MAAWANDOONAN: EARLY CHILDHOOD DISABILITY SUPPORT SERVICES IN

CONSTANCE LAKE FIRST NATION

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ABSTRACT

Maawandoonan: Early Childhood Disability Support Systems in Constance Lake First Nation

Master of Arts, 2017

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This paper details an institutional ethnography conducted in Constance Lake First Nation, a rural Oji-Cree community in northern Ontario, Canada. The study is a part of a larger project called the Inclusive Early Childhood Service System Project, which is partnered with several municipalities and service organizations in four communities across Ontario. The current project examined six family narratives of accessing disability support services for young children. The project seeks to understand how the service system functions from the perspective of families, and the impact of institutional interactions on families within the service system. Employing critical disability theory and Indigenous perspectives of child development, the study seeks to develop a culturally-based conceptualization of disability support for Indigenous children with disabilities or gifts.

ACKNOWLEDGMENTS

DEDICATION

I would like to dedicate this work to Nookumis (my great grandmother) Hattie Ineese. She was

the first person I ever visited in Constance Lake when I was a child. Even though we only met a

few times and spoke different languages, she somehow always made me feel that I was where I

was supposed to be; that I belonged to a greater web of relations. It is this sense of purpose that

has lead me along the path I am now on. I hope to continue this journey in ways that honour all

my relations; past, present, and future.

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Introduction

This research paper describes a qualitative study conducted in Constance Lake First Nation, an Oji-Cree community in northern Ontario. The study seeks to understand families' experiences of accessing various support services for their child who has a disability. Through semi-structured interviews, this work seeks to understand the ways in which families access the services available to them and the impact these interactions have on families and their children. This work also seeks to develop a conceptual understanding of disability from an Indigenous perspective, grounded in the community's perspectives and Indigenous worldview. The study is part of a larger project that is a partnership with three Indigenous early years service agencies and a guiding Indigenous Elder's council. Community members from Constance Lake were also consulted in the interpretation of the results. Indigenous perspectives, as well as decolonization literature and critical disability theory lay the theoretical foundation and inform the project overall.

Personal Location

Aanii, boozhoo, tanisi. Anishnaabe kwe. Nicole nindizhnikaaz. Constance Lake indojeba.

My name is Nicole. I am an Ojibway, Cree, and French woman whose lineage comes from Constance Lake First Nation, along the English River and the Albany Band in Ontario, Canada. I also have family ties in Europe, of which I am less familiar. Although I have never lived in Constance Lake, it is home to my bloodline, and therefore, a home of sorts for me. I was raised in Toronto by my mother, an Oji-Cree woman with an infectious laugh and endless stories which were my first teachings. I write this now as a graduate student of early childhood studies, yet my educational path has shifted from academics back into the cultural knowledge of my

family, my community, and my ancestors. I am honoured to carry this ancestral wisdom with me and have gained a deeper understanding of myself by reconnecting with my community through this project.

I begin this paper with these purposeful words of introduction for several reasons. First, it is my belief that research is a personal process; to understand one's work, we must also have an understanding of our relationship to it. Second, this project is of particular personal interest to me as it takes place in my home community of Constance Lake First Nation, of which I am a registered band member. Lastly, and certainly not of least importance, I seek in my work to honour Indigenous epistemologies of relationship and interconnectedness (Kovach, 2010). It is from this relational standpoint that I seek to understand the experiences of the families who have shared their stories with me.

Theoretical Frameworks

Indigenous Research Framework

The term Indigenous is used in this paper to refer to First Nations, Metis, and Inuit peoples of Turtle Island (North America), while also recognizing the global significance of the word. The use of this terminology is purposeful in that it is intended to align with Indigenous rights frameworks (see United Nations General Assembly, 2007) and to honour Indigenous sovereignty on the politicized lands in which this work takes place; a more thorough description of which will take place in a subsequent section.

Indigenous research is a spiritual practice that is grounded in the sharing of traditional knowledge (Kovach, 2010; Wilson, 2001). Knowledge is understood to have shared meaning which cannot be separated from the relational contexts in which human and non-human entities live (Haig-Brown, 2008). Relationship from an Indigenous research perspective does not only

refer to human interactions. Rather Indigenous worldviews generally make connections between all things and see phenomena occurring in the present as inextricable from the past and future (Battiste, 2011). Indigenous research seeks to develop holistic understandings of the relational world, which is sometimes represented in the form of a circle or wheel (see Lee, 2006 for a more thorough explanation of the Cree Medicine Wheel).

Indigenous knowledge is uncovered, rather than constructed, through empirical observation, traditional teachings, and revelation (Brant-Castellano, 2000). Indigenous research is conducted in ways that value traditional protocol and see Elders as fundamental knowledge keepers in their communities (Kovach, 2010; Lavallée, 2009). Indigenous research invites spirit into the data collection process through culturally based knowledge sharing methods, such as sharing circles or story telling (Lavallée, 2009). While the researcher is not at the centre of this sharing, the relationship between the researcher and the participants is paramount to ensuring the research is done in a good way (Kovach, 2010). The First Nations principles of ownership, control, access, and possession (OCAP) can help to ensure research is conducted in an ethically responsible manner and that relationships between researcher and community are based on reciprocity and respect, which are important concepts in Indigenous communities (Castellano, 2004). Regardless of what method is used, research with Indigenous populations should be informed by Indigenous values and belief systems rather than centering Euro-western knowledge as the normative measure of truth (Battiste, 2011). Indigenous research embodies tradition and cultural practice from the outset, honouring stories as central to the transmission of intergenerational knowledge (Chilisa, 2011; Kovach, 2010).

The larger project was particularly engaged with Indigenous partners through each stage of the study. The District of Temiskaming's Elders council (hereby refered to as the Elders

council) informed how the research was conducted with Indigenous families and the analysis of their experiences. This was done through ongoing meetings which invited cultural practice into the research process. The present study did not specifically engage in the cultural practices involved with Indigenous research in the data collection process. However, it was informed by the analytical meetings and ongoing relationships with Indigenous Elders established within the larger project. Indigenous beliefs are central to the participants' experiences and to the project overall. As an Indigenous researcher, I engage in work from a particular worldview that is based on my pluri-cultural teachings and experiences. In this project, Indigenous knowledge is foundational to understanding developmental differences in early childhood, which serves to better understand institutional responses to disabled Indigenous children. Engaging with Indigenous service providers in several communities, as well as the Elder's council as part of the larger project, allowed for the centering of Indigenous conceptualizations of children and disability rather than dominant perspectives of normative child development.

Indigenous research generally has a particular focus on Indigenous resurgence and decolonization (Battiste, 2011). All people in Canada are impacted by colonial structures that permeate society (Viruru, 2005). Colonialism has specific ongoing implications for the overall health and wellbeing of Indigenous peoples, which can in fact contribute to disablement and impact healing mechanisms (Lavallee & Poole, 2010). Being Indigenous can be disabling; as many Indigenous communities are directly harmed and isolated through colonial practices (Czyzewski, 2011; Hollinsworth, 2013). For instance, many First Nation communities in Ontario do not have access to clean water due to resource extraction developments, enduring significant health impacts as a result (Human Rights Watch, 2016). Indigenous peoples in Canada have also suffered great harms to their spirit, due to colonial tactics of assimilation, such as the residential

school system, Sixties Scoop, and presently the mass relocation of Indigenous children through the child welfare system (McKenzie, Varcoe, Browne, & Day, 2016). These exercises have disrupted traditional ways of life and methods of ceremonial healing (Ross, 2014). Many communities today are revitalizing their spiritual practices, though these healing mechanisms are largely discounted within the broader health system (Robbins & Dewar, 2011).

Physical, emotional, mental, and spiritual violence continues against Indigenous peoples in Canada, on both an interpersonal and systemic level (Robbins & Dewar, 2011). Decolonizing perspectives seek not only to expose these implicit power structures, but also take action to remove them through reinstating Indigenous control over Indigenous futurity (Tuck & Yang, 2012). This requires a thoughtful consideration of the relationships between governments and Indigenous populations that have been largely based on material ownership and control (Palmater, 2014; Tuck & Yang, 2012). By honouring cultural knowledge throughout this project, I seek to in a small way decolonize my own academic processes and advocate for Indigenous self-determination in matters that affect their communities.

Critical Disability Theory (CDT)

Disability is not a concept that is prominent in Indigenous discourse, as many feel that each member of the community has something to offer and has value in community life (Durst, 2006). This project seeks to develop a conceptual understanding of disability from an Indigenous perspective, which is largely absent from disability discourses. Critical disability theory (CDT) offers a relationally based definition of disability that may be consistent with Indigenous cultural values of community inclusion. CDT aligns with a social model of disability, seeing disablement as an evolving social construct that is characterized as a relationship between a person with an impairment, and the attitudinal and physical environment around them (Hosking, 2008).

Disability cannot be understood without a consideration of intersectional oppressions which can occur on the basis of social factors such as race or class (Goodley, 2013). CDT explores how policies and laws impact individuals with disabilities and how universal assumptions underlie regulatory bodies within society (Hosking, 2008). Within the context of this work, CDT offers a critique of neoliberal suppositions of child development and uncovers the colonial forces that contribute to the discrimination of Indigenous children in a particular context.

Difference is a natural phenomenon that Indigenous peoples have recognized from time immemorial. Rather than subscribing to the idea of disability as a hindrance, Indigenous peoples understand uniqueness as a strength to their communities (Battiste & Youngblood, 2000). In the context of this work, disability is understood as a structural response to individuals with distinct ways of navigating the world. Indigenous children are often labeled as disabled within mainstream institutions due to their different ways of learning and expressing their knowledge that are disharmonious with Euro-western knowledge systems (Ball & Pence, 2006). In this way, Indigeneity is pathologized as a disability from the outset, which can discount the experience of difference within a cultural group. Traditionally Indigenous communities functioned in ways that ensured all members were able to participate. However, colonial society has created barriers for all Indigenous peoples, especially those with unique gifts or developmental differences (Battiste & Youngblood, 2000).

From a CDT perspective, disability is contextual and influenced by societal conditions that either allow or hinder particular bodies to participate (Connor, Ferri & Annamma, 2013). CDT seeks to understand the distinct experience of disability while also considering the social disablement of marginalized peoples generally (Lee, 2006). CDT therefore serves to understand the disablement of Indigenous children as a colonial practice based on both cultural and

developmental difference. In the context of this work, the term disabled is used to reflect the institutional processes that exclude certain people rather than an internal characteristic of an individual; differences and gifts are used to refer to unique characteristics that are reflective of a cultural perspective of individual identity.

Literature Review

The early childhood education and care sector in Canada provides a variety of services to young children and their families, such as family support services, childcare, and early childhood education programs (Friendly, Grady, Macdonald & Forer, 2015). These programs vary in pedagogical models and approaches but share the common goal of supporting children and families in the early years of a child's life in order to promote optimal outcomes (Kamerman, 2000). Children who are identified as disabled or having a developmental concern in early childhood are sometimes also referred to intervention services such as speech and language supports, behavioural intervention, or various therapies (Underwood, 2012). Indigenous children with differences and gifts navigate these multiple social programs alongside other children (Durst et al., 2001), although Indigenous perspectives of development are largely overlooked within these settings (Ball, 2012). Disabled Indigenous children can be significantly marginalized through the intersection of multiple oppressions, such as racism, ableism, and poverty, among others (Durst et al., 2001). This can lead to social isolation, poor health outcomes, and a variety of other negative health impacts (Lavalleé & Poole, 2009). Considering that Indigenous children are identified as having a disability at two to three times the rate of the non-Indigenous population (Durst, 2006; Hanvey, 2002), there is a need to consider how early childhood and intervention systems can better support Indigenous families, and work in ways that are consistent with Indigenous values.

