researchers have to say—in speech or in writing. Rather, I propose that incorporating visual graphics can greatly enhance peoples' ability to engage, understand, and interpret information more effectively. Particularly in CBR, visual graphics can help make information more accessible and begin to level the playing field where the researchers and community partners can speak with common understanding. However, the value of visual graphics extends to all research that involves communication with participants, stakeholders, and target audiences that do not share the same body of knowledge. Ethical engagement with people invested/involved in research requires that researchers make themselves and their communication accessible.

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## Chapter 6

### Conclusion

My dissertation is dedicated to demonstrating and elucidating how I partially adapted a method of inquiry to exemplify community-based and Indigenous research principles. The impetus for this study was to produce research that would improve the level and quality of supports for children living with FASD and their families in two communities in Newfoundland and Labrador (NL): one rural Innu community (Sheshatshiu) and one urban community. As indicated in my introductory chapter, communities and other provincial stakeholders were engaged in the results and recommendations from my institutional ethnography (IE) study at the time of writing this dissertation. My main reason for shifting the focus of my dissertation, from discussing the findings from my fetal alcohol spectrum disorder (FASD) research to discussing the innovative approaches and processes used to conduct my study, was to engage and add to the growing field of IE, integrated and Indigenous knowledge translation (KT), and decolonizing research methodologies. In addition, writing critically about the communities and institutions that were implicated in my research findings and recommendations went against my commitment to using a strengths-based lens in presenting research findings from Sheshatshiu. While I was writing this dissertation, I was fully engaged with both the Innu and urban communities in disseminating the research findings, discussing recommendations, and collaborating on recommendations with community partners. In other words, my research *findings* were shared at the community level, while the dissertation manuscripts mainly focus instead on *process* of my IE study.

## **6.1 Side Benefits: In the Process of Doing Research...**

As I was driving to Sheshatshiu with a colleague, I was sharing how my meeting from the previous day had brought together people from within the same small community to discuss my proposed research questions and design. The particular combination of people I had invited did not know each other well. During that community meeting, one meeting attendee shared that they had been having trouble scheduling a consultant who had to fly in from a distance to conduct assessments—assessments that another meeting attendee was qualified and available to do as part of their job. My colleague encouraged me to document what I am referring to as ‘side benefits’—examples of how my research process prompted events, initiatives, or fruitful connections that were not directly related to my research. I took her advice and am including one example of an event related to my doctoral research that simultaneously advanced the FASD work in the province, without being part of my stated goals or intentions.

Part of my incentive for adding this section is to highlight that, as researchers, we are expected to document and discuss how our research process and findings are relevant, meaningful and benefit people in intended, if not always expected, ways. However, I believe that engaging with community members and investing in relationships will often add value in ways that are typically undocumented and perhaps not seen as relevant or important to a research study or its goals. In the following section, I highlight one way in which my research involvement was inadvertently fruitful.

### **6.1.1 Decision to organize a national FASD conference.**

In 2012, when it was determined that the 2013 Fetal Alcohol Canadian Expertise (FACE) Research Network's Annual Meeting would take place in St. John's, the idea to hold a provincial conference in conjunction with the FACE meeting was born. As we began planning this provincial FASD conference, we soon decided instead to plan a national conference. Around the same time, a NL provincial FASD committee of which I was also a member transitioned from an ad hoc committee to an incorporated organization. This incorporated organization strategically split into two groups: (a) an advisory board; and (b) a conference planning team. I decided to move from being a provincial FASD committee member to co-Chairing the national conference planning team.

My motivations for taking on this role were primarily for the experience and to connect people in NL with other FASD experts from across Canada and beyond. The planning committee and the conference itself were also informal platforms for some of my research KT. I was the only academic researcher on the provincial FASD committee. In addition, I had just organized the Canadian Society for Epidemiology and Biostatistics Student Conference, a national academic conference for graduate students, and felt that I had the organizational skills needed to plan a national conference.

*The 2013 National FASD Conference: From prevention to lifelong support* attracted many presenters, ranging from internationally renowned FASD researchers to community-based program directors. As part of the conference, I helped facilitate sub-committees including: (a) a round table meeting to discuss FASD diagnostic capacity across NL; and (b) an FASD prevention workshop to engage medical professionals,



family resource centre directors, and other government policy and decisions makers.

Both sessions were led by leading national and international experts in their respective fields. The conference was a catalyst for other events and initiatives. For example:

- NL health professionals formally connected with Canada FASD Research Network Action Teams.
- *fasdNL Network* became an incorporated organization, the first formal group in NL to coordinate and advocate on FASD-related issues at the provincial level.
- I was invited to work with other researchers across Canada on future FASD-related projects.
- *fasdNL Network* was awarded a provincial grant to do pan-provincial FASD training and education.
- Individuals who were not previously involved with any FASD committees joined regional and provincial FASD committees.
- Two FASD diagnostic teams were trained in one of four regions of the province.

## **6.2 Knowledge Sharing Activities and Reflections**

The terms knowledge translation, knowledge mobilization, knowledge transfer, knowledge exchange, knowledge transfer and exchange, knowledge uptake, linkage and exchange, and knowledge dissemination share similar meanings. Personally, I prefer the term knowledge *sharing* because it implies respectful, relational, and mutual exchanges between people—more so than *translation*, *transfer*, and *mobilization*. As is often the case with community-based research (CBR), knowledge-sharing activities were

intentionally planned throughout the study. Knowledge sharing in the development stage was largely focused on consulting experts and community stakeholders in the research design, aims, and goals. Knowledge sharing during the research collection and analysis stage was focused on keeping a wide range of people interested, involved, and invested in the research findings and recommendations. Knowledge sharing at the end-of-study dissemination stage was largely informed and affected by the level of knowledge sharing that happened in previous stages. In the following sub-sections, I include examples and reflections of knowledge-sharing activities that took place at each stage of research.

#### **6.2.1 Knowledge sharing at the research development stage.**

At the research development stage (see Table 6.1), I invested my energy in four areas: (a) getting to know who in NL was most involved in ongoing FASD-related work; (b) soliciting possible research questions from people who attended the 2008 Forum on FASD; (c) creating a team of informal consultants that would be a sounding board throughout my research; and (d) stemming from the expressed interest from a leader in Sheshatshiu, holding a meeting in Sheshatshiu to further discuss the possibilities of me doing research with the community. This stage involved contacting several people, many of whom I had never met, to introduce myself and articulate my interests in conducting a doctoral and emancipatory research study on FASD. My main goals for connecting with people involved in FASD work across NL were three-fold. I wanted to (a) understand peoples' priorities around FASD; (b) gauge peoples' appetite for FASD research; and (c) start building relationships.

My motivation for creating a team of consultants was to ensure that my approach and strategies throughout the research study would be smooth and as informed as possible. In addition to my resourceful PhD committee members, I included (a) an independent researcher that has done extensive community-based work in Sheshatshiu; (b) a physician with FASD expertise to provide insight into FASD champions in the province; (c) a provincial government health consultant to suggest strategic ways to engage government throughout the study; (d) an FASD consultant who conducts many educational training sessions locally and abroad; and (e) community leaders in Sheshatshiu who I anticipated would be FASD champions as the research progressed.

Since Sheshatshiu is an Indigenous community, I held a roundtable meeting in Sheshatshiu to discuss my proposed research study with a diverse group of representatives working in the fields of education, child welfare, social health, and primary health. The intent of this meeting was to establish whether or not I would do a research study in the community, decide on what the study would both entail and produce, and discuss any concerns or questions. I did not hold a similar meeting in the urban community because there was no collective group that could speak on behalf of the people that my research would involve or affect, nor was I targeting Indigenous people in the urban community.

**Table 6.1 Research Development Stage***Knowledge Sharing Activities, Partners, and Aims at the Development Stage*

Activity	People Involved	Aim/Purpose
Connected with and attend FASD Committee members and meetings, respectively	St. John's FASD Committee; Labrador FASD Team	Inform me of relevant initiatives and priorities, past and present. Build relationships and trust. Understand priorities, interests, and needs of FASD stakeholders across NL.
Consulted all known stakeholders that attended the 2008 Forum on FASD to ask about potential research questions	2008 FASD Forum attendees; FASD Committee Chairs and staff not present at the 2008 FASD Forum	Inform people of my interest in conducting research. Build a list of people who may be interested or involved in research study. Connect with people who may be invested in the outcome of FASD research.
Created an informal team of consultants to advise me at various points of the research	Key informants from community organizations, local and provincial government, and academia	Operate as a sounding board for research questions (on strategy, methodology, and ethics). Advise me on best ways to engage and approach strategic target audiences.
Conducted round table and individual meetings in Sheshatshiu to discuss research study focus, design, and potential outcomes	Key community informants including decision makers and frontline workers in social health, primary health, child welfare, and education	Establish the level of interest, commitment, and involvement of community in doing research on FASD with me. Discuss research questions and designs.

The first two activities listed in Table 6.1 took place before I applied to the doctoral program at Memorial University. My decision to apply for the PhD program rested on having a research topic that was both supported by communities and groups in NL and had the possibility of making a tangible and positive difference in those communities. I asked people who attended the 2008 Forum on FASD to identify questions they had about FASD that might (a) benefit their community or this province; and (b) be answered through a research study. Responses ranged from “What is the prevalence rate of FASD in NL”? to “What are the best strategies for preventing FASD”? As I looked at the list of research questions people proposed, very few were possible or within my area of expertise or comfort. It was at this point in my research journey—still before entering the PhD program—that I began talking with other university researchers about research methodologies that might be suitable for the kinds of questions that stood out as being the most promising. It was during one of my conversations with a faculty member in Memorial University’s Faculty of Education that the idea of using IE as an approach was introduced to me for the first time.

### **6.2.2 Knowledge sharing at data collection and analysis stage.**

The knowledge sharing that took place during the data collection and analysis stage can broadly be described as relationship building. I asked and was asked to join various FASD committees, ranging from the local FASD committee to the national Canada Research Network’s FASD Prevention Network Action Team. Being involved on these committees was a win-win arrangement whereby I was able to stay abreast of current

initiatives, events, and issues; make contributions of my time and occasionally my expertise; and share relevant information between committees.

Throughout my doctoral studies, I took the opportunity to present at various academic conferences. Depending on where I was in my research, I presented on: my research plans; FASD as a (de)moralizing medical diagnosis for birth mothers; marrying KT and IE epistemologies; mapping institutional work using IE; and critiquing the accessibility of IE terminology in the context of conducting CBR. I did not reveal, however, in any of my presentations, which communities were involved in my doctoral research nor share preliminary findings from my research. Like my dissertation, my presentations were focused on FASD in general or on the process of using IE in a particular context.

I made intentional efforts to update diverse stakeholders on my progress throughout the data collection and analysis stage. There were a few decision and policy makers that were not on any committees of which I was a part *and* were strategically important to the anticipated recommendations stemming from my research results. I took advantage of events and meetings where people who I wanted to reach were present—to introduce my research study and me.

After completing my initial analysis, I contacted all research informants to ask if they were interested in reviewing my initial findings to provide any additional information that was missed or correct any inaccuracies. Most informants were interested in meeting to discuss these initial findings. These meetings to review initial research findings proved to be very helpful. Informants were intrigued and engaged in the visual maps and suggested additional recommendations for ways to address problematic issues.

Table 6.2 outlines the various activities that took place during the data collection and analysis stage of research.

**Table 6.2 Data Collection and Analysis Stage**

*Knowledge Sharing Activities, Partners, and Aims at Data Collection and Analysis Stage*

<b>Activity</b>	<b>People Involved</b>	<b>Aim/Purpose</b>
Joined the following: St. John's FASD Committee, informal provincial FASD group that met every other month via conference call, Atlantic Intergovernmental FASD Partnership, national FASD Prevention Network Action Team, and national FASD Conference planning team	FASD Committee Members, FASD staff across NL, Atlantic Intergovernmental team, and a Canadian network of people working on FASD prevention	Build relationships. Invest in FASD-related work in the province. Remain informed and inform others of my research development, FASD work across NL, and current research by others. Network with leading researchers in FASD field in Canada.
Continued consulting with my team of consultants	Same key informants that I consulted in the research development stage	Keep consultants informed of research progress. Learn of any new developments that were relevant to my research area and two communities.
Conference Presentations	Researchers and other stakeholders in the field of FASD, qualitative health research, Indigenous health research, and IE	Mutual sharing of research developments, findings, and current areas of debate.

Formal and informal meetings with community stakeholders	Key stakeholders, community leaders, research informants, research affinity groups, FASD champions in NL, and decision/policy makers that are implicated in my research	Build stronger relationships and trust with community leaders. Share and discuss preliminary research findings. Discuss and strategize end-of-project knowledge sharing ideas.
Reviewing initial findings	Research informants	Elicit feedback on what I had collected, find out if anything was incorrect or missing, share initial findings, gauge interest in potential next steps of proposing recommendations.

The most exciting knowledge-sharing activity during the data collection and analysis stage took place after spending agonizing hours of figuring out how to display a comprehensive summary of an initial analysis. I knew that people would not be interested in reading a lengthy written document nor verbal description of what I was finding so I channeled my energy into creating illustrations that summarized findings. I printed large posters that evidenced the number of people with whom I had spoken and the documents I had reviewed. The posters showed how people fit into a large network of interconnected people and organizations, identified institutions implicated in the work of supporting people living with FASD, and were similar to a mall map where people look for the “you are here” marker. Most importantly, the posters generated a lot of comments. People located themselves on map and were able to ‘read’ my posters and ask questions like: What next? Who is doing this work? Why aren’t we having



conversations with people in [named a specific institution]? I had no idea that they were doing X. Now that I see what you are doing here, I think document X needs to be included here. The conversations that happened around the maps organically led to discussions that strategized next steps and end-of-project knowledge sharing.

### **6.2.3 Knowledge sharing at the end-of-project dissemination stage.**

The end-of-project knowledge-sharing activities can be categorically divided into three categories: (a) sharing and discussing research results at the community level; (b) sharing research results with the academic community; and (c) sharing results in the context of strategic planning and moving forward with research recommendations. At the community level, research findings were shared publicly. I specifically invited research informants, local FASD committee members, my informal consultants, and target audience members (such as policy and decision makers with whom I developed a relationship at the data collection and analysis stage). In addition to the presentations, I produced written reports: my report for Sheshatshiu was a 10-page report and my two reports for the urban community were 3 and 10 pages (see Appendix D).

Parts of my research findings are being disseminated through academic modes of sharing findings, namely through conferences and manuscripts. At the time of writing this dissertation, I have presented on the work of caregivers in the urban community at one conference and my last manuscript in this dissertation shares some findings from research in the urban community. The remaining academic contributions to date are, much like my dissertation, focused on the *how* rather than the *what* aspects of my doctoral research.

The research results and recommendations have gained traction and have resulted in two separate activities. In Sheshatshiu, I was asked if I would lead the development of community asset maps for both Innu communities, in collaboration with a team of stakeholders that represent local, regional, and federal representatives. I agreed to lead this initiative. I have played a leadership role on a provincial FASD organization called *fasdNL Network* and consequently have helped facilitate strategic planning sessions and knowledge exchange events that have taken place in the same urban community in which I conducted my research. As such, recommendations from my research are articulated and incorporated in to an FASD framework for action in NL to address FASD prevention, intervention, and diagnostic service priorities. A list of dissemination activities can be found in Table 6.3.

**Table 6.3 End-of-Project Dissemination Stage**

*Knowledge Sharing Activities, Partners, and Aims at the End-of-Project Dissemination Stage*

Activity	People Involved	Aim/Purpose
Community presentations	Research informants, target audiences, and key stakeholders	Share overview of research, findings, and recommendations. Discuss recommendations and next steps.  Identify people who are interested in strategic planning around supports and services for people living with FASD in NL.
Summary report for Sheshatshiu Innu First Nation	Innu Round Table, Innu Minuinniuin Committee, & FASD Working Group	Provide evidence to support recommendations that will inform the Innu Health Strategy and community health plans.

3-page and 10-page report on urban community study	fasdNL Network (providing permission to post this on their website), graphic designer	Create an accessible and abbreviated 3-page version of study for people in NL to be able to reference and contact me. Create an accessible and strategic summary of research as well as specific institutional-specific recommendations, targeting government policy and decision makers.
Poster and website pages	Innu Minuinniui Committee, FASD Working Group, website developers	Create two kinds of community asset maps of health supports and services available to community members – one for service providers (with funding and decision-making hierarchy included) and one for the general community (listing services, brief description of services, and phone numbers.
Strategic planning sessions in each community involved in my research	Key stakeholders, government decision and policy makers, experienced strategic planning facilitators	Hosted a one-day, facilitated session to develop a strategic plan to address key priority areas of FASD supports and services in NL.
Conference presentations		Disseminate research findings. Network with other researchers in related fields.
Dissertation and journal manuscript submissions		Fulfill academic requirements. Disseminate aspects of doctoral research to academic audiences.

There is a lot of emphasis in the KT literature on forging relationships with strategic stakeholders and key target audiences so that when the research results are complete, knowledge users are both interested and invested in the results and recommendations. My end-of-project dissemination activities and experiences were intertwined with relationships that I formed over the course of my research. I immersed myself fully in

FASD committee work that, over time, placed me in the inner circles of most FASD-related initiatives at local community, provincial, and Atlantic Canada regional levels.

Being actively and intensely involved in planning or attending FASD events, activities, and initiatives meant that it was relatively easy to find ways to include aspects of my research findings and recommendations into work that was already happening.

Because I had one foot in the research world and one foot in the FASD world of advocacy and capacity-building, conversations originally related to my research subsequently led to increased support and involvement in FASD committee initiatives. In short, the knowledge sharing was multi-directional. I would describe myself as a *connector*—connecting academic research(ers) with community members, community organizations, frontline workers (particularly in health, child welfare, education, and justice), and government decision-makers. Just as I connected people within NL, others connected me with leaders in FASD research. Some of these connections allowed me to become a provincial or Atlantic delegate at strategic meetings, national conferences, and a research think-tank.

## **6.3 Where To From Here?**

### **6.3.1 Implications.**

There are three broad themes that weave through most of my transcripts: (a) IE can be appropriate for Indigenous and CBR; (b) knowledge sharing must be relational to be effective and appropriate for CBR; and (c) other fields of practice, such as conflict resolution and graphic design, are relevant to researchers who are interested in community engagement.

Overall, academic literature on IE is easily recognized by unique terminology and ways of “speaking IE.” After reading the foundational texts, I read many manuscripts by researchers who used IE to explore how various problematic issues are organized. It was only after meeting and speaking with people like Dorothy Smith, Ellen Pence, Eric Mykhalovskiy, and Liza McCoy that I came to realize that IE is very much a *living* method of inquiry—a method of inquiry that is flexible enough to push methodological boundaries and representations of findings. For example, very few researchers have used IE for research with Indigenous people or communities or invested (documented) effort into making “what IE is” accessible and visible to research informants and partners.

