

**Banging Down Doors:
A Photovoice Project of Parents' Experiences of
Access to Autism Care Services**

by

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Abstract

Although a great amount of attention has been recently paid to the state of autism care services in Ontario, little of this attention has been focused on the services for school-aged children and the services in rural-remote regions. This study presents the access experiences of three parents of school-aged children (ages 4-12) in Northwestern Ontario. Parents take on the role of the Navigator-Advocate in order to facilitate access to services for their child in three identified systems: education, health and medical services, and community-based services. Key themes in parents' experiences include having their experience of a service being dependent on a particular individual, a lack of compassionate understanding from others, insufficiently educated service providers, and exclusion. Parents' experiences of access could be ameliorated through the development of an integrated care model for autism that is responsive to navigational experiences and the geographical and human resource challenges of Northwestern Ontario.

Keywords: Autism; Northwestern Ontario; Photovoice; Access to Services; Experiences; School-aged Children

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List of Acronyms

ABA	Applied Behaviour Analysis
AIP	Autism Intervention Program
ASD	Autism Spectrum Disorder
CCAC	Community Care Access Centre
CIHR	Canadian Institutes of Health Research
DSM	Diagnostic and Statistical Manual of Mental Disorders
DSO	Developmental Services Ontario
IBI	Intensive Behaviour Intervention
IDN	Integrated District Network
IPRC	Identification, Placement and Review Committee
LAO	Legislative Assembly of Ontario
LHH	Local Health Hub
LHIN	Local Health Integration Network
MCYS	Ministry of Children and Youth Services
NWO	Northwestern Ontario

Chapter 1.

Introduction

In Chapter 1, I begin by introducing the reader to the geographical and socio-political environment in which my study has been performed (Study Context). Having set the stage for the work being done, I then state and briefly explain the issue at hand (Problem Statement) and what my thesis is intended to do (Thesis Purpose). The intent of my thesis is intrinsically linked to the impetus and reasons for this work, as presented in the Thesis Justification. Finally, I walk the reader through the organization of this thesis (Thesis Design) and present my social location (Researcher's Location).

1.1. Study Context

My study is based in Northwestern Ontario, which is the largest geographical region in Ontario, and the furthest from the political centres of the province (Toronto and Ottawa). As compared to the other regions of the province, with the exception of Northeastern Ontario, Northwestern Ontario is characterized by fewer physical, human and structural resources for many aspects of health and social care despite comparable levels of demand. With regards to autism¹ specifically, families' experiences of access are less than optimal overall, which leaves them in crisis. However, they are likely not alone in Canada, if the stories being shared through increasing amounts of media attention are any indication of the state which families are in. For reasons yet to be concretely

¹ 'Autism' is commonly understood to be a developmental disability that affects an individual's social skills and cognitive abilities. This definition is problematic, as is attempting to define autism, as discussed in Section 2.1. This perception of autism is provided for the reader's initial contextualization of the thesis, and my operational definition of autism will be explored more extensively in Section 2.1.

established, the prevalence of autism is increasing on provincial, national and global scales (Ouellette-Kuntz et al., 2014). As a result, there is an increased demand on autism services and supports for children and adults with autism. For reasons to be explored in my thesis, parents of school-aged children with autism (defined as children aged 4-12 for my work) in Northwestern Ontario struggle with accessing the educational, health and medical, and community-based services that respond to and support their child's ongoing needs. In working through the access process, parents must interact with the provincial government, locally managed services, locally owned and operated organizations, and self-employed corporations (e.g. medical corporations), as they control service access in the region. Given that autism is gathering a large amount of attention in the media at the moment, my study is well-timed with the policy window this attention creates.

1.2. Problem Statement

As opposed to looking at autism care from a health systems or population health perspective, the emphasis in autism research is on the biological basis of the spectrum disorder, which is reflective of a predominant push towards curing autism. One of the most well-known proponents of this research direction is Autism Speaks, a self-professed advocacy and science organization. Autism Speaks is well known for its unyielding support of research “into the diagnosis, causes, prevention, and treatment of autism or its disabling symptoms” (Autism Speaks, 2015). This is reflected in a marked bias in funded autism research in Canada (Krahn & Fenton, 2012). What is missing from the research conversation is the ‘right now’ piece – that which addresses the need to provide health and social services to individuals with autism and their families to address their current day-to-day needs. Essentially, the need to conduct health systems research to inform evidence-based care and support for individuals with autism and their families is overshadowed and lost. The lack of research is reflected in the inconsistent and fractured nature of Ontario's autism care design and, more generally, developmental disorder care design. For example, autism-specific services are managed by a different provincial ministry than services which are frequently accessed by individuals with autism because of their autism or autism-associated conditions. Fractured service

provision leaves communities and individuals struggling with one or more facets of access to care.

1.3. Thesis Purpose

My thesis serves as an exploratory study of the experiences parents have when navigating autism care services for their school-aged child with autism spectrum disorder in Northwestern Ontario. My thesis seeks to elicit knowledge and understanding of these experiences to add to the growing evidence base that supports a shift in policy and program design towards Ontario's desired integrated care model (Ministry of Health and Long Term Care, 2015). Developing an integrated, collaborative model of care for autism services with the potential to ensure timely, local and seamless access to services for children in need, as well as their families, is an important public health goal. Exploring and documenting the experiences of parents with the current system is an essential step towards improving access to care. My study also sought to provide parents with opportunities for empowerment, capacity building and self-directed social change. As detailed in Chapter 3, my study went about this using a critical, action-oriented visual and story-telling approach.

1.4. Thesis Justification/Impetus for Research

As noted, families are in crisis and are struggling with a disjointed system of care that may not best meet their needs. There is an adage that says that 'if you've met one child with autism, you've met one child with autism'. Autism, unlike other conditions, manifests quite uniquely in each individual so the support and care that each individual requires will be respectively nuanced. In order to target the re-structuring of the health system from a policy and programs perspective, it is critical that service users' experiences are explored and documented for consideration and integration. In particular, given that the Ministry of Health and Long-Term Care emphasizes the importance of the patient in its health system integration efforts, it is only appropriate that patient views are reflected in the design (North West LHIN, 2014). In the case of school-aged children with autism, although they may be capable of sharing their experiences of

interacting with service providers, they are not yet actively navigating the health system for themselves. Navigation is typically done by a primary care giver such as a parent. Consequently, my study allows for the experiences of participating parents to become part of the evidence-base upon which health care decisions are made.

Interestingly, the exploration of parents' experiences in my study's setting and using my study's methods is unique in Canada, to the best of my knowledge. However, opportunities for parents, care givers, service providers and administrators to provide insight and share their experiences with policy makers have previously arisen. These opportunities have taken the form of an autism-specific forum at the national level and a developmental disability forum at the provincial level.

In 2007, the National Autism Research Symposium, facilitated by Parliament's Standing Senate Committee on Social Affairs, Science and Technology, was held in Toronto, Ontario. The Symposium provided a forum in which parents, caregivers, service providers and (to a lesser extent) individuals with autism were able to share their experiences of autism treatment in Canada. Participants voiced their concerns over access to autism treatment. Their concerns included cost and public funding, the availability of services, the lack of flexibility in treatment to accommodate different individuals, and the need for multidisciplinary teams. Severe jurisdictional differences in access to treatment also came to light. Participants noted that wait times for assessment, diagnosis and treatment were a barrier to care due to an insufficient number of professional service providers, lack of appropriate and sufficient training among medical personnel, widened eligibility criteria for treatment, and the public system. Participants, specifically parents and advocacy organizations, indicated that there are emotional and financial stressors for families, and that supports are needed not just for the individual with autism but also for parents and siblings. The Committee heard that the disability supports available for individuals or their families were insufficient. The supports are insufficient from a definitional and financial standpoint, where autism is not always considered a disability or medical expense. A lack of accurate information on autism and its prevalence make it hard for the general public and service providers alike to know how to interact with people with autism in an appropriate manner that respects the individual's agency. The consequences of the lack of information are potentially

harmful among practitioners who may not recognize, assess and diagnose individuals with autism correctly. Finally, the need for research was highlighted, particularly as pertained to treatment and intervention. Although this thesis does not research interventions or treatments, they exist within a system of care which, arguably, must be as navigable as possible to facilitate access to evidence-based treatments (Canada, Parliament, Senate, 2007).

Between October 2013 and July 2014, the Legislative Assembly of Ontario's Select Committee on Developmental Services conducted public hearings and prepared a report on the state of developmental services in Ontario. Fourteen public hearings were conducted between Toronto, London, Thunder Bay and Ottawa. The Committee heard from more than 340 participants including Ministries, community organizations and individuals. The participants could attend and present in person, provide a submission in written or video form, or present by phone.

During the public hearings, the Committee identified a “serious lack of services and supports in northern, remote, and First Nations communities” (Canada, Parliament, Legislative Assembly of Ontario, 2014, p. 3). The Committee also identified barriers to care including lengthy waitlists, non-streamlined assessment processes, and insufficient levels of primary care for persons with developmental disabilities. Of the 46 recommendations made by the Committee, two specifically address autism and rural and remote communities. With regards to autism, the committee recommended a provincial strategy be established to ensure that appropriate support services are available to individuals equally throughout communities and regions of the province. This recommendation includes, but is not limited to accessing prompt, early diagnoses and interventions, ensuring that autism service providers are professionally accredited, and evaluating the implementation of therapeutic interventions. With regards to rural and remote communities, the Committee recommended that local support options be developed so that people living in northern Ontario can have their needs met (Canada, Parliament, Legislative Assembly of Ontario, 2014).

In addition to the two aforementioned forums, autism services in Ontario have been reviewed by the office of the Auditor General of Ontario. In the 2013 Annual Report

of the Office of the Auditor General of Ontario, autism services and supports for children (under the purview of the Ministry of Children and Youth Services) were examined. Following a thorough review of spending, funding, and programming, the report outlined eight recommendations to facilitate the provision of equitable service and supports. The recommendations spoke to MCYS collaborating with other Ministries to address wait times and discharge processes, performing cost-benefit analyses with regards to providing therapies and interventions commensurate with the needs of the range of individuals with autism, applying standard program guidelines to all eligible potential beneficiaries, reviewing the provision and training of support personnel in schools, collaborating with other Ministries to develop a process for successfully transitions out of the children and youth system, tightening regulation on access and hourly cost of IBI services, conducting periodic site visits to supplement program review processes, and conducting and acting upon periodic program reviews (Office of the Auditor General of Ontario, 2013).

Thus, the ability of families to access services is recognized to be a factor that mediates a family's experience of crisis for their child. Ontario has struggled with the best way to organize autism services (Office of the Auditor General of Ontario, 2013). Fortunately, forums and formal reviews provide space for service user input into policy and programming design. However, given the uniqueness of Northwestern Ontario in terms of service needs and functional service delivery models, more work is needed to build on these national and provincial forums and reviews so as to be better informed of the needs of families in areas that are largely rural-remote.

1.5. Thesis Design

My thesis adopts a participatory action research design to elicit parents' experiences. This method was determined to be the best suited to an exploratory study of a previously unexplored topic in Northwestern Ontario. Specifically, this method allowed the parents to determine the direction of the data produced. My study takes place over a six week period using a tailored Photovoice method, supplemented with ecomapping.

My thesis begins by contextualizing autism: what it is, how it is diagnosed, the recommended treatment and management standards, and epidemiological profile of autism at the regional, provincial and national levels. In addition, the regional and provincial health care systems are explained, including the organization of services, and supply and demand - both documented and perceived (Chapter 2). Next, I present the theory behind the study in addition to the means and methods of participant recruitment and data collection (Chapter 3). Then, participants' experiences, the meanings they have created, and the understanding that they have are presented in narrative format, weaving together words and pictures (Chapter 4). Finally, the data are reviewed and their implications for public health are discussed (Chapters 5 and 6).

1.6. Researcher's Location

First and foremost, it is important to recognize that I do not have any experiences parenting a school-aged child with autism in Northwestern Ontario. I have, however, spent a substantial amount of time interacting with such parents as a secondary caregiver to their children, and been a classroom assistant and/or tutor, day-programming provider to their children. It is during my tenure in these positions throughout Ontario and Canada that I came to suspect a marked difference in the experiences that families in Northwestern Ontario might have as compared to families elsewhere in Ontario or the country. I turned to the published and grey literature in an attempt to satisfy my curiosity around whether or not a difference existed, only to find that this had never been explored. In fact, the experiences of families are rarely explored, and when they are they tend to be in prescribed areas. I read that school-aged children with autism were among the least explored group of individuals with autism in autism needs and care literature; this happened to be the group with whom I had the most interaction. In reflection, I began to question how I would feel as a parent trying to navigate services for my child with autism, building on the experience that I had with children whose parents did this for them, and children whose parents involved me in this process. Consequently, I felt a deep need to explore this experience in a research context.

I moved to develop a research project that would allow parents who had, to my knowledge, never before been asked about their experiences with services, an

opportunity to share their experiences if they so wished. However, it was very important to me that if I was going to ask parents to share their experiences that it happen in the context of a project where they had ownership over the data and the ability to do something with the data they were producing. I recognized the need for a collaborative method that would allow me to develop relationships with the participating parents because I was asking for entry into a world that was not mine but that I wanted to help shed light on. In conducting this work, I recognize that my proximity to the situation biases my reception and understanding of parents' experiences. I shall return to this at the end of my work to reflect on this in greater detail.

1.7. Conclusion

Families raising school-aged children with autism are in crisis, as parents have expressed during provincial and national forums on autism and developmental disabilities. Given the increase in the prevalence of autism, there is a need for health systems and policy-oriented research so that the increased demand on autism services can be addressed. The experiences of parents should be considered in system design, and in order to do so they need to be recorded. My thesis uses Photovoice and ecomapping to begin exploring and documenting the experiences that parents in Northwestern Ontario have when navigating services for their child in order to inform health systems policy regarding access to autism services.

Chapter 2.

Background

In Chapter 2, I begin by exploring and problematizing the uses and meanings of the term 'autism' (What is autism?). I then walk the reader through the process of getting an autism diagnosis (Diagnostic Process). In this section I discuss the differences between the recommended and actual screening timelines, what resources are available for diagnostic services in Northwestern Ontario, and what the diagnosis allows for once received. At the level of the population, diagnoses are used to inform prevalence rates and the organization of surveillance activities, as explored in Surveillance and Prevalence. I then proceed to establish the organization of health care services, both medical and social, in Northwestern Ontario (Organization of Care in Northwestern Ontario). The integrated nature of the health system then stands in contrast with that of autism services, which is subsequently presented (Organization of Autism Services in Ontario). After presenting these two systems, I examine the concept of access and present the conceptualization of access that my thesis adopts (Access). The concept of access informs our understanding of the great documented demand for an insufficient supply of autism services, as well as the perceived unmet needs of parents with school-aged children with autism, both of which are explored herein.

2.1. What is autism?

Defining autism is an incredibly difficult task. 'Autism' has been a catch-all colloquial term for the overall condition experienced by persons with autistic disorder, Asperger's disorder and other pervasive personality disorders not otherwise defined under the Diagnostic and Statistical Manual of Mental Disorders (DSM) IV, and for autism spectrum disorder (ASD) defined under the DSM-V. Consequently, any definition will be imprecise. The imprecision in the definition stems from the difference in the

colloquial and diagnostic uses of the term “autism”, as well as from the fact that autism is now recognized as a spectrum disorder because it has a large range of possible manifestations. However, as aptly pointed out by Temple Grandin in her 2013 book *The Autistic Brain: Thinking Across the Spectrum*, you do not have to be diagnosed with autistic disorder, Asperger’s Syndrome, or ASD in order to be ‘on the spectrum’ (Grandin, 2013). Ergo, a diagnostic definition of autism simply serves as a ticket for a system in which a diagnosis is the gatekeeper to specialized services.

