INDIGENOUS PARENTS OF STUDENTS WITH SPECIAL NEEDS IN EDUCATION: THE LIVED EXPERIENCE

by

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Abstract

Parents of students with special needs may experience various stressors in association with their interaction with the education system. The process of having a child assessed and assigned a designation of special needs can be stressful because meeting with multiple professionals can be intimidating for some parents, the process can be confusing, terminology used may be unfamiliar, and the feelings they may experience realizing their child is having challenges may be upsetting. In addition, following the designation, navigation of special education services can be challenging for parents.

Parents of Indigenous students with special needs may experience additional stressors when interacting with the school system. There is an incompatibility between traditional Indigenous cultural values and the values of mainstream education, there are constructs that exist in special education that may not exist in the same way for Indigenous people, and some parents believe assessment is attempted assimilation. In addition, many Indigenous parents have previous involvement with residential schools. The residential school experience was impactful for many who attended. All students who attended experienced loss of language and culture, and many also experienced abuse. These factors may impact how Indigenous parents perceive the current education system.

In the present study, the experiences of seven Indigenous parents of students with special needs in education were explored. The aim was to better understand the experience of Indigenous parents regarding the processes that lead to their child's designation and their navigation of services during the initial years following the designation. Semi-structured interviews were conducted with parents from the Lower Mainland of British Columbia. Six broad themes emerged following data analysis using Interpretative Phenomenological Analysis.

Findings indicate some commonalities between Indigenous and non-Indigenous parent experiences. The use of special education terminology may be upsetting, feelings of guilt and intimidation may arise when interacting with educators, learning how to navigate the system can be time consuming, and parents may experience stress as a result of their child being bullied as a result of their designation.

In addition, findings identified which are specific to Indigenous parents and supported by previous studies include: significant parent involvement in their child's education, the importance of relationships with educators, the inclusivity of Indigenous communities, possible cultural discontinuity between the home and school, the construct of special needs not existing or existing in a different way in traditional culture or language, and the possible impact having a family member who attended residential school may have on the current view of schools for children and their parents.

Preface

The present study was conducted by the graduate student under the supervision of her research supervisors, Dr. Laurie Ford and Dr. Jo-ann Archibald. The graduate student was responsible for the data collection, and primarily responsible for the analysis and writing components of the present study. This thesis is representative of the graduate student's work as a co-investigator and lead author. The research was conducted in the present study was approved by the University of British Columbia Behavioral Research Ethics Board (BREB) under certificate H16-00572.

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I would like to acknowledge the parent participants of the present study for coming forward and sharing their stories in contribution to the improvement of educational experiences of Indigenous children and their families. They shared deeply personal stories with unbridled honesty, emotion, and vulnerability, providing insight into their experiences as parents who have an Indigenous child with special needs in schools. I would also like to acknowledge the First Nations community members who facilitated my connection with parent participants, and contributed to my understanding of the perception of learning differences in traditional Indigenous culture. I offer my thanks to the educators in schools who supported this project and facilitated my connection with parent participants. I would also like to express my profound appreciation to Dr. Laurie Ford for her guidance and support throughout my graduate school experience, and to Dr. Jo-ann Archibald for her guidance as an Indigenous scholar in this and other projects throughout my graduate studies. Finally, I would like to express love and appreciation to my family and friends, who provide endless support to me in everything I do.

Chapter 1: Introduction

Positioning the Researcher

My mother is from the Smith family of the In-SHUCK-ch Nation and the Jimmie family of the Squiala Nation. I was given my middle name to honor my great-grandmother, the late Theresa Jimmie, who was a renowned weaver and contributed significantly to the revival of Sto:lo cultural practices. My father is French Canadian and Danish. While I identify strongly with my First Nations ancestry, I recognize that being of mixed heritage is a gift that has allowed me to see with both worldviews.

I was a teacher prior to pursuing graduate studies. My journey as an educator began while sitting in a lecture of Dr. Jan Hare's Introduction to First Nations Studies course during the third year of my undergraduate studies. As a First Nations woman I thought I knew everything about First Nations people, yet two friends who were enrolled in a social work program were insistent that I take an introductory course. I did not predict that this course would alter my path. I remember the moment it hit me: the legacy of residential schools continues to impact my family, our communities, and our children in the education system. We need more Indigenous educators. After searching my mind for answers, I realized I could contribute. I was taught that when you are in a position to help, you help. My journey began.

I was a teacher in the Lower Mainland of British Columbia for several years, working primarily in special education and Indigenous education. I worked with students in kindergarten through grade 12, as well as adult education. While I was blessed to support many families during my time as an educator, I was most drawn to working with Indigenous families who had a child with special needs. For many of these caregivers, navigating the special education system was overwhelming, yet they struggled to see educators as allies because of their family's prior

experience with residential schools. Being from a family of a residential school survivor was often one of the first experiences caregivers would share with me, and I would share the same. This communication fostered trust and mutual understanding, and implied their request of a certain level of sensitivity when working with the family.

While the BC Ministry of Education provides targeted funding to support Indigenous students and collects data each year to monitor student progress, no information is collected from parents. Caregivers are important allies for educators because they provide a more holistic view of students, they can inform educational programming, and can collaborate with schools to provide a continuum of support for students in the home. Educators will benefit from gaining a better understanding of Indigenous caregivers' experiences with the education system. In particular, it is my goal to give voice to Indigenous caregivers who have a child with special needs. While my journey as an educator is by no means complete, this research is my current contribution to the long-term goal of improving the educational experience for Indigenous children and their families.

Overview

In 2011, Indigenous people represented 4.3% of the Canadian population, and the population continues to increase (Statistics Canada, 2014). While the number of Indigenous people living in each province varies, one of the largest populations is in British Columbia (BC). According to the BC Ministry of Education Aboriginal Report (Ministry of Education, 2015), over 11% (62,491) of the student population in BC self-identified as Aboriginal during the 2014-2015 school year. The vast majority of students that self-identified as Aboriginal were not living on a reserve (54,348 or 87%), which means that the majority of Aboriginal students in BC are receiving their education in public schools.

Public school programming and funding are the responsibility of provincial and territorial governments (Indigenous and Northern Affairs Canada [INAC], 2015). Special education is one of the services for which provincial and territorial governments are responsible (Ministry of Education, 2013). Special education involves support for students with special needs. Special needs categories in BC include, among others: intellectual and learning disabilities, behavioral needs or mental illness, physical or health impairments, Autism spectrum disorder, and giftedness. Students of Indigenous ancestry have been overrepresented in several special needs categories for years (Ministry of Education, 2014). Over the past 5 school years, 5% of Indigenous students were identified as having a learning disability compared to 3% of non-Indigenous students. Similarly, 6-7% of Indigenous students were identified as having a behavior disorder, compared to 2% of non-Indigenous students.

Not only are Indigenous students over-represented in several special needs categories, but they continue to experience lower graduation rates than their peers. The BC government committed to achieving parity in educational outcomes between Indigenous students and their non-Indigenous peers by 2015 (Office of the Auditor General, 2015). While the six-year completion rate for Indigenous students has improved dramatically over the past several years, there was still a 23% gap during the 2014-15 school year (Ministry of Education, 2015). As noted by the Auditor General in a recent report on the education of Indigenous students in BC, "the gap is narrowing but more can be done" (Office of the Auditor General, 2015, p.3).

Potential issues for Indigenous parents regarding the current education system include an incompatibility between Indigenous values and mainstream educational values (Tsethlikai, 2011), constructs in special education that may not exist in the same way for Indigenous people (Mushquash & Bova, 2007), and the belief of some parents that assessment is an attempt at

assimilation. In addition, many Indigenous parents have previous experience with residential schools, which may impact their perception of the current education system (Barnes, Josefowitz, & Cole, 2006). With a better understanding of parent perceptions of their experiences as they navigate the special education process with their own children, we can begin to develop culturally responsive approaches to address the education of Indigenous students with special needs.

The purpose of this study was to explore the lived experience of Indigenous parents of students with special needs and their interaction with the education system. The main focus was to gain a better understanding of Indigenous parent experiences receiving special education services for their child. In particular, the focus was on parent experiences with the processes that lead to their child's special education designation and their navigation of special educational services during the initial years following their child receiving a special education designation.

Definition of Key Terms

Aboriginal. The term Aboriginal is used to describe the original inhabitants of North America and their descendants (INAC, n.d.). This term encompasses three separate groups of people with unique cultural practices and languages including First Nations, Inuit, and Métis. Aboriginal peoples may be living on a reserve or off-reserve.

Indigenous. The term Indigenous is also used to describe the original inhabitants of North America and their descendants (INAC, 2016) and is used interchangeably with the term Aboriginal throughout the Indigenous and Northern Affairs Canada website.

Parent. For the purposes of this study, a parent is defined as the primary caregiver who lives with the child the majority of the time. This may include the biological parents, biological grandparents, or biological aunt or uncle. Grandparents, aunt, and uncles may be included if they

are the foster parent who has had custody of the child for the majority of the child's life. In this study it is the person who is in the legal position to make decisions about educational programming.

Special Education Needs. For the purposes of this study, special education needs are defined as characteristics that make it necessary for a student to undertake an educational program unique to that student with resources that differ from those needed by the majority of students. Special education needs are identified during assessment of the student and the assessment is the basis for determining the appropriate educational program for that individual (Ministry of Education, 2013)

Summary

The vast majority of students who self-identify as Indigenous in British Columbia attend public schools. Despite the gap in educational outcomes for Indigenous and non-Indigenous students narrowing, parity has not been achieved. Potential difficulties regarding Indigenous parents and the education system include differences in values, differences in perception of special education constructs, and family experiences with residential schools. With a better understanding of parent experiences receiving special education services for their child, we can begin to develop culturally responsive approaches to address the education of Indigenous students with special needs.

Chapter 2: Review of the Literature

Introduction

The purpose of this chapter is to summarize the existing research relevant to Indigenous parents' experience interacting with special education systems. This includes an introduction to what special education services entail in BC public schools, parent experiences with having a child who has been identified with special needs, parent experiences with the identification process and subsequent program planning, family-school collaboration in special education, information about Indigenous students in BC, considerations regarding assessment and Indigenous populations, family-school collaboration with Indigenous parents, and a brief review of the continued impact of residential schools.

Special Education Services

All children with identified special needs have unique strengths and learning profile and is entitled to educational services in addition to the mainstream programming public schools offer (Ministry of Education, 2013). The nature of additional support depends on the particular needs of the student. Support is individualized and is described through the creation of an individual education plan (IEP). An IEP is a document created by educators in collaboration with caregivers and the student (when appropriate) that should be updated regularly, and adapted as needed. An IEP should include information about student strengths, challenges, school history, assessment history, current services, and whether the student has a BC Ministry of Education designation or not.

Prior to receiving a special needs designation, the student may have undergone a psychoeducational assessment. A psychoeducational assessment may involve an evaluation of an individual's cognitive abilities, academic achievement, executive functioning, behavior, and/or

social-emotional functioning. It is a comprehensive evaluation conducted by a trained professional with a goal of understanding a student's strengths and needs. Educators use the information gathered through the assessment to plan educational programming for the student. Students are referred for an assessment by their parents or by school staff when they are experiencing difficulties that school-based resources are not able to resolve.

Parent Experiences with Children with Special Needs

Parents of children with special needs may have unique experiences with parenting. When children later identified with special needs are young, they may exhibit behavioral challenges that can impact the interaction between the parent and child (Kubicek, Riley, Coleman, Miller, & Linder, 2013). Children may be less inclined to respond to parent initiation of interaction than children who are not identified with special needs, and may be less inclined to initiate engagement themselves. In addition, children may be less able to express themselves, and have less predictable behavior. Parents may respond by misinterpreting their child's behavior, withdrawing, or becoming impatient. The strained interaction may result in parents experiencing feelings of ambivalence, grief, or guilt.

Emotions associated with having a child with special needs extend beyond the interaction between the parent and their child. Upon learning that their child has identified special needs, some parents experience feelings of sadness or grief (Taub, 2006). These parents may indicate that they are grieving the loss of the dreams they had for their child. The sadness they feel as a result of their child's disability may be a continuing emotion, or it may recur intermittently. Some educators believe parents undergo all five stages of grief as a response to disability including denial, anger, bargaining, sadness, and acceptance (Alfred, 2015). With this view, the

disability is seen as a loss because it means the child is flawed. This perception can cause strain on the relationship between the parent and the child.

Swick & Hooks (2005) conducted a study with parents of five children with special needs, as well as educators involved with the children, and found that parents may experience varying emotions related to their child being identified with special needs. Initially, parents may experience shock upon receiving the news. Following the shock, parents worry that they have to prepare for a fight as they move forward in advocacy for their child. Some parents are concerned about their own ability to control their emotions when advocating for their child. Other emotions include daily upset about what the parents should be doing for their child or what they should be preparing to do next, and frustration about the amount of time parents have to spend teaching themselves about the special education system in order to advocate for their child effectively. de Boer, Pilj, & Minnaert (2010) found that an additional source of stress for parents of children with special needs is that their children may tend to be less accepted by peers, have fewer friendships than their peers, and are less interwoven in classroom networks. These emotions are not typical for families of children without disabilities and may cause additional stress for parents.

Parents of children with behavioral, emotional, and social difficulties may experience a combination of guilt and blame when interacting with the school system (Broomhead, 2013). Some educators blame parents when a child has behavioral, emotional, or social difficulties because they believe the difficulties are a result of ineffective parenting. While some believe it is common for parents to experience guilt regardless of the nature of the child's disability, Broomhead (2013), in a study of 22 parents and 15 educators, examining relationships between parents of children with special needs and educators using semi-structured interviews, found that

guilt is particularly common for parents of children with behavioral, emotional, or social difficulties because of the intense blame educators place on parents. It was also reported that formal diagnosis of behavioral, emotional, and social difficulties as an identified special need actually reduced parent blame by shifting blame to a biological condition.

Parent Experiences with Identification and Program Planning

The process of having a child assessed and identified with special needs may be stressful for parents (Cloth, 2006). There may be a shift in how the parent perceives the child after a label of special needs is assigned. There may also be a shift in the day-to-day interactions between the parents and the child, and within the family if there are significant changes in how the child will be supported at school and within the home (Merkel, 2010). Meetings may involve collaboration between parents and multiple educators, which can be intimidating for parents as educational terminology used during the meeting may be unfamiliar. In addition, difficulties may arise if the family does not value standardized assessments or does not have an understanding of what the assessments are measuring (Bevan-Brown, 2001).

Educational planning follows the assessment and identification of a child's special needs. Educational planning should be a collaborative effort that involves the parents, educators, and the student when appropriate. Planning should be formalized into the form of an Individual Education Plan (IEP), and should involve the identification of educational goals, individuals responsible for assisting the child in completing those goals, timelines for completion, and methods for assessing whether goals have been attained. Educational planning should occur at the beginning of the year, revisited at the end of the school year to evaluate progress, and can be adapted throughout the year as needed.

While all parties involved in collaboration for educational planning are working in the best interest of the child, successful collaboration between parents and educators can be difficult to attain for several reasons. It can be difficult for educators, parents, and students to come to an agreement as to which goals the student should be working towards (Goepel, 2009; Volk, Craig, Boyce, & King, 2006). There are often differences in the perception of need and misunderstanding between stakeholders. Teachers see children primarily in the educational setting, whereas parents see them in a variety of settings. If stakeholders know students in different capacities it can lead to differences in perception of student ability.

In a study of parent perception of the IEP writing process, which consisted of interviews with 20 parents who had at least one child with special needs, Zeitlin and Curcis (2014) found that the IEP meeting can be a highly emotional event for parents. IEP meetings can be depersonalized because of the focus on filling out paperwork and going through documentation instead of true collaboration. Parents may believe the IEP document is focused on the child's deficits and positions the child as an object of remediation. Parents find IEP meetings involve asymmetrical relationships because the document is hard to understand and the process is overwhelming. Parents may leave the IEP meeting feeling frustrated, dissatisfied, and dejected. It is important that parents have an understanding of the IEP conference proceedings (Harry, 2008), and feel that they are part of a genuinely collaborative process.

In an article responding to the deficit model of disability, Alfred (2015) reviewed literature that indicates some parents have had disagreeable experiences when working with educators. Parents have felt unwelcome and disempowered when working with school professionals to build an educational program for their child. When educators have the belief that parents experience the stages of grief when learning their child has a disability, it may result in

educators perceiving parents as vulnerable and more in need of support, rather than as partners in a collaborative process. Further, if educators decide a parent is in denial, which is one of the stages of grief, they may believe they have a seemingly professionally defensible justification for marginalizing a parent's opinion. Having a child with special needs may result in unique stressors for parents including a variety of difficult emotions, and challenging educational processes.