I view research as a knowledge-sharing project where certain kinds of understanding and knowledge come into view, are discovered, and are co-constructed. I believe it is important to take a relational approach in any work that will affect others. Relational approaches are evident in principles articulated by Israel et al. (2003) on community-based participatory research; Schnarch (2004) on the Ownership, Control, Access, and Possessions (OCAP) principles; and Kirkness and Barnhardt (2001) on the four Rs of research—respect, reciprocity, relevance, and responsibility. These community-based and Indigenous research principles have not filtered into much of the mainstream KT literature in the health research field. My concern is that researchers who work with Indigenous people and communities may unknowingly continue to reify colonial practices; by doing so, these practices prevent well-meaning researchers from becoming authentic partners with Indigenous peoples on meaningful and useful research. My doctoral research reveals that there is a lot more work to be done (a) to understand what best practices in Indigenous knowledge-sharing look like; (b) to understand how to

evaluate Indigenous knowledge sharing; and (c) to think critically about how to embed Indigenous knowledge-sharing principles into mainstream processes such as funding applications, proposals, and academic writings.

My background in teaching, non-profit community work on conflict resolution, foster parenting a child with exceptionalities, and doing CBR field work as a non-academic researcher has exposed me to varied ways of making sense of the world. As I entered into this doctoral research experience, I found myself incorporating approaches from previous work experiences and training in learning styles, community development, communication approaches to minimize or resolve conflict, and presentation formats for diverse audiences. I believe that the methodologies and methods used in applied health research will continue to grow as researchers borrow and adapt ideas, concepts, and skills from other disciplines and professions.

### **6.3.2 Recommendations for further research.**

Recommendations in this section are based on my findings on the *process* of conducting my study, the focus of this dissertation, and not on the FASD research itself. The following four recommendations build on what my findings have left uncovered.

At the time of writing this dissertation, both Sheshatshiu and the urban communities were in midst of using my research results to address disjunctures. A follow-up study on the short- and long-term outcomes from the research recommendations made actionable in both communities would not only contribute to the field of FASD research but also the field of KT and Indigenous KT. Such a study would analyze the methods and processes

used to translate research recommendations into policy, program, and funding changes as well as the circumstances that facilitated the adoption of specific recommendations.

Since there is little to no mention of Indigenous research principles in mainstream KT literature, I suggest that a systematic review of published and grey literature on Indigenous KT practices be conducted. A systematic review of Indigenous health research would identify best and promising practices in Indigenous KT in Canada. In addition to a systematic review, I suggest that an in-depth study of exemplary research projects can further highlight best practices, principles, and approaches to Indigenous KT.

As discussed in Chapter 2, *Reframing challenges as opportunities for transformation*, I suggest that the notion of “two-eyed seeing” may be largely absent in research and funding policies at many universities across Canada. A study that examines the compatibility between university research policies and best practices for research with Indigenous communities could provide evidence and clear recommendations that would help align university practices with the four Rs of research—respect, reciprocity, relevance, and responsibility—as described by Kirkness and Barnhardt (2001) and the Ownership, Control, Access, and Possessions (OCAP) principles (Schnarch, 2004).

Academic literature on research studies rarely details the format or content of written communication with research participants, stakeholders, and target audiences. I recommend that an exploratory study examining how and why researchers, across disciplines, incorporate visual graphics into their research communication would make a valuable contribution to the field of CBR and integrated KT.

#### **6.4 Limitations of My Study**

There are several limitations of my study. First, this study did not include any youth living with an FASD diagnosis. Ethics approval was given to include any youth, aged 11-14, that were deemed competent to participate by their physician, social worker, or other qualified health professional (such as a psychologist or counsellor); however, there were no youth that fit this criteria. At the time of conducting my research, there was only one physician who conducted FASD diagnostic assessments in NL. The lack of capacity for FASD diagnostic assessments in this province limited the number of youth and families that could be invited to participate as an informant for my study. In addition, it is often the children who exhibit very troubling and problematic behaviours that tend to be referred for FASD diagnostic assessment, suggesting that my research findings were not reflective of those children who live with FASD but are not flagged by parents or institutions as needing specific interventions.

Second, between the two communities in which I conducted my study, I was only able to recruit one biological mother as a caregiver informant. It is possible that having more biological mothers as informants would yield an added dimension that was not identified by the caregivers I interviewed. It is also not clear if findings and recommendations would have varied if fathers (biological, adoptive, or foster) had been interviewed.

Third, I was not able to immerse myself in the everyday life of the Sheshatshiu for long periods of time. My research work in Sheshatshiu required extensive funding, planning, and prioritizing what activities would be face-to-face and what activities could be done by email and phone communication. The level of observational data that I made



was in seven visits, each time spending 6-14 days in the community.

## **6.5 In Closing**

As I faced writing manuscripts for my dissertation, my supervisor reminded me that a PhD is supposed to radically shift the way I think about something. As I reflected on the richest and biggest shifts in my thinking during my PhD, these shifts happened in the moments where I struggled the most—wrestling with self-doubt, wondering if I was betraying a way of doing research, making mistakes, trying to understand how to translate principles into practice, and questioning the value of my research contributions. The process of writing and rewriting this dissertation has afforded me time (a) to reflect critically on what kind of researcher I am; (b) to read new bodies of literature such as infographics and visual graphics; (c) to imagine a career in decolonizing research; and (d) to examine how the university is socially organized around CBR. By shifting the focus of my dissertation to how IE can be an emancipatory instrument of change, my dissertation contributes a new direction for researchers practicing IE, KT, and decolonizing research.

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## Appendix A - Community Researcher Agreement

### Research Project Title

Fetal Alcohol Spectrum Disorder (FASD): examining communication pathways between multidisciplinary support systems and diagnosed youth

### Research Agreement

May 15, 2012

Melody Morton Ninomiya, a doctoral student in the Division of Community Health & Humanities (Faculty of Medicine) at Memorial University, agrees to follow the OCAP principles as described by the First Nations Principles of OCAP. The First Nations Information Governance Centre summarizes the principles as follows:

**Ownership:** Ownership refers to the relationship of First Nations to their cultural knowledge, data, and information. This principle states that a community or group owns information collectively in the same way that an individual owns his or her personal information.

**Control:** The principle of control affirms that First Nations, their communities and representative bodies are within their rights in seeking to control over all aspects of research and information management processes that impact them. First Nations control of research can include all stages of a particular research project-from start to finish. The principle extends to the control of resources and review processes, the planning process, management of the information and so on.

**Access:** First Nations must have access to information and data about themselves and their communities, regardless of where it is currently held. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized, formal protocols.

**Possession:** While ownership identifies the relationship between a people and their information in principle, possession or stewardship is more concrete. It refers to the physical control of data. Possession is a mechanism by which ownership can be asserted and protected.

Based on the principles, the following provides specific details regarding the research on FASD that will be conducted by Melody Morton Ninomiya in the community of Sheshatshiu.

1. The **purpose of this research project**, as discussed with key members (FASD Coordinator, CYFS Director and Staff, School Principal and Guidance Counsellor, Community Health Nurse, Sheshatshiu Social Health Director) of the community of Sheshatshiu Innu First Nation, is to:
  - Use a strengths-based perspective to identify best practices, gaps in both formal and informal supports and interventions for children and families living with FASD.
2. This research, as discussed with key members in the community, **will involve the following**:
  - Create a team of community consultants to provide feedback and guidance on this research project.
  - The FASD Coordinator (Natasha Hervieux) will approach individuals/families that may be willing to meet with Melody.
  - Informal interviews (recognizing that translation may be needed) will take place with family members who live with a youth between ages 9-14 who has FASD.
  - Informal interviews/meetings will be made with people who directly work with participating families.

- There will be community consultations, meetings or workshops when and if the community advisors feel it would be helpful.
3. The **methods to be used**, as agreed by the researcher (Melody) and the community, are:
- Informal interviews will (with the individual consent of the participant) be audio-recorded and transcribed in full.
  - In some cases, the interview will be translated from Innu-aimun to English.
  - In some cases where youth may want to participate, Melody may use photography or other art forms as a way to connect with them and ask similar questions that she would be asking adults.
4. **Community training and participation** will include the following:
- Melody has agreed to participate, when possible, in community meetings or trainings related to FASD (in collaboration with the FASD Coordinator).
  - Melody will meet with community members who want to address any concerns or make recommendations to this research.
  - At the end of the project, Melody will participate in community meetings/presentations to discuss the research analysis and results.
5. **Information that is collected** is to be:
- Confidential and no names will be attached to the record.
  - The electronic files that have contain research data will be encrypted; the computer used for this research will be password protected; the laptop will always be kept securely locked in Melody's home, office or will be on her.
  - Melody's addresses are: (home) 1 Parliament Place, St. John's, NL A1A 2Z5; (work office) Health Science Building, Division of Community Health & Humanities, Faculty of Medicine, Memorial University, St. John's, NL A1B 3V6.
6. **Informed consent** (written in English and Innu-aimun) of research participants will be done by:
- With families, Natasha Hervieux and Melody will review the consent form in English or Innu-aimun (which ever is preferred).
  - A copy of the consent form will be left with participants and contact information for Melody (as the researcher) and Natasha (as the FASD coordinator, research collaborator and bilingual in English and Innu-aimun) will be provided if case any participants want to contact her for additional information.
  - The informed consent document will be signed by the individual who has agreed to participate in the research and this will constitute the informed consent agreement.
7. The **names of participants and community** will be protected in the following ways:
- Individual names will be kept confidential. No participant names will be attached to research records or interview notes.
  - The signed informed consents will be kept in a locked filing cabinet. In a separate locked filing cabinet there will be a sheet containing the "key" linking participant names with their identification code. Both of these sets of documents will be accessible only to Melody and her supervisor, and will be kept separate from the transcripts and research notes.
  - Before the distribution of any final report, publication, media or presentation that identifies the community of Sheshatshiu, the community WILL be consulted as to whether the community agrees to share this data in that particular way.

8. **Project progress** will be communicated to the community in the following ways:
- In consultation with key stakeholders (Sheshatshiu Social Health Director, FASD Coordinator, CYFS Director and Staff, School Principal and Guidance Counsellor, Community Health Nurse), Melody may be asked to present (in person) on research progress on any of her visits to the community.
  - Melody agrees to present progress updates in email and document form upon request (suggesting an update after each visit to Sheshatshiu).
9. **Communication with organizations** (such as conferences and funding organizations) will be handled in the agreed ways:
- The researcher (Melody) will always inform and seek permission to include reference to research taking place in Sheshatshiu before any proposal or abstract is submitted.

### Benefits

The researcher, Melody, wishes to use this research for her own benefit in the following ways:

- Present findings at meetings/consultations where policy and decision makers will be present.
- Complete/write her doctoral thesis.
- Present research findings at FASD, Aboriginal or other related conferences.
- Write/publish articles in newsletters, academic journals and reports.

Melody will submit a final report, as may be required, to an agency that may fund the expenses of doing research in Sheshatshiu (for which, any application will be made after consultation with Jack Penashue, the Social Health Director for Sheshatshiu First Nation). **The final report will be shared and reviewed by community members (as identified by the Social Health Director) prior to publication.**

The benefits of this research for the community are likely to include the following (see next page):

### Educational

- Melody's presence in the community will provide opportunities for informal and formal education and training in FASD - for individuals, frontline workers and other professionals alike (such as teachers, social workers, health workers).
- Melody will work closely with community collaborators who may use this community-based research as a capacity building experience.
- Melody will also learn from the community and may become an advocate for issues that are poorly understood outside of the Sheshatshiu community and culture.

### Informational

- This research will provide information that may help understand and improve the kinds of supports, services and approaches we use with people living with FASD from our community.
- This research may provide the evidence to advocate for change that we need from outside of our community.

### Financial

- Research findings may help us secure finances or other resources.
- The research will help figure out which resources need to be prioritized and have the evidence to support our applications for resources.

### **Commitments**

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The community's commitment to the researcher is to:

- Recommend capable and reliable community members to collaborate on this project (already in place).
- Keep informed about the project and participate in the discussions/planning around the sharing of the meaningful results.

The researcher's main commitment to the community is to:

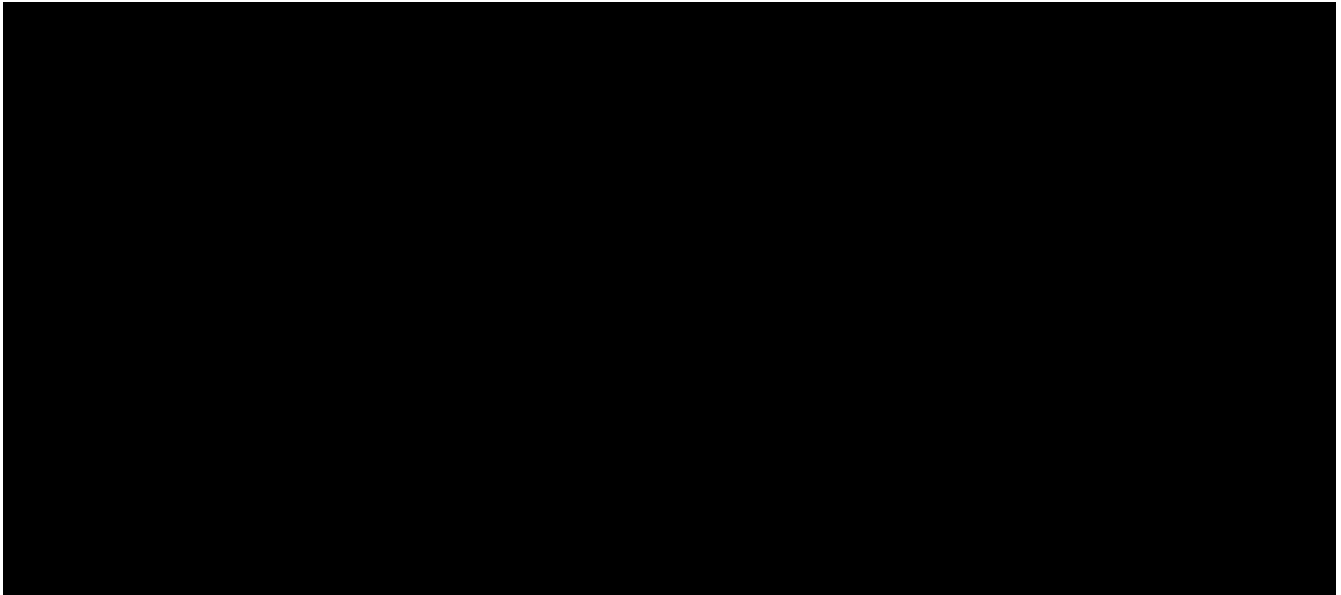
- Inform the community about the progress of the project in a clear, specific, and timely manner.
- Act as a resource to the community on FASD-related questions.

The researcher agrees to interrupt the research project in the following circumstances:

- If the community leaders decide to withdraw their participation.
- If the researcher (Melody) believes that the project will no longer benefit the community (this will be discussed before any final decision is made).

### **Signatures**

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*Fetal Alcohol Spectrum Disorder (FASD):  
examining communication pathways between  
multidisciplinary support systems and diagnosed  
youth*

### Participant Information Letter

Frontline Workers, Decision & Policy Makers

Dear potential participant,

My name is Melody Morton-Ninomiya, a PhD student in Community Health & Humanities (Faculty of Medicine) at Memorial University. The purpose of this information letter is to provide details about my research project, my connection to the area of FASD and what being a participant involves.

#### **Brief Research Project Description**

This research will look at how FASD diagnoses and behaviours influence beliefs, opinions, programs, policies and interventions by families, community and other support systems alike. One of the aims of this research is to “map” how things happen the way they do (actually draw images that connect people to organizations and textual documents - such as policies, forms, manuals). This research will provide much needed evidence to support what is working well and what areas need to be addressed.

#### **My Connection to this FASD Research**

I am passionate about research that is largely community-based. FASD is an issue that came up in the context of research work that I did previously on women in prison, young pregnant or parenting women, and housing. I also have a family member that lives with FASD so, I am intimately aware of how FASD can impact day-to-day life.

#### **Being a Participant**

Participating in this research will involve a semi-structured interview asking questions such as:

- Please describe what your role(s) is in this job.
- I understand you occasionally work with people diagnosed with FASD. I would like to hear more about how your work looks when you are working with someone with FASD.
- When you find out that someone has FASD, what happens? And how does that look – can you walk me through the steps/process?
- How do you make decisions about ....?
- Are there any documents you need to fill out? Can we look at a blank form together?
- Why is this information important to document?
- Where does this information go? What happens with this after you fill it out?
- What other documents, people, processes are involved when it comes to dealing with individuals with FASD?
- How important is the actual FASD diagnosis to your work?

#### **Included in this Package**

1. Further information about this research and what is involved in participating.
2. A consent form.

I am happy to answer any questions about information in this package. And similarly, if you are interested in participating, please do not hesitate to contact me (**Melody**).



**Faculty of Medicine**  
**Division of Community Health and**  
**Humanities**

The Health Sciences Centre  
St. John's, NL, Canada A1B 3V6  
Tel: 709-777-6213/6652 Fax: 709-  
777-7382  
www.med.mun.ca

**Research Title**

*Fetal Alcohol Spectrum Disorder (FASD): examining communication pathways between multidisciplinary support systems and diagnosed youth.*

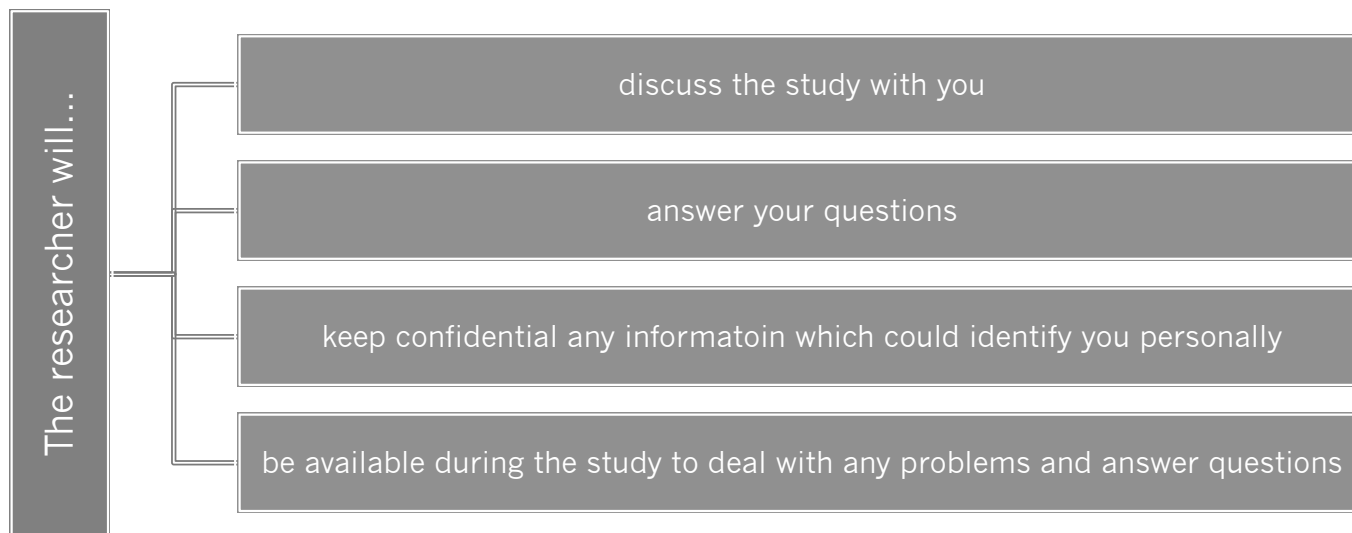
**Researcher/Investigator**

Melody Morton-Ninomiya, Faculty of Medicine, Memorial University

You have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. You can decide not to take part in the study. If you decide to take part, you are free to leave at any time.

Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you do not understand, or want explained better. After you have read it, please ask questions about anything that is not clear.



**1. Introduction**

I am a doctoral student in the Division of Community Health & Humanities. I am interested in providing comprehensive evidence of how individuals and families with FASD are connected to supports and services in their community – highlighting what is working well and identifying gaps that need to be addressed. As part of this, I am researching how the everyday lives of youth (age 9-14) with an FASD



# Informed Consent Form

## Frontline Workers, Decision & Policy Makers

diagnosis and their caregivers are affected by the policies and practices of larger institutions such as education, health care, child welfare and community groups.

### 2. Purpose of the Research Study

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The purpose of this study is to explore the experiences of youth with FASD and their caregivers in Sheshatshiu and St. John's on a day-to-day basis – and – understand how they are linked to institutions' policies, procedures and programs.

### 3. Description of the Study Procedures

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☐ **For frontline workers (institutional, government, community)**

I would like to ask you questions to understand your role in the lives of youth (and/or their families) with an FASD diagnosis; find out how your work is connected to other peoples' work – within your organization or perhaps with other institutions/systems; see what kinds of policies, procedures, or processes guide your work (this may include looking at forms that you typically fill out).

☐ **For decision or policy makers (related to interviewed frontline workers)**

I would like to ask you questions to help me understand what kinds of decisions and policies you are responsible for; how decisions or policies typically get made or changed and how they are informed; and any ideas or opinions you have on how the issue of FASD is addressed within your jurisdiction.

### 4. Length of Time

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You will be asked to participate in an approximately 30-60 minute interview, sometime between June 2012 and June 2013.

### 5. Possible Risks and Discomforts

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There may be some risk from participating in this study:

- Frontline workers and various professionals (health, social work, education, policy makers, etc.) who agree to be key informants may be concerned about risks associated with their work within institutions and community groups. As described below (under "Confidentiality"), I will make every reasonable effort to maintain your anonymity and confidentiality as a participant in this research.

### 6. Possible Benefits

---

It is not known whether this study will directly benefit you.

### 7. Liability Statement

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Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

### 8. What about my privacy and confidentiality?

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# Informed Consent Form

## Frontline Workers, Decision & Policy Makers

Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. However it cannot be guaranteed. For example we may be required by law to allow access to research records.

When you sign this consent form you give us permission to

- Collect information from you
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

### **(a) Access to records**

The only members on the research team are Melody (as Principal Investigator), a transcriptionist, and Dr. Fern Brunger (Melody's thesis supervisor).

### **(b) Use of your study information**

The research team will collect and use only the information they need for this research study. This information will include your recording and transcript from your interview.

Your name and contact information will be kept secure by the research team. It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study.

Information collected for this study will kept for five years.

If you decide to withdraw from the study, you may do so without consequence. If you decide to withdraw from the study, it is your decision as to whether or not you want the data collected up until that point to be used. This information will only be used for the purposes of this study.

Information collected and used by Melody will be stored on her password-protected laptop that will be with her, locked in her home office (1 Parliament Place, St. John's), or locked in her work office (Health Science Centre, Division of Community Health, Faculty of Medicine, Memorial University, St. John's). Melody Morton Ninomiya is the person responsible for keeping it secure.

### **(c) Your access to records**

You may ask Melody, the researcher, to see the information that has been collected about you.

## **9. Questions or problems**

If you have any questions about taking part in this study, you can meet with investigator who is in charge of the study at this institution. That person is: Melody Morton Ninomiya.

### **Melody Morton-Ninomiya**

Principal Investigator  
Graduate Student (PhD Candidate)  
Division of Community Health & Humanities

### **Dr. Fern Brunger**

Melody's Thesis Supervisor  
Professor  
Division of Community Health & Humanities

# Informed Consent Form

## Frontline Workers, Decision & Policy Makers

Faculty of Medicine  
Memorial University  
(709) 697-9492  
melodym@mun.ca

Faculty of Medicine  
Memorial University  
(709) 777-7284  
fbrunger@mun.ca

Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through:

Ethics Office, Health Research Ethics Authority  
(709) 777-6974 or by email at [info@hrea.ca](mailto:info@hrea.ca)

*After signing this consent form, you will be given a copy.*

### Signature Page

**Study title:** Fetal Alcohol Spectrum Disorder (FASD): examining communication pathways between multidisciplinary support systems and diagnosed youth.

**Name of the principal investigator:** Melody Morton Ninomiya

To be filled out and signed by the **participant**:

Please check as appropriate:

I have read the consent <i>[and information sheet]</i> .	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I have had the opportunity to ask questions/to discuss this study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I have received satisfactory answers to all of my questions.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I have received enough information about the study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I have spoken to Melody and she has answered my questions.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that I am free to withdraw from the study at any time:	Yes <input type="checkbox"/>	No <input type="checkbox"/>
• without having to give a reason		
• without affecting my future care [student status, etc.]		
I understand that it is my choice to be in the study and that I may not benefit.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand how my privacy is protected and my records kept confidential.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I agree to be audio taped.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I agree to take part in this study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>

\_\_\_\_\_  
Signature of **Participant**

\_\_\_\_\_  
Name printed

\_\_\_\_\_  
Year/Month/Day

To be signed by the **investigator**:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

# Informed Consent Form

## Frontline Workers, Decision & Policy Makers

\_\_\_\_\_  
Signature of **Investigator**

\_\_\_\_\_  
Name printed

\_\_\_\_\_  
Year/Month/Day

Telephone number: \_\_\_\_\_

# Research Title

*Fetal Alcohol Spectrum Disorder (FASD):  
examining communication pathways between  
multidisciplinary support systems and diagnosed  
youth*

## Participant Information Letter

Families in Sheshatshiu

Dear potential participant,

My name is Melody Morton-Ninomiya, a PhD student in Community Health & Humanities (Faculty of Medicine) at Memorial University. The purpose of this letter is to give you information about my research project, my connection to FASD and what being a participant involves. Natasha Hervieux has offered to translate any forms and interviews into Innu-aimun. You are welcome to fully participate in Innu-aimun and I thank Natasha for making this possible.

### **Brief Research Project Description**

I am a doctoral student in Community Health (Faculty of Medicine) at Memorial University. I am researching how individuals and families with FASD use supports and services in their community. I want to know what is working well and what needs attention. As part of this, I am researching how youth (ages 9-14) with an FASD diagnosis and their caregivers are helped by different institutions such as schools, health care, child welfare and community groups.

### **My Connection to this FASD Research**

I am passionate about research that can make a difference. I consider you, as a parent/caregiver, to be an expert. FASD is an issue that came up in research work that I did previously on women in prison, young pregnant or parenting women, and housing. I also have a family member that lives with FASD so, I am very aware of how FASD can impact life everyday.

### **Being a Participant**

Participating in this research will involve an informal interview asking questions like:

- I know \_\_\_\_ has FASD. How did you find out \_\_\_\_ has FASD?
- Does it make difference to know that \_\_\_\_ has FASD? For example, who else knows this?
- What does an average day look like, as someone who cares for \_\_\_\_?
- How was that decided?
- How do you respond or deal with it when ... happens?
- So, what exactly happens? How does that work?
- Could you explain to me how you learned or figure that out?
- What kinds of supports have you found to be most helpful?
- If you could have all the supports in the world for \_\_\_\_, what would they include?

### **Included in this Package**

1. More information about this research.
2. A consent form.

I (**Melody**) am happy to answer any questions about information in this package. And similarly, if you are interested in participating, please let Natasha Hervieux know.

# Informed Consent Form

Families in Sheshatshiu

## Research Title

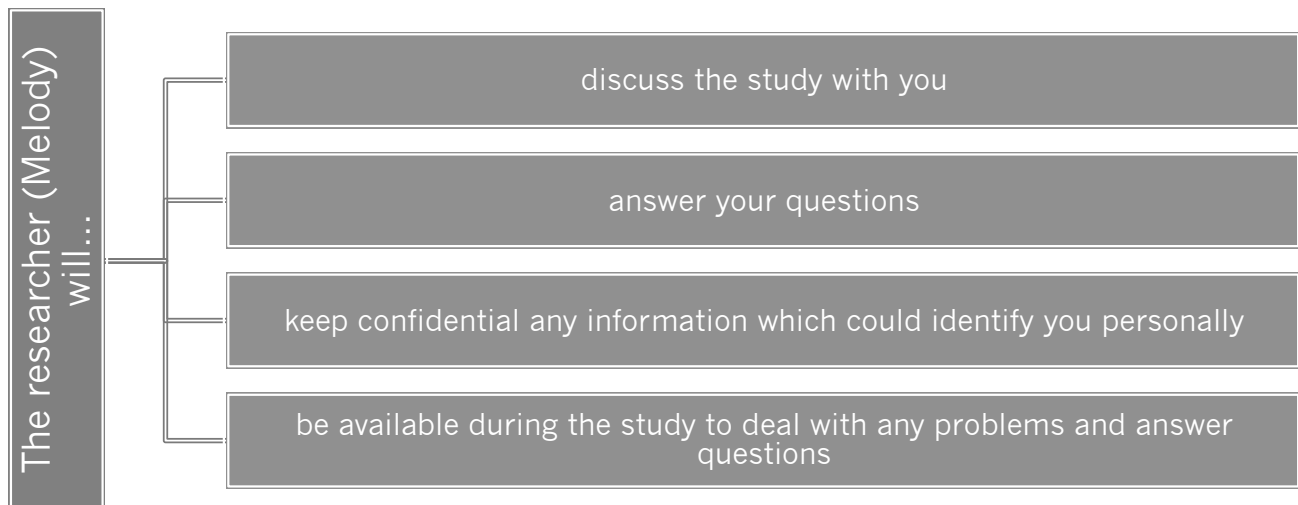
*Fetal Alcohol Spectrum Disorder (FASD): examining communication pathways between multidisciplinary support systems and diagnosed youth.*

## Researcher

Melody Morton-Ninomiya, Faculty of Medicine, Memorial University

You have been invited to participate in a research study. It is voluntary – you can decide if you want to participate or not. If you decide to participate and decide later that you don't want to be part of it anymore, you are free to stop.

Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This is a consent form. It explains the study. Please read it carefully. Take your time. You can take it home and think about it. Mark anything that you do not understand or want explained better. After you have read it, please ask questions about anything that is not clear.



## Introduction & Purpose

I am a doctoral student in Community Health (Faculty of Medicine) at Memorial University. I am researching how individuals and families with FASD use supports and services in their community. I want to know what is working well and what needs attention. As part of this, I am researching how youth (ages 9-14) with an FASD diagnosis and their caregivers are helped by different institutions such as schools, health care, child welfare and community groups.

# Informed Consent Form

Families in Sheshatshiu

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## **What you will do in this study**

I would like to ask you questions about how you got the diagnosis of FASD. I also want to know what it's like to take care of a child with FASD. This includes what systems and supports you use and your ideas and opinions on your experiences taking care of a child with FASD.

---

## **Length of time**

The interview will take ½ - 1 hour. It will be between June 2012 and June 2013.

---

## **Withdrawal from the study**

If you decide to withdraw from the study, you can decide whether or not you want the information about you to be used.

---

## **Possible benefits & risks**

### **Possible Benefits**

It is not known whether this study will directly benefit you. Some people might find it helpful to talk about what it's like to take care of someone with FASD.

### **Possible Risks**

There may be some risk from participating in this study:

- Talking about the impact of FASD can be emotional, especially if your experiences have been difficult.
- If you become upset at any time you may stop or choose not to answer a question. If you would like to talk to someone about your feelings about this study, Natasha Hervieux (FASD Coordinator) will be able to provide counselling or assistance.

---

## **Confidentiality & Storage of Information**

### **Recording Our Interview**

I would like to audio record our discussions so that I am able to review what was talked about without having to take notes during our conversation. You can, of course, request that any statement be kept "off the record" and/or have the recorder be turned off.

All interview recordings will be typed up and only my thesis supervisor and I will read them. You will be asked if you would like to read the typed version of your interview. If you do, you may add, change or delete information as you want.

### **Confidentiality**

Anything that is written about this study will not identify you. If I use something you said, I will use a made-up name that you choose. I will do everything I can to protect your privacy but it cannot be guaranteed. The only people that will know what you said will be Melody, the FASD Coordinator (if translation is needed), Dr. Brunger (Melody's supervisor), and possibly the research ethics board. It is

# Informed Consent Form

## Families in Sheshatshiu

very unlikely that anyone on the research ethics board will ask to see any data, but if they do, they will be supervised by Melody or Dr. Brunger.

### Storing Information from this Study

All consent forms, recordings and transcripts will be stored in my home office. Any papers will be locked in my filing cabinet. Anything electronic will be password-protected on my computer. Information collected from this study will be kept for 5 years.

You may ask Melody to see any information that has been collected about you.

### Reporting research results

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The data I collect will be used for:

- My doctoral thesis
- Submission to academic journals
- Community reports
- Reports to government and other institutions that may be interested in the results from this study
- Presentations

In all cases, study results will be summarized in a way that you cannot be identified. If I use direct quotations from your interview in any way, they will be identified by a pseudonym of your choice.

In Sheshatshiu Innu First Nation, there is a signed Community-Researcher agreement states that the Social Health Director (currently Jack Penashue) must give permission before including information that will identify that this research took place in the community of Sheshatshiu.

### Questions

---

You are welcome to ask questions at any time during your participation in this research. If you would like more information about this study, please contact:

#### **Melody Morton-Ninomiya**

Graduate Student (PhD Candidate)  
Division of Community Health & Humanities  
Faculty of Medicine  
Memorial University  
(709) 697-9492  
melodym@mun.ca

#### **Dr. Fern Brunger**

Professor (Thesis Supervisor)  
Division of Community Health & Humanities  
Faculty of Medicine  
Memorial University  
(709) 777-7284  
fbrunger@mun.ca

The proposal for this research has been reviewed by the Health Research Ethics Board (HREB) and found in compliance with Memorial University's ethics policy. If you have ethical concerns about the research, you may contact the HREB Ethics Office at [info@hrea.ca](mailto:info@hrea.ca) or telephone (709) 777-6974.



# Informed Consent Form

Families in Sheshatshiu

## Consent

If you sign this form, you do not give up your legal rights. If you sign this form, you are agreeing to be in this study. Researchers and other organizations involved in this research study also have legal and professional responsibilities.

## Signature Page

**Study title:** Fetal Alcohol Spectrum Disorder (FASD): examining communication pathways between multidisciplinary support systems and diagnosed youth.

**Researcher:** Melody Morton Ninomiya

For **participant**:

	Please check as appropriate:	
I have understand this information and consent form.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I have been able to ask questions about this study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand enough about this study and what I will be doing.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I have spoken to Melody and she has answered my questions.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that I am free to withdraw from the study at any time:	Yes <input type="checkbox"/>	No <input type="checkbox"/>
• without having to give a reason		
• without affecting my future care		
I understand that it is my choice to be in the study and that I may not benefit.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand how my identity and information will be confidential.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I agree to be audio taped.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I agree to take part in this study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>

\_\_\_\_\_  
Signature of **Participant**

\_\_\_\_\_  
Name printed

\_\_\_\_\_  
Year/Month/Day

To be signed by the **investigator**:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

\_\_\_\_\_  
Signature of **Investigator**

\_\_\_\_\_  
Name printed

\_\_\_\_\_  
Year/Month/Day

Telephone number: \_\_\_\_\_

*After signing this consent form, you will be given a copy.*

# Research Title

*Fetal Alcohol Spectrum Disorder (FASD):  
examining communication pathways between  
multidisciplinary support systems and diagnosed  
youth*

## Participant Information Letter

Families in [REDACTED]

Dear potential participant,

My name is Melody Morton-Ninomiya, a PhD student in Community Health & Humanities (Faculty of Medicine) at Memorial University. The purpose of this letter is to give you details about my research project, my connection to FASD and what being a participant involves.

### **Brief Research Project Description**

I am a doctoral student in Community Health (Faculty of Medicine) at Memorial University. I am researching how individuals and families with FASD use supports and services in their community. I want to know what is working well and what needs attention. As part of this, I am researching how youth (ages 9-14) with an FASD diagnosis and their caregivers are helped by different institutions such as schools, health care, child welfare and community groups.

### **My Connection to this FASD Research**

I am passionate about research that can make a difference. I consider you, as a parent/caregiver, to be an expert. FASD is an issue that came up in the context of research work that I did previously on women in prison, young pregnant or parenting women, and housing. I also have a family member that lives with FASD so, I am intimately aware of how FASD can impact day-to-day life.

### **Being a Participant**

Participating in this research will involve an informal interview asking questions like:

- I know \_\_\_\_ has FASD. Could you describe how you came to know that X has FASD?
- Does it make difference to know that X has FASD? For example, who else knows this?
- I would like to hear about what an average day looks like, as someone who cares for X.
- So, when you say they ..... what was happening?
- How was that decided?
- How do you respond or deal with it when \_\_\_\_ happens?
- So, what exactly happens? How does that work?
- Could you explain to me how you learned or figure that out?
- What kinds of supports have you found to be most helpful?
- If you could have all the supports in the world for X, what would they include?

### **Included in this Package**

1. Further information about this research and what is involved in participating.
2. A consent form.

I am happy to answer any questions about information in this package. And similarly, if you are interested in participating, please do not hesitate to contact me (**Melody**).