The Settler-Colonial Context

Constance Lake First Nation is an Oji-Cree community in northern Ontario, with an on-reserve population of approximately 820 residents (Constance Lake First Nation, n.d.). The community is a federally recognized reserve under Treaty 9, an agreement between the Canadian government and First Nation band governments in the James Bay area (Long, 1989). The treaty outlines the cessation of lands from Indigenous communities across Ontario in exchange for annuities and the provision of particular social supports (Morrison, 1986). The treaty also designates reserve lands on which Indigenous peoples are to reside (Long, 1989). Indigenous leaders entered treaty agreements in the spirit of sharing the lands with colonists, but they were not always made aware of what the treaty would actually entail (Long, 2006). These early Indigenous-settler interactions have laid the foundation for the current socio-political context in Constance Lake.

Canada is a settler-colonial state (Alfred & Corntassel, 2005; Sharma & Wright, 2008). Settler-colonialism differs from other forms of colonization, in that its intention is to eliminate the Indigenous population in order to claim land and resources (Wolfe, 2006). Not only is land appropriated and often stolen from Indigenous peoples, but Indigenous communities are and have been forcibly relocated and persecuted for practicing their traditional ways of life (Tuck & Yang, 2012; Wolfe, 2006). Indigenous children were taken from their communities through the residential school system, which had the explicit goal of "killing the Indian within the child" (Nagy & Sehdev, 2012, p. 67), in order to assimilate them into the dominant colonial society. This is now recognized as an act of genocide against the Indigenous populations of North America (Nagy & Sehdev, 2012; Wolfe, 2006). The colonial process of mass child apprehension continues to significantly impact Indigenous communities through the maintenance of hostile

relationships based on racial violence (McKenzie, Varcoe, Browne, & Day, 2016). Colonial

structures permeate through other social institutions as well, such as social services and

educational settings, as they maintain a standard of childrearing and development that is based

on imperialistic assumptions and ideals (Ball, 2012). The public education system for instance,

values particular knowledge and projects it through public policy and mass exposure (Battiste,

1998). Education in Canada teaches European languages, cultures, and values, which colonizes

not only the lands, but also the minds of Indigenous peoples (Battiste, 1998; Battiste & Barman,

1995; Neegan, 2005).

Indigeneity, Disability, & Neoliberalism

Many social institutions hold medical rather than relational perceptions of impairment

and seek to improve developmental outcomes for individuals to contribute to society (Durst,

2006; Parker Harris, Owen, & Gould, 2012). Services operating from this perspective align with

neoliberal conceptualizations of societal participation, based on individual contribution to the

economy (Parker Harris, Owen, & Gould, 2012). Disabled people are encouraged to participate

in the labour market, yet there are few mechanisms available for them to do so (Parker Harris,

Owen, & Gould, 2012). Societal disablement occurs when an individual is unable to produce and

consume within the context of the consumerist market (Kumar, Sonpal, & Hiranandani, 2012).

Neoliberalism generally subscribes to the idea that all individuals are responsible to provide for

themselves and contribute to the larger community (Altamirano-Jimnez, 2013). Yet, this is a

cultural ideal that may not apply to all societies. Further, neoliberal discourses suggest that all

peoples have equal opportunity to achieve financial independence (Springer, 2011). However,

this is not the case for all populations, as the postcolonial market positions certain citizens above

others (Greensmith, 2012; Springer, 2011). Indigenous peoples, like disabled people, are often

pathologized by their perceived differences in participating in the economic system, and are therefore devalued within society at large (Altamirano-Jimnez, 2013). Colonization, structural violence, and racism can therefore constitute disablement for Indigenous peoples regardless of individual impairment (Hollinsworth, 2013).

Traditionally, Indigenous communities operated in ways that differ from neoliberal structures, which may have been less disabling for those who are not able to contribute on an economic basis (Corntassel, 2012). Community membership from an Indigenous perspective is based on relational networks that prioritize the welfare of all members (Battiste, M., & Youngblood, 2000). The agenda of capitalism conflicts with Indigenous community values, which allow for each member to contribute in their own unique ways (Kuokkanen, 2011). Traditional Indigenous economies are also centred on living on and with the land, which has largely been disrupted for Indigenous populations (Kuokkanen, 2011). Indigenous people have been hindered from economic participation in modern society through the regulation of their traditional means of trade (Tully, 2000). Restrictions on hunting and trapping for instance, resulted in dependence on social assistance for many First Nation communities (Kuokkanen, 2011).

Indigenous Frameworks of Wellness

In order to reframe Indigenous disability away from medical pathology, we can look to Indigenous theories of wellness. For many Indigenous communities, wellness is seen as an intricate balance between the physical, emotional, mental, and spiritual realms (Ross, 2014). In order for an individual to be well, they must be well in all areas simultaneously (Robbins & Dewar, 2011). Indigenous communities do not often consider someone disabled by a particular condition (Senier, 2013). Traditionally, if an individual had difficulties navigating independently,

other community members would ensure that they were able to participate within the community (Durst et al., 2001). Individual differences are seen as gifts from the Creator that have been given for a particular reason (Alberta Education, 2005). Disability is therefore not an individual trait. When a person is unwell or is unable to live Mino-bimaadiziwin (the good life), it is because they are out of balance with the spiritual, emotional, mental, or physical realms (Lavallée, 2008). Restoring balance and healing occurs over time in a manner that takes into account the whole person as well as their web of relations to the people and non-human entities in their lives (Portman & Garrett, 2006; Ross, 2014). Holistic models of wellness have been integrated into other treatment settings for Indigenous populations, such as mental health services (Lavallee, & Poole, 2010), but culturally based disability support has yet to be integrated into service systems.

Purpose and Research Questions

The purpose of this project is to understand family experiences of navigating support services for their children who have been identified as having a disability or developmental concerns by professionals or family members. In examining the institutional interactions of families in Constance Lake First Nation, this project seeks to answer the following questions: (1) Which processes enable the service system to function for families in northern Ontario? (2) How are children and families impacted by their interactions with service systems? And (3) how are Indigenous understandings of development and disability positioned within the support service system?

This project seeks to answer these questions by examining the system level structures families engage with, through the lens of institutional ethnography. Institutional ethnography as a methodology, seeks to make visible the everyday processes that occur between individuals and institutions (Smith, 2006). Institutions in the context of institutional ethnography can refer to not

only to physical establishments, but also the larger system in which establishments exist. Institutional ethnography is interested in exploring the processes of organizations, government structures, and society at large to understand how institutions function at the individual level (Smith, 2006). The interactions between societal structures such as these, are governed by what is known in institutional ethnography as ruling relations (Smith, 2005). Society, as a conglomerate of a myriad of social institutions, is organized through a structure of power relationships (Smith, 2005). Individuals inherently formulate ruling relations through discourse, and are impacted through the social relations that occur within institutional interactions (Campbell, 1998).

Methods

This study is part of the Inclusive Early Childhood Service Systems project (IECSS) which is a longitudinal study seeking to understand family experiences of institutional interactions in the context of having young children with disabilities (see inclusiveearlychildhood.ca). The project is comprised of a large research team, who aided in the design of the interview guide and questionnaire measures. The project was developed in partnership with four municipalities: The District of Temiskaming, Wellington County, City of Toronto, and the City of Hamilton; as well as three Indigenous organisations (Temiskaming Native Women's Support Group, Niwasa Aboriginal Education Programs, and Native Child and Family Services of Toronto). The Indigenous partner organisations have also deferred to the Elder's Council who have acted in an advisory capacity in the design, implementation, and analysis of the project data.

An amendment to the ethics proposal for the IECSS project was made in May of 2016, adding Constance Lake First Nation as a fifth community in the second year of the study. This

community offers an on-reserve, rural, First Nation perspective to the study. As a band member of Constance Lake, I have personal connections to the community that enabled me to engage participants in a unique way. Being a band member allowed me to go in and out of the community freely, which had particular implications for how I was able to recruit and have relationships with both participants and service providers. These relationships also came with responsibilities which have implication for the dissemination of the results. The purpose of this document is to speak to the experiences specific to Constance Lake First Nation, while acknowledging the larger project as fundamental to the understanding of the participants' experiences in this community.

Research Study

As an institutional ethnography, this study seeks to examine the relationships families have with service providers and the impact of those relationships on their lives. This is done through the mapping of families' service interactions and analysis of how the overall system functions from the families' perspectives. Institutional ethnography as an approach to research, is one way to bridge the contentious space between Indigenous and Euro-Western ideologies, through the exposure of underlying structures within human interactions (Brown & Strega, 2005). Shifting the focus from the individual toward the institution can serve as a means to understand the experiences of particular populations without further marginalizing them (Brown & Strega, 2005; Smith, 2005). Of particular interest to this work, is making visible the colonial structure in which services operate, and the impact this can have for First Nations children and their families. Institutional ethnography has been used alongside Indigenous methodologies to explore the narrative of institutions that normalize colonialism and preserve power dynamics in settler-colonial contexts (see Restoule, et al., 2013). Seeing phenomenon as relational and

connected to a broader context from an institutional ethnography standpoint, aligns with

Indigenous ways of knowing and understanding (Battiste, 2011). Institutional ethnography in this

study therefore serves as a vehicle to explore the social phenomena experienced by families,

whereas Indigenous ontologies serve as the perspective from which these experiences are

analyzed.

In order to answer the research questions, interviews with families were conducted and

analyzed using a mixed-method design which was approved by three university ethics boards:

Ryerson University, McMaster University, and the University of Guelph. The IECSS research

team, composed of experts in child development, disability theory, inclusion theory, early

childhood education and care, and research with Indigenous communities, developed the

interview (IECSS, 2014). Extensive community consultations were also part of the development

stage of the project.

Procedure

Interviews conducted in Constance Lake, followed the IECSS study protocol. Two

community visits occurred during the summer of 2016. The first trip, in July, focused on

consultation with community leadership and service providers, in order to develop relationships

prior to data collection. A follow-up meeting with community stakeholders was suggested at that

time in order to disseminate the results. While this meeting is not included in the study, it will

happen following the submission of this work. The second community visit took place in August,

where community partnerships were further developed and the majority of interviews took place.

Two community members acted as community facilitators, aiding in the recruitment and

scheduling of participant interviews and community meetings. Over the course of the two visits,

four community stakeholders were consulted; the Chief, the health director, the family resource

coordinator, and director of child and family services in the community. Participants were asked to participate in a two-hour interview in locations of their choosing. They were offered a $30 gift card for their participation, provided by the IECSS project. The interviews were audio recorded then transcribed verbatim.

Recruitment

Participants were recruited through a community Facebook page, using flyers posted at various locations, and through personal referrals through community facilitators. Families who were asked to participate had children between the ages of 2 and 6 who had experiences interacting with resource consultants, Autism support services, speech and language services, behavior supports, physical therapists, mental health services, occupational therapists, Aboriginal supports, or other services related to the development of their child (see Appendix A for recruitment flyer).