Family-School Collaboration in Educational Processes

It is important for parents and caregivers to participate in the psychoeducational assessment process and the IEP writing process for their child (Ministry of Education, 2013). Caregivers can give insight into strengths and needs outside of the school setting and their knowledge can be helpful for educators to gain a more thorough and holistic understanding of a child and the child's adaptive functioning. Teachers can make use of parent knowledge about their child's development to inform educational programming (Swick & Hooks, 2005), as parents see their children in multiple environments in addition to the school. Further, according to the BC Ministry of Education, parents have a responsibility to support their child's education and should be offered the opportunity to engage in consultation meetings regarding the educational programming of their child with special needs (Ministry of Education, 2013).

Parent involvement with their child's education is associated with additional benefits. The results of a study that examined data of students with a primary designation of emotional disturbance, which was extracted from an American national longitudinal study conducted with elementary students with a special needs designation, indicates that greater parent involvement with their child's education was associated with greater academic success for the child (Duchnowski et. a., 2012). Mueller and Buckley (2014) found that parent involvement in their

child's education results in positive outcomes for children from all grade levels and all abilities. Their study indicated that there is a relationship between parent involvement and academic achievement, increased attendance, increased social and behavioral skills, and increased likelihood of graduation and successful transition to post-secondary. These improvements are extremely important for students with special needs because they are more likely to struggle with academics, mental health, attendance, and behavior.

Despite the reported benefits of parental engagement in their child's education, some parents of students with special needs experience barriers to involvement with schools. For example, parents reported to Mueller and Buckley (2014) that the special education system causes them to feel overwhelmed and confused. In particular, in this interview study with 20 fathers of children with disabilities, the fathers reported that the IEP meeting is particularly stressful because of the educational jargon used and the confusing procedures. Parents also described difficult interactions with educators including clashes with teachers because of poor communication, a lack of trust, and strained relationships. In fact, parents reported that challenging experiences interacting with educators have resulted in a decrease in parent involvement with educational processes.

Parents of children with special needs in a study by Rodriguez, Blatz, and Elbaum (2014), were interviewed to explore their perception of schools' efforts to engage them in their child's school. Parents reported that barriers to their engagement in schools included negative attitudes from school personnel towards cultural norms of minority groups, lack of parental social capital, and school personnel resistance to building trust. Similarly, results from a study by Hansuvadha (2009) using semi-structured interviews to explore the professional practice of 11 graduates of a special education teacher preparation program indicated that parents often find

attempts at collaboration with educators unsuccessful and disappointing. The parents who participated in the study indicated that barriers to their involvement in schools include negative educator attitudes towards families of children with special needs, linguistic and cultural differences, and parent perception that educators behave territorially instead of collaboratively. For example, parents may perceive their opinion is less valuable than educator opinion in the development of educational programming because they are not trained educators. Various stressors related to psychoeducational assessment and the IEP writing process may impact parental involvement in these educational processes.

Results from the study by Rodriguez et. al. (2014) that explored parent views of school efforts to engage them also indicate that while parent involvement in their child's education is associated with improved student success, the strength of the relationship between the school and the parents may be dependent on the level of self-efficacy of the parents. Parents of children with special needs reported being less involved in their child's education than parents of children in general education; however, parents with greater self-efficacy took more initiative to engage regardless of effort from the school to involve them. Parents with low self-efficacy were less likely to engage with schools unless the school made a concerted effort to engage them.

Indigenous Students in British Columbia

Indigenous students have been over-represented in several special needs categories in BC including learning disability, moderate behavior support/mental illness and intensive behavior support/mental illness, for years (Ministry of Education, 2014). Of particular note, Indigenous students have been over-represented threefold in the behavior categories compared to non-Indigenous students over the past five school years. Indigenous students are also under-represented in the gifted category. This is of particular importance because students with special

needs have a lower rate of graduation compared to the rate of all students in BC. During the 2013/2014 year, the overall rate of graduation for all students was 84.2%, compared to 62.2% for students with special needs. Similarly, students of Indigenous ancestry with special needs had a graduation rate of 61.6%.

A recent report to the Legislative Assembly of British Columbia by the Auditor General indicates that over-representation of Indigenous students in special needs designations is among several persistent gaps in school-related success of Indigenous students compared to non-Indigenous students (Office of the Auditor General, 2015). Other areas include lower scores on provincial assessments for reading, writing, and numeracy, as well as lower graduation rates and enrolment in post-secondary programs. Based on research conducted with representatives from the BC Ministry of Education, district staff from across the province, and members of various Indigenous communities, a form of racism in the BC education system involves educators having low expectations for Indigenous students. The Auditor General used the term "racism of low expectations" (Office of the Auditor General, 2015, p.37) to describe two trends. Indigenous students are more likely to be granted a School Completion Certificate even when they do not have a special needs designation, and Indigenous students are almost twice as likely to be enrolled in courses that limit their options for post-secondary education.

There are some discrepancies between traditional Indigenous culture and Western culture predominant in schools. While it is undesirable to make generalizations to all Indigenous groups, there are some common elements among North American groups (Dauphinais, Charley, Robinson-Zanartu, Melroe, & Baas, 2009). Indigenous groups think in holistic terms traditionally, which means all things are related. Western thinking involves linearity and categorizing. While many individuals identify with a culture other than the dominant

Eurowestern society in which we live, the differences between the two worlds for Indigenous people are great, involving basic values and belief, ways of interacting with one another and the environment, language use, and behavior. For example, Indigenous language may not have separate constructs for communication and help-seeking behavior as exists in Western conceptualization.

There is cultural discontinuity when children are socialized in an environment that is dissimilar to their traditional values and ways of knowing (Whitbeck, Hoyt, Stubben, & LaFromboise, 2001). Traditional values include sharing of resources, the importance of group success, and reluctance to speak out. Western culture encourages the partitioning of resources, individual success, and sharing of individual opinions. Cultural discontinuity may be impacting student performance in schools and the lack of educator understanding of traditional Indigenous culture may be contributing to misunderstanding of Indigenous students and possibly contributing to the overrepresentation of Indigenous students in special needs categories.

Assessment and Indigenous Populations

Differences in culture are especially important when working with culturally and linguistically diverse families. One aspect of special education processes that may impact Indigenous parent perception of receiving special education services for their child is the assessment process. One important concern is whether the construct being discussed exists in the family's culture in the same way as it exists in the dominant Western culture (Mushquash & Bova, 2007). For example, many Maori, who are Indigenous people of New Zealand, consider a member who cannot speak their traditional language disabled because that person cannot fully participate in their culture, however, this criterion does not qualify an individual to receive additional supports (Bevan-Brown, 2001). A timeframe was not traditionally placed on human

development for Maori. According to the Diagnostic and Statistical Manual – Fifth Edition, symptoms of an intellectual disability must begin in the developmental period (American Psychiatric Association, 2013). Given the lack of timeframe for human development, Maori do not have a traditional term to describe intellectual disability (Bevan-Brown, 2012).

In addition to the possibility of special needs constructs differing for Indigenous groups, the concepts of numbers, time, space, and relationships may also differ (Dingwall, Pinkerton, & Lindeman, 2013). Many cognitive assessments rely on student manipulation of numbers and mental manipulation of objects in space in order to meet task demands. Assessment of individuals who do not share the same concept of numbers and space may have implications for the validity of the results. Working with individuals who have different concepts of relationships may also pose a challenge. Assessment is dependent on the existence of a trusting relationship between clients and clinicians. Building rapport and trust may require more time when working with Indigenous peoples.

Indigenous persons may not perceive an individual with special needs as being an individual with a deficiency or disability. Disabilities are a Western construct (Pewewardy & Fitzpatrick, 2009) and the attribution of what causes individuals to present with special needs varies depending on the group. Some believe that speaking about a disability gives it power to manifest in human form. Some believe that a disability is when you have few relationships with others, and that disabilities are not caused by medical or environmental factors. Many Indigenous groups view a child with a disability as someone able to be an integral part of the community in his or her own way (Gerlach, 2008) and do not view the individual's differences as problematic. In this case, parents may be less eager to seek intervention to address a problem they do not feel exists. Some groups attribute a disability to disharmony caused by the intrusion of a spiritual

being, tension within the family, or someone within the kinship having done something wrong (Dauphinais, Charley, Robinson-Zanartu, Melroe, & Baas, 2009).

Indigenous groups may seek supports for their child through avenues outside of the school system. For example, some groups seek support such as spiritual ceremonies (Begay, Roberts, Weisner, & Matheson, 1999). Parents who sought spiritual services believed that they benefitted in several ways. Parents indicated their child showed physical and developmental improvements as a result of the ceremonies. In addition, parents perceived the ceremonies helped them cope with their child's disability, and provided more hope and positive expectations for the child's future.

Another important consideration with the assessment of Indigenous students is language use. Indigenous individuals who use an Aboriginal dialect but do not speak their traditional language are actually learning a new language when learning the standard form of English (Peltier, 2010). Aboriginal English dialects are used widely for conversation in both rural First Nations communities and urban communities by individuals who are monolingual in English. Aboriginal English dialect may differ from standard English in phonology, vocabulary use, sequencing, the connection between ideas, and the use of silence. Clinicians may misinterpret pronunciation differences for articulatory deficits. This is significant because Indigenous individuals who use Aboriginal English dialect may be at a disadvantage in the assessment process.

Family-School Collaboration with Indigenous Parents

Indigenous parents are likely to experience similar stressors associated with the psychoeducational assessment process and the IEP writing process as non-Indigenous parents, and therefore may experience similar barriers to engagement with schools. Some educators

perceive Indigenous parent involvement with schools low in general, and they attribute this to the belief that Indigenous parents do not care about education (Robinson-Zanartu & Majel-Dixon, 1996). In their study of community experiences of Indigenous education in urban settings, where qualitative data were collected in the process of a longitudinal study examining how stakeholders (students, Elders, families, and educators) could collaborate to support reform in Indigenous education in a Canadian school district, Madden, Higgins, and Korteweg (2013) indicate that while Indigenous parents were found to have less interaction with schools than desired, the barriers present did not include a lack of caring for education. Barriers included unwelcoming schools, colonized classrooms, unilateral decolonization, and the professionalization and formalization of classroom teaching.

Some Indigenous community members and school staff agree that an increase in parent-school collaboration should be a priority (Lea, Wegner, McRae-Williams, Chenall, & Holmes, 2011; McBride & McKee, 2001), and according to the report to the Legislative Assembly by the Auditor General, indicate that, "Aboriginal parents need to feel they are a more integral part of the education system" (Office of the Auditor General, 2015, p.11). According to the results of a study by Gajar and Matuszny (2002), which investigated the involvement of Indigenous and non-Indigenous parents in the IEP process via the completion of a parent involvement survey, Indigenous parents were involved in their child's school through a variety of avenues. Parents attended school events, helped their children with homework, established a home environment conducive to learning, and served as volunteers at the school. One suggested point of engagement is the development of inservice training in collaboration with parents. Topics should include how to: work with your child at home, communicate with professionals, and connect

with other parents of students with special needs. It was also suggested by the parents of this study for schools to create a bank of resources that parents can borrow for use at home.

Pushor and Murphy (2004) articulate that while all parents are marginalized from schools, Indigenous parents experience greater marginalization. Educators see Indigenous parents as difficult when they advocate, and uncooperative when they do not become involved. Indigenous parents are blamed for disparities in educational outcomes of their children and perceived to care little about their child's education. From the perspective of Indigenous parents, the dominant education system is not a cultural fit and parents often feel shamed when sharing Indigenous ways of knowing. In addition, barriers for Indigenous students include low expectations from educators, few Indigenous educators and role models in schools, and disregard for diversity in course content and assessment. Ultimately, the lack of congruency between Indigenous culture and the culture of schools, as well as educator judgment, may keep Indigenous parents marginalized and create barriers to meaningful collaboration.

Residential School

Further to the possible stress as a result of engaging in educational processes and having differing cultural constructs, Indigenous families may experience additional stress when interacting with the education system in general. Many caregivers of students currently in the education system have previous involvement with residential schools, which were lawful, government funded and controlled, church-run schools that operated from the mid-1800s (Barnes, Josefowitz, & Cole, 2006; Elias et. al, 2012; Madden, Higgins, & Korteweg, 2013) until the last one closed in 1996 (Legacy of Hope, 2012). Many students experienced neglect, sexual abuse, and physical abuse (Bombay et al., 2011; Elias et al., 2012; Pearce et al., 2008; Trocme at el., 2004).

It is important to note that the legacy of residential schools extends beyond impacting individuals who attended the schools (Truth and Reconciliation Canada, 2015). They have affected the lives of residential school survivors' children, grandchildren, and communities. Abuse suffered in schools is a gross breach of trust. For some survivors, the experience left them distrustful not only of schools, but of everyone. The residential school experience continues to impact how Indigenous individuals interact with the current education system and must be considered to some degree in the present study.

Indigenous community members report that, as a result of residential school attendance, many continue to experience fear of authority figures, mistrust of schools, and reduced ability to advocate for their children (McBride & McKee, 2001). Many Indigenous people find that schools are unwelcoming and continue to be colonized because education is still centered on European epistemologies and language (Madden et al., 2013). For some Indigenous individuals, assessment in schools is perceived as an attempt at assimilation because of the disregard for local culture (Mushquash & Bova, 2007). While it is recognized that the residential school experience had a significant impact on many Indigenous families, an exploration of residential schools is not the focus of this study.

Summary

Parents of children with special needs may have emotional and challenging experiences parenting their child and interacting with the education system, including the identification of their child's educational needs and program planning with educators. Indigenous parents of students with special needs may experience additional stressors including a lack of congruency between their own beliefs and the assessment process, unwelcoming schools, and prior experience with the residential school system. A significant gap in our knowledge is how

Indigenous parents experience the identification of their child as having special needs including the processes that precede their identification and the factors that contribute to this experience. In addition, we know little about the navigation of special educational services following their identification.

Chapter 3: Methodology

Overview

In this chapter, Interpretative Phenomenological Analysis, selected as the methodology for the present study is overviewed. The approach criteria for participant involvement as well as recruitment are described. Data collection including preliminary work, background information, semi-structured interviews, and reflective journal are detailed. Ethical considerations, detailed data analysis, and approaches to ensure rigor are explained.

Purpose

The purpose of the present study was to understand the lived experience of Indigenous parents who have a child with special needs regarding the process of receiving special education services. In particular, the focus of the study was to gain information on their experiences with the processes that lead to their child's special education designation and their navigation of services in the school during their child's initial years with a special education designation.

Research Questions

In this study, the following questions were examined:

1.) What are the experiences of Indigenous parents who have a child with identified special needs with the process of initial identification and designation?

2.) What are their experiences with post-designation navigation of special education services?

Interpretative Phenomenological Analysis

Given the focus on caregiver perceptions, Interpretative Phenomenological Analysis (IPA) served as the methodological approach (Eatough & Smith, 2008). IPA is a suitable methodological approach for research with culturally diverse populations because understanding

an individual life involves recognizing the cultural lens through which the individual experiences events. In addition, it is recognized that reality is dependent on the language of an individual's culture and that thoughts and feelings are conceived in a culturally specific language. IPA attends to an individual's belief systems and how their belief may or may not be manifested in their behavior. The focus is on the individual, as IPA concerns diversity and variability in human experience. This approach is interested in understanding the meaning of an event or concept in an individual life without placing preconceived expectations on an individual.

IPA is an appropriate methodological approach for use with parents of students with special needs. Each parent-child interaction and experience with a child's diagnosis of special needs is unique (Kubicek, Riley, Coleman, Miller, & Linder, 2013). IPA explores the lived experience and how that individual makes sense of that experience (Smith, 2004). It attends to the individual's feelings, desires, and motivations (Eatough & Smith, 2008) which are likely to be relevant when discovering a parent's experience with the school system given that having a child identified as having special needs may invoke a variety of emotions. In addition, IPA explores matters that are of considerable importance to the participants, such as a child receiving a diagnosis of special needs.