When designing this project, defining autism proved to be an incredibly difficult task. Although I would have liked to simply use “autistic” as an inclusion criterion, this would have been problematic for two reasons: first, a Research Ethics Board typically requires more strict criteria for inclusion and exclusion; second, in the Ontario health care, education and social systems, only children with a diagnosis are able to access autism-specific services. Therefore, a diagnostic definition needed to be used. The study was targeted at parents whose children were between the ages of seven and twelve for the duration of the study, but was expanded to ages four to twelve to promote recruitment. Given that the recommended screening window for children who display a potential for being on the spectrum is between 18-24 months of age, the children of participating parents should have been diagnosed using the DSM-IV.

According to the DSM-IV, autistic disorder (or classic autism) refers to a neurodevelopmental condition in which there is a) an impairment in social interaction, b) an impairment in social communication, and c) a restriction, repetition, and display of stereotyped patterns of behaviour, activities and interests (American Psychiatric Association, 2000). According to the DSM-IV, Asperger’s Syndrome is a neurodevelopmental condition in which there is a) an impairment in social interaction, b) restricted, repetitive, and stereotyped patterns of behaviour, activities and interests, c) clinically significant impairment in social, occupational or other areas of functioning, d) no clinically significant delay in language, and e) no clinically significant delay in cognitive development or age-appropriate self-skills, behaviour and curiosity about one’s surroundings (American Psychiatric Association, 2000). The diagnostic definitions (or criteria) for autistic disorder and Asperger’s Syndrome seem quite similar because they are. However, the major differences between the two conditions are as follows:

- a. The symptoms associated with Asperger's Syndrome are less severe than those associated with autistic disorder;
- b. There are no speech delays in Asperger's Syndrome, though individuals with Asperger's Syndrome may use language in different ways than people who do not have Asperger's Syndrome; and
- c. Individuals with Asperger's Syndrome want to fit in with others, whereas individuals with autistic disorder appear disinterested in others (Autism Society, N.D.).

2.2. Diagnostic Process

The first step in accessing services for a child with autistic disorder or Asperger's Syndrome is being assessed and, if appropriate, diagnosed. The Canadian Paediatric Society recommends screening children between the ages of 18 and 24 months who are suspected by a health care or otherwise trained professional to be autistic (Auditor General, 2013). In Ontario, the median age of diagnosis is 3 years of age, which is older than would be expected if children were screened according to recommended timelines. The Canadian Autism Spectrum Disorders Alliance cites the average age of diagnosis among school aged children in Ontario (defined as 5-17 years of age) as 5.22 years of age (2014). Despite the lack of published evidence, the median age of diagnosis is suspected to be higher in Northwestern Ontario given fewer resources. There are three ways in which a child can receive a diagnosis in Northwestern Ontario. The first way is through one of two public organizations that provide mental health services to children. Both public organizations are located and provide service to two different Integrated District Network areas. Both organizations accept referrals by parents or guardians of school-aged children, removing the need for a referral through a primary care provider. The second way to be diagnosed is to seek the services of psychologists that are privately paid. Private services also operate on a self- or parent/guardian referral. Finally, parents can access a diagnosis via Telehealth, which connects a patient to a specialist at SickKids Hospital in Toronto, Ontario, after a referral by a physician (most commonly a family physician in Northwestern Ontario). Rarely, the patient will be connected to a professional capable of conducting screening and providing a diagnosis in Thunder Bay. The three options presented differ from Ontario as a whole, and thus from southern regions of the province in which it is reported that paediatricians are not

only the health care professionals who most commonly diagnose children with autism, they are the providers of a diagnosis for pre-school and school-aged children even more frequently (Canadian Autism Spectrum Disorders Alliance, 2014).

After receiving a diagnosis – a process measured in months – children are eligible to access services. Autism-specific services are coordinated through the Ministry of Child and Youth Services, while general health services are coordinated through the Ministry of Health and Long-Term Care. Learning supports in the school system are coordinated through the Ministry of Education and executed at the level of the school board. Although access as a concept and practice in autism care and Northwestern Ontario will be further explored in Section 2.6, the initial interaction with services provided by the Ministry of Education are presented below given that they have been known to be the impetus, for some families, to seek a diagnosis.

Each Ontario school board has an Identification, Placement and Review Committee. The IPRC serves to “decide whether a student is an exceptional pupil and, if so, what type of educational placement is appropriate.” (Ministry of Education, 2007, p.1) School-aged children with autism are identified with exceptionality C1, which codes for communication disorders and autism. A school-aged child may come to the attention of the IPRC in one of two ways (Personal Communication, 2015). In the first scenario, a parent or guardian will submit a written request to their child’s Principal, who will then refer the student to the Committee. Alternatively, a Principal may refer a student to the IPRC provided that written notice has been provided to the child’s parent/guardian. Parents are able to attend IPRC meetings and are within their right to ask the IPRC to consider programs that would be beneficial for their child (Ministry of Education, 2007). The IPRC will then recommend the services it deems appropriate to meet the needs of the child. This plan is then sent back to the child’s school which works in conjunction with the Board to mobilize adequate resources and supports within its means (Personal Communication, 2015).

2.3. Surveillance and Prevalence

Due to the fact that all school-aged children are required to be educated through a local school board, the education system can be used to monitor and estimate the prevalence of autism among school-aged children, as is done in British Columbia (Coo, Ouellette-Kuntz, Lam et al., 2012). Even so, Saskatchewan, Quebec and British Columbia are the only Canadian provinces or territories to reliably monitor autism amongst children attending school (Norris, Pare & Starky, 2006). These provinces have noted a rapid increase in the number of children with autism, with Quebec recording a prevalence rate of 1 in 174 in 2004. This prevalence rate is consistent with data coming from the United States and the United Kingdom (Norris et al., 2006). Ontario lacks provincial incidence and prevalence statistics for autism, as does Canada at a national level. As of March 2012, the National Epidemiologic Database for the Study of Autism in Canada indicated that the prevalence rate for southeastern Ontario (the only region in Ontario for which a rate has been calculated) was 1 in 77 in 2010. The Centre for Disease Control (CDC) reports that 1 in 88 children had autism as of 2008, while 1 in 50 six to seventeen year olds had autism as of 2012 (Auditor General, 2013). Using these numbers, it is estimated that 30,000 to 35,000 children in Ontario had autism in 2013 (Auditor General, 2013).

2.4. Organization of Care in Northwestern Ontario

Northwestern Ontario is the largest geographical region in Ontario, and it encompasses three census districts: Kenora, Rainy River and Thunder Bay. Thunder Bay is the largest city in the region and is the seat of the most comprehensive and advanced health services. Thunder Bay is located in the south of this region, on Lake Superior, complicating access to services given that many of the most northern communities in the region are fly-in only (with ticket prices close to or exceeding \$1000 per trip), or are multiple days away by car. The partner health sciences centre for the region is the London Health Sciences Centre in London, Ontario. The most visible presence in the local autism community is Autism Ontario's Thunder Bay & District chapter, whose activities emphasize socialization and socio-emotional support.

Health care in Northwestern Ontario is overseen by the North West Local Health Integration Network (LHIN). Ontario's Local Health Integration Networks (of which there are 14) are corporations tasked with planning, integrating and funding local health care, as well as ameliorating access to care and the patient experience under the Local Health System Integration Act, 2006 (Ontario LHINs, 2014, E-laws). In addition to providing oversight to integration and coordination activities, the LHINs are responsible for designating funding for certain health services in their region. LHINs are predicated on the idea that local level planning for health care services results in the best outcomes because plans are based on evidence provided by people who live and experience the needs and priorities of their communities (North West LHIN, 2014). The North West LHIN, based in Thunder Bay, encompasses the districts of Thunder Bay and Rainy River and most of the Kenora District (North West LHIN, 2014). To manage this large region, the North West LHIN has subdivided the region into five Integrated District Network areas: District of Kenora (Local Health Hubs (LHH): Kenora, Red Lake, Dryden); District of Rainy River (LHH: Rainy River, Emo, Fort Frances, Atikokan); District of Thunder Bay (LHH: Nipigon, Terrace Bay, Greenstone, Manitouwadge, Marathon), City of Thunder Bay (LHH: Thunder Bay), and Northern (LHH: Sioux Lookout) (NW LHIN Population Health Profile 2014). Although the North West LHIN is the least populated LHIN, home to about 2% of Ontario's population, it is the largest LHIN geographically, accounting for 47% of Ontario's land. The North West LHIN is also home to the largest proportion of Aboriginal people in Ontario, accounting for more than 20% of the North West LHIN's population. The North West LHIN allocates funding for hospitals, Community Care Access Centres (CCACs), community support service organizations, community health centres and community-based mental health and addictions agencies (North West LHIN, 2014). Understanding the general structure and funding model for these health care service centres is important for understanding the organization of autism services in Ontario.

2.5. Organization of Autism Services in Ontario

Although autism is a health condition, Ontario organizes and delivers autism services for children through the Ministry of Children and Youth Services (MCYS), not

through the Ministry of Health and Long-Term Care and the North West LHIN. Given that the Ontario Health Insurance Plan (OHIP) does not cover autism services or supports, MCYS initiated program funding for various autism services and supports in 2000 for children and their families until they transition into adult ministries at 18. The most substantially funded programs run by MCYS are the Autism Intervention Program (AIP) which provides Intensive Behaviour Intervention (IBI), and Applied Behaviour Analysis (ABA)-based services, as evidenced in Table 1. Services are provided to those children who meet the eligibility criteria.

MCYS delivers services through approximately 90 community-based organizations or hospitals. Although these organizations or hospitals may receive funding from the Ministry of Health and Long-Term Care, the MCYS funds and controls the autism services being delivered. MCYS delegates the oversight of program delivery by agencies to its nine regional offices (Ministry of Children and Youth Services, 2015). Northern Ontario as a whole (Northwestern and Northeastern Ontario, representing almost the entirety of Ontario’s landmass) is represented by a regional office in Sudbury, Ontario (Ministry of Children and Youth Services, 2015). Between 2003 and 2013, MCYS increased their autism services budget in size by 400 percent. Currently, the Ministry offers the autism services and supports detailed in Table 1 which, in 2012/2013 were delivered on a budget of \$182 million (adapted from Auditor Report 2013).

Table 1. Ministry of Children and Youth Services Autism Services

Autism Service and Support	Number of People Served in 2012/2013	% of Total Autism Transfer Payments
Autism Intervention Program	2000 children	64
Applied Behaviour Analysis-based services	6200 children	14
School Support Program	77300 educators 1250 children served in Connections	14
Respite Services	8100 children	4
Intervention services covered outside the regular program	47 children	1
Potential Program	6800 parents/caregivers	1
Transition Services	1000 children	1
Other	Various	1

Although many children with autism and their families make use of these services, it is important to note that many individuals with autism and their caregivers make use of services not funded directly as autism services and supports, such as occupational therapists, psychiatrists, special education personnel, speech-language pathologists and counsellors. These services and supports are not the responsibility of MCYS.

2.6. Access

Given my experiences as detailed in Section 1.6., I suspected that parents may identify strengths and concerns regarding access to services. As such, access is introduced in this section to establish the understanding of access that informs my work. Access is a complex issue that has been problematized and differently interpreted in the literature among scholars and researchers. The most basic, common understanding of access is that it is an act wherein something is obtained or acquired. Etymologically, access refers to a “habit or power of getting into the presence of (someone or something)” (Online Etymology Dictionary, 2014). The etymological definition of access offers key insight into how access should be defined for two reasons. First, by defining access in terms of a habit, access implicitly means more than one single desired encounter with the resource being accessed; that is, access implies ongoing acquisition of and engagement with a resource. Second, the etymological definition acknowledges that access is a process and experience of power, which is integral to examining access from an equity perspective.

Access has been frequently probed and problematized within the context of health care. There are mixed opinions as to what should be considered access and what should be emphasized in access. Specifically, whether access should be defined by the characteristics of the service itself or a combination of characteristics of the service and the user; whether it should be a question of supply and demand, and if adjustment by either the health service (or system) and users should be included (Frenk, 1992, Levesque, Harris & Russell, 2013). As Levesque et al. (2013) point out, research in health services and policy is often compromised by a lack of clear conceptualization of access and utilization. Given that I am conducting this work in part to contribute to the

literature on the organization of autism services in Ontario and policy, the understanding of access that will guide and inform experiences that parents have must be made explicit. A useful conceptualization of access for this study must align with how parents experienced, perceived and theorized access in their time of critical reflection. In recognition of the fact that access will look and be experienced differently between systems (health, education and social services), this study needs a conceptualization that is focused yet flexible enough to be adapted to each one. Since this study is from the perspective of the legal decision maker of the user, and is thus a user by proxy, the understanding of access must be user- or patient-centered. In addition, since autism-care is typically continuous and multifaceted, access must include more than the initial acquisition of the desired service.

Taking all of these needs into consideration, the conceptualization of access that has the greatest potential to be of use is that put forth by Levesque et al (2013). Although their conceptualization has a health care focus, health care can be replaced with education or social services in the definition without affecting its integrity or meaning. Levesque et al. (2013) have defined access as “the opportunity to identify healthcare needs, to seek healthcare services, to reach, to obtain or use health care services and to actually have the need for services fulfilled.” (p.8) They suggest “five dimensions of accessibility (Approachability; Acceptability; Availability and accommodation; Affordability; Appropriateness) and five corresponding abilities of populations (Ability to perceive; Ability to seek; Ability to reach; Ability to pay; Ability to engage) to describe the system and user characteristics that influence access” (p.8). It is in the dimensions of accessibility and the abilities of populations that the power in access is most evident. The dimensions of accessibility are the areas in which service providers and service systems can exert their power to restrict or allow access to services. The corresponding abilities of populations are the abilities in which parents and caregivers can channel their power to navigate and negotiate access. The interface at which each side’s power meets the other manifests as the experience parents of and individuals with autism have when trying to meet their service needs.

In keeping with this conceptualization of access, the access process for autism begins when a child is screened for autism following the guidelines set out in Section

2.2, or when an adult (be it a parent, caregiver, health care or education professional) identifies that it would be beneficial for a child to be screened. This identification of health care needs prompts parents to seek diagnostic services, in keeping with the Levesque et al. (2013) approach to access. As discussed in Section 2.2, there are a limited number of professionals capable of providing a diagnosis in Northwestern Ontario, all of whom are concentrated in the southernmost part of the region, and Telehealth must be used in the absence of in person access to a professional. Geography and the distribution of providers, as factors affecting access, are two of the many noted barriers to care which also include personal or family finances, cultural stigma around autism, prevailing biomedical medical opinion and associated attitudes, and educational background. Barriers to access in the diagnostic process are problematic not only because they fail to allow parents and individuals with autism to have an explanation around which to frame and guide their understanding the individual's condition, but because they prevent early intervention, support and benefit from those services that would best support the child's medical, health, social and educational needs.

2.7. Documented Burden on Services

While the cause(s) of the increased number of diagnosed/documented cases of autism are still up for debate, there has been an undeniable documented increase in demand for autism services in recent years (Ruble et al, 2005, Grether, 2006, as quoted in Brown, Ouellette-Kunz, Hunter, Kelley, Cobigo, 2012). Canadian families and public sector services (such as schools and health care services) are increasingly taxed by the abrupt rise in ASD diagnoses in addition to the relatively high prevalence of ASDs in the Canadian population (Norris et al., 2006, Minnes & Steiner, 2009, Dodds et al., 2009). Using data from 2007, the prevalence of ASDs in Canada is estimated to be 1 in 166 persons (SSCSAST, 2007). The demands on public sector services are expected to continue to increase given the push towards early diagnosis and intervention in the pursuit of maximal developmental outcomes (Rice et al, 2004).