Participants

There are 67 participants in the larger IECSS study, 21 of whom identify as First Nations or Métis, 6 of whom were from Constance Lake. In Constance Lake, there are four mothers, one father, and one adoptive grandparent who are study participants. All participants have had interactions with service providers in Constance Lake and have lived in the community for over five years. One participant moved outside of the community but visits often and has relationships with service providers in Constance Lake. All participants are of Oji-Cree, Ojibway, or Cree ancestry and identify as Aboriginal on the demographic questionnaire.

The children in the study ranged from 3 to 10 years of age at the time of the interviews. The eldest child in the study was outside of the recruitment criteria age, but was included due to the nature of interactions with services in the early years of the child's life. This parent was also

beginning the process of accessing supports for her younger children and was therefore invited to

share the experience of navigating the service system for multiple children. Five of the six

children live in Constance Lake, and the other accessed early childhood services in the

community but has moved to North Bay. All children in the study have siblings and are being

raised in homes along with other children. Four of the six children have received formal

diagnoses and the other two are accessing supports identified in educational settings.

Data Collection Tools

The data collection procedure has two components: a semi-structured interview and a

programs and services questionnaire (see Appendix B and C). The interview asks families

general questions about the child, their development, and the services the child is interacting

with. Participants are also asked about their family circumstances (such as family composition

and cultural practices), routines, and perspectives regarding their child's disability. The service

check-list provides a list of support services relating to disability, early childhood and family

support, as well as community and cultural programs a family may be accessing. The check-list

quantifies service interactions families describe in the open-ended portion of the interview and

provides a detailed record that is consistent between participants. The questionnaire consists of

two standardized tools, the family outcomes survey (Bailey, et al., 2011) and the measure of

processes of care (King, Rosenbaum, & King, 1995). A demographic questionnaire derived from

the Kindergarten Parent Survey, and the Toronto District School Board parent and student census

(Yau, 2012) is also collected during the interview. This is the interview protocol for all

participants in the larger study. The quantitative measures are not part of the analysis in this

component of the project. The focus on family narratives aligns with Indigenous methods of

knowledge sharing, and allows for self-directed as well as guided responses from participants.

As part of the larger project, these families will be asked to continue being interviewed annually

for three years, which will yield longitudinal data of service interactions over time.

Data Analysis Procedure

The transcripts were read in full to identify emergent themes from the interviews

individually, and then across the group. They were then coded using NVivo software through an

iterative process. The coding identifies institutional processes experienced by children and

families, and emergent concepts relating to institutional interactions (see Appendix D for coding

frequency). This particular method is used within the larger project to organize institutional

information used in service pathway mapping. Service pathway maps are created to visually

display participants' lived experiences with service providers (see Findings). From an

institutional ethnography perspective, mapping social relationships can provide tangible

representation of ruling relations inherent in institutional interactions (Campbell & Gregor,

2002). The examination of human and non-human relations aligns with Indigenous ontologies of

post-humanistic relationships (Watson & Huntington, 2008). That is to say that Indigenous

peoples see value in understanding the non-human actors within everyday circumstances that

impact human experience (Nxumalo & Cedillo, 2017).

Thematic analysis is not an Indigenous method of data analysis per say, but it can be

useful in integrating Indigenous ontologies into Western research paradigms (Kovach, 2010).

Service maps were examined alongside themes to capture participants' overall experience of

raising their children while interacting with institutions. These analytic strategies in conjunction

with holistic examinations of each participant's narrative, allowed for contextually grounded and

relationally based understandings of families' experiences, which may more closely align with

Indigenous research processes (Kovach, 2010). This is often referred to as a two-eyed seeing

approach (Iwama, Marshall, Marshall, & Bartlett, 2009), and reflects the position I hold as an

Indigenous researcher in this project, who is navigating in a type of 'middle place' between the

academy and the community.

Findings

The data is organized into two sections: service pathway mapping, and thematic analysis.

While they are presented here as two distinct organization methods, both inform the other. The

service maps are used here to contextualize each individual service pathway where the thematic

analysis allows for an understanding of the experiences of the cohort as a whole. The stories are

woven throughout to honour the voices of the participants in the study.

Service Pathway Maps

The larger project uses service mapping to illustrate the processes and relations families

have with agencies, programs, and professionals. The maps also show the timeline involved with

accessing particular services. The maps represent each narrative as a distinct experience, while

also showing similarities between families' experiences. The protocol for the mapping was

designed in the IECSS project and follows a legend to denote different items in the institutional

interaction. Diamonds are used to represent service agencies, squares represent particular

programs, circles represent people, and triangles represent important time points in the story.

Lines are also used to show affiliation between agencies, programs, and people. Arrows are used

to represent a referral.

The maps are depicted below through the institutional interactions families described.

The intent is to de-center the family and child in order to understand the service system. From a

CDT perspective, this allows for the understanding of disablement to be focused on the

structures that create disability, rather than on individual characteristics. That being said,

diagnostic information is included in the map, as these hold significant implications in navigating

the service system. It is also worth noting that the maps are not an exhaustive list of every

institutional interaction families have, but represent the pathway families described in relation to

their child.

CL001
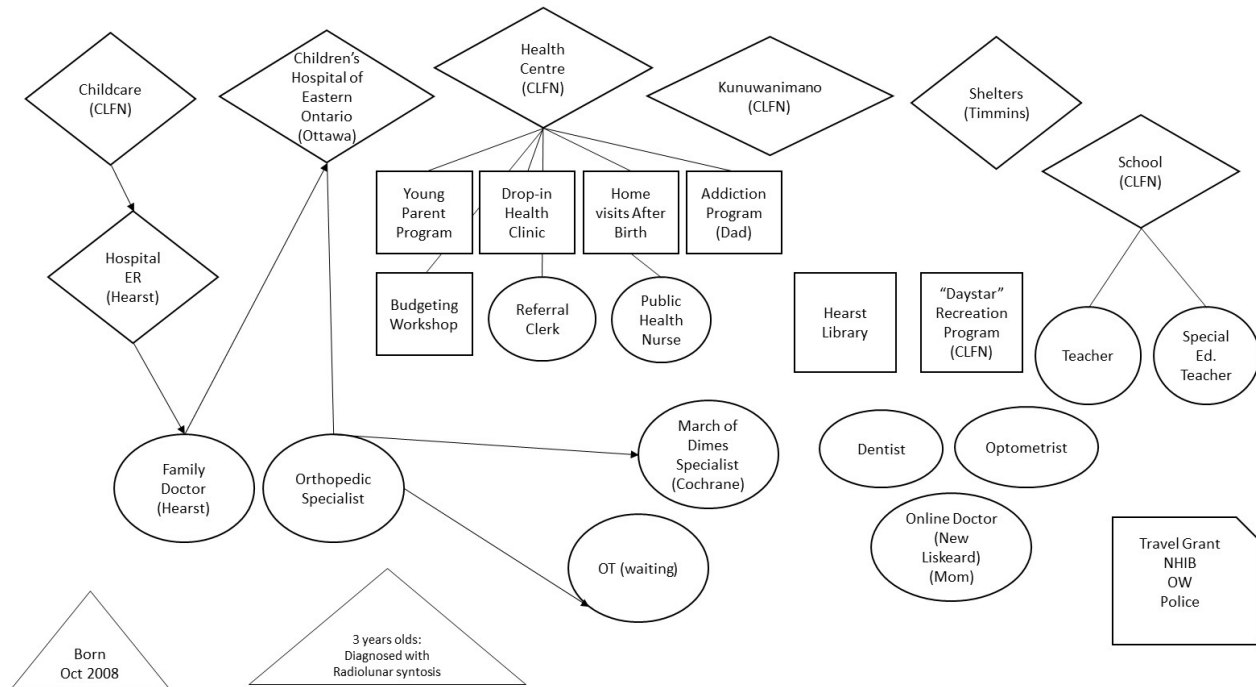
The child entered the service system through the community daycare. The childcare

worker identified a developmental concern and suggested the family go to the hospital in the

nearby town. The family went to the emergency room where some testing was done, and were

then referred to their family doctor. The family doctor then referred the family to Children's

Hospital of Eastern Ontario (CHEO) in Ottawa, where they saw an orthopedic specialist. The

specialist prescribed a diagnosis and consulted the family about surgical interventions. They

were then referred to another specialist from March of Dimes in Cochrane. Parents requested a

referral to an occupational therapist, and had an intake call with a service agency in Timmins but

had not yet received the service. The family was also involved in family support programs in
community and nearby town.

CL002
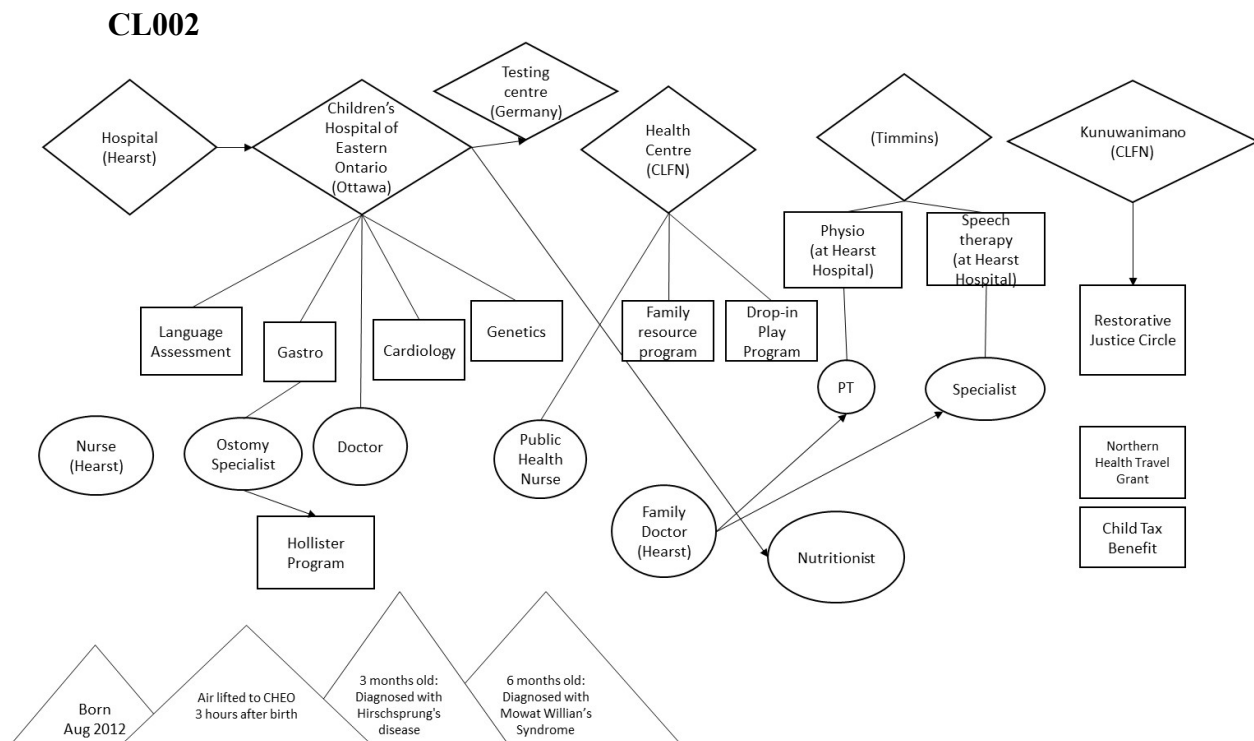
The child was born at the hospital near the community. The family doctor who delivered
identified significant concerns after birth and referred the family to CHEO. The mother was air
lifted from Hearst to Ottawa, where the child spent three months undergoing various procedures
and tests. These included geneticists, cardiologists, ostomy specialists and a doctor specializing
in the condition. The child was diagnosed at three months while in the hospital, at which point
the family was discharged. The family maintained regular check-ups at CHEO, and with the
family doctor, who referred them to a specialist and physical therapist. At six months, the child
received a secondary diagnosis from the specialist. The child accessed a nutritionist and speech
therapy at the hospital in Hearst on a weekly basis. The family accessed funding programs

related to travel and medical supplies. They also engaged with family support programs within the community.