IPA is phenomenological in that it uncovers perceptions of events and it is hermeneutic in that the analyst and participant make sense of that experience in conjunction (Smith, 2004). The initial focus is on the experience of each individual participant, followed by cross-case analysis for convergence and divergence in aspects of individual parent experiences. By delving deep into the personal experience of participants, the researcher may approach a greater understanding of universal experiences. If we understand how individuals experience an event, it allows us to

think about how we and other people might approach and make sense of a particular situation being explored.

IPA acknowledges the central role of the researcher in making sense of participant experiences (Pringle, Drummond, McLafferty, & Hendry, 2011). The researcher must gain an understanding of the participant's world and the interpretation is constructed through collaboration of the participant and researcher (Larkin, Watts, & Clifton, 2006). Further analysis results in the initial description being related to social and cultural context. Having an Indigenous researcher may facilitate the understanding of the cultural context in which Indigenous caregivers make meaning of their experiences. For this reason, it is relevant to have an Indigenous researcher conducting research with Indigenous populations using the IPA approach.

Situating IPA and the Researcher's Work with Indigenous Families

Prior to collaboration with the participant, the researcher must develop a trusting relationship. For some Indigenous communities, there must be a relationship in place to offset the mistrust associated with research (Kovach, 2010). One important aspect of relationship development is for the Indigenous researcher to describe herself and her position in the world to the Indigenous participant as an acknowledgement that research will only take place with the trust of the participant (Kurtz, 2013). Historically, researchers have disempowered Indigenous communities and conducted research that did not benefit the community, and in some cases, harmed communities (Simonds & Christopher, 2013). From an Indigenous perspective, research is linked to oppression and must be decolonized (Pualani Louis, 2007). Positioning oneself in the world as an Indigenous person in relation to the place where your community originates is an initial step towards decolonizing research.

Other elements of decolonizing research include privileging Indigenous knowledge and ways of knowing (Braun, Browne, Ka'opua, Kim, & Mokuau, 2013), the involvement of self-determination, and guidance by Elders (Kutrz, 2013). Some researchers dismiss Indigenous ways of knowing as being lesser than Eurowestern understanding of the world. For the purpose of this study, Indigenous knowledge and beliefs are accepted as truth. Self-determination concerns social justice (Smith, 2010), and places ownership of research with the participant (Kurtz, 2013). This means that the participants must be able to access the information they provide during research and they control what happens to the information. Consultation with Elders provides information about cultural protocols relevant to a specific group. Elders are the knowledge keepers in a community and can provide information about how to go about conducting research that is culturally sensitive for their communities. Elders should be involved throughout the process and can help determine what the research questions are, who is appropriate to participate in the study, help with the appropriate approach to participants, and guide the researcher through sharing findings with the community.

Relationship-building, including the positioning of an Indigenous researcher in the world, the use of self-determination, and the collaboration with Elders is essential for building trust when working with Indigenous communities for research purposes. Other elements of relationship-building incorporated into this study include respecting the diversity of the belief systems and experiences of the participants and the responsibility to share their experiences with educators in order to contribute to the healing process of Indigenous people with respect to the educational experience (INAC, 1996). Once trust is built, collaboration between the participant and the researcher will develop, leading to the facilitation of the researcher's understanding of the cultural context in which the participants make meaning of their experiences. Indigenous

scholars should lead research with Indigenous communities (Kurtz, 2013), as Indigenous people may be positioned to conduct research that upholds Indigenous culture (Kovach, 2010).

In the present study, the researcher incorporated relationship building by discussing the First Nations she belongs to, her family associations, and her background as an educator. Food and drink were provided prior to and throughout each interview, and participants shared information about their respective First Nations. Other elements of relationship-building included the researcher respecting the diversity of belief systems as each participant's worldview was accepted as truth. In addition, results of this thesis will be shared with educators from each district in which participant children attend, as well as with local First Nations. To address self-determination, each participant was given an electronic copy of their transcript and was offered the opportunity to make changes. An Elder from a local First Nation was consulted prior to conducting the interviews regarding appropriate approaches to working with Indigenous parents, and three Elders from local First Nations were consulted regarding the use of the term special needs in their traditional language.

Participants

Seven parent participants were included in the study. While the study was open to mothers and fathers, only mothers self-selected and initiated contact with the researcher. This sample size is consistent with the IPA approach, as a sample containing 5-10 participants is sufficient to get diversity of perspective while preserving the ability for in-depth analysis (Smith, 2004). A screening questionnaire was used to verify that each parent was Indigenous and biologically related to the child as the interest was in the experience of parents as Indigenous people interacting with the school system. Given the possibility that foster parents may volunteer to participate, it was decided that parents who are not biologically related to their child would be

accepted if the parent began caring for the child when the child was very young. One parent was non-Indigenous and not biologically related to the child. After a discussion with the supervisor and others in our research group, a decision was made to include her interview data in the study because of the consistency in her responses compared to Indigenous, biologically related parents. One Indigenous, biologically related grandmother was also included in the study.

The screening questionnaire also verified that parent participants had a child who was attending a public school, as the special education system in private and independent schools may differ. One parent whose child attends an independent school was included because she has experience with the public education system and met all other screening criteria. It was also verified that there was an IEP in place to ensure the parent had experienced the IEP development process. One parent was unsure whether an IEP was in place, and all other parents confirmed experiencing the IEP process. It was initially a requirement that the parent had undergone the assessment process for the first time within recent years prior to the interview. One parent was still involved in the assessment process, three had undergone the assessment within 2-4 years of the interview, and three had undergone the assessment 6-10 years prior to the interview. Parents who had not recently experienced the process were interviewed because of their eagerness to participate, and their data were included because of the consistency in responses compared to parents who had their child assessed more recently.

Table 1

Participant Summary

Participant	Indigenous	Type of School	Biological Relationship	Time Since Initial Identification	IEP in Place
Denise	First Nations	Public	Birth mother	In Process	Unknown
Melissa	First Nations	Public	Birth mother	6 years ago	Yes
Susan	First Nations	Public	Birth mother	3 years ago	Yes
Elizabeth	First Nations	Public	Biological grandmother	11 years ago	Yes

Emily	First Nations	Public	Birth mother	10 years ago	Yes
Lauren	No	Public	Adoptive mother	4 years ago	Yes
Sophia	First Nations	Independent	Birth mother	2 years ago	Yes

The children of parent participants attended five different schools in the Lower Mainland, British Columbia: one independent school, and four public schools from three school districts. Five of the participants were recruited through schools, one through a local First Nation, and one through word of mouth by a member of the researcher's lab at the university. The interviews varied in duration from 45 to 80 minutes in length, with the majority being an hour in length or greater. The data were collected over three months from June 23, 2016 to September 20, 2016. All children of participants discussed in the study were male except for one female. Children ranged in age from 8 to 18 years old, with the majority between 8-13 years of age. A brief description of the participants follows in the order that they were interviewed. Pseudonyms were assigned to the parent participants and their children to protect their anonymity. The researcher selected names from a list of historically popular names for ease of reading, and chose names for which there was no personal relationship to reduce the influence of the names on the researcher's analysis. Participant responses to the background questionnaire are summarized in the following brief descriptions of participants.

Denise. Denise, a full-time mother of five children, identifies as First Nations and English is spoken in the home. The child she discussed in this study is her son who was 8 years of age at the time of the study and currently going through an assessment with a psychologist at a pediatric facility. Denise reports that she and her son both experience difficulties with anxiety. While she did not attend residential school, both her parents and grandparents did. Denise attended school on her reserve prior to moving to the Lower Mainland.

Melissa. A First Nations woman whose territory is in central Canada, Melissa is the mother of one child who was 10 years of age at the time of the study. She attended traditional ceremonies throughout her upbringing and identifies strongly with her Indigenous culture. In the home, English, French, and the family's First Nations language are spoken. Neither Melissa nor her parents attended residential school, but her grandparents did. Her son, Richard, underwent a pediatric assessment prior to school entry and a psychoeducational assessment in the schools in early elementary. Richard was diagnosed with Attention-Deficit/Hyperactivity Disorder (ADHD) and a sensory integration disorder.

Susan. Susan is a full-time mother of three children and is a member of a local First Nation. Her daughter, whom she discussed, Janice, was 12 years old at the time of the study. English is spoken in the home. Her grandparents attended residential school, but Susan and her parents did not. Janice underwent a psychoeducational assessment in the schools two years prior to the study and received a designation of learning disability.

Elizabeth. A First Nations woman from the interior of Canada. Elizabeth is the biological grandmother of Louis, and a full-time mother of seven children. She speaks English and her First Nations language with her children. She, her parents, and her grandparents all attended residential school. Louis was 13 years of age at the time of the study and underwent a pediatric assessment as a toddler. He was diagnosed with fetal alcohol spectrum disorder (FASD).

Emily. Emily and her husband both work full-time, have three children, and she is a member of a local First Nation. She and her husband speak English and two First Nations languages with their children. Emily did not attend residential school, her parents did, and her

grandparents did not. The son she discussed in the study was 18 years of age at the time of the interview. He was diagnosed with a learning disability in early elementary school.

Lauren. Lauren is a non-Indigenous, adoptive parent to three Indigenous children who are siblings. Her husband works full-time and Lauren is a full-time mother. Her children speak English and two First Nations languages in the home. Her children also identify strongly with their traditional culture and the whole family is actively involved in cultural practices. Lauren has been caring for her children since they were very young. She indicated that none of the children's biological parents, grandparents, or great-grandparents attended residential school. The son she discussed in the study was 9 years old at the time of the interview. He underwent a pediatric assessment and was diagnosed with fetal alcohol spectrum disorder (FASD).

Sophia. Sophia is a member of a local First Nation and mother to three children. She and her husband identify strongly with their traditional culture and their family is actively engaged with their cultural practices. The family speaks English and two First Nations languages in the home. Sophia did not attend residential school, but her parents and grandparents did. The son she discussed in the study was 11 years old at the time. He underwent a psychoeducational assessment two years prior to the interview and he was designated with a learning disability.

Recruitment

Outside of Schools. Contact with a local First Nations band was one method for recruitment of parent participants. The researcher contacted the band councilor, with whom she had a prior relationship, by phone and asked how to approach the First Nation as a researcher. His suggestion was to contact the band council co-chairs. The co-chairs were emailed with an introduction to the researcher and an explanation of the importance of the study. The researcher brought a gift of traditional Indigenous medicine and teas to the band office for the co-chairs as a

follow-up to the request to work with the Nation. The researcher was directed to contact the Elementary Home School Counselor for contact with families.

A meeting with the counselor resulted in the identification of the primary method of information dissemination. Many of the parents are part of a social media group online where the counselor communicates with them regularly. It was suggested the researcher post the recruitment poster on the parent social media page with an introduction to the researcher, the importance of the research, compensation for participation, and the level of commitment while mentioning that the counselor is supportive of the research. The counselor also agreed to the researcher sending the recruitment letter home to parents through the school district in which the majority of the Nation's students attend school.

In Schools. The district administrator for Aboriginal education in a local school district with whom the researcher had a prior relationship was contacted by phone. After securing approval for the study from the district administrator, the researcher sent the superintendent of the district the provisional UBC Behavioral Research Ethics Board (BREB) approval, a summary of the thesis proposal, and the school district application. After receiving his approval the researcher met face-to-face with the district administrator to discuss dissemination of the study information.

The district administrator suggested that the researcher bring paper copies of the recruitment letter to three elementary schools and one high school with high populations of Indigenous students. All recruitment letters were sent home in envelopes. Some schools produced address labels for the Indigenous support workers to place on envelopes and send home to individual students. Others handed them out to each student of Indigenous ancestry in envelopes without address labels. The researcher had direct contact with Indigenous support

workers to explain the importance of the study and transfer the recruitment letters. The support workers were encouraged to share the importance of the study and to answer questions about the study. Participants contacted the researcher directly through electronic email or by phone.

The district administrator for Aboriginal education for another local school district was contacted with details about the study via email. While there was no response from the district administrator, the district coordinator in charge of research study approval was contacted with the following documentation: provisional UBC BREB approval, a summary of the thesis proposal, a completed copy of the district proposal for research, documents used for the study, and the abbreviated research proposal. Once approval was attained, the researcher approached school principals for approval to conduct research in their respective school communities. Two elementary schools and one high school with high populations of Indigenous students were targeted. The researcher had a previously established relationship with the administrator for one elementary school and had worked at the other in previous years. Both administrators approved the study while the principal for the high school did not respond.

The identity of potential participants was unknown to the researcher until the parents contacted the researcher by phone or electronic mail to express interest in the study. Identification beyond first name was not requested until formal consent was completed face-to-face following parent agreement to participate in the study.

Data Collection Procedures

Overview. The researcher's preliminary work is reviewed including initial engagement with the Indigenous community in this section. The researcher used a background questionnaire to collect demographic information. Semi-structured interviews were conducted to collect in-

depth information about participants and the researcher supported interpretation of the information by keeping a detailed reflective journal.

Preliminary Work. Prior to the beginning of the study, the researcher consulted with a Junior Elder and the educational coordinator from a local First Nation. It was important to consult Elders from local First Nations communities (Smith, 2010) regarding the preliminary interview protocol and to give recommendations on culturally appropriate approaches to conducting research with Indigenous parents who have a child with identified special needs. Involving Elders in the research process is one element of decolonizing research and is consistent with the guidelines for research with Indigenous populations in Canada (Canadian Institutes of Health Research, 2010). The Junior Elder expressed interest in the study and gratitude for the focus on the topic, and referred the researcher to the Nation's Home School Counselors for consultation as they work closely with parents and facilitate the assessment process when a child has been identified as requiring assessment for learning or behavioral needs.

Measures.

Background Information Questionnaire. During the initial interview, parents were asked to complete a background information questionnaire, which included information about the participants (languages spoken in the home, ethnicity, family history with residential schools, relation to the child, work situation for caregivers of the child; age, grade, and gender of the child with special needs) as well as information about when the child received the BC Ministry of Education special needs designation, the length of the process, and which BC Ministry of Education special needs designation the student received.

Semi-Structured Interviews. While a range of interview styles and other data collection methods are possible with IPA (Eatough & Smith, 2008), the most common is a semi-structured

interview (Smith, 2004), which was used in this study. In a semi-structured interview, the researcher creates a set of questions used to guide the interview but there is flexibility in that the researcher can pursue interesting areas of inquiry (Eatough & Smith, 2008). Participants are the experts of the topic being explored because their perception of the experience is the focus, and they are seen as storytellers. The semi-structured interview process facilitates storytelling by allowing the participant to guide the direction of the interview. The researcher does not dictate the course of the interview and should avoid trying to adhere to the interview schedule. The participant determines the direction of the interview and the researcher should ask follow-up questions to probe important aspects of an experience or an account when they arise. A semi-structured interview allows individuals to tailor their responses to their own perceptions and experience without being forced to respond in a limiting way as with a structured interview.

The interviews were conducted in a location in which the participants indicated they were comfortable and was convenient for them. Interviews were audio-recorded with the consent of the participants (Baker-Williams, 2000) and transcribed verbatim by the researcher in order to conduct data analysis. Interviews varied in length depending on the participant. Although interview questions were developed in advance, each participant controlled the direction and focus of the interview. This allowed the participant to guide the direction of the dialogue and supported the sharing of that person's lived experiences. Follow-up questions were asked as necessary. Following transcription, each participant was sent an electronic copy of the transcript for review. Participants were asked to inform the researcher of any changes, deletions, or additions they wanted to make to the transcript. Only one participant requested a paper copy. After numerous attempts to contact the participant over several weeks, the researcher was unable to deliver the paper copy to the participant.

Reflective Journal. The researcher kept a reflective journal to record personal reflections following interviews and interactions with participants (Lyst, Gabriel, O'Shaughnessy, Meyers, & Meyers, 2005). Notes regarding the tone and content of the interview were recorded to help clarify possible themes and document evidence for possible themes. In addition, reflective journals help researchers make explicit their biases and assumptions related to the research topic (Nastasi & Schensul, 2005).

Ethical Considerations

Prior to beginning research with the participants, ethical approval was obtained through Behavioral Research Ethics Board (BREB) at the University of British Columbia. Parents were informed of the nature of the study, which is the exploration of their perception of the education system as an Indigenous parent of a child with special needs. Participants were informed that they could withdraw participation at any time and choose not to respond to any question that makes them uncomfortable during the study (Brinkman & Kvale, 2005).

