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Running on Empty: Exploring Parent Perceptions of Special Education Processes

By

Aliyyah Datoo

A Dissertation

Submitted to the Faculty of Graduate Studies
through the Faculty of Education
in Partial Fulfillment of the Requirements for
the Degree of Doctor of Philosophy
at the University of Windsor

Windsor, Ontario, Canada

2021

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Running on Empty: Exploring Parent Perceptions of Special Education Processes

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DECLARATION OF ORIGINALITY

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ABSTRACT

Though educational legislation in Ontario promotes parental involvement in special education, collaboration between educators and families from culturally and linguistically diverse (CLD) backgrounds must be improved. Thus, this qualitative study explored the lived realities of five immigrant Indian and Pakistani families of children with autism spectrum disorders (ASD) as they navigated Individual Education Plan (IEP) meetings. Via semi-structured interviews, the study details how these parents understood, perceived, and experienced their roles in a collaborative relationship between special education and school personnel and themselves, before, during, and after the IEP meeting. The analysis was informed by four theoretical frameworks: Hoover-Dempsey and Sandler's Model for Parental Involvement (1995, 1997), Bourdieu's theory of capitals, Foucault's analytics of power, and Positioning theory. The findings suggest that Indian and Pakistani parents encounter a number of barriers that prevent meaningful participation in their child's special education, including unfamiliarity with the schooling system and a lack of knowledge regarding special education services and legislation. The participants showcased varying levels of capital, though most found themselves oscillating between five distinct positions when interacting and negotiating with special education professionals: the disenfranchised dependent, the trusting caregiver, the child expert, the lonely advocate, and the hopeful partner. Being aware of and addressing these barriers and dynamics can improve special education processes within schools, education boards, and teacher education programs.

DEDICATION

This piece of work would not have been possible without the prayers and support of family, friends, and academic mentors.

To begin, I am eternally grateful to His Highness the Aga Khan for providing both the inspiration and the means to support my interest in graduate work. I would like to acknowledge and thank the faculty at the Institute of Ismaili Studies. I dedicate this to my professors and mentors, who afforded me a rich and meaningful place to learn and grow.

I dedicate this work to the participants of this study. Your stories and voices represent the plight of so many who are systematically silenced. Thank you for having the courage, patience and perseverance to share.

I dedicate this work to my Father. You are the anchor that grounds me, provides wisdom, showers love, and endless motivation and inspiration to be the best me. You have always challenged me to change my reality, so that I may achieve my dreams. For this, I thank you.

I dedicate this work to my Sister. You are the best gift I could have asked for, and everything I forgot to pray for. Be proud of how far you have come and have faith in how far you will go. Thank you for having faith in me, supporting me, and inspiring me every day.

I dedicate this work to my Mother. You are my best friend, my teacher, my coach, and my advocate. Your love, faith, positivity, passion, and commitment to education is a transformative force that has served as a guiding light in my life. Thank you for always knowing what I need, before I do.

Lastly, I dedicate this piece to my Mama. A formidable, intelligent, and compassionate woman who against all odds, rebuilt her life on three different continents, educated her offspring, and inspired them to be the best they could be. You are a grandmother, a teacher, and a best friend. The lessons you have taught are not lost and will serve to inspire generations of strong, educated, and resilient females.

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CHAPTER 1: INTRODUCTION

It is morning. Not surprisingly, Kainaat tossed and turned most of the night. She had been worried about this day, this meeting rather, for some time now. Her son's IEP meeting was scheduled for today. As a qualified registered nurse from a prestigious University in Pakistan, Kainaat was only just able to secure a job as a personal support worker for the city of Toronto. With the help of her work colleagues, she managed to rearrange her work schedule so that she could attend this very important meeting for her son. Kainaat quietly recited her morning prayers, cleaned and dressed herself, then entered her son's room where he lay waiting for her on his bed. Together they brushed his teeth and put on the clothes they had selected the night before. He had cereal for breakfast, and then slowly put on his shoes, left first, then right. With his backpack on and jacket in hand, he stood at the door waiting for his school bus, a school day routine that has remained unchanged for the past ten years. But today, the bus was late.

Within minutes, her son started squawking. At first, the sound was tolerable, but then it grew louder and louder. Not today she thought, please God, not today. As the sound became unbearable, Kainaat could only think of giving him his iPad, a response she would traditionally reserve for more extreme circumstances. But today it could not be helped. When the bus finally arrived and with her son aboard, Kainaat knew she had little time left to prepare for her meeting.

With a quick glance over her shoulder, she assured herself that the lights were switched off, the plugs unplugged, and the taps were turned off. She snatched her purse and checked her reflection in the mirror next to the door. She rehearsed what she was going to say to the teachers, to the therapists, to anybody who cared to listen. Perhaps this IEP

meeting would be different. Surely, he could learn to count past six. He had counted many times at home, albeit not in English, but he had counted, nonetheless. So why not review this goal?

With her heart thumping, Kainaath closed and locked the door behind her and ran to catch her own bus. Once at school, she was greeted with the usual formalities and then escorted to the meeting room, where she was seated opposite the teacher, the principal, the special education teacher, and the child psychologist. On the table, she caught a glance of the completed IEP document. As she leaned in closer to have a look, as if on demand, the professionals initiated what could only be described as a long, endless monologue. It seemed to last forever. With smiles on their faces, they alternated between talking at her and pointing to the IEP document. Finally, when Kainaath had mustered enough courage to share her goals for her son, she was met with blank stares. She repeated herself slowly, thinking perhaps what she said had left the team confused. This time she was met with disapproving stares and head shakes. She tried desperately to think of another way of suggesting change, of showing them that her son was capable, nay proficient, in some areas identified as emerging by the professionals. But they seemed disinterested. She worried that if she disagreed with them overtly, they may treat her son unkindly.

Although the teachers thanked Kainaath for sharing her opinion, they were quick to remind her that this goal was rather ambitious for her son, given his skills and competencies. *But why, she wondered.* Perhaps they could review this goal next time, the principal nudged on. *At least they're willing to consider it next time, she consoled herself.* Stick to simpler, more achievable goals this time around was the resounding advice coming from professionals. *They may have a point, she told herself.* As the meeting drew to an end,

the principal slid the IEP document across the table with a pen, looked straight into her eyes and politely and dutifully asked for her signature, so that the meeting may adjourn. *Maybe, just maybe, it might be different next time she thought, as she picked up the pen.*

Families of children with exceptionalities in the province of Ontario, Canada, are regularly invited to participate in a complex network of special education processes. Generally, exceptionalities are understood as medically defined behavioural, communicational, intellectual, or physical impairments or disorders that can affect a child's educational performance (OME, 1998). Through the special education processes in place, ideally both parents and a team of educational and health care professionals may identify, plan, and provide quality educational programming and services for the child. The Identification, Placement and Review Committee Process (IPRC) is legally mandated by the province of Ontario (OME,1998). This process results in the development of the Individual Education Plan (IEP) (OME,1998). The IEP meeting, as illustrated in the above vignette, may be experienced differently by each family. A family's engagement with special educational processes will depend on variables that are either independent of the family, such as government or board regulations and general school processes, or on variables that are family dependent, such as a family's overall familiarity with the education system, understanding of parental rights, or a family's relationship with school personnel.

Families from culturally and linguistically diverse (CLD) backgrounds, in comparison to their White counterparts, often face a series of barriers that impede or entirely prohibit their meaningful participation in special educational processes (Cobb, 2014; DeRoche, 2015; Esquivel et al., 2008; Fish, 2008; Harry, 1992; Harry, 2008; Jung,

2011; Kalyananpur et al., 2000; Lai & Ishiyama, 2004; Spann et al., 2003; Tellier-Robinson, 2000; Wright & Taylor, 2014). Barriers to collaboration between school personnel and CLD families include: differing cultural understandings and expectations of parental participation in educational processes, differing beliefs and understanding of disability, inappropriate accommodations related to language and educational documentation, insufficient information about team meetings, and little respect for familial expertise or contributions by school professionals (Fitzgerald & Watkins, 2006; Gay, 2002; Harry, 2008; Hornby & Lafaele, 2011; Lo, 2012; Park & Turnbull, 2001; Spann et al., 2003; Wolfe & Duran, 2013). Compromised family engagement in special education processes may result in CLD students being subject to faulty diagnostic processes, students being subject to inappropriate placements, or students being allocated inadequate service provisions (Cohen, 2013; Gay, 2002; Harry, 2008; Ryan et al., 2010).

Despite legislative mandates that encourage direct involvement of families in planning their child's special educational programming across North America, the level of collaboration that exists between educators and CLD families of children with exceptionalities is marginal at best (Cohen, 2013; DeRoche, 2015; Esquivel et al., 2008; Friend & Cook, 2010; Harry, 2008; Jung, 2011; Park & Turnbull, 2001; Ryan et al., 2010; Spann et al., 2003; Wright & Taylor, 2014). With the growing number of CLD families settling in Canada (Statistics Canada, 2011), and knowing that parental involvement is instrumental in supporting student learning (Cobb, 2015; Harry, 2008; Jung, 2011; Tellier-Robinson, 2000; Valle, 2009), developing a sound understanding of how CLD parents have come to know and identify with the special education process, and by extension their collaborative participation therein, becomes essential.

In order to facilitate increased collaboration and participation between all stakeholders, thoughtful research must explore the life realities of CLD families as they understand, experience, and perceive their role in special education processes. It is through this exercise that educators, researchers, and policy makers alike, may come to better understand the various contextual, cultural, social, and economic variables that both help or hinder a CLD family's full and equitable engagement in their child's special education.

Rationale for this Study

For a very long time, children with exceptionalities were generally excluded from Canadian schools (Winzer, 1993). Any changes that eventually came to the provincial education systems and processes that resulted in an increase in the presence and participation of children with exceptionalities in separate or general educational settings, were in large part, the result of continuous parental and disability group advocacy (Winzer, 1993). In the province of Ontario more specifically, it was not until 1984 that the province enacted an amendment to the Education Act, commonly referred to as Bill 82, which initiated mandatory education for children with exceptionalities in the general education system (McBride, 2013). The legislation ensured that special education became a normal, integral, and functioning part of Ontario's education system.

Over time, the move towards a more inclusive educational environment, one that accounts for and accommodates all students, and one that is reflected in all aspects of school life, evolved both philosophically and practically. In the beginning, the segregation of students with exceptionalities into specialised learning environments was for some, imperative to providing the individualized instruction required by the students, based on their learning profiles (Pfahl & Powell, 2011). For others, the separation of students based

on ability or other characteristics, served as an obstruction to accessing a larger learning environment (Hallahan et al., 2005; Wedell, 2005). Gradually, Ontario's education system has come to offer students with exceptionalities and their families a variety of learning and placement options, where students may be included in a regular classroom, placed in a community classroom, or receive a combination of in class and out of class support services, so as to foster and support their personal, social, and academic development.

In addition to Bill 82 that ensured the structural and functional provisions for special education to materialize, revisions to the legislation came to include important stipulations for parent participation in the planning of their child's special education. Arguably, parents play the most important role in supporting their child's physical, emotional, and intellectual development (O'Donnell & Kirkner, 2014; Hill & Hill, 2012; Reynolds et al., 2015; Whitaker & Hoover-Dempsey, 2013).

A strong and healthy relationship between parents of children with exceptionalities and special education personnel will likely yield a better educational experience for the child. A collaborative relationship between parents and education personnel is instrumental in identifying, accessing, and providing quality educational support to students with exceptionalities (Cobb, 2014; Harry, 2008; Turnbull & Turnbull, 1990). Parents are important partners in this relationship, as their knowledge about their child's needs, preferences, and developmental history helps inform the educational programming provided to their child (Fish, 2006; Spann et al., 2003).

Meaningful parental involvement in special education often results in numerous positive outcomes for the growth and development of the child (Bailey & Wolery, 1989; Symon, 2005). Examples of such positive outcomes include greater continuity in

intervention programs (Bailey & Wolery, 1989; Spann et al., 2003; Symon, 2005); sustained maintenance of treatment gains for the individual child (Koegel et al., 1991; Spann et al., 2003; Symon, 2005) and increased social, cognitive, and behavioral skills and competencies for the child (Šukys et al., 2015). There is a large volume of empirical data supporting positive outcomes of parental involvement in special education, and more importantly, the need for the latter (Harry, 2008; Lo, 2008; Turnbull & Turnbull, 1990). However, despite numerous legislative expectations (Cobb, 2015; OME 2005), parental involvement in special education has been difficult to achieve, particularly for parents from CLD backgrounds (Garcia et al., 2000; Harry, 2008; Lai & Ishiyama, 2004; Torres-Burgo et al., 1999; Trainor, 2010).

Research involving Hispanic-American (Durand & Perez, 2013), Portuguese-American (Tellier-Robinson, 2000), and Chinese Canadian families (Lai & Ishiyama, 2004) for example, suggest that these families place a high value on education, schools and teachers, and are interested in being involved in their child's education. And yet, a significant body of research suggests that CLD parental involvement in and knowledge of special education processes is relatively low in comparison to their White counterparts (De Luigi & Martelli, 2015; Garcia et al., 2000; Kalyananpur et al., 2000; Kummerer et al., 2007; Luft, 1995; Lynch & Stein, 1987; O'Connor & Fernandez, 2006; Reid & Knight, 2006). If this research is accurate, it would indicate that there are many perceived and actual barriers that prevent CLD parents from engaging fully in special education processes.

One such barrier may be the family's cultural understanding of a parent's role in their child's education. Certain Latino families, for example, believe that parental involvement entails instilling good values in their children, providing and taking care of

their children, spending time talking to them and sending them to school clean, rested, and well fed (Araujo, 2009). For these families, their involvement does not extend into the school or classroom arena. This may be perceived by school professionals as a lack of parental involvement. The observed discrepancy in parental involvement could be further illuminated by recognizing the deference of some CLD families to school personnel as knowledge experts. From this standpoint, their belief that their involvement should remain at a minimum, given their lack of expertise and knowledge, would seem reasonable (Hanson & Lynch, 2004; Olivos et al., 2010). Although parents feel that they were being respectful of school personnel, it may be perceived by school personnel as lack of involvement, laziness, or disengagement (Park & Turnbull, 2001).

CLD parental engagement in special education processes may be hindered by other barriers including: lack of English proficiency, lack of familiarity with the education system, cultural differences in help-seeking behaviors, differing beliefs about disability, and disrespect for familial expertise or contributions by school professionals (Harry, 1992; Jung, 2011; Kalyanpur et al., 2000; Lai & Ishiyama, 2004; Tellier-Robinson, 2000; Wolfe & Duran, 2013). These barriers can intensify parents' frustrations and disappointment with educational processes. The details of the above-mentioned barriers will be explored in the following chapter.

Lack of or inadequate parental engagement in their child's education will likely bring about a parent's dissatisfaction with identification and placement processes (Cohen, 2013; Ryan et al., 2010; Tissot, 2011). Compromised parental engagement may also result in a parent's lack of knowledge related to their child's condition and the potential supports and services available to assist their child, making it increasingly difficult for the parent to

advocate on behalf of their child. Poor communication between school personnel and parents can also result in the conceptualization of an inadequate or entirely compromised education plan for a child that is not reflective of the child's abilities or potential for development (Spann et al., 2003; Stoner et al., 2005). Compromised parental engagement may also lead to feelings of isolation, powerlessness, pressure, and alienation from special education processes for the parent, resulting in increasingly less parental engagement and further reinforcing a vicious circle of perception and behaviour.

It is critical that we develop a sound understanding of how CLD parents come to know and identify with special education processes. This is especially the case, in light of the growing number of CLD families resettling in Canada (Statistics Canada, 2011), and given the importance of a collaborative relationship between parents and school personnel and the impact of this relationship on child development. A shared understanding between CLD parents and school personnel would help promote parents' more equitable participation in existing processes and strengthen their role in shaping future provincial special educational processes.

Statement of Purpose

Scholarship on CLD parental involvement in the North American special education context has gained prominence over the past few decades (Harry, 2002; Kalyanpur et al., 2000). While past research has explored exclusionary experiences associated with special education among African-American (Brandon et al., 2010), Hispanic-American (Lynch, 1987; Torres-Burgo et al., 1999), and Chinese-Canadian families (Lai & Ishiyama, 2004), comparatively less is known of the involvement of South Asian parents in special education. Considering the growing size of this community in Ontario, Canada (Statistics

Canada, 2011) and the paucity of empirical research in this area, this study aims to address this gap by investigating immigrant South Asian Canadian parents' involvement in the special education of their children.

Though there are many special education needs among this community, one of the more pressing concerns is with regard to Autism Spectrum Disorders (ASD). The rate of ASD in Canada is 1 in 66 children and youth (ages 5-17), a notable increase from the past, partly due to an increased awareness of the disorders (National ASD Surveillance, 2018). In Ontario, students diagnosed with ASD qualify for special education services. These services can range from minor adaptations in a child's educational settings to larger modifications, including working with applied behaviour analysis (ABA) support workers, occupational therapists (OT) and/or speech language pathologists (SLP). With an increasing prevalence of ASD in Ontario classrooms, and given the number and coordination of potential services and resources available to students with ASD, understanding how stakeholders, particularly parents, arrive at decisions related to the type and level of support a student receives, becomes paramount.

The analysis will explore how these parents understand, perceive, and experience their role in a collaborative relationship between special education and/or school personnel and themselves during the IEP meetings. By exploring the lived realities of five South Asian families of children with ASD, the analysis will provide the education community with valuable insights. While this study will not provide generalizable results, it will nonetheless edify on factors that enable or hinder CLD parental participation in their child's special education, so as to promote their more equitable participation in the provincial special education processes in the future.

Research Questions

Special education is a mechanism by which to advance educational opportunities among a student population with diverse learning needs. Through specialized supports and accommodations, students are afforded more equitable access to education opportunities and can expect to achieve greater academic outcomes (Brown & Parekh, 2013). Central to the special education process is the conceptualization of the IEP, a written learning plan, intended to meet the diverse learning needs of the child through the above-mentioned specialized supports and accommodations. An important part of the IEP processes is the legislated and expected active engagement on the part of the parent (Cobb, 2014; OME, 2004). The intent of this research is to better understand the CLD parental experience of the IEP related processes. Taken together, the following question and sub questions aim to explore how South Asian parents interpret the purpose of the IEP meeting. Specifically, it is important to gauge how South Asian parents understand the interactions and decisions that occur during the meeting, and how they perceive and comprehend their role as members of the IEP team, expected and actual.

The purpose of this reserch can be articulated in the following question and subquestions:

Question:

How do immigrant South Asian Canadian parents of children with ASD understand and perceive their role in the Individual Education Plan Meeting, within Ontario's special education context?

Sub-questions:

1. How do South Asian parents of children with ASD understand and describe their expectations of the IEP meeting and their role or position in the special education processes?
2. How do South Asian parents of children with ASD perceive their parental involvement as being positioned by teachers and service providers in the special education processes?
3. What are the implications of parental perceptions for meaningful relationships and partnerships between special education professionals and South Asian parents of children with ASD?

Contributions to the Broader Society

Despite legislative mandates promoting parental involvement in planning their child's special educational programming and services, the level of collaboration that exists between school personnel and CLD families of children with exceptionalities is alarmingly low (Burke & Goldman, 2018; Cobb, 2014; DeRoche, 2015; Dumciene & Sokys, 2014; Durand & Perez, 2013; Harry, 2008; Jung, 2011; Lai & Ishiyama, 2004; Reynolds et al., 2015; Tellier-Robinson, 2000; Turnbull et al., 2010). While there is growing interest in examining critical factors that may serve as a hindrance to effective and efficient parental participation in the special education process, few studies have explored the barriers to family participation experienced by immigrant South Asian families. Accordingly, in conducting this proposed study, I aim to address this gap while simultaneously adding to the existing literature on key elements that adversely affect the participation levels of CLD parents in special education processes. It is hoped that the findings of this exploration will empower CLD families, through reflection, to better understand the significance and implication of their respective positioning, for both their child and themselves.

Findings from this research may also raise new questions, both at the level of policy and practice, and as such, may pave the way for new research. The findings of this study can potentially help inform future interpretation and implementation of policies at all levels. This includes individual school boards, schools, and school personnel. By considering the lived experiences of those whom the policies are designed to serve, the findings will ultimately help promote parental participation and representation in the continued shaping of provincial educational processes.

Dissertation Organization

This dissertation is organized into six chapters. Chapter one broadly outlines the changing demographics of CLD families in the province of Ontario, the importance of parental involvement in their child's educational development, and variables that impact parental participation in special educational processes.

In chapter two, I examine relevant literature pertaining to the evolution of special education in the province of Ontario and the processes by which students come to be identified as exceptional. I then explore the supports and services in place to assist students with ASD. Next, I focus on the role of CLD parental involvement in special education, barriers to CLD parental engagement in said processes, and the perceptions of parental engagement as understood and experienced by school personnel. Lastly, I investigate the cultural construction of parenting and disability within the South Asian context and its relationship to parental engagement in their child's schooling.

In chapter three, I detail the conceptual framework used in this investigation. I outline four theoretical models—Bourdieu's theory of capitals, Foucault's theory of power, Positioning theory, and Hover-Dempsey and Sandler's (1995, 1997) Model for Parental

Involvement—and demonstrate how these theories intersect to contextualize the CLD parental experience of special education. I detail the qualitative methodology, research design, data collection tools, and analysis measures used in this study. I explain my role as a researcher, the context of and the limitations related to my research design, as well as the ethical considerations that underpin the investigation.

In chapter four, I present the South Asian parental experience with both special education processes and professionals, as described by the parents. Here, I detail five separate narratives, which provides background information about parent(s), their introduction to special education processes in Ontario, their expectations from the special education system, and their experiences interacting with special education professionals.

In chapter five, I analyze how South Asian parents position themselves in the parent-teacher relationship, based on positioning theory, their varying levels of social, economic, and cultural capital, and their perception of power. Based on this analysis, I identify and discuss how parents oscillate between the following five distinct positions when interacting with special education professionals: the disenfranchised dependent, the trusting caregiver, the child expert, the lonely advocate, and the hopeful partner.

In the final chapter of this dissertation, chapter six, I discuss contributions of this research to the existing body of knowledge, with respect to CLD parental participation within special education processes. I then explore potential implications of this research for special education processes within a school, within education boards, and for teacher education programs. Lastly, based on the data analysis, I share potential lines of inquiry for future research.

Chapter Summary

I begin this chapter with a vignette that speaks to the physical, emotional, and intellectual exercise and strain a parent may face, when preparing for an IEP meeting at their child's school. It is against this backdrop that I explore the role of CLD parental engagement in Ontario's special education system and the various factors that are perceived as enablers or barriers to meaningful and equitable parental engagement in special education processes. I then detail the rationale and purpose of this investigation, along with the research questions this study is designed to answer. Lastly, I demonstrate how the findings of this research will help fill existing gaps in the literature related to CLD parental involvement in special educational processes, inform future policies related to parental engagement in schools, and spark interest for future inquiries.

CHAPTER 2: LITERATURE REVIEW

Parents play an important role in developing effective educational programs to support their child's overall growth and development. Despite provincial legislation promoting parental involvement in special education (OME, 2004), and despite documented research on the benefits of parental involvement in special education, the research literature suggests that parent involvement is relatively low for a variety of reasons, particularly amongst CLD families (Burke, 2013; Cho & Gannotti, 2005; Esquivel et al., 2008; Fish, 2006; Lo, 2012; Ryndak et al., 2011; Stoner et al., 2005). In this chapter, I provide a review of the literature on this topic.

I begin this chapter with a brief review of special education as a system in Canada, and hone in on the specificities of the special education processes, currently stipulated by the Ontario Ministry of Education (OME). I then explore the notion of parental involvement in special education, from the perspective of CLD parents and special education personnel, respectively. Lastly, I explore the notion of disability and parenting a child with a disability, as perceived and experienced in the South Asian community. I end with a chapter summary.

Special Education: Programs, Services and Accessibility

The following section delineates the evolution of special education in Canada. Here, I hone in on the specificities of the special education processes stipulated by the OME. I then detail the two formal processes underpinning Ontario's special education system—the Identification, Placement and Review Committee (IPRC) assessment and the development of the Individual Education Plan (IEP)—and the role parents/families play in these respective processes.

Brief History of Special Education in Canada

In early Canadian history, relatively few children with special needs had access and the ability to complete their formal education (Winzer, 2000). If at all served, those with special needs were often segregated by ability, and attended to in isolation or in specialist groups (Bennett et al., 2013). The first formal specialized education establishment for individuals who were deaf or hard of hearing opened in 1831 in Quebec. Similar schools subsequently opened up in various cities across the country shortly thereafter, including Halifax in 1856, Toronto in 1858, and Winnipeg in 1884. Schools for the blind soon followed suit opening up in Toronto in 1872 and Halifax in 1873 (Bennett et al., 2013). By 1910, both the Vancouver and Toronto public school systems began to serve students with less obvious needs, by providing special classes for students with learning difficulties or intellectual disabilities (Ellis, 2018).

Given that in Canada, education is regulated by the province or territory, ‘Auxiliary Education’, as it was coined during the early 1900s, evolved differently based on the socioeconomic, political, and cultural contexts of each province and territory respectively (Ellis, 2018).

An important step forward came in 1970, when the Commission on Emotional and Learning Disorders in Children (CELDIC) was formed to address the integration of students with exceptionalities into the general education system in Canada (Pivik et al., 2002). A report by Lazure and Roberts (1970), entitled *One Million Children: A National Study of Canadian Children with Emotional and Learning Disorders*, called for the integration and instruction of pupils with disabilities to be undertaken based on learning characteristics, as opposed to categories. This landmark report supplemented the work of

professional groups such as the Council for Exceptional Children in Canada (CECC), and Wolfensberger's work at the National Institute of Mental Retardation (NIMR) in Toronto, which emphasized the importance of access to conventional learning environments for all individuals. This contributed to the abandonment of segregated special education classes, which were replaced with regular class programs that were supported with special education services (Winzer, 2000).

Circa this period, while some educationalists and researchers supported the move towards integration and inclusion of students with special needs into the conventional classroom spaces, others argued it unwise to mandate inclusive educational programs if the funding, provisions, and capacity were not there to deliver them (Bennett et al., 2013; Ellis, 2018). It was against this backdrop that Nova Scotia became the first province to initiate mandatory legislation for the education of students with special needs in 1969, followed shortly thereafter by Saskatchewan in 1971 and Ontario with Bill 82 in 1984 (Bennett et al., 2013).

Another important impetus for change occurred following the enactment of the Canadian Charter of Rights and Freedoms by the British Parliament in 1982, specifically, Section 15 of the Charter of Rights and Freedoms guaranteeing equality rights for all Canadians and which formed the basis of protection under the law. Section 15 (1) of the Charter states:

Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability (Government of Canada, 1982).

The rights of all citizens, to receive equal treatment under the law, was now guaranteed. The Charter provided the impetus to formalize such guidelines into special education policy and to actualize them into processes so as to ensure equality of access to public education for all school aged children. This equality of access had previously been slowly developing in various capacities across provinces and territories. However, the Charter formalized, mandated, and expedited this process, which in turn had a profound impact on the history of education for children with special needs across provinces and Canada as a whole.

Special Education and Legislation in the Province of Ontario

Education policy in Canada, including the curriculum, financing, and the delivery of education services, is governed by provincial and territorial legislative assemblies (Winzer, 2000). Each Ministry of Education is obliged to adhere to the tenets within the Charter of Rights and Freedoms, as well as include compulsory education laws that allow for the inclusion of all students. This includes students with special learning needs, as well as aboriginal students. The Charter is in place to ensure that all students receive a free and appropriate education (Sokal & Katz, 2015; Winzer, 2000).

In 1984, Ontario enacted Bill 82, which initiated mandatory education for children with special needs in the general education system (McBride, 2013). The legislation ensured that special education became a standard, integral, functioning part of Ontario's education system. Bill 82 delineates the roles and responsibilities of the Ministry, school boards, and the Ontario Special Education Tribunals in their endeavour to conceptualize, implement and revise special education programs and special education services respectively. Some of the original provisions contained in Bill 82 have since been removed

entirely or amended, to reflect language and program evolution, changing practices, and policy environments.

Special education legislation in Ontario stipulates that children with exceptionalities must have access to appropriate accommodations and modifications of the curriculum that are commensurate to their needs (Dworet & Bennett, 2002; Starr & Foy, 2012). Special education regulations also state that children with exceptionalities should be placed in the least restrictive environment (LRE) where they can receive maximum benefits of education; such placements may include full or partial inclusion in general education classrooms, special education classes, home instruction, and/or residential placement (Hill & Hill, 2012). As a result, each school board within the province is required to implement procedures for early and ongoing identification of student's physical, behavioural and academic needs, and thus, must establish an Identification, Placement & Review Committee (IPRCs) as per Regulation 181/98 (OME, 1998). Each school board is also obligated to provide special education programs and services for students with exceptionalities. Accordingly, each school board is required to establish a special education advisory committee (SEAC) to advise on matters of special education programs and services. Ultimately, each school board must develop an Individual Education Plan (IEP) for every student that has completed the formal IPRC process and has been identified as a student with an exceptionality. School boards also have the discretion to develop an IEP for students who have not been formally identified as exceptional but who are receiving special education programs and/or special education services (OME, 2005).

How to Qualify for and Access Special Education in Ontario

To meet the diversity of learning needs among students, Ontario's special education programs and services provide instruction and assessment that are different from those provided to the general student population (OME, 2001). Identification of learning needs or exceptionalities enables school boards to place exceptional learners in the appropriate educational settings and provide relevant and meaningful education to the child (OME, 2001). It also allows for the equitable distribution of funding across the province to support specialized programming (OME, 2001). It is important to note that while all children are theoretically entitled to receive a free and appropriate education under the law, a formal identification of exceptionality is required to access the right to special education. Although the identification process is outlined in all provincial government documents, internal policies and discretionary powers may further limit which children receive supports, as well as the quantity and quality of supports (Cobb, 2016).

The process to identify a student as exceptional can be long and difficult. The formal process includes the IPRC assessment, followed by the development of an IEP. All School Boards within the province of Ontario are required by provincial law (Regulation 181/98) to establish IPRCs to identify those students who need special education programs and services. An IPRC meeting can be initiated by either of two parties. If a parent feels that their child would benefit from special educational programming, then the parent sends a written request to the child's principal who will then initiate an IPRC. Alternatively, the school principal may refer a child to an IPRC if he/she and the child's teacher believe that the child would benefit from special education support (Toronto District School Board [TDSB], 2005; York Catholic District School Board [YCDSB], 2013; York Region District School Board [YRDSB], 2013).

The IPRC uses psychological assessments, physician records, academic reports, and the guidelines set forth by the Ontario Ministry of Education to identify a particular student as being legally “exceptional.” The IPRC process culminates in a decision identifying the areas of the child’s exceptionality, and the best placement option for the child (Starr & Foy, 2012). Lastly, the IPRC will review the identification and placement of the child at least once a year (OME, 2005). The details of the IPRC and their respective processes will be explored later in this section.

Sometimes, a classroom teacher may repeatedly observe a child struggling to complete their academic work, and may suspect a learning need or a social/emotional imbalance. In this case, the teacher may conduct a variety of assessments to measure a child’s performance against the expectations delineated by the provincial curriculum (TDSB, 2005; Bennett et al., 2013; YCDSB, 2013; YRDSB, 2013). After evaluating both observations and assessments, and while also considering the student’s strengths and needs, the teacher will then consult and discuss the child’s learning needs with administrators and/or a special education teacher at the child’s school. The aim of this meeting is to develop and implement a growth plan that includes resources and instructional strategies to support the child’s learning, and to identify how the teacher can benefit from further guidance and support (*Learning for All, K-12*).

Learning for All, K-12, more specifically, describes a process of assessment and instruction to improve student learning. The process includes three components that are interconnected: personalization, precision, and professional learning. Personalization and precision aim to provide instruction and assessment that align with a student’s specific learning and motivational needs. Professional learning allows for dedicated, on-going

learning for each educator, that enables them to connect new conceptions of instructional practice with student assessment (Fullan et al., 2006).

Having consulted with the necessary stakeholders, the teacher then makes observations to assess the effectiveness of the growth plan. If additional or extensive intervention is required, the teacher will make a referral to the school program team. If, upon implementing new interventions suggested by the program team, the student is still having trouble with achieving the desired outcomes, another team meeting is held, at which time further assessment may be suggested (TDSB, 2005; YCDSB, 2013; YRDSB, 2013). If it is decided that the child is to be formally assessed, then the child is placed on an assessment wait list, providing parental consent is obtained (TDSB, 2005; YCDSB, 2013; YRDSB, 2013).

Depending on the teacher, and the school culture, parents may be invited to any of the above-mentioned meetings, however, it is important to note that their physical presence at these discussions does not necessarily lead to their inclusion within the larger conversation and decision-making process (Cobb, 2016; Rogers, 2003). In undergoing a formal assessment, with the informed consent of a parent, a child is assessed by a medical practitioner (i.e a medical doctor, speech language pathologist, educational psychologist etc.). The assessment is believed to offer a standardized means of developing a learning profile and identifying learning capacities within different skill areas (OME, 2005). When the psycho-educational assessment or other relevant assessment tools are completed, their results are discussed among school personnel. Results are also shared with parents at this stage of the special education identification process (Cobb, 2016). An IPRC meeting is then scheduled on behalf of the child. IPRC meetings can only be conducted with the

consent of a child's parent/guardian, and parents/guardians must be invited to the IPRC meeting (TDSB, 2005; YCDSB, 2013; YRDSB, 2013).

As mentioned earlier, the chief function of the IPRC is to identify whether a student is exceptional and then decide on a placement for him or her. IPRC meetings are chaired by school administrators, and are attended by a panel, which includes at least one representative from the child's school, the child's parent (if he/she chooses to attend the meeting), an advocate to support to the parent and represent the child's best interest, a school board psychologist, and a special education consultant (OME, 2004). During the IPRC meeting, the committee will review and consider all available information about the student. As per the Ontario Ministry of Education (1998), information related to the student includes:

- educational assessments of the student
- medical, psychological, speech and language, and/or social work assessment conducted by a qualified and registered practitioner
- interview with the student (if applicable)
- any relevant information that a parent submits about their child

The IPRC will discuss the student's strengths, needs, and the programs and services that are currently available. The IPRC will then make recommendations regarding the identification of the child's exceptionality, as well as indicate the special education programs, placement, and services available for the student (OME, 2004; TDSB, 2005; YCDSB, 2013; YRDSB, 2013). If the parents agree with the recommendations from the IPRC, parents sign the Statement of Decision indicating their agreement with the identification and placement decisions that have been made. If the parent does not agree

with either the identification and/or placement decision made by the IPRC, they are not to sign the statement of decision, and may request a second meeting or submit a notice of appeal with the secretary of the board (TDSB, 2005; YCDSB, 2013; YRDSB, 2013).

Subsequent IPRC review meetings often include special education consultants, school administrators, the student's teacher(s), and based on circumstances, other professionals. While parents must, by law, be invited to attend initial and review IPRC meetings, their attendance and/or participation may or may not lead to their meaningful inclusion in the process (Cobb, 2016; Rogers, 2003).

After the IPRC meeting, the staff begins the development of the IEP and ensures there is parental consultation during the development of the IEP. The IEP is the school's written plan, created to outline programs and services that are available to the child whose academic needs do not align with the standard curriculum (Boyd et al., 2015). Children need not be legally *identified* as exceptional through the IPRC process in Ontario to receive an IEP; however, the IEP is not a legal document, and therefore the school is not obligated to adhere to the IEP until the student has been identified as having an exceptionality through the IPRC process (Boyd et al., 2015). The IEP is a working document that encompasses several factors. The document is largely comprised of a description of the student's exceptionality or exceptionalities. It also includes both a summary of the services and programs that are needed to support the individual child and an explanation of the identified goals and expectations for the child. The IEP also details an explanation of how these goals and expectations will be monitored to determine if the accommodations and modifications are effective is included. Moreover, a transition plan that details the specific goals, actions required, person(s) responsible for actions, and timelines for each education

transition where the student requires support is covered as part of the plan (Boyd et al., 2015; OME, 2005). Finally, it describes the student's progress. A formal review and update of the IEP should take place at least once every reporting period, and team members should continuously monitor and adjust the plan as necessary.

The OME describes the development of the IEP as a collaborative process in which teachers, parents/guardians, principals, healthcare practitioners, and other professionals are to work together in the development of the document (Boyd et al., 2015). Ontario's Education Act, much like the United States' Individuals with Disabilities Education Act (IDEA), is used to ensure that parents are *legally* and meaningfully involved in the development and the implementation of the IEP, and in the evaluation, meetings, and placement decisions regarding their children (Belanger & Taleb, 2006; Cobb, 2013; Hill & Hill, 2012; Reid et al., 2020). Parent involvement is important in the process of determining goals and objectives, as parents can provide information about their child's strengths, abilities, and educational needs that may not be observed in the educational setting (Belanger & Taleb, 2006; Cobb, 2013; Hill & Hill, 2012; Reid et al., 2020).

Schools are required by law to provide a student's parent or guardian with the following: the legal information about both the IEP and IPRC processes, adequate notice and scheduling accommodation for an IEP or IPRC meeting, an outline of the purpose of the meeting, and notification informing parents of their right to bring other individuals to the meeting (Belanger & Taleb, 2006; Cobb, 2013; Reid et al., 2020). Once the IPRC meeting has been conducted, the school is responsible for the implementation of the IEP that was developed for the child, and to inform parents that while the IEP is not a

guarantee of performance, it is a legally binding guarantee of resources and services (Belanger & Taleb, 2006; Cobb, 2013; Reid et al., 2020). Unfortunately, research has revealed that the development and implementation of an IEP often does not always manifest in practice as outlined in legal policy (Boyd et al., 2015; Trainor et al., 2016; Reynold et al., 2015). All too often, the IEP document is viewed by many as mere paperwork to be filed away and forgotten, rather than a guide to support the child's educational needs (Yell et al., 2013).