CL003
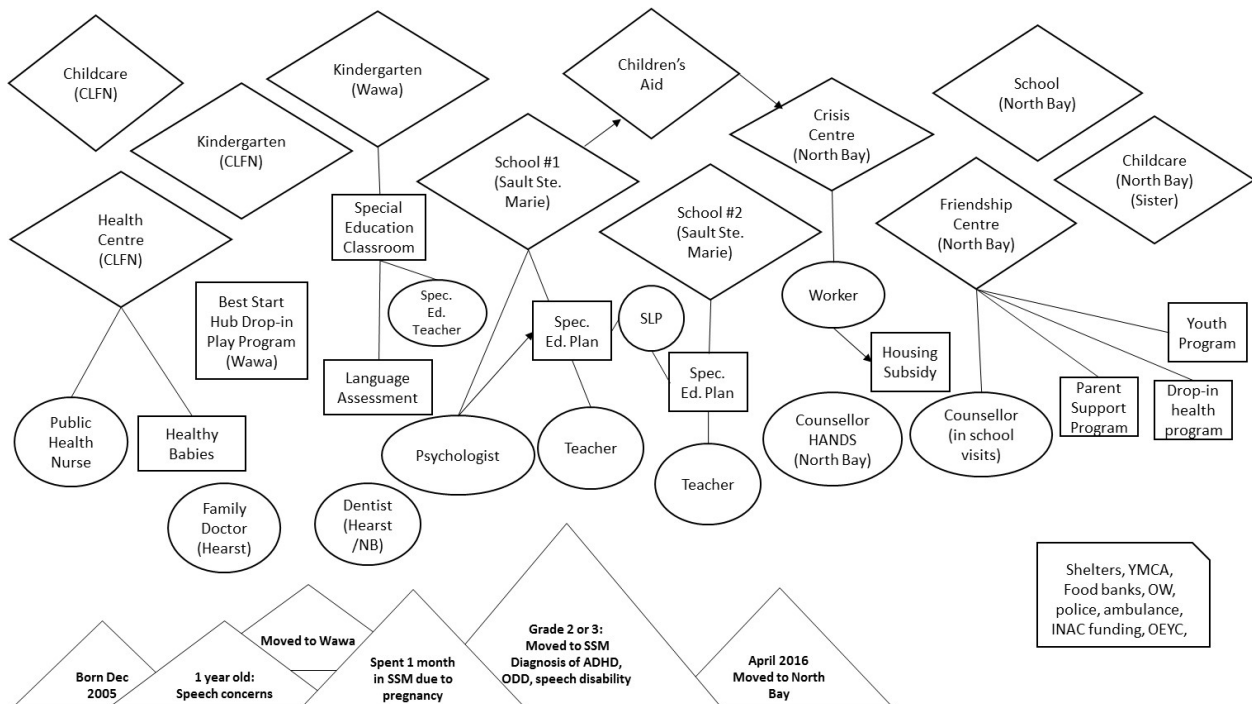
The child attended kindergarten in the community. The family then moved to Wawa, where a teacher identified a developmental delay. The teacher suggested the child repeat kindergarten. The child was placed in a special education classroom, with a special education teacher for part of the day. The family moved to Sault Ste. Marie where the child attended grade 1 and was assessed by the school psychologist. The psychologist gave three diagnoses which led to the development of a special education plan in the classroom. The school called the family to tell them that Children's Aid Services were called after an incident with a teacher. The child was removed from the school by the parent and placed in a second school with a special education plan. A year or two later, the family moved to North Bay and began accessing school, friendship centre, and children's mental health services.

CL004
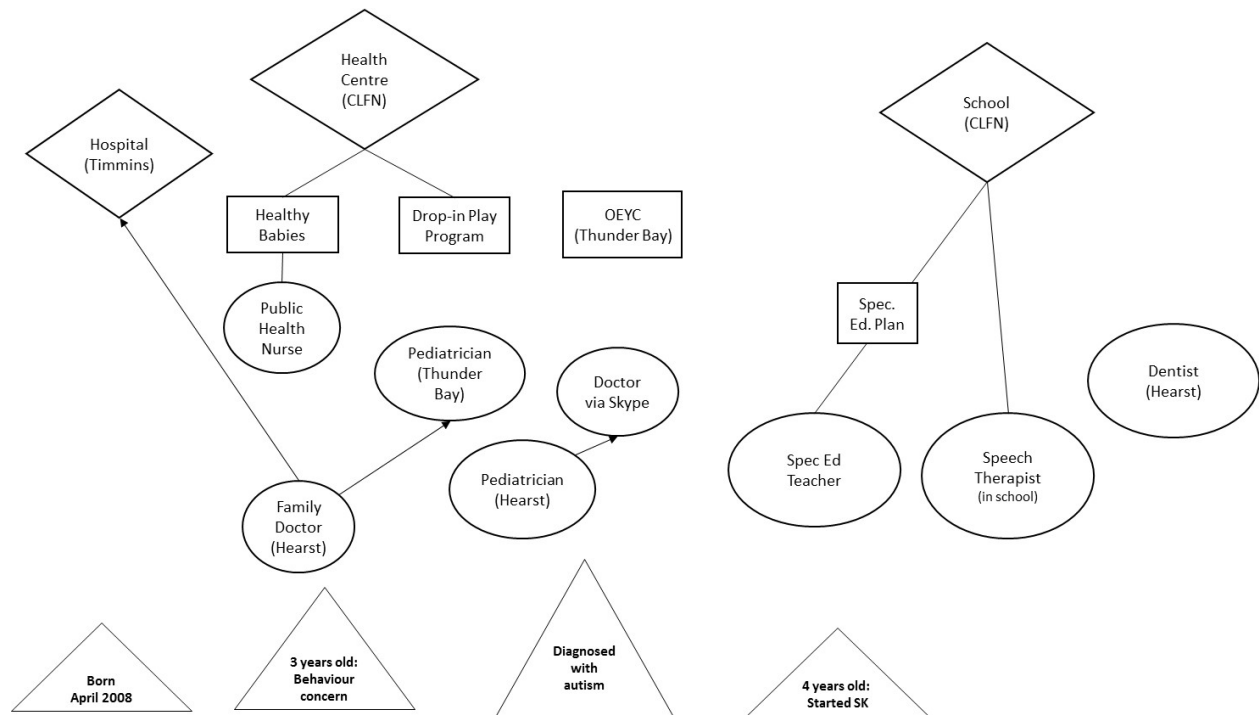
The family was referred to the hospital in Timmins due to complications relating to mother's health prior to birth. The mother and child spent one month as inpatients at the Timmins hospital, then returned to the community. Concerns about the child's behaviour were identified by the family doctor around age 3, during a regular check-up. The doctor referred the family to a pediatrician in Thunder Bay, however the appointment was cancelled. The family saw another pediatrician in Hearst who referred them to an online pediatrician. The family had a one-hour video conference with the pediatrician based in Toronto, who gave the child a diagnosis. The child entered school in the community at age four where he accessed a special education teacher and a speech therapist.

CL005
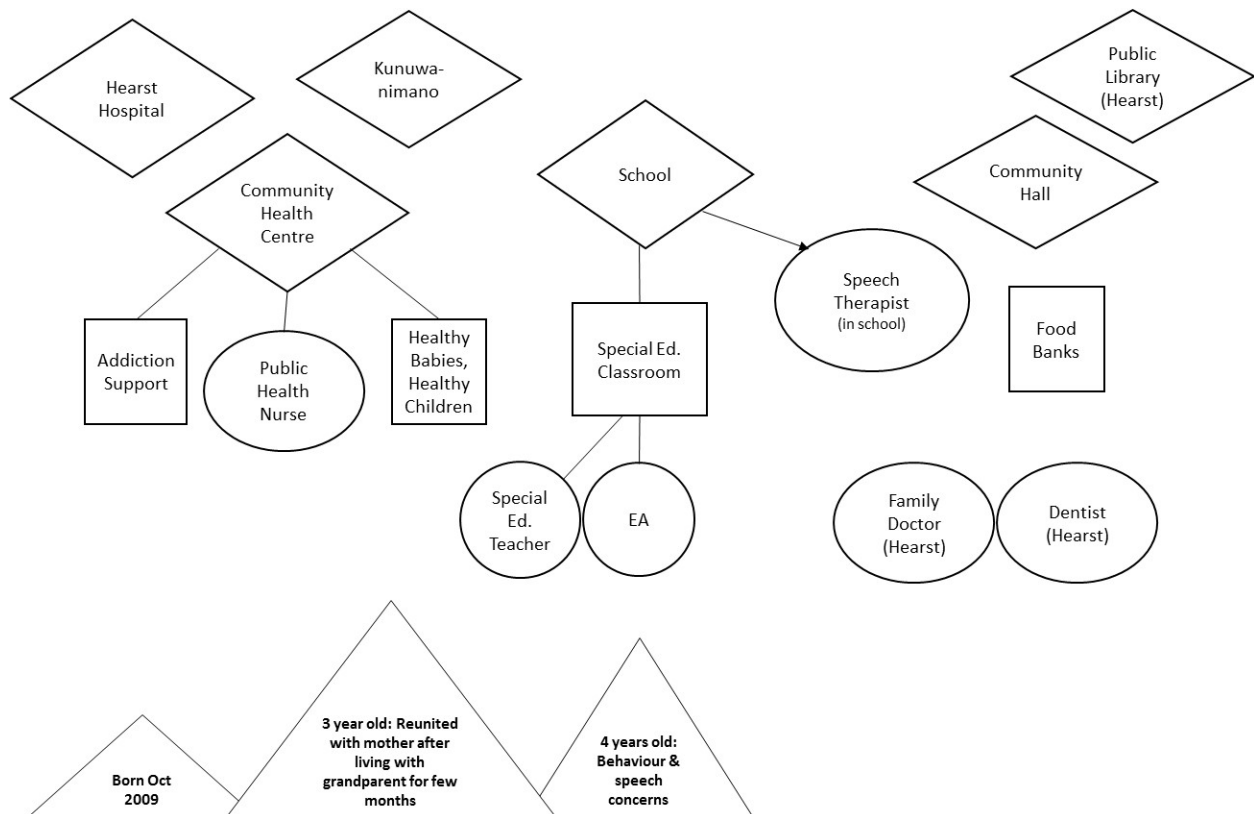
The child was born at the hospital in Hearst. The family accessed parent support and

addiction support programs at the community health centre, before and after the birth of the

child. The family was involved with the community child protection agency when child was

three. The child was placed in the custody of the paternal grandparent for several months. The

child returned home and attended kindergarten at the school in the community, where he was

placed in a special education classroom due to behavior concerns identified by the staff. The

child receives support from a special education teacher and educational assistant in the

classroom. A speech therapist also comes into the classroom from an external agency. The

family also accesses community events at the hall, food banks, and public libraries in the nearby

town.