2.8. (Perceived) Unmet Need and Experiences

In tandem, evidence consistently documents perceived or actual unmet needs of families with children with ASDs (Brown et al, 2012). Parents commonly report difficulty maneuvering through the autism service system, as well as a lack of information and service continuity (Kogan et al, 2008 as quoted in Brown et al, 2010; Brown et al 2012; Siklos and Kerns, 2007, SSCSAST, 2007, as quoted in Krahn & Fenton, 2012). Two points of concern arise with regard to service continuity: the transition from young/Pre-K child to school-aged child, and the transition from a legal minor to adult. While multiple studies exploring perceived unmet need have been performed, there is a call for a greater focus on families with school-aged children with autistic disorder or ASDs. When multiple ages are grouped together, the specific needs of families with children at different stages in their development and social/educational trajectory may be hidden. Consequently, this facilitates the divide between research on and services/policies for these needs (Brown et al., 2012). Unfortunately, while (perceived) unmet need in the context of service utilization is being explored, rarely are these unmet needs contrasted with the recommended standards of practice, especially using recent data and focusing on young children (McLennan, Kukulak, Sheehan, 2008).

The current literature focuses on several factors posited to influence the needs of parents, and as such also their (perceived) unmet needs. Brown et al. (2010) explore the relationship between functional independence and parents' unmet needs. They find that families with children whose functional independence is low are at an increased risk for unmet needs as compared to their counterparts in families with children with moderate functional independence. Brown et al. also find that, within their study population, families with older children (grades 4-8) seemed to be at a greater risk of unmet need when compared to families whose children with ASDs were in grades 1-3. While this is hypothesized to be the result of a loss of intervention services available during early childhood, this has yet to be demonstrated. In 2012, Coo et al. explored the impacts of rural area residency and lower household incomes on the age of diagnosis. They found that children in rural areas throughout British Columbia and Manitoba (the full sample in their study) did tend to be diagnosed at a later age than children in urban areas. Coo et al. (2012) indicate a need for future studies to explore whether health system

characteristics are significant factors of a child's age at diagnosis. There is a need for more study on whether the above mentioned factors, and factors like them, adversely impact the age of diagnosis.

Woodgate, Ateah & Secco (2008) helped to shift the focus in this small research area from documenting unmet need to seeking an understanding of parents' experiences of parenting a child with autism. Based in a western Canadian province, they were able to identify isolation as a common and critical experience, in addition to three key challenges of the parenting experience. Not unlike previous studies, the idea of one or both parents indicating that they were their child's primary case officer drastically impacted their experience. In the same vein, Mackintosh, Goin-Kochel & Myers (2012) set out to learn from parents what their likes and dislikes were with regard to their treatment process experiences. Woodgate et al. (2008) called for more research to be done to gain a knowledge and understanding of childhood autism from the perspective of parents.

Given the small, but growing, literature base examining the experiences of parents of children with autistic disorder or ASDs, service utilization patterns, or their intersection, it is not surprising that there is little evidence coming from a Canadian context. Krahn & Fenton (2012) have further demonstrated a marked bias in funded autism research in Canada with minimal Canadian Institutes of Health Research (CIHR) funding (~13%) going towards both the Health Systems and Services, and Population and Public Health research pillars as of November 2011 (5% and 8% respectively). This is in sharp contrast to the 52% of CIHR funding in autism going towards biomedical research and 11% towards clinical research in the search for a cause and cure for autism. The National Autism Research Symposium foregrounded the non-negotiable need for research supporting the development of a greater understanding of societal supports, parental supports, and educational supports are necessary to ensure successful outcomes in individuals with autism, especially from the perspective of what families identify as needs (Krahn & Fenton, 2012, CIHR, 2008). Such an understanding is integral to the ability to support persons with autism and their families in living with ASDs from a perspective that it is not a pathological or atypical trajectory of development (Krahn & Fenton, 2012).

2.9. Experiences of Parents of Children with Autism

There is very little research regarding the experiences of parents of children with autism. What research does exist (Cashin, 2004, DeGrace, 2004, Glass 2001, Gray, 2002, Woodgate, Ateah & Secco, 2008) tends to rely heavily on urban populations for a sample. As Hoogsteen & Woodgate (2013) point out, very few researchers have explored the experiences of families who have children with disabilities, let alone autism that live in rural regions. With regards to autism specifically, it had not yet been explored at the time of their paper or at the time of this project proposal in 2012. Hoogsteen & Woodgate undertook a study to gather the parenting experiences of those families living in rural regions in a Western Canadian province in 2013. It is the only known published study to solely include or actively involve rural families with children with autism in Canada. Although this project seeks to contribute to this literature gap, it is important to recognize that Northwestern Ontario does contain one large remote-urban centre that is included in the project's catchment area. This project remains the only known study to specifically ask about experiences with health and social care systems for the purpose of informing policy development and program design.

2.10. Conclusion

Defining autism is challenging because each individual who is or may be 'on the spectrum' presents differently. The consequences of an imprecise definition are endless in health care, education and social service systems that use a diagnosis as a ticket to service access. That said, even a diagnosis does not guarantee service access because certain programs have additional requirements to regulate access to the program, mitigating and exacerbating the demand on resources which has increased in recent years. In Ontario, autism-specific services are the responsibility of the MCYS. The MCYS does not have a regional office in Northwestern Ontario; there is one office for all of Northern Ontario, consistent with the incredible challenge regional geography poses in service organization and access to services. In this small field of research, there has been a small shift in focus to understanding and documenting parents' experiences of parenting a child with autism, but there is more research that needs to be done. This thesis aims to help fill this research gap.

Chapter 3. Methodology

In this chapter, I will proceed to present and explain Photovoice and Ecomapping, the two methods used in this study. The theoretical basis of each method is presented, followed by a description of the method's core components and procedures. The emphasis in this chapter is on Photovoice because it was the primary method used. Photovoice uses photographs to document reality and lived experiences, as well as to guide change-oriented discussion among participants. Ecomapping was incorporated into the study design as a processing and facilitation tool for participants as they identified the services they were accessing, how they were accessing them, and what their experiences were.

3.1. Photovoice

Photovoice is a visual-based qualitative research method developed by Caroline Wang and colleagues in the mid-1990s (Wang, Yi, Tao & Carovano, 1998; Catalani & Minkler, 2009). Photovoice is a process that allows participants to “identify, represent and enhance their community through a specific photographic technique” (Wang & Burris, 1994, p.369). In this process, enhancement involves, at the very least, the initiation of individual and community level change (Wang & Burris, 1994). Through still photography, Photovoice allows participants to document their reality and lived experiences. Participants are then able to engage in critical reflection and discussion predicated on the sharing of their experiences, knowledge and expertise as represented in the powerful visual images they have produced. Fostering and creating space for expression and empowerment is central to the Photovoice process. Wang and Burris state that Photovoice has three primary goals: a) to enable participants to document and reflect on strengths and concerns in their community; b) to “promote critical dialogue and knowledge about important issues through large and small group discussion of

photographs”; (Wang & Burris, 1997, p. 369); and c) to create or facilitate social change by influencing policy makers (1997).

According to Wang & Burris (1997), Photovoice can be used in one of three ways: 1) to meet participatory objectives in health promotion work, 2) to engage a variety of groups, communities and populations in health, and 3) to explore many issues encompassed in public health practice and research. Photovoice is not restricted to use in a health context though, as it can be used to explore a variety of topics specific to a community’s unique needs and concerns. Some examples of Photovoice studies or projects include:

- a) Exploring barriers to children’s physical activity and healthy diets (Findholt, Michael & Davis, 2010)
- b) Exploring community concerns in an internal displacement camp (Green & Kloos, 2009)
- c) Gaining an understanding of what a ‘healthy body’ means to First Nations girls (Shea, Poudrier, Chad & Atcheynum, 2011)
- d) Examining the experiences of African American adolescents with regards to HIV to inform HIV prevention planning (Woods-Jaeger, Sparks, Turner, Griffith, Jackson & Lightfoot, 2013)

3.1.1. Theoretical Grounding

Photovoice is rooted in Friere’s concept of critical consciousness, feminist theory, and documentary photography (Wang & Burris, 1997). In addition, similar to attempts made by community photographers and participatory educators before them, Wang and Burris (1997) designed Photovoice to challenge assumptions relating to representation and documentary authorship.

In 1973, Paolo Freire introduced a critical education approach that championed the importance of critical reflection on matters identified by an individual as fundamental to their life or community through dialogue. As a result, people could identify common themes between their experiences and realities, explore the fundamental causes of the matter reflected in the themes, and develop solutions to these matters in priority order (Freire, 1973, Jurkowski, 2008). In Freire’s approach, the images that reflected social and political forces in action were to be pre-produced and provided by facilitators.

Photovoice, however, empowers people to develop their own images, using still photography, thus allowing their personal reality to be captured in the picture. Once personal realities and experiences are captured in visual images, they can then be reflected and acted upon (Wang & Burris, 1997).

Photovoice draws upon feminist theory as it adopts the theory's critique of the status quo representation of a group lacking power by a group possessing more power. The incorporation of this critique from feminism is a crucial complement to Freire's methods, which failed to acknowledge male domination of women (and other groups), despite his theory possibly reifying such domination (Maguire, 1987, Jurkowski, 2008). In addition, Freire's work also did not account for non-outsider or expert-created knowledge (Maguire, 1987, Jurkowski, 2008). With such a perspective, participatory research could, in fact, reinforce the invisibility of the oppressed, past and present. Photovoice permits subjective experience and insider information to be valued and recognized as valid and important knowledge while simultaneously acknowledging the underlying inequality (Wang & Burris, 1997). Photovoice creates an inclusive space for participation by those who are oppressed and those who are not literate in the presiding language because most people can be taught to use a camera to create images. When used in combination with dialogue after the photographs have been taken, Photovoice has the potential to facilitate participation by persons who are not typically able to participate in research or social action (Wang & Burris, 1997).

Finally, Photovoice draws upon documentary photography. Stryker (1963) and Rosler (1987) describe documentary photography as a pictorial language to present social consciousness (as cited in Wang & Burris, 1997). Although similarities between Photovoice and documentary photography exist, Photovoice goes beyond documentary photography in that it "adopts the challenging assumptions related to representation and documentary authorship and places cameras in the hands of insiders" (Olibris, 2014). In the context of my research, parents were asked to identify the services that they use, how they manoeuvre between services, and what their experiences of the services were. Parents were specifically chosen for their expert knowledge of the experience of the service system(s), which would paint a different picture than what would be expected from a Ministry official or a service provider.

3.1.2. Core Components

Photovoice has three core components: facilitators, participants, and building capacity for action. First and foremost, both the success and safety of a Photovoice project is contingent upon the quality of the facilitator. A Photovoice facilitator is an individual who is dedicated to the kinds of social change in question, and is accountable to those engaging in the Photovoice project. Facilitators must be highly aware of the political nature of Photovoice, and sensitive to power and ethics and how they relate to photography (Wang & Burris, 1997). Facilitators must be sensitive to individuals' distinctiveness in the photograph-taking process, and be able to provide the appropriate support. Facilitators must be able to facilitate socially- and politically-grounded conversation pertaining to the photographs created. Finally, facilitators must have an understanding of the community's (or relevant participant environment) history and culture (Wang & Burris, 1997). Ideally, the facilitator is an insider; however, in the event that an outsider must serve as the facilitator, it is critical that they acknowledge themselves as learners and conduct themselves with humility, honesty, and openness (Fernandes & Tandon, 1981). There is some concern among qualitative researchers about facilitators being insiders because they may assume shared understandings with participants (Barbour, 2010). However, the insider perspective is valued in Photovoice because they would be equally well-versed in the community's history and culture. Photovoice participants, conversely, can be anyone. Within the context of a particular study, the individual's identity and location must be considered in the planning process.

3.1.3. Photovoice Procedures

When conducted in the context of a participatory needs assessment, Photovoice involves training for the participants, facilitated small and large group discussions, and a three-stage participatory (data) analysis (Wang & Burris, 1997). While it could be argued that these three elements are requisite for any participatory research process, they have come to establish the scaffolding of a Photovoice project conducted in various settings. There is some flexibility in working with the Photovoice method, however, so that it can be tailored to the community using it. That is, Wang & Burris designed the method to be adaptable. Unfortunately, guidelines for what adaptations are permissible or not have not

yet been established. The rule I've come to adopt after having completed a systematic review of the use of Photovoice with children and youth as the primary participants is that if the adaptations do not result in the loss of one of the three core elements or the social action piece of the method, then the adaptations are okay.

The first of the three core elements is training for the participants. Participants must be educated on the Photovoice method. Given that Photovoice is still a relatively new method in terms of when it really began to gain traction, and given that it is not as mainstream (and thus not as familiar) as one-on-one interviews, participants will rarely be in possession of a sufficient understanding of the purpose and aims of Photovoice in particular. Although there is some flexibility in how training can occur, participants must be guided through a discussion about ethics and power of photography, how to see photographs, and the philosophy of intra-community photograph sharing (Wang & Burris, 1997). Training should also include an overview of the mechanics of camera use, but this should be presented in moderation so as not to hamper creativity. Most importantly, participants should be engaged in a frank discussion about how the photographs and any associated data will be used going forward.

In this project, I originally planned to train all of the parents together, as per usual Photovoice protocol. Unfortunately, multiple scheduling conflicts prevented collective training from taking place. Consequently, the researcher arranged with each participant to conduct the training in the same meeting as the finalizing of consent. Participants were trained according to the Photovoice Training Guide (Appendix A) which encompassed all training areas as stipulated by Wang & Burris (1997), with one exception. In this project, participants had the option of being provided with a digital camera, using a digital camera of their own, or using a camera on their cell phone (if so equipped). All parents opted to use their cell phone camera since they would already have their cell phone on or close to them. After training, parents completed the first draft of their ecomap (see Section 3.4 for more information).

Pursuant to training, Photovoice projects involve small and/or large group discussions guided by the facilitator. Group discussions provide participants with the opportunity to reflect on their photographs both individually and collectively. In this

particular Photovoice project, participants were brought together in a sharing session during or shortly after their third week of taking photographs. Participants were able to engage in critical reflection individually as they developed freewrites for their photographs, and then collectively as they shared their freewrites and engaged in conversation with each other. The sharing session facilitated the third elemental component of a Photovoice project – a three-stage participatory analysis process. Stage 1, selection, is when participants choose which of their photographs most reflect the experience being explored which, in this project, are the experiences parents have navigating health and social services for their child. Stage 2, contextualization, concerns the telling and sharing of stories of meaning as pertains to the photographs in question. Stage 3, codifying, consists of identifying (recognizing and naming) issues, themes and/or theories that emerge from the photographs, description and discussion of their meaning. In this project, participants moved through stages 1 and 2 during the sharing session, as well as during the one-on-one interview.

3.1.4. Photovoice Concerns

When using Photovoice, it is important to be aware of the possible political ramifications of this method given that photographs are political. Consequently, Photovoice is inherently political. In response, participants may self-censor, biasing the photographs collected as the project comes to a close. In addition, despite the revelatory nature of the method, it is important to acknowledge that there is data in what is not photographed, and the reasons a participant has for leaving an experience unphotographed (Wang & Burris 1997). What is and is not photographed is dependent on the photographer, their personal judgment, context and timing. The complexities of the data collected in a Photovoice project contributes to the difficulty of data analysis and use. Similar to other forms of PAR, it is possible for Photovoice to exacerbate or perpetuate inequalities between groups depending on the resource ownership and sharing dynamics between them. Although Photovoice participants are empowered to take ownership over the data, the data ownership and publication rights are typically not in the hands of the participants and, in this particular study, they are in the hands of myself and SFU. Finally, although a methodology may seem ideal for addressing a particular issue, it may not be feasible as a result of current social and political contexts

– endangering participants is not an option (Wang & Burris, 1997). Fortunately, this is not of concern in this study.

3.2. Ecological Map

3.2.1. Background Information

In this study, I decided to include ecomaps as a complementary tool to Photovoice. Given that parents were answering a question about their experiences for the first time in a research setting, I thought that the ecomap could help them process and organize their service network so that they would not become overwhelmed with the topic at hand. The ecomap is a diagrammatic tool developed by Hartman in 1975 in a social work setting (Hartman 1978). In an attempt to reconcile general systems theory and tangible practical methods to be used by social work practitioners, Hartman capitalized on the “potential a systems orientation has for altering cognitive styles and enabling practitioners to organize and process increasingly complex systems of variables” (1978, p.465). Hartman sought to develop a value-added conceptual model that reflects perceptions of reality.