Program Planning for Students with Autism in Ontario

The Ontario Ministry of Education aims to be responsive to the needs of the students in Ontario. To better support students with ASD, their families, and their educators, the Ministry is providing additional training and development for existing and incoming teachers, additional funding for classroom supports, and expanding after school skills development programs (Policy/Program Memorandum No.140, 2007). The following sections provides a definition of ASD, and how students with ASD are supported in the classroom.

What is Autism Spectrum Disorders?

Autism Spectrum Disorders (ASD) are complex neurological disorders that impact brain development. The result is that most individuals with ASD experience communication problems, difficulty with social interactions, a tendency to repeat specific patterns of behaviour or exhibit behavioural challenges. They may also have a markedly restricted range of activities and interests (Boucher, 2009).

Autism is known as a spectrum disorder because there is a wide variation in the type and severity of symptoms people experience. ASD includes conditions that used to be diagnosed separately, namely Autistic Disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) (Boucher, 2009). Generally, students diagnosed with ASD have development characteristics, medically described as ‘abnormal’ or ‘impaired’ in social interaction and communication, and a restricted repertoire of activity and interests (Sussman, 2012). Such students often show a preoccupation with one narrow interest and an insistence on following routines. Abnormalities in the development of cognitive skills and in posture and body movements may be present. These impairments are accompanied by a delay or abnormal functioning in social interaction, language used in social communication, or symbolic or imaginative play that was recognized prior to three years of age (The Diagnostic and Statistical Manual of Mental Disorders, 2013).

It is important to note that the degree of impairment can range from mild to profound and will affect individuals very differently. In many cases, comorbid (or additional) disorders, such as an anxiety or mental disorder, are diagnosed in individuals with ASD. The effects of the symptoms of other disorders can increase the severity of impairments for individuals with ASD.

Supporting Students with ASD in the Ontario Classroom

Many students with ASD are identified by the IPRC as exceptional students under the Communication–Autism category (Policy/Program Memorandum No.8, 2014). The IPRC will determine the most appropriate placement to meet the individual needs of the said students with ASD. While the needs of some students with ASD may be met in a

regular class placement with appropriate supports, other students may be placed in special education classes for part or all of the school day.

Based on a thorough assessment and understanding of a child's strengths and needs, the team develops an IEP detailing the program and/or services required by the student. This includes any accommodations, modified expectations, or alternative expectations to help a student learn and demonstrate learning (OME, 2007). Highly effective IEPs for students with ASD include core goals related to function/spontaneous communication, social skills instruction, cognitive development, play skills, and proactive approaches to behavioral challenges (Iovannone et al., 2003).

For many students with ASD, an effective education program includes a combination of instructional goals based on the Ontario curriculum, with carefully planned accommodations or modifications that are evaluated regularly, using a variety of formal and informal assessments. The IEP may also include alternative programs with specific goals and activities to support the development of functional skills for the student, but that are not represented in the Ontario curriculum (OME, 2004).

To better facilitate school boards' support of schools and teachers in providing students with ASD appropriate educational programming, the Ministry of Education issued a Policy/Program Memorandum providing direction on how best to utilize Applied Behaviour Analysis in the school setting for students with ASDs (Bennett et al., 2013; Policy/Program Memorandum No.140, 2007). In addition, the Ministry published the document *Effective Educational Practices for Students with Autism Spectrum Disorders* (2003) as a supplementary resource to help teachers understand and teach students with ASDs. Finally, to better support schools and teachers, many school boards in Ontario have

established school-based support teams that play an important role in helping teachers to plan and implement programs for students with exceptionalities.

The following section discusses the notion of parental involvement within the network of special education.

Parental Involvement in Special Education

Despite the importance of parental involvement in special education, research suggests that numerous parents, particularly CLD parents, remain less involved in their children's special education process (Burke, 2013; Cohen, 2013; Esquivel et al., 2008; Fish, 2008; Mueller et al., 2008; Ryndak et al., 2011; Turnbull et al., 2010; Wolfe & Duran, 2013). The following section explores the cultural underpinnings of parental involvement in special education, the idea of parental involvement as a discursive practice, and the CLD parental experience of the IEP process. I then explore potential barriers to parental involvement from the perspective of CLD parents, as well as from the perspective of special education professionals.

Special Education Legislation: A Not So Culturally Neutral Ground for Parents

Kalyanpur and Harry (2012) posit that special education, although its own entity, exists within the larger institution of the school system. As a natural extension of the general education system, special education will reflect the "beliefs, values, and ideas" regarding both the ends and the means of education, which in turn reflect those of the national microculture (p. 6). The legal mandates that govern special education practices in North America are largely driven by mainstream, White, middle class, Eurocentric, cultural group values (Kalyanpur et al., 2000). These values include individualism, choice, and

equity; values that are not necessarily universal across cultures (Harry & Klingner, 2014; Kalyanpur, 1999; Kalyanpur & Harry, 2012; Kalyanpur et al., 2000; Park & Turnbull, 2001; Ryan et al., 2010; Skirtic, 1991). It follows that the embedded uncommon values in special education legislation, when lived out through special education processes, may inevitably lead to positioning parents against professionals, unnecessary conflict, and misunderstanding.

The mandate for parent involvement described in the policy and program memorandums concerning special education in the province of Ontario, similar to the policies underpinning the American legislation, IDEA, emerge from the “socialized expectation of participatory democracy” (Marshall et al., 1989, p.70). Participatory democracy is underpinned by the values of equity, individualism, and the notion of choice. While not shared values, these ideals are nonetheless expected to help foster a healthy and collaborative relationship between parents and educational professionals.

With respect to the value of equity, participatory democracy strives to distribute the balance of power between professionals and parents evenly (Kalyanpur et al., 2000). Traditionally, the thoughts and actions of professionals have been privileged over those of parents. As a result, participatory democracy ensures that parents can have a share in the decision-making process about their child’s education with educators. While this measure aims to provide equity, it assumes that CLD families also value equitable distribution of power between parents and professionals. In some cultures, those who exhibit expert knowledge, such as school psychologists and special education teachers, are unequivocally considered superior, and are often deferred to or relied upon for their insight (Harry, 2008; Jung, 2011; Lai & Ishiyama, 2004). In the same vein, participatory democracy also implies

that parents value the freedom of choice. It suggests that CLD parents would like to, or are comfortable with, making educational choices for their children, selecting from a range of programs and provisions, to determine the appropriate services that would benefit their child (Jung, 2011).

Within the framework of participatory democracy, parents are accorded rights that are protected under government legislation, and by extension, are expected to participate on behalf of themselves or on behalf of their child (Cobb, 2013; Friedman, 1990). Embedded in this argument is the individualistic understanding that individual parents are responsible for understanding and exercising their own rights. By extension, it assumes parents have a certain level of assertiveness needed to exercise their rights, and that they are aware of appropriate avenues for redress, in the event of a disagreement (Cobb, 2013; Friedman, 1990).

In sum, the principle of parent participation, as stipulated in North American special education legislation, is based largely if not exclusively on the ideals of the dominant North American culture (Kalyanpur et al., 2000). And while it fulfils the needs of the majority of the families who are familiar with and subscribe to these values, it does not meet the needs of all (Kalyanpur et al., 2000). It is conceivable, therefore, to understand the discomfort, misalignment of values, and potential mistrust, that may develop between CLD parents and school professionals.

Parental Involvement: A Discursive Practice

Governments, educators, and parents, discursively construct and reproduce the meaning of parental involvement (Freeman, 2010; Lai & Vadeboncoeur, 2013). Although

parental participation, parental engagement, and parental involvement are interchangeably used, they have very different connotations.

The discourse of parental involvement shapes and is shaped by institutional policy and practice. Institutional policies can often work to normalize the official discourse of parental involvement. A critical analysis of institutional policy documentation related to special education revealed lack of clarity, contradicting values, and ambiguity, which could hinder or entirely impede a parent's full participation in special education processes (Kalyanpur et al., 2000). The language used in provincial documentation offers a more specific example: while intended to assist school boards in developing programs and services for students with special needs, the language often fails to adequately define important and guiding principles, such as partnership, inclusion, and collaboration (Lai & Vadeboncoeur, 2013). Moreover, the roles and responsibilities of key stakeholders who would maintain the above-mentioned relations are ill defined (Lai & Vadeboncoeur, 2013), allowing for increased miscommunication between stakeholders, lack of accountability, and increased chances for friction to arise. In addition, the language choice and placement of words, style and tone, often positioned parents and educational professionals hierarchically, with parents at the bottom (Lai & Vadeboncoeur, 2013). Language such as 'may' or 'can' reinforces educational authority and expertise, further suggesting that certain actions or behaviours are not mandatory (TDSB, 2005; YRDSB, 2013), further disenfranchising the parent. While parents must comply with the requests of school personnel, parents cannot demand the same of the school personnel (Cobb, 2014; Lai & Vadeboncoeur, 2013). The positioning of the parent as the subordinate in relation to the teacher continues to shape the way in which some school personnel construct and perceive

parental involvement (Esquivel et al., 2008; Fish, 2008; McKenna & Millen, 2013; Zetlin et al., 1996).

With respect to practice, what people in authoritative positions, such as school counsellors, principals, and teachers, say or do, around or to parents, further reinforces the discourse (Lai & Vadeboncoeur, 2013). The dominant discourse of parental involvement, be it in general education or special education, is based largely on White, middle class values and practices (Artiles et al., 2010; Olivios et al., 2010). The dominant discourse holds that good parents support their children's educational experience in a way that serves the school's interest, and can be recognized by school personnel, thus normalizing a certain ideological perspective of a good parent (Auerbach, 2010; Brandon et al., 2010; Flynn, 2007; Lareau, 2003). Parental involvement inside the classrooms, chaperoning field trips, organizing fundraisers or attending information sessions held at the school, are recognized as legitimate and valuable acts by school staff (Brandon et al., 2010; Flynn, 2007; Lai & Vadeboncoeur, 2013). Thus, the resulting narrow understanding of parent involvement places undue emphasis on school-based involvement, the priorities of educators, and co-operation between parents and school personnel, that assumes shared goals and an equal playing field for all stakeholders (Auerbach, 2010).

This understanding of parental involvement also reduces the options for CLD parents to contribute to their children's educational experience, should they not be able to ascribe to these practices, and normalizes a certain cultural perspective on good parenting (Lai & Vadeboncoeur, 2013).

Parental engagement, unlike parental involvement, centres on building trusting relationships with the school and community. It acknowledges the values, beliefs, and

ideals of parents as essential to creating strong relationships between the school and home. It alludes to parents being equal partners in their child's education and explores ways that allow both the parent and the school to support the learning, development and health of the child (Auerbach, 2010). In this vein, engagement incorporates the home and community aspect of family life to include community cultural capital, a notion that is of particular importance when it comes to exploring relationships between CLD parents and non CLD school personnel (Constantino, 2003).

Parent participation and parental engagement varies relative to a parent's understanding of parental rights and expectations from the school system, their beliefs about child rearing, available resources, and their relationship with school personnel (Hoover-Dempsey et al., 2005). The following section explores how ineffective collaboration mechanisms between CLD parents and school personnel, among other things, results in IEP meetings that leave parents feeling uninvolved and dissatisfied with the IEP process (Esquivel et al., 2008; Fish, 2006; Jung, 2011; Mueller et al., 2008).

CLD Parental Perception of Barriers to Involvement in Special Education

Research suggests that CLD families commonly exhibit lower levels of participation in, and lack of knowledge about the special education processes in comparison to their White counterparts (Burke, 2013; Children & Chambers, 2005; Hanson & Lynch, 2004; Hess et al., 2006; Knopf & Swick, 2007; Mueller et al., 2008; Tobin et al., 2012; Turnbull et al., 2010; Wolfe & Duran, 2013). Over the recent past, numerous barriers to CLD parental involvement have been identified including, but not limited to: attitudes and beliefs about disability, differing expectations about the child's ability, school programs and professional/parental responsibilities, language barriers, differing help

seeking behaviours, and past experience with school personnel (Araujo, 2009; Burke, 2013; Cobb, 2014; Harry, 2008; Lo, 2012; Lundebj & Tossebro, 2008; Mueller et al., 2008; Prezant & Marshak, 2006; Ryndak et al., 2011; Wolfe & Duran, 2013). Some of the above-mentioned barriers will be discussed below, and the remaining barriers will be explored in next section of this chapter.

Firstly, attitudes and beliefs about disability of CLD families may differ significantly from the White, Eurocentric, Canadian mainstream understanding. CLD parents of children with exceptionalities are products of their experiences, ones that likely differ from those of some school personnel (Araujo, 2009; Burke, 2013; Cho & Gannotti, 2005; Hanson & Lynch, 2004; Harry, 2008; Luft, 1995; Kalyanpur et al., 2000). CLD families bring to the system different expectations and beliefs about their child's disability. For example, families often have misgivings about their child's disability: there is sometimes disagreement that the characteristics identified constitute a disability, or disagreement about the developmental trajectory of the child (Garcia et al., 2000; Harry, 2002; Hwa-Froelich & Westby, 2003; Sameroff & Fiese, 2000). It follows that a parents' understanding and belief towards disability, will profoundly influence their overall engagement in disability related, educational discourse.

Secondly, some CLD parents may be entirely unfamiliar with the schooling systems in their host countries (Altschul, 2011; Brandon et al., 2010; Hart et al., 2012; Lai & Ishiyama, 2004; Tinkler, 2002; Trainor et al., 2016; Wolfe & Duran, 2013). For families who belong to cultures that believe they cannot challenge school authority, the resulting compliance to policy decisions is considered a sign of their trust in the school authority (Hammond et al., 2008; Harry, 1992; Jung, 2011; Tamzarian et al., 2012; Wolfe & Duran,

2013). More especially, in South Asian, East Asian, and Central Asian cultures, where education is highly valued and teachers are highly respected, parents are likely to rely entirely on educators as experts and accept educational decisions for their child coming from the school and school personnel, as being decisions that are grounded in best practice and likely to benefit the child (Heer et al., 2012; Jung, 2011; Lo, 2012; Lai & Ishiyama, 2004; Wolfe & Duran, 2013; Sohn & Wang, 2006).

For those families who are somewhat familiar with Western schooling systems, they may espouse different expectations and beliefs about school processes and formal education that differ from those of the school personnel (Al-Hassan & Gardner, 2002; Altschul, 2001; Esquivel et al., 2008; Fish, 2008; Hanson & Lynch, 2004; Olivos et al., 2010; Ryndak et al., 2010; Trainor, 2010). Research involving some Portuguese parents, for example, illustrates that these parents share in the mainstream understanding of parental involvement, and spend time volunteering in the classroom, take part in field trips, and help organize school fundraisers or after school events (Lo, 2012; Tellier-Robinson, 1996, 2000). Certain Latino families, on the other hand, understand parental involvement to mean providing support outside of school, and out of sight of what would be perceived as supportive (Garcia et al., 2000; Kummerer et al., 2007; Olivos et al., 2010; Rodriguez, 2014). For many of these parents, involvement entails instilling values, providing, and taking care of their children, spending time talking to them, and sending them to school clean, rested, and well fed (Araujo, 2009; Tellier-Robinson, 2000). Some CLD parents are unaware of several elements of the educational processes with which they are involved: the inherent expectations, what information or resources need to be sought and from where, and their own rights or the rights of their child. Due to this lack of knowledge, it will be

less likely for these parents to fully engage in educational processes (Brandon et al., 2010; Goldenberg et al., 2001; Hart et al., 2012; Lai & Ishiyama, 2004; Lalvani & Hale, 2015; Lo, 2012; Rossetti et al., 2016; Sheehey, 2006; Trainor et al., 2016; Wolfe & Duran, 2013). CLD parents' lack of knowledge of how to best interact with the school system and its experts will likely result in their children receiving less or inadequate support, while the parents continue to be perceived as being less engaged with the special educational system.

A third barrier may lie in communication styles. Families that come from high context structures, where communication is heavily dependent on subtle messages of the interaction such as body language, facial expression, and timing of silence, are assumed to experience difficulty in effectively participating in low context structures, where communication is straightforward, specific, and logical (Chiang & Hadadian, 2010; Jung, 2011; Lo, 2008). The type of communication itself then, becomes a barrier. In the same vein, another communication barrier may be limited English proficiency (Lai & Ishiyama, 2004; Lo, 2008; Tellier-Robinson, 2000). In this circumstance, procedural safeguards, the IEP process, and the selection of educational goals may be overwhelming for parents. Limited English proficiency also hinders a CLD parent's ability to communicate freely in an IEP meeting, as a parent may take time or struggle to translate and/or explain their thoughts (Araujo, 2009; Esquivel et al., 2008; Fish, 2006; Lai & Ishiyama, 2004; Lalvani & Hale, 2015; Lo, 2008; Olivos et al., 2010; Ryndak et al., 2011). While limited level of English proficiency may not be a direct barrier to communication, it can frequently be perceived as such (Harry, 1992; Trainor, 2010; Wolfe & Duran, 2013). Although translators may be made available to parents, parents are often concerned about the limited language proficiency in both languages, the translator's knowledge of educational

terminology, and their translator's connection to the school district (Jung, 2011; Lai & Ishiyama, 2004). In this circumstance, despite a parent's willingness to interact, the enabler (the translator) effectively becomes the disabler to active engagement, based on the accuracy of the translation process.

A fourth barrier may be a CLD parents' immigrant and economic status. Although there may be other minority communities that espouse a similar understanding to parental involvement as the mainstream understanding, given their status as immigrant or belonging to low-income families, CLD families may face several logistical barriers. For example, many parents may not have time to volunteer at school due to their work schedule, lack of transportation, or family responsibilities, such as arranging appropriate childcare (Friesen & Huff, 1990; Jones & Gansle, 2010; Lee et al., 2017; Kemp, 2012). In the same vein, many CLD families struggle to attend IEP meetings, connect with school staff during school hours, or implement academic and therapeutic interventions at home, given their demanding schedules (Friesen & Huff, 1990).

Lastly, the perceived and experienced attitudes and behaviours of special education personnel can often serve as a barrier to parental involvement. Special education personnel, including psychologists, social workers, teachers, and therapists, sometimes demonstrate a lack of cultural reciprocity and sensitivity towards the religious beliefs or family traditions a family may espouse (Brandon et al., 2010; Burke, 2013; Cho & Gannotti, 2005; Esquivel et al., 2008; Hammond et al., 2008; Harry, 2008; Jung, 2011; Park & Turnbull, 2001, Ryndak et al., 2011; Turnbull et al., 2010; Wolfe & Duran, 2013). In a study conducted by Zions, Zions, Harrison and Bellinger (2003), over a third of surveyed parents felt that the school did not treat them as collaborators. CLD parents repeatedly mentioned how school

personnel dismissed their understanding of their child's needs as less valuable in comparison to the professionals' expert opinion, and how often school personnel reverted to the use and misuse of educational jargon when in conversation with them (Jung, 2011; Lai & Ishiyama, 2004; Olivos et al., 2010; Turnbull et al., 2010). The inappropriate behaviour displayed by school personnel has often led many CLD parents to feel and believe that several teachers and administrators hold a deficit view of CLD families (Brandon et al., 2010; Hess et al., 2006; Lo, 2008; Mueller et al., 2008; Sheehey, 2006; Trainor, 2010; Turnbull et al., 2010).

These barriers, amongst others, serve only to increase parents' frustrations and disappointment with special educational processes, inevitably leading to increasingly less parental engagement. The following section hones in on the CLD parental experiences of one specific special education process: the IEP meeting.

CLD Parental Experiences in IEP Meetings

Literature suggests that CLD parents are not actively involved in the IEP processes (Brandon et al., 2010; Cobb, 2014; Fish, 2006; Harry & Klingner, 2014; Rueda & Windmueller, 2006; Steeley & Lukacs, 2015; Wolfe & Duran, 2013). Studies found that the area of intersection between parents and educators, or between parents and school processes is often fragmented, and poorly integrated. Frustration, confusion, tension, anger, and low levels of cooperation often emerge, affecting the overall efficacy of service delivery and the eventual well-being of those being served (Lake & Billingsley, 2000; Mueller et al., 2009; Olivos et al., 2010).

To begin, Staples and Diliberto (2010) suggest that the structure of the IEP process is itself, difficult to navigate, and can be perceived as disabling by CLD parents. IEP related

documentation is hard to understand. Mandic et al. (2012) and Lo (2014), using various readability formulas and tools used to estimate the difficulty of written material, argued that IEP communications were at a readability level that was not accessible to many of the parents that participated in their study. According to their findings, parents had trouble with reading and correctly interpreting their rights, and the rights of their child, before, during and after the IEP process. Next, parents identified the structure of the in-person meeting to be overwhelming (Hart et al., 2012; Mueller et al., 2008; O'Conner, 2008; Worcester et al., 2008). Parents felt small, underprepared, and invisible, among the volume of school personnel who could/would attend each meeting (Burke, 2013; Cho & Gannotti, 2005; Flynn, 2007; Li & Wang, 2008; Ryndak et al., 2011; Sheehey, 2006). With respect to determining the child's goals, potential services, program availability, or eligibility criteria, CLD families felt that many fundamental decisions were made in advance of the IEP meeting, making the school personnel the primary decision makers (Ruppar & Gaffney, 2011; Soodak & Erwin, 2000). This positions CLD parents, and their children, as passive recipients of accommodations and supports presented by the school system. CLD parents also felt that the structure of the meetings did not reflect an open and collaborative space. To this end, CLD parents felt that there was insufficient time to complete the meetings, lack of support from school personnel to discuss alternative goals than the ones already stated, and a lack of encouragement to bring additional advocates to the meeting (Altschul, 2011; Lai & Ishiyama, 2004; Prezant & Marshak, 2006; Reiman et al., 2010; Salas, 2004; Trainor et al., 2016;).

While some CLD parents of children with special learning needs felt that their insights and suggestions about their child were valued by the school professionals, and

incorporated into their child's IEP (Araujo, 2009; Harry, 2002; Kummerer et al., 2007), many more parents described school professionals' inherent attitude and perspectives towards them as distant, patronizing, or indifferent (Cho & Gannotti, 2005; Esquivel et al., 2008; Fish, 2006; Lai & Ishiyama, 2004; Reiman et al., 2010; Tellier-Robinson, 2000). When parents attempted to share their experiences and insights during formal meetings, parents felt that school personnel became increasingly insensitive and impatient with them (Lai & Ishiyama, 2004; Lo, 2008; Ryndak et al., 2011; Sheehey, 2006). CLD parents felt as though their insights were considered unreliable or inaccurate because they were not generated in the same way as those of the school professionals, and were often dismissed. Parents' knowledge was not always reflected or used at the decision-making stages of the process (Hess et al., 2006; Knopf & Swick, 2007; Tobin et al., 2012; Wolfe & Duran, 2013). Moreover, because school professionals often display their expert knowledge using inaccessible jargon, parents feel vulnerable, inadequate, and incompetent to provide meaningful feedback for the development of the IEP (Brandon et al., 2010; Flynn, 2007; Hart et al., 2012; O'Conner, 2008).

As CLD parents feel increasingly marginalized and disenfranchised, their involvement in their child's education, in whatever shape or form, may decrease (Wolfe & Duran, 2013). Many CLD parents, based on their context, may give up advocating for their child, lest their persistence negatively impact school personnels' behavior with their child (Jung, 2011; Lai & Ishiyama, 2004; Lo, 2008). A cycle may develop where school professionals may interpret low parental participation as a lack of interest and as such, over time, continue to share less and less information with CLD families regarding services and supports available to these families, inevitably further isolating CLD parents (Hammond

et al., 2008; Harry, 2008; Jung, 2011; Lai & Ishiyama, 2004; Lo, 2008; McKenna & Millen, 2013; Rehm et al., 2013).

Professionals' Perception of Parental Involvement

Hilton and Henderson (1993) suggest that while teachers value parental involvement, there are a limited number of practices that are explicitly specific, and family centred. Of the limited practices that do exist, some special education personnel believe that their interactions with parents, be it conversations, meetings, or written communication, are professional, inviting and meaningful, void of biases, and in the best interest of the child (Bezdek et al., 2010; Lareau & Horvat, 1999; Simon, 2006).

Bezdek, Summers, and Turnbull (2010) examined professionals' attitudes on partnering with families of children with disabilities. These scholars argue that professionals have specific ideas regarding the *right type and amount of involvement*, which was appropriate for parents. Affectionately known as the *goldilocks perception*, professionals felt that parents who asked too many questions, provided too many suggestions or alternatives, and parents who disagreed with the professional assessment of their child's progress, were considered to be *too involved*. More specifically, parents who resolved to using the internet to conduct their own research, and entered the academic realm, were considered to be a "challenge" or "difficult". Conversely, parents who did not participate in school related activities, or did not value academic activities as teachers did, were considered to be disengaged (2010). Interestingly, the parents who followed the teachers' lead, suggestions, and participated in teacher suggested exercises at home, were considered 'just right' with respect to parental involvement. It follows that, rather than engaging in an equal partnership, the teachers in this study reported they felt that the right amount of

involvement corresponded to following the teachers' instructions, and completing the tasks the teacher thought valuable for the child's growth and development.

The difference in cultural values and beliefs between personnel and CLD families may also go unnoticed by many school personnel. This is particularly true with respect to parenting expectations, understanding of disability, beliefs related to child rearing and development, and the role and responsibilities of the educator vis a vis the parent. These differences may lead to misunderstandings, mistrust, and tense relationships between parents and teachers, which has been identified in the literature (Delpit, 1995; Nieto, 2010; Sheets, 2005; Spring 2012; Valdés, 1996, 2001; Valenzuela, 2010; Wildcat, 2001).

Despite their efforts, the lack of reciprocity has led many school personnel to view CLD families of children with special needs as passive in their involvement in their child's education, compliant with authority figures, unaware about school procedures, uninformed about their rights and duties as parents, and overwhelmed with their life circumstances (Burke, 2013; Harry, 2008; Jung, 2011).

These perceptions, although not entirely representative, helps clarify what parents are currently experiencing. Attitudes and behaviours espoused by teachers may contribute to the development of power differences between parents and teachers (Araujo, 2009; Burke, 2013; Esquivel et al., 2008; Hammond et al., 2008; Lo, 2008; Ryndak et al., 2011; Wolfe & Duran, 2013). Jung (2011) argues that stereotyping families, denying parental expertise and knowledge about the child, withholding information, or using educational jargon when discussing placement and programming options with families by certain school personnel, prevents meaningful collaboration, which ultimately influences the relationships, communications, and experiences of parents within the education system.

Understanding the Cultural Contexts of the Canadian South Asian Hybrid Community

The limited or complete unavailability of current literature and research focusing on Indian and Pakistani Canadian parental involvement in special education processes, highlights the compelling need to fill the gap in this area of research. Although, for the purposes of this research, I draw from South Asian related literature as whole, it is important to note that South Asians are a culturally diverse and heterogeneous group, made up of a number of sub-groups. Each sub group is equally diversified, with variations in terms of languages, religious practices, migration histories, financial status, education levels, and acculturation levels (Hatton, 2004). These factors can influence how parents understand their child's disability, and the ways in which assistance is sought and provided.

In the following section, I explore the following constructions and their potential intersections as perceived and experienced in South Asian cultures: the family unit, disability, accepting disability, and parenting a child with a disability.

The Family Unit

The essential pattern of family membership in the South Asian context is as follows: a man, his wife, his sons and their wives, and his grandchildren. South Asian families are often, patriarchal in nature. At marriage, daughters leave their natal birth homes and become members of their husbands' family (Kashyap, 1989). In this worldview, mothers are responsible for the care of all children, including those with special needs (Edwardraj et al., 2010; Kashyap, 1989). Fathers are typically considered to be family providers with exclusive responsibility for all important family decisions. This includes methods of care,

education, and program participation for the children (Pal & Chaudbury, 1997). In some cases, this can create a conflict, as it is the mother, who is sometimes the only one with knowledge of the needs of the child with a disability. Due to this family structure, the mother is frequently unable to make crucial decisions or advocate for needed support for the child or family, without the support of her husband (Pal & Chaudbury, 1998; Peshawaria & Menon, 1991). She may be bound by family roles and may have to defer to the father's wishes, regardless of her beliefs. If the father's views are different than those espoused by the professionals, this may act as a barrier to parental participation, given that the mother may be unable to articulate or express their concerns, goals, or desires for the future of their children's program.

In the South Asian culture, it is also typical for multiple families to live in the same household, in a joint-family structure (Goldbart & Mukherjee, 1999; Luong et al., 2009). At any point, there may be relatives from multiple generations and close family friends living either together, under one roof or in the same neighborhood (Peshawaria & Menon, 1991; Bezdek et al., 2010). While this arrangement allows for sharing domestic and childcare responsibilities, which is particularly helpful when caring for a child with a disability, this can also become a barrier. In the circumstance where one parent can participate in parent education programs, the strategies learned may not be implemented by the several additional caregivers who may spend significant time with the child. Where extended relatives, friends, and other community members may support the recommended course of action, they may also impose their beliefs regarding the best methods for supporting the child which could contrast with professionals' recommendations (Peshawaria & Menon, 1991).

Cultural Understandings of Disability

A culture's construction of disability informs how members of that community come to include or exclude people with a disability. This is of particular importance, as the mainstream Canadian society interprets disability differently from the South Asian culture (Harry & Kalyanpur, 1994; Hwa-Froelich & Westby, 2003; Parashar et al., 2008).

Within Canadian society, establishing a comprehensive definition of the term disability, accounting for both its origins and for the full range of conditions that may manifest because of the disability, is a complex matter (Ontario Human Rights Commission, 2018). The way in which policy makers address impairment depends largely on the paradigm of disability that is employed. Two of the more prominent models of disability found in literature, include the medical model, which heavily informs our special education system (Snyder & Mitchell, 2010), and the social model. The medical model locates the disability diagnosis to the individual's body and aims to cure or manage the illness (Harry, 1992). The social model of disability, a direct response to the former model, posits that it is society, inclusive of its attitudes, systemic barriers, and constructed environments, that limit the full and equitable participation of all people in society. The social model of disability is based on a distinction between two terms: impairment and disability. Impairment refers to the biological condition affecting function, while disability denotes the structural barriers that restrict full social, economic, and political participation of individuals with impairments (Shakespeare, 2006; Thomas, 2004).

Within South Asian cultures, there are significant variations with respect to beliefs about what causes a disability, the rhetoric related to how a disability is defined, and the importance of and/or need for intervention. There exists significant variation in beliefs,

practices, or philosophies between members of the same ethnic group (Hanson & Lynch, 2004). These inherent differences will ultimately affect a family's perception of their child's challenges, their motivation to seek support, and their willingness to participate in disability services. It is critical, therefore, to examine a family's understanding of a given disability, the reason or cause explaining the disability, and their perception of the stigma associated with the disability.

Disability as a Result of Karma

Though traditionally an Indian notion, communities living in Nepal, Punjab, Pakistan, Bangladesh, Sri Lanka, have appropriated to a certain extent, the doctrine of Karma and destiny (Dalal & Pande, 1999; Edwardraj et al., 2010; Pal & Chaudbury, 1998; Parashar et al., 2008). Karma, which states that a person's actions in their present life will dictate their experiences in their next life (Dalal & Pande, 1999), is a deeply ingrained belief throughout many South Asian communities. As such, it is not surprising that parents, community members, and educators across South Asia, have expressed that disability is the consequence of some wrong doing committed by the parent in a previous life (Dalal & Pande, 1999; Edwardraj et al., 2010; Hanson & Lynch, 2004; Jacob, 2011) and is a 'punishment' for their past sins. Because parents believe that having a child with a disability was an act of God, and that they were predestined to live with this fate, some parents believe and feel that there is no action they can perform which will alter their fate (Dalal & Pande, 1999; Kalyanpur & Harry, 1997). The view that children with disabilities will not make progress through treatment or intervention, or more importantly, need not make progress, is also shared by some professionals (Edwardraj et al., 2010). Parents who

shared in this understanding, felt powerless, and accepted that their child was simply not meant to learn (Hwa-Froelich & Westby, 2003).

Disability Caused by Supernatural Powers

Within South Asian traditions, a number of medical conditions, including mental illness, deafness, or epilepsy for example, “are believed to have supernatural, magical or demonological causes” (Braddock & Parish, 2001, p.17). The belief held by many South Asians then, is that the person with the disability is possessed by supernatural powers such as demons, ghosts, or evil spirits (Chan, 1986). The ‘evil eye’ or a peculiar prenatal event, such as meeting a disabled person (Heward, 2006), are also thought to account for the onset of a disability. As a result, parents might seek help from religious men, priests, or shamans, who might perform chants and provide lucky charms made from herbs to be ingested, or hung in the house, or kept on the person with a disability (Chan, 1986). Often, an amulet containing a piece of folded paper, with a prayer on it, is put on the person with a disability, to protect the child from continued torment, struggle, or future spells.

Disability as a Gift from God

In contrast to the above perspectives, for some South Asian parents, having a child with physical, intellectual, or developmental disabilities is regarded as a gift from God, and could bring good fortune to the family (Danesco, 1997; Heward, 2006). Interestingly, in certain traditions, it is sometimes assumed that the child has the prenatal choice of how he wishes to be born and, if (disabled), is so by choice. Only those with a strong sense of spirituality are privileged to be born in this way and born into a family that can support their alternate way of being. In either case, given that this was an act of God and that the children were predestined to live with a disability, some parents are of the view that there

is little they can do, to alter their circumstances (Kalyanpur & Harry, 1997). The prevalence of such ideological beliefs within the South Asian cultures, however, remains uncertain.

Disability Caused by a Child's Laziness

Unlike physical, developmental, or cognitive disabilities, learning disabilities are sometimes harder to identify. Some South Asian families believe that hard work, dedication, and practice will lead to success in learning (Chan, 1998; Hwa-Froelich & Westby, 2003). The inability to perform academically, therefore, is often understood as the result of some personal characteristic, such as laziness or stubbornness, and is not necessarily attributed to a potential learning disability (Hwa-Froelich & Westby, 2003). Consequently, parents sometimes enforce stricter discipline strategies and/or provide additional tutoring and coaching classes, to ensure that their children can perform academically, without recognizing that they may be putting forth great effort already. The child's continued poor academic performance may lead the family to believe that their child is disobedient or defiant. Most parents are unlikely to seek professional support, and would expect their child to study harder, and outgrow their learning difficulties, as they grow older.

Understanding and Accepting a Diagnosis

The birth of a child with disabilities or the discovery that a child has a disability, is a turning point in the lives of many parents. Cognitively, parents need to understand the meaning and implication of the diagnosis for themselves and their child (Thwala et al., 2015). Emotionally, parents will experience and express a spectrum of feelings based on their understanding of the impact of the disability on their child and their family. While parental stress and adaptation will vary based on the type of disability, and the variables

specific to the parent profile, research suggests that the stages that parents go through when reacting to the discovery of disability parallel the emotional stages of bereavement (Baker et al., 2003; Crnic et al., 2005; Gupta, 2007; Hill & Rose, 2009).

In a parent's initial reaction to the birth of a child with disabilities, or at the discovery that a child has a disability, the first stage may include a degree of numbness or denial (Thwala et al., 2015). The onset of a disability may have shattered a parent's dream, aspirations or fantasies they may have attached to their child, leaving parents in a state of disbelief. This stage may be followed by pain and guilt. Sometimes, the parents blame themselves or each other for their child's impairment (Scorgie & Sobsey, 2000). Often, parents question why it is them, and not someone else, who has a child with an exceptionality. This stage is followed by a period of anger and grieving. Physically, their child is not lost; they are right there with them. Instead, during this phase, parents are grieving for the loss of their *imagined child*, the child they were expecting, who never arrived (Moses, 1983). Parents need to re-evaluate and adjust their expectations and hopes for their child in the face of the uncertainties that are inherent to the child's diagnosis, both in terms of caregiving responsibilities and cost. For many parents, it is during this phase they realize that they will be perpetually in a parenting role. They come to understand that their caregiving responsibilities towards their child may look and feel different than what they had previously imagined, as feeding, clothing, bathing, and diapering may extend beyond the early childhood years and into their child's adulthood (Dabrowska & Pisula, 2010; Thwala et al., 2015). At the same time, parents will need to recognize and contend with financial costs associated with their child's disability. Parents will need to consider and plan for the rising costs of additional health care, therapies, medical or educational

equipment, care giving expenses, private education, and/or specialized transportation (Thwala et al., 2015).

Assuming parents have understood their new reality, the last stage in this cycle is that of acceptance and adaptation. However, unlike in the grief cycle where one eventually stops resisting the reality of the situation, parental acceptance and adaptation to this new reality is especially hard given the evolving nature of the child's disability. More specifically, a parent may understand and accept the extent of a child's impairment, but they may not experience the grief associated with the impairment until they witness their child not meeting set milestones in their developmental journey. By extension, for each developmental phase in their child's life, the parent is likely to relive and experience emotions anew, be it grief, loss or sadness. And so, a full acceptance is unlikely to occur. This developmental unfolding will impact a parent's social, emotional, and cognitive well-being, to a lesser or greater extent, based on variables including but not limited to their age, gender, financial status, social support, and coping strategies, as well as their child's disability and developmental stage (Pozo et al., 2014).

Caring for a child with a disability brings about significant changes in family functioning. It does not only impact the parents, but also the other children in the immediate family, and the extended family, including grandparents, aunts, and uncles. Parents will experience varying levels of stress, as well as feelings of depression, anger, denial, guilt, self-blame, and confusion (Heiman, 2002). It follows that the sequence of stages and the time needed to adapt to the new normal is different for every parent (Thwala et al., 2015).