Confidentiality was ensured through the use of pseudonyms for participant identity, securing the data collected in a locked drawer for physical files, and password-protecting electronic files. Pseudonyms for the participants and for their children were used and documents pertaining to the study were identified by a code number. Participant names and contact information were separate from the interview transcripts, which themselves had coded identification. I also met the requirements of the research with Indigenous populations aspect of Tri-Council by engaging with First Nations communities in the Lower Mainland through consultation with Elders from local First Nations, and the extent of the researcher's community engagement was determined jointly with the community.

Data Analysis

In the IPA method, the researcher plays a central role in analyzing the data, or interpreting the meaning of a participant's account (Pringle et al., 2011). IPA can be thought of as double hermeneutic, or involving double analysis because it involves the researcher making sense of the participant making sense of a phenomenon (Smith, 2004). Analysis in IPA is not meant to be a prescriptive process; rather, it is flexible to allow unexpected themes to emerge. IPA is idiographic and analysis must begin with detailed examination of the first individual case. Specific data analysis was conducted following the process described by Smith, Jarman, & Osborn (1999) as follows. The researcher performed data analysis by hand and not through using electronic data analysis programs.

Step 1: Looking for emerging themes. The first step involved the researcher reading the transcript of the first case repeatedly while inserting initial comments about anything striking or interesting, including observations and preliminary interpretations. The repetition was important because increasing intimacy with the account may result in uncovering new insights. This step was completed with each transcript in electronic form. This was repeated for each transcript in the order the participants were interviewed. This process was repeated, but with summaries of participant statements in place of initial comments, resulting in two documents with comments for each transcript; one with initial comments, and one with summaries of participant statements. Finally, the researcher used initial comments and the summaries of participant statements to go through each transcript again to record broad emerging themes.

At this stage all information was considered potential data.

Step 2: Looking for connections. On a separate piece of paper, the researcher listed themes that emerged to look for superordinate concepts or themes for each participant. A table of

themes was created to explore relationships between terms. This facilitated the identification of broad themes and subthemes. Themes that were not rich in evidence in the transcript were dropped. Transcripts were reviewed for each broad theme to avoid researcher bias to influence theme selection. Once broad themes and subthemes were identified for the first transcript, all excerpts identified as belonging to the broad theme were moved into an Excel sheet so the excerpts could be reviewed altogether for cohesiveness.

Step 3: Continuing the analysis with other cases. The researcher began the preceding process anew with the second interview and all remaining interviews. Analysis is a cyclical process and themes emerging from analysis may shift the focus of the project. Once the researcher reached the fourth transcript, some broad themes common to each transcript began to emerge. As new themes emerged, they were checked against transcripts of interviews already analyzed. Some broad themes and subthemes from transcripts analyzed earlier in the process were reviewed and updated as new themes and subthemes emerged in later transcripts. This was repeated until a core group of broad themes was identified as shared across the majority of the participants. Any subthemes that were not shared by at least four participants were excluded from the analysis. See Table 2 in Chapter 4 for a summary of the broad themes and subthemes included in the analysis.

In addition to the preceding process, field notes were recorded following each participant interview to record general impressions and key points (Lyst et al., 2005). Throughout data analysis the researcher also engaged in reflective commentary (Shenton, 2004) to record personal reflection on the effectiveness of techniques, patterns emerging, theories, thoughts, and ideas. Field notes and a reflective commentary were analyzed during the theme identifying process

because the researcher chooses what data are important and what data are excluded (Ryan & Bernard, 2003).

Ensuring Scientific Rigor

The scientific rigor of qualitative studies can be discussed in terms of trustworthiness (Smith & Heshusius, 1989). The interpretation of and proof for trustworthiness in the present study will follow the outline and description provided by Shenton (2004), which includes credibility, transferability, dependability, and confirmability.

Credibility. Several indicators of credibility were used in the present study. First, procedures chosen for data collection and analysis were chosen based on ***methodologies previously used successfully with comparable participants***. Interpretative phenomenological analysis was selected because the approach has been previously used to investigate family engagement in special education (Eatough & Smith, 2008). Second, ***triangulation*** was used, which results in conclusions that are more credible when more than one source gives rise to the conclusion (Tracy, 2010). Information used to draw conclusions was taken from interview transcript analysis, researcher field notes, and researcher reflective commentary. Finally, tactics to increase ***participant honesty*** were used including providing participants the opportunity to withdraw or refuse questions, building rapport prior to engaging in questioning, and indicating to the participants that there are no correct answers (Shenton, 2004).

Transferability. Transferability refers to the ability of findings to be transferred to other situations (Shenton, 2004). Transferability is more appropriate for use with qualitative studies than the similar concept of generalizability because qualitative studies are in-depth analyses of historically and culturally situated phenomena where the goal is not generalization (Tracy, 2010). Some knowledge gained through qualitative methods can transfer to other settings. If there is

sufficient description of the phenomenon being investigated, participants involved in the study, and details about data collection and analysis, the reader can compare the phenomenon being described to instances they have seen emerge in other situations (Shenton, 2004). Sufficient information about Indigenous parent experiences with the education system was collected as evidenced by the inclusion of seven participants, which is sufficient to get diversity of perspective while preserving the capacity for in-depth analysis (Smith, 2004). In addition, boundaries of the study were conveyed to the reader to consider prior to transference including the number of schools and districts involved in the study, restrictions on participants, the number of participants, data collection methods, the number and length of data collection sessions, and the time period over which the data were collected (Shenton, 2004). This allows the possibility of drawing comparisons to the experience of other Indigenous parents of children with special needs in similar environments.

Dependability. Dependability refers to how reproducible the research process is (Shenton, 2004). This term is more appropriate for use with qualitative studies than reliability because the goal of qualitative research is not to duplicate findings. The process can, however, be replicated if the researcher provides sufficient detail about steps taken during the study. The researcher for the present study provided detail about the research design and implementation by providing a copy of the screening questions, background questions, and interview questions in the appendix of the study, information about data gathering in the Findings chapter, and evaluation of the effectiveness of the process in the Discussion chapter.

Confirmability. The concept of confirmability involves the researcher ensuring as much as possible that the findings are a result of the participant's experiences and not the characteristics of the researcher (Shenton, 2004). This was confirmed through the use of

triangulation as previously described, the formation of an audit trail, and the adoption of a reflexive approach (Alvesson, 2003). A ***reflexive approach*** involves the researcher challenging interpretations produced, exploring multiple possible sets of meaning, and acknowledging ambiguity in the findings (Alvesson, 2003). The researcher checked results with another graduate student to ensure the findings are not a result of the researcher's characteristics.

In addition to the procedures to ensure trustworthiness by Shenton (2004), and consistent with approaches to IPA, direct quotes from participant accounts are used (Pringle et al., 2011). Themes are illustrated and may be clarified with the use of direct quotations. Findings are supported and anchored in direct quotes from participants.

Summary

In this summary, a description of the IPA methodology was provided with support for its use in answering the research question presented in this study. Selection criteria for participants were described along with methods for recruitment and a brief description of each participant included. Procedures for data collection and data analysis were provided. Ethical considerations and issues of scientific rigor were discussed.

Chapter 4: Findings

Overview

The purpose of this study was to gain a greater understanding of the lived experiences of Indigenous parents who have a child with special needs regarding the process of receiving special education services, more specifically, the focus was on processes that led to their child's special education designation and navigation of services during the initial years following the designation. Interpretative Phenomenological Analysis was used to analyze the interview data from seven parents of Indigenous children who had been identified or were in the process of being identified as having special needs at the time of the study. The emphasis of this study was on how parents perceive and describe the meaning of this experience.

This chapter presents the findings of the study as identified in the broad themes identified from the analysis of participants' descriptions of their experience and its meaning. Six broad themes were identified across the analysis of the information from the seven participants. In addition to the themes that more directly addressed the research questions for this study, two additional broad themes were identified as being independent of the research questions – Indigenous Worldview and Indigenous Experiences. A summary of the themes and subthemes for the study is highlighted in Table 2. After a discussion of the data with members of the research team and supervisor it was decided that these are best identified as broad contextual information for the participants in the study. These two themes are presented in this chapter, prior to the themes more directly related to the research questions to facilitate the reader's understanding of parent experiences from an Indigenous perspective. The remaining themes and subthemes are presented within the context of the research questions. Subthemes discussed by

less than three participants were not included in the analysis in order to ensure sufficient density of evidence for each broad subtheme (Smith, 2011).

Table 2

Themes and Subthemes that Emerged from the Data Analysis.

Broad Themes with Subthemes	Number of Participants who Discussed Subtheme
Indigenous Worldview	
Indigenous Ways of Knowing	5
Cultural Practices	3
Indigenous Experiences	
Residential School	5
Experiences in Schools	5
Experience in the Community	4
Relationships	
Elements of Positive Relationship	6
Child Relations	5
Communication	
Identification	4
Assessment and Designation	4
Communication in the Community	4
Emotions	
Power Imbalance	4
Concern for the Child	4
Resources	
School	5
Community	5
Home	4

Contextual Considerations: Indigenous Worldview and Experiences

Theme 1: Indigenous Worldview. The theme Indigenous Worldview includes topics related to participant conception of the world which are common to many Indigenous groups. The significance of community, traditional learning and knowledge, and culture are discussed. The two subthemes identified within the broad theme are Indigenous Ways of Knowing and Cultural Practices.

Subtheme 1.1: Indigenous Ways of Knowing. Several elements of Indigenous Ways of Knowing arose during parent interviews, which are relevant to understanding parent experiences,

including the importance of community and inclusion of all members, sources of knowledge, and traditional learning.

Prior to beginning the study, the researcher contacted an Elder and language teacher from a local First Nations band to ask about terminology used to discuss the construct of special needs in traditional language. To her knowledge, no terminology exists to describe the construct. She recalls asking her late grandmother whether there is a term to describe a person who is intellectually challenged, as her sister was identified with an intellectual disability. Her grandmother was even more fluent in their language and confirmed the lack of terminology. She said the only term that may approximate the construct describes a person as 'weak minded.' The Elder described her sister as follows:

> She was my older sister. She was never not an Elder to me. Even when I 'passed' her in school. She was always there for me, with me, and never-ending kind. This is the way she was seen and perceived by all of our contemporaries. She wasn't treated differently by our friends and family. She wasn't excluded or shunned. She was included in all things to best of her capabilities. If we did tasks, she had hers too, some the same as everyone, some less demanding. We talked, played and grew together, each to our own best potential, choices, likes and dislikes.

The importance of community and the contribution of all members were discussed by several participants. For example, Susan noted the inclusiveness of ceremonial places, "Kids are supposed to be there." Sophia described inclusivity in the greater community, "In our communities, everybody is a part of the community," and she explains, "We work with kids that have different needs. It talks about inclusion; it talks about belonging. They're not excluded, they're not ignored, they're part of the collective, of who we are." Similarly, Elizabeth talks

about inclusiveness in her community, “My people are really kind-hearted to their kids, to all their kids.” For example, “I find that we’re more accepting to two-spirit[1] people,” and, “We don’t shun them, we celebrate them.”

One important component of the story shared by the Elder and language speaker prior to beginning the study is that each member of the community is viewed as a contributor. This point is further illustrated by Melissa when she contrasts the perception of her son in school and Indigenous communities:

> We call them Windigo but their purpose is, yeah they are very challenging and very frustrating, you know, but they’re our mirrors and they teach us that we don’t always have to conform and we can do things differently, and they teach us leadership, and so, from an Indigenous perspective, from where we’re from, he’s a gift, and he’s going to teach us so much, but from, like, a colonial, Western perspective, like in the school system, he’s frustrating, he’s got ADHD, he’s defiant, he’s all of these things that we look at and we, we treasure, and we think this is special.

Another element of Indigenous Worldview discussed is sources of knowledge. For Indigenous populations, knowledge does not traditionally come from books. Knowledge comes from Elders, ancestors, the land, and the spirit world. When discussing her gift of intuition, Elizabeth attributed her gift to her grandfather’s ability by stating, “My Mooshum was a Medicine Man.” Sophia describes knowledge shared with her about the ancestors:

> In our world, school does not start at 9am, school starts just before the sun comes up because that’s when the animals are out, that’s when it’s time for you to come inside, not to be moving so much, that’s when the ancestors are moving.

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[1] Two-spirited people carry male and female spirits. This term is used to describe sexual orientation, gender identification, or spiritual identity

Finally, traditional learning was also discussed. Traditional learning occurred outdoors because there were no schools prior to residential schools. Traditional learning was accomplished through observation, community socialization, oral teachings, and through ceremony. Traditional learning was experiential. During the assessment feedback session, the evaluator for Emily's son acknowledged that traditional learning did not involve a written system; rather, it was an oral system. Sophia provided the following description of her teaching her children how to harvest cedar to contrast learning in schools:

> What tree are we looking for, what kind are we looking for, how do you pull the tree, like the bark from the tree, how do you separate the inner bark from the outer bark because no book can teach you that and you have to be there and you have to be present…and no book can teach you the thrill of seeing a grizzly, we saw a grizzly this past year in the mountains, it was beautiful, we all kind of went, oh, it's the feeling of being in wild places, being a part of the landscape instead of separate from it.

Subtheme 1.2: Cultural Practices. Another subtheme related to Indigenous Worldview concerns cultural practices described by several participants. In particular, the importance of place for Indigenous people and the importance of protocol with respect to cultural practices were reflected in their explanations.

Some of the descriptions reflect the importance of place for Indigenous people. Indigenous culture, traditional knowledge, and language are born from and based on the traditional territory. Ceremonial practices are specific to each group. Melissa described her family's engagement in cultural practices, "My mom's done like eight years of [traditional dancing] and my uncle has a [traditional ceremony] and I remember, just a little girl, maybe four

or five, going to sweats and [traditional ceremony].” Lauren’s son illustrates the importance of place for traditional practices:

> My son describes it best because he [traditional] dances, and he’s like, I shouldn’t even be doing it here because all the dances down here, they just dance like the animals, like, that’s true, West Coast dancing is more, you dance like a raven or dance like an eagle, so he understands that, but as a, as a society we don’t understand that very well, we just, you know, it’s a little bit silly actually.

Each Indigenous group follows specific protocols for traditional practices and ceremonies. Melissa describes the protocols associated with her son being identified as a Windigo or backward spirit. First she describes the individual’s identification as being a backward spirit:

> You would get gifted something, right, like if you went to [traditional ceremony] and you woke up in the morning and had an eagle fan in front of your tent with the black, and white polka dots, someone’s acknowledge that you’re backwards, then we have our own ceremony for them.

Melissa also explained how the protocol for individuals identified as backward spirits differs from the rest of the community members:

> So, we have [traditional ceremony], is one of our most sacred ceremonies, right? We have a certain way of going in, and protocol and everything, when, at the end of the ceremony, they come in the opposite way and do everything totally backwards.

Lauren described a simple way for schools to use language that is more inclusive for Indigenous families. Many Indigenous groups refer to traditional practices conducted at gatherings as ‘work’ or ‘good work’ to indicate the importance of protocol. Lauren suggests that

schools can use these terms when addressing the group at school gatherings to help Indigenous families feel more included, “Ok, we’re sitting here, we’re excited, let’s do some good work and this is what our plan is, right, even that, but an Aboriginal family will be like, oh that fits in to what I know.” She also explained how her sons use their traditional protocol when the school hosts an Indigenous presenter:

> My boys, whenever they have an Aboriginal presenter and they do, like we work with the teachers, they have like a script saying, you know, introducing themselves in the traditional way, saying thank you to the person that’s imparting the knowledge and giving them a gift.

For many Indigenous groups, individuals traditionally go through ceremonies to mark significant transitions or significant events in their lives. Sophia described the ceremony her family is planning for her son:

> So right now for my son, we are planning a puberty rites ceremony, so we’re getting ready for him to become a man, so in April we are going to do some work in the [place of ceremony], so what we’re doing is, we’re going through the process as a family and him and his cousin are going to go through together. They’re going to be talked to, they’re being trained right now to go through a process of how, how do you carry yourself, how do you present your family and your grandparents, and how do you, how are you in a relationship, you know, how can you be a provider, how can you be mindful of supporting your community, when you go hunting you share food, our hope is that he’ll kill his first deer this year and feed his own people at his ceremony.

Theme 2: Indigenous Experiences. There were several experiences described by parents, which may be unique to Indigenous families, given the historical and ongoing paternal

relationship with the Canadian government and cultural differences between Indigenous communities and schools. Three subthemes were identified – Residential School, Experiences in Schools, and Experiences in the Community.