The term ecomap is derived from the word ecology, which is the study of the existence and nature of relationships between living things and their environment(s). Human environments are quite complex, given that the environment in question extends far beyond the physical into the highly nuanced social. In the tool, however, Hartman has selected to use uniquely human elements. That is, Hartman developed a tool that would represent an individual's self-created relationships and systems. Although the ecomap was first developed as a needs-assessment tool to be used by child welfare social workers to examine families (1978), its use has since been expanded outside the realm of social work.

3.2.2. The Ecomap as a Research Tool

Although originally developed in a therapeutic context, ecomapping continues to establish itself as a valuable research tool. Ecomapping is inherently designed to visually

organize networks while facilitating discussion about the networks being mapped. For the purpose of this study, ecomapping allowed the parents to identify the health and social services/supports that they use and discuss their experiences associated with the players and relationships on the map. Initiating the ecomapping process during the Photovoice training session also allowed parents to begin to consciously process the health and social services with which they interact to give them an idea of what they might photograph. In addition, mapping carried out over more than one session results in the production of more reliable data (Ray & Street, 2004).

3.2.3. Ecomapping Procedure

Ecomapping is a simple paper and pencil method of mapping an overview of the dynamic interactions in a family's ecological system (Hartman, 1978). Ecomaps consist of an inner circle in which the family is contained, typically taking the form of a family tree. For the purposes of protecting identities, the inner circle included only the parent(s) with the assumption that their child was there, simply unwritten. Surrounding this central circle, there are multiple other circles that represent elements of the family's social network. These other elements represent the major systems that are present in a family's life. Lines representing relationships connect the inner circle to the outer circles. In a typical ecomap, the type of line used (be it thickness or number) depicts the strength of the relationship between the two as well as the direction of resource flow (or lack thereof). Counter to the standard ecomap, Hartman found that when used as an interviewing tool, it proved more useful to have the family describe the connection between itself and the map elements and the use a brief synopsis or description along the line to qualify the relationship as opposed to using different line types. As such, this was the method used in this study. When drawing connections, connections can be drawn to the family as a whole or to individuals in the family unit. This allows for the comparison of connections between family members (Hartman, 1978).

In order to meet the study objectives, two modifications to the ecomap were made:

- a) Participants were able to draw lines and qualify relationships between elements on the ecomap to account for the relationship of the family, parent or child to one element by means of another.

- b) The circles for the elements were not pre-drawn for the participants so that they had the option of using distance as a qualification of frequency of use or nature of their experiences with that element (e.g. good or bad, reassuring versus stressful).

It is encouraged that ecomaps are developed cooperatively between the family (or parent, in this case) and the researcher because it results in a more active participation by the parent and thus a richer, more detailed map (Hartman, 1978). When an ecomap is developed through a collaborative interaction, reflexivity is promoted on the part of the participant. However, when both the researcher and the participant are involved in the creation of the ecomap, it is critical that the researcher is actively aware of the effect of their involvement, and mitigating the risk of influencing the outcome (Ray & Street, 2004).

3.3. Participant Recruitment Process

Participant recruitment occurred over a period of seven and a half months. The overall strategy for recruitment was to begin with free advertising with resources within the autism community for targeted recruitment, as well as to capitalize on snowball sampling, for self-selection into the study. In Phase I of recruitment, the Thunder Bay and District Chapter of Autism Ontario and Children's Centre Thunder Bay were contacted. Community Living Thunder Bay was also contacted by email and multiple follow-up phone calls, but contact with them was not successful. Autism Ontario dedicates a section of their primary website to research. Following procedure, Autism Ontario reviewed the project and the associated ethics certificate. After being approved for dissemination, a notice of the study posted on their research page along with the Information Sheet, and it was also included in the email newsletter to the members of the Northwestern Ontario chapter. The project was included in email newsletters twice, once each in May and June.

In a similar manner, I contacted Children's Centre Thunder Bay. When I was unable to touch base with someone by phone, they received an in-person visit to leave a letter and information sheet for the Autism Family Worker. Once in touch with the Autism Family Worker, the Autism Family Worker offered to send a notice of the study out to

their email list of clients. All of the organizations contacted in Phase One serve, theoretically, the region, with the exception of Community Living Thunder Bay.

In Phase II of recruitment, I focused on the region's major school boards. Three major school boards were contacted, two of which responded between 3 and 5 months later. Both responding boards were contacted by phone and by email, and the contact person was identified by special needs personnel with the school board. Both school boards had the project reviewed by their committees that oversee special education within the board. I requested that each board provide the study information to the special education personnel in their schools so that these instructors could provide the study information to the parents of the children that were on record as having a diagnosis autistic disorder or Asperger's Syndrome. One board offered to send an email to the Principals and Vice-Principals of all schools, along with a poster and the Information Sheet. It would then be at the discretion of the Principal of each school whether or not the information would be passed on to the special education personnel. Follow-up with the school board contact revealed that none of the Principals made the decision to pass the information on to the special education personnel. The second board made the decision to pass the information on to the special education personnel directly, and the personnel quickly distributed the study information to the appropriate families.

Phase III of participant recruitment occurred while I awaited a response from the school boards. Phase three involved posting recruitment notices in all of the major newspapers in Northwestern Ontario, of which there are three. Ads were placed both in 2 print papers and 1 online paper in the classifieds section for anywhere from 3 to 30 days, depending on the cost associated with the ad. In addition, the social services board of a major centre in the region sent out a notice of the study to all child care centres.

3.3.1. Participant Sample

Sixteen families responded to advertisements or word of mouth about the study. Of these sixteen families, four parents did not contact me directly; they chose to contact me through a friend (one parent) or a school representative (a group of three parents). In

both cases, the parents sought to pre-screen me through another individual, and to have their questions about the study asked through that individual before they revealed their identities to me. Six parents from six different families agreed to participate in the study. While in the process of confirming a meeting time to sign the consent forms and undergo Photovoice training, three parents decided that participating was, in fact, not right for them at the time due to high burdens of obligations at the same time. The remaining three parents were consented and thus enrolled into the study. Given the difficulty in finding a time for all of the parents to be trained in Photovoice together, the three parents were trained separately, each the same day as they were consented.

3.4. Obtaining Consent

Interested research participants were required to read a one-page information sheet about the study, which detailed the purpose of the study, the risks and benefits associated with involvement, as well as the inclusion and exclusion criteria. Interested participants were then provided with a consent form for review. Participants were able to email me with any questions they had regarding the information contained in the information sheet or consent form. Participants wishing to participate were subsequently met with. I reviewed the information in the information sheet and the consent form, and restated their ability to withdraw at any time without fear of consequences and the fact that participation and the provision of any information was voluntary. Once the participants determined themselves to be sufficiently informed, they were asked to sign the consent form and they were given an original copy for their records.

3.5. Data Collection and Analysis

3.5.1. Data Collection

In this project, data creation occurred continuously over the six week study period, while data collection occurred on three occasions.

In a Photovoice project data creation is continuous, beginning and ending with the start and end of the project respectively. After each participant completed the consent process and was trained in Photovoice, they were able to start photographing their experiences. Approximately three weeks into their photo-taking time, participants came together in a sharing session. Participants chose the photographs they deemed most important to share during a group discussion and were given the time to freewrite about these photographs. Participants structured their freewrites using the SHOWeD method (Wang, Morrel-Samuels, Hutchison, Bell & Pestronk, 2004):

What do you See here?

What is really Happening?

How does this relate to Our lives?

Why does this problem or strength exist?

What can we Do about it?

For this project, a modified set of SHOWeD questions was used in recognition of the fact that the researcher is not a member of the group to which the study participants belong. Consequently, two questions were rephrased as follows:

How does this related to Our lives --> How does this relate to yOur lives?

What can we Do about it --> What can you Do about it?

Following the completion of their freewrites, participants engaged in conversation with one another, sharing their photographs and freewrites and critically reflecting on and questioning the causes and nature of their experiences. Following the sharing circle, participants disbursed and were able to continue taking photographs for three weeks before they would join me in a one-on-one interview. During this interview, participants were able to do two things. First, they were able to discuss share photographs and the experiences they represented with me. Second, they were able to revisit and complete their ecomap through an active conversation with myself.

Critical Reflection

The data collection process was long and despite my intense desire to do this work, there are times when lulls in participant recruitment felt discouraging. However, I was quickly able to move myself away from this mindset by remembering that members of vulnerable populations or those which find themselves at the centre of a lot of media attention may not be immediately willing to participate in a research study. Autism is currently at the centre of a lot of media and research attention, and there are polarized views in the community and the general public about how autism should be approached. Therefore, although newspaper and online ads can be effective, it was critical to be mindful of the sources that this population might trust and distrust, and then channel my recruitment through trusted individuals or organizations.

Once data collection began, it felt quite humbling to be playing the role of the research tool (partially). I am always so grateful when people are willing to share their stories with me, be it in a research context or not. It was a privilege to witness the participating parents move through the project, and it was that privilege that kept me motivated to stay sharp, attentive and honour the data as well as I could. Sometimes it was difficult to be a research tool, particularly when a participating parent commented on larger, systemic issues and I could not engage until after the study was over. During data collection and analysis, it was also quite difficult to strip the children of their identities, because it sounded so cold to use “your child” or them/them in the sessions that were recorded.

3.5.2. Data Analysis

In the nature of inductive research, data analysis began from the outset of parent engagement. All of the data collected in this project – photographs, freewrites, sharing session and interview conversations, and the ecomaps, were used in the data analysis process. As per the suggestion by Wang & Burris (1998), participants were involved in the three-stage process that allows for data analysis, particularly as pertains to their photographs, freewrites and focus group session: selection, contextualization, and codification. Participants were able to engage in selection by choosing which photographs they would like to share, as well as those that were the most important,

according to them, as pertains to the research question at hand. Participants also took the lead on the contextualization of their experiences because this stage is, in essence, storytelling (Wang & Burris, 1998). Participants storified during the sharing circle and during their individual interview with me. The parents were able to narrate and caption their photographs. Finally, participants engaged in the third stage, codifying the data. Through guided questions or probes during the sharing session or the individual interview, participants were asked to identify the issues they wanted to draw attention to. During the contextualization phase, participants had identified themes in and patterns of experiences during the sharing session and began to theorize why they may be.

The transcript for the sharing session, which contained the participant-led data analysis, was then taken with the interview transcripts and freewrites and analyzed by myself. I started with a complete read of each, with a second read done for the focus group transcript due to its depth and length. Then, I began the processes of rereading the transcripts and coding them. A combination of a priori and in vivo codes were used. A priori codes were those derived from major sets of experiences as identified by the parents during their data analysis. I identified in vivo codes as I went along and they took the form of a word I selected or a quotation from the transcript itself. Codes were then reviewed and they naturally began grouping into categories and then themes. Freewrites were analyzed in place of “seeing” photographs to reduce the likelihood of misinterpretation. Photographs were carried with codes through to categories through to themes. During the coding process, I referred to my field notes and the parents’ ecomaps to ensure that my reading and understanding of the transcripts matched the emotions, body language and characterizations of relationships supporting the text.

During this analysis process, I noticed that there was great similarity and consistency between the experiences being discussed in the sharing session and the individual interviews. As such, in Chapter 4, I present excerpts primarily from the sharing session because there is great value in the interaction between parents and collaborative theorizing and problem solving. In addition, although photographs and freewrites are included in Chapter 4, the ecomaps are not presented. The ecomaps contain the names of organizations which, if removed for the purposes of confidentiality, would strip the ecomaps of their meaning, thereby *negating* their inclusion.

3.6. Special Considerations

A very important consideration of the proposed project is twofold: research can be a therapeutic process, and participants may perceive the specific research project as therapeutic. Consequently, boundaries become even more important in this work. During the Photovoice training, the roles of the researcher, or facilitator as it is termed in Photovoice, and the participants are clearly defined. The Photovoice facilitator role is set up to ensure the safety and success of a Photovoice project. Safety includes not only the physical safety of participants but the emotional and mental safety/wellbeing. Acting in this manner, operating within established boundaries, and engaging in continuous conversation about these boundaries will increase confidence on the part of the participants that the work is being undertaken in a professional and respectful manner.

Despite established boundaries, it is reasonable to anticipate that the work may increase individual and collective vulnerability. In anticipation of such an event, I connected with a counselling service and established an arrangement with them so that I could offer participants a safe individual and safe space to engage in a more in depth debrief and examination of the thoughts and feelings that arise as a consequence of participation. While ideally the counsellor would have been familiar to the participants, such as by being a counsellor that works in conjunction with a relevant specialized service or school board, this becomes a precarious decision to make when the research at hand serves to examine experiences with such services. As such, a counsellor and counselling service was chosen that was not likely to be accessed by parents at this time. This study gave me an opportunity to begin to learn how to balance participant safety with the integrity of the research process.

3.7. Conclusion

Parents self-selected into the study upon review of study information posted during participant recruitment. Of the 16 families that responded to the advertisements, three parents ultimately participated in the project. These three parents shared their experiences of accessing services for their school-aged child with autism using Photovoice, a visual-based method that allowed them to capture their reality and lived

experiences. Parents also used ecomaps to organize their interactions with service systems.

Chapter 4. Results

In this thesis, I have chosen to present the results and the discussion together. In Photovoice, as discussed in Section 3.1.3., the small group discussion (the sharing session) provides a space for participants to engage in the three-stage participatory analysis. During this discussion, participants select and reflect on experiences, contextualize their experiences, and then codify these experiences. That is, participants present and discuss their data, which is in narrative form, simultaneously. It therefore makes sense to mirror that process in the writing of this thesis. In doing so, I can present the experiences that the parents selected as important, contextualize these experiences in narrative form, and present the coding of these experiences as done by parents and by myself. In the three chapters that follow, I approach the results from the perspective of trying to understand the parents' experiences as connected to the larger issues of service in Northwestern Ontario while simultaneously staying true to the uniqueness of each parent's experience. By virtue of each child with autism being unique, parents may share life situations from a global perspective, but their experiences or the nature of their experiences may be different. The following chapter is divided by shared systems the parents identified that they encounter, and then within them shared and unique experiences are further explored.

Prior to exploring these experiences, however, the parents are introduced so that the reader can better understand the perspectives and experiences they share. Throughout this chapter, you will read the names Snowman, Sunshine Brock and Alice. These are pseudonyms chosen by the participating parents who had the option of using a pseudonym or using their true name. In order to respect and protect the privacy of minors and service providers with whom the participating parents have contact, gender-neutral language is used to describe everyone other than the participating parents or adults who consented to be so identified. While I understand that such language may

seem cold and clinical, and quite counter to a participatory approach, it is a necessary precaution for this thesis.

4.1. Parent Profiles

Snowman is the parent of a 9 year old child with Asperger's Syndrome. Snowman parents with her partner in a two-parent, one child home. Snowman and her partner both have full-time occupations. Snowman's child was diagnosed at the age of 7 by a Psychological Associate at a service centre in Northwestern Ontario. Snowman's child also lives with an anxiety disorder and possibly a neurological disorder.

Sunshine Brock is the parent of a 12 year old child with Asperger's Syndrome. Sunshine Brock parents with her partner in a two-parent, one child home. Sunshine Brock and her partner both have full-time occupations. Sunshine Brock's child was diagnosed at the age of 6 by a Psychologist. Sunshine Brock's child also has neurological conditions.

Alice is the parent of a 6 year old child with Autistic Disorder. Alice parents with her partner in a two-parent, two child home. Alice works part-time and her partner works full-time. Alice's child was diagnosed at the age of 2.5 years at a service centre in Northwestern Ontario. Alice's child does not live with any other conditions.