Language, Labelling, and Stigma Related to Disability

Theorists suggest that ideas communicated through language predominately shape one's perception (Farrell, 2010; Rao, 2001, 2009). According to this view, how disability is conceptualized is revealed in how it is named. Developments in Western public discourse has put forth the idea of the 'person first' language, which suggests that "one might refer to 'a child with autism' in preference to an 'autistic child', underlining that one is interacting with a child and not a condition" (Farrell 2010, p. 55). Within the South Asian context, conversely, Rao (2001) observes that many traditional Indian languages do not have words which correspond to terms such as 'retardation', 'disability' or 'handicap'; they use names which are much more descriptive of the disability like 'one arm' or 'one who walks with a limp'.

As a result, the 'label' associated to an individual's disability affects the way in which their identity is constructed and perceived (Dattoo, 2010). In cultures where identity is defined collectively, such as South Asian cultures, severe disabilities such as cognitive delay and physical or sensory disabilities, might be perceived as reflecting on the whole family (Harry, 1992), and may bring shame or dishonor upon the family (Chan, 1986). In such circumstances, family members go to great lengths to hide the disability or the family member with the disability from the public, as it may reflect on dysfunctional genes, and impact marriage prospects for the remaining family members.

It follows that the construction of disability will influence the attitude one has towards disability, ranging from complete religious acceptance for example, to wholehearted rejection and isolation of both the individual and the family (Chan, 1986; Kalyanpur et al., 2000).

Help Seeking Behaviours and Attitudes Towards Interventions

The belief system espoused by the parent and family will, inevitably, impact parents' willingness to seek services or their desire to participate in the programs their child may already be receiving. For example, some South Asian families may not see the benefits of education for their child with a disability if they hold the belief that it was "God's will" which brought them a child with a disability, and that the disability does not need to be addressed (Dalal & Pande, 1999; Kalyanpur & Harry, 1997; Kashyap, 1989). Parents who believe and accept their child's disability as unchanging and final may be less motivated to access supports as they may not see any possibility for improvement. As such, parents may benefit from educational interventions that explain the benefits of additional supports for both their child and their families, respectively. Professionals must be capable of understanding and empathizing with a family's beliefs and apprehensions surrounding the available services so as to provide culturally responsive recommendations which are in the best interest of both the child and the family.

Another factor which may limit a family's willingness to seek support is the perceived stigma of having a disability (Respler-Herman et al., 2012, Tiwari & Wang, 2008). The embarrassment and shame associated with having a family member with a disability may influence a parent's readiness to share his or her concerns with educational professionals (Edwardraj et al., 2010; Luong et al., 2009, Parashar et al., 2008), regardless of the possible benefits. In South Asian countries, family identity and family reputation are one that is collective and may be regarded as more important than seeking supports for an individual with special needs (Heer et al., 2012; Kalyanpur & Harry, 1997; Rizvi, 2017).

Lastly, it is important to note that within many Asian cultures, there is a strict observance of hierarchical order, and a belief in professionals' higher status (Cheng-

Gorman & Baiter, 1997; Edens, 1997; Esquivel et al., 2008; Walz, 2013). This may prevent parents from sharing their opinions with school personnel, and families may feel more comfortable participating as observers than as equal partners. Often, South Asian families may view service providers and teachers as a source of unquestionable knowledge (Kalyanpur & Harry, 1997). Parents may expect direct advice, recommendations, and strategies to support their children “since professional knowledge is scientifically based, is assumed to be objective, [and] is ranked higher than knowledge that is anecdotal and therefore subjective, such as parents’ perspectives of their child” (Kalyanpur et al., 2000, p. 123). South Asian parents may look to the professional as an authority figure rather than an equal partner. Consequently, a partnership or collaborative model may be incompatible with a family’s expectation of support services.

In the end, a parent’s inherent belief about the cause of their child’s disability, combined with their cultural values related to shame, honour, and stigma may inhibit, if not altogether curtails a family’s ability to seek and/or access initial supports such as assessments, evaluations, or diagnostic support (Kalyanpur & Harry, 1997).

Chapter Summary

Since the 1980s, parental involvement in the special education process has been mandated through legislation, guaranteeing free and appropriate public education for all children. As research suggests, there are many advantages to including families in the education process for children with exceptionalities, and yet low levels of parental involvement are consistently observed, particularly among the CLD parental population (Araujo, 2009; Burke, 2013; Cho & Gannotti, 2005; Esquivel et al., 2008; Fish, 2006; Lo, 2008; Lundeby & Tossebro, 2008; Mueller et al., 2008; Park & Turnbull, 2001). CLD

parents often appear as passive participants in special education processes, such as the IEP meeting. Their respective involvement is mediated by a variety of factors that can be both enabling or disabling, as discussed in this review. The review also highlights how—despite their efforts—a number of educators may not be aware of cultural differences that may hinder true parent-educator collaboration as intended by the legislations (Altschul, 2011; Brandon et al., 2010; Goldenberg et al., 2001; Hart et al., 2012; Lai & Ishiyama, 2004, Sohn & Wang, 2006; Tinkler, 2002; Trainor et al., 2016).

This review ends by providing a general overview of different cultural understandings underpinning the notion disability, and parenting a child with disability among the South Asian population. Currently, the voices of South Asian families, particularly those from Indian and Pakistani backgrounds, are missing from the existing literature related to CLD parental involvement in special education. There is a need to hear their unique experiences with regards to the IEP meeting process. Knowledge of these experiences, both positive and negative, will help inform policies and procedures, and open up much needed dialogue to help strengthen the parent-teacher relationships.

CHAPTER 3: METHODOLOGY

In the previous chapter, I explored literature related to the evolving nature of special education in Canada, CLD parent-teacher partnerships within the field of special education, and a brief and generalized account of disability related beliefs and family organization in immigrant South Asian groups. In this chapter, I begin by highlighting the conceptual framework used to guide this study. I then describe the design of the proposed research study, including (a) overall research design, (b) the rationale for the research design, (c) sampling and participant recruitment, (d) data collection and data analysis, (e) validity and reliability of findings, (f) ethical considerations, (h) my role as a researcher, and (i) study limitations. I conclude with a chapter summary.

Conceptual Framework

Professional relationships between CLD parents and special education professionals are fraught with inequity, where much of the knowledge and decision-making power continues to reside in the hands of school professionals (Altschul, 2011; Brandon et al., 2010; Fish, 2006; Harry, 2008; Lo, 2008; McKenna & Millen, 2013; Olivos et al., 2010; Riddell et al., 1994; Rossetti et al., 2016; Trainor, 2010). Knowing that one requires specialized types of cultural and social capital to meaningfully engage in special education processes, I feel it becomes increasingly important to explore not only the process of parental involvement, but the relationships that govern the various parental engagement processes, through the lens of both culture and power.

Accordingly, I draw upon Hoover-Dempsey and Sandler's (1995, 1997) model of parental involvement, to understand the relationship between a parents' perception of the

special education processes and their involvement therein, in comparison to the actual manifestation of their involvement. I also use positioning theory, to complement the parental involvement model, with the aim of capturing how parental perceptions of parental involvement are constructed and positioned by themselves and the special educational professionals with whom they interact. Lastly, I use Foucault's theory of power and knowledge, and Bourdieu's theory of capitals as ways by which to explore the nuances that may underpin the relationships between CLD parents and special education professionals. The following section details the conceptual framework that is used to guide this investigation.

Hoover-Dempsey and Sandler's Model of Parental Involvement Processes

Research on parental and family involvement in both in general education and special education, has repeatedly illustrated the positive effects of parental involvement on student academic and non-academic achievement (Dorfman & Fischer, 2002; Epstein, 1988; Hoover-Dempsey & Sandler, 1995, 1997). Literature demonstrates that many CLD families value education, hold teachers in high regard, and espouse high educational aspirations for their children; however, the behaviours that they associated parental involvement may differ from the behaviours typically expected or observed by North American educators (Garcia Coll et al., 2002; Gillanders & Jimenez, 2004; Reese, 2002). To develop a more comprehensive understanding of parental motivation and contribution to student learning or performance outcomes, Hoover-Dempsey and Sandler (1995, 1997) proposed a theoretical model of parental involvement, grounded in educational, developmental, and social psychology research.

Hoover-Dempsey and Sandler's model of parental involvement processes (1995, 1997) is a holistic model which aims to detail types of parental involvement, motivators of parental involvement (Fan & Chen, 2001), and how parent involvement makes an impact on the student (Hoover-Dempsey & Sandler, 1995, 1997). This model is constructed in five sequential levels, the first of which will be used for the purposes of this study. The first level identifies three categories of parents' motivations for involvement: parents' motivational beliefs, contextual motivators of involvement, and parents' perceptions of life-context variables.

Parents' Motivational Beliefs

Hoover-Dempsey and Sandler's model (1995, 1997) suggests that motivators of parental involvement consist of two constructs: namely, parental role construction for involvement, and parents' sense of self-efficacy for helping their children succeed in school.

Grounded in role theory (Briddle, 1986), parental role construction can be understood as a parents' beliefs and convictions about what they are supposed to do in relation to their child's schooling. Parents develop these principles based on their own and important others' expectations. How a parent ought to behave may also be deeply rooted in their cultural and religious constructions of parenthood. In this case, grounding parental roles and responsibilities in a tradition helps parents imagine and anticipate how they might behave in relation to a host of activities relevant to their child's educational success (Hoover-Dempsey & Sandler, 1997). In turn, parental role construction influences student outcomes as it allows students to perceive and understand a range of activities that parents

interpret as important, necessary, and permissible for their own engagement (Hoover-Dempsey & Sandler, 1997).

Parents' sense of self-efficacy refers to parents' beliefs about whether their involvement is likely to positively influence their children's educational experience. Grounded in Bandura's (1989) social cognitive theory, self-efficacy refers to a parents' beliefs in their ability to act in a way that will produce desired outcomes. In other words, a parents' beliefs will shape their personal behaviour. Applied to parental involvement in their child's education, a parents' perception of their self-efficacy in helping their child succeed will influence parental goals and their persistence. It is also likely to help shape parents' beliefs about what not to do, or the limitations to their involvement choices, when placed in uncertain or discouraging situations (Hoover-Dempsey & Sandler, 1997).

Contextual Motivators of Involvement

Hoover-Dempsey and Sandler's model (1995, 1997) posits that parents' perceptions of contextual invitations, including general invitations from the school, the teacher, and/or the child are particularly powerful in prompting parental involvement. Explicit requests or invitations from the school or the teacher to attend curriculum sessions, parent-teacher meetings, when perceived to be welcoming, as reflected in the attitudes and behaviours of school staff or in their communication strategies, suggests to parents that they are valued members of the community and valued participants in their children's education (Griffith, 2001; Mueller et al., 2009). Invitations of involvement from the child are also noteworthy, partly because parents want their children to succeed in school and are motivated to respond to their child's needs (Grusec, 2002).

Unlike regular education, however, parent involvement in special education is formally acknowledged through legislation (OME, 2005). In Ontario, parents are required to participate in the assessment, placement and/or programming decisions for their child, and are also invited to attend IEP meetings (Cobb, 2015; OME, 2005). Since parents are invited to participate in school processes by design, school and teacher invitations cannot be measured in this study. In the same vein, it is unlikely that the children of the participants in this study will extend an invitation to their parents for their involvement. As such, only those invitations extended by school personnel that were outside those required by Ontario legislation, will be explored in this study.

Perceived Life-Context Variables

The last component in the first level of Hoover-Dempsey and Sandler's model of parental involvement (1995,1997) posits that parents' levels and forms of involvement are influenced by their perceptions of the skills and knowledge they bring to involvement, as well as the time and energy they believe they can give to involvement.

Parents' ideas about their skills and knowledge influences the level and type of involvement decisions across their child's educational journey (Hoover-Dempsey et al., 2005). Lareau (1989) argued that parents with little general education not only felt less able than their more educated counterparts to assist their children with homework, but also felt less able to communicate with teachers, and were more likely to feel as though they do not belong at the school. Further research must be conducted to understand better the ways by which parental knowledge and changes in parental knowledge is associated with changes in child development and behavior (Shears & Robinson, 2005). It is probable to assume that parents with limited English proficiency skills, and limited knowledge about

educational processes and expectations, may experience similar struggles, limiting their level and type of involvement in their child's education.

Parents' perceptions of the expendable time and energy they have, can serve either as an enabler or a barrier to their involvement. Family responsibilities, such as caring for other children, caring for parents, inflexible or over taxing work schedules, and transportation concerns can consume much of a parent's time and energy, limiting their availability to attend to school requests (Garcia Coll et al., 2002; Pena, 2000; Weiss et al., 2003).

Hoover-Dempsey and Sandler's model of parental involvement (1995, 1997) offers us a framework through which one can examine the relationship between a parent's perception of involvement experiences and their actual involvement in their children's education. It must be noted that the researchers operationalized both their predictors, and their sub constructs (i.e., parents' perceptions of the value of school, respect for school personnel, and their expectations for children's school success) in terms of White, European, middle class norms (Olivos et al., 2010). The model also assumed a level playing field of voluntary parent action, understanding the constraints of class, race, culture and school structure (Hoover-Dempsey et al., 2005). Lastly, it must also be noted that since this model was developed to describe parental involvement in the general education setting, it may call for adaptation when applied to parental involvement in the special education setting.

Positioning Theory

As parents become increasingly involved in the network of special education process, from engaging in IEP meetings and discussing alternative supports, to

understanding evaluations and assessments, parents must examine and re-examine the roles they play as their child's representative, caregiver, and advocate. Positioning theory presents a framework for conceptualizing parents' identities as dynamic, discursive products of the local context. Using people's conversations, the theory aims to understand parents' implicit and explicit patterns of reasoning. Positioning works as a metaphor to understand how people locate and define both the self and the others who are participating in, and producing the shared narrative (Harré & van Langenhove, 1999; Tirado & Gálvez, 2008). People's narratives reveal, based on their social and cultural repertoires, how they see themselves, and the position(s) they hold (Haste, 2014). By adopting a position, one ascribes to themselves *rights*, what a person is owed, and *duties*, what a person owes to others (Harre et al. 2009). Whenever someone positions themselves they also, simultaneously, position the other (Van Langenhove & Harre, 1999). The theory's focus on the dynamic process of social interactions and the positioning of self and others sheds light on three phenomena: (1) social and cultural systems of meaning making and their respective interactions, (2) how these systems serve to regulate human behaviour, and (3) how people perceive the choices available to them at a given time and place.

Positioning theory is comprised of three key elements: positions, speech acts, and storylines, which constitutes the "positioning triangle" (Harre & Moghaddam, 2003). Together, the three parts of the triangle form a "stability between actors' positions, the force of what they say or do [speech acts], and the storylines that are instantiated in the sayings and doings of each episode" (Van Langenhove & Harre, 1999, p.10). The

following section explores the definition of each element as it applies to parent-teacher relationships.

Positions are defined as discursive productions of a “diversity of selves” (Davies & Harre, 1990, p. 47), where participants deliberately adopt a self-construction, or are positioned in one, through their interactions with others. Within a position, there is a “momentary assumption or ascription of a defined cluster of rights, duties, and obligations with respect to what sorts of things a certain person, in that position, can say and do” (Harre, 2003, p. 697). As such, different positions carry unique rights and duties, the limits of which are set by their social repertoire, their cultural repertoire, or a combination of repertoires (Harre et al., 2009). It is important to note that positions are temporary, dynamic and often change as interactions proceed based on the situationally and contextually embedded self-constructions that reflect the multiplicity of positions characterizing the parent-teacher relationship (Van Langenhove & Harre, 1999). For example, a parent may adopt the position of a trusting caregiver, when seeking the expert opinion of a teacher, but swiftly shift to the advocate position, if they feel their child’s needs have not been addressed.

Speech acts are described as the acts of saying and doing that have both illocutionary and perlocutionary force (Davies & Harré, 1990). The illocutionary (social) force manifests itself when the speech act is performative, such as a question, command, or comment; the perlocutionary force then manifests in the answer, denial, or counterargument (Davies & Harré, 1990). By examining speech acts, one can study how a parents’ desired position of the self or others is enacted in specific storylines. Drawing on speech act theory, speech acts in positioning theory do not simply convey information but

are also created for the purpose of action (Neff, 2008). As suggested by Slocum-Bradley (2007), “words, phrases and concepts do not have rigid meanings intrinsic to them, but rather people use them to *do* things” (p.637). For example, when teachers sharing their expert suggestions on ways forward for the child invite opinions on potential alternatives, parents only expecting to be asked whether they agree or not, may be confused. In this way, speech acts are part of storylines, but can also disrupt unfolding storylines and relocate participant positioning (Harre et al., 2009).

Lastly, storylines can be understood as the contexts, or the setting “within which an action is interpreted as an act or given meaning” (Slocum & Van Langenhove, 2003, p. 227). They can exist prior to the interaction, or be created in the conversations, as they enable certain speech acts while excluding others (Harré & Moghaddam, 2003; Slocum-Bradley, 2010). For example, parents’ questions regarding learning goals for their child may be welcomed during an IEP meeting storyline but not during a classroom instruction storyline. As such, the same acts, in this case questioning, can assume different meanings in dissimilar storylines, and storylines, in turn, can be changed by different speech acts (Davies & Harre, 1990).

Given that positioning is dynamic, it will undoubtedly fluctuate depending on the narratives, metaphors, and images through which they are constructed. As such, the resources people draw on, when relating their experiences with others, are evidence of a certain time and place, and of a specific relationship one is trying to build (Boxer, 2003). Accordingly, how one positions oneself in one’s accounts with others reveals how one sees oneself or understands one’s identity and position among others in a social world,

hinting at the ‘kind of person’ one is seeking to be and enact here and now (Harre & van Langenhove, 1999).

It is important to note that whenever someone positions themselves, they simultaneously position someone else (Harré & van Langenhove, 1999). Davies and Harré (1999) use the term *interactive* to describe the situation in which one person inevitably positions another through what he/she says. Contrastingly, *reflexive* positioning occurs when one positions oneself. How individuals position each other “entails a ‘call’ to look at themselves in certain ways, act in certain ways, and relate to others in particular ways” (Davies & Harre, 1990, p.119).

In this way, positioning theory is especially appropriate for analyzing relationships because it assumes that it is an interactive process which is situationally developed and whose analysis must be conducted based on the active role that the agents take on in such a process. It also helps us address the way in which power and privilege is constructed, distributed, and localized through discursive practice (Boxer, 2003). These subjective positions, and their related power differentials, are intimately connected to the broader historical, socio-political, and discursive context within which they operate (Foucault, 1988). In using the framework of positioning, we can gain insight into positions CLD parents assert for themselves and others that are thrust upon them, as they navigate special education processes and interact with special education practitioners.

Bourdieu’s Theory of Capitals

Sociologist Peirre Bourdieu articulated theories related to understanding class, social reproduction, and education. Unhappy with economic theory’s inherent assumption that non-economic capitals were insignificant, Bourdieu sought to define two forms of non-

economical capital. According to Bourdieu (1986), there are three types of capital: economic capital, social capital, and cultural capital. Bourdieu's theory of capital (1986), heavily influenced by German philosopher Karl Marx, suggests that there are inequalities in having or being able to acquire capital. The more capital one has, the more powerful a position one occupies in social life.

He argued that capital can be both material or immaterial, and can be accumulated over time. Capital can be reproduced in the same form, or converted from one form to another. In the present study, Bourdieu's theory of capital is used to understand how parents' use their existing capital, or convert their capital into other forms of capital, to navigate the IEP meetings, and secure educational opportunities and provisions for their child.

For Bourdieu (1986), economic capital refers to financial assets, such as money or property, that is tangible and material. For the purposes of this study, economic capital refers to both parental financial resources, such as their financial income and the monetary supports provided by private or government funding. Research suggests that of the three capitals, sound economic capital is the most transformative, as it provides parents the opportunity to support their children through additional services and therapies (Pan, 2018).

Social capital is defined by Bourdieu (1986) "as the aggregate of the actual or potential resources which are linked to possessions of a durable network of more or less institutionalized relationships of mutual acquaintances and recognition-or in other words, to membership in a group" (p.248). Essentially, social capital amounts to an individual's ability to access goods and/or services through their social relationships and networks. The amount of social capital one possesses is dependent on the size of their respective social

networks, and the amount of economic, social and cultural capital these groups hold in return (Bourdieu, 1986).

The third and final capital, cultural capital, manifests itself in three ways (Bourdieu, 1986). The first way by which cultural capital may appear, is the ‘embodied state’, which is directly connected to the individual, from one’s values and accents, to one’s disposition and tastes (Grenfell & James, 1998). Cultural capital may also appear in the form of an ‘objectified state’, seen primarily in cultural goods, such as books one chooses to read or the type of cars one chooses to drive. Finally, cultural capital may also appear in the ‘institutionalized state’ in the form of educational qualifications (Bourdieu, 1986).

Social, cultural and economic capitals are integrally linked to two related concepts from Bourdieu’s theory: *habitus* and *field*. Bourdieu argues that one’s total cultural capital for example, is the product of the match or fit between the individual’s culture and the culture of the institution and uses the terms *habitus* and *field* to explain this. *Habitus*, refers to the physical and easily discernible embodiment of cultural capital, and the socialization of people into a certain set of habits, skills, and dispositions that we presume to be value neutral (Bourdieu, 1986). A *field* can be understood, both at the micro and macro levels as structured systems and the contextual environment in which people exist, act, and interact (Webb et al., 2002).

Individuals exist and operate in a field, where their respective capital interacts with the capital of that certain society, i.e., institutions, policies and practices. It must be noted, however, that not all capital has the same value in a given field. Lee and Bowen (2006) argue that when parents come from the same social system as the institution with which they are interacting, their combined economic and cultural capital automatically leads to

the procurement of additional capital. In this way, information and resources gathered from parent teacher conferences, assemblies, or parent-to-parent networks, have an increased capacity to influence their children's success.

CLD communities generate and sustain cultural capital and perspectives that mediate how they interact with and respond to their social, political, and economic surroundings, including those of the school. This is a dynamic process subject to the transactional forces of acculturation, enculturation, assimilation, and socialization (Gollnick & Chinn, 2013; Nieto & Bode, 2007). CLD families may be operating with less cultural capital, as they may not come from the same social system. In the case of parental involvement in special education, CLD parental understanding and command of English, educational terminology, cultural differences in help seeking behaviors, and differing beliefs about disability, places them at the periphery of such systems, which in turn, influences their ability to impact student achievement (Lee & Bowen, 2006). Thus, the parental involvement activities that teachers favor and that benefit Euro-American students may not have the same breadth of impact on CLD students and families (Wolfe & Duran, 2013).

Applying Bourdieu's theory of capitals to the present study will enable me to understand what forms of capital are available to Indian and Pakistani Canadian parents of children with ASD, and how they are actualizing or transforming their capital to navigate special education processes, the IEP meeting, and where possible, securing services and provisions for their child's growth and development.

Foucault's Analytics of Power

Foucault's analytics of power provide a particularly useful lens to explore the power relations that underpin parent-teacher relationships. Foucauldian concepts of discourse, surveillance, as well as empowerment and resistance, and their respective relationship to a parents' position in a parent-teacher relationship, are of particular importance to this study.

Michel Foucault was a philosopher, a historian, political activist and a literary critic. Through his works such as *The Birth of the Clinic* (1963) and *Discipline and Punish* (1975), Foucault aims to reposition and extend the conceptual understanding of power. Power is traditionally understood as the capacity of an agent to impose his will over the will of the powerless, or the ability to force them to do things they do not wish to do. In this sense, power is understood as possession, as something owned by those in power. Foucault argues that power is everywhere. He asserts that power is not something that can be owned, but rather something that acts and manifests itself in a certain way; it is more an exercise than a possession, it is a relation. For him, the concept of power "must be analyzed as something which circulates, or as something which only functions in the form of a chain . . . Power is employed and exercised through a netlike organization . . . Individuals are the vehicles of power, not its points of application" (Foucault, 1980, p. 98). As such, both the powerful and the powerless are, to some extent, involved in the production and circulation of power (Wetherell et al., 2001).

Foucault (1988) explains how power can be understood as a set of relations dispersed throughout society:

I am not referring to Power with a capital P, dominating and imposing its rationality upon the totality of the social body. In fact, there are power relations. They are

multiple; they have different forms, they can be in play in family relations, or within an institution, or an administration. (p.14)

For example, the power a parent exercises over a child is different from the power a teacher exercises over their pupil. While a parent's power may include caring and providing for the child's overall well-being and development, and as such, ensuring all needs related to their education, health care and finances are met, a teacher may exert their power on the pupil by manipulating their power over the curriculum, classroom activities, and evaluation criteria. To say that a parent or a teacher is exercising power is rather vague. What matters is how the teacher or parent is exercising power, in what context, over whom, and with what effects.

Within discourse, power is enacted and exercised through linguistic processes, and regulated through internal rules of engagement (Fairclough, 2001). The exercise of power is defined by Foucault (1986) as a "mode of action upon the action of others" (p. 212). More specifically, institutional conversations are governed by a set of specific rules, which determine to a large extent, what is expected, appropriate, relevant and possible within that particular framework. Foucault questions how some discourses have shaped and created meaning systems that have gained the status and currency of 'truth'.

These particular discourses of 'truth' dominate how we define and organize both ourselves and our social world, whilst alternative discourses are marginalised and subjugated. He argues that there is no fixed or definite structuring of the social world, in which the subject is completely socialized; rather, beliefs and practices are a function of historically specific discourses. In this way, discourse, for Foucault, offers a way of speaking or writing about a reality that determines what can and cannot be included in the

description of that phenomenon, at a specific time in history (Gutting, 2005). Accordingly, those who have the power, such as doctors, lawyers or teachers, may determine the ways by which a specific subject may be represented by constructing the knowledge that is used to represent it (Gutting, 2005). This is of great importance for my study, as exploring the conversations that occurred between parents and teachers provides a window into how, through discourse, the enactment of power worked to govern participants, and affect their subsequent thoughts and actions.

Foucault posits that the discourses of knowledge and power are inextricably linked, where knowledge is an exercise of power, and power a function of knowledge. Foucault (1988) claims that power and knowledge are situated in and with the "one who speaks, the positions and viewpoints from which they speak, the institutions which prompt people to speak about it and which store and distribute the things that are said" (p.11). It follows that special education professionals who speak about a topic, read about a topic, and write about the topic through progress notes or evaluations, become the authority, and their knowledge about the topic becomes the truth. On the contrary, some CLD parents who do not have a grasp of the educational jargon, educational expectations, their legal rights, or the rights of their child, may become less engaged, as their knowledge or cultural capital is less acknowledged, leaving them with less power in the professional - parental relationship. Here again, we can see that what matters is who is exercising power (teacher or parent), in what context (school processes), over whom (teacher or parent), and with what effects (enhanced or compromised parent-teacher relationships).

Surveillance is another theme in Foucault's work. Here, Foucault posits that individuals are constructed as both objects and subjects of power under the constant 'gaze'

of others (Foucault, 1977). Foucault suggests that hierarchical observation operates from the top down, and occasionally, from the bottom up or laterally (1977). Consequently, while subjects are scrutinised, so too are the supervisors. Through the operation of surveillance, individuals become agents of self-regulation in relation to specific institutional discourses of knowledge or 'truth' (Foucault, 1977). Within the parent-teacher relationship, the way in which parents position themselves as agents of surveillance within the discourse helps to explain the effect of such regulatory control. It also provides insights into several processes, such as how parent and teachers establish and negotiate responsibility for the child, how their respective expertise is 'talked up', and how their expertise is accepted or contested within the talk. Thus, examining parent-teacher relationships can offer insights into how power functions at the local level and the impact this has on a parent's understanding of their position.

Lastly, empowerment and resistance are an important Foucauldian concepts that have relevance to this study. While Foucault sees power as being both oppressive and enabling, there is always the possibility of resistance. He argues that resistance is itself produced by power. For Foucault, "discourse transmits and produces power; it reinforces it, but also undermines and exposes it, renders it fragile and makes it possible to thwart" (p.100). Similar to the way power is distributed across a network rather than being located at a specific point, or with a specific person, resistance is spread out, existing where power operates (Shumway, 1989). According to Shumway (1989), "professionals such as doctors, lawyers or teachers often command our attention and respect through being viewed as holding 'some kind of exclusive expertise' and in this way, can be seen to hold power over us" (p.161). For Shumway, it is only possible to resist such disciplinary power being

exercised over people if individuals “recognize that it is power and not truth that is being spoken” (1989, p.162). When exploring the power struggles that may exist in the parent-teacher relationship, examining ways by which parents may display resistance in their conversations or actions will help me in understanding how parents perceive and understand their individual position in the collaborative relationship, and oscillate between positions.

Parents are considered important participants in their child's education, and many scholars firmly believe that a healthy partnership between parents and educational professionals is essential to a child's successful educational journey (Cobb, 2014; Harry, 2008; Jung, 2011). However, for this to occur, parents must have a shared understanding of, and appreciation for parental involvement practices, which is not always the case for many CLD parents. Accordingly, using the Hoover-Dempsey and Sandler’s model, the positioning theory, Bourdieu's theory of capitals, and Foucault theory of power, I seek to highlight how and why South Asian parents perceive and position themselves in Ontario's special education processes the way they do, so that their insights will help address any gaps that may exist, and later, increase their participation in the special education processes.

Research Design

The following section outlines the research design, and details why certain decisions were made. It highlights the processes underpinning participant selection, data collection, and data analysis. Where possible, I share the advantages and limitations of each component.

Research Questions

The purpose of this research can be articulated in the following question and subquestions:

Question:

How do immigrant South Asian Canadian parents of children with ASD understand and perceive their role in the Individual Education Plan Meeting, within Ontario's special education context?

Sub-questions:

1. How do South Asian parents of children with ASD understand and describe their expectations of the IEP meeting and their role or position in the special education processes?
2. How do South Asian parents of children with ASD perceive their parental involvement as being positioned by teachers and service providers in the special education processes?
3. What are the implications of parental perceptions for meaningful relationships and partnerships between special education professionals and South Asian parents of children with exceptionalities?

A Qualitative Approach

There are many ways by which to understand the world, the nature of knowledge, and the nature of reality. Qualitative researchers understand the social world, and the value of human experience, quite differently than quantitative researchers, and espouse different views about realities, knowledge and how knowledge may be obtained (Creswell, 2013; Hammersley, 2013; Jackson & Verberg, 2007; Savin-Baden & Major, 2013; Silverman & Marvasti, 2008). The basis of qualitative research lies in its

interpretive approach to social reality. It assumes that there are multiple realities or multiple truths based on one's construction of reality (Berger & Luckmann, 1966). Constructivists tend to believe that reality cannot be separated from the knowledge of it, and that all knowledge is a compilation of human-made constructions (Raskin, 2002). In this paradigm, knowledge is not independent of the knower, but rather, constructed through dialogue and negotiation.

Accordingly, qualitative research allows the researcher to explore the behaviour, perspectives, and experiences of the people they study (Holloway, 1997; Given, 2008; Robson, 2002). It focuses on how “people interpret and make sense of their experiences and the world in which they live” (Holloway, 1997, p.2). Qualitative research effectively places emphasis on understanding the social world from the participant's point of view (Jackson & Verberg, 2007). Given the aim of my exploratory research, adopting a qualitative approach will allow me to understand both the way meanings are constructed and how such meanings are presented and used through language and action by South Asian immigrant parents, as they engage in IEP processes.

Qualitative research is not without its limitations. Qualitative researchers seek to understand multiple realities; the setting is natural, and this lack of control can lead to complexities in the research approach (Hammersley, 2013; Savin-Baden & Major, 2013; Silverman & Marvasti, 2008). In qualitative research, the researcher is the human instrument, thus introducing several questions about the level of subjectivity involved in various research processes, ranging from the creation of data collection instruments, to data analysis. To address this limitation, I will ensure my instruments are compatible with those used in similar investigations and correct for researcher bias where possible. I will

also follow a strict data analysis framework to help reduce researcher bias. In addition, qualitative researchers may not be able to always provide definitive conclusions, or statistically significant conclusions, that may be generalizable (Creswell, 2013; Savin-Baden & Major, 2013). Given that this exploratory research aims to provide rich and detailed descriptions of a specific phenomenon, extrapolation and generalizability of the findings to the larger CLD population becomes less important in this particular endeavour.

Case Study Research Design

Given the purpose of this study, I utilized a multiple narrative case study approach. As Descombe (2003) suggests, case studies focus on a few instances of a “particular phenomenon with a view to providing an in-depth account of events, relationships, experiences or processes occurring in that particular instance” (p. 52). The aim is to gain insights by looking at individual cases, that would not have come to light through the use of another strategy. The case study approach allows the researcher to engage with the subtleties and intricacies of complex situations, within a particular context, through thick and rich descriptions (Descombe, 2003; Savin-Baden & Major, 2013). As an approach, multiple case studies can involve the use of different cases from the same organisation to study different issues, or as is my case, the same issue (CLD parental experience of the IEP meeting) in a variety of contexts (within different schools) within the same organisation. The goal is to shed light on the general by looking at the particular.

The narrative case study approach allows me, the researcher, to pursue the goal of studying the human experience, by exploring how people create themselves, position themselves, and understand themselves and their reality, through story (Creswell, 2013;

Savin-Baden & Major, 2013). In the retelling of their experiences, parents will select events and give them order, cohesion, meaning, and direction. Kermode (1967) argues that storytelling allows people to make meaning from their experiences: Storytellers explain how one event happened in relation to an event that preceded or followed it, allowing them to create a sequence that could suggest causality. Through the iterative process of story construction and interpretation, participants are able to ascribe meaning to their experiences (Clandinin & Connelly, 2000).

As with other research methods, the case study approach has both advantages and limitations. Case studies are widely valued for their ability to offer rich information by answering ‘how’ and ‘why’ questions (Yin, 2011); thus, such an approach is helpful when there is a need to investigate poorly understood aspects of a particular phenomenon (Savin-Baden & Major, 2013). This includes CLD parental experiences engaging with the IEP processes.

The case study approach is often criticized in relation to the credibility of generalizations made from its findings (Denscombe, 2014). To this end, I must indicate to what extent the cases are similar to or different from others of a comparable type. Another limitation of the case study approach is that the volume of the complex data generated throughout the investigation has to be sifted through by the researcher, whose bias during the collection stages, the documentation stages, or the reporting stages, may compromise the research (Savin-Baden & Major, 2013). To help ensure integrity of data representation, I will have participants review their interview transcripts, along with the thematic analysis that took place, and identify any areas that need to be clarified.

A case study methodology is particularly relevant to the exploration of the subjective experience of immigrant South Asian parental involvement in special education process, as it provides an avenue for participants to recount their experiences and make meaning of these experiences. Sharing these stories can also be understood as a transformative process for all, in that the process of sharing stories provides an opportunity for transformation of the story, the narrator/s, and the listeners/reader (Hones, 1998).

Sampling and Participant Recruitment

The parents who participated in this study met the following inclusion criteria: (1) they were self-identified English-speaking immigrant Indian or Pakistani Canadian parents, (2) they had a child with ASD, (3) their child was placed either in an inclusive classroom setting or an alternative school/therapy center, and (4) their child was enrolled in a Toronto District School Board (TDSB) or York Region District School Board (YRDSB) school or facility. I choose to recruit a small, purposive sample, as I wanted a group of participants who shared similar characteristics in knowledge or experience about the research topic (Clandinin & Connelly, 2000; Creswell, 2013; McMillan & Wergin, 2010; Savin-Baden & Major, 2013). With respect to sample size, the studies conducted by Lai and Ishiyama (2004) and Tellier-Robinson (2000) suggest a small sample size between 5-10 participants allows for a rich variety of narratives and perspectives. Based on this, I aimed to recruit at least five and no more than 10 participants. Ultimately, I was able to recruit five participants.

To help with the identification and recruitment of participants, I had initially planned to advertise at the following community networks known to the South Asian demographic: Canada Pakistan Cultural Association, Council of Agencies Serving South

Asians, South Asian Women's Centre, Community Social Planning Council of Toronto, and Aapna Community. However, with the onset of the COVID-19 pandemic, the above-mentioned organizations were no longer providing respite care services. I then changed my sampling method to convenience sampling, followed by snowball sampling. The aims of my research project were shared with the leadership of the local Ismaili Muslim Community, who kindly agreed to communicate the details of my investigation to members of the congregation, through community networks. Those who were interested in learning about this research were given my contact information and instructed to connect with me directly. Interested volunteers were reminded that my research was not endorsed by the religious community in any way, and should they choose to participate, their involvement would remain private and confidential.

Once I shortlisted two participants from the congregation, I remained transparent in the goals of this endeavor and ensured that both participants understood that their participation in this research would not bring any harm to them or their child. I also asked the volunteers to share the objectives of this study with their friends they felt would be interested in this research (snowball sampling). Through snowball sampling, I shortlisted an additional three participants, for a total pool of five participants. Once selected, participants were provided a brief overview of the investigation, the purpose, the methods, and their role in the process. Participants were also made aware of their right to continue or terminate their involvement with the study at any point, until the analysis and coding of their data, with the assurance that they would not experience any adverse reactions from their decision.

Participants were informed that, in order to uphold confidentiality in both the recording and reporting of data, the participant along with identifiable institutions/programs/people will be given a pseudonym. Additionally, the data gathered from the participant will be communicated in a way so as not to compromise the confidentiality of the participant, the places, networks, or persons to which she/he referred to in the interview. Lastly, the participant was provided with the consent form via email and asked if she/he had any clarification questions. Once the participant provided verbal consent, they were able to participate in the study.