Subtheme 2.1: Residential School. A discussion of the ongoing impact of residential schools was initiated by 5 of the 7 participants. Many caregivers of children currently in the education system have previous involvement with residential schools, which were created with the goal of assimilation of Indigenous peoples (Barnes, Josefowitz, & Cole, 2006). Many who attended experienced neglect and abuse (Bombay et al., 2011; Elias et al., 2012; Pearce et al., 2008; Trocme et al., 2004). Denise describes her family's experience and how it impacted her mother:

> They were not allowed to speak their language my grandmother said, how they got abused, my mom got abused sexually in residential school, yeah. My mom had it hard for residential school where she, it affected her so bad, she got into drugs, into drinking and stuff.

Similarly, Elizabeth articulated her family's experiences and the subsequent impact on family function. She is a member of the fourth generation to attended residential schools in her family, and her great-grandfather was raised from infancy in the schools. In response to some people's view that Indigenous people should no longer focus on the trauma of residential schools she says, "How can you get over 130 years of abuse by residential schools?" and attributed her parents' addictions to their experience in residential schools. She reflects on their experience:

> I couldn't imagine sending my kids to residential school when they're like 5 or 6 and not see them until they are 16. I just, I couldn't imagine what they went through, you know, as a child going away. My dad's residential school, he would look out his window and he

> would see his mom's house, his grandparent's house, which is like a, not even half a mile away from the place, and my mom was sent all over the place.

Elizabeth attributed the time she spent living on the streets of the Downtown Eastside of Vancouver as being a result of her family's experiences with residential schools. "The dysfunction attracted me because I'm a residential school survivor, and my dad, and my, all my, I'm a fourth-generation residential school survivor." Further, she stated, "I had a crazy life. I grew up with parents who were alcoholics, um, my dad was a binge drinker. My mom couldn't raise me." It is not uncommon for traditional parenting practices of residential school survivors to be impacted given that children were completely removed from their families during their upbringing. The goal was assimilation through the separation of children from their communities, culture, and language.

Susan commented that several generations of her family members attended residential school and stated, "Growing up, my parents weren't really parental support." Not only did Susan experience a lack of parental support, her family also experienced a decrease in cultural engagement over recent generations. This is evidenced by her statement, "I don't know a lot about my history." She explains further, "My grandma and my great-grandma were super, super traditional, my mom was less so, and what she grew up with, she didn't share with me either." Sophia describes the continual loss of language as a result of residential schools:

> The way that our language is, is like a precious baby. It's so precious, and it's so precious because we have so few speakers left, so it's so highly valued, the people who do speak, they're held up by our people.

Further, having a family member who attended residential school may impact an individual's current perception of schools. Denise attributed her lack of trust for schools, in part,

to hearing stories about what her family and other community members experienced. “I wasn’t in residential school, but just talking with my families and stuff, and other people.” She compares the abuse she suffered while attending the school on her First Nations reservation to residential schools. “I also went to a school that a lot of bad things happened to me.” Lauren notes, “Even if the person didn’t go to residential school, that there still can be a lot of issues from residential school, so for that person to step foot into school can be very difficult.” Finally, Sophia describes, “You know, for a long time, our people fought going to school and it hasn’t been that long since we stopped fighting.”

Subtheme 2.2: Experiences in Schools. Several participants discussed the impact of differences between school culture and home culture. Lauren articulates that she finds, “Aboriginal kids, depending on their at-home setting, school is super different, they don’t know what the rules are and no one really tells you what the rules are of that place you’re in.” She explains further, “I find that transition really hard for them because they are used to being able to be one way, and then expected to be another way,” and, “if they are special needs it’s going to take them a bit longer to learn those things.” In her experience, “it rears its head as a behavior problem,” and, “it’s important for people to know, recognize it’s not the disability, it’s just not having the knowledge.”

Melissa notes the differences in culture when talking about educators. “They see things differently than how we do, and we have a different lens for things.” This is echoed in Emily’s comment about the need for Indigenous educators in special education to support families when she says, “Community members will communicate more with an Indigenous educator,” because of a greater understanding of “both the culture, and the life, and the things that they’ve, may have seen or done, or, you know, I think that all would just tie it all together and help make it easier to

support them." Sophia describes her attempt at reconciling the fact that her son lives in two worlds; his traditional world at home and the Euro-western environment of schools:

> Inside I struggle. I know my son needs both worlds, I know he does, he's going to need to survive in a modern system, like it or not, but I just don't want him to drop all of who he is just to get there. I want him to value who he is and I don't know how that, how it all intersects.

Finally, there was some evidence of strained interactions between Indigenous populations and educators. For example, Elizabeth experienced racial disadvantage when educators did not support her family during a negative interaction with a non-Indigenous community member. She stated that, "They believed her because she is a non-Native," and identified micro-aggressions from the educators: "They wouldn't give any negative comments but you could tell because of their expressions on their face." Sophia shared a story about an interaction she had with an Elder concerning how Indigenous people are disadvantaged in schools because books used in classrooms are not written from an Indigenous perspective. The Elder would not look at a book she was trying to share, and when Sophia asked why, the Elder said, "My parents, my grandparents told me that people write lies about our people, the Haida, so we are not allowed to read these books because it's not who we really are."

Lauren cautions educators against viewing Indigenous people as being a homogeneous group. In her experience, many educators assume a student who is Indigenous will have special needs, and they perceive both labels as negative. "It's like two strikes against you." When talking about Indigenous students with special needs she states that educators should be "cognizant that they're Aboriginal and that they're special needs and that isn't the same thing." In addition, she encourages educators to learn more about the families they are working with before assuming

there is financial need, as there are Indigenous families from varying backgrounds and experiences in the Lower Mainland:

> Whenever we've gone to a new school, we always get some free buns because the kid's Aboriginal…and my kids are like, what did we get this for? I said you must have done a really good job today, you got a thing of buns, haha.

Subtheme 2.3: Experiences in the Community. For many First Nations people, the community includes the greater Canadian community as well as First Nations reserves. Beginning in the 1600s, First Nations people were displaced from their traditional territories and forced to live on reserves, which are typically of inadequate size and resources (AANDC, 1996). This resulted in the isolation and impoverishment of communities as the federal government did not, and still has not in many cases, provided appropriate infrastructure for basic needs of life. Reserve land belongs to the Crown and for a long period, First Nations people were not allowed to leave their reserve without permission from Indian Agents. Resources, rights, and cultural acts were controlled, and unfamiliar systems of social structure were imposed. Although there have been changes made to the Indian Act, which still controls First Nations people registered as status Indians, many reserves continue to suffer from the inequalities imposed.

Denise shared her experiences attending the school on her reserve. Not only did she parallel her experiences with abuse to residential schools, she recalls the distance she travelled as a child to get to school because of the lack of access to educational services that continues for many reserves today:

> We had to catch a bus, we had to catch a boat, and we had to hike up a hill. That's how we got to school every day. It took us an hour and half to get to school every day, and have a return trip home.

Elizabeth also shared her experiences with reserves. She describes the disadvantages people in her community experience as a result of the lack of infrastructure needed to sustain life. “When I go home it’s just like third world living conditions on the reserve, so it’s just like, they don’t got running water, it’s like really harsh.” She also expresses relief that her father took her and her siblings off the reserve. According to Elizabeth, even though she grew up in poverty as a result of her father’s lack of education, her living conditions were preferable over living on her reserve. “I’m so lucky compared to my other cousins out there.” She expresses regret concerning colonization and the impact the reserve system had on her people:

> The Plains people, they slaughter our buffalos, that’s the way they control us, right, they take away our food supply, and they force us on the reserve, they force us to do this, and meanwhile, we should have been one of the most wealthiest people in Canada and we’re one of the poorest.

Lauren discusses how her children, and other Indigenous children are often targets in the greater Canadian community. She illustrates with an example when she took her children shopping at a department store. Lauren had to visit the washroom but did not want to take her children in with her because they were at the age where it is awkward for other women to have male children there. She told her children to pick out a summer item, and realized after she left them that store staff may become suspicious of her children:

> Sure enough when I went back, there was a security guard watching them. I was like, is there a problem? And they’re like, oh, are they with you? Yeah, they’re my kids. Oh, nothing, walked away, and I was like, damn you.

Lauren also commented on how she limits her daughter’s freedom walking around in the greater community because of the Missing and Murdered Indigenous Women phenomenon. “My

daughter doesn't walk by herself. She's like, well why can't I walk by myself, and I'm like, because I don't want you on a poster thank you very much." She is open with her children about the fact that Indigenous people are often targeted in ways non-Indigenous people aren't. "I hate to say it but it's true, it's something that they have to deal with."

Sophia relates residential schools to the number of children apprehended and placed in the foster care system, and overrepresented in special needs categories. She addresses the number of Indigenous children in the foster care system, the impact it has on children, and the parallels with residential school:

> I think 80 percent-ish in Vancouver alone, in what person's mind is it ok to apprehend 80% of one race of people? Can you imagine 80% of white children apprehended? Oh no, it would not ever happen but it does happen in our communities. Is that because we are all bad parents? Not it's not, there is a huge power imbalance here that continues to happen and the people who suffer are our children. When you remove children from their home, you remove them from their language, family, their networks, their communities, their ceremonies, and no dream catcher workshop will make them more Native, it doesn't work like that.

Sophia describes the need for educators to consider each child's context when identifying which children require additional supports and the nature of those supports. She makes reference to the overrepresentation of Indigenous children in special needs categories in relation to the overrepresentation in the foster care system:

> How does that reflect in children who are diagnosed as special needs with learning disabilities when you don't look at a child as a whole human being? You are going to

miss the boat. That child will never be properly diagnosed, they will not be properly supported, it won't work.

Research Question One: Experiences with Identification and Designation

The purpose of research question one was to explore the parents' experiences with the process of having their child identified and designated as a student with special needs. Three broad themes emerged from the interviews – Relationships, Communication, and Emotions. Students may be identified prior to entering the school system, which occurs more frequently with children with developmental disabilities. In schools, the process typically involves the teacher identifying possible learning or behavior needs. Teachers vary instructional approaches to evaluate the child's response, and consult with parents regarding their child's progress. If the child continues to struggle, the teacher will collaborate with other school-based educators to consider the appropriateness of additional supports, which may include assessment and eventual designation. Given the nature and sensitivity of the process, the three broad themes identified are not surprising.

Theme 3: Relationships. The theme Relationships describes participant perception of the significance of relationships with educators and the influence of peer relations for their child. Two subthemes were identified as part of the broad theme Relationships, Elements of Positive Relationships and Child Relations.

Subtheme 3.1: Elements of Positive Relationships. Parent participants described several characteristics of positive relationships with educators, the two most prominent being communication and parent perception of how educators treat their child. Communication is discussed in this section as it pertains to relationships with educators and is revisited as a separate broad theme, as it pertains to the process of identification and designation.

When talking about her son's school, Emily attributed the positive relationship, in part, to the level of communication she has with staff, "I always emailed the teachers and then, the, I was on texting terms with the LAC (learning assistance class) people." Similarly, communication was central to Melissa's account of a positive relationship with her son's school, "We get to know the principal, and the teachers really well. We know the secretary really well, his SSW (student support worker), like, we're just constantly in communication, so it's actually a very strong relationship." For Susan, communication with the teacher and attendance of school events evidenced a good relationship.

Communication is such a significant component of a positive relationship for Denise, that a lack of communication was perceived as a breach of trust, and she used the term betrayal to describe the feeling. Not only did educators approach Denise about her son's assessment without prior discussion, the teacher that approached her was not someone with whom she had a relationship. Her initial reaction was, "I'm out of here, and you guys betrayed me." She elaborates on her reaction:

> I think that's where it was, a little bit, the betrayal comes in a bit, the upsetting, you think that, I thought maybe they would talk to me, chat with me, make me, you know, a little bit more aware of their thoughts I guess because it just doesn't happen overnight. I was telling the one teacher, Ms. Smith, it's like you guys must know this. Did you guys have a meeting? Like how did this all come about?

After attending a meeting with a psychologist from a provincial healthcare center for children, Denise was looking for information about the next steps of the assessment. When she approached educators, they asked her what was happening with the assessment. This appears to have further impacted Denise's perception of her relationship with educators:

> That's why I still have one foot out the door, kind of thing, and just the process of them not knowing anything and coming to me for results when, I'm like, I came to you, I mean, I put my hand out, you guys are helping me, and now you're asking me? I don't even know what's going on.

It is important to note the possible influence positive relationships may have on parent action. While several participants identified educators with whom they had an exceptional and trusting relationship, both Denise and Susan describe the significance for their children. Both parents were initially opposed to the assessment, and each experienced a strong emotional reaction. During the initial meeting with educators to provide consent for the assessment, Denise was intimidated but coped because the teacher she trusted was there. "I focused on the one lady I trust," She also eventually agreed to the assessment and signed the forms, "because I had trust in…Ms. Smith."

Similarly, after refusing to provide consent for her daughter, Janice, to be assessed, Susan was approached by the teacher with whom she had a trusting relationship. Ms. Adams explained that assessment and designation would benefit Janice and that earlier identification is better. This influenced Susan to provide consent. Initially, Janice was also uncomfortable, but agreed after talking to Ms. Adams. The decision to have their children assessed was greatly influenced by a relationship with trusted teachers in both Denise and Susan's situation. Further, each mother's relationship with other educators was also impacted. Denise stated the following about Ms. Smith, "She is the reason why I started trusting everybody around here." When a new administrator came to the school, Susan "trusted because they trusted."

Another element necessary to ensure positive relationships was the parent perception that educators treat their child well. Elizabeth describes why she considers the teachers at her child's

school effective, “They’re really nice…they really love the kids, you can tell that they love the kids.” She also notes that while the teacher of her youngest children was not their favorite, “he was still a good teacher, you could tell that they’re, they’re learning.” Melissa describes the importance of her son being included in his new school. At his previous school, he was not allowed to play outside when other children were playing, and the staff frequently sent him home. She described the moment she realized the level of exclusion he experienced at the previous school:

> I didn’t really know that was happening until my boy, one day when I was putting him to bed, he said, “Mom, today was my lucky day.” I said, “Why was it your lucky day, my boy?” and he said, “Because they let me play outside at recess.”

Sophia explained her view of educators at her son’s previous school when they did not provide services to meet his needs. He was attending an independent school when his teacher identified the possible need for additional supports. The teacher said, “Maybe it’s just getting, you know, kind of too hard for him, so you should think about sending him to another school.” Sophia’s perception of that comment was, not only were they unable to provide service to her child, they were choosing not to provide him services. She also perceived a moral and ethical issue at hand because of the impact on the child:

> A lot of kids shut down and that’s where my son was going. He was just internalizing it. He was basically being taught by other people that he wasn’t good enough, he didn’t fit in, he didn’t belong, this place was not for him, and that there was something wrong with him.

Subtheme 3.2: Child Relations. The other subtheme identified in the broad theme Relationships, was Child Relations, which describes a child’s relationship with peers. Several

participants described their child's experience with bullying. Susan's daughter experienced bullying when receiving pullout support for academic subjects. This involved an educator taking a small group of peers to a location outside of the class to provide direct support. Peers who stayed in the classroom teased her about needing extra help. Sophia's son also experienced difficulties with peers as a result of needing additional supports. Special education services were limited at his previous school, and he was placed with students with more significant learning needs than his. This translated to negative interactions with peers on the playground and impacted his social-emotional well-being.

Emily's son was bullied in preschool and in elementary school. He kept this a secret for years because it is not part of his nature to complain. Emily discovered what was happening during elementary school when her son kept visiting the nurse's office because of a sore stomach. She and the nurse determined that he was getting bullied and that there was nothing wrong with his stomach. Lauren's son experienced bullying "to the point of, he was suicidal. He attempted suicide when he was 7." The family encountered further stress when educators did not react appropriately to the gravity of the situation because of her son's profile as a learner. Lauren stated, "Through his special needs he's a bit impulsive, he is loud," and she had to get professionals in to every meeting to advocate for her son in order for educators to listen.

In addition to bullying, two participants reported their child's concerns with peer perception of their ability. Elizabeth's son, Louis, was so concerned about his performance in school and peer perception that he did not want to attend school. "He knew that he was behind, right, and he wanted to stay home." Elizabeth completed a writing activity with him to show him that he is capable. "I go, you know how to write, you're, I go, and he goes, but I feel stupid, and I go, you're not stupid Louis. He, he goes, everybody thinks I'm stupid." Similarly, Emily's son is,

“Always worried about the way people look at him, when, if he has to say he’s got a learning disability.” Although he qualifies for the support of technology, “he doesn’t want to bring his laptop into class because he doesn’t want anybody, everybody to think he’s dumb.”