4.2. Education

In Ontario, all children aged 4-12 must be receiving education consistent with the Ontario curriculum under provincial law, be it in a formal or home school. As such, all parents are forced to encounter, if not engage with the education system. In the education system, parents are accessing teachers, school support program personnel (SSPs) or special education teachers, speech-language personnel, and administrators. Parents expressed that the education system was their biggest concern. One main theme that emerged was that of the experience of a service being personnel-dependent. All of the parents identified, first and foremost, that in order for their child to receive the

services and supports they required, an education personnel needed to take an interest in their child, and occasionally the family. During the sharing session, Sunshine Brock, whose mixed experiences with the education system tend towards the unfavourable, succinctly summarized this phenomenon as follows:

If it wasn't for the Resource teacher and the Special Ed teacher at (school) we would be, [my child] would be totally be falling through the cracks again, which happens every year. Grade X was [my child's] best year, [their] teacher was all about [them] and making sure that all [their] abilities were reached.

For Sunshine Brock, her child's success at school can be attributed to individuals who, like herself, are working to prevent her child from falling through the cracks, as she put it. Although this was first brought up by Sunshine Brock, it became a dominant topic of conversation throughout the focus group, primarily but not exclusively with regards to the education system. Within the education system though, these specific individuals also have the ability to affect how those around them service the child. The experiences Alice has with the education system, which are largely positive, are predicated on the specific individual's ability to foster a similar attitude in other staff and students.

This is [my child's] Special Ed teacher, Z, and she's also fantastic. It wasn't her but when she was on maternity leave they got, the school got [my child] this iPad and because [my child is] non-verbal, this [my child's] communication tool and [my child] uses [software], which is [in Figure 1]. This is [my child's] home [software]. The school did a fundraiser and they sold Fudgsicles in [grade] and the money went to [my child's] iPad.



Figure 4.1. Communication Software

Note: This is an iPad application the school board provided to [my child]. [The app] is a communication based application that allows [my child] to communicate through the iPad to others. This program has allowed [my child] to become more independent and to communicate in a more normal fashion. [My child] has learned to ask for things, and to have basic communications with people. As [my child] becomes more comfortable with the program more skills and conversations will be added.

The parents posited that the interest leads to the formation of a relationship; this relationship provides both them and their child with three key supports: understanding and compassion, inclusivity and belonging, and parent support. By providing these supports, education personnel increase the likelihood that the education system and the services it provides are approachable and accommodating, consistent with the Levesque et al. (2013) definition of access as presented in Section 2.6. However, the education setting appeared to be an environment in which the general rule of quality over quantity does not apply. Given that time is needed to develop a relationship and then execute programming tailored to a specific child's needs, parents express discontent with the amount of support time their child is receiving. Sunshine Brock explained the general

classroom support trend to me during her individual interview while she discussed how her son came to get services at school:

When we transitioned to Grade X [my child's support staff] asked for 110% help so then [my child] would get more than needed to start, but now [my child is] down to about 50. So, [my child] did have full time help and then [the administration] just [decides] amongst themselves when they decrease it without giving [my child] or us a warning. When [my child] went back after Christmas, the same thing in January, [my child went] from 80% to 50 with no warning, so then [my child is] anxious because [my child] has no idea who is going to be helping [them] and when [they have] this help. Then after March Break they'll reduce it again and by the end of the year [my child] probably won't have any help or about 20 percent. And every year that seems to be the trend.

Parents recognize that the constructive relationship their child forms with a staff or support teacher who has an interest in them must be consistent and reliable, particularly with children with autism. As much as an interest and relationship have positive ramifications for the parents and their child, the lack thereof result in a simultaneous lack of understanding and compassion, inclusivity and belonging and support to the parent. Snowman, whose experiences of the education system were largely negative, explains that she feels that education personnel both bully and facilitate the bullying of her child by other staff and students.

I almost feel like with [my child], because of the way the teachers have treated [my child], the students feel like they can treat [my child] like that as well and get away with it – and they often do.



Figure 4.2. At the end of the line

Note: Always at the back of the pack with an adult (SSP). Slower than the rest, not as compliant – no friends willing to be with [them].



Figure 4.3. Alone at lunchtime – as usual

Note: [My child] has a severe aversion to fruit and classmates have learned to sit away from [my child].

As Snowman shared this behaviour during a sharing session, and has captured two examples (Figures 2 and 3), she also shared that even her child can identify the lack of understanding displayed by staff and identifies feeling being purposely excluded.

[My child is] coming home constantly saying 'These people are torturing me, they don't understand me.' [My child will] say to the kids, the teachers and the SSPs, 'You don't understand, you don't understand me,' and they will say "We do understand you, get with the program, get to work," or "We understand you, you're just being a spoiled brat" basically.

One of the teachers one day – [my child] has sensory issues, sound as well – went behind [my child], humming. [The teacher] just wanted to see what would happen. Well [my child], I don't know how many times [my child] asked her to stop or I don't even know if that happened but [my child] said to [the teacher], "Don't mess with me." [The teacher] took [my child] out in the hallway and [later told me], "I had to talk to [your child] for 45 minutes and I gave [your child] a lecture about respecting teachers." What about respecting my child?

Such experiences do not reveal understanding and compassion on the part of the education personnel, and serve to further alienate children who are already labelled as different against the best efforts of parents who cannot be present at school to monitor staff at all times. All of the parents expressed a concern about the treatment of their child at school by at least one, though in most cases multiple staff members. By proxy this concern extends to their child's fellow classmates given that children model behaviour from the adults they interact with and because 'kids are mean.' The treatment of the parents themselves is sometimes not so different; all of the parents shared that they had been told by education personnel that their child's behaviours were the result of "bad parenting."

Based on such experiences at either end of the support spectrum, I see the effects of ableism playing out in micro-aggressions. I have also noticed that it is because of these experiences, amongst others, that parents take on the role of the Navigator-Advocate, which also emerged as a main theme throughout all systems. The Navigator-Advocate is an individual who "[bangs] through doors" and makes the needs of their child known in order to determine and secure access to relevant services and service providers for their child. The Navigator-Advocate is akin to a case worker – identifying, seeking access to, and following up on the services required to attend to the needs of their child. Unlike a case worker, however, who has presumably received special training in service system navigation, case management and advocacy, the Navigator-Advocate's abilities are primary or entirely experientially-based, using knowledge

gathered from the day-to-day care of and interaction with their child. As such, it is a role of continuous learning and education. As parents become more comfortable and well-versed in the role, they become more empowered decision makers and their ability to manage the various situations in which they find themselves is strengthened.

In the context of the education system, wherein the pathway to service access is clear and well laid-out for parents, the Advocate actions of the Navigator-Advocate role are more frequently employed. Parents expressed that they were constantly fighting, repeating that if they did not “fight” for their child, then no one else would. In their never-ending fight, I’ve identified resilience, both of which are neatly detailed and displayed by Sunshine Brock as she speaks about her experiences with the education system during the sharing session, “We’re going to keep fighting because that’s all we’ve got”, with Snowman simultaneously pointing out that the fight simply “regenerates.” Fighting is a strong word that is accompanied by imagery of conflicts, battles, and barriers to be overcome. The use of “fight” as the verb of choice would seem to imply that the parents experience an “us versus them” reality. To select ‘fight’ also recognizes that there are power dynamics in all of the parents’ experiences, perhaps even revealing the nature of these power dynamics. In schools, administrators and school board personnel are able to exert more power over a child’s classroom situation that perhaps a parent can, so they fight, and they recognize that this does not always result in them being perceived as nice (as is, again, the nature of fighting).

Sunshine Brock: And that's what I said. People might think I'm the biggest bitch around but I really don't care because [my child]'s all I've got and I'm going to fight for [my child] and I said that at our meeting with a bunch of ladies who are like between 60 and 80 and they were horrified but that's my life!

Snowman: I said that to the [head of institution] after I had that meeting with the two [institution leaders], [institution leaders' titles], I said "I'm going to come across here as the bitch because I'm - "

Sunshine Brock: - fighting -

Snowman: "complaining about what they said to me. I'm going to be the bitch"

Sunshine Brock: Yeah, that's my own famous word - I may be a bitch but I'm fighting!

Beyond the implication of barriers that comes with fighting imagery, the notion of physical barriers as metaphors for system and service barriers is brought up frequently by parents. As Snowman says, “If I didn’t push, I wouldn’t be getting anywhere. I have to constantly be walking into offices and pushing down doors.”

In spite of pushing down doors in order to talk and meet with school staff and administration regularly or when needed, the lack of constructive communication is of concern for parents, particularly as pertains to conversations around who their child’s teacher and SSP will be in the following school year. As discussed above, one staff member can define a child’s experience and, by extension, that of their parent. As such, parents advocate for their child to have a particular teacher or support person at their school for the following year, given that the teachers and support staff interacting with their children can change year to year. Parents expressed a lot of frustration with the secrecy among education administrators about who homeroom teachers and support staff will be for their child the following year. As Snowman points out during the sharing session,

Why does it have to be a secret?! If it's going to make my child comfortable knowing the whole summer, you know, stressing about who [their] teacher's going to be why can't you just tell us?! But no it has to be a huge secret!

The secrecy is particularly problematic for parents because, “transitions are hard” and some of their children require that advanced planning and gradual transition phase back into a school routine.

In addition, parents as Navigator-Advocates are the only common link between all of the services their child needs and uses both within and external to the education system. Consequently, parents find themselves communicating to all of the service providers in the absence of communication with each other. The action and attitudes displayed by a parent in the Navigator-Advocate role facilitate parents’ ability to perceive and interact with education services, which corresponds to some of the abilities a population must have in order to interact with services to successfully secure access as per Levesque et al. (2013). Although it is not expected that parents play this role, it is

expected, under the Levesque et al. (2013) definition of access that parents are facilitating access through their behaviour, which they appear to be doing.

4.3. Medical and Non-Medical Health Services

Parents expressed grave concern at the state of medical and non-medical health services in Northwestern Ontario as a result of their experiences. Medical services refer primarily to paediatricians, but also include family physicians, nurses, and emergency room staff. Non-medical health services include physiotherapy, occupational therapy, speech-language therapy, pharmacotherapy, respite care, counselling, and other such services and the associated staff. Most parents reported invalidating, dismissive interactions with medical services and professionals, and mixed experiences tending towards constructive with non-medical health services.

Consistent with the literature (Canadian Autism Spectrum Disorders Alliance, 2014), most of the parents are seeing family doctors and paediatricians more often than they are using other types of medical services. This pattern of use makes sense because given the child age range of interest in this study, the designated point of contact for medical services is the family physician or paediatrician, barring an emergency. With the exception of the parent who knows one of their child's medical providers in a personal capacity, parents report stressful, uninformative and unproductive experiences and interactions with medical professionals, once they were actually able to get in to see them. During the sharing session, Snowman explained this experience using the example of trying to have her child assessed for autism:

We had to wait for 7 months to see the paediatrician, so I had all that time, 7 months. We went in to see her and she gave me a questionnaire basically. She said it could be AS, but maybe it could also be ADHD. So she sent me home with a questionnaire, a 10 page questionnaire whatever it was. She said, "Just bring it back to the office and we'll call you to make another appointment." Within a day I had it back to her office and left it there. Through Christmas we had to wait and it ended up being about 3 months of waiting and thinking she's going to call me; that she's looking through these papers and she's going to call me. Ends up she never did so I called back and was told by the receptionist, "Oh you're supposed to call us, we don't ever call you" - well this paediatrician was new in town so I guess she didn't

know the process. So we booked an appointment and then it's another 3 months so we're over a year now from the initial [contact].

Snowman's experience provides insight into waitlists which, during the sharing session, set the foundation for considerable admonishment by the parents as a group. Given that children need to be diagnosed with autism in order to access health (and social) services relating to their autism, getting a diagnosis in a timely manner is essential. In addition, it is well established that autism interventions are more effective with an early start and therefore a younger age. However, even once a diagnosis is had, parents explained that the waitlists continued. Alice, whose child is the furthest along the autism spectrum and was diagnosed at the earliest age, has been on a waitlist for respite services for almost two years and was told the typical wait time was 4 years, while her time on a waitlist for occupational therapy has been 4 years and she continues to wait. Her wait list for IBI services was 2 years, about which she says,

Yeah. I know my [child] came up for the IBI program and, ah, it's kind of been an interesting story because [my child] was on the list for 2 years and my husband had [our child] at the paediatrician and he said, you know, "I really want you to get [my child] in IBI. [My child]'s been on the list for 2 years and we haven't heard anything yet." So he agreed and he actually wrote a letter, gave it to [organization] and we got calls from all the people in Sudbury. We got the same, "Oh well you know we can't tell you where you are on the waiting list," and "We have to be fair," and "We don't know how long it's going to be." Blah blah blah same old story. They called within a week and said they had a spot for [my child].

It is evident that Alice is quite frustrated with the waitlists as she exclaimed, mid-conversation, "We need it now, not 4 years from now, we need it now! We're like in crisis mode here and we can't get any help!" Although Sunshine Brock did sympathize with the other parents over waitlists for medical and non-medical health services, she did not note any specific experience with waitlists. She acknowledged that she was already accessing services for her child with a service provider when her child was diagnosed and as such it was simply added to her child's care plan without going on a waitlist. Parents identified that communication was critical to not only check-in on their child's waitlist status but to make sure they were still on the waitlist and being ranked appropriately, which Snowman related back to the education system and waitlists for

school-based services as well. Sunshine Brock aptly points out that it makes a difference to “actually [be able to] tell somebody your story about [your child]” which must suffice “until they get to know [their] kids.”

Once the parents are in front of a provider, particularly medical providers, parents identified that medical personnel lacked sufficient knowledge of Asperger’s Syndrome and autistic disorder, similar to education personnel. However, going back to medical personnel as frequently being the first point of contact with care and being the designated care provider for children in the case of a paediatrician, this posed a severe barrier to care, one that hindered the development of constructive relationships between the parent and the medical professional. The parents proceeded to critically examine this lack of knowledge in the sharing session

Sunshine Brock: What do you do?

Alice: What am I supposed to do now?

Snowman: They gave no answers -

Alice: There's no answers. I don't think they know, or they don't think it's a big deal.

Sunshine Brock: But that's not the case

Snowman: if they don't have a child that they're living with 24 hours a day, how can they possibly know?

Sunshine Brock: Because they only know what they learn -

Snowman: Right, the education that they get.

Sunshine Brock: And that's....

Snowman: They're not living with it. Sure you have all these theories on paper but that's the one thing I found nice about [community organization] [...].

The above exchange is particularly interesting because the parents moved quickly from identifying an issue to theorising about the cause and nature of the medical professionals’ lack of knowledge which they attributed to their lack of sufficient or relevant education. With an increasing number of children being diagnosed with autism,

medical professionals should be armed with sufficient information just as they would be made to do in the case of an epidemic (Norris et al., 2006). The parents have also posited that medical professionals are unable to help because even with autism their children are medically healthy. As Alice and Snowman discussed,

Alice: I find that the doctors don't really have any good advice for us.

Snowman: I agree with you there.

Alice: I find all they want to do is medicate, and I've gone to my [medical professional] with questions and he doesn't know the answer, not that they're supposed to know the answer for everything, but they don't know, you know, I don't think it's something that a doctor can really help with unless it's some kind of neurological issue going on.

Alice also noted that, "they're more for if your kid, if [they're] sick or something medically is going on."

The distinction drawn by the parents is essential to recognize because it enunciates a critical difference in perspectives on autism. Given that these parents do not perceive their autistic child to be medically ill simply because they are autistic, their approach to care and what they deem appropriate care has the potential to differ from medical professionals. Alice points out above that "all they want to do is medicate" the autism. Alice in particular has had a very strained experience relating to pharmaceuticals for her child:

So we brought [them] to the paediatrician, we told him what was going on and he said "Well you know we could try giving [them] some Risperidone so that'll calm [them] down and help [them] sleep." So we thought, okay, you know, so we tried that and that was fine. It did, it helped [them] sleep and it helped with some of the other behaviours as well. When we went back, I told him how things were going well, you know, no trouble, [they're] calming down, [they're] sleeping at night, everything's working out well. And he said "Well, maybe we could try a little bit of Prozac just to kind of even it out and help with a few of the other behaviours." And my husband and I were a little bit apprehensive about it because it's just another drug, you know, [they're] 5 years old, you know, and you're starting to push the drugs. So we tried it for a little while, it wasn't working for [them] with us, we didn't find it helpful and we were just uneasy about it, so we took her off. The next time my husband took [our child] for another follow-up visit, the paediatrician got mad at him because we took [our child] off the Prozac and he explained to her, to him sorry what our issues were

and instead of just saying "okay, I understand" he's like "no, I think you need to put [your child] back on it because it's going to help [your child], the older [your child] gets the worse it's going to become for [your child] so you need to start [your child] on this now". [...]. So [my husband] goes and gets a follow-up appointment with his secretary - it's six months down the road! [...]. So the doctor's going to put my kid on anti-psychotic drugs and he's not going to see [my child] until April, like 6 months from now?! That's just, that's not fair. That's not right. [...]. We've taken [them] off of it, we're not putting [them] on it, but I know when we go back in April he's going to be mad about this.