Data Collection Method

In this research, I choose to conduct semi-structured interviews, where participants responded to a series of questions designed to elicit a chronological account of their experiences with the special education system. Interviews in qualitative research have a “unique potential for obtaining access to and describing the lived everyday world” as it “provides a unique access to the lived world of the subjects, who in their own words describe their activities, experiences and opinions” (Kvale, 2008, p. 9). This is most important, as I hoped to capture the lived experiences and perceptions of immigrant South Asian parents, as they participated in the discursive practice of parental involvement in special education.

Semi-structured interviews allowed for the use of large, open ended questions, which enabled the participant to be a narrator, and share their story on the issue under inquiry (Corbin & Morse, 2003; Creswell, 2013; Hammersley, 2013; Savin-Baden & Major, 2013). The format also allowed participants to have some control in the interview process, as they could elaborate on questions posed, and offer additional insights based on

their comfort level (Chase, 2005). The researcher's role in this type of interview is active in the sense they provide attentive listening and may ask questions, probe and respond to questions, but the focus remains on the participant and their story (Corbin & Morse, 2003).

It is important to note that the instrument by which the data was gathered, was not neutral. The questionnaire, although informed by research (Cobb, 2014), was also informed by the researcher. Denzin and Lincoln (2005) caution that the researcher is not neutral and may be motivated and shaped by their social class, which includes power, race, class, ethnicity, language, culture, sexual orientation, and gender. To reduce potential biases, I had my supervisor and committee members review my interview questions and provide feedback.

The first cluster of questions enabled parents to share biographical details about themselves, their children, and their experiences. The second set of questions were related to the identification process, the IEP meetings, the types of relationships they had with educators and administrators, and the resources and support they received or were receiving.

Parent interviews were conducted in English, over a private Zoom line, on a day and time of their choice. As suggested in the literature, interviews were audio recorded, and as a researcher, I choose to take notes on the body language of the participants, so as to capture what the audio recordings would miss (Denzin & Lincoln, 2005; Hammersley, 2013; Savin-Boden & Major, 2013). Prior to the interview, I explained their role and their rights as a participant in this voluntary study. I reminded participants that they could skip questions that made them uncomfortable or stop the interview entirely. I also reminded parents that they could withdraw from the study at any time.

Interviews were conducted face-to-face, over Zoom to build rapport and a sense of trust (Clandinin & Connelly, 2000; Creswell, 2013; McMillan & Wergin, 2010; Savin-Baden & Major, 2013). I began by introducing my own narrative and the reasons why I was conducting this research. I decided this was the best course of action for the participants to understand that they were not the object of my research, but rather, that they were active in helping me understand what was occurring in the system, and how they felt empowered or disempowered by a system that was designed to help them access education for their child.

Data Analysis

The audio recording of each individual parental interview was transcribed by the researcher. Participants were given an opportunity to review the transcripts (member checking) to ensure that what had been transcribed, was indeed, what they intended to share. I then used a heuristic framework (RITES) suggested by Leggo (2008), to engage with, and analyze the narratives. After completing the first two steps, I developed a coding system, that allowed me to thematize my findings.

Table 1

RITES Framework

Step 1: <i>Read</i>	The researcher reads the whole narrative to gain a general sense of the story.
Step 2: <i>Interrogate</i>	The researcher asks some basic questions: Who? What? Where? When? Why? How? So what?
Step 3: <i>Thematize</i>	The researcher reads the narrative again with a focus on a theme, and spells out the parts of the story which relate to the theme.
Step 4: <i>Expand</i>	The researcher expands on the theme by reflectively and imaginatively drawing connections and proposing possible meanings.

Step 5: <i>Summarize</i>	The researcher summarizes the theme in a general statement or two in order to indicated clearly what is learned from the narrative.
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Qualitative Research and Data Integrity

Guba and Lincoln (1994) identified four components of data trustworthiness: truth value, applicability, consistency, and neutrality. In quantitative research, these are also referred to as internal validity, external validity, reliability, and objectivity; in qualitative research these are referred to as credibility, transferability, dependability, and confirmability (Creswell, 2013; Hammersley, 2013; Trochim & Donnelly, 2001).

Credibility refers to the how confident the researcher is in the truth of a particular inquiry (Guba & Lincoln, 1994). For this study, the I had to rely on the assumption that the participants were honest and open in their responses to the interview questions. Trust and rapport were established through the effective use of active listening skills. However, the risk remained that the participants may have responded in a manner most agreeable to the researcher, due to their understanding of the purpose of this research. In addition, it is also important to note that although I took every precaution to ensure that the participant's anonymity and confidentiality was respected, I indicated that complete confidentiality may not be guaranteed, since there exists a possibility that family or family friends may have access to the research findings in the future. As such, complete honesty and openness in parental responses cannot be guaranteed. Member-checking was also used with the participants to verify that the information they shared was accurately captured and congruent with what they stated during their interviews (Creswell, 2013). This allows

participants a voice in how the findings are presented, and an opportunity to correct any possible misinterpretations or misrepresentation on the part of the researcher. Member-checking ensures that the data is representative of the participants' experiences (Clandinin & Connelly, 2000; Creswell, 2013; Silverman & Marvasti, 2008).

Transferability refers to the extent to which findings can be applied to other contexts, subjects, and situations (Guba & Lincoln, 1994). The purpose of this study was to provide a space where CLD parents could share their unique understandings and experiences with the special education system. Moreover, the use of purposive sampling greatly restricts generalizability. As a result, the transferability of this study is low .

Dependability refers to the consistency and replicability of the study (Guba & Lincoln, 1994). If the study were repeated with the same subjects, they may provide the same or similar responses; however, the effects of time and the accumulation of knowledge subsequent to the study may affect and change participants' perceptions. Replication of the study with subjects from a similar background may produce similar perceptions as the participants in this study (Hammersley, 2013; McMillan & Wergin, 2010; Savin-Baden & Major, 2013).

Confirmability refers to the “degree to which the findings of an inquiry are determined by the subjects and conditions of the inquiry, and not by the biases of the researcher” (Guba & Lincoln, 1994, p. 290). In this investigation, question verification, along with member checking, were methods used in order to decrease researcher subjectivity.

Ethical Considerations

Ethical research demands respect and consideration for the rights of the participants, the context of the research, and the prospective readers of the study (Creswell, 2013). This research plan was reviewed by University of Windsor's Research and Ethics Board (REB). The REB helped ensure that the research was aligned with the highest ethical standards, and that the greatest protection from any potential harm, was provided to the participants who participated in the investigation (Creswell, 2013).

For this study, I developed an information package to share with participants, that provided a brief overview of the study, the purpose of the study, the methods, and their role as a participant in the process. It also included information related to their participation and withdrawal from the study, as well as the potential benefits or drawbacks risks related to their participation in the study, and a potential list of resources for families of children with ASD (Neuman, 2003). Lastly, participants were informed that the findings of this research would be placed within the public domain, and that every effort would be made to protect their privacy and confidentiality. Each participant received a consent form, and the information on the consent form was reviewed verbally by the researcher. Participants were encouraged to seek clarification and ask questions. The participants were provided 2 weeks to review the package prior to being asked to provide consent. Only those participants who provided verbal consent were included in this study.

Every research investigation carries with it a potential for risk. Any risks related to the physical, psychological, or social well-being of the participants were clearly identified prior to the investigation and shared with participants prior to their participation in the study. Given the nature of this study, it was possible that in sharing certain personal

experiences, participants may have encountered feelings or recollections that were unsettling. Participants were reminded that should they feel discomfort with one or more of the questions being posed in the interview, they may choose to skip it. It was also made clear to the participant that answering questions is voluntary, and as such, they may end the interview at any time. However, it was hoped that the participants would find the interview process to be beneficial. Hutchinson, Wilson, and Wilson (1994) have found that qualitative interview participants often experience catharsis, increased self-worth and self-awareness, and a new sense of purpose. In addition, qualitative interviews give voice to disenfranchised populations who often feel voiceless, and participation in such can be empowering (Hutchinson et al., 1994). The interview process provided participants with a safe place and a safe person with whom they could share the realities of their everyday experiences and any feelings associated with that reality.

Participants were not deceived in any way for this study. Participants were informed that all transcriptions and analysis of data will be stored on a password protected computer, as stipulated by the REB. Participants were told that their names would not be associated with any of the data. Instead, they will be assigned a pseudonym. Participants had opportunities to review all drafts and the final results of their investigations, so as to ensure that the thoughts, feelings and concerns of the participant were accurately represented.

My Role as a Researcher

Before beginning my own research, I must acknowledge that a researcher's motives and objectives cannot be divorced from their history and lived realities. Milner (2007) contends that the knowledge derived from education research is shaped by what researchers know, their views, and biases. What is known and how researchers

understand their world are directly linked to the type of knowledge that they produced. Accordingly, I must acknowledge my own biases as a researcher, my privilege, and my identity, to ensure I am able to create research that has integrity and merit.

I acknowledge that I am a female Canadian of South Asian and East African descent. I am a learner, researcher, educator, and advocate. Over the past ten years, I have worked as a community educator, a teacher mentor, and as an instructional designer. In that time, I have worked in early childhood education, elementary and high schools, and in the adult education sector. In these various contexts, I have supported students from diverse socioeconomic and cultural backgrounds. Their stories have deeply shaped how I see opportunity, challenges, and hope in education and special education systems. I have worked alongside families who have successfully navigated special education processes, secured appropriate provisions and services for their child, and experienced relatively smooth transitions from one school or program to the next. I have also supported families who were unsuccessful in identifying the appropriate placement or securing the adequate supports for their child. In a few cases, parents felt they had no option but to withdraw their child from school. Witnessing this spectrum of experiences highlighted the complexities associated with special education policy and practice as interpreted and enacted by each school board, particularly for members of CLD communities.

I also recognize that my individual family history with disability and the education system must be considered carefully in relation to the validity, integrity, and trustworthiness of this research. As a researcher, I have taken care to acknowledge any personal bias in the conceptualization and implementation of this investigation and during data analysis by employing best practices found in the literature. It must also be

noted, however, that my unique position as a researcher who shares some similarities with her participants has also afforded me a special insider perspective into the experiences of special education. As such, I feel that I bring forth nuances to this research inquiry that otherwise may be missed given my familiarity with and understanding of the South Asian community. I hope that my existing and ever evolving understanding of this community helps provide a voice to a group that has, until now, remained largely underrepresented.

Limitations and Delimitations

The limitations of the research approach, instrumentation, and data analysis have been systematically addressed throughout this chapter. It is important to note that the data presented and analyzed in this inquiry draws upon the experiences of five Indian and Pakistani Canadian parents. As such, the findings of this research will not be generalizable to the larger South Asian Canadian population. However, the purpose of the investigation was not to generalize, but rather to shed light on the experiences of the South Asian community as they navigated the special education system in Ontario.

Given that this research examines the perceptions of parents' lived experiences, the author will collect interview data from parents only. Consequently, the voices of school personnel and children will be absent in the data.

Chapter Summary

Currently, the field of special education research has largely excluded the voices of South Asian Canadian parents who have children with exceptionalities, attending public or private schools. The purpose of this study was to explore how South Asian Canadian

parents of children with ASD, understand, experience, and perceive their role, as they engage in the IEP processes within Ontario's special education system.

To this end, the current chapter was dedicated to detailing the rationale and design of the investigation, specifying participant sampling and recruitment mechanisms, and describing data collection and analysis strategies. The chapter also explored the trustworthiness of my research findings, highlighted ethical considerations related to the entirety of the research endeavour, situated my role as a researcher, and systematically considered research limitations. The following chapter will identify, summarize, and present the major themes emerging from the thematic analysis of the data.

CHAPTER 4: FINDINGS

Individual education planning is the process whereby teachers, support personnel, and parents collaborate as a team to identify and strategize on how best to address the needs of students whose academic requirements do not align with the standard curriculum (Boyd et al., 2015). Together, the team develop goals based on a student's current needs and abilities, and write a plan for the school year. However, for many CLD families who take part in the IEP meetings, the planning process is not experienced as a collaborative endeavour, and the meeting does not translate into the identification or selection of appropriate support programs and/or provisions for their child (Burke, 2013; Cho & Gannotti, 2005; Esquivel et al., 2008; Fish, 2006).

To better understand how families of CLD backgrounds experience the IEP process, this study examined how immigrant Indian and Pakistani Canadian parents of children with ASD understand and perceive their role in the IEP meeting, and by extension, in a collaborative relationship between school personnel and themselves.

In this chapter, I present the stories of five families, and their experiences leading up to, during, and after the initial IEP meeting and/or subsequent IEP meetings. To preserve the anonymity of the participants, of the schools, and the communities where the families reside and work, all names have been replaced with pseudonyms and any details that might reveal the identities of the participants have been removed. In an effort to preserve the communicative intent of the participants, I maintained the vocabulary choice used by participants during their interview, in the transcription and narration of their stories. I end with a chapter summary.

Participant Stories

In articulating the stories of each participant, I begin by providing a biographical narrative for each parent to provide the reader with some context. I then explore their evolving understanding of parenting, particularly once they learn of their child's diagnosis, and the impact this has on them and their family. Lastly, I describe their experiences as they were introduced to Ontario's special education processes and personnel. The experiences are narrated in chronological order, so as to help demonstrate any shifts in parental dispositions as time elapsed, and/or as their familiarity with the education system increased.

Afreen's Story

The name Afreen has many meanings, one of which is *brave*. The following section details the story of Afreen, a Pakistani immigrant and a single mother to her only son, Alim.

A Brief Description of Afreen and her Family

Afreen describes herself as a vibrant, thoughtful woman, with an incredible zest for life. She is a mother, a daughter, and a sister. Afreen spent her childhood and early adulthood in Pakistan. She completed her nursing degree from the Aga Khan University, and upon graduation, worked at the Aga Khan Hospital. After her marriage, she moved in with her in laws, and had her first and only child. Within a few years, Afreen, her son Alim, and her husband moved to Canada for a few months, prior to moving to the United States of America (USA). Afreen has three brothers, all of whom are married with children, and settled in the USA. It was for this reason Afreen felt comfortable moving to the USA to start a life for her and her family.

There, she continued to work as a nurse, and her husband worked as a mechanic in a local garage. At this time, Afreen was diagnosed with an autoimmune disease. Afreen's mother eventually joined them in the USA, as Afreen required assistance to help care for Alim. Within a few short years, Afreen applied for Canadian citizenship, alone. Having separated from her husband, she moved to Canada, and settled in the city of Toronto. Afreen later sponsored her mother and son to come live with her. Afreen currently lives in a two-bedroom apartment, with her son, a roommate, and her mother.

Alim is currently 13 years old. Alim was formally diagnosed with ASD at the age of eight. He is a calm teenager, who is partially verbal. He enjoys watching Urdu dramas and *SpongeBob*. He absolutely loves cars; in fact, he is obsessed with the make and model of all cars. He scripts conversations and is able to repeat monologues from movies. While Alim can greet people when he meets them, he is unable to carry a conversation. Alim has come a long way since he moved to Canada. Afreen currently works as a part-time personal support worker (PSW). She needs a flexible schedule to be able to care for her son. As a part time PSW, she can take her son to additional therapies, recreational programs, and to religious services. Afreen is in the process of renewing her nursing licence and hopes to continue working as a nurse in the telehealth field, once Alim is older.

Construction of Parenthood

The following section explores Afreen's evolving understanding of parenting. The section begins with Afreen's initial reactions to Alim's diagnosis, and the impact his diagnosis had on her and their family. Subsequently, I explore how Afreen continues to support the physical, social, emotional, and intellectual development of her son.

Understanding the Diagnosis. Afreen first learnt of Alim's condition when he was 18 months old. The doctors in Pakistan initially labelled the condition as a developmental delay and a speech delay. Afreen was working as a nurse at that time. She had come across a number of children who developed at a slower pace than other children. A lack of clarity and information around the initial diagnosis left Afreen confused.

As she reflected on the initial doctor visits, she shared: "We knew he has a problem...and since we were in Pakistan, I was able to put him in a special school for special kids." She went on to explain that:

They kept saying it was delay until he was four years old. He was re-evaluated then. We were thinking he had Autism, but it was not official until he was eight years old, here in Canada. It came on paper here, in Canada. But we knew he had a problem.

As a nurse, Afreen understood the importance of early intervention. She knew she had to find ways to help support her son's development; however, Afreen felt her husband did not share her convictions. Alim's behavioural outbursts often led to many fights between Afreen and her husband. From Afreen's perspective, Alim required continuous support, from toileting to dressing. Her husband did not participate in providing care or support for Alim. In her opinion, her husband's resentment towards their son had grown exponentially since they had left Pakistan. Afreen was alone in assisting Alim complete daily living activities, until her mother's arrival. Her husband actively kept her and their son from engaging with people in their faith-based community, be it attending the regular religious services or partaking in community planned events. Although Afreen felt isolated from her religious and cultural community, she empathized with her husband's concerns.

She understood how Alim's disability reflected on the family unit. To fill this social void, where possible, Afreen discreetly sought assistance through government supports, where she was less likely to meet someone of shared heritage. With time, Afreen became increasingly worried about her husband's seeming dislike and indifference towards Alim's needs. Eventually, the couple filed for a separation and then a divorce. Afreen choose to move to Canada, where she hoped to provide her son with better educational and health care opportunities.

Role of the Parent. When asked about her responsibilities towards her child, Afreen was unequivocally clear: "I have always been mother first. Then a wife, daughter, or sister." As the matriarch of a traditional Pakistani household, she felt that there were a number of expectations to be met. For Afreen, it was expected that she complete household responsibilities, as well as any external work-related responsibilities: "I am a single mom now, and he is my only one son. Once I found out officially that he has Autism, I had to find all the resources for him, because I have a disability too." As a mother, Afreen had dreams for her son: to be happy, healthy, and be able to care for himself. With the onset of her own disability, she shared that the burden of responsibility was significantly larger: "Who will care for my son when I pass away, or if something happens to me? No one." Her changing health conditions strengthened Afreen's resolve to help Alim lead a healthy and happy life.

As his mother, Afreen plays multiple roles. She is his primary care giver, his advocate, and a lifelong learner. With respect to Alim's home life, Afreen shared that her responsibilities and involvement changed over the years:

For personal care, I used to do a lot for him. Now he is much better. Also, it's harder for me to do it with my disability. I get a personal social worker from the government that can help with all that. He is much better, but still he needs help. I need to supervise him to make sure he wash himself and shower properly. Sometimes he needs help with the shampoo, so I do that, but he is very independent now; eating, toileting, all those kinds of stuff, he is okay with that.

For Alim, physical exercise and socializing with others is hard. As Afreen reflected on his social habits, she shared the following:

He doesn't like outdoor; he doesn't like to go playground since he was young. And he doesn't like to go for a walk. You know, he just wants to be in his own environment. It was very hard when he was young but now it's a little bit better...but still he wants a routine. I try to be random because you know you don't have a same thing...so I try to make him like random. If something changes, he can adapt.

Alim's increasing independence, although slow, has helped Afreen develop more confidence and courage to continue to seek resources and provisions for her son. As a mother, she dedicates a significant amount of time doing research. "I have to learn. Learning it's good" is a sentiment she re-iterated many times throughout the interview. Through her researching efforts, Afreen was able to identify and secure funding for various therapies. Although she wasn't sure which therapies would be most beneficial, Afreen wanted to secure something. Each time she was able to access therapy of any sort, she connected with the professionals at that institution, and often, they were able to direct her to more resources and services that would be of interest.

However, services and supports came with a cost. As Afreen reflected on the importance of securing the appropriate provisions, she highlighted the following with respect to the funding associated with the different programs:

I got very lucky with that. I got a lot of private funding and government funding and through that I did lot of therapy for him like speech therapy, occupational therapy, behaviour therapy. I tried to do it as early as possible because he is young, and young is better. He has improved a lot in the last four years.

Her comfort with and confidence in government assisted programs and private resources have increased over time. Although not all programs are suitable to Alim's needs, or enjoyed by Alim, the services offer Afreen an opportunity to develop Alim's physical, social, and cognitive faculties. Confidently, she stated: "I know everything in and out of the whole system. And that's good."

As his mother, she also describes herself as his advocate: "As a parent, I don't just want Alim to be." As she shared, she compared herself to a detective. She explained that she must constantly observe her son, note down and analyze what the need may be, and then determine who or what could help in addressing that need: "Maybe therapist, maybe teacher, maybe social worker. They know lots of stuff." In addition to seeking out professional help, Afreen relies on her social networks, including other parents of children with exceptionalities, to share their experiences and resources. She said: "If I see something I like, or hear about something, I talk to the right person. I work for it."

Experiences with Special Education Processes

The following section describes Afreen's experiences as she was introduced to Ontario's special education processes and personnel.

The Dream. Alim did not complete any formal early education while in Pakistan, as he was placed in a special school for special kids. Schooling in the USA, in the state of Georgia, was filled with opportunities and challenges. The hope was that schooling in Canada would be better. Upon arrival in Canada, Afreen first came to access special education in Ontario, through the Toronto District School Board (TDSB).

I lived in North York, when Alim came here. He was eight at that time. You know, this is my first child, and I never had a clue about schooling. In Toronto it works like you have to go to school according to your postal code. So, I went to the Hilroy Public School, which is in my area, and I said I need to put him school and all these kinds of stuff. I told them that Alim has ASD and they said they don't have a special kind of program, and they referred me to go to another school, the Parker Public School.

Connecting with the professionals at Parker Public School, the school that offered special education, was done rather efficiently. From what Afreen could recollect, it was a rather seamless process:

I went to meet the teacher in the new elementary school, and they said he would qualify for a special program at the Parker Public School, and that he would need a special IEP, and because of Autism, we can place him there.

When asked what she thought special education would look like, Afreen shared that her vision was a combination of what she experienced in the USA and what she hoped for. She shared: "I thought maybe you know like he is going to be with regular children. Maybe he is going to get 1:1 support." Afreen understood that her son had exceptionalities, but she felt that if Alim was placed in a regular classroom, he would pick up some habits that

developmentally typical children display. She hoped for an environment where teachers and assistants would provide individualized and concentrated support, in an environment that was open and friendly.

Accessibility to Special Education Assessments and Provisions. When asked about her introduction to the special education processes, initial evaluations, and meetings, Afreen was happy and satisfied with her experiences. The identification process, the evaluations, and the potential services that would be offered to Alim came quite easily:

At the school, we discussed everything. There was a meeting, I don't know what the meeting is called, but there was a meeting. In the meeting, there was a speech therapist from the school board, a teacher, me, principal, ok those people ... and we discussed everything regarding Alim. In the same school they did speech evaluation, occupational therapy evaluation, psychologist evaluation, behaviour thing. They told me that all the assessments are done, and this our recommendation.

Afreen often used the word “lucky” to describe her experiences. She was aware that the process she followed, while not easy to navigate, was often very difficult for other parents to complete. When reflecting on her initial experiences, she shared:

The thing is I think I was very lucky. I heard from other people that TDSB takes so long to do assessment. Alim was very lucky that he started grade three and the same year he got all the assessment done and the teacher was so good and everything was so good.

Having completed the formal evaluations, and having connected with his teachers informally a few times, Afreen then attended her first IEP meeting, alone. She detailed the process leading up to the meeting, and what happened during her first meeting:

They send me a letter that you know this is a meeting, and this is the place, and whoever is going to be there, teacher, speech pathologist, psychologist, principal, and then we made a group. Alim was not there. They told me that this is the thing. If you have an input then share. They came prepared. They asked me what are his interest, strength and weakness. Then they made IEP. Then they said that we will discuss in the meeting, and that if you want to add something or bring your own therapist to the meeting, you can do that. I think it was pretty good.

When asked about the documentation shared at the meeting, or subsequent meetings, Afreen indicated that she received a copy of all the evaluations, assessments, and IEPs. While she had access to the appropriate documentation, she shared that she did not necessarily understand everything that was written in it. As her son transitioned from elementary to middle school, it was indicated to her that Alim was to receive another psychoeducational assessment. When he started this school, Afreen requested another assessment. She did not receive a response, and then the COVID-19 pandemic began in early 2020. She is hopeful that they will resume assessments once it is safe.

Meetings with Educators and Other Professionals. Afreen attributes her level of comfort with Ontario's special education system to her experiences in the USA. As she reflected on very first meeting in the USA, Afreen acknowledged her anxiety, stress, and nervousness. For her first meeting, she was in the city of Atlanta. At that time, Alim was very young. She said:

Pre-kindergarten or kindergarten, that time I was very nervous. I had no clue what is that. Then I asked so many questions in that meeting. Then I had a little bit

knowledge. So, when I came here, I knew a little bit: what to listen, what to ask, and all those kinds of stuff.

When reflecting on her Canadian experiences, the atmosphere of the meeting, and the attitudes of the professionals, it seemed that Afreen was satisfied with their efforts. She shared that the team was happy and helpful. She felt that the people she worked with espoused the spirit of comradery, collaboration, and communication. Together, she felt that they worked well as a cohesive unit. Afreen felt that she was an active member of the decision-making team, as the educators solicited her input regularly. When asked if there were moments of hesitation or disagreement between herself and the team, she shared that such disagreements rarely occurred, if at all. In her reflections, she shared:

They were talking and I was listening first. Then they asked me what do I think and what is my input. And then I put whatever I think that they missed or whatever is Alim's routine at home, and what he needs help with. I put my input and we collaborate together. But if I disagree, I have to speak up for my son. But so far, I have never had a problem with them. I just put my input with them. They said that he does this at school and I say NO! He does more than that at home. You know those kinds of stuff.

Afreen was very complimentary of two team members in particular: the teacher and the social worker. With respect to the teacher, Afreen shared that while she was disappointed that her son would not always receive individualized attention, the teacher made every effort to ensure Afreen was aware of the learning goals, and how best to support his development at home. The teacher's knowledge, approachability, and openness to constant communication was very much appreciated by Afreen:

I was so lucky, and he had an excellent teacher for all of the elementary. They don't work 1:1 with the child, they just bring the parent in and then teach them. They work in the school while Alim is there with the teacher, and then I work with my son at home.

In Afreen's view, the social worker was kind, warm and caring. She was empathetic, patient, and often open to sharing her personal experiences. She introduced Afreen to numerous services that proved to be quite helpful:

They gave me so many stuff ... they gave me a program for POP (parent outreach program). I never knew about it. It's a parent something ... it's from the government. The agency sent a lady once a week for two years and she helped a lot. For example: Alim has a problem putting a t-shirt on. I never knew about that. She said if you want to make him comfortable and learn, she said take a bigger size of t-shirt and it's easier. She showed me all these tricks and I loved it. I learned a lot. And then I taught Alim and it got better slowly and slowly. Then I did that program for two years. I never knew that program exist. There were some programs that Alim was not qualified for that. But they were able to bring some programs to school. So, he got a reading buddy.

Summary

Afreen is an educated and independent woman, who is the primary bread winner and caregiver for her household. Single mother to her only child Alim, Afreen took a keen interest in her son's special education since his childhood. She leveraged her experiences in the USA to navigate Ontario's special education processes. Afreen was able to complete the necessary evaluations, and have Alim assigned to the appropriate class, rather

efficiently. Overall, she was able to work well with both the educators and other allied professionals to secure additional programs and services to support Alim's development.

Sabrin's Story

The name Sabrin comes from the Arabic word, Sabr, meaning *patience*. The following details the story of Sabrin, a Pakistani immigrant and mother to her only son, Ahyan.

A Brief Description of Sabrin and her Family

Sabrin describes herself as an inquisitive, passionate, and family-oriented woman. Born in Pakistan, Sabrin spent her childhood and adolescence between two homes: Pakistan and Qatar. She received her nursing degree from the Aga Khan University in Pakistan. In her mid-twenties, Sabrin moved to Canada. She spent some time completing her nursing requalification requirements, as she wished to continue working as a nurse. Sabrin helped care for her younger siblings that were already in Canada.

Shortly thereafter, she was introduced to a family friend, and the two were soon married. Sabrin and her husband have one child together: Ahyan. Her husband is an accountant, and Sabrin is a nurse; the former works in the west end of Toronto and the latter works downtown Toronto. The family currently lives in a detached home, in the city of Toronto, close to Ahyan's school.

Ahyan is an only child, who is 14 years old. Ahyan has ASD. He is a very energetic teenager, who is non-verbal. Ahyan enjoys sports. He is an avid swimmer, ice skater, and more recently, a skier. He enjoys riding his bicycle. Ahyan is also a foodie. He enjoys eating all types of cuisine, with a preference for fast food. Sabrin and her husband share caregiving responsibilities for Ahyan. Given her line of work, Sabrin often relies on the

support of her mother, and sister in-law, to help care for Ahyan. Sabrin is in her early fifties and is looking to continue working in the nursing field, both as a nurse and nurse educator for the foreseeable future.

Construction of Parenthood

The following section explores Sabrin's evolving understanding of parenting. The section begins with Sabrin's initial reactions to Ahyan's diagnosis, and the impact his diagnosis had on her and their family. Subsequently, I explore how Sabrin continues to support her son's physical, social, emotional, and intellectual development.

Understanding the Diagnosis. Sabrin first noticed a change in Ahyan's behaviour, when he was approximately 18 months old. She described this drastic change in disposition and behaviour as a "brain wash." She shared that there was a noticeable regression where: "He stopped talking, stopped making eye contact. He started hiding himself in corners, could not stand noise, spinning like crazy, flapping his hands, (and) walking on his tippy toes." As a mother and a nurse, she was incredibly concerned. Sabrin immediately reached out to her sisters. "They were very afraid to tell me anything" she recalled. Sabrin's eldest sister recognised some of these behaviours from traditional tales, and how these behaviours may be indicative of developmental delay. These tales detailed how frequent fevers during infancy may lead to epilepsy, or how delayed speech and walking on toes may lead to cognitive delays. "So, they never told me anything. But my elder sister, younger sisters, and mom, they said 'keep an eye Sabrin.'" And she did.

Sabrin first learnt of Ahyan's possible diagnosis of ASD, thanks to a routine medical check-up:

Ahyan had aspirated meconium. He was in Sick Kids [Hospital] when he was born for three weeks, because he was on nitric oxide. They have to watch the growth of the child from then on. That's why he was being followed for 2 years and assessed by Sick Kids for mental development. This was my last appointment when I was going to the hospital with him and that's the only appointment that my husband didn't accompany me, otherwise he accompanied for every single appointment. And when I told them I'm seeing this weird behaviour in my son, they said 'Oh, he could have autism'.

Sabrin remembers that meeting, as though it were yesterday. Teary eyed, Sabrin recalled the moments leading up to that appointment, and the moments that followed. As she continued to reflect on the meeting itself, she shared that the team was very compassionate but candid. They knew that as a nurse, Sabrin would understand what they had to share:

They shared that we would need to get assessments to confirm, but there are delays, and this, that and the other. But I just had to get out. And when my husband called me, I'm all upset and crying. And I said to him they said something, something I don't understand. I couldn't even remember the word. That's how bad it was for me. And he said, did they say he has autism? And I said yes, that's what they said he has. And I remember thinking, what is it? Because I've never learnt about it when I did my nursing. That night, when my husband came home, he came with a whole bunch of print outs for me to read on autism, and we read.

Sabrin believed that the diagnosis was inaccurate. She struggled with this diagnosis for quite some time. For her, accepting this reality was a long and emotionally exhausting process. She explained her journey:

It took me six months to accept that my child has autism. I was to the point that I didn't want him. I'm not going to lie. There was a day we sat down and my husband tells me: 'what do you want? If you don't want him, I'll take him and go away.' And I was like, no I want *it* to go away...this is not fair on me. I'm being punished.

Initially, Sabrin was hopeful that with early intervention, she may be able to reverse the neurological damage. From what she had read, this seemed like a real possibility. She said:

I still had the hope that my child will become...because when you go to the assessment, they tell you he will get better. They tell you he is progressing and I'm thinking oh yeah, he will get better, he will start talking, he will start doing things. You keep dreaming.

Sabrin shared her frustrations, and her disillusionment with her understanding of the situation. She was, in her own words, "broken". Eventually, she had to overcome her disappointment, and slowly readjust to her new reality:

Of course, my dreams gone into the drain, because while my pregnancy I was looking at all schools. I want him to learn French, I want my son to learn this or do this.... as a parent you dream for your child. I was 35 when I had him. I wasn't sure if we were going to have another child. So, I want to have the best for him. All my dreams went in to the drain. It was very hard. It was very, very difficult.

At some point, they had to accept this new reality. “Then came a point we accept it, this is what he is. This is a gift from God, and we have to live with it. Then it was like a struggle. Struggle with speech therapy and then behaviour.”

Despite the routine struggles of helping Ahyan develop daily living skills, Sabrin continues to be encouraged by Ahyan’s growth and development:

There was one point I used to think, we use to say, Ahyan is not capable of doing this, or doing this. And then there came a point that how do we know he is not capable unless if we do not give him an opportunity? That’s when we opened the doors for him. We did anything and everything. We said let’s expose Ahyan to everything and let’s see what your able to do. He surprised us.

Sabrin noticed a number of positive changes in Ahyan, and continues to take her lead from her son.

Role of the Parent. When asked about her responsibilities towards her child, Sabrin was clear that being a mother is her first, most important, and according to her, a “forever” job. This was not typical motherhood, but rather, perpetual parenting. Sabrin shared that initially, she was:

Doing everything for Ahyan, A through Z. As a young child, he couldn’t feed himself, he couldn’t go to the toilet. He was wearing diapers longer than other kids. And he was not sleeping well. That was another big problem. We were both working. So, I was doing everything, from A through Z.

She recalls that when Ahyan was young, she would often get phone calls from the school about his behaviour. It was she, and not her husband, who would go to collect Ahyan: “Many times I had to leave work to go to school, which working in the hospital, is

very hard for us to get out of work. I didn't have a choice but to leave." While Sabrin would have liked to have stayed at home and cared for Ahyan when he was a child, this was not a possibility financially. In her opinion, it had to be a two-income household if they wanted to support Ayhan's additional therapies. Sabrin also shared that while she was quite worried about losing her job, she was blessed to have always been working alongside an understanding team of doctors and nurses, who covered for her when needed.

Today, Ahyan is physically an adolescent, transitioning through puberty. As such, her responsibilities entail caring for his most basic needs, to anticipating his needs. Ahyan can dress himself, clean himself (brush his teeth and shower), and he is able to feed himself. However, he is only able to dress himself if his clothes are pre-selected and laid out for him, he is only able to brush his teeth if the tooth paste and soap are available in the designated spot in the bathroom, and he is only able to eat if the food is prepared and served to him. Sabrin works alongside their private behaviour therapist to help teach Ahyan daily living activities. This includes how to do laundry, fold and put away clothes, identify the appropriate clothes (i.e., day clothes vs pyjamas etc.), assist with personal hygiene (i.e., how to use deodorant, put gel in his hair etc.), and to help cook simple foods independently (i.e., bake nuggets, fries, make a sandwich etc.).

To adequately support Ahyan's physical, intellectual, emotional, and social development, Sabrin acknowledged that a fair amount of her time is spent researching available therapies and recreational activities. Once she is able to find an activity that is open to children with exceptionalities, or Autism specifically, she sees if it is affordable and a good fit for her son. She said: "I go with him for everything...indoor, outdoor activity with him, I do not skip a single one, I don't let anyone else take him. I make sure I'm there.

I love to watch what he does.” Finding new avenues to help develop his skills has become an important priority for Sabrin, as she is becoming increasingly aware of her own age. She worries that with time, she may not be able to support her son as much as she would like. Consequently, Sabrin is making every effort to make him as independent as possible, as quickly as possible.

In addition to being a full-time mother, researcher, and Ahyan’s biggest cheerleader, Sabrin also shared that she is his only advocate: “I speak up for him. I’m there with him for every step in his life right now until I know that he is capable of taking care of himself.” Sabrin noted that she must speak for her son, at all times: this includes school, therapies, additional programs or family gatherings. She shared that she is constantly observing and constantly watching over her son:

I am his voice. Wherever I see my son is not given attention, I am one of those cruel mothers who will stand up and say excuse me, my son needs attention, you need to show him as well. Ahyan is good, but I would not say he is as high functioning as some of the other kids I see. My mother always says look at the people below you. I get jealous when people say oh that kid is doing so well, even though it’s the same autism, which is not a good a thing, but that also motivates me to push my son.

Sabrin firmly believes that she does not want to limit her son’s potential, and as such, she will encourage Ahyan to try everything, and she will be sure to support him throughout the process. In this way, Sabrin sees her responsibilities extending to all realms of his life.

Experiences with Special Education Processes

The following section describes Sabrin’s experiences as she was introduced to Ontario’s special education processes and personnel.

The Dream. Ahyan began his schooling in regular daycare, but soon started showing strong behaviours. Sabrin and her husband did some research and came across a private centre that provided speech language therapy, physical therapy, occupational therapy, and behaviour therapy. After a series of interviews and evaluations, and after a short waiting period, Ahyan was granted a spot in a private learning centre. She explained: “We didn’t want any regrets. And so, we said let’s go ahead. This was our introduction to special education.” The cost of attending this learning centre was five thousand dollars per month, not including speech language therapy.

When reflecting on what she understood special education to be, and how it would help Ahyan, Sabrin shared:

I thought he would start talking. I was thinking that he was a very hyper child. There were behaviours and I thought they would cater him on his behaviours. He had a lot of sensory issues. His problems were very prominent. We thought they would cater for us.

Sabrin was very satisfied with what was being provided at the centre, and with Ahyan’s progress. But the financial burden was becoming increasingly difficult to sustain. The debate between keeping Ahyan in a private school versus moving him to a public school ended abruptly when Sabrin lost her funding for Ahyan. She explained: “He got funding at the age of five, after being on the wait list. And then it was taken away because at the age of six, they close it.” Disheartened, she detailed what life was like for them, at that point and time:

Financially we were breaking down. We had taken loans and we were trying our best. Everything was falling apart. And we were like what do we do? And we were

having behaviours at home. So, we couldn't stay in an apartment. I was broken into pieces. I was happy with his progress and I didn't want to move, but I couldn't support it. So, we decided to go public.