Theme 4: Communication. The theme Communication describes participant perception of the importance of communication during the initial identification and assessment of their child, and challenges accessing services in the community. Three subthemes were identified as part of the broad theme Communication: Identification, Assessment and Designation, and Communication in the Community.

Subtheme 4.1: Identification. Identification involved ongoing communication between educators and parents prior to the child being assessed. It is important that parents understand the process and the purpose of the assessment. In many cases this did not occur because of terminology used by educators. In addition, educators were not able to identify the child’s specific difficulties or articulate exactly what will happen after the assessment as this information is often discovered through the assessment process. This lack of communication was evidenced by Lauren’s statement, “I don’t think most of the parents know what it means to be identified, they just tick the box and no one tells them what that means for their kid.”

Denise was first approached about her child being assessed by an educator with whom she had no prior relationship. This educator used terminology Denise did not understand and she responded by saying, “You guys think my child is A, B, C, D, it was when the one lady explained it to me,” and, “I got really upset when they presented that to me, was, I was thinking, is my child not up to par?” When she probed further, the educators were not able to explain the child’s learning profile in a way that justified the need for the assessment. “They stated that he skates through things by just telling people what they want to hear and but he may not

understand it they're trying to tell me, and I'm like." When she asked again about his level of understanding, the response was, "Well, we're not too sure."

Similarly, teachers that Emily was in communication with during her son's early elementary years identified that he was experiencing difficulties but did not communicate specifics and did not impress on her the level of difficulty until they decided he needed an assessment. When explaining his performance they said, "His scores are down here and everybody else is up here." News of him needing an assessment brought additional concern as staff at her son's independent school told Emily outright that they could not offer services to meet his needs. She moved him to public school.

Susan recalled an emotional reaction because she, "Didn't understand what he was saying," as he, "explained it in, like technical book terms." Not only did she not understand the assessment process, she did not want the teacher who approached her to label her daughter, which indicates that she did not understand the purpose either. "I shot him down right away, I was like, no, no, I was like, I need to learn more about that, I need to understand why you're trying to do that with my daughter." The teacher told her to take some time to think about it. When he saw her again he:

> Mentioned a little bit more that it was, but then I still really didn't understand, so, I didn't understand why he wanted it, why it was so important, that's the one thing they didn't tell me at first is why it would be so important for her to have a, for her to have a designation.

Subtheme 4.2: Assessment and Designation. In this subtheme parent experiences with the assessment process and subsequent designation of their child as having special needs was discussed. Susan experienced some tension during the assessment process because of Janice's perception of the evaluator. "The lady kind of rushed her and was…really strict actually, she

kind of yelled at her." Janice was talking while reading and the evaluator slapped the table and told her to read. When Janice played with her hair the evaluator "got really upset with Janice." During the feedback session, however, the evaluator communicated the results clearly. "She told me the term that they use (learning disability) and then she told me what exactly it means." Emily also experienced clear communication as the evaluator explained that although her son performed in the low average range, he qualified for a designation of learning disability because of the significant effort needed to complete the tasks.

Melissa experienced significant distress during her son's assessment because of the way the evaluator treated her. "We met, and then she met with Richard, and she just asked me, are you sure you weren't drinking when you were pregnant, like, just, why, because I'm Native?" This occurred after the initial parent interview where Melissa explicitly stated there were no prenatal conditions that would impact his development. Further, the evaluator asked her if she wanted to put her son in foster care part time. It appears it is not uncommon for Indigenous parents to experience this type of systemic racism. Melissa explains her perception:

> They had no idea that I was in my third year at [university], they had no idea about any of that, they automatically assumed because I'm Indigenous, that I was a certain way, that my son has FAS (fetal alcohol syndrome), that he needs to go into care, all these things.

What complicated matters further was when the evaluator interviewed Melissa's son, he told her stories that were outrageous and untrue. For example, he told he evaluator his mother allowed him to walk around [the city] by himself at night. The evaluator chose to include this information in the report. Melissa explains, "I lived in fear literally for two years of my life, thinking that my son was going to be taken away even though I was a good parent." It was only

after Melissa confronted the evaluator two years later and had the report removed from the file that she felt relief.

Sophia recalls reading her son's report and gaining a better understanding of the struggles he was experiencing, "I remember reading it and feeling really bad. I felt so sad, it was pretty devastating as a parent." She also questioned the assessment process, "Who sets those standards? Who says my son's not, not where he's supposed to be? According to who?" She explains her perception further:

> Look at the assessment, look at what it's asking my child. It's asking him, you know, reading, writing, memory, all these kinds of things, and it's one cultural value system that's not his. So it's like, how well are you assimilating? Hmm, not very well, hmm, yeah, yeah, not really working for you. We need to tweak you up a little bit, let's get you to do more of this and more of that and then you'll be more assimilated.

Communication in the Community. Denise visited a psychologist at a provincial healthcare center for children, regarding her son's assessment. She was hoping for more information about her child's learning needs and a more accurate overview of the assessment process. Unfortunately, the lack of communication from the psychologist resulted in further confusion about the process. "I don't know what [name of center]is, or what, I don't know. We went to go see the psychologist and then he was supposed to get back to us. They never did." She describes the brief interaction she had with the psychologist. "The psychologist, yeah, and I sat in front of him for three minutes and he says, ok, I'll be in touch with your, with the principal, and dadada, and so I don't know." She further describes her misunderstanding as a result of lack of communication from the psychologist. "I just don't know where we go or what the

expectation of [name of center] is, or what they expect is going to change so differently with us doing this."

Parents of Indigenous children may experience additional complications when navigating systems if they are registered members of a First Nations band. Emily explains the complications associated with navigating two different systems in order to access resources to support her son. Not only did she have to learn how to navigate the school system, she also had to learn her First Nation's system of support:

> It's hard because there isn't a handbook, right, it's the school will say one thing, that the Nation will help pay for this, then you go to the Nation and they're like, no, we don't do that…it's just back and forth all the time.

Elizabeth experienced racial tension through communication with the pediatrician who assessed her son for fetal alcohol spectrum disorder (FASD). She identified the need for the assessment when she had to confront the mother about drinking while she was pregnant. Even though she and her son continually confronted her, the mother drank until five months of gestation were complete. During the assessment, the doctor accused Elizabeth of taking her grandson's food for herself because of his small size. "She goes, oh he, doesn't look like you're starving." Elizabeth perceived this as racism because of the comment, the doctor's attitude, and, "you could tell that she was really racist because the way she was looking at me." Elizabeth has also experienced difficulties accessing services when taking her grandson to the emergency room on more than one occasion, and attributes this to reluctance to work with Indigenous families. She has also been accused of allowing her grandson access to drugs. She noted this type of racism is even more prevalent in central Canadian provinces than in British Columbia.

Lauren accessed support for her children through an infant development program with focused services for Indigenous children. She noted that while the services themselves were adequate, given the focus on cultural responsiveness, there is no system in place when families transition from one city to another. “Transferring to [a new city] and making sure all that happened, it’s a big job and it doesn’t, there’s no plan for seamless services,” and, “there needs to be better bridging between.” Further, she notes the services discontinue once the child reaches school age unless there is a significant crisis.

Theme 5: Emotions. The theme Emotions describes common feelings experienced by participants during the initial identification and assessment of their child, and following the finding that their child has special learning needs. Two subthemes were identified within the broad theme Emotions – Power Imbalance and Concern for their Child.

Subtheme 5.1: Power Imbalance. A variety of emotions arose for parents during the assessment process that indicated a perceived imbalance of power between educators and parents. The most prominent were feelings of inadequacy, disempowerment, and blame. Denise expressed feelings of inadequacy navigating the assessment process. “Some families, some, I get it, sure, they put us there and I probably should have the tools to follow through and do it but I just don’t, right, like, I don’t know what to do.” With reference to asking her main contact at the school for more information she said, “I feel silly if I have to go up to her and ask her but I know I have to, I know I have to.”

Melissa began to question her parenting abilities as a result of her negative experiences. “I second-guessed myself as a parent, like am I going ok?” She lived with the unresolved power imbalance and the fear that her child would be removed because of the information in the report until she confronted the evaluator two years later. “I almost clammed up again, but I didn’t, but I

wasn't able to look her in the eyes and I started to cry." She told the evaluator how she felt as a result of the assessment and pointed out that the evaluator had likely never experienced the same because of her racial and socio-economic advantage. "You've probably never feared one day in your life that your children would be taken away and she said, you're right."

Denise reported that she felt intimidated by educators during the assessment process. Not only was she upset because she did not understand what was happening, she said, "I felt like I had to do it." When asked why she felt like she was pushed into it, she responded, "Because of the way, the paperwork was there, the principal was there, everybody was there too, I'm like oh my gosh." When discussing her experience, Sophia stated, "Does it, would it sound funny to be kind of like, I don't know how there's shaming in there, but there feels like a sense of shaming." She also noted, "I would have suspected he needed more time but I don't know, somehow it sounded more official coming from somebody else on a piece of paper." She explains further:

> As a parent if I went and said that to a teacher would it carry the same weight because I don't have credentials behind me to do an assessment on my own son and yet tell them that, I could tell them that he needs more time, he's struggling, his reading is like, a little bit, you know, start and stop, he needs some support for fluency or comprehension or whatever that might be.

Feelings of blame and guilt were also shared. Melissa indicated that she felt judged by educators and attributed this to several possible reasons. "I'm young, I'm Indigenous, my son had behavioral challenges, so I felt like they felt like it was because of me." Sophia also shared feelings of blame. "There is a certain implication there, this is sort of your fault as a parent…you walk away feeling bad…did I do something wrong? Have I really done something wrong when

my son has a learning disability?" She questions, "Why should anybody, why should I be treated like less of a parent?"

Lauren acknowledged the guilt parents may feel when they have a child with special needs. "It's tough for, like, parents, biological parents, especially when it's a drug or alcohol special disability issue. It's because there's that guilt factor that they have to get over too." She acknowledges the difficulty and recognizes that she does not have to live with guilt associated with her children being born with fetal alcohol syndrome as the adoptive mother. "I didn't have to deal with the guilt. It wasn't me, right, so it makes it a lot easier to, to deal with."

Subtheme 5.2: Concern for the Child. The other subtheme identified in the broad theme Emotions was Concern for the Child. This section discusses parent feelings of protectiveness, concern for their child's social-emotional well-being, and concern for the future. Denise recognized her motivation to help her son despite her own struggles with social-emotional wellness. "I know I have my issues but I want to also be able to help my son." She relates her passion for helping her children to her own negative experiences with parenting as a child. "I only ran away when I was 14, somebody come for me right, that's what I thought right? Nobody did…that's why I will never give up on my children no matter what mistake you make I say to them."

Susan described her ongoing advocacy for her daughter. She noted that she typically communicates in a kind and appropriate manner with educators, but that her feelings of protectiveness increase when her child experiences significant upset. "When she's crying her eyeballs out and really, like really emotionally hurt, that's when I got, that's when I yelled at him. I got upset." She recognizes the strong protective feelings she has experienced since her daughter was designated. "It's like I almost want to just shelter her, it's bad, I know I shouldn't."

Several mothers expressed concern for their child's social-emotional wellness. Denise expressed conflicting emotions concerning her son, "He's only in grade 3, he does not like school, he doesn't like school. He's only in grade 3 and he does not want to come to school." With reference to the assessment process she feels reluctance. "I don't want him to be singled out…you need this kind of treatment. I don't want him to feel that. I want him to feel like everyone else." She also stated, "It's going to be ok to get help if he needs it, but I want to make sure he needs it."

Similarly, Susan expressed concern about her daughter's self-perception during the assessment process. She said, "I was afraid that they were going to tell her that she was, like, I was afraid that she was going to translate it that she was dumb, that she was stupid," and Susan, "was afraid of her self-esteem dropping." When approached about assessment, Janice became quite upset. "She cried and she didn't want to come back to school."

Finally, concern for their child's future was common. Elizabeth related her concern for her children's success in school to her own negative experiences with schools and the time she spent living on the street. "I was just really panicking because I, I fell through the cracks of the school system and I didn't want them to have my lifestyle, that I had, that I was forced to have to survive." She wants her children to have, "A better, out of poverty, a better way of life. Like to me, if I was given a proper education, I wouldn't have had, end up on the streets." Sophia articulates her concern for her son after the assessment was completed:

> I worried about the future of my child, because I'm like, what is going to happen to him if he's going to struggle academically? What does that mean for him down the road, and in some ways it might mean life might not be easy.

Research Question Two: Experiences with Navigating the System

The purpose of the second research question was to explore the parents' experiences navigating special education services following the assessment process. Services required to support an individual depend on their learning profile and may include services such as speech or occupational therapy, academic intervention, behavioral intervention, or changes to educational programming. In general, parents will require some support understanding their child's disability, learning about supports in the school and community, and planning for long-term support for their child. Public schools offer services; however, some resources may be accessed from the community.

Theme 6: Resources. The theme Resources describes parents' perception of which resources were important following the finding that their child had special learning needs. This includes resources that were present or lacking in the school, community, and home. Three subthemes were identified in the broad theme Resources – School, Community, and Home.

Subtheme 6.1: School. Parents identified several resources of importance. Academic and social-emotional resources are discussed, followed by resources that are lacking, and some experiences navigating the school system. Susan was pleased with the recommendations that her daughter has access to additional time, as well as support for reading, mathematics, and Social Studies. Similarly, Sophia noted the advantage to her son's new school consistently focusing on his academic skills. "They're working with him every day on those skills, like on the fundamental skills, you know, literacy, numeracy." She described other advantages to his new school:

> Way smaller class size, they use computers every single day, they use headphones, they use microphones, they have all sorts of adaptations that are already happening so that he

can thrive. He does, he loves the computer, it works for him, and that's, that's all that it needs to be for him. They do way more hands on work when they do science and stuff like that, and he gets it.

Lauren noted the importance of social-emotional supports in schools. While she recognized the supports are there, she advocates for a new approach to service delivery because currently "it's not proactive, it's reactive." She notes, "The system is broken because it doesn't really address how to improve what's going on, it's more crisis management it seems." In particular, she focused on the use of Aboriginal support workers in schools because in the current system, they effectively perform crisis management in her eyes. "It would be way, way better practice to employ half that many behavioral specialists to set up positive behavioral structures," as "there still needs to be kind of like, a, some kind of solution base so that [students] can be more successful, so they can build their skills."

There were several resources identified as lacking in the school system. Melissa noted that her son's previous school lacked resources to support her son. "They would send him home often, if there was, like, an altercation, or if they couldn't handle." It happened so frequently that she was prevented from continuing her university studies and was forced to apply for social assistance to care for him. She described this as a humiliating and disempowering experience. Similarly, Elizabeth noted a lack of support for her son. "Once we hit the inner city schools, it was horrible. They wouldn't give my grandson a designated worker." Lauren discussed her children in relation to support: "They don't have an SEA (special education assistant) with them every day, they just get a certain hour or something, it's crazy."

Emily commented on her inability to follow through on recommendations from her son's assessment because of a lack of resources. "They said the school district has an occupational

therapist but they're only allocated so many hours and all of those hours are taken up with the special needs kids." In addition, her son's report stated that he should be doing all of his work on the laptop, "but nobody has one for him, and the Nation wouldn't, wouldn't help pay for one, and the school didn't have any." Sophia commented on the greater educational system:

> There is something wrong with the system that will teach a child that they are not good enough, there is something really wrong with a system that will not bend to the needs of the children, there's something really wrong with a system that will not take the time to alter their curriculum, really to alter it.

Melissa shared what she has learned about system navigation. Aside from the work she put into learning about what designations are, she learned that she has access to her son's student file and has control over which documents are in the file. She removed documents regarding incidents from kindergarten and grade 1 because they describe personal opinion of the teachers without describing the incident itself. "I didn't really think it was relevant, and I don't think it's accurate in terms of who my son is." She contrasted the use of language used to document incidents at her son's current school with his previous school:

> If there is an incident with Richard, you know, here, he is not malicious, but he's impulsive, and you know the language used here is very different than what they used at [his previous school] where they would be like, Richard is violent, and you know, just painted it, it was, and you know, here, if you look into his file and there's an incident, there is going to be documentation on the incident itself.