**Faculty of Medicine**  
**Division of Community Health and**  
**Humanities**  
 The Health Sciences Centre  
 St. John's, NL, Canada A1B 3V6  
 Tel: 709-777-6213/6652 Fax: 709-  
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## Research Title

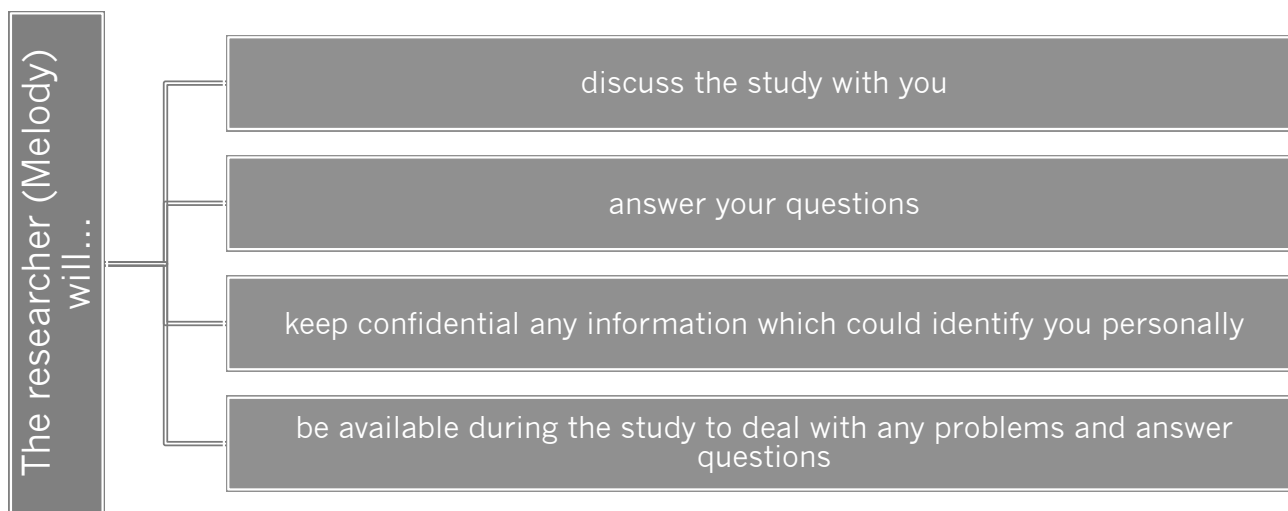
*Fetal Alcohol Spectrum Disorder (FASD): examining communication pathways between multidisciplinary support systems and diagnosed youth.*

## Researcher

Melody Morton-Ninomiya, Faculty of Medicine, Memorial University

You have been invited to participate in a research study. It is voluntary – you can decide if you want to participate or not. If you decide to participate and decide later that you don't want to be part of it anymore, you are free to stop.

Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This is a consent form. It explains the study. Please read it carefully. Take your time. You can take it home and think about it. Mark anything that you do not understand or want explained better. After you have read it, please ask questions about anything that is not clear.



## Introduction & Purpose

I am a doctoral student in Community Health (Faculty of Medicine) at Memorial University. I am researching how individuals and families with FASD use supports and services in their community. I want to know what is working well and what needs attention. As part of this, I am researching how youth (ages 9-14) with an FASD diagnosis and their caregivers are helped by different institutions such as schools, health care, child welfare and community groups.

# Informed Consent Form

Families in [REDACTED]

---

## **What you will do in this study**

I would like to ask you questions about how you got the diagnosis of FASD. I also want to know what it's like to take care of a child with FASD. This includes what systems and supports you use and your ideas and opinions on your experiences taking care of a child with FASD.

---

## **Length of time**

The interview will take ½ - 1 hour. It will be between June 2012 and June 2013.

---

## **Withdrawal from the study**

If you decide to withdraw from the study, you can decide whether or not you want the information about you to be used.

---

## **Possible benefits & risks**

### **Possible Benefits**

It is not known whether this study will directly benefit you. Some people might find it helpful to talk about what it's like to take care of someone with FASD.

### **Possible Risks**

There may be some risk from participating in this study:

- Talking about the impact of FASD can be emotional, especially if your experiences have been difficult.
- If you become upset at any time you may stop or choose not to answer a question. If you would like to talk to someone about your feelings about this study, David Martin (or, if you have a CYFS social worker that you trust) will be able to provide counselling or assistance.

---

## **Confidentiality & Storage of Information**

### **Recording Our Interview**

I would like to audio record our discussions so that I am able to review what was talked about without having to take notes during our conversation. You can, of course, request that any statement be kept "off the record" and/or have the recorder be turned off.

All interview recordings will be typed up and only my thesis supervisor and I will read them. You will be asked if you would like to read the typed version of your interview. If you do, you may add, change or delete information as you want.

### **Confidentiality**

Anything that is written about this study will not identify you. If I use something you said, I will use a made-up name that you choose. I will do everything I can to protect your privacy but it cannot be guaranteed. The only people that will know what you said will be Melody, a transcriptionist, Dr. Brunger (Melody's supervisor), and possibly the research ethics board. It is very unlikely that anyone on the research ethics board will ask to see any data, but if they do, they will be supervised by Melody or Dr. Brunger.

# Informed Consent Form

Families in [REDACTED]

## **Storing Information from this Study**

All consent forms, recordings and transcripts will be stored in my home office. Any papers will be locked in my filing cabinet. Anything electronic will be password-protected on my computer. Information collected from this study will be kept for 5 years.

You may ask Melody to see any information that has been collected about you.

## **Reporting research results**

---

The data I collect will be used for:

- My doctoral thesis
- Submission to academic journals
- Community reports
- Reports to government and other institutions that may be interested in the results from this study
- Presentations

In all cases, study results will be summarized in a way that you cannot be identified. If I use direct quotations from your interview in any way, they will be identified by a pseudonym of your choice.

## **Questions**

---

You are welcome to ask questions at any time during your participation in this research. If you would like more information about this study, please contact:

### **Melody Morton-Ninomiya**

Graduate Student (PhD Candidate)  
Division of Community Health & Humanities  
Faculty of Medicine  
Memorial University  
(709) 697-9492  
melodym@mun.ca

### **Dr. Fern Brunger**

Professor (Thesis Supervisor)  
Division of Community Health & Humanities  
Faculty of Medicine  
Memorial University  
(709) 777-7284  
fbrunger@mun.ca

The proposal for this research has been reviewed by the Health Research Ethics Board (HREB) and found in compliance with Memorial University's ethics policy. If you have ethical concerns about the research, you may contact the HREB Ethics Office at [info@hrea.ca](mailto:info@hrea.ca) or telephone (709) 777-6974.

# Informed Consent Form

Families in [REDACTED]

## Consent

If you sign this form, you do not give up your legal rights. If you sign this form, you are agreeing to be in this study. Researchers and other organizations involved in this research study also have legal and professional responsibilities.

## Signature Page

**Study title:** Fetal Alcohol Spectrum Disorder (FASD): examining communication pathways between multidisciplinary support systems and diagnosed youth.

**Researcher:** Melody Morton Ninomiya

For **participant**:

	Please check as appropriate:	
I have understand this information and consent form.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I have been able to ask questions about this study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand enough about this study and what I will be doing.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I have spoken to Melody and she has answered my questions.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that I am free to withdraw from the study at any time:	Yes <input type="checkbox"/>	No <input type="checkbox"/>
• without having to give a reason		
• without affecting my future care		
I understand that it is my choice to be in the study and that I may not benefit.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand how my identity and information will be confidential.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I agree to be audio taped.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I agree to take part in this study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>

\_\_\_\_\_  
Signature of **Participant**

\_\_\_\_\_  
Name printed

\_\_\_\_\_  
Year/Month/Day

To be signed by the **investigator**:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

\_\_\_\_\_  
Signature of **Investigator**

\_\_\_\_\_  
Name printed

\_\_\_\_\_  
Year/Month/Day

Telephone number: \_\_\_\_\_

*After signing this consent form, you will be given a copy.*







## Appendix D - Research Report for Sheshatshiu

# Supports & services being accessed by children/youth living with FASD Sheshatshiu, Labrador



Melody Morton-Ninomiya  
PhD Candidate  
Community Health Division  
Memorial University  
[melodym@mun.ca](mailto:melodym@mun.ca)

Submitted March 2014

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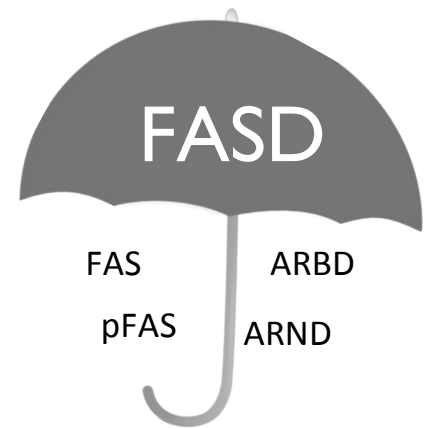
## Brief Background

For the purpose of this report, I will summarize what other researchers have found and written about – in a few areas that may be of most relevance.

### What is fetal alcohol spectrum disorder (FASD)?

Nobody is actually diagnosed with “FASD”. There are four possible diagnoses that are included in the spectrum:

1. fetal alcohol syndrome (FAS)
2. partial fetal alcohol syndrome (pFAS)
3. alcohol related neurodevelopmental disorder (ARND)
4. alcohol related birth defects (ARBD)



Any of the above diagnoses are directly caused when a fetus (baby in a mother’s womb) has alcohol in their system. There is something called teratogens in alcohol that affect the development of the fetus – causing damage. It is not easy to predict who will be affected because there are so many different aspects to consider including:

- ✗ what part of the fetus’ (unborn baby) body is developing when the alcohol is consumed
- ✗ how much, how often and how strong the alcohol is
- ✗ nutrition of the pregnant mother
- ✗ environment of the pregnant mother – stress level, physical health, etc.

However, we do know that a fetus is developing its brain throughout the whole pregnancy so, there is a certain level of brain damage that occurs. As a result, people living with FASD sometimes struggle with planning ahead, thinking through consequences of actions, organizing their day, understanding abstract thinking, and more.

### Diagnoses

Currently, diagnoses are complex and typically require a team because there is no test that can absolutely confirm it. It usually requires confirmation that alcohol was consumed during pregnancy and ruling out all other explanations for a child’s developmental challenges. The diagnostic guidelines are also written for children that are about 7 years old or older (but not an adult!). There is suggestion that new guidelines for very young children and adults will be released soon.



Some researchers have conducted studies to measure evidence of alcohol in babies when they are first born by taking samples of their first stool (poop). This kind of study only helps estimate how many children are likely exposed to alcohol and *may* potentially on “the fetal alcohol spectrum”. This kind of study is controversial, expensive, and women participate anonymously.

### “Secondary Disabilities”

This term is used a lot in FASD literature. Secondary disabilities refers to anything that someone is *not* born with. They are disabilities that affect young adults and adults - resulting from all of the challenges they have faced in their childhood. Secondary disabilities include:

1. Inappropriate sexual behaviour
2. Trouble with law
3. School drop out
4. ADD/ADHD/ODD labels
5. Mental health issues
6. Addictions
7. Finding and keeping job/housing

### Interventions

There are numerous kinds of interventions that have been studied and are known to make a difference – some small and some big. It is not a surprise some of the most important interventions are also the most challenging and require a family to be stable, caring, structured, consistent, committed to raising their children in a supportive environment, and being experts and advocates for their children (to health services, education, and other programs/services). This is clearly a huge challenge - one that is addressed in the FASD Report by Cathy Jong. Concrete examples of interventions that are known to be effective are in the table below.

Environmental	Specific Examples
Minimal distractions	Keep the walls relatively bare & noise constant.
Physical activity	Allow children to burn off their energy and be active.
Nutrition	In addition to a healthy diet, they encourage children to have extra amounts of Omega-3.
Structured day	Have a consistent schedule; use simple lists (pictures are particularly helpful) to remind people what steps need to happen; use special clocks/watches that display time (look up <i>Time Timers</i> ).
Repetition & clear language	People living with FASD often benefit from repeated instructions, expectations, plans, etc. Remembering details can be a challenge. It is important to keep information short and simple.
Predictability	People living with FASD often take on the emotions of people around them – and get caught up in the moment. However, when there is a surprise, sudden change in plans or moods, they may have trouble controlling their emotions or understanding what is going on.
Building on strengths	Often, people with FASD will struggle with aspects of school. Find, use, and celebrate their strengths. It may require creativity using a lot of visual cues, music, or physical ways of learning.

### Trauma-informed Approaches

Trauma can result from many things – abuse, neglect, sudden loss of family, accidents, and more. There is currently more talk of using trauma-informed approaches to any programs, supports, and services related to mental health or addictions. The term *trauma-informed* recognizes that:

1. people have experienced trauma (common and relevant to Innu community's history)
2. trauma affects how people respond to programs, services, systems, etc.
3. people working with people that have experienced trauma need to consider how they may need to change/adjust their approach and expectations.
4. When people who have experienced (or are experiencing trauma) are often unable to cope with everyday decisions, problem solving, learning, and more.
5. The effects of trauma are similar to the effects of FASD – and – it is common for people with FASD to also live through a lot of childhood trauma (consider children that go into care), increasing the chances of experiencing secondary disabilities.



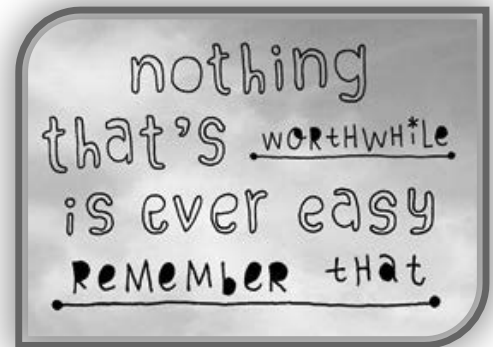
Key elements of trauma-informed approaches carefully consider how to ensure the following:

- |                                   |  |  |
|-----------------------------------|--|--|
| ✓ safe                            | ✓ collaborative  | ✓ strengths-based                        |
| ✓ trustworthy & transparent       | ✓ address historical, cultural, and gender specific issues | ✓ be open to change (as an organization) |
| ✓ inclusive                       | ✓ include peer support & self-help                         |  |
| ✓ empowers through choice & voice |  |  |

### Why this research?

To be brief, my reasons for doing this research are as follows:

- ✎ I did a number of community research projects (such as foster care emergency placements, women in prison with complex health needs, and community plans for safe and secure housing) where FASD was a reoccurring issue.
- ✎ I know this issue is one that affects a lot of people across Newfoundland & Labrador but the needs of people living with FASD are not being met.
- ✎ Research can sometimes provide the “evidence” or documentation needed to get appropriate resources.
- ✎ FASD is complex, challenging, controversial, and real. It exists and must be addressed if we want to prevent it and improve the lives of people living with FASD. Everyone matters.
- ✎ I deeply care about this issue. I am raising a child living with FASD and there is a lot of joy and hope, despite her FASD-related challenges.
- ✎ I thrive doing research that actually matters and contributes to positive change.



## Research Questions

---

1. How are supports and services organized between **systems and children/youth diagnosed with FASD** and key systems that they interact with? Examples of systems include health care, education, corrections, child welfare, social services.
2. How do institutions (such as health, corrections, child welfare, social services and education) **apply intervention, training, and policies** to individuals (and their families) with an FASD diagnosis?
3. How do institutional policies, procedures and programs **coordinate the lives of individuals (and their families)** who live with an FASD diagnosis?

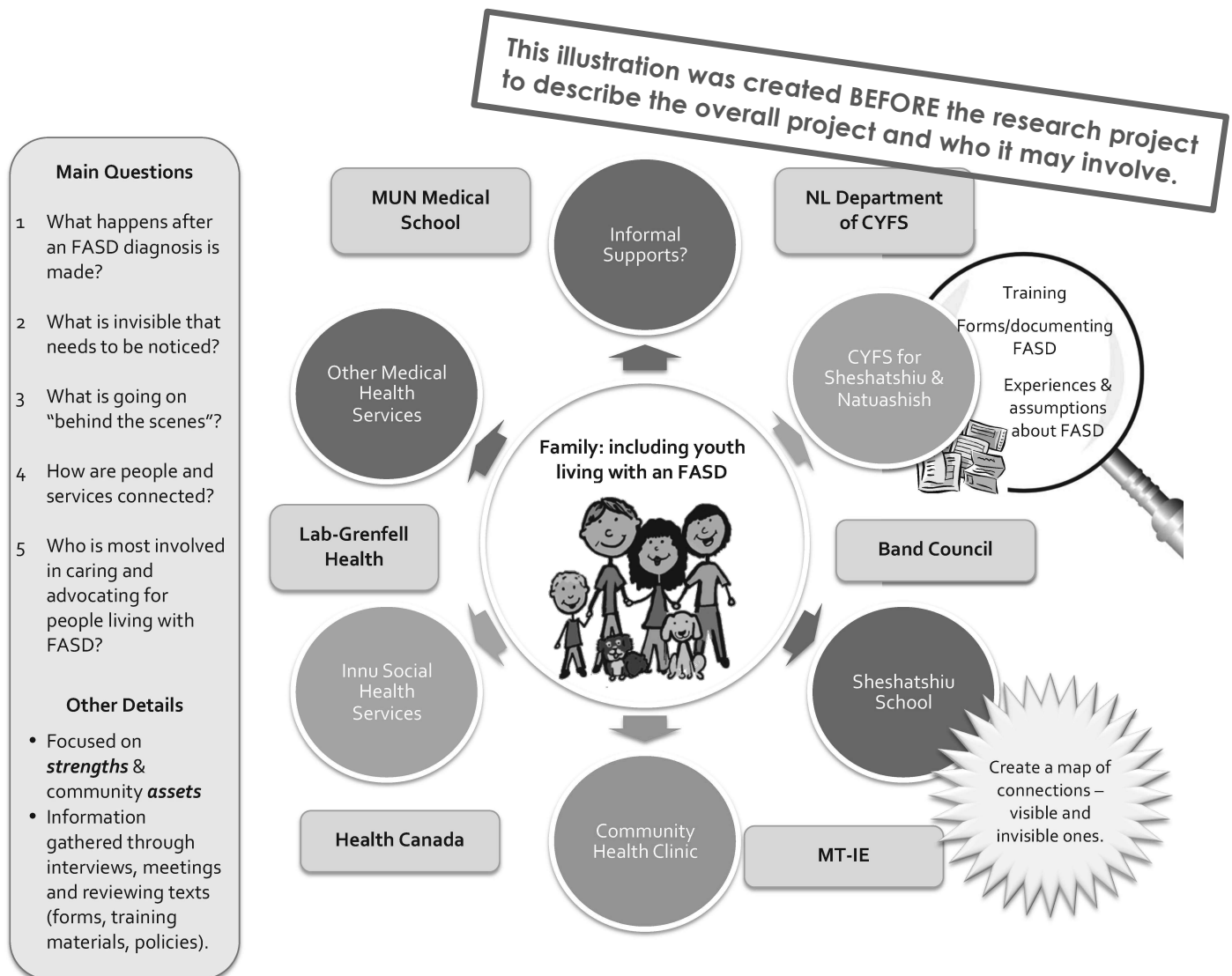
## Methodology – how research was conducted

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This research used something called *institutional ethnography*. The main purpose of institutional ethnography is to uncover the ways institutional systems (at many levels) are involved in organizing/coordinating peoples' everyday activities. The reasons I picked this method of doing research include:

- ✂ It honours first-hand accounts of people who are subject to being “monitored”, “regulated”, “coordinated”, or “observed”.
- ✂ It specifically looks at taken-for-granted (assumed) knowledge that inform health policies, program, and services.
- ✂ It can offer evidence-based recommendations for programs, services, and policies.