When they transitioned to the public system, Sabrin was somewhat hopeful. The teachers and therapists from the private institution offered to support the transition and share their documentation with the team at the public school. As Sabrin reflected on the transition, she recalled feeling flustered:

I had no clue about it. I didn't understand the concept of this whole thing. Ok, in my head, he was going to be in a special school in a special class. Teachers will be trained, just as we were catered in the private schools. They tell you there will be so many kids in the classroom. But there is no program discussed with you.

While this was not ideal, Sabrin forced herself to remain hopeful. They were transitioning from a private education system to a public education system, and she knew that it may take some time to adjust.

Accessibility to Special Education Assessments and Provisions. When asked about her introduction to the public special education processes, initial evaluations, and placements, Sabrin shared her frustration and disappointment with the lack of transparency, and systemic dysfunctionality with the system. As they transferred from the private system to the public system, Sabrin was under the distinct impression that once the appropriate assessments were conducted, the recommended services would be provided to Ahyan. Sabrin, her husband, and the team from the private school attended what Sabrin feels was her first IEP meeting. From what she could recall, it was a rather large group, with many people. She shared:

Somebody from TDSB board person was there, principal, some kind of therapist, some autism team and us. They told us that these services are provided at school. And when we join to the school, we will get the services accordingly. But it doesn't work that way. There is a huge wait list at school as well. They tell us they will do an assessment. And we have never ever been able to get an assessment. They tell us oh no, you have to wait. So as a parent, you want to know what is happening.

Sabrin went on to share a few examples that illustrated the vulnerabilities in the system. As a parent, she felt she was always waiting: waiting for an assessment, waiting for a meeting, waiting for communication. She said: "The school was nice, the principal was outstanding, but the teacher had no idea how to deal with the kids." As she reflected, Sabrin repeatedly alluded to the fact that there is, in her own words, a serious "trust issue." She suggested time and again that she is unsure whether the recommendations in the assessments are being followed by the teachers and the educational assistants, whether Ahyan is receiving the supports that the school promised, or whether they are truly giving him the attention he needs to improve.

Meetings with Educators and Other Professionals. Over the years, Sabrin has met a number of educators and allied health professionals, who work in both the private and public special education systems. These encounters have shaped her understanding of the special education system. Unsure whether she should blame her genuine naivety, her childish hopefulness, or her unconditional trust in the professionals and the system, Sabrin felt that when planning for Ahyan's educational supports, something would "always go wrong".

After Ahyan's first placement in a public special education classroom, Sabrin recalls receiving multiple calls a month. With each call, the teacher would inform her that Ahyan had an incident, and that she must come collect her son. One day, when she was called by the teacher to come collect Ahyan, she stood outside the classroom window, out of sight, to observe Ahyan and his behaviour. She shared the following with me: "You are not going to believe. My son was wearing headphones and sitting in a corner. I watched for over 45 minutes. And the rest of the kids were working." Eventually she went in to meet the teacher:

So, I asked the teachers, I said what is he hearing on the headphones? She goes 'nothing'. I said: So, he can't hear anything? I said ok. 'Oh, that's just to make him calm down' she said. So, I said ok, how often do you use the headphones on my son? And she said '80% of the day'. You mean 80% of the day my son doesn't hear anything? I lost it. I literally lost it. I went to the principal. I said this is not how to treat a child. It means you have isolated my child from the rest of the classroom. This is a special needs class. This is beautiful garden, beautiful flowers and this, [Ahyan], is a weed that you have thrown out. That's how I feel my child is. That's when the battle started.

An emergency IEP meeting was arranged, as Sabrin and her husband were not satisfied with the level of support Ahyan was receiving in his class. The teacher felt that Ahyan was unable to cope in this environment, and had been placed in the wrong classroom. Sabrin spent numerous days preparing for this meeting.

I made my presentation on my son. I prepared a booklet and a presentation at home. What he was doing and what he is capable of doing. And then made a presentation

by videotaping him. I was tired of hearing that my son is not capable of not doing this. I know my son is very capable. So, I showed it. The teacher didn't like it.

The teacher, as Sabrin recalled, presented a contrasting view. "Teacher came in with her books and said, he can't do this or can't do this." Sabrin went on to share that the team thanked her for her beautiful presentation. Then, they reminded her of the teacher's qualifications, years of experience, and the important role the teacher has played in the life of many families, to which Sabrin responded:

And I said it doesn't matter. She doesn't know how to deal with autistic kids. 25 years of experience will go in garbage if you don't know how to deal with these kids. It's very hard for me to say cruel words to the teacher, but it was like that.

Ultimately, Ahyan was moved from the Development Disability (DD) class to the Intellectual Disability Moderate (IDM) class. As she reflected on the end of that meeting, she shared the following: "I left crying. I couldn't stand it. You know, they are just putting my mental status so down. You are treating Ahyan as a failure."

Having openly disagreed with the school team and having lost, still Sabrin was not dissuaded. She was her son's advocate. In her own words, she was going to continue the "battle". Sabrin escalated her concerns. She was so furious, and she was not going to stop until this was resolved. She said:

I kept going up and up. I went to Laura who was the head of TDSB. I called her and emailed her. And I said I'm not happy with this. She listened to me. Of course, this is their team. They have to support them. And she was like this is in the best interest of Ahyan, this will work out. And my husband was like, "What can you do? We have no choice."

When reflecting on her more recent IEP meetings, Sabrin shared that she had become more “cautious”, and was learning how to “survive” the system. When reflecting on the documentation, Sabrin shared:

I googled. I still don't understand TDSB's language to be honest with you...it's not clear. A lot of the things they don't tell you. See when your child goes into the public school, they don't sit down and say this is what the IEP is, this is what you should expect. Explain to us. We are dumb parents. We are going through the stress that we only know our child; we don't know anything else. They just send you the papers. And they are like fill it in. I learnt a lot from other parents. Oh, you know according to the thing, section 2 so and so, they should be able to give it to you, but they don't tell you in school.

Sabrin validated this recollection by sharing a conversation she had a few months later, when she was discussing Ahyan's behaviour, and was offered additional support in the form of a Special Education Resource Teacher (SERT). She shared the following: “We didn't know about it. They don't tell you about it. They were like we have this. Do you want this? And I was like what is this? Of course, I'll take this. They don't educate parents.”

With respect to teachers, Sabrin felt that for the most part, teachers were not adequately trained. Their approach to each child should be grounded in the child's needs. “I think that is something a teacher should be able to say. These are some of the things he is doing. These are some of the things he can't do and we are working on it.” She went on to share that communication is often difficult, because the teacher expects the parent to listen to them: “They would expect me to listen. And accept.”

As a proactive parent, Sabrin tries to help bridge the gaps she is able to identify. She shared the following example:

My son comes home. I don't know what he did because he can't tell me. Whose responsibility it is to tell me? That part of responsibility I don't think people think is important. I prepared a communication chart for them. I need to know did he eat, did he do this, did he do a behaviour, for how long? I need to know. When I'm told he had a behaviour, I need to know what triggered it? How long was it? What was the situation at that time?

While she is not happy about the lack of communication, she feels that by providing teachers with the resources, and lessening their "workload", maybe she will be better able to support her son at home.

Summary

Sabrin is a full-time registered nurse, wife, and mother. Over the years, Sabrin has placed her son Ahyan in both private and publicly funded special education institutions, to best support her son's changing needs. In this time, she has learnt which supports and provisions are available to her through the school systems, and which services need to be acquired privately. Sabrin has also observed that some educators and allied health professionals are more familiar with the system, have experience working with children with ASD, and have the requisite training, whereas others do not. Over the years, her experiences have led to her to both build and burn bridges with educators and school personnel in her attempts to support Ahyan's development.

Bedar's Story

The name Bedar has a few meanings, one of which is *fearless*. The following details the story of Bedar, an Indian immigrant and father to three children: Nabeel, Zahra and Anwaar.

A Brief Description of Bedar and his Family

Bedar describes himself as a funny, outgoing man, who enjoys reading and discussing politics and business. Bedar came to Canada from India, at the age of 18. He is one of six kids. His brothers and sisters completed their schooling and post graduate studies in Canada. Bedar is an electrical engineer by profession. He met his wife, while at university in Nova Scotia. His wife is a family physician. Bedar and his wife currently own and operate two medical clinics in a small city northwest of Toronto, and one Applied Behaviour Analysis (ABA) Therapy centre. They are the proud parents of three children: their 20-year-old son Nabeel, their 17-year-old daughter Zahra, and their 12-year-old son Anwaar. They moved from Nova Scotia to Ontario seven years ago.

Anwaar, their youngest, has ASD. He is a talented artist. He enjoys coloring, sketching, and drawing, the latter being his most favorite pass time. Anwaar also enjoys playing video games. And like the rest of the family, Anwaar is a foodie. He enjoys eating all types of food, with a preference for pizza, nuggets, and fries. Bedar currently lives in Queen City, in a single detached home with his family. He lives within 20-30 km of his siblings, who reside in neighbouring cities. Being able to spend time with his family, nephews, and nieces is very important to him.

Construction of Parenthood

The following section explores Bedar's evolving understanding of parenting. The section begins with Bedar's initial reactions to Anwaar's diagnosis, and the impact his

diagnosis had on their family. Subsequently, I explore how Bedar and his family support Anwaar's physical, social, emotional, and intellectual development.

Understanding the Diagnosis. Anwaar is the youngest of Bedar's three children. When reflecting on Anwaar's early childhood, Bedar shared that there were some obvious differences in Anwaar's behaviour as a toddler, in comparison to his siblings. With his wife being in the medical field, Bedar shared that often, they worried excessively about the smallest things. So, when they first noticed his behaviours, they dismissed their observations as their "parental over protectiveness" or their "paranoia."

As Bedar reminisced, he went on to suggest that perhaps it was "denial" or perhaps it was a "knee jerk reaction", he is not quite sure what it was, but both him and his wife felt that more evidence was needed, before this diagnosis could be recognized and accepted as such.

The evidence came when Anwaar was around four years old, as noted by Bedar: "We were in Nova Scotia at that time." It was there, after a few medical assessments, that Bedar and his wife officially received a diagnosis, indicating that Anwaar was on the Autism spectrum. He said: "Basically, as soon as we got his diagnosis, we knew that this is going to be a special life. Special opportunities and challenges. All of those things together."

Bedar shared that once it was official, his son's life flashed before his eyes. He was overwhelmed by the number of questions and concerns that flooded his mind: "What would his childhood be like? Will he be independent? Will he be able to earn a living? What will happen to Anwaar when I pass?"

According to Bedar, the family went through a period of adjustment. Initially, their goal was to keep him happy. This meant playing with him, giving him attention, and at times, giving him what he wanted. But as time went on, they tried to more actively ensure they were able to develop his cognitive, physical, and social/emotional faculties, through therapies and respite activities.

Role of the Parent. When reflecting on his role as a parent, and his responsibilities towards his child, Bedar was very candid: “We share the responsibilities, we have to be a team.” As a father, he is a caregiver, a chauffeur, a researcher, a teacher, and an advocate for Anwaar. When Anwaar was younger, he needed more care. Bedar explained: “My wife and I were there to help feed him, bathe him, dress him, pick up/drop off from daycare...normal stuff...like we did with our other children.” The difference in parenting strategies came when Anwaar was almost two years old. Initially, Bedar would dismiss Anwaar’s stubbornness, his absolute rigidity or his crying fits as tantrums. For Bedar, tantrums were not out of the ordinary: “All children have them.” But Anwaar’s tantrums would last much, much longer. Unlike his other children, there was no negotiating, reasoning, or bribing Anwaar. There was no way out of a tantrum. At the time, Bedar did not think to observe what may have triggered the tantrum. They were unpredictable; but he came to learn to “wait them out.”

By the time Anwaar was nearing four years of age, he had stopped sleeping: “He hates sleeping. Ok, all kids hate sleeping, but he really hated sleeping. We are still struggling with sleeping actually.” By age five, Anwaar started developing increased comfort with structure and responded well to familiar or routine activities. Upon reflection,

Bedar shared that it was perhaps “unplanned or unpredictable events/people that may have caused melt downs”, when Anwaar was much younger.

Once Anwaar received an ASD diagnosis, the couple did not waste any time in observing and logging Anwaar’s behaviours, with the hope of identifying potential triggers. By age six, Anwaar had a laundry list of sensitivities: “He was unable to communicate verbally, unable to understand or express feelings, sensitive to loud noises, severe sensory issues etc. etc.” Both parents very purposefully began researching therapies to help remedy these concerns. The parents identified and began to provide Anwaar with private speech language therapy, physiotherapy, social/play skills therapy, and IBI/ABA therapy.

According to Bedar, the couple remain committed to helping their son develop: “We are active, we are very, very active in helping getting our child what he needs.” Bedar sees himself as Anwaar’s voice, as his advocate: “I have to be able to share what my son thinks, feels, wants or does not want, because I know him best.” To Bedar, even though a parent can identify the needs of the child, it doesn’t always mean that they can provide for it. He counts himself lucky, as he is able to provide for his son. Bedar explained his rationale using the following examples:

We have gone through days when he wanted Dairy Queen or A&W for lunch or supper, and it would be a \$10 meal every evening. We have gone through multiple broken iPads, phones, tablets. We were able to spend all of that and able to provide for him. But the people who cannot do that it is really, well, I can imagine it would be very challenging. There needs to be more resources for these kids available.

Experiences with Special Education Processes

The following section describes Bedar's experiences as he was introduced to Ontario's special education processes and personnel.

The Dream. Special education in Nova Scotia was not noticeably different than regular education for Bedar. According to Bedar, there was little mention of a "tangible process", and so the idea of special education was basically regular education, but "slower". When reflecting on some of the meetings he had with the educators in Anwaar's kindergarten class, Bedar shared the following: "It was that insignificant, that I don't remember much about the meeting. School was more like play school for him."

With respect to the accommodations, modifications or provisions that were provided to support Anwaar's learning, Bedar shared the following:

Initially, when they were trying to teach him, and keep everything regular, it was quite stressful for him. He was trying to run away from the situation and come out of the school. And they got some emergency assistance for him. They got him 1:1 support with an EA. After that there were no behaviours. However, in terms of education, he did not learn anything. All the time somebody was playing with him, keep him happy, and then he would come home no problems.

When they arrived in Ontario, Anwaar was admitted to a regular grade 1 classroom. The parents felt that he may be able to integrate, as this was a new environment, with a new teacher and new peers. When reflecting on this decision, Bedar shared the following:

Anwaar started having so many challenges and struggles, and he was running away from the playground, towards you know the area outside of school. Similarly, in the class he was not calm enough. It was quite a bit of challenge.

When Bedar and his wife discussed their son's experience in Nova Scotia and his diagnosis with the educators at the school, there didn't seem to be any supports in place or the possibility of acquiring support for Anwaar. Bedar explained: "They suggest he moves to an autism class or a community classroom, in another school."

With the help of the principal, Barkat and his wife were able to connect with another school that offered the community classroom program. When they sat down to connect with the principal, they were told that Anwaar would receive special education, with special provisions to support his needs. "They transferred him over to that school. And over there, an IEP was made. They promised that this would be a smaller class, with five other kids in that class, two support staff, and one teacher." For Bedar and his wife, it seemed like a reasonable way forward.

Accessibility to Special Education Assessments and Provisions. When asked about his official introduction and immersion into the public-school special education processes, initial evaluations and placements, Bedar shared his overall displeasure with both the people and the processes.

When reflecting on his very first IEP meeting, Bedar shared the following: "From what I can recall, it was the teacher, principal, myself, my wife, and there might have been somebody from the special education team. They put down some basic things to control his behaviour and some learning stuff." From Bedar's recollection, the meeting appears to have been more procedural rather than conversational. Reflecting on the implementation of the IEP, and the impact it had on Anwaar, Bedar offered the following: "There was really nothing significant that changed him or made life easier. It was actually, practically, it was a hard year for us."

The process was not always this mechanical, or procedural. Reflecting on a subsequent IEP meeting, Bedar shared the following:

I think we were comfortable with the contents, with the discussion. The thing is, there were things like consultancy from school board. However, that's a vague term. And we didn't really question them at that time, like what that consultation would look like.

While the subsequent IEP conversations appeared more dialogical in nature, the content discussed during the meetings was still complex. Bedar expressed that he felt betrayed by what he was told and what remained untold during that meeting. He explained:

It was not an honest communication on their part. If they had told us that our son will have one visit, if any, with a speech language pathologist in a year, we would have never have signed off on that IEP. It almost felt like they were writing these things down on the paper and getting us to sign off on the plan. However, practically, none of these things were done to support our child.

At the same time however, Bedar was very forgiving of the institution. He wanted to give the team, and more specifically the teacher, the benefit of the doubt. His thoughts are reflective of his misplaced trust:

I honestly felt that teacher is trying. She was very nice lady, and you know from what she was going to try to do, it felt that she was really trying. And she was presenting the right information to us. And I think her role, it felt like, she was thinking that those consultancy services would be provided, and she forwarded that to us. Her role was to present that information to us, and for us to agree on that. Now, God knows whether she had the history, and she knew that you know what,

good luck. You are going to sign this, we are going to put it in the closet, and it will never come back and help you. I really hope and wish that she did not know that. If she did know that I would be very angry and hurt.

At some point, Bedar and his wife noticed that many of the items discussed during the meetings were not being met. They raised this issue with the teacher and the principal. Bedar rationalized it as follows:

I think we felt that even though we stand up for our kids, and ask for services, I think we failed to question what they were offering and how it will become a reality. We did speak up more, when we were not seeing any supports. We were so desperate for support.

Given the lack of support from the public-school system, Bedar and his wife choose to leave the public-school setting and opt for a private institution instead. They landed on the Orange School; a school dedicated to providing therapies and education to children with autism.

Bedar, especially impressed by the therapies provided at the school, the teacher student ratio, and the parent-teacher communication, described his excitement:

They have one BCBA (Board Certified Behaviour Analyst) for 24 students. They have a full time SLP, a full time PT and sometimes, they have music therapy too. You could see why kids will behave properly, and develop and learn properly, and shine in this environment when they are given those resources.

Meetings with Educators and Other Professionals. When reflecting on the IEP meetings, the atmosphere of the meeting, the dispositions of the professionals present at

the table, and on the parent-teacher partnership, Bedar felt he had received the short end of the stick.

Bedar shared repeatedly that he felt deceived, and by extension, disempowered. When reflecting on the IEP meetings, Bedar expressed: “my job was to listen and sign. The decisions were all made. We read through it and signed off on it.” Bedar felt that in the public school, there was no time or space for real discussion. When reflecting on the documentation used in the meetings, he further explained that:

The language is quite misleading where they are not specific ... with specific goals, how everything will be accomplished, what kind of supports will be in place. If someone was to read it, they would be like, this looks like a good IEP. It will pass all the ethical guidelines or all the criteria that you need for an IEP, but is it a functional IEP? Will it have the supports the child will need? No. Not knowing what a functional IEP should look like, especially having two other typical kids, growing normally, we never had issues, so this was something where we thought it looks good. How would we know?

In his conversation, Bedar made a direct link between what it means to have knowledge, and how sharing knowledge could help build trust between all parties involved. As he reflected on his role, he shared that perhaps he failed as a parent, because of what he did not know. He said:

It was us not knowing what is available. Also, we were trusting the information that they were providing. I have learnt over a period of time that you cannot trust the school, or the board, it's unfortunate but that just the way it is.

Perhaps the most striking part for Bedar, was not the IEP meeting, or the vagueness of the language that peppered the documentation, but rather learning about the educators and their dispositions. Bedar shared a few anecdotes, that he felt, alluded to the lack of honesty, training, and professionalism, displayed by various school personnel. For him, it was not one piece of the system (i.e. the IEP) that was more functional or dysfunctional in comparison to the rest, but rather the entirety of the system that needs to be carefully studied and re-assessed. The following reflection details an incident between Anwaar and another child, and how the incident was misrepresented to the parent:

In the class, one child was having some anger issues, and he would use a lot of colourful language. My son knew that it was not appropriate. Anwaar would say to the other child, don't do that, and the kid would get angrier about it. The teachers did not have any means to handle that properly. They let it go.

In his opinion, as Bedar recalls, the teacher did not know how to handle, teach, or calm down both the child, or Anwaar. And this was not an isolated incident. Anwaar would regularly tell the other child how to behave, or what to say, and each time, the teachers would minimize the incident, or the aggression that followed. The following reflection details how, when an incident occurred, the teachers would deflect the blame:

Anwaar would come out yelling and screaming, having a full-blown melt down. I'll be picking him up and the teachers would say it was me. I was being blamed, because he doesn't like dad. And when we would read the notes that they left in the book, it was like one of his peers was angry, and that made him upset. This was not upset.

On another occasion, when Bedar went to school to pick up his children, Anwaar was outside having a meltdown. He shared the following:

Me and my daughter would always pick him up. He was just sitting outside the main door, slowly calming down, and principal then comes and yells, ‘Amaar you have to leave now’. And inside (our minds) we were like Oh my God! What are you doing? He started crying again. And going back into melt down. I mean this was the principal. You could imagine how the whole school was broken, the total system was broken. Like from the top to the bottom. EA’s did not know how to handle, teacher did not know how to handle him, principal also. So, I think it’s the whole system. IEP is one piece.

Summary

Bedar is a successful businessman, husband, and father of three. Once they learnt of Anwaar’s condition, both Bedar and his wife spent a considerable amount of time and energy working to secure supports for Anwaar’s development and growth. Over the years, Bedar has experienced both the public and the private special education systems, where well intentioned staff, lacking training and experience, attempt to support children with exceptionalities. With time, Bedar has learnt more about the entire special education process: what to expect in an IEP meeting, how to read IEP documentation, when to advocate, and what types of services and provisions are available to his son through the school and should be requested, and what needs to be procured privately.

Shradha’s Story

The name Shradha is Sanskrit in origin and has multiple meanings, one of which is *faith*. The following details the story of Shradha, an Indian immigrant mother of two: Shellina and Shafiq.

A Brief Description of Shradha and her Family

Shradha describes herself as an enthusiastic, bubbly, and a shrewd businesswoman, with an outgoing personality. Her family migrated to Canada when she was quite young. She completed her high school education in Ontario and went on to complete her BA at the University of Toronto. Shradha then continued to pursue a graduate degree. She completed the certified management accounting program. Shradha met her husband in school. They married once she completed her education. They now have two children: Shellina who is 17 years old, and Shafiq who is almost 14 years old. Shradha is currently working in a prestigious bank, as a senior manager in the business management area. Her husband works in information technology (IT), supporting all University Hospital Network (UHN) facilities. The couple and their children live in a single detached home in Markham, close to her husband's family, and extended family. Both the daughter and the son have attended York Region Schools their entire lives.

Shafiq has ASD. He is a happy child. He is very shy, but likes to be around people. Shafiq's best friend and most cherished relationship is with his older sister Shellina. He loves to play, dance, and have fun with her and the family. Shafiq also enjoys camping and travelling. When with his family, Shafiq likes to see new things, do new things, and sometimes, try new foods.

Construction of Parenthood

The following section explores Shradha's evolving understanding of parenting. The section begins with Shradha's initial reactions to Shafiq's diagnosis, and the impact his diagnosis had on their family. Subsequently, I explore how Shradha, and her family continue to support Shafiq's physical, social, emotional, and intellectual development.

Understanding the Diagnosis. Shradha had learnt a lot about early childhood development through her first child Shellina. As she began to compare Shafiq's behaviours and growth patterns to the Ages and Stages developmental framework, she noticed a number of misalignments. But for each missed milestone, Shradha found a reasonable justification. For example, she was somewhat concerned when Shafiq was not babbling or using words by a certain age. However, delayed speech seemed probable, given that he was being raised by his grandmother, and was never around other children his age.

After a few visits to the doctor, and some intensive conversations with specialists, Shradha and her husband were told that Shafiq had Autism. From what she recalled, she felt quite guilty: "When you find out your child has a disability, your first thought is, oh my God what did I do wrong? It must have been me. I did something." Shradha shared that as a mother, these thoughts continued to percolate in her mind for quite some time. Shradha described how she replayed events in her mind, rewinding, forwarding, trying to pinpoint where she could have gone wrong. She went on to share:

Once you have entirely dissected your life, from pre-pregnancy to the present day, you move to the "hero" stage, where you try and problem solve. From being the only culprit, you continue along a spectrum. You move on from that to how do I change him. You know, how do I make it better? It almost becomes your obsession...trying to fix this problem.

Shradha was also worried about her first born, and the toll this would take on her. She shared the following sentiments with me when reflecting on the impact a disability has on the family: “It’s a challenge on the entire family because I have another child who suffers. She suffers because you're focussed on one, and you can't focus on two at the same time.”

Shradha shared that accepting her reality, all things considered, was quite hard. This was a struggle unlike any other. The realization that you are powerless as a parent, was devastating for Shradha. When reflecting on the earlier parts of her journey, she shared the spectrum of emotions she oscillated between:

You can’t make it better. I can't make it better and I can't fix this and nobody can.

You move to how do we live with it; how do we make the best we can for him, and how could he have the best life possible. That's when you start looking at okay, what resources are out there, how do we give him everything that he needs.

From Shradha’s perspective, accepting Shafiq’s disability is a continuous challenge because you learn something new about the disability or its impact on Shafiq, every day. Sometimes it’s a good thing, and sometimes, it’s bad. The challenge is constant: possibly the only constant in their lives.

When reflecting on their approach to living with a son who has ASD, Shradha shared the following reflection:

I think that’s why the family unit becomes really important, and I said to my husband, I am taking care of him so she (Shellina) is on you. So, you spend that time with her. We really did we try to make it the best for both. And we really did.

Role of the parent. When asked about her role and her responsibilities towards her child, Shradha shared that being a mother was a full-time job. Over the years, her responsibilities may have changed in nature, but her time investment remains the same.

When Shafiq was a toddler, Shradha's primary role was that of a nurturer, caregiver and learner. When reflecting on Shafiq's early childhood, Shradha shared a few stories: "You know, for the longest while, he didn't speak, until he was like over four. And at that point he was acting. Like mimicking. He would just repeat what he just heard. It's called echolalia." Unlike other toddlers or pre-schoolers, Shafiq was significantly delayed. Shafiq was unable to feed himself, dress himself, or clean himself. All daily living activities required assistance. Shradha went on to explain:

We went to so many classes...we went to communication classes to help change echolalia to actual speech. It took years of speech language therapy, behaviour therapy, social therapy, to develop the skills he has.

But it wasn't just Shafiq who went to classes. This was a family endeavour. The parents were expected to attend classes as well. As a learner, Shradha was constantly reading and trying new things. She described her efforts by providing the following example:

We attended a lot of courses through Kinark and Carrie's Place, just to see how do we work better with him, how do we communicate better with him, how do we encourage him. You just want him to be happy you know.

Today, Shafiq is far more independent than he was as a child. As a teenager, he is able to dress himself, clean himself, cook basic foods, and take the school bus to and from school. More recently, while still the primary caregiver, Shradha is paying closer attention

to other skills that she needs to develop in Shafiq, to help him become increasingly independent. It's a delicate balance, she says, because while you want to him to develop, you also don't want to see signs of regression in his behaviour. In her words, watching someone on the spectrum, is like watching something unpredictable.

As the ever-effective administrator, Shradha shared that she spent and continues to spend, a considerable amount of time researching and educating herself, and her husband on everything. From therapies to diets, from physical exercises to mindfulness reflections, she is constantly researching. Shradha went on to explain:

There is no one stop shop where you get handed a paper that says okay, your child has autism, here is a list of resources that you can contact to get started on therapies. At least there wasn't one when I was a parent. It's basically you do your own research. I also work full time, so I spent a lot of time on my lunch hours instead of going downstairs and meeting people for lunch or walk whatever, I spent that time doing research or interviewing people to find a good behaviour therapist or a good speech therapist.

But it wasn't enough. She would have to continue researching at home as well. For Shradha, researching was both exhausting and isolating. It was disheartening, and often a lonely place: but it had to be done. She acknowledged the difficulties she endured:

It got to a point where I didn't even see my family or my extended family. I didn't actually see them because this was my world, this was my bubble, and I felt that they couldn't really understand or support me.

Researching funding and eligibility is a different ball game altogether. Shradha worries about the sustainability of the resources available to her son:

Sometimes you don't have the government funding, so then how do you pay for all of these extra resources? That's where you go okay; second mortgage. What do you need to do to make this happen? Because this is your child, and you will do anything to give him the best life possible.

Overtime, Shradha has become the manger, organizer, and advocate for her son. She manages domestic responsibilities, oversees her daughter's school schedule, and lastly, manages her son's school and therapy schedules. Shradha has worked hard to instill the spirit of collaboration and open mindedness in her family. The analogy she shared with me, is the same one she uses with her family: "For the cart to move in the same direction, there needs to be trust and communication. We would just say, okay, there's four of us. Let's make this work. How can we do it?" Balancing the wants and needs of four individuals is not easy. "It was a challenge for the family, and it still is, I think. But it also brought our family closer together because we realized that in order for everybody to function, we all need to work together."

Experiences with Special Education Processes

The following section describes Shradha's experiences as she was introduced to Ontario's special education processes and personnel.

The Dream. Shafiq started school at a private Montessori. The move to put Shafiq in a Montessori was based on a recommendation from the doctor: "We put him into Montessori. It was recommended by his pediatrician. Because he wasn't talking. It was a smaller class, and he was around kids his age." Shradha went on to share how things changed once they received the diagnosis. She said: "I think it was like after a year maybe two, I can't remember exactly, but when we got the diagnosis, we wanted to keep him

there.” According to Shradha, it was the administrators of the Montessori who refused to support him:

They didn’t have the personnel or the provisions. They said you’re better off going to a public school because they will be able to provide support...to the extent that you will have an autism team, and you’ll have a special education teacher, and you will have all these resources that we cannot provide you.

As Shradha reflected on this part of the journey, she shared that changing schools was not their first option. The process of identifying the number of resources required was quite overwhelming. She described the following:

That’s when we found out that we would have to go to a public school to get the extra resources. We actually got lucky. We registered him in a public school close to home. The principal was very involved in special education, and she was very good about any accommodations he might need at the time.

Shafiq was placed in a typical classroom, and Shradha was told that supports would be provided. She explained: “York Region School Board has access to supports, and Shafiq was placed in a typical classroom with typical kids and a support worker, an EA or sorry a child youth worker, was there.” This was special education: a dedicated support worker present in a typical classroom, who would work with Shafiq individually and help support his development.

Accessibility to Special Education Assessments and Provisions. When asked about her introduction to the public-school special education processes, initial evaluations, and placements, Shradha shared that overall, it was never really clear: be it the process, the documentation, or the conversations. When reflecting on their first experience of Shafiq

being placed in a typical, public school classroom with supports, accommodations, and modifications, Shradha shared the following:

See the youth worker was in there but it was only for part of the day, for part of the instructional time so possibly one third of the instructional hours. For the rest of the time, he really wasn't participating or doing much else and that became routine for him. There really wasn't much else.

Shafiq remained in the same school and was placed in a typical classroom for 3 consecutive years: junior kindergarten, senior kindergarten, and Grade 1. Additional supports were theoretically going to be provided to Shafiq, but it wasn't until Shradha initiated a conversation, that any form of evaluation or support was discussed. She recalled: "I learned, from another teacher, that I need to make the principal have the autism team come in, and have a discussion, and do an assessment." And so, the therapists came: "OT came, assessed writings skills, and how he was managing in terms of fine motor skills and gross motor skills, and put accommodations in place, and gave some exercises for him to work on." The biggest assistance, in Shradha's opinion, was a matter of mere luck: "In grade one, I was lucky enough to have a teacher who was a BCBA (Board Certified Behaviour Analyst)."

For Shradha, the developmental differences were hard to ignore. By Grade 1, "the gap was getting bigger and bigger, and it became more and more apparent that he wasn't able to function very well in a typical classroom. To the point where it stood out to the other kids." Shradha went on to explain how a particular event, a school trip, became a turning point for her:

I actually attended, I think it was a field trip to the Science Center. He just didn't quite fit in and honestly, it's quite heart breaking. You see your kid just sitting there. He has classmates that were like really nurturing but that also made him stand out a lot more. I even had other parents saying "Oh why is he really shy and why is he clinging to you?" I think even he could tell that he didn't really fit.

That's when Shradha and her husband started to look for another educational option for Shafiq. The public system, in their view, was failing him.

Housed under the wings of YRDSB, Shradha and her husband landed on a private institution, the Blue School. The Blue School was dedicated to providing therapies and remedial education to children with Autism. Initially, they wanted to test the waters with the Blue School and see how Shafiq would fare. It was a private institution, so the registration process was both easy and efficient. Shradha recalled what the first few months were like, at the new institution:

I would say by the second week, he was so comfortable being there that it wasn't a struggle to get him up in the mornings anymore. Like he actually wanted to get up. He actually wanted to go to school...and I can really only attribute it to the fact that he probably felt like he belonged there. He wasn't the outsider anymore. He just felt comfortable. So, one year stretched into oh gosh maybe like seven years that he ended up staying.

Meetings with Educators and Other Professionals. When reflecting on the IEP meetings, the atmosphere of the meeting, and the dispositions of the professionals present at the table, Shradha concluded that her experiences ranged on a spectrum, from engaging

with a mildly collaborative team of professionals to dealing with a stubborn, uncooperative group of professionals.

Her first experience of an IEP meeting was when Shafiq was much younger, and in the public system. Her reflections were a mixture of positive and negative reviews. She shared the following:

We had a teacher who understood him and would help us by saying these are what are his strengths are these are what his weaknesses, these are the accommodations, and this is where I feel we should work towards, and this is how we can get there. Let me know your thoughts.

For Shradha, the teacher appeared to care, but did not have the support to help Shafiq develop. She said: “We worked together to develop the IEP. But again, we didn’t know much. And they didn’t say much.” Upon reflection, Shradha attributed her mixed feelings to this being their first IEP meeting. There were no expectations. The fact that someone was willing to provide help, any help, was itself, heartwarming. It was understood and experienced as more an act of benevolence, from the part of the educators, rather than a parental entitlement.

As time passed, Shradha, as a parent, became much more informed about what she can and cannot demand. “Over the years, I have become very candid. I don’t think I was being unreasonable because I know he can develop. He has been developing. I know what he is capable of.” When reflecting on her more recent IEP experiences, Shradha said:

I thought the goals were predetermined beforehand and not too much of my input was included. In fact, I don't think I even signed the last IEP for that reason because

I didn't feel that my input was included in there, and I felt like regardless of what I said that I wanted them to work on, I don't think I was being heard.

Shradha shared that she was especially frustrated with the team for two reasons. Firstly, she felt both ignored and devalued as an informed parent. Secondly, as a paying parent, she expected the team to be more understanding. She went on to share:

I got the impression, the distinct impression that I was asking for too much of them. I didn't think I was because the classroom is small, and they do have enough support so, I don't know why that would be an issue. But also, I think I got the impression they thought my expectations of him were too high. I got the impression that they were quite happy to have him just kind of be in a classroom where he gets life skills...like knowing money so you can buy something. I don't find them really working hard to get the children much more than that, and that is very frustrating because we see our kids as having futures, as being able to be employed and being independent.

Shradha went on to describe the futility of the goals written in the IEP: "They were written in a way to make sure he could achieve the goal that they set for him. I felt that his development would be lacking, like there was no challenge. If that makes any sense."

When asked about her role in this partnership, Shradha responded with the following: "I think they actually expect you to comply, because they see themselves as the expert, and they see themselves as the one who knows what your child is capable of." It really didn't matter how many meetings they had, or who was present. Shradha shared the following sentiments: "I get the distinct feeling that as long as a child can get by in life, the IEP doesn't really mean much to them." From her perspective, while some educators are

dedicated to cultivating the minds and hearts of the future, others are not. Her frustration with the system and the ‘bureaucratic redundancy’ is summed in the following reflection:

I felt like we would take two steps forward and one step back. I don't think educators, to a certain extent, see the full potential of the child and is willing to invest the time and resource to help them get there.

Summary

Shradha is a senior manager in a financial institution, a wife, and a mother to two children. Her husband and extended family help with the caregiving duties that come with raising two teenagers. Of the two parents, Shradha has consistently played a prominent role in her son's education: researching educational institutions, educational programs, additional therapies, and potential funding, so as to help support Shafiq's growth and development. Her familiarity and knowledge of the special education system has increased dramatically, in part due to her own research, and in part due to the assistance she received from kind-hearted teachers, or fellow parents. With time, she has become a stronger advocate for her son. Relentless and determined, Shradha continues to advocate for her son and exercise her power as a parent, as she struggles to redefine IEP goals, secure additional provisions, or evaluate the services currently being offered to her son.

Sapna and Akaash's Story

The names Sapna and Akaash are of Sanskrit origin, meaning *dream* and *sky* respectively. Sapna and Akaash are Indian immigrants, and parents to their only child, Marah.

A Brief Description of Sapna and her Family

Sapna describes herself as a kind, gentle, and soft-spoken woman. She was born and raised in North India. Sapna completed her secondary and post-secondary education in India. She lived with her parents and younger sister until she married her husband Akaash. Sapna and Akaash have one beautiful daughter named Marah. Marah was born with a neurological and developmental disorder. Having evaluated the medical and educational resources available to them, Sapna and Akaash made the decision to move Canada, so that they may provide Marah with a better future: medically, educationally, and socially.