Snowman: Yeah, they're going to give you a lecture.

Alice: But, when you

Sunshine Broke: You know your kid best

Alice: Exactly,

Sunshine Brock: So that's not helping.

It would appear to be that the autism is not why parents are seeking medical assistance – they differentiate particular behaviours that are completely or partially influenced by the autism from the autism itself, and it is the behaviours that they seek assistance for. For these specific behaviours, parents have had some constructive experiences with the medical professionals. In Alice's case, "they were helpful with [my child's] aggressive problem. They were helpful with that, with the medication."

In Sunshine Brock's case, her go-to medical professional is "against medicating until she tries everything first, but that's also how she operates". In addition to the medical professional's stance on medications, Sunshine Brock acknowledges that she has a very good [medical professional] and that she has excellent relationships with both medical professionals who attend to her child. Sunshine Brock has noted that the medical professionals are actually able to engage in conversation with her child, reflective of constructive patient relation skills which clearly impact her experience with them as a service user. Says Sunshine Brock, "any time we have any problems or questions or even just concerns we can phone them and they'll help us like we don't even have to go in."

The first medical professional with whom Snowman spoke on the path towards a diagnosis for her child, however, did not appear to be in possession of the same skills:

[...] so we went to see the family doctor. I had no clue, I heard about autism but I didn't know about Asperger's Syndrome, I don't think I'd ever heard the term and um, went to see the family doctor, he read the note from the [education professional] and he said to me "well, we want to make sure your [child] is not crazy so we'll send you to the paediatrician" and that's all he said to me. He didn't say it could be this this or this, that's all he said to me, "We want to make sure [your child's] not crazy".

In this comparison, the theme of one person defining the experiences parents and their children have surfaces. There is inconsistency in care between paediatricians, so families suffer. Sunshine Brock commented to the Snowman that it was apparent that her paediatrician did not have an interest in her child. A medical professional should not need to take an interest in a child, or any patient, in order to provide them with appropriate care.

Another concern raised by the parents was that of insufficient communication and differences of opinions between medical professionals and providers. Most notably, discrepancies between physicians and pharmacists have raised red flags for parents and have resulted in some tense and scary experiences:

Alice: The pharmacy at [location] wouldn't give us the Prozac at first because they didn't think it was suitable for someone -

Sunshine Brock: - so young -

Alice: - yeah, they wouldn't do it. They had to call the doctor's office and ask them what was up with it. They didn't think it was suitable. And that was another red flag in my head!

Snowman: Right?

Alice: I'm thinking, "Okay, if the pharmacist isn't going to release, if they don't think it's a good idea, they know drugs I think better than the doctor, is this not a good idea!"

Sunshine Brock: They deal with drugs everyday.

Alice: Exactly.

Finally, parents have noted a tendency for their concerns to be ridiculed or dismissed by medical professionals:

I tend to bring - because [my child]'s non-verbal, if [they're] sick, like really sick with a fever or you know something's just really off, I tend to bring [them] to the hospital a lot because I don't know, you know, [they] can't tell me what's going on. And a good example was just even a couple weeks ago. [They were] feverish, and [they] had a really bad cough and I thought [they] had [...] and so I brought [them] to the [hospital]. Some people are like "Why'd you bring your kid to the [hospital] for that?" or like "[They've] just got a cough" but like I just don't know, right? [...]. So, um, sometimes the nurses there are like, even the same attitude like "Why are you doing this?" you know? But anyway, when we got there, we met the doctor and he was really good, I explained you know "I don't mean to minimize this or anything but [they're] autistic, [they] can't talk, I don't know what's going on, I can tell you what [their] symptoms are but I want to make sure it's nothing worse" right? And he's like, "Okay, I fully understand, we'll do, I'll do a good exam" and sure enough [they] had a [medical condition]. Didn't even know, because [my child] can't tell me.

The discussion of pharmaceuticals and Alice's particular experience with her local emergency department brings back the role of the Navigator-Advocate. As Alice points out, in medical care, she is her child's only voice and so she must rely on her observations and intuition to identify the possibility of illness where her child is unable to tell her. In discussing pharmaceuticals and medical professionals, her whole story (not included here) includes resistance and resilience with regards to following medical guidance that did not feel right for her child, whom she knows best, also bringing back the fighting piece of the Navigator-Advocate role.

As already alluded to with the discussion of the pharmacist above, the parents have access to non-medical health services and providers for their child who do make the parents feel understood, who display compassion, who make them and their child feel like they belong and who, essentially, fight alongside the parents for the wellbeing of the child. For Alice, it is her pharmacist, while for Snowman it is a social worker. Although Sunshine Brock's child's paediatrician has a great relationship with her child, Sunshine Brock also identifies a particular allied health treatment centre as providing in great service and support for her family, as captured in Figure 4. Non-medical health

service providers, in general, tend to foster more positive, validating interactions with the parents –at least once the parents are able to engage the service.



Figure 4.4. George Jeffrey Children's Centre

Note: Very important in our lives – second home for our family. [My child] has attended since 20**. Continue to receive services and support as needed for transition to [school], adulthood and every day activities.

Based on the experiences of parents, it is evident that there is a disconnect between what the medical system has to offer and what parents are seeking for their child. It is also evident that this disconnect is not as pressing, or present in some cases, between non-medical health services and parents. Medical and non-medical health services may be physically available to the parents in their particular postal codes, but they cannot be acquired in a timely manner. As a point of comparison, one parent is contemplating a move to a city in southern Ontario. When she made inquiries as to how long the waitlist would be to get a service that has a 4 year waitlist in Northwestern Ontario, she was told there was no waitlist, but there could be a delay of a couple of

weeks if they were unable to find a support worker that fit her family. Such a finding is not surprising as it is taken as common knowledge that Northwestern Ontario simply does not have the number of providers necessary to service everyone in a timely manner as a result of funding and ability to retain talent. The lack of personnel and services at all, depending on which city, town or First Nations Territory you are in, are characteristics of the health system that severely impede access to care. In addition, the medical and non-medical health services are not appropriate or adequate for all of the children and families in need of autism services. That is, the services are not appropriate because they do not fit well with the service users in question, there is an experience of technical and interpersonal inadequacy, and they are not timely (Levesque et al., 2013). Consequently, the services are not adequate from the perspective of the user because they are not appropriate and they are not of sufficient quality, as evidenced by the dismissive and invalidating experiences parents have had. Although parents did not explicitly state that the fractured nature of the autism service system resulted in a lack of satisfaction with the system, thus perceiving it as less adequate than the system thinks it is, this should be noted as they did allude to it while discussing the lack of communication between systems. Although the lack of communication between systems transcends the health system itself, the lack of communication between family physicians, paediatricians and pharmacists best exemplifies this practice. As a response to the care their child is or is not receiving, parents have increased their health literacy and advocacy skills to ensure that care is directed in the best interest of their child. Therefore, parents are again displaying abilities necessary to secure access under the Levesque et al conceptualization of access.

4.4. Community-Based Services

The parents participating in this study are accessing an array of community-based services. Parents are accessing socialization and leisure programs, charity programs and funds, not-for-profit organizations, community hubs, and child care. The Canadian Autism Spectrum Disorders Alliance survey (2014) indicates that the most common, recent non-health services being used for school-aged children (as per their definition of five to 17 years of age) were activity-based programs, recreation/leisure

programs, social skills programs, respite care and behaviour therapy for behaviour management. The array of services used most recently, and commonly, by the parents participating in this study seem to align with those identified in the Canadian Autism Spectrum Disorders Alliance survey, but there was not a sufficient amount of information about the survey categories to make anything but a superficial comparison.

Overall, community-based services, based on the experiences shared by the parents, seem to foster welcoming, understanding and validating experiences for parents and their children. In fact, community services are in some ways described as safe havens of support that parents can rely on, and are therefore a source of support for the parent and the child, and make both the parent and child feel understood like they belong. One of these community services is not, in fact, meant specifically for children on the spectrum or children with special needs. However, Alice found it and tailored it to her needs:

So, I like to bring [my child] here [Figure 4.5], and I like to go there myself too, and it's just a resource centre, like a little miniature library. They've got books and toys and um, we can take out five books per kid, five toys per child, you get them for three weeks. It's all free, you take them home, they can play with them, you return them and get more stuff. It's really nice because they have a nice assortment of toys. If I bring [my child], it's small and there's not a lot of kids there so [they] can play if [they want] to. The [building], it's in a [building], and it's not a busy [building] so if [my child] were to jet out of there I could get [them]. I wouldn't, I'm not too worried about [them] getting into mischief or anything. [My child] doesn't have any other kids bothering [them], [they] can do what [they] want, you know, and they've got like a lot of toys there that [they like] to play with, they've got a lot of good books, and they're friendly. And it's just a nice, it's just a nice service. Instead of going to the library, where it can get really busy and crowded and noisy and so it's a nice, it's a nice little, it's a nice little place to go with [my child].



Figure 4.5. [Organization]

Note: This is an organization in town that offers a free library and toy exchange for all children. I like bringing [my child] here because it is a small location and very few children are there at once. This allows [my child] to feel more comfortable to browse through the books and play with the toys. They have a lot of sensory toys that [my child] enjoys playing with.

In adapting this community resource to meet her needs, Alice is creating a space of inclusion for her child that also seems to provide some comfort to Alice insofar as

knowing she can create the semblance of a normal child outing in a place that is more conducive to her child's needs. Since it is a self-directed, self-serve resource, there is no waiting, facilitating access for this family. Alice performs this as part of her Navigator-Advocate role, discovering and working through community resources to fill the needs of her child.

All three of the parents touched on two community-based services that they had all accessed – one with positive experiences across the board and one with mixed reviews tending towards the negative. The first organization provides programming for both children with special needs and their parents. Based on the way the parents discuss the organization, it would appear that they go above and beyond in terms of service and support. For Snowman, this organization provides support to her child, her partner, herself and soon her child's teaching staff as well:

Right now we're going through a Secret Agent Society at [the organization]. It's a social club. I have the ABA consultants there that I've been working with for a long time. I've taken the Triple P Parenting course there and I know the facilitators quite well there. They are now coming into the school to be giving a workshop to the teachers and the SSPs, and the Principal and the Special Ed teacher are very much on board with this. [...] My husband is now taking a parenting course at [the organization] where I find that they are very helpful as well.

Snowman is not alone in this sentiment, as Alice indicates that she also finds the organization supportive and capable of meeting the needs of both her child and herself:

Yeah, we've done more just individual ABA training with a consultant and we've been doing that for a while. My [child] had trouble potty training, and [they've] only recently been potty trained, but we had a huge struggle with that. They really helped us put the planning in place and stick to the plan, so they've been really helpful with that. Everybody there is really supportive and friendly and anytime you know, I had a question or just needed to talk about something, they've been really supportive.

Sunshine Brock has also completed a parenting course with the organization.

The second community-based organization named by all of the parents is a region-wide program that provides opportunities specifically for children with autism to

get together and engage in recreation or activities while working on their social skills. The get-togethers also provide an opportunity for parents to get together and network, which provides critical insight into the system they are trying to navigate. Snowman introduced this organization during the sharing session, indicating that she liked that “[my child] likes to go there, [my child] fits in there, [my child has] made lots of friends there. [...] It’s just being with children who are similar.” (Figure 4.6) Although all of the parents agreed that this organization provides some great opportunities and that, at least for Sunshine Brock and Snowman, their kids feel like they can relate to others and fit in there (once again a community-based organization being inclusive), Sunshine Brock and Alice currently feel excluded from the programming. Alice moves the conversation in this direction during the sharing session with the sharing of the following experience

I didn't really like [this program]. I put my [child] in a couple of their programs and [my child is] 6, so [they] must have been 4 at the time, and we felt pretty excluded. I’m not sure why everybody seemed nice and friendly and they had good activities but [my child is] non-verbal and at the time [my child] was very sporadic. [They] would just do whatever [they] wanted so that could have been part of it, that [my child] didn't want to participate with the other kids. But I still, we still kind of felt a little excluded because nobody really paid attention to us. Now, I'm not sure, maybe it was just the activities we were doing or the kids were older or, it just didn't seem like a great fit at the time.

Although the parents have discussed exclusion before, this is the first time exclusion is discussed in the context of a setting that is specifically for children like there and is meant to be welcoming and inclusive of all children on the spectrum. In addition, during these discussions I sensed a greater feeling of insult and observed more guarded body language when talking about feeling excluded by this particular organization as compared to the education system, for example. Sunshine Brock, who has had a positive experience with the organization until this year, capitalizes on this discussion thread to explain another exclusionary practice the organization has:

Sunshine Brock: We've had a couple issues just this last few months with the fact that everything there's up to 12, or 16 and older or French.

Snowman: French! That drives me crazy seeing those!

Sunshine Brock: It's over 12 so [my child] can't go to that. [My child] isn't between 12 and 16, we're not a French family even though we could still register but that wouldn't do anything for us.

Alice: What's the reason for the French?

Sunshine Brock: I don't know that and I've asked. I was told there's 7 active French families – but there's 50 English, I mean 50 other families so I've been very frustrated because there's been very few opportunities that we've been able to do this last few months. I understand their leadership council changes every year and they all have different ideas, and any one of us could submit ideas on things to do, but I understand you don't want younger kids and older kids together but what about those 12-16 year olds or the English-speaking families? So we have had issues with that. Like I paid the membership fee like everyone else, and I just found that the last few months, every time I get one I'll say to my husband, "Oh there's an opportunity, oh wait that doesn't apply."

Evidently, parents are not taking kindly to feelings of exclusion, and tolerance for exclusionary practices seems to be lower among parents with regards to community-based organizations. Although there have been some negative experiences of exclusion with community-based programs, experiences at this user-provider interface tend to be more positive in nature. The positive experiences parents have had with community-based organizations like this one really highlight the differences in service provision, program availability and provider-user interactions as compared to the education and medical/health systems. From what I can gather from the insights provided by parents, community-based organizations tend to fight alongside the parents, not against the parents (in a real or perceived way) and prioritize the importance of supporting the family as a unit – a critical difference from the perspectives of the other two large systems parents identified. It is possible that it is from the support of community-based organizations and sometimes family (parent-dependent and not discussed in detail in the presentation of results) that help parents regenerate the fighting energy they have, as Snowman and Sunshine Brock put it.