CL006
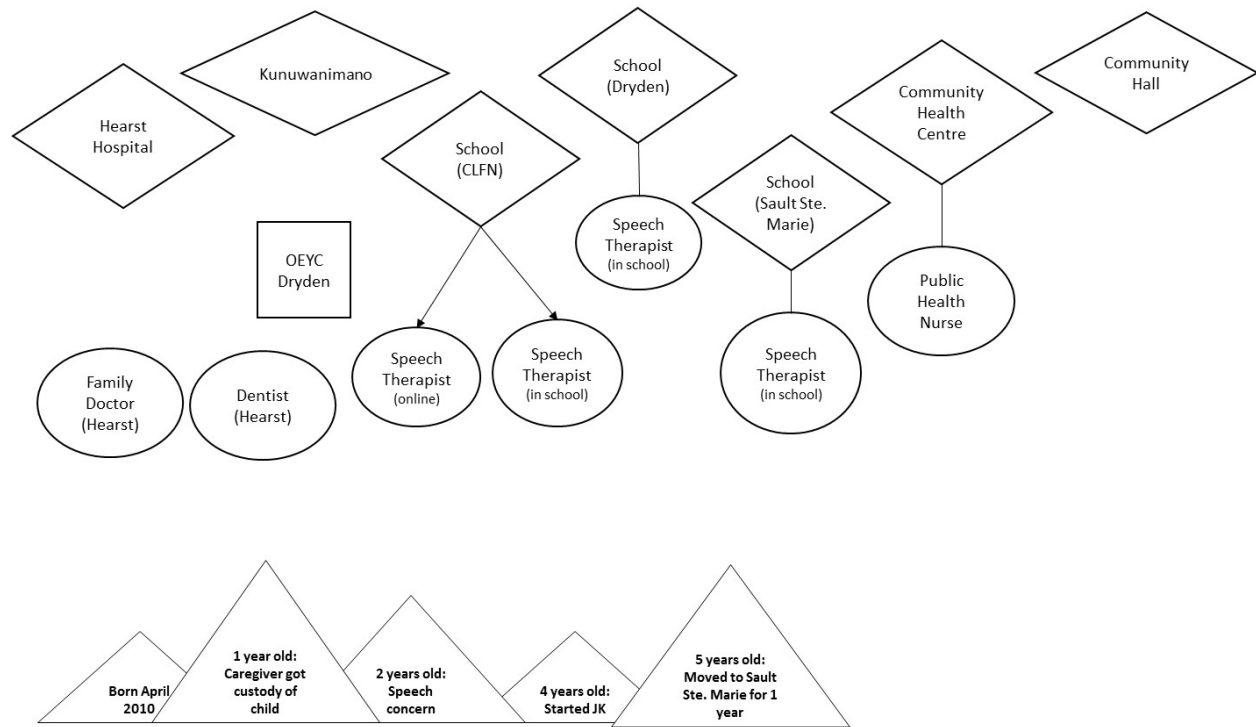
The child was born at Hearst hospital. At age one, his grandmother became the child's

legal guardian. When the child entered the community kindergarten, the child was enrolled in

speech services and received speech therapy in the class and online. Both the child and their

older cousin moved to Dryden, where they attended school and received speech support. The

child attended senior kindergarten in Sault Ste. Marie where he accessed speech support daily.

The child returned to the community the summer after to attend grade 1. The family additionally

accesses community programs such as the community hall and health centre.

Thematic Analysis

The 36 thematic codes identified from the interview data, yielded several key themes in

experience of accessing intervention and family support services in Constance Lake First Nation.

These themes are distinct entities in this section. However, Indigenous perspectives of

interconnectedness (Lavallée, 2009) inform the research process and the understanding of these themes as a larger phenomenon.

Relationships with Service Providers

Families interact with doctors, nurses, speech and language pathologists, occupational therapists, teachers, early childhood educators, resource teachers, early years management staff, community health workers, dentists, psychologists and other professionals. These professionals work within a variety of organizations related to health, education, and intervention. Service agencies are located across Ontario and have different models of service delivery. For instance, some professionals come to the community from external urban agencies. In other cases, families leave the community to meet service providers. Community programs offer some services while some families connect with service providers through remote technology.

The manner in which services are offered to families, impacts the quality of the relationship families have with professionals as well as the level of service they are able to access. The vast majority of the service providers that families interact with are from outside the community, and families do not have a lot of information about these agencies. For instance, one father said "I don't know where that doctor comes from but he goes from… […] I don't know where she comes from. Timmins, city to Timmins but then Timmins to Hearst just to go see just my boy." Families often do not know which professionals are working with their child, or what agency they are from. The institutional structure of the service system is not explained to families and as a result, families are not aware of the menu of services that are available to them.

Families spoke about their interactions with service providers in different ways depending on the type of service or where the service is offered. For instance, many describe interactions with their local doctors to be a positive experience, whereas interactions with

medical service providers in larger city hospitals are generally less supportive. Caregivers are often confused by medicalized language used by service providers, especially in cases of rare conditions or treatment procedures. For instance, one mother described getting multiple referrals for her child to have surgery but was confused about what that would entail. She decided to not access medical interventions for her child for several years. For many families, relationships with service providers affect the decision-making processes involved in their child's care and in some cases determine what services the child receives.

Educational settings are another sector in which families have service provider interactions. Many families have strong opinions regarding their children's educational experiences and make choices about placement depending on the quality of those interactions. One mother described an instance of physical harm from a teacher, which led to her removing her children from the school. She chose to seek educational supports for her son at another school and contacted a community agency for counselling in the classroom. Many families describe positive interactions with teachers and support staff in the community school, but describe a lack of communication regarding their child's experiences in the classroom. Many families also describe children being put into specialized services without consultation with the family. One participant said,

> JK. And that's when they put him into those kind of services there. 'Cause his speech too wasn't really good eh? He couldn't really talk and I guess that's what they did with him and I didn't… Yeah, they didn't really let me know what was going on.

Institutional Processes

This study asks questions about how the service system functions. For families in Constance Lake First Nation, there are a number of processes involved in accessing services,

regardless of where the services are offered. Families speak about attending doctor's appointments outside of their community, which require time away from work and school, as well as money. These appointments are necessary to acquire documentation to qualify for services. One father continuously asks his family doctor write letters in order to prove that his child requires colostomy bags, in order to access funding to purchase them. In order to access specialist appointments, families have to meet with their family doctor or community health worker in order to get a referral, organize accommodations, and to access travel funding. This is an extra process that families have to navigate in order to see professionals and access services for their child.

Navigating the service system in northern Ontario requires a substantial amount of effort on the part of the family. One participant described her experience in accessing supports: "Because when I first moved to North Bay, we moved there, we had nothing. All I had was my kids' clothes and their toys. That was it. And I busted my butt getting all the things they needed. School, counselling, whatever else. And in order". However, not all families convey the same level of self-advocacy, and as a result may receive less service for their child. For instance, one mother identified a developmental concern early in the child's life but did not pursue a pathological diagnosis. When the child received a diagnosis, the family was not made aware of the need for intervention and the child received no service. She spoke about the diagnostic process: "It was [Doctor A] and then we saw [Doctor B] but pretty much they just asked me like the same things. Questions over and over but nothing. No programs or anything like that". This suggests that the service system functions in a manner that enables particular families to receive supports that others are not aware of. Many feel that there are no supports available in the community, making comments such as, "Yeah, but not here. They don't do that here". Lack of

community services diminish the capacity of families to self-advocate, as they feel there are limited options for them and their children.

All participants expressed a desire for a simpler process to access services for their children. The retelling of the story to multiple professionals is burdensome for some families, as they feel there is little benefit to doing so. For instance, one mother said: "Like when I went to see a doctor they would refer me to this one but it was like the same thing over and over again. Like the asking about it and things like that. Saying they'll send me to someone else kind of thing". The system reliance on institutional referrals puts additional work on the family, who must relay information from professional to professional. Many spoke of the community health clinic as a place that was able to coordinate some of the institutional processes involved with accessing support services. Community health workers aid in the paperwork involved in accessing travel grants and booking hotel stays, as well as accessing referrals. Some describe these services as very beneficial, while others do not explicitly use them or know what supports they are able to offer. Most participants also describe the process of scheduling appointments to be onerous and spoke about a lack of follow-up with health professionals. This leads to gaps in service, while families wait for the rescheduling of a canceled appointment or referrals that never come.

Access to Service

Constance Lake has a variety of programs and service agencies within the community that families access or which are available. The community school runs from junior kindergarten to grade 12, with a childcare in the school. The school also offers training and post-secondary certificates in the evening for adults in the community. Constance Lake also has a community health centre, which provides general community health checkups with a nurse practitioner,

home visits for postnatal women and the elderly, crisis intervention, addiction support, and a

family resource program. There is also a child and family service agency which negotiates

custody arrangements and the fostering of children in the community. Participants also attend

community events that are often held at the community hall. Although not mentioned in the

interviews, there is also a band office, where community stakeholders meet, a community store,

and a youth centre. Not too far from the community is also a traditional area where ceremonies

are held.

Many families describe a lack of service within their community. The support offered

within the community is limited for children with disabilities forcing families to access services

elsewhere. Families accessed services in Constance Lake, Hearst (40 km from Constance Lake),

Ottawa (985 km), Toronto (1010 km), Thunder Bay (495 km), Timmins (300 km), North Bay

(630 km), Sault Ste. Marie (520 km), Dryden (820 km), and Wawa (300 km). Accessing external

supports in many cases requires multiple trips outside of the community, which takes time away

from children to participate in their classrooms and community. Traveling to services also has an

impact on other members of the family, who may attend trips with the family (but receive no

funding) or remain in the community with siblings of the child. In either case, families described

the travel involved in accessing services as "hectic".

The institutional structure determines how and where services get offered to families.

Some services are offered remotely, such as online or by telephone. These consultations enable

families to get a diagnosis or referral for their child without having to leave the community.

Families felt disconnected from service providers in these circumstances and expressed

uncertainty about the professionals they consulted remotely. For instance, one mother received

an autism diagnosis through an internet video consultation with a doctor in Toronto but she could

not recall the agency where the doctor worked. The mother also expressed uncertainty about the result of this consultation, as a referral that the doctor made was never completed. In the context of remote service interaction, the diagnosis becomes an institutional process, rather than a meaningful interaction for families. The referrals that result from these diagnostic meetings are therefore less connected to the families and are easily lost. Services are also accessed within the community, generally after a diagnosis is gained externally. These supports include speech and language pathology, physical therapy, and educational support. All of these services are offered at the school but therapists and consultants are from institutions outside of the community. There is currently no disability supports available to children within early years programs.