Emily got tips on navigating the education system from teachers. In particular, she was directed to initiate communication with staff at the high school when he transitioned and to set up a meeting to discuss his individual education plan (IEP). "I guess, well, there were some

teachers at the elementary school who were, who were giving me a heads up, like when we realized that he had a learning disability." She elaborated on actions taken by educators following her son's assessment:

> They just explained to me what a IEP was and what that meant to him, and what I would do to support it, and then we got him into an Orton-Gillingham Center right away, and I got a lot of support and feedback there too.

Subtheme 6.2: Community. Similarly, there were several resources identified as important in the community. One recommendation for Emily's son was occupational therapy. While there are many occupational therapists in the community, "All the occupational therapists work with, work with Elders, or with WorkSafe BC. There was no occupational therapist for children." Lauren describes the process of having a child identified through a child developmental center. "You don't usually get officially assessed until you are like 5, just because there is a long waitlist, so you might be put on the list at 18 months or whatever but you're going to have to wait."

Both Susan and Elizabeth identified the importance of medical support in the community. Susan has concerns that her daughter may have attention-deficit/hyperactivity disorder (ADHD) and that her symptoms seem to have intensified in recent years. She is concerned about how to begin the process because her doctor may be leaving the clinic. "I don't, right now our family's doctor's leaving our, the clinic that we've been going to, that she's been going to since she was born, so I don't even know who to ask." Elizabeth noted the importance of the relationship with her doctor because of his sensitivity when working with Indigenous populations. "You can't retire, he's 86, I tell him you can't retire, you can't retire." She also noted the difference in

receiving services from a Hispanic doctor during another child's assessment compared to the non-Indigenous doctor with whom she experienced racial tension.

Specific to First Nations populations was support from their First Nations band. Sophia describes the importance of the support she receives from her band. "Lucky for me we have a community and the [First] Nation who supports our family with tuition. If I did not have that my son could not be there, I couldn't afford the cost of that school." Emily received support for her son's tutoring services from her band, however, it was only partial funding and her family "had to fight tooth and nail with the Nation," in order to secure the funding.

Subtheme 6.3: Home. Parents described several ways families themselves provide resources and support for children in the home. Susan looks to Janice's report card for teacher suggestions on how she can support her child over the summer and prepare her for the following school year. Emily's parents provided support to her son by purchasing him a laptop when she could not access one for him through the school or through their Nation.

Lauren recognized that her children "have good teams around them to be able to perform well." In addition, she discussed the research she did prior to adopting her children, as she knew they would qualify for a diagnosis of fetal alcohol spectrum disorder (FASD). She did a lot of reading about FASD and training on how to work with individuals with FASD. She also did trauma informed practice and attachment work.

Elizabeth talked about the ways she supports her son and other children at home. To encourage her son to practice reading, she buys him comic books, and notes that he buys himself comic books when he has extra money. She also used technology to encourage her children's continuous curiosity:

> I'm going to get all you guys iPads. You driving me crazy with all of the questions you're asking me, and you google it, and so he said, so they said, ok, so he, whenever he needs a question, he'll just google it.

Summary

Six broad themes were identified across the analysis of the information provided by the seven participants. Two broad themes were identified as being independent of the research questions and were presented prior to the remaining themes to provide contextual information for the participants – Indigenous Worldview and Indigenous Experiences. Significant findings from these themes include the absence of the construct of disability in traditional Indigenous culture, the inclusivity of communities and contribution of all members, cultural differences between homes and schools, and the significant impact having a family member who attended residential schools may have on the current perception of schools for parents or their child.

Three themes were identified in relation to the first research question in regards to parent experience with the identification and assessment processes including Relationships, Communication, and Emotions. Significant findings from these themes include the importance of relationships between parents and educators, the possibility of strained peer relations as a result of disability, challenges associated with educators using terminology that is not accessible to parents, and the feelings of guilt and intimidation parents may experience during identification and assessment processes. One theme was identified with regard to parent experiences navigating special education services following their child's special education designation or diagnosis – Resources. The most significant findings include lack of resources identified in the school and community, as well as the importance of parents learning about their child's disability and about navigating the education system.

Chapter 5: Discussion

The purpose of the current study was to gain a better understanding of the experience of Indigenous parents who have a child with special needs in schools. Of particular interest is their experience with processes leading up to identification and designation, and subsequent navigation of the school system. Seven mothers participated in semi-structured interviews that were analyzed for emerging themes using an Interpretative Phenomenological Analysis methodological framework. Two broad themes relevant to Indigenous populations were identified independent of the two research questions, which illustrate Indigenous worldview and experiences of Indigenous people in schools and in the community. Three broad themes were identified in relation to the first research question concerning parent experience with their child's identification and designation, which illustrate the significance of relationships with educators, the importance of communication, and the emotions involved in the processes. One broad theme was identified related to the second research question concerning navigation of the school system, which describes resources in the school, community, and home.

In this chapter, significant findings are discussed in relation to the current literature. Implications for school psychologists and other educators are discussed, as well as the study's strengths and limitations. Finally, recommendations for future research in this area are identified.

Discussion of Themes in Relation to Literature

Indigenous Ways of Knowing Theme. Two aspects of the assessment process identified as possibly impacting Indigenous parent perception of receiving special education services for their child are whether the construct of disability exists in the same way for the family's culture (Mushquash & Bova, 2007), and how individuals with learning differences are perceived by the community (Pewewardy & Fitzpatrick, 2009). An important finding of the current study is that

participants indicated that the construct of disability does not exist in their traditional language and culture. A related finding is the inclusivity of Indigenous communities, regardless of an individual's ability. This contrasts with the experiences of the majority participants in schools, whose children were excluded from activities in the school or from the school itself because of learning or behavioral difficulties. In one case, the child identified as defiant in schools was actually seen as gifted from the perspective of the Indigenous community. This difference in perception of disability is relevant because it may cause tension for Indigenous parents interacting with educators and the special education system. This is also relevant when building collaborative family-school relationships and may impact parent perception of the feedback session following an assessment.

Indigenous Experiences Theme. The two most prominent experiences of participants, which are described in the literature, are the ongoing impact residential schools have on Indigenous people (Truth and Reconciliation Canada, 2015) and the cultural differences between schools and Indigenous communities (Dauphinais, Charley, Robinson-Zanartu, Melroe, & Baas, 2009). The majority of participants identified the differences in culture and almost all participants identified residential schools as continuing to impact Indigenous children and communities. While Indigenous children live in Canada, it is important to recognize that the culture in the home and community may differ significantly from the school, making transitions between the two environments difficult. Cultural discontinuity may impact school performance and the lack of educator understanding of the differences may contribute to the overrepresentation of Indigenous students in special needs categories. Cultural differences and behavioral expectations should be taken into account when considering special education services. This is also relevant for effective home-school communication and partnership.

Based on the results of this study and previous research, the residential school experience continues to impact Indigenous communities in several ways. Parents and grandparents of children currently in the system may experience, or have experienced, significant social-emotional difficulties as a result of attending residential schools or having a family member who attended. This may have an impact on family functioning and on the children attending our schools. Loss of culture and language are also common in Indigenous communities, which may impact community functioning and healing practices that would be protective factors if intact. Perhaps of greatest importance is the finding that having a family member who attended residential school may impact how other family members perceive schools. This is especially relevant when considering child perception of schools and family-school collaboration with Indigenous families. This may also impact parent perception of the assessment and designation process.

Finally, all participants described ways in which they are engaged with their child's school, which supports the results of a study by Gajar, Matuszny, & Pennsylvania State University (2002), and is in contrast to some research from an educator's perspective that Indigenous parents are less involved than educators desired (Madden, Higgins, & Korteweg, 2013), and do not care about education (Robinson-Zanartu & Majel-Dixon, 1996). It is important to note that several participants experienced significantly negative interactions with educators, yet continue to engage with schools in order to help their children succeed. Indigenous parents in the present study are involved with their child's education and care deeply about their child's success and social-emotional well-being. This is relevant for educator perception of Indigenous parents, and for effective family-school collaboration.

Relationships Theme. The importance of relationship development with Indigenous people during the assessment process (Dingwall, Pinkerton, & Lindeman, 2013) was evidenced in this study. While several participants described the importance of their relationship with a specific staff member, in two cases, parents who initially refused to have their child assessed, decided to continue with the process because of the trusting relationship they had with a specific educator. In both cases, the educator explained the process in accessible terms and helped the parents understand the purpose and benefits of the assessment. Participants attributed their decision, in part, to their trust in the educator. This is relevant for educators, as a parent who does not have a strong relationship with a specific educator may experience reluctance to engage in assessment processes. This may extend beyond the experience of Indigenous populations; therefore, it is important for educators to be mindful for all families to have a relationship with at least one educator in the school. It may be beneficial for school psychologists to include the trusted educator in feedback sessions following an assessment.

The other element of the Relationships theme, which is discussed in the literature and evidenced in the present study, is the additional stress parents may experience as a result of their child with special needs being less accepted by peers (de Boer, Pilj, & Minnaert, 2010). The majority of participants reported their child's experiences with bullying, or their child's concern with peer perception as a result of their disability. Children who are identified with disabilities may be at higher risk for negative social interactions with their peers and social-emotional difficulties, which may have implications for educational program planning. Educators should take this into consideration when planning supports for individuals identified with special needs.

Communication Theme. It is identified in the literature that parents may experience difficulties interacting with educators concerning special education terminology used (Merkel,

2010). In the present study, two participants had a strong emotional reaction to the perceived lack of communication because of terminology used. Parents were upset as a result of the terminology used, as educators ineffectively explained what the assessment process is, what the purpose is, and how children may benefit from it. Parents may withdraw from the process if they are scared that their child will be negatively impacted by a special education label, or if they perceive the educator message that is there is something wrong with their child. A related area is whether difficulties arise as a result of the family not valuing standardized assessments (Bevan-Brown, 2001). Although this was only expressed by one participant, it is important to note this participant expressed significant engagement with her traditional culture, which may indicate the possibility of a relationship between strong identification with an Indigenous worldview and decreased value of Eurowestern practices of evaluating individuals against norms.

Emotions Theme. In many cases, parents experience feelings of guilt regardless of the child's disability, and parents with children with behavioral, emotional, and social difficulties experience this to a greater degree (Broomhead, 2013). Many participants reported feelings of inadequacy and guilt when interacting with educators in the present study, with two participants expressing blame from teachers. Similarly, feelings of intimidation may be present for parents when interacting with educators (Merkel, 2010), which were evidenced by several participants in the present study. These findings are important when developing collaborative family-school relationships, and for long-term relationships with parents for program planning. It may be beneficial for school psychologists to discuss common feelings of guilt during the feedback session following an assessment to alleviate some of this stress.

Another area of the literature related to emotions, which emerged to some degree in the present study, is parent concern about their ability to control their emotions when advocating for

their child (Swick & Hooks, 2005). While several parents described emotionality when advocating for their child, one parent described a specific example where she became extremely emotional and lost control when advocating for her daughter as a result of her daughter experiencing significant distress.

Resources Theme. A prominent area in the literature that was not addressed by many participants is their involvement with the process of collaborating with educators to plan their child's individual education plan (IEP). This may be a result of IEP planning not being a collaborative process as three participants mentioned educators created the IEP and parents agreed to it. According to BC Special Education Polices and Procedures, parents are supposed to have an active role in the process of developing the IEP; however, that does not seem to be the case for the participants who discussed their child's IEP. The focus of parent discussion about their experiences after their child was designated was resources. An area identified in the literature related to resources is the time parents spend learning about the special education system (Swick & Hooks, 2005). Some participants indicated that educators in elementary school explained initial steps to them including the importance of communication, some stated that they approached the educator with whom they had a relationship if they had a question about the system, and some explained that they spent a significant amount of time learning about the system and about their child's designation on their own.

Limitations and Strengths of the Study

Limitations. While the present study has added to the understanding of Indigenous parent experiences with the identification and designation process, as well as subsequent navigation of the special education system, there are some limitations. The initial focus of the study was parent perception of their experiences, yet only mothers were included. A more broad

perspective that includes paternal perspectives would have been preferable; however, no fathers expressed interest taking part in the study. There may be differences between mothers' and fathers' experiences with the designation process and navigation of the system, associated with parental roles and responsibilities. It is possible these differences could lead to different themes being identified, which is a limitation of this study.

A second limitation relates to the participants included in the study. Participants included in the study chose to respond to an advertisement poster created by the researcher requesting participation. Initial contact with the researcher involved a process of self-selection and initiation from the participant. There may be particular characteristics of participants who choose to volunteer for research studies; therefore, it is possible that the mothers who volunteered had different attributes or experiences than parents who did not choose to participate.

Another limitation is the variability in time since designation. The initial criteria were for participants to have gone through the assessment in recent years in order to ensure clear memory of the experience and the associated emotions. While three participants had their child assessed six years ago or greater, recall of the experience including the emotions associated seemed intact for two. The third participant whose child's initial assessment was greater than six years ago did not recall details and feelings in the same way as other participants. This is a limitation of the study as emerging themes may have been different had all parents gone through the assessment process in recent years. This participant's child is also at least five years older than other children in the study, whose ages varied from eight to thirteen.

Another limitation may be the variability in how strongly each participant identified with, currently practices, and was raised with their traditional culture. Some parents were raised without their culture, some were involved intermittently, and some were strongly connected to

their culture throughout their upbringing. Parent responses seemed to vary to some degree depending on whether participants were raised with their culture and discussed cultural practices their families participate in currently. Parents who discussed their cultural upbringing and current cultural practices identified more strongly with an Indigenous worldview. This may impact parent perception of Eurowestern assessment practices and the construct of special needs.

Another limitation is the nature of the assessment completed for children. Two of the participants had their child assessed through a pediatrician in the community prior to school entry. Both parents knew their child would likely qualify for services because of prenatal conditions, so they did not have the experience of having school staff identify their child as needing additional assessment. Another parent identified the need on her own and actively pursued the assessment and designation in order to access services for her son. It is likely a different experience for parents to identify their own child as needing assessment compared to an educator approaching them about their concerns with the child's academic or behavioral functioning.

Strengths. Despite the limitations of the present study, there are also some clear strengths. The significance of the present study is that it provides insight into the experiences of Indigenous mothers who have a child with special needs and special education processes. This is an area where little research has been conducted despite the overrepresentation of Indigenous children in special needs categories. A number of themes emerged that are relevant for educators to consider when working with Indigenous parents prior to, during, and following the assessment process. This information will help educators deliver more culturally responsive services when working with Indigenous parents and develop more meaningful and collaborative family-school relationships.

Another strength is the diversity in the participants with one grandparent and one adoptive parent. This is a strength because, despite the variability, emerging themes did not differ from biological parents to the biological grandmother or the adoptive mother. While there were some difference in responses, there did not appear to be greater variability than between responses of biological mothers. This is especially important for the themes identified in relation to Indigenous worldview and Indigenous experience. It is not surprising that the adoptive mother did not discuss Indigenous ways of knowing, given that she is not Indigenous; however, one biological parent also excluded Indigenous ways of knowing from her discussion. The adoptive mother and biological grandmother both discussed all three subthemes related to Indigenous experiences.

Another strength is the methodology used. Interpretative Phenomenological Analysis (IPA) served as the methodological approach. This is a strength of the study because it involves understanding an individual's experience by recognizing the cultural lens through which they experience events (Eatough & Smith, 2008). This is especially relevant given that the focus of the study is the experience of Indigenous parents. IPA concerns diversity and variability in human experience, which is appropriate for this study because the children had a variety of learning needs and parents had differing backgrounds and experiences. The semi-structured interview approach centered the focus on parent voice and allowed each participant to guide the direction of the interview.

IPA is also relevant for use with parents of children with special needs as each parent's experience is unique (Kubicek, Riley, Coleman, Miller, & Linder, 2013) and it attends to the individual's feelings and motivations (Eatough & Smith, 2008). IPA explores the lived experience and how that individual makes sense of that experience (Smith, 2004) and it explores

matters that are of considerable importance to the participants, such as a child receiving a diagnosis of special needs.

Finally, elements of decolonizing research were included in the study. The researcher's positioning of self in the world as an Indigenous person in relation to their community originates in one element (Pualani Louis, 2007). In addition, natural centering of participant voice through the IPA methodology and privileging Indigenous knowledge and ways of knowing were also included (Braun, Ka'opua, Kim, & Mokuau, 2013). Further, self-determination, which involves control of participants over information and access to the information they provide during research was included (Kurtz, 2013). Consultation with Elders and community members was conducted, including a review of the appropriateness of the interview schedule with an Indigenous community member. Finally, relationship-building was conducted prior to initiating questioning with the inclusion of food and drink and a discussion of the researcher's experiences as an educator.