The illustration on the following page outlines the overall design of the research study.



### Step 1: Consultations

- I consulted with key people in the community that were working closely with individuals living with FASD.
- Research questions and methodology were discussed and decided. The illustration above is a summary of what was discussed at a particular meeting.

### Step 2: Approvals

- A *Community-Research Agreement* was drafted, discussed and signed (with Jack Penashue). This agreement outlined, in particular, the ways in which I was incorporating the First Nations ownership, control, access, and possession (OCAP) principles into every stage of the research study.
- A presentation was made to the Mamu Tshishkutamashutau/Innu Education Board of Trustees to seek approval to include school staff in this research. Approval was granted.
- Research ethics applications were submitted and approved by the provincial health authority and Labrador-Grenfell Health.

**Step 3: Interviews and Document Collection**

- Interviewed parent/caregivers of children in the community with an FASD diagnosis (identified by the FASD Coordinator).
- Interviewed people who directly support or provide services to children (or caregivers) living with an FASD.
- Interviewed people who manage, supervise, or are responsible for the employees providing direct supports/services.
- Collected forms, training materials, policies and guidelines used by the institutions.

**Step 4: Analyses, Community Engagement & Sharing Knowledge**

- Shared & discussed initial results with people interviewed.
- Shared recommendations with interested stakeholders.
- Joined the FASD Working Group meetings.
- Collaborated with Cathy Jong (on contract work on FASD in both communities) and Leonor Ward on a health information system.
- This short report for IMC consideration.
- Remain engaged to see how my skills and research may be an asset in the Community Work Plan developed by the IMC.
- Write 1-2 papers, have them reviewed by several community members, and submit them for publication (if community members agree that it is suitable). Please remember that I remain committed to the OCAP principles and intend to write any research results related to Sheshatshiu with a strengths-based lens.
- Remain committed to this research until December 2014. After that, I will naturally be interested (and perhaps involved) but will no longer officially be a graduate student working on FASD research.



## Research Result Highlights

This report is written with the intent of informing Work Plans and the *Connecting the Pieces* document. While there is a lot more that can be said about each point below, I am summarizing key findings that I think will be most interesting.

### 1. Parents/caregivers do not access (or know of) all services available.

- Some caregivers were not aware that there was an FASD Coordinator in the community.
- Improved supports may have been available at school if their diagnosis was disclosed.
- There are numerous resources available providing advice on how to parent, teach, or work with people living with FASD.
- People can request to receive: 1) speech and learning pathology (SLP) until school age; 2) direct home services from behavioural/child management specialists (CMS/BMS); and 3) Mapping the Way staff of occupational therapist (position now vacant) or social worker.

### 2. Supports & services are not coordinated with each other.

- There are MANY intake forms that caregivers must be present to fill out. These forms request the same information – over and over again.
- Very little information is shared. Reasons for this range from institutional policy, lack of awareness of other services that collect the same information, and the lack of time/support to make information sharing happen.
- For example: 1) the school does not know which children have a diagnosis; 2) the health clinic and school are not necessarily informed when a child moves into a new home (“in care”); and 3) relevant assessments that take place in the school (by guidance counselor) are not shared with the FASD Coordinator or allied health professionals (like SLP, OT, PT).
- A child often goes through multiple assessments and the documentation is not consistently shared with the same people. In addition, when information is shared (faxed or mailed), there is no process to ask questions or discuss the assessment or recommendations.

### 3. Diagnoses do not matter (as children/youth) unless a service adds cost.

- Very few services required a diagnosis to access resources, supports or services.
- The only place that indicated the need for diagnosis is the school. To further explore this, there is an assumption that a child with FASD requires additional staff, resources, or equipment. This may not always be the case – there are classroom strategies that can benefit the whole class (including the teacher) – that will help student living with FASD (with or without a diagnosis).
- The following supports/services do not require diagnosis: Family Support Program, FASD Coordinator support, SLP (up to school age), CMS/BMS (through Labrador-Grenfell Health), emotional support and inquiries from Foster Families Association (for foster parents), and Mapping the Way.



**4. We expect parents/caregivers to do a lot of WORK (time + effort + intent).**

- Services, programs, and consultations frequently require a caregiver/parent to: 1) agree to or make an appointment; 2) figure out the transportation to *most* appointments; 3) often coordinate child care for children not involved in the appointment; 4) sit through the intake, assessments, and treatments (often separate appointments); 5) occasionally expected to work with their child on an issue/behavior between appointments; 6) appointments tend to happen during “business hours” which is difficult for parents that work outside of the home; and 7) a lot of this work falls on the mother.
- This is a lot of work to expect of parents.
- It requires a lot of planning and coordination for ONE child (and there are usually multiple children at home). If a parent is affected by FASD themselves, there is nobody to help support them getting to these appointments.

**5. There is a lot of repetitive intake & assessment forms.**

- Upon close examination, it is clear that the intake and assessment forms collect a lot of the same information. In other words, there is a lot of duplication and redundancy in information that parents/caregivers need to provide to each institution/service.

**6. There is very little FASD training, approaches, policies and interventions.**

- There were no FASD-specific policies, guidelines, protocols, or interventions in any institutional documents that related to services for community members of Sheshatshiu (except to refer someone for diagnostic assessment). The only exception was Mapping the Way, who acknowledge their awareness of FASD in the work that they do.
- FASD training does happen in a few ways: 1) FASD Coordinator has contracted Dave Martin to do a full-day FASD workshop with school staff (without follow up, it is hard to gauge how much teachers adapt their teaching/classrooms); 2) LGH FASD Coordinator or the Nunatsiavut FASD Coordinator occasionally will organize an in-service for select people; or 3) an organization may request the FASD Coordinator to do a presentation to their staff. This training however, is not proving to be effective in boosting the confidence or effectiveness of teachers, social workers, health professionals, or community workers.

**7. There is a lot of hope. A lot of capacity exists. The infrastructure is mostly in place.**

- A lot of the services and supports exist.
- People are working in fields that provide important services/programs.
- There are many good and competent people working in the community.
- The IRT, IMC, and Working Groups are demonstrating (and facilitating) great leadership and collaboration.

## Recommendations

### Key Elements

- **Review all policies, programs, and services** in Social Health, Primary Health, CYFS, Education, and more - revising them to be: 1) trauma and FASD-informed, 2) culturally safe, 3) strengths-based approaches & language (using harm reduction), and 4) family-centred approach.
- Recognize that **FASD is not a woman's fault or a woman's issue**. It requires the effort/support of whole family and community.
- Address the issue of healthy parenting, healthy families, and the **strain on/of child welfare** in the community.
- Use **language** that has does not carry stigma for programs, services, and job positions.

### Within Community

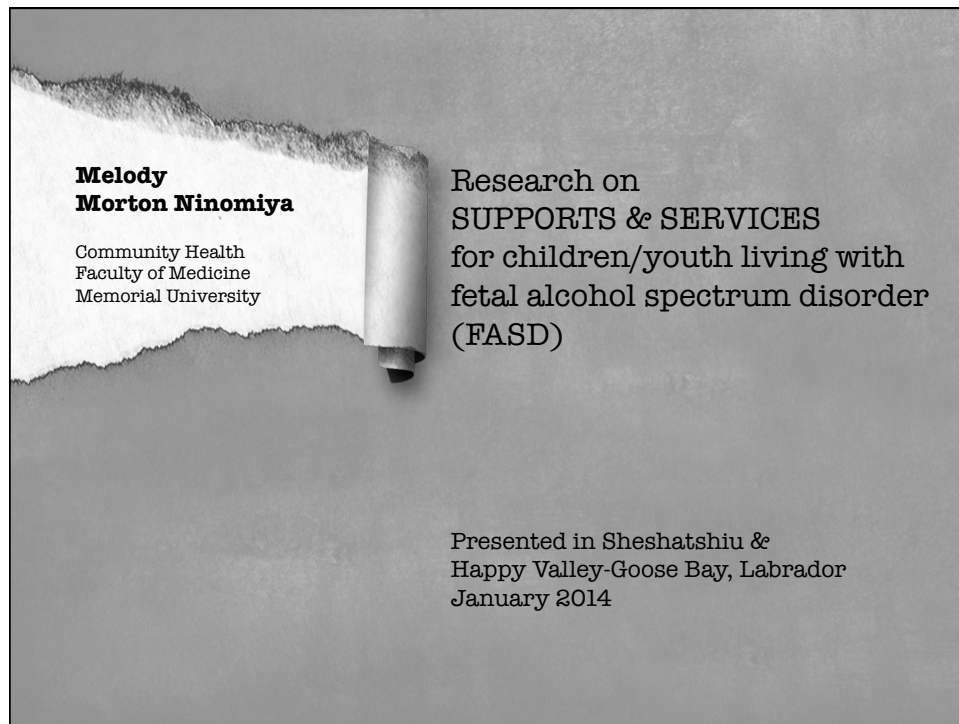
- **Engage community** in how to take care of the children, the future of the community.
- **Not require diagnoses** to get support. Use FASD-informed strategies and interventions in school and all community supports/services.
- **Promote** the work of the FASD Coordinator (rename this position?)
- **Increase day care capacity**; offer **respite care & extracurricular activities** for parents of children/youth with developmental/behavioural challenges.
- **Community partners** (education, primary health, social health, CYFS, etc.) meet regularly to **exchange information & collaborate**.

### Capacity Building

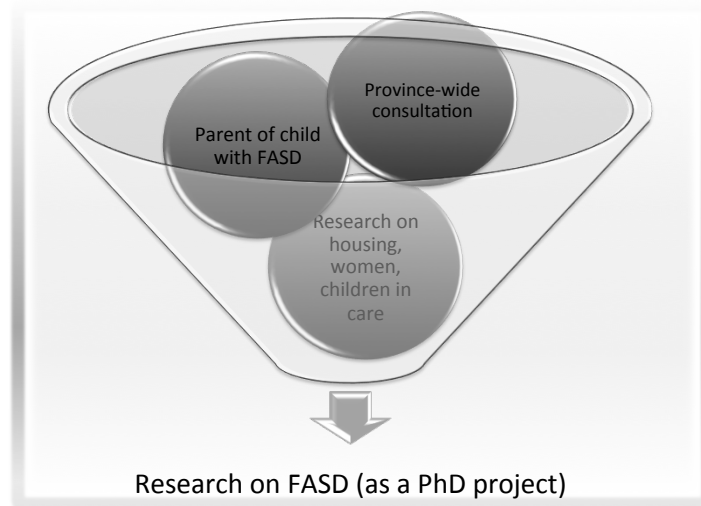
- Create a **dedicated team** with an SLP, OT, and 2-3 Key Workers/Mentors (visit, accompany, & advocate with families that have members living with FASD).
- **Train FASD Coordinator** to educate, advise & support community organizations & institutions.
- Hold a special meeting/workshop to **review** & implement parts of the ***Guidelines for the FNIHB Atlantic Region Maternal Child Health & FASD Programs***.
- Hire and train 2 **life coaches** for adults most affected by FASD.
- Consider training Family Support Workers to be key workers/mentors and life coaches.

### Education

- **Train** health professionals, allied health professionals, social workers, social health and community-based workers in trauma-informed approaches (e.g. required orientation)
- Start a **parent support group** (one for foster parents, one for birth parents) and incorporate educational workshops as desired by group.
- Include FASD in **health units for students in school** BEFORE they are sexually active.
- Create an **Asset Map** of all community supports/services for Sheshatshiu - for community members & service providers alike.



- 1** Who are **YOU**? And **WHY** do this research?
- 2** What are the **RESEARCH QUESTIONS**?
- 3** What did you find out? Highlights of **RESEARCH RESULTS**.
- 4** So, what's **NEXT**?
- 5** Sample recommendations. Thoughts. Ideas. Opinions.  
**DISCUSSION.**



**1** Who are **YOU**? And **WHY** do this research?

### Re-thinking. Re-framing.

#### What we've heard...

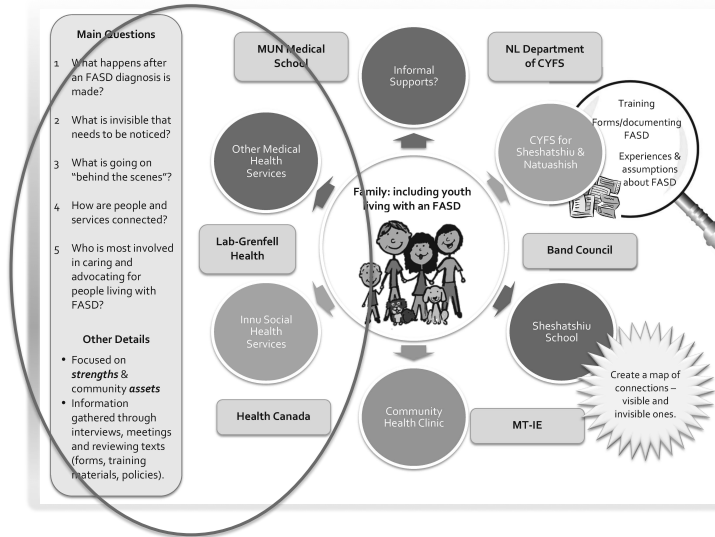
- FASD = preventable
- Women need to change
- Permanent damage
- Can tell by "the face"
- Aboriginal problem
- Secondary disabilities:
  - Sexual behaviour
  - Trouble with law
  - School drop out
  - ADD/ADHD/ODD
  - Mental health
  - Addictions
  - Job/housing/etc.

#### Consider...

- Community health
- Women know best
- Trauma & environment
- hidden
- Prevalence studies
- Known to help:
  - Early intervention
  - Strategies and supports at home + school work
  - Caregiver support
  - Exercise + nutrition
  - Stability + consistency

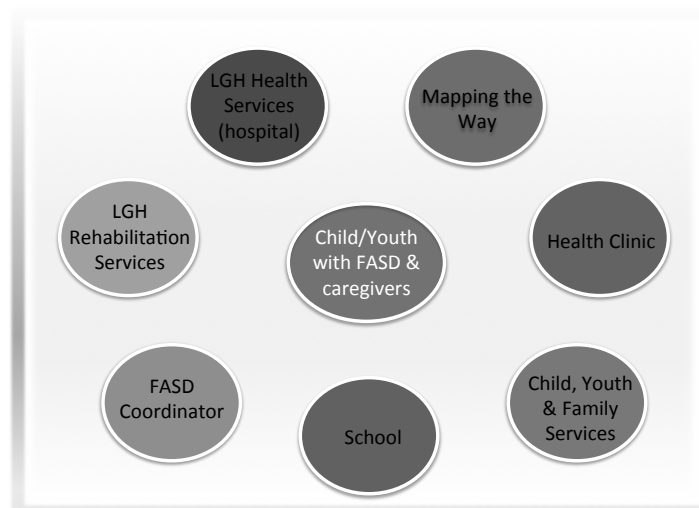
**1** Who are **YOU**? And **WHY** do this research?

## Research design and questions – in a nutshell



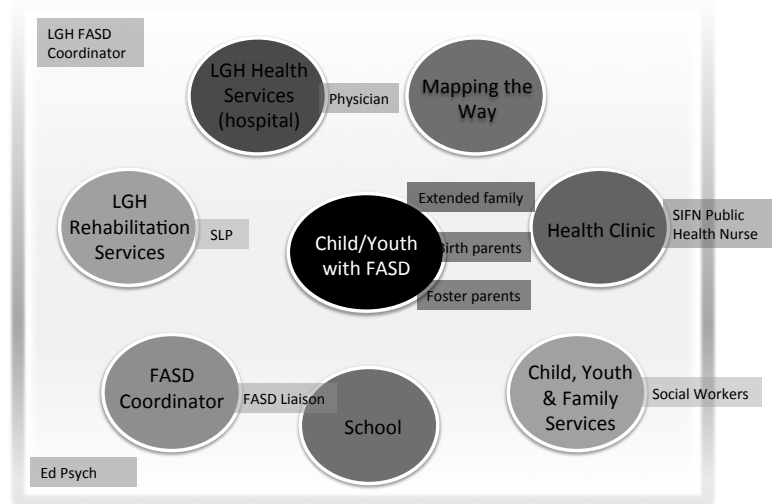
## 2 What are the **RESEARCH QUESTIONS**?

## Key People & Organizations

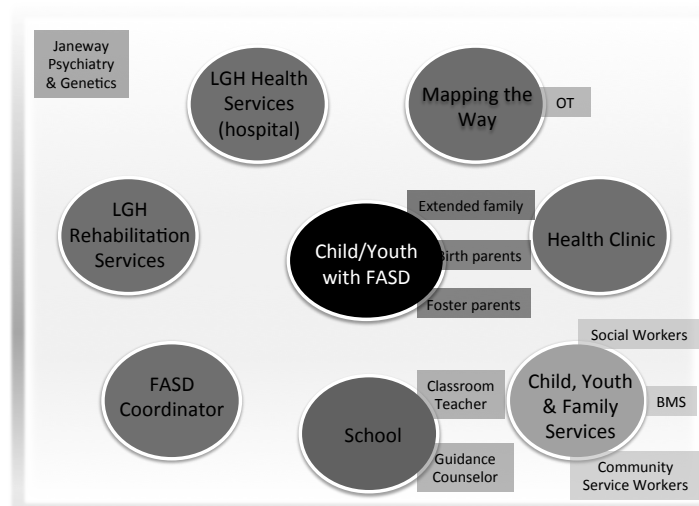


## 3 What did you find out? Highlights of **RESEARCH RESULTS**.

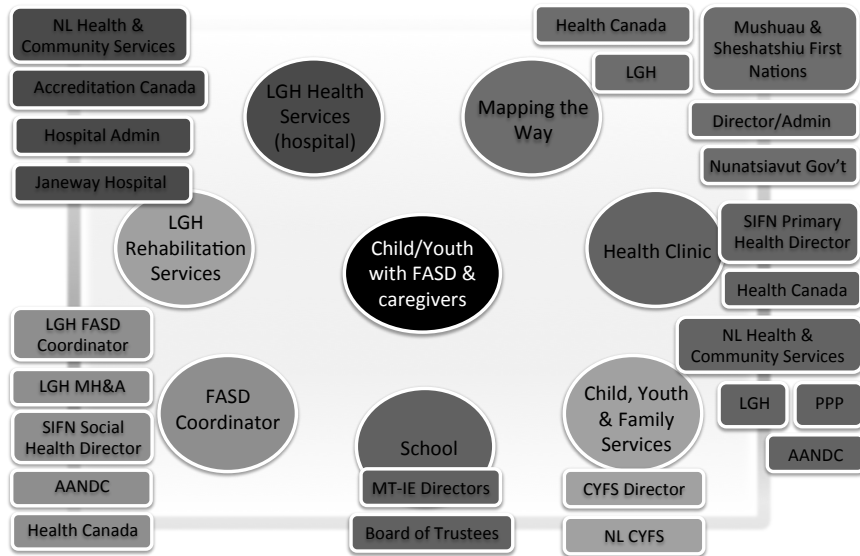
Involved with referral, assessment, or diagnosis.