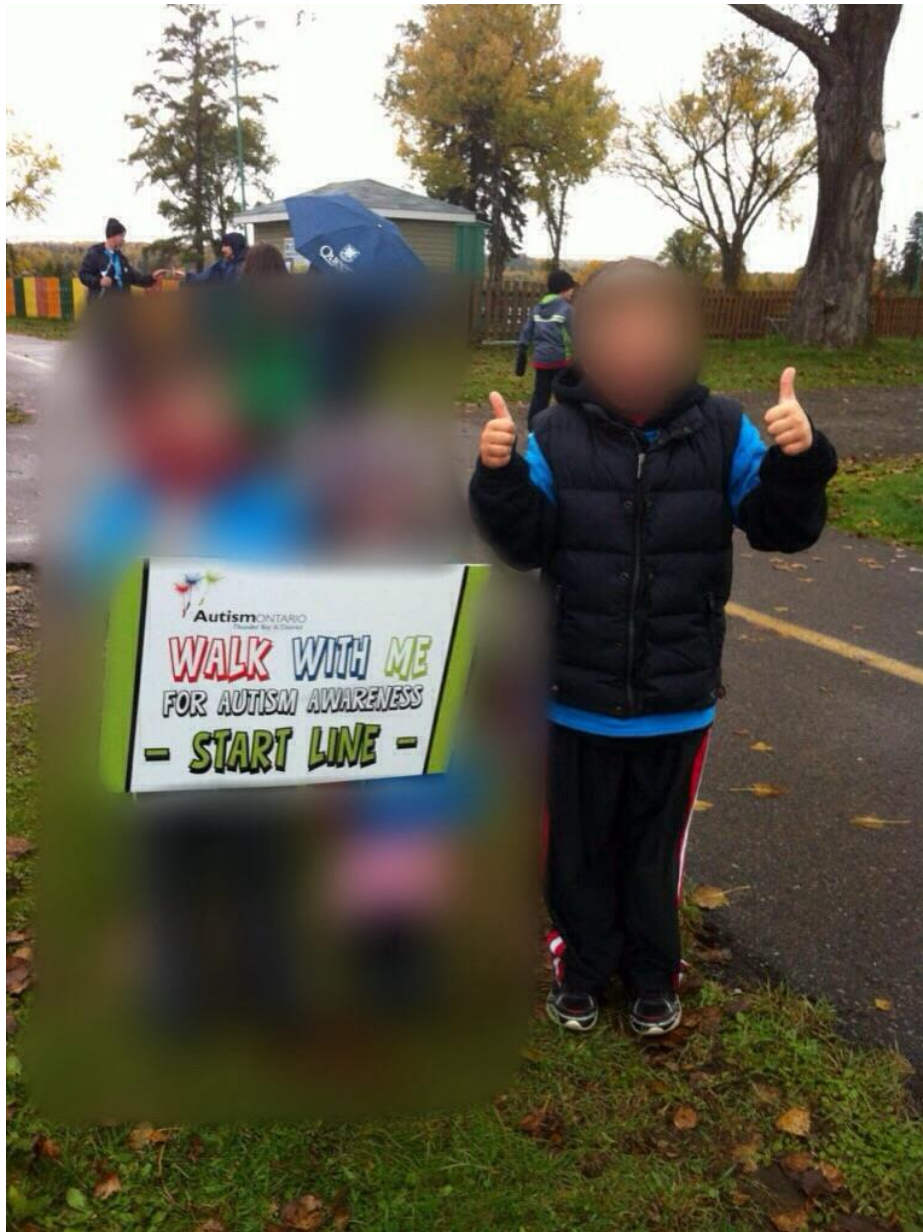


Figure 4.6. Another Autism event

Note: Happy! When with a good friend (few of those) anything can happen. Two [children] who didn't care to have a long walk were able to complete the whole 5km because their conversation kept them going. They have a common interest and can discuss nonstop.

Chapter 5. Discussion

The purpose of this research was to explore the experiences that parents raising school-aged children with autism in Northwestern Ontario had while accessing health and social services for their child. The study used Photovoice, which is grounded in feminist theory, documentary photography and Freire's notion of education for the purpose of critical consciousness as a primary means of data collection. The study also used ecomapping to supplement and guide parents through their narrations. Field notes taken throughout the sharing circle and the interviews were used to contextualize the transcripts in the data analysis process.

One sharing circle and three individual interviews were conducted with three parents during this project. In addition, three ecomaps and 36 images were produced. The themes and patterns of experiences that emerged from the data are rooted in or come directly from the experiences shared by the three participating parents.

This study is the only study known to examine parental experiences at the parent-system interface, and the only one to examine parent experiences in Northwestern Ontario. These findings describe the role adopted by parents, issues of concern to parents (adverse experiences), and areas of strength (constructive experiences). It was found that parents adopt the role of the Navigator-Advocate while raising their child along this parent-system interface. The education system was found to be of greatest concern to the parents, as was the medical system.

5.1. Reflecting on Methods

Photovoice is a very powerful research method that allows group or community members to take control into their hands. As such, this method is an excellent fit for parents who are accustomed to taking control of the lives of their child and their family

for the purpose of securing necessary support from health and social services. Parents pointed out that they had never been asked the question at the centre of this study. As a first encounter with the question, it may be easier to capture an experience with a photograph taken in the moment and then use a series of questions (the SHOWeD method) to guide the description of the experience as opposed to explaining experiences in a traditional one-on-one interview format. Asking participants to take a photograph on their own time is also less labour-intensive and time consuming than memo-ing, journaling, or other methods of recording experiences. Photovoice is, however, limited to participants' in-the-moment recognition of an experience they wish to document. Photovoice is also limited by participant self-filtering whereby they will select certain experiences to document, though this is not known to have been an issue in this study. On the contrary, because participants were so eager to show a full range of experiences beyond the scope of being able to photograph in 6 weeks' time, participants used photographs taken prior to the study (e.g. photographs from their personal collections). It was decided at the time to allow this because certain services and supports are only available or are only seen once or twice per year, and it was important to allow the parents to guide the data as much as possible.

The use of Photovoice in this project to explore this topic proved to be very successful. Photovoice is strongly rooted in building capacity and providing opportunities for empowerment to facilitate individual and social change. Given that this work focused on experiences with a system that is not working for parents and their children as is, change is required. The change required ought to be informed by user-experiences. The parents who participated in this study really embraced the opportunity to critically reflect on and theorize the strengths and concerns with the autism care system in Northwestern Ontario. Parents seemed to really like the possibility of engaging in social action at the end of the project, particularly because they noted that although they frequently perform actions to bring attention to the needs of their child, they would really like the opportunity to take it to the next level. The parents are currently in the process of planning a series of letters to key individuals in their school boards and in local and provincial politics. Although Photovoice's empowerment for change is focused on the participants and not the facilitator, I feel empowered to continue this work and take it forward in a similar

project on a larger scale to continue to collect experiences and work towards developing an integrated care model for autism care services.

Supplementing the Photovoice method with ecomapping appeared to be helpful for the parents as they worked their way through a question that they had never answered in a research context before, particularly given short length of the study. That being said, while ecomaps are a powerful, different tool for research purposes, it is possible that 6 weeks was not a sufficient amount of time to develop a nuanced map that reflected the services accessed by parents and their children as well as their experiences with them. It was also noted that in suggesting parents describe the nature of their relationship with a particular element on the map in order to probe them to speak, parents would freely share their experiences but then they would restrict themselves to a limited set of descriptors to qualify the relationships on the ecomap itself. Consequently, parents were guided back into the reductionist thinking that ecomapping seeks to avoid (Harman, 1978).

5.2. Strengths and Limitations of the Data

In spite of the great interest in the study, only three parents were able to participate. Many parents indicated that the time commitment of 6 weeks was not feasible given their schedules. Given that the study had already been reduced to a 6 week study from a 12 week study, a red flag is waved in terms of being able to successfully engage parents in multi-session qualitative research. From three parents alone one cannot reasonably expect to reach both informational and theoretical saturation in all aspects of a qualitative research project (Sandelowski, 2008). In this particular study, the concept of saturation is precarious. Given that no two children with autism are the same, and therefore rarely will two children with autism will have the same service needs, the nuances of their service experiences will differ from one child to the next. Therefore, informational saturation would be difficult to achieve on a microscopic level, since redundancy in data is not likely to occur. On a macroscopic level, informational saturation may be possible, when sufficient narratives of experiences such as needing to play the Navigator-Advocate have been heard and it can be anticipate from other parents before they even begin to share their experiences. I think

that in this respect, saturation was met in this study with regards to the role of the Navigator-Advocate. More importantly, I think that because of the thick description that resulted from the time, intensity and detail that I got out of this work, I reached theoretical saturation with regards to navigation experiences so as to name the concept of the Navigator-Advocate. I'm confident that the conceptualization and characterization of this role that I put forward will fit data on navigation experiences that have yet to be collected. Further, I think that I can use this role to explain other experiences and actions of parents as they move through the autism care system for their child.

I recognize that in order for the concept of the Navigator-Advocate to be further explored in research and adopted in practice, program designers and policy makers would need to be convinced of the credibility of the data that informs it. I maintained prolonged, deep engagement with my participants, and was continuously engaged in observation of my participants (as reflected in my field notes). I used member-checking during focus group and interview discussions, and also upon creation of the transcripts. I have received sufficient feedback from the participating parents that the data reflects what they sought to convey. Given that I engaged in reflexivity throughout the research process, I was aware of possible effects of my biases or motivations to do this work, and as such I was able to scrutinize my data analysis process to ensure that the understanding extracted from the data was as neutral as possible. Finally, because autism is only one of a multitude of conditions affecting children in early- and mid-childhood, program designers and policy makers should be assured that these results are transferable to other conditions and their associated service systems. Children with complex health conditions draw on services across systems, so it is important to understand how parents and guardians might go about negotiating access to services for their children.

5.3. Barriers to Participation

One of the most critical limitations of this study is that participation was restricted to parents whose children had been diagnosed with autistic disorder or Asperger's syndrome. School boards need a diagnosis prior to providing autism-related services to a child. MCYS requires a diagnosis to be had and an additional set of inclusion criteria to

be met to qualify for some of its programming. Those two organizations aside, a diagnosis is not necessarily needed to access some of the services that children with autism also happen to use. Therefore, the study failed to include individuals who are accessing services but whose experiences are not being captured. Another barrier to participation was time. The study was modified from its original 12-week structure to a six week structure, with one interview less, in order to accommodate parents interested in participating. Given what I have come to learn in this study about the demands on parents as they play the Navigator-Advocate role for their child, in addition to the time spent simply being a parent, it is not surprising that time was a barrier to participation. Finally, there was a self-imposed barrier to participation for some parents who did not want to participate without their partners, and their partners were unable to participate for different reasons.

However, in spite of these barriers to participation, participation was also facilitated for parents in that interviews and the sharing session were organized around their schedules, and they were able to choose the meeting location. Child care stipends were available for the Photovoice training session and the sharing session because they were going to be longer than one hour and thus likely held during the evening or weekend. As such, I determined in my planning stages that child care may be more likely to be needed during these times.

5.4. Critical Reflection

Throughout the data collection and analysis processes, I found it challenging to keep my researcher hat on as opposed to the support person hat I typically wear around parents of children with autism. Given my history of interaction and engagement with children with autism and their parents, my perception and understanding of their experiences is more intimate than that of the general population. Needing to maintain a distance from the comments or conversations parents would have casually outside of the interview and sharing session time was difficult because parents did naturally want to talk about issues related to this work, about which they were very excited. By the same token, it was critical that I remain aware of my natural tendency to empathize with parents as I read the transcripts and proceeded with data analysis. Fortunately, my field

notes were sufficiently detailed that I was able to identify where I had empathetic or emotional reactions during the interviews and sharing session. I was able to refer to these notes and really examine my coding of the text corresponding to these moments. Conversely, I think that my past experience with parents and children provided me with the cultural understanding required of facilitators by Wang & Burris (1997). I think I was better able to build a rapport with the women and ask productive follow-up questions because I was familiar with the environment that they are navigating.

Chapter 6. Conclusions

In this section, I summarize the research findings and explore their implications for policy and programming. Prior to suggesting future directions for research in this area, I discuss the extent to which the study's objectives were met and situate the study in the literature.

6.1. Summary of findings

This project finds that the experiences of parents raising school-aged children with autism in Northwestern Ontario are possibly just as varied as are children with autism. Parents take on the role of the Navigator-Advocate as a result of the fractured nature of service delivery in the region. Personal or vicarious adverse experiences with the education system leave parents concerned for their children on a day-to-day basis. Parents also report adverse experiences with medical professionals given different perspectives on the conflation between autism and behaviours influenced in whole or in part by the autism as well as approaches to management. Parents theorize that the root cause of adverse experiences is two-fold: insufficient education and insufficient interest in their particular child, the second of which relates to the idea of one person having the ability to determine a service experience. Where parents' experiences with the health and medical systems fail to meet their needs, community organizations and family support may step in to serve, when they are present and able to be accessed in a timely manner.

6.2. Extent to which the objectives were met

The objective of this exploratory project was to use visualization and narrative to elicit experiences that parents raising school-aged children with autism in Northwestern

Ontario had with the health and social services they interacted with while caring for their child. I believe that the objective of the study was met. Although the participant sample was small, this is an exploratory project that is part of a continuing research portfolio. In the context of the larger research portfolio, this project helped identify the health and social services of most and least concern to parents. The project also helped to identify and name some patterns and themes in experiences that could benefit from more in-depth exploration. From a methodological approach, this study also successfully met the primary goals of Photovoice. As reviewed in Section 3.1., Photovoice has three primary goals, the first of which is to enable participants to document and reflect on the strengths and concerns in their community. The participating parents did an excellent job of reflecting on strengths, such as family and the commitment made by certain individuals to support their child, but also on the concerns they had. When taking photographs, parents were able to capture not only strengths and concerns but strategies for navigating services and ameliorating their child's experience. Such rich data allowed participants to engage in critical conversation during the sharing session about issues they identified, meeting the second main goal of Photovoice. Finally, participants are currently engaged in creating a document to facilitate social change by influencing policy makers, meeting the third goal of the method. As such, the Photovoice component of the project was done quite successfully.

6.3. Policy and Programming Implications

Autism is not an acute condition; it is a lifelong condition that, at present, requires parents to be supported while raising a school-aged child with autism. This means that parents will interact with services and service systems habitually over a period of several years. Given the fractured nature of the autism care system at present, in order to know where to focus policy and program initiatives, it is critical that we know where parents are having access issues. Next, from the perspective of redesigning experiences, policy and program initiatives can be targeted at these areas of friction or lack of contact between service users and providers. When going about the policy and program reform process, it is critical to consult with users. My research has demonstrated the value of talking with users; having taken the time to listen and seek a deep understanding of

experiences, I have collected incredibly rich data that provides very unique insight into the autism service system. In listening to parents, this project has identified implications for three key policy domains: navigation and integration, and credentialing.

6.3.1. Integration and Navigation

Although the need for an integrated system and the need to address navigation of the system are two implications for policy in their own right, they are intricately connected and thus they are presented together. As noted in this work, parents must seek services managed by three different provincial ministries for their child with autism: autism care through the Ministry of Children and Youth Services, learning support through the Ministry of Education, and general health services through the Ministry of Health and Long-Term Care. While regions in southern Ontario may be able to overcome a fractured system simply due to the mass concentration of services and providers, Northwestern Ontario is too large and too resource poor, in terms of the resources defined as necessary under the current system, to thrive under the same model. The experiences shared by the parents were heavily centered on navigating services for their child, and needing to fight for their child, which is captured in the Navigator-Advocate role. The tasks and actions that parents report taking in these roles indicate that the Navigator-Advocate is a compensatory mechanism whereby parents fill the gaps and pitfalls in the system such as clear, logical pathways between services and communication between providers. Parents are, essentially, acting as case workers for their children, and have adopted activities that are expected of a service system. With a more integrated system, parents would not need to be the sole common link and communicator between various service providers, nor would they be delayed in accessing care because they are not sure how it is accessed or who is responsible for which service. In this way, the navigation component of the Navigator-Advocate's role would move beyond being a compensatory measure to an empowering component of caring for their child. Essentially, the navigation component of this role is currently too labour intensive, and the burden of responsibility for the navigability and accessibility of a system should not be solely that of the parent.