Community Inclusion

Having a disability in early childhood significantly impacts children's ability to be included in their community. Barriers to accessing early childhood education and care within the community are experienced by all children in Constance Lake. Some families families were told by the community childcare program that there were no supports available for their children in the early years. Children were discouraged or denied attendance at the child care. One mother said:

> [H]e never went to daycare but as soon as JK/SK he didn't really go and 'cause they
> didn't have any workers who would work with him. He was gonna be in grade 2 this year
> but it's too late moving him up because he -- Because when he's at school he can't sit
> still for a while, a long time. So he needs somebody to be there to take him out when he
> needs to be relieved I guess. […] It was like my choice [to keep him out of school]
> because they kind of made me feel like… I don't know how to explain it. Like they didn't
> really say it, but they didn't say to bring him in so I didn't really want to bring him in.

Many families express a desire for their child to be included in the social programming offered to children in the community. Families want their child to be able to make friends, and to have opportunities for recreational activity. Families feel that this could be achieved with the appropriate supports for their child. For instance, one mother said "I just want, like wanted him to feel comfortable in school and be well, I don't know, like well taken care of I guess. So mainly like with extra support and things like that". When asked about what supports are needed to facilitate their child being included, the majority of participants spoke of smaller class sizes and more one-on-one support.

Families refer to their children as active members of their community, but recognize challenges children have in being involved in community activities and programs. Children are seen as being included within the structure of their family. Families spoke about adapting to the needs of their children in ways that are not evident in institutional settings. Accessing support services outside of the community impacts not only the child, but the family and community as well. One mother shared: "When we travel to Ottawa he misses about almost a week because it's like a day trip just going there and we have to stop like halfway because we have kids. So yeah, he misses a week and -- Plus we take his, we take my other son too so they both miss school because of his travel". Participants also express a sense of guilt when leaving their community as they may have other responsibilities that they are leaving behind. Rumors and bullying are also a concern of families, not only directed at the child, but also towards other family members. This is an example of disability specific discrimination that takes place in the community, as it does in many communities. Rumors about adults are concerning, as families feel community members discuss their personal circumstances, which impacts the likelihood that they would seek support from community members outside of their immediate family.

Family Circumstances, Beliefs, and Culture

Families in Constance Lake First Nation have a wide array of experiences and circumstances which make each of their stories unique. All families grew up in the community, even if they do not currently live there. One parent lives in North Bay but had lived in the community when her child entered the service system. Participants describe their community as being family oriented, usually with extended family living nearby. Families describe having grandparents or other family members who are able to offer childcare, drive to appointments, or talk with them about their concerns. All children in the study live with siblings or other family members who are close in age. Many families spoke about positive sibling relationships between the child and other family members. Families with multiple children have service pathways that include the whole family rather than just one disabled child. This may reflect a cultural value of communality which has implications for the design of service that is currently child, rather than family-centred.

Families describe situations in their own lives that may have an impact on their child, and their institutional interactions. For instance, all families had interacted with a child protection agency, usually in the circumstance of custody agreements with other biological parents. In some cases, children had also had foster care. In one instance, the child's grandmother had been fostering the child and then later adopted him. Participants also described accessing interventions or supports for themselves. These services include addiction supports, shelters, and mental health services. This is an important institutional ethnography consideration, as the time and processes within these services impact the manner in which families are able to support their child and how much time can be spent interacting with services relating to the child. Families did not access

any Indigenous specific supports in the community, but almost all participants described culture

as important to their child's development and wellbeing.

Wellness and Conceptualizations of Disability

When asked about their child's disability, many participants described their children as

being unique or special. Some parents describe their children as having a disability, and others

feel that the labels given to their child do not accurately portray their abilities. Differences in

development are sometimes only seen as specific to institutional programs, while at home

children's characteristics are not seen as problematic. One mother said:

> They'd call us every day and I told his step father that he is -- That it doesn't make sense.
>
> Because he would be just a normal hyper, overactive, hyper child when he got home and
>
> the child that we had at home compared to school were two, two -- They were explaining
>
> two very different kids.

This leads to tension between families and professionals when family understandings of a child's

abilities are not acknowledged. This particular mother removed her child from school due to

continuous instances of misunderstanding with the school staff. She felt that ongoing counselling

would be the most appropriate support for the child, as she felt concerns were related to the

development of the child's spiritual gifts. This perspective was discounted in the school setting,

where the child was placed in a special education classroom due to perceived behavioural

disorders.

Families understand the contextual responses of their child within particular

environments. For instance, one mother said: "Like when he has outbreaks, tantrums and things

like that. Like when he can't -- 'Cause he gets overwhelmed like with noises and things like that.

And at school it's loud sometimes and he doesn't like being around other people sometimes

when they overcrowd him sometimes". Families often felt that programs did not account for children's individuality in programs, which may account for negative behavioural responses. Disability in this sense is not seen as a characteristic of the child, but a characteristic of the environment which does not work for the child.

Families express a desire for support services to be more holistic. For instance, one mother wanted counselling for her son who would potentially need surgery for his rare bone condition. She felt that counselling would be helpful not only for his emotional state generally, but also in order to mentally prepare for the intervention. Other families echoed similar sentiments, seeing support for their children as not only within the context of one area of development, but also encompassing the child's emotional state as a result of their difference or gift. This may be explained as a cultural perspective to wellbeing particular to Indigenous families.

Discussion

Families' interactions with the disability support system in Constance Lake, reflected a particular geo-political circumstance experienced by many northern communities in Ontario. Being remote, northern, and rural, may have significant implications for accessing services for young children with disabilities or gifts (Graham & Underwood, 2012). From the larger cohort of participants in the study, it has been observed that children in rural and remote communities in Ontario do not have the same access to services as families in urban settings (IECSS, 2017). Supports are provided through a provincial structure, which means that children in Temiskaming may receive support from the same agencies who serve Constance Lake, even though these communities are nearly 500 kilometers apart. These supports are infrequent and are often delivered without an ongoing relationship with the child or the family. Supporting a child's

development from an Indigenous perspective is seen as a relational practice that occurs within

the context of the family and larger community (Connors & Maidman, 2001). Similarly, research

on early intervention generally indicates that relationship and family-centred practice are

essential for effective outcomes (Bruder, 2000). The supports received by families in the study

are delivered as individual interventions, decontextualized from the community and family. This

is inconsistent with Indigenous methods of childrearing, and with the literature on high quality

early intervention (Ball & Pence, 2006; Bruder, 2000).

Living on-reserve may also have particular impacts on children's access to institutional

supports. Services in First Nation communities are funded through federal budgets, which have

not been structured to handle the demands of social services (Adelson, 2004). First Nation

communities receive less funding for social supports than non-reserve communities (Blackstock

& Trocmé, 2005). Further, in cases of complex care needs as related to disability in childhood,

jurisdictional processes between federal and provincial governments create significant barriers to

accessing supports in a timely and appropriate manner (Blackstock, 2012). Although this was not

the case in any of the participant's experiences, these jurisdictional issues do create additional

institutional processes that families must navigate in order to gain service. For example, funding

for medications or assistive equipment is funded for First Nations children under the Indian

Health Policy (Lavoie, Forget, & Browne, 2010). However, the provision of medical,

educational, and early intervention services is the responsibility of the province (Blackstock,

2012). This creates additional processes for families in order to obtain their desired level of

service.

First Nations families are identified on an institutional level by the use of Indian status

cards for health benefits, which can potentially lead to discriminatory interactions with service

providers (Browne & Fiske, 2001). Participants describe their interactions with service providers as unsupportive when professionals do not offer opportunities for parents to voice their opinion, or to make decisions about the interventions their child receives. Communication between families and professionals is influenced by a number of factors, such as previous relationships with service providers or level of knowledge about a child's particular condition. Service providers may also make assumptions regarding First Nations families that hinder full participation in decision making about their own children.

Families spoke about their children in ways that reflected both Indigenous and medicalized conceptualizations of disability. Some describe their child having unique gifts while others focus on deficits in their development. In either case, only one parent accessed culturally specific services, such as a friendship centre which provided counseling to the child in the classroom. This is because she lives in North Bay and a cultural agency is available. Families living in Constance Lake do not have access to cultural services relating to disability. Participants did not talk about cultural practice in the community. Within the larger project, the Elders council have shared how important language and culture is to the development of young children. The Elders explain that many of the diagnoses that Indigenous children receive are due to cultural misunderstandings between Indigenous families and non-Indigenous professionals. One parent explicitly described feeling that her child's behavior was a spiritual gift. Other parents felt that the concerns practitioners had with their children were valid, even if they had not observed the problem themselves.

Families generally accepted the diagnosis or explanation of their child's disability from medical professionals. However, families did not seek out diagnoses for their child on their own volition. The diagnosis was necessary to access services. Children entered the disability service

system when they began interacting with specialists, such as teachers or doctors, who initiated the diagnostic process. In every case in this study, the professional who gave the child the diagnosis or referred them to support services was a non-Indigenous practitioner. In some cases, children were placed into special education services without informing the family. The institutional processes families must navigate are not structured for family input, which is commonly experienced by Indigenous people in health related settings (Kurtz et al., 2008). Colonial racism in healthcare and educational settings continues to impact access for Indigenous peoples and negatively affects self-esteem (Allan & Smylie, 2015; Denis, 2007). The manner in which service providers interact with families in Constance Lake impedes the self-efficacy of parents, as they are not treated in ways that value family understandings of the child, which are grounded in relational and cultural knowledge.

The lack of discussion of Indigenous culture in family narratives may be explained by colonial pressures experienced by First Nations peoples. Indigenous cultures have been attacked and denied within settler-colonial society, which has impacted mechanisms for engaging in cultural practice (Alfred & Corntassel, 2005). Western knowledge systems disregard Indigenous ways of knowing and conceptualizing wellness, which contributes to the ongoing colonization of Indigenous bodies and minds (Lavallee & Poole, 2010). Although it was not a topic that emerged from the participants, many community members in Constance Lake are residential school survivors (Wells, 2012). Participants in the study may have been impacted by the disruption of cultural learning in the community and do not practice cultural traditions as a result. Children in the community may therefore have limited access to cultural teaching, which may impact their cultural understandings of their gifts and identity overall (Ball, 2012; Ball & Pence, 2006).

Developing a sense of cultural identity is an important objective of early years teachings

for Indigenous children (Greenwood & de Leeuw, 2007). Indigenous models of early childhood

education focus on cultural teachings and relational learning in which children are able to

understand themselves in relation to others (Best Start Resource Centre, 2010). Indigenous

children with disabilities, differences, or gifts have unique experiences that are intersectional,

which impacts the development of self-identity. In Constance Lake, there are few resources

available for children to learn about their culture. There are even fewer to learn about disability

culture. It would therefore be difficult for children to develop a cultural understanding of their

disability or gift. Children may only be exposed to pathologizing perspectives of development

within the educational and intervention services they interact with. Children's experiences within

the service system can therefore impact the development of their identity as a disabled

Indigenous person on multiple levels.

Conclusion

Indigenous children in Canada are disabled through multiple structural mechanisms that

hinder their full participation in society (Ball, 2004). Indigeneity is conceptualized as a

pathological characteristic within social institutions which can constitute disability and position

settler-colonial embodiments of ability as the normative ideal (Greensmith, 2012; Hollinsworth,

2015). Indigenous children with developmental differences and gifts can be further marginalized

due to the intersection of oppressions they may face (Durst, 2006). This is further compounded

when children live on reserve, or in rural or remote areas where supports are not available

(Blackstock, 2012; Graham & Underwood, 2012). Disabled Indigenous children are both

simultaneously overrepresented and underserved within disability support settings, which

illustrates a significant institutional gap in the provision of services for Indigenous children

(Durst, 2006; Inter-Agency Support Group on Indigenous Peoples' Issues (IASG), 2014).