Direct involvement with school-aged children and/or caregivers



### Indirect involvement (largely invisible to caregivers & youth).



### Psychiatry & Develop't Pediatrics

1. Intake & Questionnaire for parents
2. School Report & Questionnaire
3. Assessments
4. Report & Letter to Referral orgs

1. Intake
2. Referral to Psychiatry (Janeway)
3. Referral to Developmental Pediatrician

### OT, SLP, CMS & BMS

1. Intake
2. Assessments
3. Reports

1. Ed Psych Consent to Evaluation
2. Intake
3. Assessment
4. Consent for Release
5. Report

1. FASD Team Consent
2. Preliminary Information
3. Public Health
4. Referral to Mapping the Way

1. Proposals for project funding.
2. Annual Report

### Paperwork that was completed.

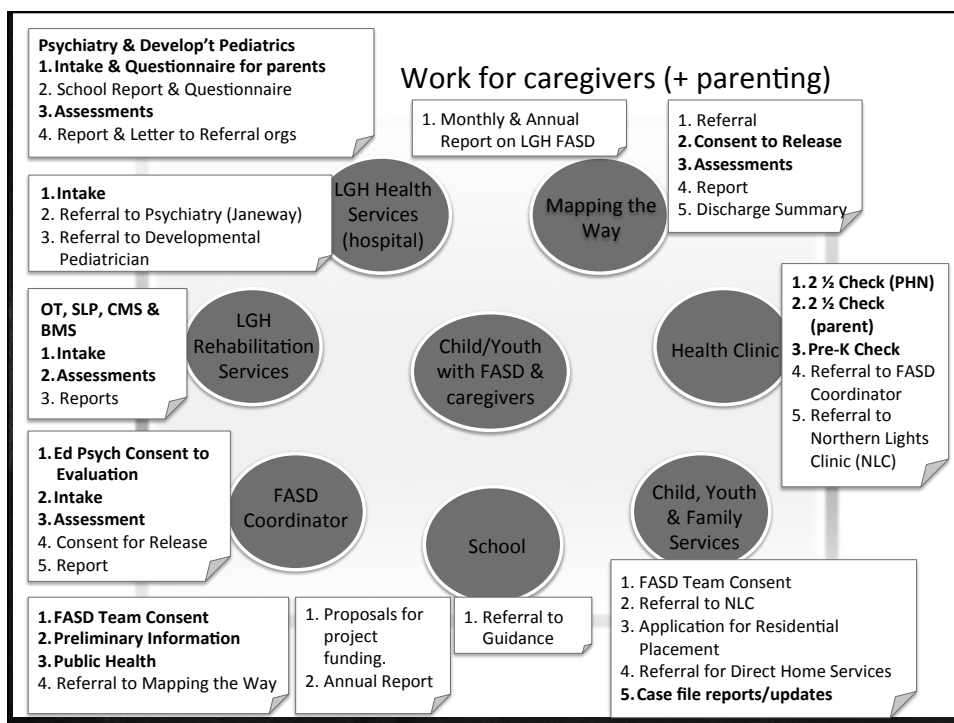
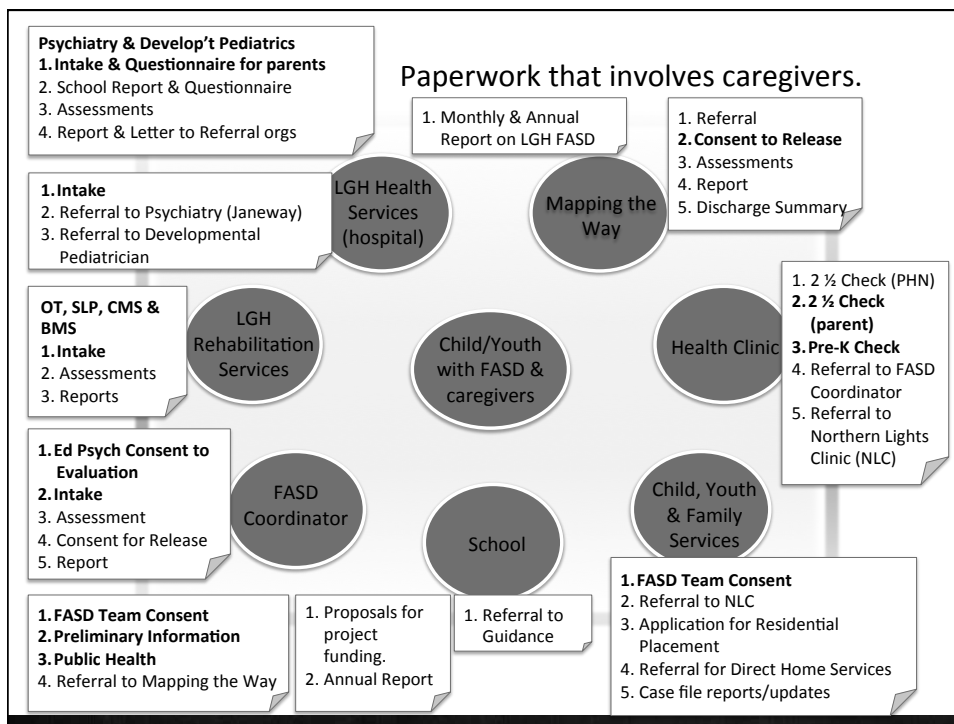
1. Monthly & Annual Report on LGH FASD

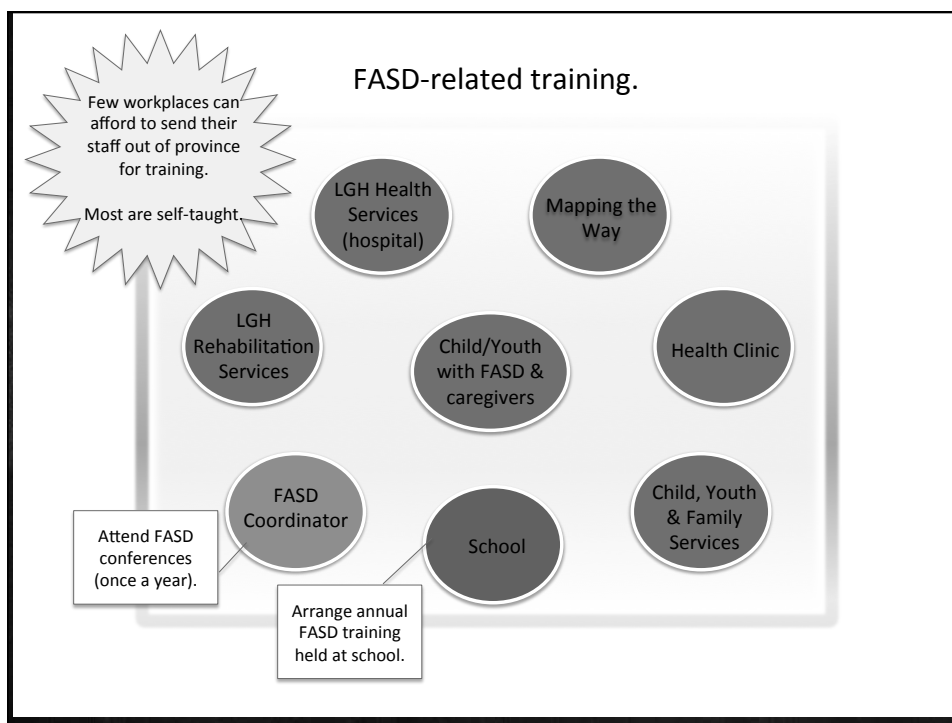
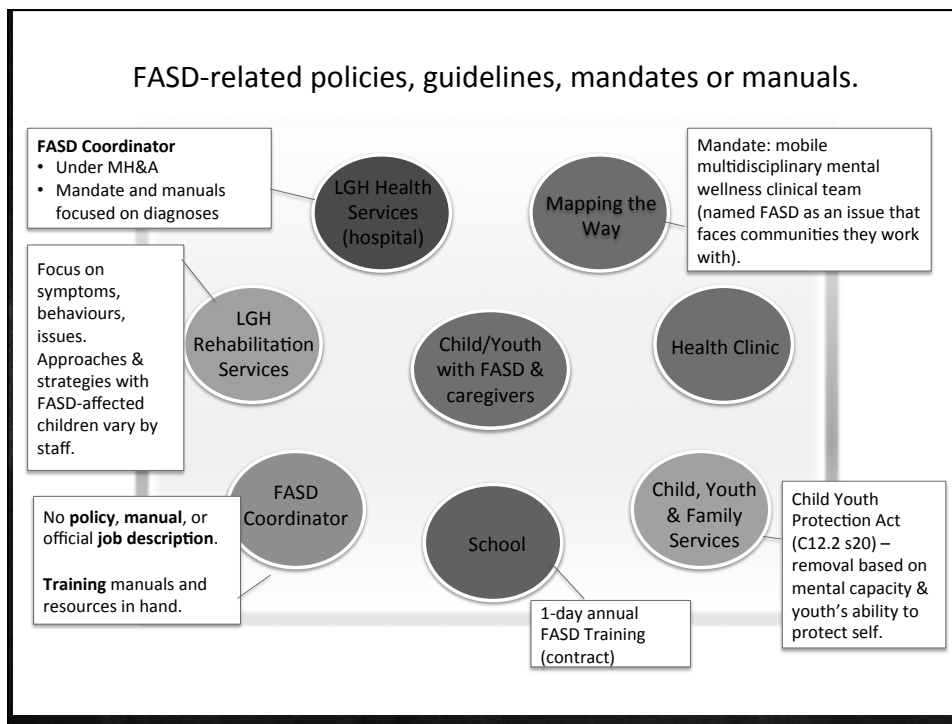
1. Referral
2. Consent to Release
3. Assessments
4. Report
5. Discharge Summary

1. 2 ½ Check (PHN)
2. 2 ½ Check (parent)
3. Pre-K Check
4. Referral to FASD Coordinator
5. Referral to Northern Lights Clinic (NLC)

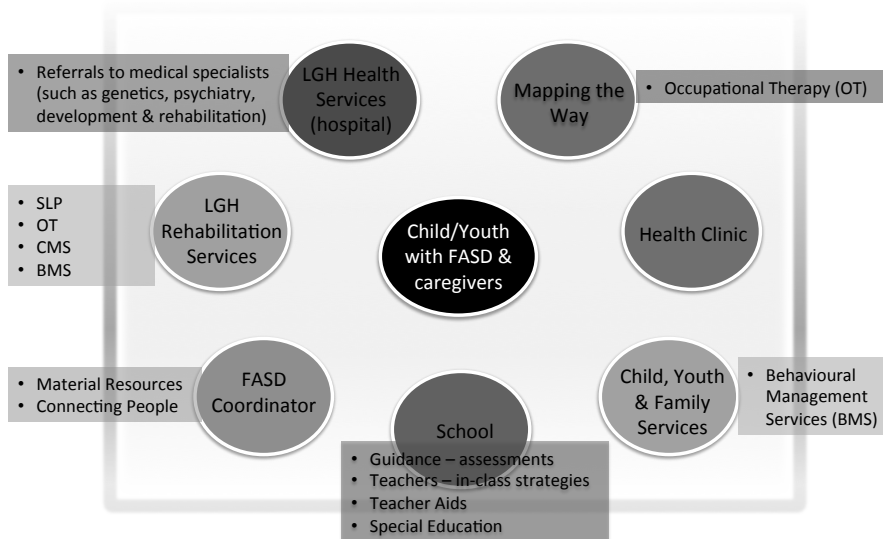
1. FASD Team Consent
2. Referral to NLC
3. Application for Residential Placement
4. Referral for Direct Home Services
5. Case file reports/updates



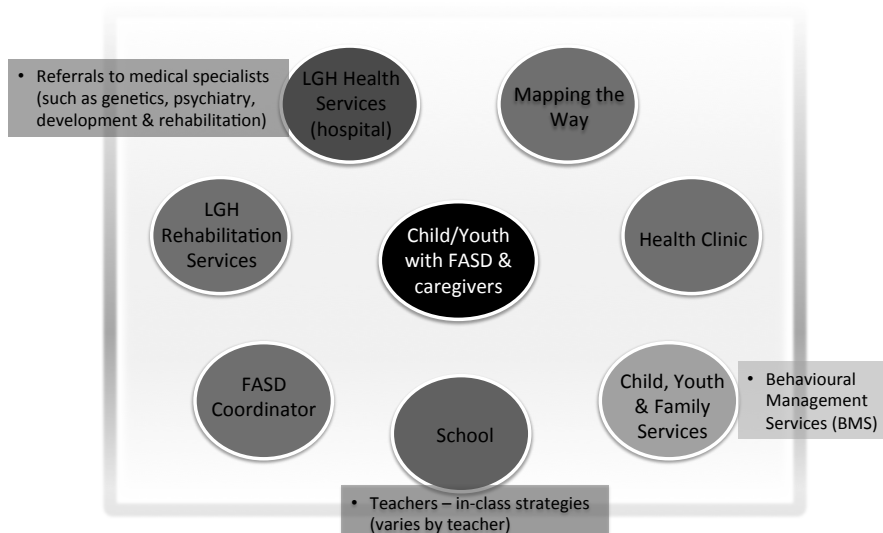




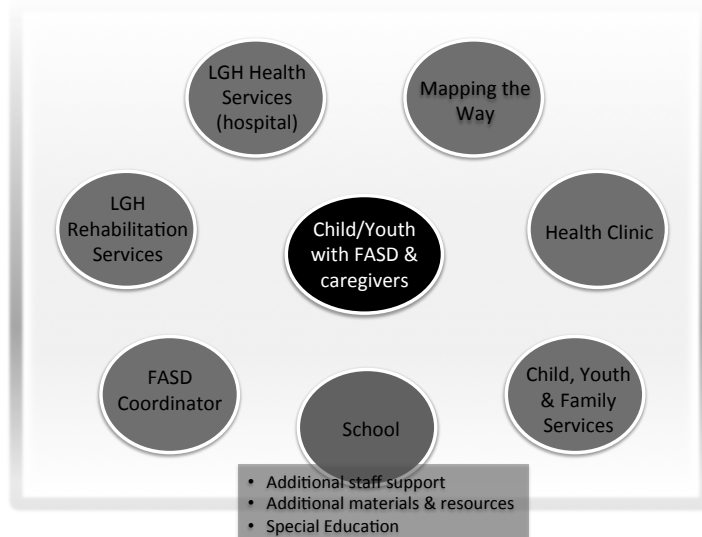
### Supports and services available.



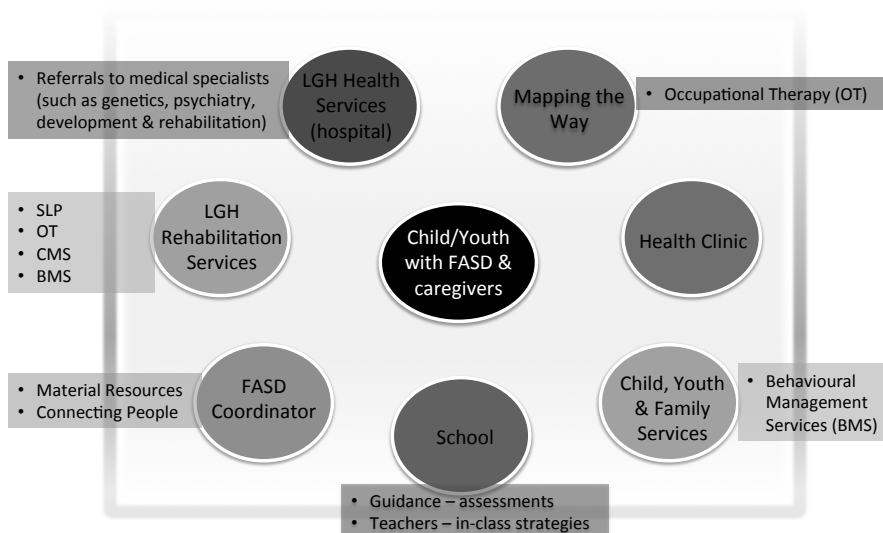
### Supports and services used by interviewees.



### Supports and services that REQUIRE DIAGNOSIS.



### Supports and services that do NOT require DIAGNOSIS.



### Key Findings

1. Parents/caregivers do not access (or know of) all services available.
2. Supports & services are not coordinated with each other.
3. Diagnoses do not matter (as children/youth) unless a service adds cost.
4. We expect parents/caregivers to do a lot of WORK (time + effort + intent).
5. There is a lot of repetitive intake & assessment forms.
6. There is very little FASD training, approaches, policies and interventions.
7. There is a lot of hope. A lot of capacity exists. The infrastructure is mostly in place.

### 4 So, what's NEXT?

- 1 Discuss (FASD Working Group/community stakeholders).
- 2 Consult (key stakeholders).
- 3 Plan (to be determined).
- 4 Act (stay tuned).

As a researcher, I need to consider:

- Thesis
- Publish in academic journals
- Presentations

**Anonymous**  
(participants & community)

**Community Approval**  
(Jack Penashue & others? MT-IE Board of Trustees?)

**Strengths-based**  
(OCAP Principles & Aboriginal Health Research)

Let's eat.  
Let's talk.