Marah is an energetic, mischievous, and intelligent five-year-old girl. She has ASD, and poor muscle control. Despite her mobility issues, Marah loves to play indoors and outdoors. She loves the playground, the swings and the slides. She enjoys playing with Peppa Pig, leafing through books, and completing puzzles. Sapna, Marah, and Akaash live in a 1-bedroom apartment, in the city of Toronto. They live walking distance from a children's playground, an elementary school, a middle school, a TTC bus stop, and an outdoor mall. Akaash has a full-time job as an information technology consultant. Sapna is a housewife.

Construction of Parenthood

The following section explores Sapna's evolving understanding of parenting. The section begins with Sapna's initial reactions to Marah's diagnosis, and the impact his diagnosis had on their family. Subsequently, I explore how Sapna and Akaash continue to support Marah's physical, social, emotional, and intellectual development.

Understanding the Diagnosis. Sapna was married for a very short time before she became pregnant. She was especially careful during her pregnancy, and took good care of her health, maintaining a balanced diet and a regular exercise schedule. Within a few

months of Marah's delivery, Sapna noticed that Marah had difficulty feeding and reaching. Her initial reaction was: "What am I doing wrong?" After consulting their pediatrician, and completing selected evaluations, Sapna and Akaash were told that Marah has hypertonia; a disease that causes tightness or stiffness of the muscle caused by damaged to the central nervous system. Upon hearing this diagnosis, Sapna and Akaash immediately looked into securing physiotherapy sessions for Marah, so as to help her relax and exercise her muscles.

At nine months, Marah was diagnosed with Global Developmental Delay (GDD). This was very hard for Sapna. It was as if her daughter's diagnoses were accumulating. From what she could recall, she remembered feeling sad and hopeless: "I was so sad. It was sad for both of us, you know? You won't survive in India. I mean special people [people with exceptionalities] get made fun of." Sapna was particularly worried about Marah's future: "My daughter won't be able to live alone. People will be mean." Amongst the Indian population, the spectrum of intellectual and physical disability is met with an equally broad spectrum of recognition, acceptance, and rejection. Initially, Sapna and her husband tried to secure the necessary medical provisions to support their daughter's growth and development. With a diagnosis such as GDD, there was much unclarity as to what would be the best way forward for Marah. As parents, they often encountered conflicting medical advice, where some neurologists would suggest brain surgery to remove the cyst, whereas others would warn against the dangers of surgery, particularly at a such a young age. It was with a heavy heart that Sapna and Akaash made the decision to leave India, to leave their families, friends, and their jobs behind, for the betterment of their child's health.

With a firm resolve, Sapna and Akaash moved to Canada when Marah was three years old. They settled in the Toronto area, and Akaash found a job nearby. Upon their

arrival in Toronto, they had to start from scratch. They connected with a pediatrician, who recommended they go to Holland Bloorview Kids Rehabilitation Hospital for assistance. After a short waiting period, Marah was seen by the specialists at the centre. Marah was assessed and diagnosed with Autism. Sapna shared the following reflections, with respect to the initial experiences with Canadian doctors and healthcare professionals: “Again, we were sad. But we knew that is why we are here. We were sad yes, but at least there is a name: Autism. We can learn about it.” With a growing list of diseases, the parents were working concertedly to build a support team for their daughter.

Role of the Parent. Prior to the pandemic, Akaash would go to work every day. Now he goes into the office every other day. Akaash is the breadwinner. Sapna is responsible for all domestic affairs, including but not limited to: purchasing groceries, cooking, cleaning, laundry, dishes, paying the bills, and taking care of Marah. When asked about her responsibilities towards her child, Sapna was clear on her role and responsibilities as a mother: “I’m 34 years old, and I’m a mom to a special needs child. I’ve travelled from India to Canada for my daughter better future.”

As she reflected more deeply on her responsibilities, Sapna shared: “I am a special needs mom ... I have to do everything for Marah.” With respect to daily living activities, Sapna bathes Marah, brushes her teeth, and dresses her. Marah does not have the strength nor the understanding on how to complete these activities, independently. Marah has difficulty eating. Sapna shared that each task, becomes greater than what typically may be expected. To help illustrate her point, she shared the following example: “My daughter cannot eat by herself. So, I follow her (around the house) and she takes bites.” Marah has poor muscle control in her mouth, so she is constantly drooling. Sapna shared that be it

breakfast, lunch or dinner, she is always following her child around the house: “It’s okay. I wipe. As long as she is eating something, I am happy.” With respect to mobility, Marah has difficulty walking and running. She has bruises, from head to toe, because she keeps falling. As Sapna explained: “I’m doing the exercises the physiotherapist taught us back home. I open the door and let her run (in the hallway of the apartment). I go outside every day, even winter. You can’t miss a day...it’s bad for her muscles. They get weak.”

As she reflected on her short term and long-term goals for Marah, Sapna shared the following: “My aim right now in life is to get my daughter to become independent. I wouldn't say absolutely normal but to make her closer, bring her as close as possible.” To this end Sapna tries her best to ensure Marah is getting the right nutrition, the right exercise, and as much sleep as possible: “It’s hard. She does not like to sleep.” Her eating habits are selective, and exercise is always a challenge. She said: “It’s ok. I go with her outside, or I play, just to get her to smile. One goal is just to make her happy and keep her smiling.”

Sapna shared that while she is new here, she is slowly trying to find the right professionals to support Marah’s growth and development: “I keep looking for opportunities and activities which help her.” It was through the rehabilitation centre that Sapna was able to secure a social worker. Through her personal support network, she secured a private behaviour therapist. Sapna is currently searching for a speech language pathologist.

As new immigrants, Sapna and Akaash wanted to make it on their own, without financial support from their family or the Canadian government. However, the costs of Mahrah’s therapies were adding up quickly. Sapna spends what little time she has

researching government funding opportunities and is currently applying for province wide funding to help support Marah's therapies.

Experiences with Special Education Processes

The following section describes Sapna's experiences as she was introduced to Ontario's special education processes and personnel.

The Dream. Sapna was unaware that Marah would qualify for special education. Sapna was under the impression that all children learn together, and additional supports are provided where needed. Within weeks of their arrival to Toronto, Sapna and Akaash went to the elementary school located steps from their apartment building, to see how they could arrange Marah's enrollment. They set up a meeting with the principal. Reflecting on that initial encounter, Sapna detailed the following: "First we approach normal kindergarten principal and she straight away refused to take my daughter in the school. And then she made us meet with other social worker, which then instigated the meeting."

Attempts to enroll Marah in school were happening around the same time that Marah was being assessed at the rehabilitation centre. During one of their appointments, the doctor provided his expert opinion. Sapna shared what the doctor had relayed: "We went to a psychologist and he said, 'it's all because she is a special child, she will need special attention, especially in school.'" Once Sapna and Akaash received their social worker from the rehabilitation centre, they connected her to the school social worker.

The social worker came to Sapna's house and explained how special education works in Ontario. Sapna recalls the meeting clearly:

Social workers came to our house and they also had meeting with us and they assured us that she will get proper attention. They said that in the normal

kindergarten class there is one teacher to 20 kids and here it will be one teacher, two staff to less kids. Safety will be important concern in Canada, in the schools. In TDSB there will be at least three staff which will be with these five to eight kids, so safety is their prime concern outdoors and indoors.

While nothing specific was promised to Sapna and Akaash, Sapna was under the impression that Marah would be in a special education kindergarten class, where she would get much more attention. A meeting would be scheduled to discuss the details at a later date.

Accessibility to Special Education Assessments and Provisions. When asked about her introduction to the public special education processes, initial evaluations, and placements, Sapna and Akaash were hugely disappointed. When sharing their reflections on their first meeting, Sapna remembered not knowing what to expect. Sapna was unaware of the purpose of the meeting, who would attend, and what was to be discussed: effectively the entire process was a mystery. Her first observation was the sheer volume of staff that were present: “There was like four to eight members, plus our social worker. We met them for the first time ... no more like eight to ten people. I don't remember their names.” Sapna was present for the first few minutes, and then left with Marah.

Akaash shared what happened next: “They introduced themselves and they spoke. And they kept speaking. So much information was coming and coming.” Neither of them could confirm the duration of the meeting, if an agenda was shared, or what, if anything, was being documented. Sapna added “Akaash told him that these are our concerns.” Akaash doesn't remember having a real discussion with the professionals. And so, he explained: “They didn't discuss anything with us. They already had it in their mind.”

Ultimately, Akaash left the meeting knowing that their daughter would be going to school: “they provided us with the diagnostic junior kindergarten program.”

Sapna and Akaash shared that they were not sure what to expect, but that they trusted their social worker to have their best interest in mind. Marah started junior kindergarten at the Yellow School. Shortly thereafter, Sapna received, what she refers to as the IEP plan. When asked about the IEP, Sapna shrugged her shoulders: “It was easy to understand and I filled it myself. I mean they asked me to give some points and then I think they might have made a sheet and they gave it to me.” Today, Marah is in senior kindergarten, at the same school.

Meetings with Educators and Other Professionals. Given that Sapna and Akaash only had one meeting, Sapna choose to share her experiences meeting with the special education teacher, the principal, and the educational assistants, both formally and informally.

Sapna opened with the following reflection: “Every day I am scared to send my daughter to school because I don’t know what is happening with her.” Sapna then elaborated: “I was nervous in the beginning. I would go watch my daughter for five to ten minutes at recess. I would see that my daughter is getting beaten up, and I’m not being told about it.” Livid, Sapna came home and shared the incident with Akaash. She went the very next day and spoke to the teacher. Sapna shared: “And then I was assured by the teacher that everything will be taken care of and that she is controlling everything. But it was the exact opposite.” Sapna shared that her daughter would come home with bruises and scratches. Very little was being written in the daily diary. It was always general, and always vague.

If it wasn't during recess, it was in the class itself. Sapna shared that "there were kids who are literally hitting her, and I was coming to know from other parents who were there sometimes." Akaash added a separate but similar incident to help illustrate the point. "Other parents would tell us that your daughter was thrown on the floor, and she was being kicked on her face, and her stomach by another wild child." Akaash, visibly angry, scowling, went on to say:

I'm not going to portray the other child as a villain. It's just that he has got different needs. You need to protect my daughter from that guy. If he has a fit, it does not mean that my daughter should be his designated piñata. You are supposed to keep her safe.

Frustrated, Sapna reflected on her options. Connecting with the EA and the teacher did not seem to resolve the problem. She eventually escalated the matter to the principal:

By going again and again to the principal nothing was happening. I asked for an IEP meeting again and again, and nothing was happening. I'm still waiting for that meeting to happen yet and this happened last to last December.

When asked about her experiences this year, Sapna was equally perplexed. Given the circumstances surrounding the pandemic, there are less children in the classroom. As such, Marah is with 4 other children only. It was mere luck that the more aggressive children are no longer in her class. Sapna felt that the new teacher, although trained in special education, does not seem to understand Marah's needs.

This year, Marah has a new teacher. When reflecting on her more recent experiences, Sapna shared the following:

There is a new teacher who said she's experienced and I believed her. She is very strict and she follows routine...with special need kids she should be a little bit lenient, that is my opinion. But still, I try to educate the teacher but she did not seem to listen. I told her don't make my daughter wear a mask she cannot wear masks because she is drooling.”

Sapna shared that when Marah would come home, she would open the school bag, and her masks would be soaked in her saliva. This means that Marah sat in her spit all day, whereas at home or during the pre-covid era in school, she would normally wear and change her bib regularly. Sapna continued:

And because I said no she stopped using the mask, and then she started using the mask she has in the school so that I don't come to know. I literally have to fight for her and I'm not getting the outcome.

Equally distraught, Akaash wondered aloud, how normal thinking adults, could display such inhumane behaviour. He went on to share:

I hate that they take advantage. I will never forgive them for that, because she can't come back and complain. It's very cruel. To tell you the truth, it's like every time I would go to work, it's like having a monkey on your head. You're just waiting for the office to get over so you can go and get your daughter at 3:30 and bring her home.

Sapna worries that the teacher's disposition, which she sees as being rigid, is creating a disabling environment for Marah. Sapna shared an example related to Marah's lunch:

They don't give her enough time to finish her food. She takes a lot of time to finish her food because she has low muscle tone in her mouth. I told her teacher. If she (Marah) has to finish food by 10:15 it won't be 10:16. She (the teacher) is not flexible.

Akaash also felt that the teacher's lack of flexibility was disabling for his daughter's progress. He added:

See I know what my daughters' needs are and you are running a school. You are running a school so you run things in a certain way yeah. And that's fine. But every time there is a child that has different needs, you have to adjust. As long as child is not in harm's way. I'm not okay that you're giving her 15 minutes to eat snack. I guess I'll feed her earlier in the morning and I'll feed her more in the evening.

Sapna and Akaash shared that for each incident, they tried talking to the teacher, and when that didn't work, they tried talking to the principal. With little response, they tried to escalate it further. Akaash added:

Look, see in this situation, we went up to, I don't know the higher than a principal...the superintendent. And we went to that level also just for this and it didn't work out. Nothing happened and nobody helped us.

When reflecting on her interactions with the educational assistants, teachers, and principals at the Yellow School, Sapna shared: "See my job is to educate about my daughter's safety, about my daughters' likes, her comfort, what she wants that she cannot tell them." Despite her efforts, Sapna feels strongly that the school professionals do not care to hear from her. According to Sapna, the educators have a predetermined attitude, that parents should adopt:

Whatever they say we should agree with them, without putting our thoughts into it. We should praise them for however they are handling our kids, and we should just be sweet and calm and not counter argue with them. We should just agree with everything. And whatever happens, don't escalate the matter, whatever the dangerous situation, is don't escalate the matter. And if you dare to do that, they are not going to talk to you. They are going to ignore you. They will behave badly with you. They are going to avoid you. These all things happen.

Akaash, having sometimes connected with the teachers with his wife, and sometimes alone, shared the following reflection with respect to his experience with the educators:

Teachers need training. It's very annoying for me because they keep coming to me as a parent and telling me that she touched her face again today. Are you crazy? I know this. Why are you coming to tell me over and over again? Then what's the point of you? Aren't you supposed to be helping?

As a parent, Akaash feels that he has a sound understanding of his daughter, her abilities, and her potential. He also feels that he has realistic expectations of the teachers and of the system. He shared the following:

She's not going to sit down and learn ABCD and all of that. She is coming to learn how to be calm, to be socially acceptable. You need to ensure as a teacher that she has environment where she is nurtured to the best of her abilities, and not become a complaint box for the parents: 'she did this and she did this'. I can't do anything about it. She is under your custody for six to eight hours.

When reflecting on his role as a parent advocate for Marah, Akaash shared that at this point, it's just survival:

In a nutshell, you see my wife, she is still outspoken, and she will go and fight. But she is a mother, she has all the right. But I don't try anymore because somebody has to be hot, and somebody has to be cold. Otherwise, I would not be able to get any information that we are supposed to.

Summary

Sapna and Akaash are newly arrived immigrants to Canada. While Akaash goes to work, Sapna oversees domestic responsibilities and caring for their only child, Marah. Sapna, while not too familiar with the Ontario special education system, is learning how to navigate the various processes. While she has access to a support worker, Sapna has learnt about school routines and procedures from her informal and formal conversations with teachers, educational assistants, and fellow parents. Where necessary, both Akaash and Sapna have escalated their concerns to higher authorities but have failed to achieve their desired outcomes. They remain undeterred to help support their child in her educational journey, and are using the Covid-19 pandemic, and the unusual circumstances that come along with it, to learn about Ontario's special education system, government funding, and community services that may be helpful for their daughter.

Chapter Summary

As stipulated in educational legislation, parents are considered to be key participants in their child's educational journey (OME, 2005). Healthy partnerships between parents and educational professionals can help promote, create and/ or sustain a meaningful educational experience for both the child and their respective family

(O'Donnell & Kirkner, 2014; Reynolds et al., 2015; Whitaker & Hoover-Dempsey, 2013). However, limited parental involvement and parent's negative experiences with the special education system, continues to be reported in educational literature, particularly amongst CLD parents and families (Burke, 2013; Prezant & Marshak, 2006; Ryndak et al., 2011; Stoner et al., 2005).

To better understand the CLD experience, this investigation explored the lived experiences of five South Asian families, as they navigated the complexities of the special education IEP processes. Based on the findings, parents shared their perceptions of engaging with both the administrative processes surrounding special education, along with their experiences engaging with educators and related professionals. The findings of this research will be discussed in the following chapter.

CHAPTER 5: DISCUSSION

Literature surrounding parental participation in special education processes often refers to parents as invaluable members of a team (Hill & Hill, 2012; O'Donnell & Kirkner, 2014; Whitaker & Hoover-Dempsey, 2013). Theoretically, parents are important partners in this relationship, as their knowledge about their child's needs, preferences, and developmental history is critical in supporting their child's educational journey (Fish, 2006; Spann et al., 2003). Practically, however, the realization of a collaborative relationship between parents and teachers continues to remain elusive, particularly for CLD families (Kummerer, 2012; O'Connor & Fernandez, 2006; Reid & Knight, 2006).

The primary aim of this qualitative study was to better understand how immigrant Indian and Pakistani parents of children diagnosed with ASD, understand, perceive and experience their role in special education processes, with a particular focus on the IEP meeting. To this end, this study used positioning theory (Harre & van Langenhove, 1999) informed by Hoover-Dempsey and Sandler's model of parental involvement, Foucault's theory of power, and Bourdieu's theory of capitals, as a way by which to explore the nuances that underpin the relationships between South Asian parents and special education professionals.

This chapter puts forward an analysis of the findings presented in chapter four. The first section of the analysis focuses on the position(s) parents assert for themselves during parent-teacher interactions. Drawing on parents' reflexive positioning repertoire, which is used to position oneself, I identify five self-positions Indian and Pakistani parents embrace and between which they oscillate as they engage with special education professionals. These positions include: the disenfranchised dependent, the trusting caregiver, the child

expert, the lonely advocate, and the hopeful partner. Building off the first section, the second section of the analysis reviews involvement practice through a Bourdieuvian lens. Bourdieu's concepts of field, habitus, and capital help develop a critical understanding of a parent's capacity to both become involved with special education processes and professionals, as defined by Hoover-Dempsey and Sandler (1995, 1997), and how, by extension, they perceive themselves positioned, within the parent-teacher relationship. In the third and final section of the analysis, parent experiences are analyzed using a Foucauldian lens. A closer look at the socially constructed notions of discourse, surveillance, as well as resistance and empowerment, helps create an understanding of how parents' perception of themselves influence the extent to which they are authentically able to engage in special educational processes or with special education professionals.

The Many Sides of Positioning

While the major part of this section will hone in on the conversational or discursive acts of 'positioning', it is important to note that positioning happens in an embodied way and /or through concrete materiality (Mathiesen, 2015). This means that every interaction includes an element of structure, materials, and interpersonal communication that simultaneously positions the parent and the teacher. Each position is afforded different allowances with regard to ways of being, responsibilities, or acts; thus, varying degrees of power are connected to each position (Mathiesen, 2015). The following section explores how positioning occurs through structure, the use of knowledge, and interpersonal communication.

Positioning Through Structure

The findings of this study suggest that there are several storylines where the teacher or the school personnel has the right and responsibility to lead interactions, whereas the parent has a smaller scope of participatory possibilities. Consequently, there is limited room for ‘speech’ if parents do not wish to act inappropriately or create conflict.

In formal meetings, for example, the teacher and the school personnel are positioned as an ‘expert’ in a variety of ways. The setup of the IEP meeting is itself a positioning of the teacher as an ‘expert.’ The conference is held in the institutional context of school, where the teacher welcomes the parent as they enter. The teacher thereby becomes the host and the parents the guests, thus making the teacher responsible for the proceedings. As shared by Sapna, their first formal experience was overwhelming: “There was like eight to ten people, I don’t remember their names, plus our social worker. But I came out with my daughter and he (Akaash) stayed.”

Teachers then introduce everyone present, often with the parents being last on the list of introductions, further reinforcing the teacher’s position as the chair of the conference and the designate responsible for the proceedings. Hence, the teacher has both the right and duty to speak, whereas it is inappropriate for parents to claim the right to speak until they are invited to do so.

Each IEP conference begins with an orientation about how the child is doing academically, socially, and physically. After this, the school personnel go into greater detail about the identified goals for the year; thus, the meeting takes on the set-up of the teacher informing the parents. The teacher and team have formally prepared for the meeting, with detailed documentation, such as assessments, graphs, and written resources. Through the use of material artifacts, they can assert their position as the experts, as they

predetermine both what information needs to be documented, and what needs to be shared with parents. Sometimes, an awareness of the teacher's familiarity with additional resources may be a comfort and reassurance for the parent, an indication that the teacher is indeed trained to support their child. This was the case for Shradha: "She [the teacher] walked in with a book called ... *More Than Words*. I saw her walk in with this book in her hand, with it all tagged, up which means she had read it. I was really impressed." Alternatively, the use of additional resources or documentation without a conversation relating to what has been written can sometimes be a deterrent, as was the case with Bedar. When referring to one of his earlier IEP meetings, Bedar shared the following perspective: "Her role [the teacher] was to present that information to us, and for us to agree on that."

Once the relevant information has been shared, the teacher invites the parents to contribute their thoughts to the conversation. In this way, the turn-taking thus becomes mechanical, leaving it up to the teacher to determine when it is the parents' turn to speak. As shared by Afreen, this was often the case for her, where she and the school personnel would alternate taking turns sharing information. She recalled: "They asked me that this is the goal, and this is the time, and he fulfilled his goal. We think he needs improvements in this part. What is your input?"

The structure of the conference, the location of the school setting, the preparation of the teacher and team, and the mechanical turn-taking, in and of itself positions the teacher as the "speaker" who has the knowledge that is worth conveying, and positions the parent as the receiving participant.

Informal structures, however, allow for parents to position themselves in a more active manner, whereby they are able to use *speech acts* to open up spaces for dialogue and

conversations. Conversations at the end of the day when parents are collecting their children, short phone calls, or emails do not follow the same structure as formal meetings. Parents, as participants in this study illustrated, often leverage these informal opportunities to inch closer to their desired outcomes. As shared by Sabrin, while the meetings were important, getting useful information on a daily basis was practically impossible. The journal that came home was rather vague. Sabrin explained:

I used to go once a week purposely, so I could talk to the teacher and the principal, because I wanted them to know that I am there for this boy and remember my face. I will come and talk to you. I will keep coming. I will send out an email twice a week, saying, "Hey I haven't heard from you, hope everything is fine." I shouldn't have to. So, I used to come pick him up early and sit with the teacher.

Thus, the structure of the IEP conferences overall, whether by design or happenstance, creates power dynamics that have the potential to limit parental agency.

Positioning Through the Use of Specialized Knowledge

Positioning always occurs as a relational process, where one party is positioned and re-positioned, based on the other party's position (Harré & Moghaddam, 2003). When teachers are positioned as the expert with the knowledge that is worth knowing, it produces a limited scope of participatory possibilities for the parent. One way by which teachers and school personnel actively position themselves as expert, as per the participants in this study, is by drawing on their educational qualifications, years of experience, and professional language. Professional language allows teachers to claim that the knowledge they hold is of more value than knowledge expressed by parents, and teachers see it as giving them the right to speak while devaluing parental knowledge.

On Marah's first day at her new school, her hair was pulled by another student in the playground. Sapna shared:

We were three people standing and we could not separate his hands from my daughter's hair. He was pulling it so strongly. I realized that there is one teacher for all of these kids. This teacher who did not have any special needs experience. It was also her first day in the school.

When Sapna addressed her concerns with the teacher immediately after the incident, the teacher reminded her that as a teacher, she is qualified to care for and teach such children. In this case, when the expert position is taken up by the teacher or school personnel, then the position of listener or receiver is simultaneously imposed upon the parent. This narrows the scope of possibilities for participation and sets limits with respect to what the parent can say or do when interacting with educators.

Another way in which teachers actively hold the position of expert is by claiming ownership over everyday knowledge (i.e., they know what happens in school). This is later documented in material artifacts, such as assessments, graphs, data collection sheets, etc. and later used to inform the IEP. It follows again that what is observed and captured by the teacher is a more accurate and trustworthy description of reality in comparison to what might be observed and shared by a parent. The cultural and social capital parents bring to the table may be dismissed as biased, subjective, or inaccurate. We see this through Sabrin's example, when she requests an emergency meeting after the teacher reports a behavioural incident. She shared:

Teacher came in with her books and said, he (Ahyar) can't do this or can't do this. And then all what she was saying was that he can't do this. I had to show what he

can do. I was told teacher has 25 years' experience of teaching, and she has a child with special needs. And I said it doesn't matter. She doesn't know how to deal with autistic kids. Her 25 years of experience will go in garbage if you don't know how to deal with these kids. It's very hard for me to say cruel words to the teacher, but it was like that.

Based on the findings of this study, parents perceive school personnel's academic and specialized educational knowledge to be more objective and empirically sound than their own, thereby creating a power differential that has the potential to limit parental agency.

Positioning Through Interpersonal Communication

In Davies and Harre's positioning theory (1990), the scholars distinguish between *reflexive* and *interactive* positioning. The former delves into the intentional, self-defining aspects of speech acts, whereas the latter zeroes in on the importance of audience interaction in any positioning attempt. I focus exclusively on *reflexive* positioning since my data addresses parents' accounts of the positions they adopted whilst conversing with school personnel.

I identify a meta-positioning skill that I termed the *parent positioner*, which involves meta-reflection on the different positions outlined below, and on the shifts between them (see Table 2 for an overview). This skill involves (a) increased awareness of different positions available to the parent, and (b) the ability to engage in certain speech acts that enable repositioning. This skill enables parents to purposefully reflect on and oscillate between relevant positions that can promote the desired outcome from their perspective, and manage any conflicts that might arise as a result.

Table 2*Parent Positions*

Position	Articulated As	Approach to parent-teacher relationship	Examples of Storylines	Rights and Duties	Speech Acts
Disenfranchised Dependant	Someone who feels powerless in their knowledge of existing services or provisions, or the process by which to acquire the above, that will support their child, and relies almost entirely on the expert opinion of professionals to assist in making decisions for their child.	Parent-teacher relationship is based on complete trust, where the parent believes that the educator is the expert and will provide the necessary guidance to support their child's development.	Informal Settings: chats during child pick up/drop off, telephone chats or correspondence via email. Formal Setting: IEP meeting.	Right: listen to the information presented. Responsibility: to comply with the suggestions provided by the professionals.	Listening to the observations and recommendations provided by school personnel. Agree with recommendations provided by school personnel.
Trusting Caregiver	Someone who cares unconditionally for their child, and has a rudimentary understanding of special education processes. Relies on the professional to share information and provide guidance, so that the parent can evaluate their options, and make informed decisions.	Parent-teacher relationship is based on respect, where the parent believes that the educator is in a position to assist their child and provide counsel and guidance where necessary guidance to support their child's development.	Informal Settings: chats during child pick up/drop off, telephone chats or correspondence via email. Formal Setting: IEP meeting.	Right: listen to the information presented. Responsibility: to evaluate and select from the suggestions provided by the professionals.	Listening to the observations and recommendations provided by school personnel. Agree to the suggestions that appear most reasonable to the parent.
Child Expert	Someone who is confident in their knowledge about their child's abilities, and has a working understanding of special education processes. The parent believes themselves to be an expert, but is repositioned as a non-expert by the professional. In this case, the professional believes that a parent's understanding of their child may be compromised by their biological relationship to the child.	Parent-teacher relationship is tenuous, as both parties believe and behave as though they are the child expert. Parents feel that their input is not valued, as the educator operates with the understanding that they alone are the expert.	Informal Settings: chats during child pick up/drop off, telephone chats or correspondence via email. Formal Setting: IEP meeting.	Rights: listen to the information presented; provide information about their child strengths and needs to the professional. Responsibility: to evaluate the suggestions provided by the professionals.	Listen to what is shared about the child, including observations and recommendations. Provide insights about the child, including strengths and areas in need of development.
Lonely Advocate	Someone who understands their child's abilities and has a sound understanding of special education processes. The professional is positioned as an expert and the parent is positioned as an advocate, researcher	Parent-teacher relationship is strained, in that the professionals lack the adequate knowledge and appropriate training, to best help support the needs of the child. Parent is consistently negotiating and	Informal Settings: chats during child pick up/drop off, telephone chats or correspondence via email.	Rights: listen to the information presented; provide information about their child strengths and needs to the professional; question the decisions, programs, services being suggested	Listen to what is shared about the child, including observations and recommendations. Reflect, evaluate, and question recommendations that are misaligned with the child's

	and negotiator. The parents' aim is to broaden the professional's understanding of the child and their needs, but may be perceived as 'challenging' or 'difficult' individual, and be repositioned as a non-expert by the professional.	advocating, with the aim to provide the child with the services and provisions they are entitled to.	Formal Setting: IEP meeting.	by the professional. Responsibility: to evaluate and determine whether the suggestions provided by the professionals meet the needs of the child.	developmental trajectory. Provide insights about the child, including strengths and areas in need of development. Provide insights about alternative programs and provisions that should be made available to the child, and that is in line with the child's developmental trajectory.
Hopeful Partner	Someone who understands their child's needs, but may or may not have a sound understanding of special education processes. Nevertheless, they feel that the professionals are equally invested in aiding and supporting their child's physical, emotional and cognitive development. Both the parent and the professional are positioned as equal and legitimate contributors to the relationship.	Parent-teacher relationship is equal, in that the trust, respect, communication and decision-making powers are equally distributed between both parties.	Informal Settings: chats during child pick up/drop off, telephone chats or correspondence via email. Formal Setting: IEP meeting.	Rights: listen to the information presented; provide information about their child strengths and needs to the professional. Responsibility: to collaborate with the professional, to create a thoughtful plan of action for the child.	Listen to what is shared about the child, including observations and recommendations. Share observations about the child, including strengths and areas in need of development. Collaboratively determine an educational plan that meets the needs of the child.
Parent Positioner	Awareness of different available positions and ability to engage certain speech acts that enable re-positioning.	Parent- teacher relationship is based on the understanding of the special education system policies, and the rights and duties of both the school personnel and the parent. Parents can oscillate between relevant positions and select the one(s) that likely yield the desired outcome.	All of the above.	Allocating time to various positionings, deciding when to switch positioning.	Changing pace and tone of voice.

Based on the findings of this study, I was able to identify five dominant positions that parents can oscillate between, each comprised of their own respective speech acts,

rights and duties, and a storyline. They include disenfranchised dependent, trusting caregiver, child expert, lonely advocate, and hopeful partner. In line with positioning theory (Harre, 2012), these positions are not mutually exclusive, but can change quickly, and sometimes overlap. The patterns described by these five positions exist within educational literature that explores the positioning of parents in parent-teacher or parent-school personnel relationships (Kummerer et al., 2007; Reid & Knight, 2006). The five positions are presented below, followed by the meta-positioning skill.

Disenfranchised Dependant

The disenfranchised dependant was articulated as the default position by all participating parents, and as the baseline for identifying other positions. A parent feeling powerless due to their non-existent or limited knowledge of existing policies, services or provisions, or the processes by which to acquire the latter, is the most commonly reported parent position in educational literature (Trainor et al., 2016; Wolfe & Duran, 2013). As noted by Altschul (2011), Jung (2011), and Sohn and Wang (2006), some CLD parents may be entirely unfamiliar with the schooling systems in their host countries and may come to rely entirely on school personnel for the dissemination of appropriate and relevant information. As echoed by both Sapna and Afreen, the processes surrounding general schooling in a new country can easily become overwhelming for parents. As Afreen shared: “You know, this is my first child, and I never had a clue about schooling.”

Special education processes require parents to have specialized knowledge around specific provincial and board regulations, funding, programs, and services. This dynamic adds another layer of complexity for parents to navigate.

For Sapna, identifying the right school and the right program became a challenge. For Shradha, when reflecting on her introduction to special education processes and personnel, she mentioned that: “As parents, we didn’t know much.” It was understood by the parents that school personnel, by virtue of being in that position, with their qualifications and experience, should be considered and treated as the expert. This notion of explicit trust and reliance on educators is reflected in educational research, where parents may rely entirely on educators as experts and policy/regulation interpreters. They accept the educational decisions for their child coming from the school as being decisions that are grounded in what is best for the child (Jung, 2011; Lo, 2008; Wolfe & Duran, 2013).

Parents in this study trusted that school personnel would share the appropriate information on provisions, services, or programs, based on the needs of the child. Echoing the sentiments of the other participants, Sabrin shared that she relied entirely on the experts: “We only know our child; we don’t know anything else.” Furthermore, at some point over the past few years, participants in this study noted that they have relied entirely on the expert opinion of the professional for advice and counsel to assist in making the appropriate decisions for their child. Examples of *storylines* that support the disenfranchised parent position include formal and informal meetings leading up to, during or following IEP meetings, where school personnel are consistently providing their expert interpretation of the situation, followed by their professional opinions on possible next steps.

With respect to their *rights and duties*, participants who were positioned as disenfranchised parents were expected to listen to school personnel and agree with and abide by their professional opinions without necessarily relaying their own thoughts or concerns. When reflecting on the IEP meetings, participants genuinely felt that the

personnel had the knowledge and the responsibility to share what was in the best interest of their child. The experiences shared by the participants in this study corroborates what has been documented in educational literature (Trainor, 2010; Wolfe & Duran, 2013). For CLD parents who were unaware of the educational processes, school expectations, their rights or the rights of their child, they were likely to defer to school personnel as the experts (Brandon et al., 2010; Lo, 2012; Rossetti et al., 2016). When reflecting on a formal meeting with a teacher, Bedar shared that the teacher: “Was presenting the right information to us.” Ultimately, for him, it was simple: “My job was to listen and sign. We read through it and signed off on it.”

Because participants described the position of disenfranchised dependent as the default position they assumed at some point in their interactions, the *speech acts* of any meeting setting with school personnel, reinforced the disenfranchised dependent position. Examples include listening to all options school personnel present, nodding along in agreement, trusting their recommendations, and complying with their suggestions. In this study, parents noted that school personnel believed themselves to be the experts and did not feel the need to consult with the parent. As noted by Akaash: “They introduced themselves and they spoke. And they kept speaking. So much information was coming and coming. Then, they provided us with the diagnostic programme.” There was no room for a conversation, for clarification, or for debate.

The disenfranchised dependent position is also reinforced when parents attempt to read and understand assessments and reports. Literature suggests that special education documentation is laden with educational jargon, making their readability level inaccessible to many parents (Mandic et al., 2012). As shared by Sabrin “I still don’t understand TDSB’s

language to be honest with you. It's not clear." The language used throughout the documentation is not discernable, and forces English speaking parents to rely heavily on the opinions and suggestions of the personnel to inform their decisions.

Trusting Caregiver

The trusting caregiver position emerges from the disenfranchised dependent position. Unlike the default disenfranchised dependent position, trusting caregivers have minimal knowledge and experience with special education policies, procedures, and provisions. As mentioned in the literature, parents with limited knowledge of the educational system, and those who belong to cultures that believe they cannot challenge school authority, will place a considerable amount of trust in school personnel to help make informed decisions (Hammond et al., 2008; Tamzarian et al., 2012).

As parents, the trusting caregivers consider themselves to be objective stakeholders who have a reasonably sound understanding of their children's capacities and potential for growth. By extension, parents believe that they have a balanced vision of where their children could be in the future, and the basic daily living skills their children should develop in order to lead a happy and fulfilling life; however, they continue to rely on the professional for school personnel expert opinions. For Sabrin, this meant finding programs and school personnel that can help her son Ahyan develop daily living skills such as toilet training, eating independently, and communicating. Sabrin shared: "This private school catered for what we were looking for, except the speech path. They tried different things (for speech). They tried PECS (picture exchange communication system) and Proloquo2Go. Ahyan would do it at school."

As trusting caregivers, parents espouse the belief that while school personnel are the authority in their field, they should provide parents with their professional assessments and suggestions. For trusting caregivers, there is a high level of confidence and conviction that the information shared with them is accurate, transparent, and in the best interest of their child (Jung, 2011; Lai & Ishiyama, 2004; Lo, 2008). It is up to the trusting caregiver to carefully evaluate all the information that has been shared, and thoughtfully select next steps, from the suggestions provided. While trusting caregivers may not necessarily agree with all the suggestions, they are willing to trust the experts and the process. As reflected in Bedar's sentiments, parents may agree to a particular service, even though they are not in actual agreement: "I think we were comfortable with the contents, with the discussion. However, we didn't necessarily agree with what they had to offer to support our child." Trusting processes or suggestions that one does not agree with may be more common among families from Eastern cultures, where education is highly valued and teachers are highly respected, for these parents often assume that educators' decisions are made to optimize student outcomes (Jung, 2011; Lo, 2008; Sohn & Wang, 2006; Wolfe & Duran, 2013).

Storylines that support the trusting caregiver position include formal and informal meetings leading up to, during, or following IEP meetings where school personnel are engaged in a dialogue. In terms of *rights and duties*, the trusting caregiver has the right to hear, evaluate, and select from the information provided by school personnel. Here, the professional can provide their expert opinion and parents are encouraged to reflect on the options provided. By evaluating the presented information, parents can select what they feel will best meet the needs of their child. For Shradha, the teachers presented goals that

would help her son Shafiq develop. They also highlighted areas where accommodations would be provided for additional support. Shradha shared: “I felt that we were good for Shafiq because they presented enough challenges, but also recognize where he needed accommodations. And the right accommodations are built into the system.”

Speech acts that signal a parent’s position as a trusting caregiver take the form of an empathetic listener, who makes explicit that their child’s best interest remain at the centre of all decisions. Participants expressed that they felt they had choice in the decision-making process. As shared in the following statement, Afreen’s reflections shows how school personnel offered a variety of additional supports for her son Alim: “They gave me a program, POP (parents outreach program). I got somebody from the agency. She showed me all these tricks (to help Alim) and I loved it.”