The lack of support for disabled Indigenous children often leads to the relocation of

Indigenous families, as they are forced to seek services in urban centres (Durst, 2006; IASG,

2014). Being outside of one's own community can increase dependency on social services,

which can contribute to the institutionalization of Indigenous children (IASG, 2014). Disability

increases the likelihood that children will be separated from their families and communities

(Blackstock, 2012; ISAG, 2014). The processes of institutional intervention can reaffirm colonial

mechanisms of assimilation (Rand, 2011). In contexts which have historically displaced and

institutionalized Indigenous children, this can perpetuate colonial violence and exacerbate the

harmful effects of intergenerational trauma (McKenzie et al., 2016).

The institutional structure of disability support services can be culturally unsafe for

Indigenous children, which increases barriers to access (Ball, 2009; Kendall & Marshall, 2004).

This is a significant service gap that can impede access to the full realization of human rights

(Gillespie et al., 2016). The United Nations Declaration on the Rights of Indigenous Peoples

(UNDRIP) declares that

> States shall take effective measures and, where appropriate, special measures to ensure
>
> continuing improvement of their economic and social conditions. Particular attention
>
> shall be paid to the rights and special needs of indigenous elders, women, youth, children
>
> and persons with disabilities. (United Nations General Assembly, 2007, p. 9).

Without accessible and culturally safe disability support services, many Indigenous children

receive inadequate service which may be harmful to the development of their cultural identity as

an Indigenous child with gifts (Ball, 2008; United Nations, 2016).

The title of this work, Maawandoonan, is an Ojibwe word meaning 'to bring together'. Indigenous cultural supports and disability services remain dichotomous within the current service system, which can be challenging for Indigenous families. For Indigenous children, learning about their culture is central to their understanding of themselves (Ball, 2012). Most disability services are not offered within culturally safe spaces. This means Indigenous children accessing supports for their disability spend time in settings that are potentially culturally dissonant, and have less time to access programs relating to culture. Considering the long lasting impacts colonial interventions have had on Indigenous children in Canada (McKenzie, et al., 2016), there is a need to decolonize the disability support system in order to mitigate colonial harm (Goodley, 2013; Hollinsworth, 2013). 'Bringing together' disability support services and cultural practices may be one way for Indigenous communities to self-develop culturally safe programs for children with various abilities and gifts to learn and develop.

Appendices

Appendix A

IECSS Recruitment Flyer

We would like to hear your story

Was your child born between 2010 and 2015?

Do you want to talk to a researcher about your experience with getting support for your child? Examples of support include:

- A resource consultant
- Autism support services
- Speech and language
- Behavior supports
- Physical therapy

- Mental health services
- Occupational therapy
- Aboriginal family supports

- Other advice or assessment related to your child's growth or development

If you have used (or are waiting for) any of these services **we would like to hear your story.** The Inclusive Early Childhood Services System Project wants to learn from your experiences in getting support for your child. The study hopes to learn more about how early childhood services are meeting the needs of Ontario families. Participation in the study is voluntary and involves:

- A 1.5 to 2 hours interview that will be audio-recorded.
- Child care and/or translation if needed
- The opportunity to participate in an interview once a year until 2017
- A thank you gift for your time (value $30)

If you would like to join our study or find out more information please contact the project office at, inclusion@ryerson.ca, 416-979-5000 ext. 7637.

IECSS · District of Timiskaming Social Services Administration Board · Conseil d'administration des services sociaux du district de Timiskaming · www.dtssab.com · RYERSON UNIVERSITY · Everyone Makes a Mark

Appendix B

Interview Script

INTERVIEW SCRIPT

Introduction

We would like to ask you some questions about your goals for your child and the supports that he/she gets in early years programs and/or childcare.

1. Tell me about your child/children. What is a typical day like?

Do you have developmental concerns about your child?

When/why did you become concerned?

Have you spoken to anyone about your concerns?

What is your child's experience in programs?

Tell me about your child's social relationships?

Does your child participate in all parts of the programs they attend and/or in your family routines?

Are weekdays different from weekends?

2. Young children develop at a rapid pace and in many ways. Tell me about your child's current developments.

What are major situations that you have to deal with in the life of your child/family?

What are your current goals for your child, in terms of his or her strengths? (for e.g. some children might be learning to feel comfortable in new situations)

Do you have the information you think you need to support your child?

Are there other supports you wish you had?

Will your child attend school next year (JK)?

What do you imagine will be his/her biggest successes at school?

What do you imagine will be his/her biggest challenges?

3. How does support happen for your family?

What does it mean for you to feel supported?

For your child?

Are you getting the support you need?

Families are unique: Do the programs and services that you attend with/for your children consider the circumstances of your family in their interactions with you?

Are your family language and culture respected and acknowledged in these programs? Do you find you have a good rapport with the service providers who support your child?

Do you feel that the programs that serve your child address your families' needs (e.g. cultural perspective, or child rearing values)?

In your experience, has there been appropriate sharing and coordination of information programs and services?

Does your family attend any family support programs (e.g. OEYC, PFLC, Aboriginal Head Start Centre, etc.)

Appendix C

Programs and Services Questionnaire

PROGRAMS AND SERVICES QUESTIONNAIRE

Please check off the box to the right to indicate the programs and/or services that your family and/or your child have used in the past year. Mark an 'X' where you have accessed the service and a 'W' if you are on a waitlist.

Program or Service Name		Program or Service Name	
Health, Disability and Early Intervention Services		**Social Services**	
Family Physician		Children's Aid Services	
Infant Hearing and/or Vision Screening		Crisis counselling	
Occupational Therapy		Domestic violence supports	
Physical Therapy		Shelters	
Drop-in health/infant clinics		Other (please specify)	
Home visits after birth		**Community Services**	
Enhanced 18 Month Well Baby Visit		Community Centres	
Nippissing District Developmental Screening (or other developmental checklist)		Recreational Programs	
Infant hearing programs		Fitness Centres	
Blind/Low-Vision supports for children		Food banks	
Dental Screening		Housing subsidy	
Healthy eating/dietician/nutritionist services		Home management program	
Public Health Nurse		Ontario Works	
Infant mental health services		Police Services	
Children's mental health services		Public libraries	
Support for adults living with mental health issues		**Culturally Specific Services**	
Addiction support (alcohol, gambling, drugs)		Aboriginal supports	
Language Development Assessment		Francophone supports	
Speech and Language Supports		Newcomer supports	
Autism support		**Parenting Support Programs**	
Behaviour supports		Ontario Early Years Centre (OEYC)	
Respite		Parenting and Family Literacy Centres	
Supports for adults with developmental delays/disabilities		Drop-in play programs	
Referral service (Toronto-City Kids; Contact Hamilton; Guelph-KIDSLINE)		Young parent programs	
Other (please specify):		Other Parenting Support Programs (please specify)	
		Child Care	
		Child Care Subsidy	
		Resource Consultant/Teacher/Educator	
		Home child care	

Would you like to access any other supports or services?

Are there any qualifying criteria your child or family must meet before receiving further supports?

PROGRAMS AND SERVICES QUESTIONNAIRE

Please respond to the following questions as they relate to your experiences in accessing supports for your child.

Family Outcomes						
Having Support Systems	**Almost always**	**Usually**	**Sometimes**	**Seldom**	**Never**	**Not Applicable**
Many people feel that talking with another person helps them deal with problems or celebrate when good things happen. How often does your family have someone your family trusts to listen and talk with when they need it?	○	○	○	○	○	○
Families sometimes must rely on other people for help when they need it, for examples, to provide a ride, run an errand, or watch their child for a short period of time. How often does your family have someone you can rely on for help when you family needs it?	○	○	○	○	○	○
Most families have things they enjoy doing. How often is your family able to do the things your family enjoys?	○	○	○	○	○	○
All children need medical care. How often does your family's medical care meet your child's special needs?	○	○	○	○	○	○
Many families want their child to play with other children or participate in religious, community, or social activities. How often does your child participate in these activities right now?	○	○	○	○	○	○

Additional Comments:

PROGRAMS AND SERVICES QUESTIONNAIRE

Please complete this survey for the 2 or 3 programs and/or services that are most important for your child

Program or Service Name	Name and locations: Postal code:
Time spent	Start date: End Date: Number of visits (per week or month): Time spent at each visit:
Referrals	Who referred you to this program/service? What programs/ services were you referred to through this program?
Assessment	Has your child undergone a developmental assessment through this service? Yes No Did the assessment help you to access programs/services? Yes No Did the assessment give you information that was useful to you? Yes No
Purpose of Attending	Why did you attend this program/service?

To what extent do the people who work with your child…	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not At All	Not Applicable
…help you feel competent as a parent?	○	○	○	○	○	○	○	○
…provide you with written information about what your child is doing?	○	○	○	○	○	○	○	○
…let you choose when to receive information and the type of information you want?	○	○	○	○	○	○	○	○
…make sure that at least one team member is someone who works with you and your family over a long period of time?	○	○	○	○	○	○	○	○
…provide opportunities for you to make decisions about your child?	○	○	○	○	○	○	○	○
…give you information about the types of services offered at the organization?	○	○	○	○	○	○	○	○
…give you information about the types of services offered in your community?	○	○	○	○	○	○	○	○
…have information available about your child's disability (e.g., its causes, how it progresses, future outlook)?	○	○	○	○	○	○	○	○
…have information available to you in various forms, such as a booklet, kit, video, etc.?	○	○	○	○	○	○	○	○
…provide advice on how to get information or to contact other parents (e.g., organization's parent resource library)?	○	○	○	○	○	○	○	○

PROGRAMS AND SERVICES QUESTIONNAIRE

Please complete this survey for the 2 or 3 programs and/or services that are most important for your child

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Assessment	Has your child undergone a developmental assessment through this service? Yes No Did the assessment help you to access programs/services? Yes No Did the assessment give you information that was useful to you? Yes No
Purpose of Attending	Why did you attend this program/service?