## **5** Recommendations. Thoughts. Ideas. Opinions. **DISCUSSION.**

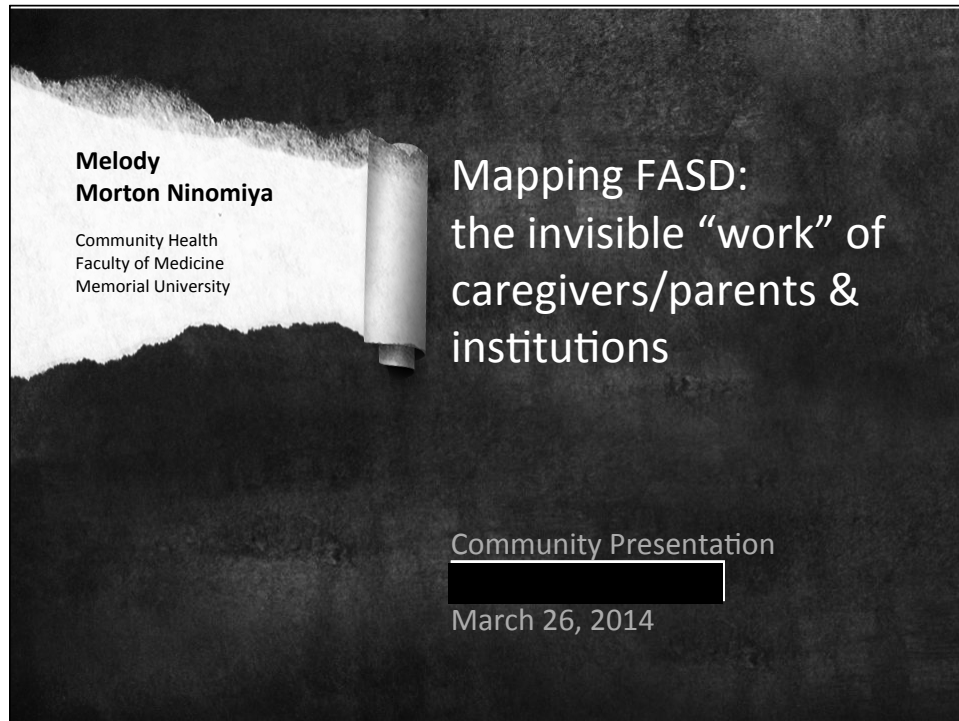
- Questions?
- What do you think needs to happen next?
- Who needs to be involved?
- Are there good opportunities coming up?
- Recommendations from research participants (see handout).
- How can we talk about FASD in the community without blame or judgment?
- Diagnoses – do they matter to you?
  - If “yes”, consider how difficult it is to get one.
  - If “no”, how do we support children who *may* have FASD?
- What do you think needs to happen first?

Staying in touch...

Thank you.

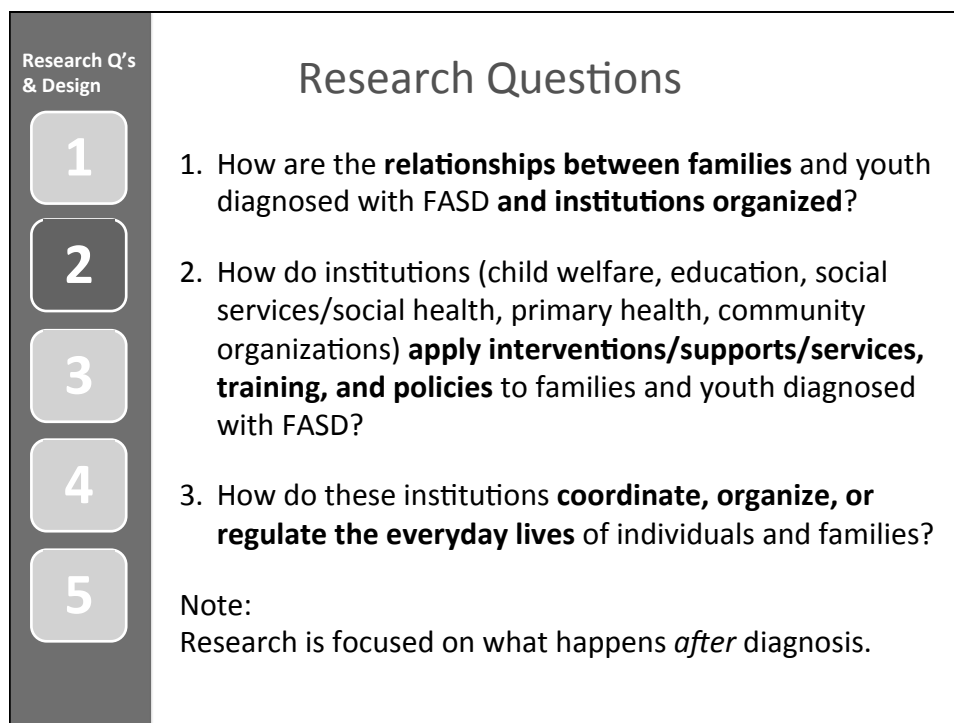
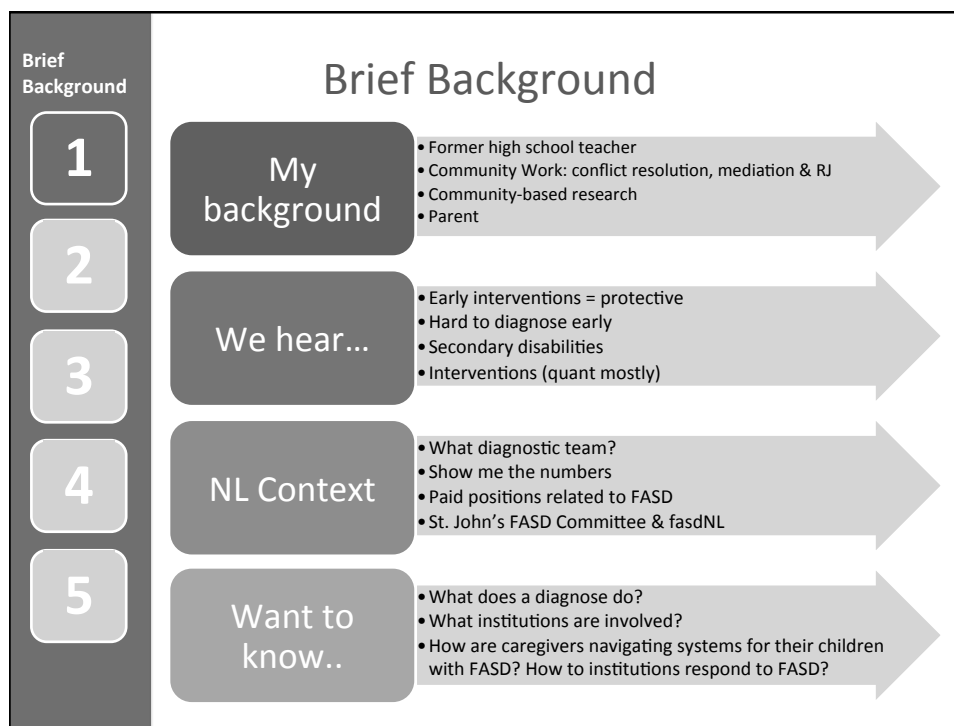
Feel free to email:  
[melodym@mun.ca](mailto:melodym@mun.ca)

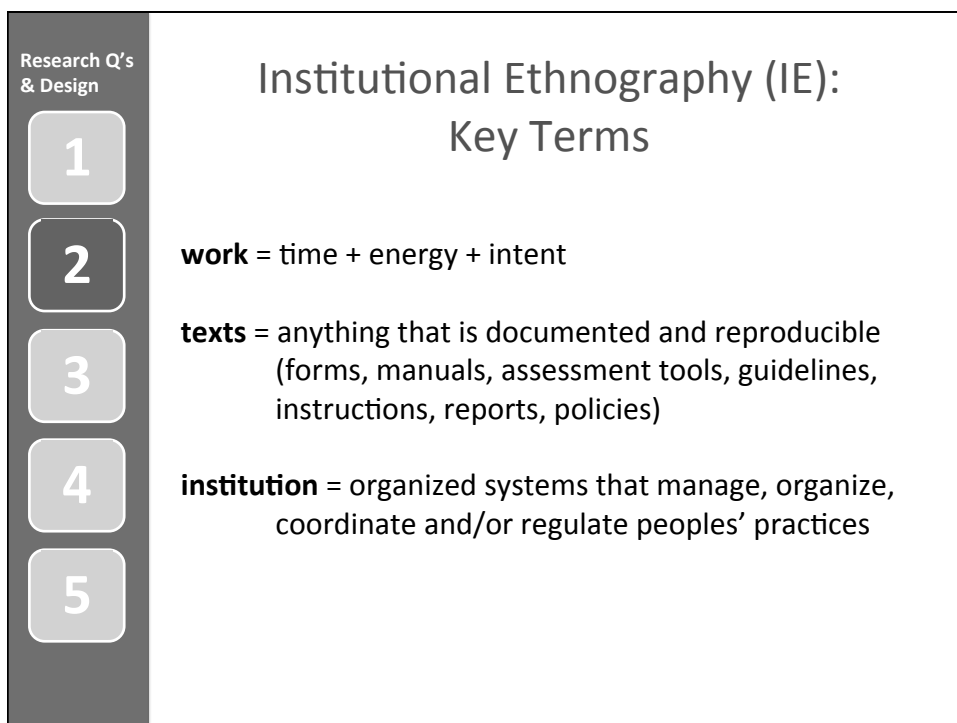
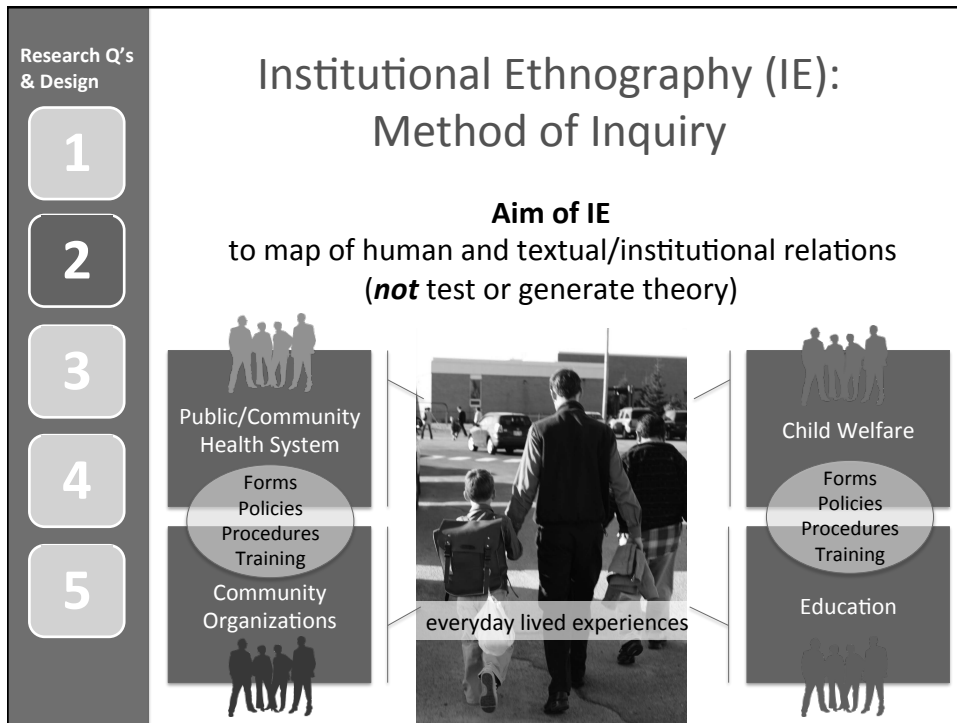
## Appendix F - Urban Community Presentation Slides



1	Brief Background
2	Research Questions & Design
3	Key Findings: “invisible work”
4	Next Steps
5	Discussion







Research Q's  
& Design

1

2

3

4

5

## Urban Community

**Data Collection**

- 25 semi-structured interviews
- 21+ documents (forms, policies, training manuals, assessment tools)
- field notes (most interviews done in work places)
- follow-up individual & group interviews

**Participants**

Caregivers (3) of five children diagnosed with FASD

	Health	Education	Child Welfare	Community
<b>Frontline Workers</b>	3	11	1	1
<b>Decision/Policy Makers</b>	1	3	1	1

Research Q's  
& Design

1

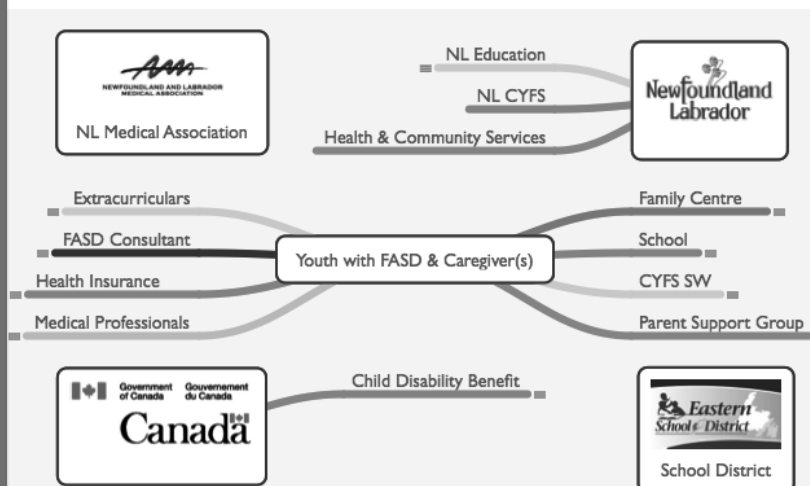
2

3

4

5

## Mapping everyday lives to institutions



Research Q's  
& Design

1

## Analysis

**When analyzing transcripts, look for:**

- How are people informed?
- What are the experiences?
- What concepts are people drawing on?
- What words/phrases are reoccurring?

2

3

4

5

**When analyzing texts, look for:**

- Who is the author?
- Who is the intended audience?
- What does the text intend to accomplish (overt/covertly)?
- How is the text constructed?
- What institutional organization is assumed?
- What "work" is being referred to? Implied? Leading to more work?
- What records are being produced through this document?
- Whose interests are being served? Ignored?
- What is left unexplained?
- How is this process being coordinated or coordinating other processes/decisions?

## Key Findings

1

## Findings: the work of parents

**caregivers' everyday work**(visible, though not to institutions)

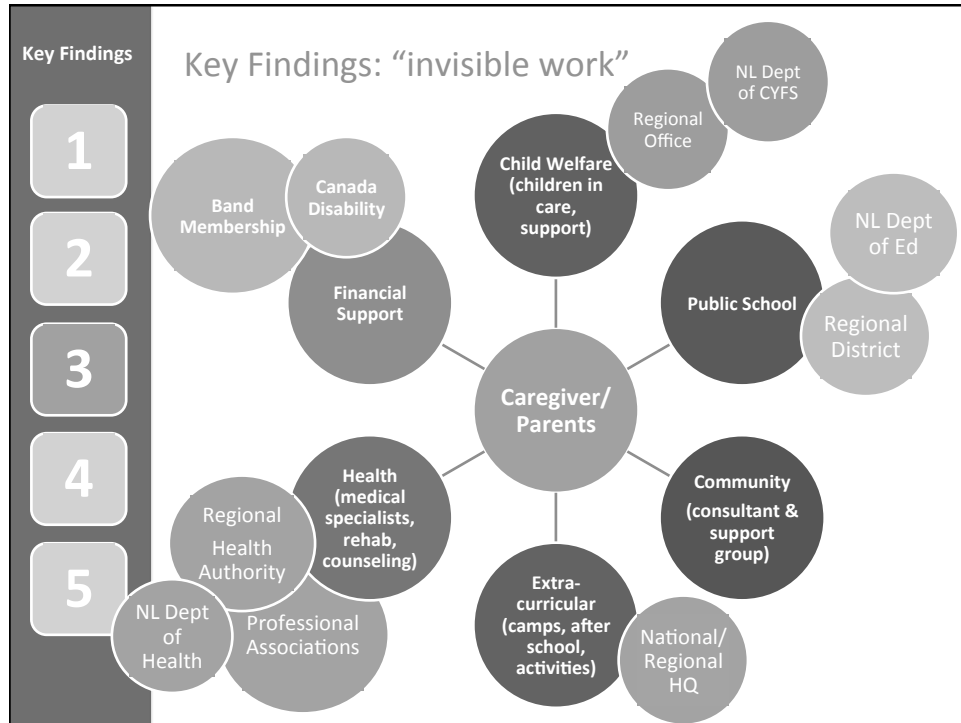
2

3

4

5

- **vigilance** around eating, hygiene & school prep
- **negotiating school** work & curriculum material
- administer **medication**
- frequent conversations with **teachers**
- **meet** with social workers (or try to reach SWer)
- multiple medical **appointments**
- decide **who to tell** re: diagnosis (and prove diagnosis)
- **defend** parenting decisions
- find **babysitters**
- secure **funds** to support meds & activities
- find **suitable** camps, after school programs
- attend **support** groups



**Key Findings**

**How do these institutions coordinate, organize, or regulate the everyday lives of individuals and families?**

Category	Work by Caregivers/Parents
<b>Child Welfare</b>	<ul style="list-style-type: none"> <li>• Host monthly visits &amp; yearly assessments at home</li> <li>• Prove competency &amp; advocating for supports</li> <li>• Demonstrating need for services, if asking</li> </ul>
<b>Parent Support Group</b>	<ul style="list-style-type: none"> <li>• Attend bi-weekly meetings</li> </ul>
<b>Extra-Curricular Activities</b>	<ul style="list-style-type: none"> <li>• Find alternatives for after school &amp; holiday camps after age 12</li> <li>• Afford &amp; find activities suitable for child</li> </ul>
<b>Health Care</b>	<ul style="list-style-type: none"> <li>• Attend &amp; coordinate appointments, assessments, medications, take-home exercises/practices</li> <li>• Navigate value/meaning of FASD to individuals</li> </ul>
<b>Health Coverage</b>	<ul style="list-style-type: none"> <li>• Afford health coverage</li> <li>• Apply for Canada Disability, FN/I/M Status benefits</li> </ul>
<b>School</b>	<ul style="list-style-type: none"> <li>• Participate in IEP and ISSP meetings</li> <li>• Provide persuasive and regular messaging around needs/challenges</li> </ul>