Implications for Educators

There are several implications of the present research for educators working with Indigenous families. Firstly, several experiences are common between Indigenous parents in the present study and parents of children with special needs in previous research. For example, the use of terminology that is accessible to parents is important in order to reduce parent concern regarding the assessment process. This is relevant for special education teachers and school-based educators who would likely be the first to approach parents about assessment for their child. This must be done in a way that parents understand what the assessment process is, what the purpose is, and how their child will likely benefit. Secondly, it is important for teachers and school psychologists to be mindful that parents may experience feeling of intimidation or guilt

when interacting with educators. This is important for teachers to be mindful that they are interacting with parents in a way that reduces judgment about the child having special needs. This is also relevant for school psychologists when delivering information during the feedback session following assessment.

Another important implication is the number of parents who reported their child experiencing bullying. While difficulties with peer relations is common for children with special needs, it may be compounded for Indigenous children given the racial tension that may be present in schools and in the community. As a result, it is perhaps even more important for educators to take peer relations and child social-emotional well-being into account when planning educational supports for Indigenous children with special needs. Finally, it is important that educators provide parents with information about navigation of the special education system. While many participants noted that they ask a trusted educator when they have a question, it is more desirable for parents to hold the information in the event that the trusted educator is not accessible, or if the family changes schools.

One element that is important for consideration with all families, but has even more significance when working with families who have children with special needs, and with families who are Indigenous, is relationships. This is especially relevant given the importance of engaging parents who have a child with special needs in their child's education and in program planning. Research supports the various benefits to parent inclusion including academic success, improved social-emotional functioning, and increased graduation rates (Mueller & Buckley, 2014). For Indigenous parents, this is relevant given the possible difficulties with engagement in schools as a result of their family's prior involvement with residential schools and the experiences of Indigenous people in schools and the community.

There are other experiences described in the present study that are specific to Indigenous populations, which have implications for educators working with Indigenous families. It is important for educators to recognize that the construct of disability likely does not exist in Indigenous culture, as it is a Eurowestern concept. It is also important to recognize that all community members are contributors in traditional Indigenous views. As a result, if Indigenous parents perceive their child to be excluded from the class, school activities, or the school itself, this may cause additional tension. The possible contrast in perception of disability must also be taken into account when educators approach families about assessment, and when school psychologists are providing information during a feedback session following assessment.

Other findings that have implications when working with Indigenous populations are the possible differences in culture between the home and school, and the ongoing impact of the residential school experience. Cultural discontinuity between the home and schools may result in difficult transition for children, may impact school performance, and may contribute to overrepresentation of Indigenous children in special needs categories as a result of educator lack of understanding. Cultural differences and behavioral expectations should be taken into account when considering special education services. Having a family member who attended residential schools may impact family functioning as a result of the social-emotional impact, and the loss of culture and language, which may be protective factors for families. Perhaps of greatest importance is the possibility that having a family member who attended residential schools may impact parent or child perception of current schools. This may be relevant for teachers when approaching parents about assessment.

Each of the above implications is important when developing collaborative family-school relationships with Indigenous families. Not only do Indigenous parents share experiences with

special education processes with families from prior research, they may experience additional stressors when interacting with the education system because of perception of the construct of disability and the role of community members, cultural differences between the home and school, and family experiences with residential school. This indicates the requirement for culturally responsive approaches to working with Indigenous families as well as greater educator knowledge about Indigenous culture and experiences of Indigenous families in schools and in the community.

Recommendations for Future Research

Findings from this study and the above limitations suggest a number of areas for future research development, by way of replicating the present study or extensions of the current design with different participant groups. First, research that includes paternal experiences with having their child identified and designated, as well as the subsequent system navigation should be conducted. Parents may have different reactions to having their child assessed and navigating the system, especially if their role in the home and educational environment differs. This may provide a more broad understanding of Indigenous parent experiences and a more accurate understanding of how educators can develop more culturally responsive approaches to working with Indigenous families.

Second, it would be desirable to include only parents who have gone through the assessment process in recent years. The variability in time since assessment is a limitation of the study; however, recruiting Indigenous populations can be difficult given the negative history of research conducted with Indigenous populations, and recruiting parents who have a child with special needs is also often difficult because of the nature and privacy of the experience. Recruiting Indigenous parents who have gone through the assessment process in recent years

may provide a more accurate understanding of their experiences, as their memory of the events, including emotions involved may be more precise.

Finally, it may be beneficial to conduct studies with more cohesive populations concerning the type of assessment conducted. Parents who identify their child as possibly benefitting from further assessment may experience special education processed differently than parents who are approached by an educator about concerns with the child's academic, behavioral, or social-emotional functioning. As a result, it may be beneficial to conduct research with parents who had their child assessed prior to the school years separately from those who had their child assessed during the school years. In addition, given the possible difference in educator perception of parents depending on the disability, more cohesive groups may contribute to greater understanding of the differences in experience.

Conclusions

The present study represents an initial exploration of the experience of Indigenous parents who have a child with special needs with receiving special education services. In particular, the focus was their experience with assessment and designation, as well as their navigation of the school system in recent years following the designation. While prior literature focused mainly on Caucasian populations, the present study focused on Indigenous populations. Four broad themes with two or three subthemes were identified relative to the assessment, designation, and navigation processed. These themes illustrate the importance of relationship development with parents during special education processes, the importance of effective communication, and the emotions experienced by parents during the process. Two broad themes with two or three subthemes were identified as independent of the research questions and specific to Indigenous populations. These themes describe the role of Indigenous worldview in

assessment processes, as well as experiences of Indigenous populations in schools and in the community, which may impact parent perception of the assessment process.

The findings from this study expand previous work in the area of maternal experience with special education processes, including identification, assessment, and navigation of the special education system. With reference to Indigenous populations in particular, the findings that Indigenous parents may approach the assessment process and their interaction with schools with a different cultural lens, and the ongoing impact of residential schools on family functioning and engagement with schools have implications for educator approach to working with Indigenous families. It is hoped that future research will continue to explore Indigenous parent experiences with the special education system, in order for educators to develop a greater understanding of the assessment process from an Indigenous perspective, which will allow educators to develop more culturally responsive approaches to working with Indigenous populations.

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Appendix A: Screening Questionnaire

Aboriginal Parents of Students with Special Needs in Education: The Lived Experience
Screening Questions

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1. Do you identify as First Nations, Métis, or Inuit?
2. Does your child attend a public or band-run school?
3. Are you a biological parent, grandparent, aunt, or uncle who has been in a primary caregiver role since the child was very young?
4. Has your child recently been identified as having special needs?
5. Does your child have an Individual Education Plan (IEP) in place?

Appendix B: Interview Schedule

Aboriginal Parents of Students with Special Needs in Education:
The Lived Experience Interview Schedule

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1. Describe your relationship with your child's school.
2. Tell me about the communication you have had with the school.
3. What does the term 'special education needs' mean to you?
4. What do you recall about the testing your child had when identified with special educational needs?
    a. What involvement did you have in their testing?
5. What was your experience with hearing that your child was identified with special educational needs?
    a. Who was the person that talked to you about your child's needs?
    b. Did the person give it a name?
    c. Was it done in a respectful way?
    d. Was it done in a way that was respectful to your culture?
    e. Did they tell you what to do next?
    f. Did the report seem to match the child you know?
6. What has your involvement been since you found out about
    a. Were there meetings?
    b. What were the meetings about?
    c. What has been your experience navigating the special education system?
    d. Did anyone talk to you about your rights as a parent?
7. As an Aboriginal parent, now that you have gone through these processes, what do you wish schools would know?

Appendix C: Recruitment Flyer

Do you have a child who has been identified with special needs?

Do you wish to share your experience to help improve special education services for Aboriginal families?

If YES, we would appreciate your help!

My name is Melanie Nelson and I am Samahquam (In-SHUCK-ch Nation) from the Smith family and Squiala (Sto:lo Nation) from the Jimmie family. I taught in special education and Aboriginal education in Vancouver and North Vancouver for 10 years. I am doing my Masters in School Psychology at UBC.

We are studying how we can improve special education services for Aboriginal children and families. We want to learn more about the experiences of Aboriginal parents to help us. Each participant will receive a $25 gift card for their time.

If you would like to help us and learn more about the work we are doing, please contact us at email or phone listed below.

Contact: Laurie Ford (Principal Investigator) or Melanie Nelson (Co-Investigator)
Email: xxxx@ubc.ca
Phone: xxx-xxx-xxxx
Website: https://blogs.ubc.ca/cfclab/

Appendix D: Initial Contact for Parents

Aboriginal Parents of Students with Special Needs in Education: The Lived Experience

Initial Contact for Parents

Principal Investigator: Laurie Ford, Ph.D.
Department of Educational & Counselling Psychology & Special Education
Phone: xxx-xxx-xxxx Email: xxxx@ubc.ca

Student Co-Investigator: Melanie Nelson
Department of Educational & Counselling Psychology & Special Education
Phone: xxx-xxx-xxxx Email: xxxx@ubc.ca

Dear Parent/Guardian/Caretaker,

We are writing to invite you to be part of a research study about the process of receiving special education services for your child. Your participation is very important to help us better understand experiences you have had as an Aboriginal parent of a student receiving special education services. We would like to tell you about our project in hopes you might like to take part.

What is the purpose of the study?

The purpose of the study is to explore the experience of Aboriginal parents who have a child with identified special educations needs receiving services from schools. A positive experience receiving services for a child with special educational needs has the potential to create a collaborative and welcoming environment for parents. A collaborative relationship with the school has the potential to stimulate positive and communicative relationships between caregivers and schools. There is not much research that has explored the experience of Aboriginal parents who have a child with identified special needs. In addition, there is little information on Aboriginal parent experiences with the process of having their child identified as having special educational needs and working through the system in the initial years. In this study, we want to explore the experience of Aboriginal parents who have a child with identified special needs receiving services for their child from the school. We hope the results of this study will help us better understand effective ways to provide services for Aboriginal parents who have a child with identified special education needs.

What is involved if you take part in the study?

The research study involves taking part in a one-to-one interview with the researcher. The interview will take about 90 minutes and will be conducted at a time and place you and the researcher agree on. There may be a need for a brief follow-up interview to expand on or clarify information from the first interview but we will decide that at the end of our first meeting. With your permission, the interviews will be audio-recorded and transcribed. Your identity will remain confidential, but parts of your interview and/or direct quotes from the interviews may be used in

Ms. Nelson's thesis without sharing any identifying information. If you would like, a summary of the results will be sent to you once the study is completed. We will give you a small gift of a card for shopping at a local business as a thank you. If you need some help watching your child while you take part in the interview we may be able to help by asking a member of our team watch your child if there is space.

Taking part in this study is voluntary and you may refuse to take part or withdraw at any time. Information will not be shared with anyone other than members of our team. Your participation will have no impact on services received from your child's school or your First Nation. More details will be given when you provide your informed consent prior to the interview if you decide to take park.

If you would like to learn more about the study or would like to take part, please contact Melanie Nelson by email or phone number listed at the beginning of this letter.

Sincerely,

Laurie Ford, Ph.D.
Associate Professor
Principal Investigator

Melanie Nelson, B.Sc., B.Ed., Dip.Sp.Ed.
M.A. Student in School Psychology
Co-Investigator
Samahquam (In-SHUCK-ch Nation)

Appendix E: Parent Consent

Aboriginal Parents of Students with Special Needs in Education:

The Lived Experience Parent Consent

Principal Investigator: Laurie Ford, Ph.D.
Department of Educational & Counselling Psychology & Special Education
Phone: xxx-xxx-xxxx Email: xxxx@ubc.ca

Student Co-Investigator: Melanie Nelson
Department of Educational & Counselling Psychology & Special Education
Phone: xxx-xxx-xxxx
Email: xxxx@ubc.ca

Dear Parent/Guardian/Caretaker,

Please read the following carefully. This is a request for you to take part in the study we are doing with Aboriginal Parents with a child receiving special education services in the school. If, after reading this letter, you would like to take part in this research study, please sign one copy and keep the other copy for your records.

Purpose:
The purpose of the study is to explore the experience of Aboriginal parents who have a child with identified special education needs receiving services in the schools. We are talking to Aboriginal parents who have a child with identified special needs to better understand: 1) their experience with receiving services for their child with identified special educational needs, and 2) their experience with the process of having their child identified as having special educational needs and the navigation of the system in the initial years.

Research Study Participation:

1. Taking part in the study means that you will take part in a one-to-one interview about your experiences receiving services for your child with identified special educational needs including your relationship with the school, your perception of terminology used in special education, your experience with meetings with school personnel, your experience getting information about your child from school personnel, the process of working with school staff to plan an educational program for your child, and your experiences after your child was identified as having special educational needs.

2. The interview will take place at your home or another location mutually agreed upon that is quiet and works well for you.

3. The initial interview will take approximately 1 to 1.5 hours. We might ask if you would like to take part in a follow up interview. If so, we will decide that at the end of the first interview and the 2nd interview will not last more than an hour.

4. The interview will be audio-recorded and notes will also be taken. After the interview, the researcher will transcribe the audio recording.

5. If you agree to take part in the study, we will ask you to answer a background questionnaire following the interview.

6. After the interview is transcribed the researchers will contact you to give you an opportunity to review the transcript for accuracy, clarification, and need for any changes. This may take up to 30 minutes and will be done in person or over the phone, your choice. If it is done over the phone, the transcript will be emailed to you in advance via password protected file so you have it in front of you review while we talk with you.

7. We are not aware of any risks if you take part in the study. If, however, you feel uncomfortable, you may choose to stop at any time. If any of the questions in the interview make you feel uncomfortable, you may choose not to respond to those questions. You are welcome to contact us with any questions.

8. Taking part in the study means that you agree to the information being used for the purpose of reporting the results of the research in presentations or publication without the inclusion of any information that would identify you or your child.

9. The information you give us is strictly confidential. **No individual information will be reported and no participant identified by name** in any reports about the study. The information collected will be stored in a locked filing cabinet and any electronic files will be password protected and encrypted at the university office of the researchers. The only people who will have access to the information you give us are the researchers working on this study.

10. To thank you for your time, each person who takes part in the study will receive a $25 gift card to a local business. The researchers will also provide child-care on-site if needed.

11. If you have any concerns or complaints about your rights as a research participant and/or your experiences while taking part in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics, at 604-822-8598 or if long distance, email RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

Consent to Participate in this Research Project

By signing below, it means you consent to take part in this research study. When you sign below is also means that you have received a copy of this consent form for your own records.

_____
Your Name (Please Print)

_____
Your Signature Date

Additional Questions

If you would like a summary of our results upon completion of the study, please indicate below and provide your email and mailing address so we can send you a copy.

_____Yes I would like a summary of the research when your work is completed.

Email: _____ OR

Mailing Address (include postal code):

_____

_____

_____

Appendix F: Background Information

Aboriginal Parents of Students with Special Needs in Education:
The Lived Experience Background Information

About the Child:

What is your child's age? _____ Years _____Months

How is your child's gender identified? (male, female,

other)_____

What is your child's first language? _____

About You:

What is your first language? _____

What is the primary language spoken in your home? _____

Is your child exposed to their traditional language in the home? _____

How do you identify? _____First Nations _____Métis _____Inuit

Other: _____

With which Nation, band, or group do you identify with? _____

Do you or any of your childhood caregivers have previous involvement with residential schools?

If so, who? _____

What is your relationship to the child?

_____Biological Mother
_____Biological Father
_____Grandmother
_____Grandfather
_____Aunt
_____Uncle
_____Other

How many people currently live in your home?
_____ Number of adults including you
_____ Number of children and youth aged 19 or younger

Are there other adults living in your home and providing a caregiving role for your child?
_____Yes _____No

Please describe the current employment status for each of the following caregivers currently living in your home:

	You	Other Caregiver (Specify) _____
Working full-time	_____	_____
Working part-time	_____	_____
Full-time student	_____	_____
Part-time student	_____	_____
Full time parent	_____	_____
Other	_____	_____

What is the approximate date that your child had testing done to determine whether they have special education needs?
_____

Who conducted the testing?
_____School District _____Private Psychologist

Was your child given a diagnosis or a BC Ministry of Education designation?
_____Yes _____No _____Do not know

If yes, what is your understanding of the diagnosis or designation given?

_____

_____

_____

_____