6.3.2. Credentialing

An alluded to above, an integrated care model for Northwestern Ontario that uses our resources in efficient, innovative ways is needed. As a general take-away, the experiences that parents have with this system informs a growing list of southern-designed and decided provincial models of care that are not developed with Northern Ontarians in mind. In keeping with the inappropriate service design and the inability to try a one-size-fits-all approach, Northern Ontario does not have the service or human resources to run or float a fractured system with gaps and duplications in service that do not make for a user-friendly experience. The lack of resources poses an availability barrier to access. Northern Ontario does not have centres like the Geneva Centre for Autism or Kerry's Place, so when families access services they are accessing services from multiple locations, which makes coordination and communication between providers difficult. In addition, the region lacks the credentialed human resources the current system needs to operate in a smoother manner. Were the region allowed to work with, for example, a non-credentialed provider system, the region may be better able to support services. By this I mean that requiring that each intake exam to begin the diagnosis process must be done by someone with at least a graduate education in psychology, or for support workers to have a Bachelor or Master's of social work is not realistic in this region. The Sioux Lookout Meno Ya Win Health Centre partnered with Confederation College to create a Maternal Infant Support Worker (MiSW) program that responds specifically to the need for trained birth attendants throughout the region's rural and remote communities. Creating programs and credentials that address a region's need would allow for greater flexibility and specificity in a care model.

6.4. Situating this work in the literature

The body of literature exploring the experiences of parents with autistic children is relatively small compared to other areas of research, even just within the confines of autism research itself (Hoogsteen & Woodgate, 2013). As such, this work adds to this small but growing body of literature. Specifically, this study offers a unique perspective to the literature in two ways. First, the work is situated in Northwestern Ontario, and it is the first study of its kind in the region. Second, there is a focus on the parent-system

interaction experiences which has not previously been teased out for specific examination.

6.5. Application of findings and directions for future research

Despite the small participant group, the findings of this study, however cautiously taken, still have tangible applications in public health. First and foremost, the experiences of parents have been recorded through the research process and are now considered part of the evidence in the literature upon which program and policy decisions can be made. Northwestern Ontario voices have begun to be heard. As is a key component of the Photovoice process, participating parents are able to exert ownership and control over their data and engage in social action using their data. Future research could use these findings to inform the development of a research tool to gather data on experiences from a larger sample of parents. Future research should also engage in further knowledge translation activities (from parents to researchers) and collaborative projects with parents to determine how the autism services system could be better informed or arranged so as to mitigate or eliminate the adverse experiences reported by parents.

In addition, exploring experiences is a critical aspect of policy and program design. Program and policy evaluation may provide information about program performance and outcomes, but fails to capture data on the journey to those outcomes for service users. Bringing back the conceptualization of access that this paper adopts (Levesque et al., 2013), user experiences mediate and are mediated by five key abilities of users in the access process, particularly as relates to the user's perception and ability to engage with the service and system. As such, insight into user experiences provides information on how users move through the access process and would help policy and program designers in their work. In addition to continuing to collect parent experiences, I would recommend that experiences are examined together with data on the policies and programs relevant to a particular set of experiences, such as the diagnosis process, for example. We could then see where the gaps and tensions along the user system

interface are. It is at these points where experience redesign would be focused through policy and program change.

The work done in this thesis highlights the value of taking the time to gain deep insight and understanding of individuals' experiences with a care system. I believe this to be of importance to program and policy makers because of the rich insight and guidance it would provide in their work. In addition, it is simply logical to include user experiences in system design under the current paradigm of patient- (or client-) centered care.

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Appendix A.

Information Sheet

Information Sheet

Title of the study: Health Service Experiences of Families Raising School-Aged Children with an Autism Spectrum Disorder in Northwestern Ontario

Principal Researcher: Brienne Olibris, Master of Public Health Candidate in the Faculty of Health Sciences. Brienne Olibris can be contacted by email at [REDACTED]

Supervisor: Dr. Malcolm Steinberg of the Faculty of Health Sciences. Dr. Steinberg can be contacted by phone at [REDACTED] or by email [REDACTED]

As a part of novel research examining the experiences of health and health service needs of families raising school-aged children with autism, we are seeking participants from Northwestern Ontario to collaborate with us for 6 weeks between October and March 2015 in a Photovoice project. This special interest is placed upon those families whose children are aged 7-12. The research in question aims to add to the growing evidence base for a shift in policy and program design, as well as to provide an opportunity for empowerment, capacity building and social change.

The research will be based off of one interview lasting approximately 60 minutes and one group sharing session lasting approximately 180 minutes. The interview questions will be largely open-ended, with an emphasis of the interviews being driven by the participant and what they feel is important to share. Question areas or topics of discussion will likely include the following:

- What are your experiences of raising a school-aged child with autism in Northwestern Ontario?

We would like to audio-record the interviews and group sharing session. Following the interviews, a verbatim transcript will be developed, the participant will have the opportunity to look it over to verify that the integrity of their words and meanings have been maintained. Upon completion of the verbatim transcript, the tapes will be erased. All transcripts will be kept securely with the rest of the research data for 7 years, beginning in April 2015. Every effort will be made to maintain the confidentiality of the interview material. Participation in this study is voluntary and will be stipended \$10 for each interview/group session. Child care for the Photovoice training session and the group sharing session may also be stipended 30\$.

Requirements for Participants

- a) Have at least one child currently aged between 4-12 years (for the duration of data collection) with a diagnosis of autistic disorder.
- b) Currently engaging with or actively attempting to gain access to pertinent social, educational, public health or medical supports.
- c) Reside and have resided in one of the following Census Canada Districts for the previous four (4) years: Thunder Bay District, Rainy River District, Kenora District.
- d) Are Canadian citizens.
- e) Speak English or French.

This information sheet is yours to keep. If you have any questions about this study or your participation, please do not hesitate to contact either the Principal Investigator or Supervisor.

Thank you for your interest in this research.

Appendix B.

Consent Form

Title of the study: Health Service Experiences of Families Raising School-Aged Children

Principal Researcher: Brienne Olibris, Master of Public Health Candidate in the Faculty of Health Sciences. Brienne Olibris can be contacted by email at [REDACTED]

Supervisor: Dr. Malcolm Steinberg of the Faculty of Health Sciences. Dr. Steinberg can be contacted by phone at [REDACTED] or by email at [REDACTED]

Sponsor: This study is being funded a Mowafaghian Child Health Practice and Research Award.

This research is being conducted under the permission of the Simon Fraser University Research Ethics Board. This Board aims to protect the rights of human research participants.

This research will form part of a Master's Thesis, which is a public document.

Invitation to Participate: You are invited to participate in the abovementioned research study conducted by Brienne Olibris, under the supervision of Dr. Malcolm Steinberg.

Purpose of the Study: The purpose of this Master's Thesis pilot study is to gain an understanding of the experience of the health and health service needs of families raising school-aged children with autism. This study seeks to elicit knowledge and understanding of experiences navigating autism services in Northwestern Ontario and their meanings to a) add to the growing evidence base for a shift in policy and program design, and b) provide an opportunity for empowerment, capacity building and social change.

Participation: Your participation will consist of one Photovoice training session (approximately 4 hours), one one-on-one interviews with the PI (approximately 1 hour), and one group sharing session with the other research participants (approximately 3 hours). The interviews have been scheduled for (place, date and time of each session). The interview and sharing group session will be audio-recorded. Following the interviews and group sharing session, once a transcript is available, you will be given the opportunity to review the transcript over a ten (10) day period to ensure that the integrity of what you aimed to divulge and convey has been maintained. You will also have the option of attending a group social at the end of the research.

Risks: Your participation in this study will entail that you volunteer your name (which will be assigned a pseudonym following the interview unless you choose otherwise), demographic information, details about your experience interacting with health supports for your family and your child with autism. This may cause you to feel identifiable or vulnerable, and may cause you to relive experiences with stressful or emotional psychological effects. You may also experience psychological and/or emotional discomfort when critiquing/evaluating the services that your family and your child receive. You have received assurance from the PI that every effort will be made to

minimize these risks by ensuring that your interview takes place in an area in which you feel comfortable and safe, by not requiring that you answer any questions with which you feel uncomfortable in doing so, and by having a counsellor available for referral. Additionally, pseudonyms will be used in the data and resulting research paper unless you choose otherwise.

Benefits: Your participation in this study will allow you to share and critically examine your experiences of navigating autism service supports, allowing your voice to be heard. You will be able to network with other families in the community and extend your personal social support system. Your participation in this study will advance knowledge and contribute to an increasing evidence base for the need to both fund research and establish effective supports for families raising school-aged children with autism. You will have the opportunity to contribute to an informational base that shapes the development of informed healthy public policy both through publications arising from the research and through knowledge translation activities you and other study participants may choose to participate in.

Confidentiality: You have received assurance from the PI that the information you share will remain strictly confidential. You understand that the contents will be used only for identifying experiences and ramifications of autism serve navigation and that your confidentiality will be protected both through the use of pseudonyms in both the data and research paper (unless you choose otherwise), storing your data separately from your name and identifying information, as well as by limiting access of identifying information to the Principal Investigator and Project Supervisor.

Conservation of Data: The data collected in the form of audio recordings, notes, transcripts, and consent forms will be kept in a secure manner through password, viral and firewall protection on the Principal Investigator's laptop, or within a locked room within the Principal Investigator's workspace. During the period of retention, a copy of everything except audio recordings will be held by the Project Supervisor on a secure drive. The data will be conserved for 7 years, beginning April 2015. The data may be used as comparison data in further research, as the Principal Investigator's PhD research will build on this project.

Voluntary Participation: You are under no obligation to participate and if you choose to participate, you can withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative consequences. If you choose to withdraw, all data gathered until the time of withdrawal will be securely deleted or shredded as is appropriate to the form in which the data is kept.

Acceptance: I, (*Name of participant*), agree to participate in the above research study conducted by Brienne Olibris of the Faculty of Health Sciences, whose research is under the supervision of Dr. Malcolm Steinberg.

If you have any questions about the study, you may contact the Principal Investigator or Project Supervisor.

If you have any questions or complaints regarding the ethical conduct of this study, your rights as a participant, or the duties of the researchers, you may contact Dr. Jeff Toward, Director, Office of Research Ethics, Simon Fraser University, Burnaby, B.C., Canada, V5A 1S6.

Tel.: [REDACTED]

Email: [REDACTED]

Appendix C

Photovoice Training Guide

(Principal Investigator's Use)

Introductions

- ❖ Nametag creation, circle introductions

Icebreaker

- ❖ Circle go-around, describe a photograph that you have found powerful and share why

Group Rules

- ❖ Allow participants to come up with whatever ground rules they deem necessary to ensure that this is a positive, productive, safer group experience for everyone
- ❖ Must include (to be added by PI if they do not arise): confidentiality, punctuality, attendance, respect, conflict resolution, sensitivities (ie scents, food allergies)

What is Photovoice?

- ❖ Open discussion on what participants' understanding of Photovoice is
- ❖ Explanation, with a worked through example from a published article, of a Photovoice project
- ❖ Explicitly describe role of participants in terms of the what and why

Themes and What is Important

- ❖ Facilitated discussion on what a theme is, how they are identified
- ❖ Allow participants to share something that is important to them related to the research topic, and guide the identification of a theme as an example

This is Your Project

- ❖ Initiate empowerment component of Photovoice by ensuring participants know that they set the direction for where the project goes (direction), and have control over: what pictures will be shown, what captions or words say, themes to be used, where pictures are shown, who gets to see the pictures
- ❖ Begin discussion on social action that comes from the collection of the data

Keeping Track of Your Experience

- ❖ Discuss means of keeping track of the experience, such as keeping journals

The Camera

- ❖ How to use it
- ❖ What can and cannot be photographed?

Consent

- ❖ How to introduce yourself (if person is unknown to you) and how to introduce the Photovoice project
- ❖ How to ask someone for permission to take their picture
- ❖ How to use the photo consent form (to be provided to participants)

Safety

- ❖ Discussion around safety in process of taking photographs (who, where, when, how)

Discussion/Debrief

Appendix D

Demographic and Baseline Information Form

Participant Information

Pseudonym: _____

Postal Code: _____

Age: _____

Occupation: _____

Circle One: Full-Time Part-Time

Number of children with autism: _____

Relationship to child(ren) with autism: _____

Partner Information (if applicable)

Name: _____

Postal Code: _____

Age: _____

Occupation: _____

Circle One Full-Time Part-Time Relationship to child(ren) with autism:

Do you parent together (circle one): Yes No

Child's Information

Age: _____

Diagnosis: _____

Age at Diagnosis: _____

Diagnosis Provided By (specific practitioner type, eg Paediatrician):

Supports/services used with relation to the diagnosis:

Does the child live with other conditions for which a diagnosis has been provided (circle one)? If yes, please name below.

Yes

No

Appendix E

Photograph Consent Form

You are invited to have your picture taken by a participant of a Master's Thesis Photovoice project documenting the experiences that families raising school-aged children with autism in Northwestern Ontario have when navigating health services. This project is funded by a Mowafaghian Child Health Practice and Research Award.

Photovoice has 3 primary goals:

- 1) Photovoice seeks to allow participants to record and reflect areas of strength and areas of improvement in their community.
- 2) Photovoice promotes critical conversation and the sharing of knowledge about important issues through photograph-based group discussion.
- 3) Photovoice aims to influence policy makers for the purpose of social change.

Pictures taken as a part of this Photovoice project will be shown to others for the purpose of creating awareness about the experiences and needs of families raising school-aged children with autism in Northwestern Ontario. This may include gallery displays, presentations or reports to stakeholders, or digital media articles. Others viewing the photographs may recognize you, but there will be no names, contact information, or other identifying information included. Photographs will not be used to make money.

By signing this form, you agree to have your photograph taken by a participant of this Master's Thesis Photovoice project, and you agree to have it shown to others for the reasons stated above.

If you would like a copy of the photograph taken of you, please include your email address below.

If you have any questions or complaints regarding the ethical conduct of this study, your rights as a participant, or the duties of the researchers, you may contact Dr. Jeff Toward, Director, Office of Research Ethics, Simon Fraser University, Burnaby, B.C., Canada, V5A 1S6.

Tel.: [REDACTED]

Email: [REDACTED]

Subject Name

Name of Photographer

Signature

Date

Email (Optional)

Appendix F

Photograph Release Form

Photovoice seeks to use photography as a means of working towards positive social change in one's community. One way of doing so is to make people with decision-making power more aware of experiences and needs of families in Northwestern Ontario who are raising school-aged children with an Autism Spectrum Disorder. Pictures taken in this Photovoice project may be shown in gallery displays, public shows, presentations to stakeholders, or digital mediums.

Do you permit to have your photographs used in public displays regarding *Health Service Experiences of Families Raising School-Aged Children with an Autism Spectrum Disorder*?

Yes

No

Do you permit to have your photograph used in public dissemination (such as thesis papers and conference presentations) directly related to this research project?

Yes

No

Do you want your research name (your pseudonym, unless otherwise chosen) listed as the photographer?

Yes

No

Please include any concerns:

Remember, you are free to change your mind at any time. If you change your mind, please let Brienne Olibris know.

Name of Photographer/Participant

Signature

Date

Appendix G

Confidentiality Agreement

It is understood and agreed to that the participants in the Master's Thesis study *Health Service Experiences of Families Raising School-Aged Children with an Autism Spectrum Disorder* in Northwestern Ontario may provide certain information that is and must remain confidential. To ensure that this information is protected, and to preserve any necessary confidentiality, it is agreed that

1. The Confidential Information to be disclosed can be described as and includes:
 - a) Names of other participants, their spouses/partners and their children, and any other identifying information (including, but not limited to workplace, area of residence and child(ren)'s school(s))
 - b) Diagnoses and health status information of participants and their children, as well as their healthcare/educational/social support providers
 - c) Stories, experiences and sensitive material shared in the safety and confidence of the study group unless explicitly given permission otherwise
2. The undersigned agrees to not disclose such confidential information to anyone unless required to do so by law.
3. If any of the components of this Agreement are found to be unenforceable, the rest shall be enforced as fully as possible and those deemed unenforceable shall be modified as minimally as permits full enforcement of the Agreement.

By signing this Confidentiality Agreement, you agree to voluntarily uphold the confidentiality and privacy of the above-stated material.

_____	_____
Name of Participant (Print)	Signature of Participant

Date	
_____	_____
Name of Principal Investigator	Signature of Principal Investigator
<u>(Date)</u>	