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…help you feel competent as a parent?	○	○	○	○	○	○	○	○
…provide you with written information about what your child is doing?	○	○	○	○	○	○	○	○
…let you choose when to receive information and the type of information you want?	○	○	○	○	○	○	○	○
…make sure that at least one team member is someone who works with you and your family over a long period of time?	○	○	○	○	○	○	○	○
…provide opportunities for you to make decisions about your child?	○	○	○	○	○	○	○	○
…give you information about the types of services offered at the organization?	○	○	○	○	○	○	○	○
…give you information about the types of services offered in your community?	○	○	○	○	○	○	○	○
…have information available about your child's disability (e.g., its causes, how it progresses, future outlook)?	○	○	○	○	○	○	○	○
…have information available to you in various forms, such as a booklet, kit, video, etc.?	○	○	○	○	○	○	○	○
…provide advice on how to get information or to contact other parents (e.g., organization's parent resource library)?	○	○	○	○	○	○	○	○

PROGRAMS AND SERVICES QUESTIONNAIRE

Please complete this survey for the 2 or 3 programs and/or services that are most important for your child

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…help you feel competent as a parent?	○	○	○	○	○	○	○	○
…provide you with written information about what your child is doing?	○	○	○	○	○	○	○	○
…let you choose when to receive information and the type of information you want?	○	○	○	○	○	○	○	○
…make sure that at least one team member is someone who works with you and your family over a long period of time?	○	○	○	○	○	○	○	○
…provide opportunities for you to make decisions about your child?	○	○	○	○	○	○	○	○
…give you information about the types of services offered at the organization?	○	○	○	○	○	○	○	○
…give you information about the types of services offered in your community?	○	○	○	○	○	○	○	○
…have information available about your child's disability (e.g., its causes, how it progresses, future outlook)?	○	○	○	○	○	○	○	○
…have information available to you in various forms, such as a booklet, kit, video, etc.?	○	○	○	○	○	○	○	○
…provide advice on how to get information or to contact other parents (e.g., organization's parent resource library)?	○	○	○	○	○	○	○	○

PROGRAMS AND SERVICES QUESTIONNAIRE

Please complete this survey for the 2 or 3 programs and/or services that are most important for your child

Program or Service Name	Name and locations: Postal code:
Time spent	Start date: End Date: Number of visits (per week or month): Time spent at each visit:
Referrals	Who referred you to this program/service? What programs/ services were you referred to through this program?
Assessment	Has your child undergone a developmental assessment through this service? Yes No Did the assessment help you to access programs/services? Yes No Did the assessment give you information that was useful to you? Yes No
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To what extent do the people who work with your child…	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not At All	Not Applicable
…help you feel competent as a parent?	○	○	○	○	○	○	○	○
…provide you with written information about what your child is doing?	○	○	○	○	○	○	○	○
…let you choose when to receive information and the type of information you want?	○	○	○	○	○	○	○	○
…make sure that at least one team member is someone who works with you and your family over a long period of time?	○	○	○	○	○	○	○	○
…provide opportunities for you to make decisions about your child?	○	○	○	○	○	○	○	○
…give you information about the types of services offered at the organization?	○	○	○	○	○	○	○	○
…give you information about the types of services offered in your community?	○	○	○	○	○	○	○	○
…have information available about your child's disability (e.g., its causes, how it progresses, future outlook)?	○	○	○	○	○	○	○	○
…have information available to you in various forms, such as a booklet, kit, video, etc.?	○	○	○	○	○	○	○	○
…provide advice on how to get information or to contact other parents (e.g., organization's parent resource library)?	○	○	○	○	○	○	○	○

PROGRAMS AND SERVICES QUESTIONNAIRE
Demographic questions

Are you the child's: ○ Mother   ○ Father   ○ Other (please specify):

When was your child born?   Month: Day: Year:

Which of the following best describes your family situation?

○ One Parent   ○ Two parents at a home   ○ Two parents sharing custody   ○ Other (please specifiy):

How many siblings does your child have?

○ None   ○ 1   ○ 2   ○ 3   ○ 4+

In which community do you live or access services?

○ Wellington   ○ Toronto   ○ Hamilton   ○ Timiskaming

        ○ Other(s):

What is your postal code?

How long have you lived in this community?

○ Less than 1 year   ○ 1 to 3 years   ○ 3 to 5 years ○ More than 5 years

In the last 3 years, how often has your child moved to a different home?

○ Never   ○ Once   ○ Twice   ○ 3 times   ○ 4 times   ○ 5+ times

What best describes where you live?

        ○ Rent
        ○ Own
        ○ Other, please specify (e.g. live free with family, no permanent housing, shelter, in transition)

How long have you lived in Canada?

        ○ Always   ○ More than 10 years   ○ 6 – 10 years   ○ 3-5 years
        ○ 1-2 years   ○ Less than 1 year

What is *your* highest level of education? Choose only one answer.

Did not complete High School	Completed High School	College diploma or Trades Certificate	Undergraduate Degree	Graduate Degree
○	○	○	○	○

What is the highest level of education in *your household*?

PROGRAMS AND SERVICES QUESTIONNAIRE

❍ Elementary   ❍ Some High School
❍ High School graduate   ❍ Some post-secondary (college or university)
❍ Graduated college   ❍ Graduated university
❍   Post graduate or professional degree

What is your total household income? (generated from the 2011 Census)

❍ Under $5,000	❍ 5,000 to $9,999	❍ $10,000 to $14,999	❍ $15,000 to $19,999
❍ $20,000 to $24,999	❍ $25,000 to $29,999	❍ $30,000 to $34,999	❍ $35,000 to $39,999
❍ $40,000 to $44,999	❍ $45,000 to $49,999	❍ $50,000 to $59,999	❍ $60,000 to $69,999
❍ $70,000 to $79,999	❍ $80,000 to $89,999	❍ $90,000 to $99,999	❍ $100,000 to$144,999
❍ $150,000 to $199,999	❍ $200,000 to $249,999	❍ $250,000 and over	

What is the language(s) most often spoken in your home? You may choose more than one.

❍ Albanian	❍ Arabic	❍ Bengali	❍ Cree	❍ Chinese	❍ Dari
❍ English	❍ French	❍ Greek	❍ Gujarati	❍ Hindi	❍ Korean
❍ Ojibway	❍ Persian (Farsi)	❍ Portuguese	❍ Punjabi	❍ Romanian	❍ Russian
❍ Serbian	❍ Somali	❍ Spanish	❍ Tagalog	❍ Tamil	❍ Turkish
❍ Urdu	❍ Vietnamese				

❍ Other(s):

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Which of the following best describes your racial identity: (Pick one only.)

❍ Aboriginal
❍ Asian- East (e.g., China, Japan, Korea)
❍ Asian- South (e.g., India, Pakistan, Sri Lanka)
❍ Asian- South East (e.g., Malaysia, Philippines, Vietnam)
❍ Black - Africa (e.g., Ghana, Kenya, Somalia)
❍ Black - Canada
❍ Black - Caribbean Region (e.g., Jamaica, Trinidad and Tobago, Barbados)
❍ Latin American (e.g., Argentina, Chile, Costa Rica)
❍ Indian-Caribbean (i.e., Guyana with origins in India)
❍ Middle Eastern (e.g., Egypt, Iran, Israel, Palestine)
❍ Mixed background
❍ White - Canada
❍ White - Europe (e.g., England, Greece, Italy, Portugal, Serbia)
❍ Other(s):

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What is your ethnic or cultural background?
You may write more than one. Fill in the box.

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(For example, African, Arab, Canadian, Chilean, Chinese, Cree, Dutch, East Indian, East African, English, Filipino, French, French-Canadian, German, Greek, Grenadian, Inuit, Irish, Italian, Jamaican, Lebanese, Mennonite, Metis, Micmac, Mohawk, Ojibway, Polish, Portuguese, Russian, Scottish, Somali, Ukrainian, Vietnamese, West African etc.)

Appendix D

Coding Frequency

Code	Definition	Sources	Ref.
INSTITUTIONAL INTERACTION	Top code: Includes any information relating to interactions with the service system	6	561
PRACTITIONER INTERACTION	Mention of an interaction with a worker within a program/service	6	194
SERVICE LOCATION	Geographic information about service	6	65
INFORMATION	Parent perception of the quality of information they receive from practitioners	6	46
INSTITUTIONAL PROCESS	Actions that make the system function (i.e. paperwork)/ how the service functions (i.e. service delivery method)	6	37
SERVICE GAP	Lack of service. Can be related to services not offered in proximity, service that ends, service that was inadequate, or family desires for service they do not have	6	32
COMMUNITY PROGRAM	Mention of program/service offered on-reserve	5	30
ASSESSMENT_SCREENING	Any instance where the child is assessed or measured. May be medical, developmental, or educational	5	27
REFERRAL	Formal or informal referral to a service	5	27
TREATMENT_INTERVENTION	Services and procedures to mitigate disablement (i.e. therapies, medical procedures)	5	20
IMPACT ON FAMILY	Ways in which the service system had influence on the family/made the family adapt to the system	5	13
COMMUNICATION	Ways in which service providers communicate with familys	3	12
SERVICE COORDINATION	Relaying of information between service providers	2	11
ENTRY POINT	Time at which child entered the service system	6	9
REASON FOR ATTENDING	Family explanation for why the service was accessed	5	8
WAIT TIME	Time spent waiting for a service	3	7
SERVICES FOR OTHER FAMILY MEMBERS	Information regarding institutional interactions other family members had (i.e. mental health supports for family)	3	6
QUALIFYING CRITERIA	Requirements of the system in order for families to be able to access	2	4
END OF SERVICE	When/why service ended	2	3
FAMILY PERSPECTIVE	Top Code: Family thoughts, feelings, and perception of service or circumstances	6	88
FAMILY GOALS_WANTS	Family desire for service/their child	5	20

FAMILY CONFUSION_UNAWARENESS	Gaps in knowledge regarding service	5	15
DIFFERENCE IN OPINION	Circumstances where family did not agree with practitioner	3	5
TIMELINE	Temporal information related to story. Order in which services were accessed.	6	49
SCHOOL	Information regarding school (kindergarten and up)	6	45
DOCUMENTATION	Reports from the school	3	6
DISABILITY_DIAGNOSIS_CONCERN	Descriptions of child's specific disability, developmental difference, formal diagnosis, or area of concern in terms of development	6	35
FAMILY CIRCUMSTANCE	Contextual information about the family including family composition, employment situation, custody situation, etc.	6	34
FAMILY SUPPORT	Descriptions of whether or not familys felt supported themselves by practitioners or other individuals	6	32
DISTANCE_TRAVEL	Information regarding distance, travel methods, or descriptions of how families reached a service	5	22
CHILD CHARACTERISTICS	Descriptions of the child's behaviour, personality, or physical characteristics. May be in relation to disability.	6	19
PARTICIPATION_INCLUSION	Descriptions about how the child participates in the environments they interact with. May be cross-coded with family wants when referring to desire for child to be included	5	15
CHILD SOCIAL RELATIONSHIPS	Descriptions of child's interaction with other children	6	14
FAMILY WORK	Actions of familys that facilitated support for the child	4	14
FAMILY INVOLVEMENT	Descriptions of other family member's engagement in the life of the child. May be cross-coded with family circumstance	5	14
LIFE EVENT	Significant events in the child's life that may have impacted their development or service pathway	5	13
ON-RESERVE SITUATION	Specific mention of being on-reserve/on-reserve service versus non-reserve	3	13
LANGUAGE_CULTURE_RACE	Mention of languages spoken in the home/ cultural identity/ cultural beliefs/ cultural practices/ racial identity	4	10
CHILD PROGRESS	Differences in child's behaviour, ability, development over time	5	10
FUNDING SOURCE	Sources of funding for programs or travel	3	10
CHILD RESPONSE	Child's reaction towards service, life event	4	9
CHILD STRENGTHS_LIKES	Descriptions of what the child likes to do or is able to do well	4	8

CONCEPTUALIZATION OF DISABILITY	Ways in which families speak about child's disability which are not individual characteristics of the child or a diagnosis	4	7
RECREATION	Parent perspectives regarding recreational experiences or opportunities for recreation	4	6
OTHER FAMILY MEMBERS DISABILITY_DIFFERENCE	Descriptions of other family members with disabilities, differences, or gifts	2	5
OTHER PEOPLES PERCEPTION	Comments or statements from others about the child	3	4
BULLYING	Parent concerns about their child being bullied. Explicit use of the term "bully"	2	2

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