Echoing the literature, findings from this study suggest that the trusting caregiver struggles to navigate special education documentation (Mandic et al., 2012; Lo, 2012). For some parents, the purpose of the documentation was unclear. When asked about documentation, Sapna shared: “I only got an IPRC. And then an IEP plan. It was easy to understand, and I filled it (out) myself.” This suggests that while Sapna completed some written formalities, she is unclear what documentation she completed, the purpose of that documentation, and how the documentation is to be used.

For other parents in this study, the documentation represented a safeguard that was intended to secure supports for their child. At the IEP transition meeting, Sabrin was informed in writing that Ahyan will be placed in a special class with specially trained teachers, and that the school will provide all necessary supports. Sabrin said: “But it doesn’t work that way. There is a huge wait list at school as well. They tell us they will do an

assessment. They tell us ‘Oh no, you have to wait.’” For Sabrin, knowing which resources were available for Ahyan was unclear, as was the process by which to acquire these resources. But Sabrin and her husband trusted the principal and the teacher, and so they waited. Similarly, Bedar shared the following reflection on the services promised to him in writing, for his son: “The thing is, there were things like consultancy from the school board on speech and occupational therapy; however, that’s a vague term. And we didn’t really question them at that time.” The terminology used was broad and could easily be misinterpreted. As highlighted in the literature, parents trust that what has been documented and promised to the child will be delivered (Brandt, 2011; Bryant, 2014; Fish, 2008).

Child Expert

The third position emerging from my data, the child expert, focuses on parents who are confident in their knowledge about their child’s abilities and can identify areas of growth and development that will benefit their child. They also have a working understanding of special education processes, services, and provisions. Unlike the trusting caregiver, the child expert shares a tenuous relationship with school personnel. Both the parent and school personnel believe and behave as though they are the child expert; however, parents in this position, do not feel valued in the relationship. As highlighted in the literature, many CLD parents described school professionals’ attitude and perspectives towards them as distant, patronizing, or indifferent (Esquivel et al., 2008; Fish, 2006; Lai & Ishiyama, 2004; Reiman et al., 2010). By extension, when parents attempted to share their experiences and insights during formal meetings, parents felt that school personnel

became increasingly insensitive and impatient with them (Lai & Ishiyama, 2004; Lo, 2008; Ryndak et al., 2011; Sheehey, 2006).

The findings of the current study align with what has been documented in literature (Esquivel et al., 2008). Parents who see themselves as the child expert often find themselves in opposition to school personnel who are viewed as not necessarily having identified the appropriate goals for their child. School personnel will support their decision to pursue an alternative path based on data and educational jargon that parents do not understand or agree with.

A *storyline* that supports the child expert position includes meetings where processes are completed as a formality. Bedar illustrates this tension by describing one of his earlier experiences in an IEP meeting. After having shared his son's needs, previous schooling experience, and examples of potential supports that would prove helpful for Anwaar, he noted: "They put down some basic things to control his behaviour and some learning stuff. However, there was really nothing significant that changed him or made life easier. It was actually, practically, it was a hard year for us."

Another example may be when the parent, as a child expert, is implicitly or explicitly reminded that they are just the parent and that their input should remain minimal or shared only when requested. This phenomenon is echoed in Shradha's sentiments. After listening to school personnel during a formal IEP meeting, Shradha shared her input about Shafiq. She shared where she believed Shafiq was in his learning journey, where he could be in his developmental journey, what supports he would need to get there, and, finally, how the IEP goal may be modified in order to reflect this change. As far as Shradha recalled, not one of her suggestions were reflected in the IEP. She said: "The goals were

predetermined. I didn't feel that my input was included in there. In fact, I don't think I even signed the last one (IEP)."

Shradha was confident in her understanding of her son's abilities and felt that the teachers should not have been so quick to dismiss her observations, saying: "I know he can develop and he has been developing. I know what he is capable off. I don't think I was being unreasonable." The phenomenon of teachers dismissing the notion that parents can be experts is supported by existing literature (Esquivel et al., 2008; Fish, 2006; Ryndak et al., 2011). CLD parents are regularly positioned as 'non-experts' by educators and made to feel as though their insights are considered less reliable or inaccurate because it is not generated in the same way as that of the school professionals (Hess et al., 2006; Knopf & Swick, 2007; Tobin et al., 2012).

As a child expert, parents have the *rights and duties* to explicitly voice their knowledge about their child, their aspirations, and their concerns regarding the developmental plan and identified goals for the year. They have the responsibility to evaluate the suggestions provided by the professionals and select the options most suitable for the child's developmental trajectory.

Speech acts include listening to all options school personnel present, evaluating the options presented, and sharing information related to the child or potential programs/services that have been overlooked. When reflecting on one instance in a private setting, Shradha shared that while she relayed information that she felt was pertinent for the meeting, school personnel appeared to be indifferent. She said: "I got the distinct impression that I was asking too much of them. I got the impression they thought my expectations of him were too high."

Consistent with the literature, findings from this research suggest that while some child experts were able to have their voices heard during informal and formal meetings, their input was not reflected in any formal documentation (Hess et al., 2006; Tobin et al., 2012; Wolfe & Duran, 2013). Like other participants in this study, Shradha felt that select IEP goals reflected in the document were already mastered by the child. For Shradha, the goals were not necessarily designed to help develop the child's capacities. She said: "I don't think educators, to a certain extent, see the full potential of the child and are willing to invest the time and resource to help them get there." For her, the IEP documentation continued to reflect the recommendations of the teacher experts, irrespective of parental input.

Lonely Advocate

The fourth position is the lonely advocate and emerges from the child expert position. It focuses on parents who are confident in their knowledge of their child's abilities, and are able to identify areas of growth and development that will benefit their child. The lonely advocate also has a sound understanding of special education processes, services, and provisions, as well their parental rights. Unlike the child experts, the lonely advocates have a strained relationship with school personnel. Through personal research and external consultation, these parents have acquired the knowledge and the appropriate training to advocate for their child. They are aware of private and public therapies, services, and funding options that may be of use for their child.

In this case, the parent finds themselves negotiating and advocating for their child with the aim of securing the services and provisions their child is rightfully entitled to. Literature suggests that professionals are often frustrated with the lonely advocate because

they are typically the type of parent who asks too many questions, provides alternatives, or disagrees with professional assessments (Bezdek et al., 2010; Turnbull et al., 2010). While the parent may continue to position themselves as the advocate, they are often repositioned as parents who are “difficult” or “challenging” by professionals, and their feedback is disregarded (Jung, 2011; Lai & Ishiyama, 2004; Olivos et al., 2010; Turnbull et al., 2010). Parents in this study felt and believed that numerous teachers and administrators held a deficit view of CLD families, especially when they were chastised for requesting what is rightfully theirs, and this paralleled what has been reported in previous literature (e.g., Brandon et al., 2010; Lo, 2008; Mueller et al., 2008; Trainor, 2010; Turnbull et al., 2010).

For Shradha, the battle is ongoing. She shared: “Every time we actually had a meeting to discuss the IEP, I felt like we would take two steps forward and one step back, because it almost seemed like he was being downgraded for one reason or another.” Shafiq is able to complete complex math equations using numerals at a level appropriate for his grade; however, he is unable to do so when given word problems. For Shradha, working on word problems or reading comprehension is not important. Her son is able to complete numerical math problems and, as such, she would like to develop that competency instead. The debate around changing the IEP goal for math has been unending for the past three and a half years. She described the constant back and forth as: “Very frustrating, because we see our kids as having futures and being able to be employed and being independent.”

Examples of *storylines* that create or confirm the lonely advocate position are similar to that of the child expert position. These include meetings where procedures are completed as a formality. Parents in this study felt that meetings were a mere formality echoing the literature. More specifically, there was insufficient time to discuss or complete

the meetings and there was a lack of support from school personnel to discuss alternative goals than the ones already stated (Altschul, 2011; Cho & Gannotti, 2005; Prezant & Marshak, 2006; Trainor et al., 2016).

Similar to the child expert position, examples of lonely advocate *storylines* also include formal or informal settings, where parents are reminded that they are just the parent, and that their input should remain minimal or shared only when requested. In such circumstances, lonely advocates often challenge the established authority of school personnel, and openly reflect on the expertise and experiences of the experts in question. As Bedar shares: “We did speak up more afterwards, when we were not seeing any supports, and we were so desperate in support.” For Bedar, the entirety of the system was failing. Each aspect of the system, be it the teacher or the process, had in some shape or form disappointed him. He shared: “See, we were trusting the information that they were providing. I have learnt over a period of time that you cannot trust. It’s unfortunate.”

As a lonely advocate, parents have the *rights and duties* to explicitly voice their knowledge about their child, their aspirations, and their concerns regarding the developmental plan and identified goals for the year. They have the responsibility to evaluate the suggestions provided by the professionals and select the options most suitable to the child’s developmental trajectory. They also have the responsibility to inform school personnel about the developmental goals that have been overlooked and why they are worthy of further consideration. Parents also have the right and responsibility to highlight any programs or provisions that should be provided to their child, and to clarify the frequency and expectations related to that service.

After witnessing a critical incident where Sabrin determined that the teacher's behaviour towards her son was unacceptable, she called for an emergency meeting. With her hands in the air, she shared: "I know my son is very capable. That's when I made my presentation on my son. I prepared a booklet and a presentation. (The) teacher came in with her books and said that 'he can't do this or can't do this.' I had to show what he can do." For Sabrin, the meeting and the aftermath were devastating. Irrespective of what she showed or what she shared, the teacher had the support of the entire special education team. Her son was moved from a Developmental Disabilities classroom (DD) to an Intellectual Disability-Moderate (IDM) classroom. Sabrin appealed to one of the school board trustees. She explained: "I called her and emailed her. She was like this is in the best interest of your son, this will work out." Despite relentlessly advocating, Sabrin felt she was left with no choice but to move her son to the IDM classroom or find another school.

Speech acts include listening to all options school personnel present, evaluating the options presented, and sharing information related to the child or potential programs/services that have been overlooked. Speech acts may also include language that may appear less compliant, challenging, or even non-compliant, as parents attempt to forge and/or stand their ground. Parents may also choose to appeal a decision made by a group of personnel and, as such, they may use a rights-based discourse. Sapna and Akaash shared that their child, while younger, was regularly mistreated in the diagnostic kindergarten program. They asked repeatedly for an IEP meeting, but nothing happened. Sapna also recalled that there was no additional information being communicated to her regarding any of the services that were discussed at the beginning of the IEP process. Sapna shared: "She wasn't getting any physiotherapy or any speech. But look, she was getting beat." Sapna

and Akaash escalated their concerns to the principal, and when they saw no change, they went straight to the superintendent: “My husband and I complained to the superintendent...but still nothing happened.” From their perspective, the teachers, the services, and the safeguards were failing the people they were designed to serve.

Findings from this research suggest that these lonely advocates debated and escalated their concerns to the immediate school personnel, and later to members of the larger school board. Most of these parents were unsuccessful at having any such changes recorded or reflected in their IEP or planning documentation. To this end, some parents did not return a signed copy of the IEP to the school. The IEP documentation continued to reflect the recommendations of the teacher experts irrespective of parental input.

Hopeful Partner

The final position is the hopeful partner; a position that most parents were never fully able to experience. Parents that occupy the hopeful partner position experience a culture of trust, respect, and collaboration. Parents feel that both school personnel, as well as themselves, are equally invested in supporting the child’s physical, emotional, and cognitive development. As a hopeful partner, the relationship is one of mutual trust and respect, where communication is open and dynamic, and cooperation is key. Parents feel that their opinions are valued and that they are equal partners in the decision-making process. Both parents and school personnel exchange information, build on one another’s ideas, and collaboratively develop goals that both parties agree are in the best interest of the child. While less common, Araujo (2009) and Harry (2002) both noted that partnerships exist where CLD parents are valued as true partners by educational staff, and where their insights and suggestions about their children are incorporated into the IEP.

In line with this, *storylines* that support the hopeful partner position include formal and informal meetings leading up to, during, or following IEP meetings where school personnel are engaged in a dialogue. Here, the professional is positioned as a contributor or a partner, and the parent is positioned as an equal and legitimate contributor to the relationship. In terms of *rights and duties*, the trusting caregiver has the right to hear, evaluate, and select from information provided by the personnel. The parent has the right to provide additional information that may have been overlooked or potential programs/provisions that may be beneficial for their child. As Shradha reflected on one of her more successful IEP meetings, she shared the following about what the teacher had communicated: “These are what are his strengths are these are what his weaknesses. These are the accommodations, and this is where I feel we should work towards, and this is how we can get there. Let me know your thoughts.” For Shradha, this was perceived as a genuine invitation to collaborate.

Hopeful partners have the responsibility to listen, share, debate, and collaborate with school personnel to create a thoughtful educational plan for their child. For Afreen, she frequently felt like a partner in each process. From the very beginning, Afreen found school personnel to be approachable, respectable, and well informed. She said: “We discussed everything regarding Alim. In the same school, we did speech evaluation, PT/OT evaluation, behaviour psychologist evaluation, and they told me that all the assessments are done, and this our recommendation.” Afreen found that the teacher and the principal were helpful in explaining the assessments, the services, and the accommodations that would be made available to Alim. She recalled: “They asked me about his strengths and

his weaknesses, and we made the goals. Short term and long-term goals. And then we worked on it.”

Speech acts include listening to all options school personnel present, evaluating the options presented, and sharing information related to the child or potential programs/services that have been overlooked. It may include re-evaluating existing options, researching alternative options, or seeking further expert consultations. In this case, parents trust and respect school personnel as experts in their field, but one with equal power and authority as themselves. For Afreen, she was confident in the mutually respectful relationship she had built with the school personnel. In the event of a discrepancy, Afreen was comfortable disagreeing: “They said that he does this in school, and I say no. He does more than that at home. You know? Those kinds of stuff.”

Findings from this research suggest that hopeful partners are involved at all levels of IEP planning beginning with the meeting, culminating with a written document. Their understanding of their child’s strengths and areas of development are articulated clearly in the co-constructed IEP goals developed by the hopeful partner and school personnel.

Becoming Adept at Meta-Positioning: The Parent Positioner

The meta-positioning skill is developed as parents experience formal or informal interactions with school personnel, and reflect on and learn from their experiences. Parents take stock of the different positions from which they operated during the parent-teacher interactions, on the potential benefits and challenges associated with each position, and on the perceived need to oscillate between positions if the situation calls for it. Parents skilled at meta-positioning can deliberately leave one position and adopt another by adeptly managing speech acts during the engagement.

The parent positioner differs from the five first-order positions in that it has no specific storyline, but enables oscillation between storylines through two important characteristics instead: increased awareness of different available positions and the ability to engage certain speech acts that support repositioning. Renegotiating positions and associated storylines while allowing rules to change during conversations requires positioner skills.

The following examples demonstrate how parents oscillated between *storylines*. Participants in this study went from relying on school personnel as the sole authority, to leveraging their previous experiences as social capital, and using that to reposition themselves in subsequent interactions with teachers. Instead of acting from the default position of the disenfranchised dependent, when Bedar arrived in Ontario from Nova Scotia, he now knew that one of his first steps would be to enroll his son in a special education class and complete an IEP for his son. As Bedar engaged with school personnel, he oscillated between the disenfranchised dependent position and the trusting caregiver position, as he carefully navigated the accommodations and modifications proposed by the team at his son's elementary school.

Similarly, Afreen leveraged her experiences with the special education system in the USA to learn about and navigate through the special education system in Ontario. She also oscillated between the disenfranchised dependent position and the trusting caregiver position, as she started to learn about Ontario's special education processes. Afreen recalled:

When we were in the U.S., he started school there. That time I was very nervous. I had no clue what is that. Then I asked so many questions in that meeting, in Atlanta.

Then I had a little bit knowledge. So, when I came here, I knew a little bit. That's how to get into the system. What to ask and all those kinds of stuff.

As a meta-position, the parent positioner has its own set of rights and duties and speech acts. The parent positioner is characterized by being in-between, in flux, and in reflection. It makes room for reflection on the current situation and awareness of the potential for changing positions.

The following examples demonstrate how, after having allocated some time to reflection, parents oscillated between *rights and duties*. Sabrin was called to school to collect her son after he had pushed a teacher to the ground. Sabrin shared how she switched from patiently listening to the information being presented by the school professionals and evaluating the reasons/ suggestions provided by the professionals as a trusting caregiver, to assuming the role of a lonely advocate. She shared that while listening, she tried to remain objective and asked questions for clarification, so that she could rebuild the incident in her mind. Sabrin shared:

I said, "What happened?" And when the teacher said "He beat me, he hit me," I'm like, "What do you mean he hit you?" I know my son will not attack people. He will not harm himself or harm anybody. He will be vocally loud. The most he will do is push you away because he needs his space.

In another instance, Sabrin had been called from work to collect her son from school, due to a behavioural incident. Sabrin shared how she switched from being a trusting caregiver, to actively embracing the position of a child expert. Upon arrival, she noticed her son was wearing noise cancelling headphones and was made to sit in the corner. Sabrin shared her recollection of that informal conversation with her son's teacher: "I know my

child is capable. This is a beautiful garden, beautiful flowers and this is a weed that you have thrown (referring to her son).”

Participants in this study displayed awareness that power imbalances occur during meetings when parents default to or favour certain *speech acts*. The following example demonstrates how participants in this study went from questioning and challenging school personnel’s decisions as lonely advocates, to eventually complying with school personnel as disenfranchised dependents for fear of not receiving pertinent school and program-related information. Sapna and Akaash shared their frustrations with the lack of empathy, care, and protection towards their daughter, as she was consistently beaten up in her classroom on a daily basis. Akaash shared:

My daughter was thrown on the floor, and she was being kicked on her face and her stomach by another wild child. And I'm not going to portray the other child as a villain. It's just that he's got different needs. And you need to protect my daughter from that guy. These are reasonable people. But they (teachers and educational assistants) [are] not reasonable people; they don't have any senses. They have no understanding of what special education is. The point I'm trying to make is that if I was to make a conversation with a principal, a teacher, it would be like a conversation with a 10-year-old child. Who is a fool there? In that case I cannot have a mature conversation with them because they don't understand the concept that every child is different from the other in special classes. But I don't try anymore, because somebody has to be hot, and somebody has to be cold. Otherwise, I would not be able to get any information that we are supposed to. So, I let her (Sapna) do the fights.

The following example demonstrates how a participant in this study went from questioning and challenging the teacher's communication strategy as a lonely advocate to providing a solution, inching closer to the hopeful partner position. For many parents in this study, their children are non-verbal; hence, they are not able to come home and share what they did during the day. For Sabrin, the daily journal completed by the teacher was incredibly vague, with few details on the events of the day. She shared:

My son comes home, I don't know what he did because he can't tell me. Whose responsibility it is? I need to know did he eat? Did he do this? Did he do a behaviour? I need to know what triggered it. How long was it? What was the situation at that time? I prepared a communication chart for them. It was easier.

For Sabrin, shifting her approach from advocate to partner allowed her to reposition herself as a collaborator. It also allowed her more 'power' to control the situation. In this way, she was able to solicit the information she would otherwise be unable to access.

In sum, the meta-positioning draws on meta-reflection to aid navigation between different positions. For each position, the parent can enact different discursive acts with distinct rules. Ultimately, this empowers parents to acquire the outcomes they desire. Parents with this skill consciously reflect on and oscillate between all relevant positions that can promote the desired outcome, select the most appropriate position for the particular context and situation, and address the potential conflicts that might arise.

Having explored the individual interactions between Indian and Pakistani parents and special education personnel in detail as a starting point, the following section takes the analysis one step further, and explores how the different types of capital South Asian

parents bring to these interactions influences their overall involvement with special education processes and personnel.

Inequitable Distribution of Capital

Bourdieu argues that one's total capital is the product of the match or fit between the individual's total capital and the capital of the institution and uses the terms *habitus* and *field* to explain this. CLD communities generate and sustain capital and perspectives that mediate how they interact with and respond to their social, political, and economic surroundings, including those of the school. This is a dynamic process, subject to the transactional forces of acculturation, enculturation, assimilation, and socialization (Gollnick & Chinn, 2013; Nieto & Bode, 2007). CLD families may be operating with more or less capital, as they may not come from the same social system within which they now operate. The capital they espouse and activate will place CLD parents either at the centre, the middle, or the periphery of the system under investigation.

For Bourdieu, everyone within society occupies a general position in the whole of social space (Winzler, 2014). From the social space stems various specific fields. In any given field, at any given time, different people espouse different forms of capitals, placing them in a particular position. As these parents manoeuvre within the arena of their social spaces in order to advance their interests and respond to the activities of others, they continuously position and reposition themselves. The following section will explore how the participants in this study perceived their experiences of the intersection of the two fields.

The Fields

The social world, according to Bourdieu, is comprised of a variety of distinctive arenas or fields, each with their own unique set of rules, knowledge, and forms of capital (Bourdieu, 1986). While fields can overlap, Bourdieu sees each field as being relatively autonomous from the others. Each field has its own set of positions and practices, and as such, people operating within a particular field mobilize their capital, manoeuvre within it, and struggle to stake claims within that domain (Bourdieu, 1986).

The Family

The first field I identify in this study is that of the family. For the purposes of this study, a family can be defined as a “socially recognizable group (usually joined by blood, marriage, cohabitation, or adoption) that forms an emotional connection and serves as an economic unit of society” (van Tubergen, 2020). This includes, but is not limited, to the nuclear family, the constituted family, the single parent family, and the extended family. For sociologists, the family acts as the primary source of socialization of children, whereby the child first learns the basic values and norms of the culture within which they grow up (van Tubergen, 2020).

Although migration and relocation of South Asian families to North America has led to some change, the overall structure of family membership in the South Asian context remains. The family consists of a man, his sons and grandsons, together with their wives and unmarried daughters (Edwardraj et al., 2010; Kayshap, 1989). Daughters leave their natal home after marriage and become members of their husband’s family. All relationships within the family are hierarchical, between the sexes, between generations, and between older and younger family members within the same generation (Ballard, 1982; Kayshap, 1989). Superordinates are expected to support and care for their subordinates, while

subordinates are expected to respect and obey their superordinates. Ideologically, the obligation to the group is always put before self-interest. Both parents are expected to support and care for their children in some shape or form. Fathers are largely considered to be the financial provider, whereas mothers are often considered the designate responsible for regular domestic tasks and care for the children (Kashyap, 1989). More recently, women have also become wage earners, but they are still expected to perform regular domestic tasks.

The Education System

The second field that is of relevance to this study is the field of education, with the subfield of schools. Sociologists define schooling as an intentional process, outside the family, by which societies transmit knowledge, values, dispositions, outlooks, and norms to prepare young people for adulthood (Little et al., 2016). Special education, in a similar vein, aims to meet the needs of students who have behavioural, communicational, intellectual, physical or multiple exceptionalities (OME, 2005), so that they can prepare for independent adult life. The subfield of school is the institution or organization by which knowledge, values, and norms are passed down (Little et al., 2016). The above is passed down through a thoughtfully crafted curriculum which reflects society's most valued disciplines, guided instruction, and defined roles of teacher (and educational administration) and learner (Ang, 2020; Clark, 1997; Gobby, 2017).

Parent involvement in a child's special education is detailed in policies and memorandums written by the Ontario Ministry of Education and facilitated through processes created by each respective school board. As Daniel (2000) argues, the ministry encourages parents to ensure that the selected educational programs meet the individual

child's needs, and that the appropriateness can be monitored or challenged. However, the language of provincial documents places more restrictions on parents than educators, and when provincial policy is translated into local school board documents and subsequently into processes, a further narrowing of parental involvement occurs (Lai & Vadeboncoeur, 2013). As per the legislation, parents are entrusted with the role to safeguard their children's educational rights (OME, 2005); however, they are often positioned hierarchically against educational professionals with the latter at the top and the former at the bottom, thus limiting their role.

In the South Asian tradition, education is of great importance. A sound education provides a child with strong values, character, and worth, so that they can become meaningful and contributing members of society. The belief is that a highly educated individual will have a better life, including higher social status, a better job, and a better marriage and family relationships, thereby improving the quality of life for the entire family (Cheon, 2006; Hildebrand et al., 2008; Lien, 2006; Louie, 2004). It follows that most South Asian families emphasize the importance of receiving a sound education. Within the education system, both the teacher and the curriculum are to be respected. Teachers are revered and admired as the authority figure, as they are the ones who impart knowledge to their child. Parents will often assume the subordinate role and defer to the teacher when reflecting on how best to meet their child's academic needs (Huang & Gove, 2015).

A Shared Habitus

The participants in this study share a common habitus. Although the process of acculturation will account for individual adaptation and adjustment to the Canadian lifestyle, participants share a common heritage, with a baseline repertoire of dispositions, behaviours, norms, and values. Consequently, these individuals will perceive the social world around them in a particular light and react to it accordingly. For Bourdieu, habitus functions to structure activity of human agents as an integrated scheme or as *internalized dispositions* for making sense of the world (Bourdieu, 1986). These dispositions, habits of mind, and impulses are passed down from one generation to the next. By extension, what is considered normal and what is not, be it the behaviour, roles, or constructs, are evaluated accordingly.

In the following section, I analyzed the participants shared habitus, using the Hoover-Dempsey and Sandler framework. In this way, I was able to explore four phenomena: (1) how the participants of this study understood their role as a parent, (2) how they processed their perceptions of contextual invitations, (3) how they evaluated their sense of self-efficacy as a parent, and (4) how they reflected on the ways in which their skills and knowledge have helped them navigate both fields respectively.

In the Family

Parental Role Construction. Parental role construction can be understood as a parent's beliefs and convictions about what they are supposed to do in relation to raising their child. How a parent ought to behave is based on their own and others' expectations (Hoover-Dempsey & Sandler, 1997). Their behaviour is also deeply rooted in their cultural and religious constructions of parenthood as part of their habitus (Biddle, 1986). Traditionally, in South Asian families, the father is the bread earner and the mother is the

nurturer (Kashyap, 1989), with the mother taking on most caregiving responsibilities for all aspects of the child's physical, moral, social, emotional, and intellectual development (Hays, 1996). However, parents in this study have come to understand that parenting for them will not look or feel like traditional parenting. This means that the parents in this study have developed a consciousness of their habitus of parenting, and have adapted it to the new circumstances in which they find themselves. This new understanding has led to increased collaboration between parents, resulting in strengthen relationships in some cases and the dismantling of relationships in others.

Each mother in this study described their primary role as the one who oversees all caregiving responsibilities for their child. Afreen, a single mother, bears all caretaking responsibilities for her son. Sapna, a stay-at-home mother, also bears all the caretaking responsibilities for her daughter while Akaash is at work. Shradha and Sabrin, while supported by their respective husbands, remain the primary caregivers for their respective sons, while they continue to work a full-time job and oversee the household responsibilities.

Sense of Self-Efficacy. A parent's sense of self-efficacy refers to their beliefs about whether their involvement will produce the desired outcomes (Bandura, 1989). This is intimately linked to the concept of habitus. What parents see as self-efficacy is inherited from their tradition. Closely related to a parent's sense of self-efficacy is a parent's perception of the skills and knowledge they bring to their involvement, as well as the time and energy they believe they can give to it (Hoover-Dempsey & Sandler, 1997).

With respect to their sense of self-efficacy, all participants felt that their involvement in their child's life was not only expected, but paramount to their child's

physical, intellectual, and emotional development. Bedar was a father of two, prior to the arrival of Anwaar, and Shradha was a mother to one, prior to the arrival of Shafiq. Both parents were seemingly more confident in their roles initially, until they received a diagnosis for their respective children. All five participants shared that understanding the ASD diagnosis, and living with the diagnosis, changed the meaning of parenting for them entirely.

While all participants agree that they have the skills and knowledge to be loving caregivers, learning about ASD is an ongoing process that requires a great deal of time and energy. Learning about additional programs or therapies that may be beneficial for their child, identifying funding options, and caring for the evolving needs of their child also requires time and energy. For the parents in this study, any time and energy invested in the above is time and energy removed from: parental responsibilities towards their other children, responsibilities towards their own parents and extended family, and responsibilities towards their spouses or for themselves personally.

For participants in this study, the responsibility of a parent extended beyond caring for their child's immediate physical, emotional, social, and intellectual needs. It now included anticipating their child's future needs. They are perpetual parents. This is not necessarily easy for all parents, as the tradition or habitus of parenting they have inherited now requires adaptation. Parents must now respond to and anticipate needs that they would otherwise have done at an instinctive level. Now, they must aim to both provide for their child while alive and able, as well as anticipate and arrange for their child's needs to be met once they pass on.

In the Field of Education

Parental Role Construction. Parental role construction can be understood as a parent's beliefs and convictions about what they are supposed to do in relation to their child's schooling. How a parent ought to behave in their child's education is based on their own and others' expectations (Hoover-Dempsey & Sandler, 1997). Their behaviour is also deeply rooted in their cultural and religious constructions of parenthood (Biddle, 1986); something which forms part of their habitus. As stated earlier, education is of great important in the South Asian culture as it is a means to ensure social mobility. Consequently, many South Asian parents play an active role in their child's education (Huang & Gove, 2015), and are deeply invested in acquiring desired outcomes. Like other Asian parents, South Asian parents believe that it is their responsibility to help strengthen and support their children's educational endeavours (Huang & Gove, 2015). By extension, parents hold themselves accountable for their children's academic performance. They take their children's academic failure as an indication of their failed parenting since they were unable to help their child succeed. Low achievements or failure brings shame and embarrassment to the family (Fan & Chen, 2001). If parents do not have the skills required to provide the necessary education, they will resort to additional, remedial or accelerated programs to help their child fulfill this need. A child's success represents the triumph of the entire family and is considered a family achievement.

While their children's educational outcomes may differ from the traditional purpose of education highlighted above, all parents in this study agree that education is, nevertheless, important. Each parent in this study has an aspiration for their child. For example, both Afreen and Shradha feel that one day their sons can live fully independent lives. It follows that the education they receive today should help them develop the skills

and dispositions needed to do so beyond the current instructions related to basic daily living activities. To this end, parents such as Sabrin, Shradha and Bedar continued to switch schools until they were satisfied that their children were receiving the best education available.

Parents in this study felt that in addition to understanding what is happening in school, the goals for their child could be further strengthened and supported at home. For Afreen, it was important to continue to build on the behaviours and skills being taught at school in the home environment. She remained in contact with the teacher, understood what was being covered at school, and practiced the same at home, so that her son was able to grasp the concepts more easily. Afreen also aimed to supplement what was not taught in school through private therapies.

For Sabrin and Shradha, there was little to no work sent home for their children. Consequently, both mothers hired private professionals to conduct speech and behavior assessments. Then, they then proceeded to hire private behaviour therapists to help their children develop academically. In this way, the children were able to learn how to read, write, and complete simple mathematics. They were also able to learn daily livings skills, such as bathing, cooking, cleaning and physical exercise. The boys also took part in sports and social play in order to develop other abilities.

Sense of Self-Efficacy. As mentioned above, a parent's sense of self-efficacy refers to their beliefs about whether their involvement will produce the desired outcomes (Bandura, 1989). Closely related to the latter is a parent's perception of the skills and knowledge they bring to involvement, as well as the time and energy they believe they can give to the involvement (Hoover-Dempsey & Sandler, 1997). All parents felt that they did

not know much about ASD initially; however, with time and extensive research, each participant has arrived at some understanding of how ASD has impacted their respective child.

As the child ages, they may show signs and symptoms that were not previously present. As a result, the learning is continuous for all parents. Afreen, Shradha, and Sabrin sought additional support to address the evolving needs of their child, particularly since they were not being met through school programming. They enlisted the help of professionals, either through private means or government funding, to help ensure their child could continue to develop. While they may have been confident in their knowledge about their child's strengths and weaknesses, the data from this study shows that the parents were made to feel that their knowledge and their perceptions were not as valuable as the educators. Although the mothers demonstrated a level of resilience and perseverance, the parents often admitted to feelings of disappointment and frustration with both the teachers and the system as a whole.

While Bedar, Sabrin, Afreen, and Shradha faced challenges that required their ongoing attention, they managed to get by because of the support that was available to them. With caregiving responsibilities distributed among many immediate or extended family members and friends, it was easier for parents to divide time among caregiving tasks, respite care, and self-care.

Contextual Invitations

In the field of special education, parent involvement is formally acknowledged through legislation (OME, 2005). Nevertheless, general invitations for involvement from the school or the teacher, either formal or informal, have been identified as powerful

contextual motivators. In formal settings, such as the IEP meetings, some participants reported that the schools seemed welcoming and that the attitudes and behaviours of the staff were open, kind, and positive. For other participants, the formal settings were exactly that: formal. Parents felt like they were guests or visitors, entering a host's home for a short encounter. The host, or the educational staff, would set the terms of the meeting, the outcomes, the duration, and would ensure that the guest was comfortable. In return, the guest would be courteous and not make any of their wishes known.

The same was observed in informal meetings. In some cases, when communicating with teachers at the end of the day, through phone calls or emails, Sabrin and Afreen found the teachers to be quite helpful and considerate. On the other hand, in some instances, informal communication led to increased anxiety, frustration, and mistrust, as teachers were apathetic, disengaged, or provided inaccurate information, as was the case for Sapna and Bedar.

It is important to note that the observed behaviours may be the result of the internalized habitus of the educators. Teachers may have learnt to behave in a particular manner within the structured environment of schools or meetings, in which a set protocol is exercised and set responses are elicited. To this end, the same socialization of teachers to certain dispositions may be applied in the field of education, in which educators and parents become positioned differently. The educators assumed the dominant position, while the parents found themselves on the margins, because the teacher may have been taught to believe that they are indeed the expert.

Varying Forms of Capital

Although the participants in this study share a common habitus, they do not necessarily share the same sources of capital. While the participants operate in the same field, their social position is relational, in that people's social position depends on their relationship to the position of others in social space (Bourdieu, 1986). The relationship, by extension, depends on the possession and activation of three forms of capital, which then determines a person's power and position in any given field.

These three forms of capital are economic, social, and cultural. Economic capital refers to material assets that are "immediately and directly convertible into money" (Bourdieu 1986, p. 242). It includes all kinds of material resources (for example, financial resources, land or property ownership) that could be used to maintain or acquire other resources. Social capital resides in the individual and is linked to the social connections that a person can utilize for their advancements. For Bourdieu, social capital are resources acquired by individuals thorough the possession of "more or less institutionalized relationships of mutual acquittance and recognition" (1986, p.248). Lastly, Bourdieu (1986) distinguishes between three forms of cultural capital. Cultural capital in the institutionalised state refers to educational attainment. Objectified cultural capital concerns the possession of cultural goods. The embodied cultural capital refers to people's values, skills, knowledge and tastes.

For example, Afreen has acquired enough cultural capital through her education as an English-speaking registered nurse to enable her to integrate more easily into Canadian society. She has a strong social network: her family members, nursing colleagues, and friends who are also parents to children with exceptionalities. Through both formal and informal social networks, Afreen can capitalize on provisions to help support her son's

development. Afreen also has the support of her mother, who can share the burden of caregiving responsibilities with her. Afreen is a single mother, caring for three individuals including herself. To compensate for her lack of economic capital, Afreen leverages her cultural and social capital to identify and secure private and public funding to help provide services that would benefit her son.

Sapna and Akaash, on the other hand, rely heavily on their cultural capital to build their social and economic capitals. Their education allows them a firm command of English, which in turn, enables them to do the necessary research to identify and apply for additional supports. Their economic capital is limited. With their disposable income going towards daily living expenses, there is little surplus to help support their daughter's additional therapies. The couple is also hesitant to apply for government assistance for fear they will be perceived by government authorities as immigrants who are unable to sustain themselves. As they join different support programs, they can connect with professionals or other parents of children with exceptionalities. While only few, these informal networks have proved invaluable for the couple. Lastly, despite being physically distanced from their family in India, Sapna and Akaash are in close connection with them, along with medical practitioners, who are constantly providing guidance and direction to the couple, as they familiarize themselves with the Canadian systems.

Sabrin, having completed her formal nursing degree, espouses sound cultural capital that is recognized in Canada. Having lived around the world, Sabrin speaks numerous languages. She has a good command of English with a distinctive accent. Sabrin has varying levels of economic capital. At one point, she was able to afford private schooling for her son. When that was no longer possible, she complemented public

schooling with private therapies. Both Sabrin and her husband work hard to live a comfortable life. They try to provide for their son's every need. As such, their son is often showered with electronic gifts, clothing, and sports equipment. Because their combined income is above the set threshold, they often do not qualify for government funding, which limits their son's therapies to what they can support independently. Sabrin relies on her social capital of family and friends to help with caregiving responsibilities. More specifically, she depends on her husband or her mother to share in the caregiving duties. She also relies on a compassionate team of colleagues at work. Thanks to them, she is able to enjoy a rather flexible schedule at the hospital. In this way, she can attend school meetings scheduled during work hours, take calls from the nurse's station, or on the odd occasion, drive to school to pick up her son.

Unlike the other three participants, Bedar completed his secondary and post-secondary education in Canada. This enabled Bedar to operate with increased intellectual capital, and by extension, cultural capital in this milieu. His familiarity with the education system, all be it through the regular education stream, as a student himself and with his other two children, better prepared him for school expectations, teacher expectations, and teacher-parent interactions. His embodied social and cultural capital, such as his command of the English language, his current employment, and neighbourhood of residence, reflects upper middle class to upper class standards. Bedar's cultural capital is inextricably linked to their economic capital. He is able to spend disposable income on increased therapies and recreational activities for his son. He is also able to provide for his son's changing interests, and as such, has bought his son a number of art related supplies and electronics. Bedar currently has his son enrolled in a private special education schools dedicated to working

with children with ASD. Lastly, Bedar espouses strong informal and formal support networks. Bedar lives in close proximity to his immediate family, who play an active role in sharing caregiving responsibilities. Through the private therapies, recreational activities, and community-based activities, Bedar shared that he has developed a network with other parents, who are often an important source of knowledge and resource sharing (i.e., changes to education legislation, new online resources for children with ASD, etc.).