**Key Findings**

**Operating Concepts**

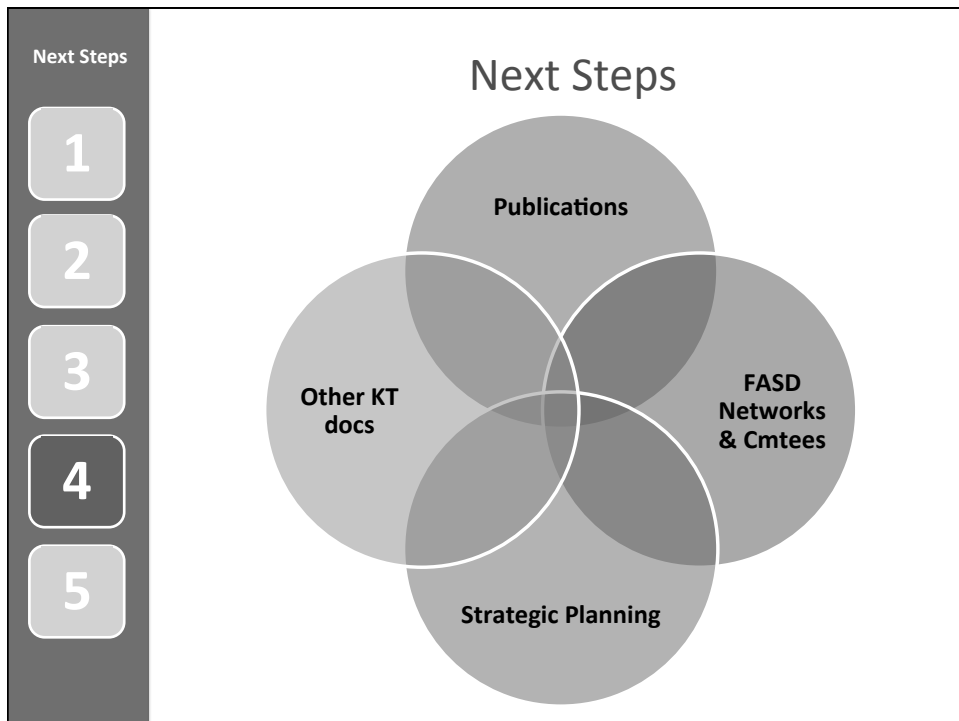
- Why get a diagnosis? It's just stigmatizing. Plus, it's not like there are any services anyway.  
~ Jaded
- We need a team to diagnose our kids (and adults). Without the diagnosis, we don't know what will work or what we're dealing with.  
~ Prescriptive
- I'm so relieved to have a diagnosis. Finally. Until I had the diagnosis, I couldn't understand what was wrong. It was helpful and reassuring to know it wasn't just me.  
~ Judged
- Why do we need to bother with diagnoses? The diagnosis is just another label – a stigmatizing one to both the person living with it **and** their birth mother. Why can't we just support the evident needs?  
~ Pragmatist
- Our hands are tied. If people want supports and services, we need proof. We need a diagnosis to justify what we do.  
~ "the bureaucrat"

**Key Findings**

**"Disjunctures": Contradictions & Cross-Purposes**

	#1: School	#2: Child Welfare	#3: Autism
1	<b>Parent:</b> Got child on Pathways Program to get accommodations.	<b>Parent (with FASD):</b> Lost child to care earlier – child back in her custody. Working a job without benefits. Can't find babysitter & calls a SWer.	<b>Medical Specialist:</b> Diagnosed child with Autism SD, unsure of FASD, but knowing ASD provides services, programming & support before school.
2	<b>School Staff:</b> Need diagnosis to justify programs & supports. Implement accommodation (an unhelpful one).	<b>Social Worker:</b> Overworked & rarely gets back. Can help support with some respite but parent needs to find it.	<b>Parent:</b> Appreciated pre-school in-home support. Pursued FASD diagnosis (after Autism diagnosis). Accesses Child Disability Benefits with Autism diagnosis and strategies in school are FASD-informed.
3	<b>Medical Specialist:</b> Schools are deficit driven & diagnoses do not matter. School respond to deficits & impairments.	<b>CYFS Act:</b> "offer support services to the child & family; refer the child & family to other resources" (before protective intervention)	
4			
5			

Key Findings	Finding Highlights
1	1. Insufficient institutional <b>expertise</b> or <b>training</b> .
2	2. Weight of diagnosis (except in parts of the medical community).
3	3. Facilitating <b>early interventions</b> as a protective measure is not organized.
4	4. Parents/caregivers not at the institutional tables.
5	5. School practice ≠ provincial service delivery model (e.g. ISSP).
	6. School supports require a lot of <b>work by classroom teacher</b> (driven by problematic behaviour or academic “failure”).
	<b>7. Non-institutional supports</b> = most helpful (FASD consultant & support group)
	8. FASD missing from training/professional <b>curriculum</b> (education, social work, medicine, ECE, Pride for foster/adoptive parents).
	9. Increased financial for <b>foster parents</b> than birth or adoptive parents support (e.g. day care, respite, BMS, extra-curricular activities).



Discussion

1  
2  
3  
4  
5

## Questions? Comments? Thoughts?



**Get more food?**


Please take a look at:

- ❖ Recommendations Handout
- ❖ Map of Institutional Connections (on wall)

Thank you.

Email: [melodym@mun.ca](mailto:melodym@mun.ca)

Supported by...



RDC

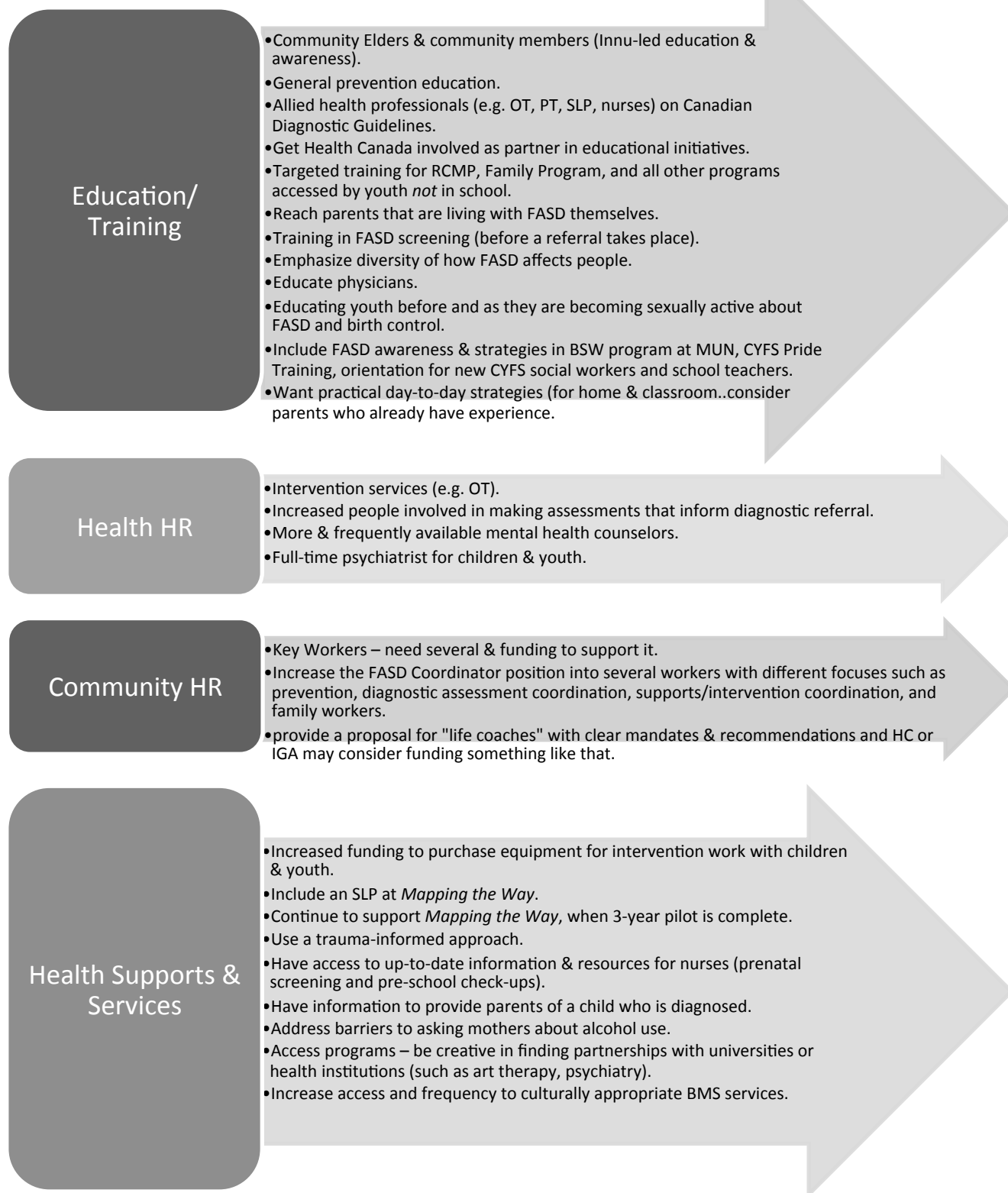
CIHR IRSC  
Canadian Institutes of Health Research / Instituts de recherche en santé du Canada

Aboriginal Affairs and Northern Development Canada

MEMORIAL UNIVERSITY



## Appendix F - Recommendation Handout for Sheshatshiu



## Community Supports & Services

- Partners (CYFS, Social Health, Primary Health, others?) implement existing *Planning Circles*.
- Have an organized way of knowing which children & youth live with FASD.
- Increase awareness on prevention.
- Build capacity and strong network of intervention options within the community.
- Increase number of people with specialized knowledge on FASD who can also do policy development (on FASD) in CYFS, corrections, child therapies, adult therapies, corrections/justice.
- Start a caregiver-support group.
- Increased FASD-informed & frequent supports to caregivers (parenting children placed in care).
- Parenting courses that are culturally and FASD relevant (maybe include BMS workers).
- Provide respite care for people caring for children with FASD (regardless of birth or foster parent).
- Offer tips/resources that help extracurricular staff (e.g. judo sensei's).
- Increase day care capacity by A LOT.
- Rather than add HR, look at ways to augment job descriptions to include FASD-friendly or helpful services.

## Approaches

- Use a trauma-informed approach.
- Harm reduction approach with women at risk of having children affected by FASD.
- Use family-centred/culturally relevant approach.
- Advocate for "universal " approaches - where what is good for ONE is good for ALL (not relying on diagnoses)

## Addressing Stigma

- Change the language & terminology to get away from the stigma that "FASD" has.
- Create attitudes that do not shame or stigmatize – normalize the possibility of someone living with FASD.
- Open a community dialogue about FASD.
- Think carefully about how the diagnosis implicates both the child *and* the biological mother.
- Consider renaming job titles and services to something without "FASD" in it.

## Diagnosis-related

- Diagnostic team for referrals.
- Culturally familiar (preferably Innu) people to navigate diagnostic referral & assessment process.
- Fit FASD diagnoses into priorities that fit into Accreditation Canada.
- Fund computerized diagnostic tools/technology for facial images/measurements & outside consultations.
- Monthly face-to-face meetings of diagnostic team.

## Appendix G - Recommendation Handout for Urban Community

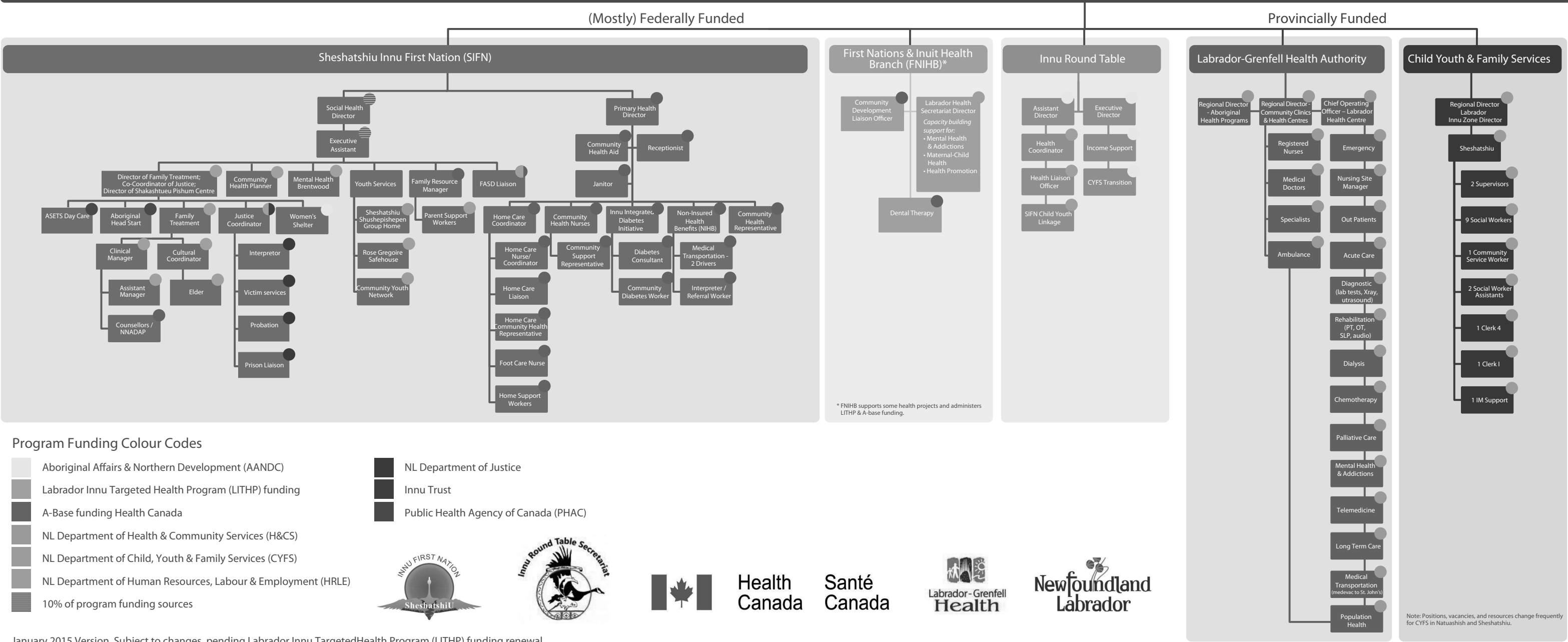
### Note to Reader

The recommendations below came from a combination of research participants and the researcher. There will be meetings to address recommendations that are up for immediate discussion. **If you are keenly interested in participating in meetings that discuss particular recommendations below, please let Melody (melodym@mun.ca) know.**

Area/Category	Recommendation
Community-Based Resources	<ol style="list-style-type: none"> <li>1. Create a <b>local</b> and <b>provincial FASD Coordinator</b> position. Their roles would involve building awareness, provide training, coordinate supports and services, advise caregivers, manage a resource library, serve as a community consultant for organizations/institutions, and help facilitate diagnostic process.</li> <li>2. Train and create an interdisciplinary FASD <b>diagnostic team</b> at the Janeway.</li> </ol>
Curriculum-based Training/Education  * Canadian-based curriculum for university-based education and social work has already been developed.	<ol style="list-style-type: none"> <li>1. Include FASD-related content in <b>Bachelor of Education (B.Ed.)</b> curriculum at Memorial University – course on exceptionalities.</li> <li>2. Include FASD, trauma-informed, harm reduction, and gender analysis in the Bachelor and Master of Social Work (<b>BSW &amp; MSW</b>) curriculum at Memorial University.</li> <li>3. Include FASD in the Undergraduate Medical Education (<b>MD</b>) curriculum at Memorial University.</li> <li>4. Include FASD and trauma-informed approaches to Early Childhood Education (<b>ECE</b>) and Child &amp; Youth Care Worker (<b>CYCW</b>) curriculum at colleges.</li> <li>5. Include FASD and trauma-informed approaches in all of the <b>PRIDE curriculum</b> for all prospective foster and adoptive parents (<u>just</u> been added to the Level 3 training).</li> </ol>
Educational System	<p>In the classroom...</p> <ol style="list-style-type: none"> <li>1. <b>Incorporate supports and strategies</b> that do not single out individual students (when possible).</li> <li>2. <b>Consult with parents</b> about what they (parents) know works well and discuss any accommodations being made in the classroom.</li> <li>3. Experiment with <b>FASD-informed strategies</b> and <b>inform parents/caregivers of successes</b>.</li> <li>4. Do not wait for or expect a diagnosis. Similarly, do not make assumptions that people are living with FASD (it could be trauma).</li> </ol> <p>At the Regional Level...</p> <ol style="list-style-type: none"> <li>1. Offer <b>professional development</b> to teachers on FASD and trauma – how to recognize it, understand how they may present, effective strategies, and who to consult at the regional level.</li> <li>2. Train or hire someone (with expertise in FASD &amp; trauma) to <b>facilitate training &amp; provide consultations to school staff</b>.</li> <li>3. Hire an <b>occupational therapist</b> that will come to schools and consult on classroom adaptations.</li> </ol>

	<p>At the provincial level...</p> <ol style="list-style-type: none"> <li>1. Create a <b>user-friendly guide/map/flow chart for parents</b> – to understand how services, supports, and accommodations are made (and their role in each process).</li> <li>2. <b>Work with schools to</b> understand and <b>implement</b> the <b>Service Delivery Model for Students With Exceptionalities</b>.</li> <li>3. <b>Critically examine</b> how (and how often) an Individual Support Services Plan (<b>ISSP</b>) is being implemented and followed. Address how the ISSP can be better “taken up”.</li> </ol>
Training & Education	<p>Deliver customized <b>training</b> to groups including:</p> <ol style="list-style-type: none"> <li>1. Correctional Officers and Staff</li> <li>2. Medical professionals</li> <li>3. Allied health professionals</li> <li>4. Legal System Staff (judges, crown attorneys, legal aid, mental health court, unified family court, etc.)</li> <li>5. Educators in the public school system</li> <li>6. Social Workers within CYFS</li> <li>7. Janeway Family Centre</li> <li>8. Parents – general public (maybe through City, schools, PHN)</li> <li>9. Nurses – particularly public health nurses</li> <li>10. HRLE – NAVNET*</li> <li>11. Other – behavioural management specialists, child &amp; youth care workers, family support workers, etc.</li> </ol> <p>Build capacity by training a team of interdisciplinary trainers (including experienced parents) that can deliver workshops.</p>
Approaches/Frameworks – across all disciplines	<ol style="list-style-type: none"> <li>1. Recognize that many individuals living with FASD have compounding challenges. In other words, they are <b>rarely just dealing with the effects of FASD</b>.</li> <li>2. Use <b>trauma-informed approaches</b>.</li> </ol>
Other	<ol style="list-style-type: none"> <li>1. Advocate or create supports for parents/caregivers such as: <ul style="list-style-type: none"> <li>• Access to <b>respite care</b> (especially for non-foster parents).</li> <li>• Access to an <b>FASD consultant</b>.</li> <li>• Access to good academic <b>tutoring</b> for children</li> <li>• Funds to support <b>extra-curricular activities</b> that support children with exceptionalities.</li> <li>• Access to <b>afterschool programming</b> for children <b>over age 12</b> that is financially &amp; geographically accessible (most after-school care ends at age 12).</li> </ul> </li> <li>2. Create <b>Circles of Care</b> (or resurrect the ISSP with an FASD-informed Manager to facilitate the meetings) that brings together a multidisciplinary team of people that provide supports &amp; services to child with FASD. The frequency of the meetings can vary depending on the caregiver, child's needs, or the realistic availability of key team members.</li> </ol>

# Sheshatshiu Innu Health & Healing Services



January 2015 Version. Subject to changes, pending Labrador Innu TargetedHealth Program (LITHP) funding renewal.