Of the five participants in this study, Shradha has lived in Canada the longest. Having completed her secondary, post-secondary, and post-graduate education in Canada, Shradha has acquired recognizable cultural capital over time. She is familiar with the Ontario education system and the expectations that come along with it for both parents and students. Her embodied cultural capital, such as her command of the English language, her current employment, and her neighbourhood of residence, reflects upper middle class to upper class standards. Shradha also enjoys increased economic capital. She makes it a point to take an annual family vacation to a destination outside of Canada. Shradha is also able to afford and provide additional provisions for both children, ranging from private schooling and private therapies, to acquiring and disposing of toys, electronics, or food items for her son. Shradha is also surrounded by a strong network of informal and formal social support systems that include her immediate or extended family, work colleagues, or friends, who are able to share in the caregiving responsibilities. Shradha has developed a network with other parents, who are often an important source of knowledge and resource sharing. While helpful, parent-to-parent information exchanges have the potential for incorrect information being shared unintentionally. On occasion, this may result in the parent missing out on opportunities for their child (Cobb, 2014).

Intersecting Fields: Oscillating from One End to Another

The position of each participant in the field is a result of the interaction between the specific rules of the field, the participant's habitus, and the participant's combined capital. Given their shared habitus, but varying levels of capital, each parent finds themselves in varying positions within the fields. When fields interact with one another, they assume a hierarchical relationship where the field of family becomes subordinate to the field of education.

Within the family, Afreen, almost always finds herself to be at the centre of the playing field. As a single mother, Afreen uses her social and cultural capital to ensure she is able to provide her son with the proper housing, food, clothing, and education. Leveraging her informal support networks, she is able to rely on her mother and close friends to share any caregiving burdens as they arise, drawing upon this reliance from her acquired habitus. This support, in turn, allows her to navigate the field of education more freely. Initially, Afreen found herself to be on the periphery of the field, given she had no knowledge of Ontario's education system, her rights and the rights of her child with respect to special education, and with limited knowledge about her child's diagnosis. While on the periphery, Afreen found herself needing to oscillate between two parent positions: disenfranchised dependent and trusting caregiver, as she navigated through the processes. With time, she was able to develop her cultural capital and inch her way closer to the centre of the education field as a hopeful partner. Her evolving insights helped her identify and secure additional provisions for her son's development. As such, she became increasingly well versed in the IEP language, the services that are provided by the boards and individual schools, and the supports that can be found in the community. Having dedicated most of

her time and energy to her son and his development, Afreen was able to forge strong partnerships with her son's teachers and EAs. As the two fields overlapped, Afreen found herself more at the centre, as she leveraged her cultural and social capital to secure her place as a parent in the parent-teacher partnership.

Sabrin found herself oscillating between the centre and the periphery within the field of the family. She was at the centre of the field when she was a homemaker, a mother, a daughter, a sister, or a wife. She began to swing closer and closer to the periphery when she needed to balance her work life with her domestic responsibilities. While she drew upon her social capital to create a support network for her son and herself, it was not always balanced, given the many obligations she had to juggle. When her economic capital was stable, she was able to secure a position closer to the centre of the field of education. She felt confident in her cultural capital and made strong partnerships with the educators in the private school, who seemed to provide her with the support she required. However, with changes to her economical capital, Sabrin found herself navigating the field of special education for a second time, but from a public lens. She went from the position of a hopeful partner to a disenfranchised dependent and/or trusting caregiver overnight.

As the two fields overlapped, Sabrin became increasingly dependent on her social capital to help her survive in the field of education. She relied on her work colleagues to accommodate last minute schedule changes; in the event she is called to school. She relied on her mother and her husband to share in caregiving responsibilities, so that she could recompense any accommodations made for her at work.

What she was able to leverage from one field allowed her to navigate more easily in the other, but not without putting a strain on her personal and professional relationships.

Despite Sabrin's attempts to build her cultural capital with respect to the special education processes, her rights, the rights of her child, and the provisions and services in place to support her child, she often found herself at the periphery of the educational arena.

Within the family field, Bedar, the father of the household, finds himself at the centre of the playing field. He is a loving husband, father to three children, a caring son, and brother. While he plays an important role in his son's life, his wife takes on more than half of the caregiving responsibilities. Bedar relies on and leverages his economic capital to help support the functioning of the home and family, and facilitate the development of the social capital he and his wife share. Initially, when his son attended public school and was placed in a regular classroom, Bedar found himself to be on the periphery, as he was unaware of his son's diagnosis and the potential need for specialized educational services. After the appropriate assessments and placements were complete, Bedar found himself on the periphery of the educational field once again, as his understanding of the processes, services, and provisions was limited, and his relationships with the teachers, poor. He oscillated between disenfranchised dependent and trusting caregiver, as he tried to find his footing. Leveraging his cultural and economic capital, Bedar sought out a private school to help meet the needs of his son. Having increased his knowledge about both his son's condition and special education legislation, Bedar was better able to articulate what he needed for his son, and create stronger, more transparent relationships with the educators. As both fields overlapped, Bedar was able to leverage his economic, cultural, and social capitals to position himself at the centre of both arenas.

Shradha finds herself oscillating between the centre and the periphery within the field of the family. She is at the centre of the field when she is a mother, a daughter, or a

wife. Similar to Sabrin, Shradha found herself closer to the periphery when she needed to balance her professional life with her domestic responsibilities. Much like Bedar, Shradha initially found herself on the periphery of the education field. With her son in public school and placed in a typical classroom, the developmental gaps were difficult to ignore. As she learned about the specialized educational services that may be available to her, she began to develop her intellectual capital. Leveraging her economic capital, Shradha was able to identify and place her son in a private educational setting that met his needs. Here, she felt closer to the centre of the field, as she leveraged her cultural and social capital to navigate the field. With time, as Shradha became increasingly familiar with the processes and additional public or private therapies she could access, she was able to articulate the needs of her son with greater confidence. She worked alongside the private therapists to help Shaqil achieve and master certain goals that were either unidentified by the school team, or considered unrealistic based on her son's developmental abilities. Sadly, her increased capital left her at the periphery of the field once again, where she was more often than not, positioned as a lonely advocate. As her two fields overlapped, she continued to leverage all her capital from one field to carve out a legitimate position of authority in the other.

Sapna finds herself at the centre within the field of the family. She is a homemaker, a mother, and a wife. With limited economic capital, Sapna relies primarily on her social and cultural capital to navigate both fields. Much like Afreen, Sapna had no knowledge of the Canadian general education system, her rights, or the rights of her child. Once the appropriate special education provisions were in place, Sapna began to leverage her cultural capital to familiarize herself with special education services in the school. Initially, Sapna felt that she was constantly on the periphery of the educational field, oscillating

between the disenfranchised dependent and child expert positions. Her loneliness was further amplified by her experiences with what she perceived as uncollaborative and dishonest educational staff. However, as she continued to leverage her social capital, where fellow parents share information about existing resources, her rights, and funding opportunities, Sapna repositioned herself as the lonely advocate. While on the periphery of the field of education, Sapna is determined to support her child's development, and aims to continue to develop her formal social support networks, so that she can leverage her behaviour therapist or social worker to help her navigate the arena better.

In summary, Bourdieu's card game metaphor provides a good synthesis for the subtleties of involvement practice. According to Bourdieu (1986), the chance to win in a game (field) is determined not only by the cards (capital) held in your hand, but also by your familiarity with the rules of the game (habitus), the subjective feel (habitus) for the game and the skills of the players (capital).

On one hand, some South Asian parents may have the cultural, social and economic capital valued by the school, and therefore, have a natural advantage over other parents, since what happens in the special education system seems sensible to them. On the other hand, some South Asian parents may not have the necessary capital, and subsequently experience a compromised involvement in school. The findings of this study suggest that for the most part, parents were able to compensate for their lack of capital by leveraging other capital, so as to maximize their involvement their children's education.

Finally, it is important to note that despite having the appropriate amount of recognizable capital, some parents continued to struggle when navigating the special education processes or conversing with special education professionals. The resulting

compromised partnership is not only the result of unequal distribution of capital, but also of navigating and leveraging the discourses, positions, and power made available to either party. The third and final section of the analysis will take a closer look at how power serves to position the parent from the parent's perspective.

A Power Struggle

Effective partnerships reflect and encourage the sharing of power and responsibility (Fine, 1993). While policies and memorandums created by the Ontario Ministry of Education (OME, 2005) reflect a democratic discourse through promoting the democratic participation of parents, research suggests that professional discourse continues to dominate the parent-teacher partnership, and maintains barriers to achieving effective partnership. This section of the analysis draws from Foucault's analytics to explore how discourse, surveillance, as well as empowerment and resistance, serve to position the parent in the parent-teacher relationship through the perspective of parents.

The Power of Discourse in Positioning

For Foucault, discourse offers a way of speaking or writing about a reality that determines what can and cannot be included in the description of that phenomenon, at a specific time in history (Gutting, 2005). In this way, those who have the power determine the ways by which a specific subject may be represented, and do so by constructing the knowledge that is used to represent it (Gutting, 2005). Foucault systematically interrogates how and why some discourses have shaped and created meaning systems that have gained the status and currency of 'truth', and dominate how we define and organize both ourselves and our social world, while other discourses are relegated or marginalised. In line with his

understanding of discourse, Foucault maintains that some knowledge is validated and celebrated, that of the professional, whereas the experiential knowledge of the individual is frequently devalued by professionals who assume a more privileged position of expertise through specialist and scientific knowledge (Foucault, 1969).

While one parent found that professionals were open to hearing her observations about her child, the remaining parents in this study found that their own detailed knowledge of their child's abilities was frequently questioned or devalued by teachers. During the IEP meetings, participants of this study noticed that the knowledge of specialists and teachers was generally preferred to theirs, because the knowledge they had was merely anecdotal. When Sapna shared with the teachers that her daughter is capable of eating, but that it takes her more time, she was told that there is a set time for eating, and that changes to the schedule cannot be accommodated. It becomes more problematic when the anecdotal knowledge offered by parents contradicts the professional's clinically based views. When Shradha shared her son's capabilities of completing more complex math problems, her observations were noted and then later dismissed, while the resulting IEP goal remained unchanged. After highlighting their observations and concerns, the mothers reported that education professionals made them feel as though they were naïve and over ambitious parents rather than investigating the concerns.

Skritc (1991) draws on Foucault's theory of disqualified or devalued knowledge to critique the overemphasis of a functional approach in special education. He argues that other forms of knowledge, such as parental observations, continue to be devalued because of an overemphasis on objectivity, assessment, and measurement by specialists. Most parents perceived the language of the meetings to be technical, the terms unfamiliar, and

the documentation inaccessible. Teachers continuously referred to these documents when sharing, explaining, clarifying or validating their suggestions and/or decisions. By referring to the documentation, particular types of assessments, or specific types of pedagogies, the professionals asserted the role of *expert*, while simultaneously relegating the parent to the position of subordinate, dependent, or listener. Although parents brought in evidence of their own, they were made to feel that their observations and documentation lacked the empirical integrity needed to be recognized as valuable data by education and other related professionals.

After finding that their attempts to communicate with the professionals were unsuccessful, some parents brought in external professionals, or adult supports, to the school to attend IEP meetings or to re-read and decipher IEP documentation. As shared by Sabrin, she no longer attends any IEP meeting without her behaviour therapist. She shared: “They speak to her differently, and they listen to what she has to say.” This observation suggests that parents can sense that they are valued or positioned differently than a professional in the field.

Rather than remain passive in their attempts to communicate with teachers and support staff, parents deliberately used the specialised knowledge and status of other professionals to reinforce their own position. Sapna brought in a social worker, while Sabrin brought in a behaviour therapist. Acknowledging their agency, they attempted to utilize the professional discourse of one professional as a strategy for the changes they sought from another (the child’s teacher). Although they were able to mobilise some positive change for their children through this strategy, they remained largely devalued and

disempowered with the discourse of professionalism. Their need to use other professionals illustrates and reinforces their subordinated position.

The Power of Surveillance in Positioning

Foucault's writings on the Panopticon outlines a model of power which bears striking resemblance to the modern school (Foucault, 1977). Schools are often understood by social researchers as panoptic spaces, where power is exercised through constant surveillance and monitoring. Surveillance is a key theme in Foucault's work whereby individuals are constructed as both subjects and objects of power under the constant 'gaze' of others. Hierarchical observation is a type of surveillance that operates from the top down and, Foucault claims, occasionally functions from the bottom up (Foucault, 1977).

Within the realm of special education, the concept of surveillance can provide a useful standpoint from which to view the ways in which parents and teachers negotiate responsibility for the child.

In special education, all children are the objects of scrutiny in schools. IEP meetings make this scrutiny visible. Children are constantly under this gaze: they are observed, their behaviours analyzed and supervised, and their performances reported to parents. Teachers attempted to bring the parental gaze onto the child through their expert conceptualisations of developmental norms. This was apparent in the ways they provided accounts of the children's behaviour and achievements to parents, comparing these to judgements of what the child should and should not be able to do at his/her particular stage of development. For example, Shradha was told that her son should have a particular stage of comprehension for his age. Bedar was told that his son has unprovoked meltdowns, which was considered atypical by his son's teachers. Sapna was told that her daughter is unable

to eat quickly enough for her age. In this way, professionals, with their repertoire of expertise, are able to impose a picture of appropriate and inappropriate or desirable and undesirable traits in students for parents, and normalize particular behaviours or traits during both the formal and informal encounters (Bezdek et al., 2010).

Similarly, parents were also under careful observation by the trained eye of the professionals. Parents shared that they felt they were being watched and assessed. “It’s like we’re under microscope,” shared Sapna. Parents observed that teachers often noted how frequently they communicated, either via email or phone, whether they attended school or class events, and their availability for informal or formal IEP meetings. The parents’ performance was judged by teachers according to “their standards”. As research demonstrates, professionals have a preferred level of parental involvement, which is deemed appropriate (Bezdek et al., 2010).

If parents feel they are being evaluated, then the evaluation is coming from someone with authority, which in turn, places them in a position of lesser power. Shradha, Sabrin, Afreen, and Sapna noted that professionals often made observations about their roles as mothers who might need additional support. To this end, some teachers provided participants in this study with advice on parenting, on how to better understand their child’s development, and how best to support their child’s development at home. While Afreen found the teachers’ interest in her home life supportive and encouraging, Sabrin, Shradha and Sapna found their comments unsolicited and patronizing. Interestingly, parents were also expected to act as agents of surveillance for the school, filling in gaps of knowledge related to the child’s development, only when solicited, and ensuring the devised support programs were implemented in the home.

Conversely, parents in this study regularly demonstrated their agency, and consistently exercised their gaze on teachers. Sapna and Akaash, for example, observed that their child was being mistreated by other students and brought this to the attention of the teacher, and later, to the principal. Bedar noticed that his son would have a meltdown almost every day if he had an altercation with one of his classmates. He brought this to the attention of his son's teacher. Sabrin noticed that her son was being isolated for 80% of the day and was made to wear noise cancelling headphones. She escalated her observations to the teacher, and later to the special education team. In each case, the gaze of the teacher was either misdirected or altogether absent. By redirecting the teacher's gaze to the child, the parent attempted to assert their own position as a parent and as a member of team who expected a level of accountability from their partner, the professional.

Empowerment and Resistance in Positioning

For Foucault, power is everywhere. Foucault (1980) asserts that power is not something that can be owned, but rather something that acts and manifests itself in a certain way. It is more a strategy than a possession; it is a relation. It is viewed as circulating through society in a "net-like organization" operating within every aspect of social life (1980, p.98).

In the same way that power is distributed across a network rather than being located at a specific point, resistance is spread out, existing wherever power operates (Shumway, 1989). Shumway asserts that it is only possible to resist such disciplinary power being exercised over us if we "recognise that it is power and not truth that is spoken in each case" (Shumway, 1989, p.162). Analysing how parents and teachers position and reposition

themselves, and the strategies employed to achieve this, provides some insight into the enactment of such power.

MacLure and Walker (2000) suggest that a similarity exists between the interactional structure of parent-teacher meetings and doctor-patient consultations, and how the expert (the doctor or the teacher) is able to gain and maintain power or control over the meeting. Literature suggests, much like the findings of this study, that teachers conduct the IEP meeting in a particular way. Educational staff set the agenda of the meeting, provide an uninterrupted diagnosis at the outset of the meeting, use specialised vocabulary throughout the interaction, and later invite contributions from parents, prior to concluding the meeting.

Based on the perspectives of the parents who participated in this study, teachers use particular strategies during the IEP meetings to shape and control their development. The first of these is the control exercised by teachers over the agenda setting. Teachers decide what is to be shared and when it is to be shared. In Afreen's reflections, for each of her meetings, the teachers came prepared, shared what they felt was relevant information with her, and then turned to her for her thoughts on what they had shared. In Akaash's reflection, he shared that he was talked at throughout the meeting. In some cases when teachers shared information or observations that were inaccurate, or suggested ways forward that did not resonate with the parents, the latter remained silent. For some, silence was an active position purposefully selected to indicate they did not accept certain issues raised by teachers as important, or to note disagreement without having to verbalise their resistance to what was being said. For others, it was the only option, for fear that overt resistance may have negative consequences for their child.

The second area of control appears to arise during the establishment of what constitutes a problem. As identified in the literature and corroborated by the findings of this research, parents often faced difficulties in getting teachers to acknowledge that a problem existed concerning their child if, in the first instance, this problem had not already been identified by the teacher (MacLure & Walker, 2000). For instance, Shradha shared repeatedly that aspects of the curriculum were not challenging enough for her son and her observations were dismissed. According to Shradha, the professionals appeared disinterested, as it did not align with their observations. Sabrin presented the team with tangible evidence that her son was capable of completing grade-level work, and that there was another factor present in the classroom that might help explain his behavioural outbursts. Similarly, Sabrin's observations were dismissed, as the teachers had evidence which suggested otherwise. While parents were expected to follow through on suggestions made by the IEP team or to address certain problems identified by the team, parents often had difficulty in securing similar commitments from teachers. When Bedar, for example, requested more detailed incident reports to be included in his daily communication, he received the same misinformed comments from the EAs.

The third and final area of control arises when parents overtly challenge the teacher's or the professional's authority. From this, blaming sequences emerge in which the professional attempts to shift the responsibility onto one another, the student, or external circumstances. When Sapna confronted the teacher regarding her lack of involvement in protecting her daughter and threatened to escalate the matter, the teacher was quick to blame external circumstances, re-share her qualifications, and provide a simplistic plan of action that would reduce the observed behaviour in the future. When

Shradha shared that her son was not challenged by the existing curriculum, teachers countered with lengthy explanations as to why it was important for him to repeat certain concepts, despite having mastered them already. It was not so much that parents felt powerless because they were coerced into taking certain actions; rather, parents felt powerless because they did not trust the teachers, the professionals, or what they represented. Each parent found a way to resist what they felt was being imposed upon them, and by extension, their child. While Sabrin and Sapna appealed to higher authorities, Shradha refused to sign the IEP document.

The outcome of attempts at resistance varied based on the parent, the nature of the institution (private or public), and the IEP team. In some cases, the teacher would simply dismiss the parent's response, while on other occasions, the teacher would be forced to defend her position. However, as demonstrated in the findings of this study, the exercise of parental resistance had very little effect on the existing power dynamics.

To conclude, analysis of the parent-teacher interactions from a Foucauldian perspective has been both helpful and revealing. It has highlighted the ways in which discourse, surveillance, and empowerment serve to position parents in relation to teachers in a parent-teacher interaction.

Chapter Summary

In summary, although special education policies encourage parental involvement in special education processes, a productive relationship appears out of reach. The findings and analysis of this study suggest that South Asian parents oscillate between a number of positions when interacting with special education professionals, namely: the

disenfranchised dependent, the trusting caregiver, the child expert, the lonely advocate, and the hopeful partner. Parent interactions with special education professionals were also mediated by variables such as their habitus, the total capital they espoused, and the power they choose to exercise. Together, parental understanding and exercise of their capital and power played an important role in how parents positioned themselves in relation to the professionals.

Given that parents and teachers have different responsibilities and interests, it is unlikely that that they will be equal partners in dialogue. The nature of their roles (as well as how those roles are defined and interpreted) will, to a large extent, shape how they might access privileges. When school stakeholders respect and appreciate the merits of different cultures, empathize with parents' abilities and difficulties, acknowledge and accept parental knowledge, and where possible, empower the parents to seek the appropriate guidance, then perhaps as a team the two can create documentation that is reflective of the child's true potential, and that will perhaps help with the child's overall growth and development.

CHATER 6: SUMMARY & CONCLUSION

Families of children with exceptionalities in the province of Ontario, Canada, are regularly invited to participate in a complex network of special education processes. It is hoped that parents and a team of educational and health care professionals can identify, plan, and provide a quality educational programmes and services for the child. One such example of a process is the IEP meeting, where participation from the aforementioned parties is encouraged in provincial legislation (OME, 2010). A family's engagement in the special educational process depends on a number of variables that can be framed within two broad categories: those that are independent of the family and those that are family specific to the family. The variables that are independent of the family include government or board regulations and general school processes; the variables that are family specific to the family include a family's familiarity with the education system, understanding of parental rights, or a family's relationship with school personnel.

Despite legislative mandates that encourage direct involvement from parents or guardians in planning their child's special educational programing across North America, the level of collaboration that exists between educators and CLD families of children with exceptionalities is marginal at best (DeRoche, 2015; Esquivel et al., 2008; Ryan et al., 2010; Wright & Taylor, 2014). This research focused on providing clarity and a better understanding of the CLD parent experience of the IEP meeting. To this end, I interviewed five South Asian participants regarding their personal experiences with the special education process and its providers. This study set out to answer the following question: How do immigrant South Asian parents of children with ASD understand, pereceive and

experience their role in the Individual Education Plan Meeting, within Ontario's special education context?

In sharing their narratives, participants in this study detailed their experiences from the moment they suspected that something was different with their child to their earliest memories accessing and securing educational provisions for them. This includes the IPRC process and their more recent experiences with IEP meetings. Based on the findings of this investigation, CLD parental involvement in their child's special education varies based on a number of key factors: a parent's understanding of their child's condition, their beliefs about child rearing, the effort and means required to support their child's education, and finally, knowledge of and expectations from the school system.

While all participants in this study share a common habitus, they espouse varying forms of social, cultural, and economic capital. This in turn influences both how they are able to navigate the special education process and how they perceive their relationship with educators. In the retelling of their experiences, parents shared how they positioned themselves in the parent-teacher relationship and how they perceived themselves being positioned by the special education professionals. Using reflexive positioning, I identified five different positions that parents oscillated between when interacting with special education professionals: the disenfranchised dependant, the trusting caregiver, the child expert, the lonely advocate, and the hopeful partner.

The most prevalent position, one that each participant had experienced on at least one occasion, was the disenfranchised dependent. Here, the parent relied solely on the expert, or the educator, for guidance to support their child's development. Stemming from the first position, is the second position; that of the trusting caregiver. In this case, the

relationship is based on trust, where the educator is positioned as an expert, responsible for sharing the appropriate knowledge, and the parent is positioned as an evaluator. The child expert is the third position. Here, the educator is positioned as the authority and the parent is positioned as the ambitious caregiver whose understanding of the child's needs is compromised by their relationship to the child. As such, decision making is always deferred to the impartial, more knowledgeable, teacher. Stemming from this position, is the lonely advocate. In this case, while the professionals perceive themselves to be the experts, the parents perceive them as lacking knowledge and appropriate training to best help support the needs of their child. The parent is consistently negotiating and advocating with the aim of obtaining services and provisions to which their child is entitled. The last position, one that was seldom enjoyed by participants, is the hopeful partner. Here, the professional is positioned as a contributor and the parent as an equal and legitimate contributor to the relationship. Together both parties strive to appropriately identify and thoughtfully design, meaningful educational plans. Each experience varied, and parents often found themselves shifting between positions in order to achieve the desired outcomes.

Using a Bourdieuvian lens and the Hoover-Dempsey & Sandler model (1995, 1997) of parental involvement, I analysed parental narratives to see how the varying forms of capital played an important role in how parents perceived their position in the parent-teacher relationship. Where parents felt they lacked cultural capital, such as being unaware of Ontario's schooling and special education processes for example, they were likely to feel disenfranchised and be more dependent on the teacher for guidance and recommendations. Conversely, if parents had a strong understanding of special educational processes and espoused economic capital that facilitated options from the private sector,

they were often in a position to challenge the recommendations put forth by educators and fiercely advocate for their child. The findings of this study suggest that despite not being endowed with all three forms of capital, parents were nevertheless able to compensate where required and leverage on the capital they espoused, so as to maximize their involvement in school.

The findings of this study also suggest that despite having the appropriate amount of recognizable capital, some parents continued to struggle when navigating special education processes, or conversing with special education professionals. The resulting compromised partnership, as perceived by parents, was not so much a result of the disparity in capital between school professionals and themselves as it was perhaps the uneven balance of power between the two parties. Using Foucault's analytics, I explored the ways in which discourse, surveillance, as well as empowerment and resistance, served to position parents. Here, the findings suggest that parents for the most part, were positioned as subordinates to the teachers. Teachers systemically used educational jargon, referred to complex assessments, and devalued parental knowledge. In this way, despite their level of education, professional competence, or economic stability, parents felt that educators controlled and manipulated the events during a meeting, the type of engagement that was permitted, what could be discussed, and what was to be documented in the IEP. While one parent experienced a collaborative relationship with special education professionals, where she felt her voice was both solicited and reflected in the IEP documentation, the remaining four families felt that the special education processes, personnel, and the barriers that were erected, consciously or unconsciously, were disempowering.

Despite special education policies highlighting the role of a parent as an equal partner in the parent-teacher relationship, the participants reported feeling as though the educational professionals whom they worked with had more authority in the relationship. This was in part due to the fact that the participants felt that they and teachers had different roles and by extension different responsibilities and interests, which in turn fostered an imbalanced parent-teacher relationship. The nature of their roles, as well as how those roles are defined and interpreted, will shape how each party might access the privileges that are associated to them. Consequently, unless thoughtful measures are taken, it is unlikely that both teachers and parents will be equal partners in dialogue.

Learnings from this Study

Educators, administrators, and policy writers who wish to move beyond the rhetoric of partnership need to consider ways to promote an effective relationship between CLD parents and school personnel. The following section explores potential recommendations to strengthen such relations, as suggested by parents in this study.

Learning About the Parents/Caregivers

According to this study's findings, each parent learnt about their child's diagnosis differently. The journey from receiving a medical diagnosis to accepting it was also experienced in myriad of ways. Once parents accepted their child had ASD, every dimension of life as they knew it, daily living activities, relationships, finances, school and health care, changed. The participants in this study went from being quintessential parents to being perpetual parents.

As parents of children with exceptionalities often are, participants in this study were often consumed with daily tasks, from feeding, bathing, and dressing their child to driving

them to doctors or therapy sessions. Time and energy were dedicated to researching and identifying funding opportunities, support networks, recreational activities, respite care, and where possible securing educational provisions. As noted in this research, the varying levels of social, economic, and cultural capital, play an important role in how parents navigated their daily routines at home, and later in school. As the two worlds overlapped, parents often experienced varying levels of satisfaction and disappointment from their interactions and expectations from school personnel.

Recommendations

Given that special education policies in the province of Ontario value and encourage parental involvement (OME, 2005), school boards and school personnel must take the necessary steps to create and sustain collaborative relationships. Relationship building means taking the time to get to know CLD families. At the beginning of the academic year, teachers are likely unfamiliar with the details of each student, and their respective families. What is important is that educators be willing to learn where families are from, what their expectations are from special education, what their aspirations are for their child and why. Teachers must take the time to converse with parents frequently and genuinely listen to what is being shared.

When getting to know CLD parents, educators should take the time to ask families about their familiarity with and understanding of special education processes, special education documentation, and their child's diagnosis. When educators develop a deeper understanding of a parent's aspirations for their child, they can be more empathetic and informed in their approach to relationship building. As the more privileged partner in the parent-teacher relationship, the first step in building a collaborative relationship rests on

the educator. To continue fostering a collaborative relationship, educators must value and promote regular communication, commitment, equality, competence, trust and respect (Blue-Banning et al., 2004).

The importance of relationship building can be supported through a thoughtful educational approach, beginning at the preservice level, where new teachers are explicitly introduced to this topic, through to professional development, post-graduation. As a system, relationship building can also be supported through internal infrastructure. This means that time (i.e., a designated number of days per term) should be built into the academic calendar, so teachers are able to formally connect with families, outside of the required IEP meetings. The more opportunities that teachers have to invest in parent-teacher relationships, the more likely they will be able to build trust and respect.

The IEP as a Process

The majority of parents in this study felt that their initial IEP meeting was less than positive. Parents who shared positive experiences, also expressed disappointment with subsequent IEP experiences. The experience of negative IEP meetings is consistent with other studies that reported on parents' first and subsequent experience with IEPs (Fish, 2008; Hammond et al., 2008; Harris, 2010; Jones & Gansle, 2010; Valle, 2009).

Although the IEP process is familiar to most educators, parents are often unaccustomed to it. To help parents better understand the process, each school board in the province of Ontario has created an IPRC parent resource guide that includes information related to the development of the IEP. However, participants in this study were not aware of such a resource. Their lack of awareness suggests that the IPRC guide was either not in circulation when they had their first IPRC meeting, or that the guide was never shared with

them. Participants in this study entered their first IEP meetings with a degree of anxiety and apprehension, and with little understanding of what to expect from the meeting. From their perspective, the meeting was structured with very little flexibility. During the meetings, each of the participants noted that a large number of people were present in the room, most of whom they had never met or heard of. Regarding conversations that occurred, participants perceived it to be largely one-sided. They noted that they were neither informed of their rights nor the types of services they were entitled to. Concurrently, the five parents were unclear on why certain goals were prioritized, how decisions were made, and what happens to their child during the interim, as they wait for assessments to be completed and provisions to be secured.

Recommendations

It becomes imperative that educators who are familiar with the IEP process, and who will be largely responsible for guiding parents and students through the process, familiarize themselves with the parents' level of comfort and understanding of the IEP process. Building on the previous recommendation, when learning about the families with whom they work, the OME (2007) suggests that educators should consider a variety of questions when evaluating family's levels of comfort and understanding of the IEP processes. Of these questions, there are three that have potential to be of particular value:

1. How do educators want parents to experience their IEP process?
2. What is the parent's current understanding and comfort level with the process, and its' purpose?
3. What mechanisms does the school have in place to address parents' needs?

For each identified area of need, educators should have a specific action plan that should be shared with parents.

To help position parents as meaningful partners in the relationship, educators can help build a strong knowledge base, something participants in this study repeatedly shared they lacked. Educators can direct parents on how and where to seek the appropriate knowledge and resources to support their child with respect to both educational services and disability related services. To this end, school boards have prepared different types of literature related to the IPRC and IEP processes. It may be helpful to share and review these resources with parents, so that they can begin to develop their understanding about the different processes that exist, their rights, and their roles therein. The school should create needs specific materials that can be shared with parents and or guardians (i.e., IPRC parent resource guide to be shared with any family coming into the system for the first time etc.).

Educators may also find it beneficial to share what provisions and services can be made available to parents, through the school board. When explaining the process of identifying a particular service for example, it is important for educators to also share the different steps required to secure such services, as well as what happens to the child in the interim. This allows parents to have a clear understanding of what services are available to their child, how each service will aid the child's learning, how frequently this service will be provided, and for what duration (i.e., an occupational therapist will work with child once a week for one hour, on his fine motor skills).

There are number of interventions that can also be adopted by schools and educators alike to help share relevant and valuable information with parents. These can range from weekly emails and infographics, to pre-recorded webinars, in person meetings or mini-

lecture series. A study conducted by Jones (2006) involved a mini-conference intervention before the actual IEP meeting to determine whether parent participation would increase. Results showed that although there did not seem to be a significant difference in parent participation, there was an increase in the level of satisfaction of the parents' overall IEP experience as a result. Such an intervention, or something similar, would potentially allow parents to familiarize themselves with the process, the structure of the meeting, expected outcomes for their child, and how parents participate in this process prior to experiencing it for themselves. Another example can be the use of pre-recorded webinars, for parents to access based on their schedules, where potential changes to government programming or funding can be shared. This allows parents to receive the most up to date information regarding programming, and are then able to connect back with educators to see how this will impact their child.

Learning About the Child: Personalizing the IEP

Findings from this study suggest that many parents felt the educators' approach to creating IEP goals were often mechanical and generic. In most cases, IEP goals were predetermined. Consistent with literature (see, for instance, Banks & Banks, 2007; Simon, 2006), for some participants in this study, the IEP goals were based solely on aspects identified and privileged by teachers, and did not reflect their input. Parents perceived this as troubling, for it appeared that the teachers did not consider the child's current interests and abilities, nor did it consider observations and concerns raised by parents. This was further exacerbated when the identified goal had already been mastered by the child. With convoluted IEP goals, and only modest expectations for student achievement, participants

felt that their children were being deprived of both their right to an education, and personal growth and development.

Recommendations

Personalizing an IEP is contingent upon how well the educators know and understand the student on an individual level. Learning about the students likes and dislikes, abilities and areas for growth is tantamount to identifying and articulating age and ability appropriate goals. While educators may know each child, based on their assessments and observations, this understanding may not be comprehensive. It follows that educators should be learners and listeners of the families. When parents are sharing their observations, it becomes imperative that teachers make additional efforts to collaborate with them and identify whether the same observations were missed at school and/or could be explored in the future. It means that educators must be open to alternative sources of insight. In addition to listening to parents' observations, it is important for teachers to ask how their observations can be integrated into the goal setting activity, and by extension, modify the goals to better reflect the child's abilities, the parent's aspirations, and educational guidelines. Teachers need to demonstrate the same trust and confidence in parents and their knowledge as parents do with teachers. If the IEP is treated as a living document, it must always be current because the teacher is monitoring, documenting, and addressing the child's needs for progression. In this way, the goal or goals can be closely monitored and modified as necessary.

Finding their Footing: Working Towards a Collaborative Relationship

Participants in this study perceived a clear power imbalance between the professionals and themselves. Consistent with research findings, the majority of

participants in this study reported feeling powerless, disabled, and helpless when interacting with special education professionals (Bezdec et al., 2010; Durand & Perez, 2013; Harry, 2008; Turnbull et al., 2010). In formal settings, such as IEP meetings, parents felt they lacked specific knowledge with respect to the type of education their child will receive, the types of services and provisions available to them, and knowledge the educators readily espoused. Here, participants found themselves relying on the mercy of the educator entirely. Fortunate parents had educators and other special education professionals who were forthcoming with important information. Where this was not the case, parents were left to fend for themselves. In informal settings, such as in person conversations or over phone calls, most parents felt that their observations and suggestions were dismissed by the professionals (Durand & Perez, 2013; Jung, 2011; Turnbull et al., 2010). Often, parents perceived educators to be resolute in their knowledge and authority as an expert, and frowned upon any information that suggested otherwise.

Whilst participants fluctuated between the aforementioned five positions of interaction, in time, most parents learnt to negotiate these different positions, based on their desired outcomes. Participants noted that teachers preferred a particular type and amount of involvement, also known as the *goldilocks perception* in educational literature (Bezdec et al., 2010). Although participants were fierce advocates for their child, often times they felt disheartened. In said meetings, participants were either advocating for or appealing a particular suggestion, the outcome was no longer driven by level of cultural capital, as parents were adequately versed in their rights and the rights of their child. It was now a clear power struggle between the experts and the parents.

Participants perceived the entirety of the system to be disorganized, infantilizing, and untrustworthy. At times, the emotional stress and the mental gymnastics was incredibly taxing, and unnecessary, as the outcome could almost always be predicted in advance: the expert opinion would almost always outweigh that of the parent. Over time, participants learnt when they should advocate for their child and when they should compromise, not because they felt that this was the right option, but more so, because this was the only option.

Recommendations

Special education decision making processes are intricate. For parents, these processes, including IEP meetings, can feel overwhelming. This is further complicated with nuances of evaluations, availability of resources, and changes in the child's behaviour and dispositions.

It is the school's responsibility to create a safe, welcoming, and enabling environment, where parents feel at ease to voice opinions and concerns related to the IEP process, and the day to day activities a child will experience (Flanagan, 2001). Building on the prior recommendations, a safe and welcoming environment is underpinned by established teacher-parent relationships, built on mutual respect, trust, and appreciation (Summers et al., 2005). Teacher training programs should devote time and space for teachers to learn about parent psychology, ways to build and maintain effective partnerships, and explore strategies on demonstrating trust and respect through ongoing communication, active listening, constructive thinking and knowledge sharing practices, amongst others.

However, irrespective of the established partnership, disagreements may nevertheless arise over aspects of the student's IEP program, such as goals, or curriculum modifications etc. The severity of the disagreement, and its outcomes, will be greatly influenced by the type of relationship both parents and teachers share, thus reinforcing the importance of creating and maintaining positive relationships. Consistent with existing literature, program planning conflicts occur when both parties do not have access to the same information, have different understandings of the available programs and services, or have different understandings about the outcomes. Implementation conflicts arise when parents perceive plans for special education programs and services to be implemented inadequately, or be implemented by staff that do not have the requisite training.

To this end, educators should be familiar with conflict prevention strategies. The Ministry of Education has created various resources for teachers, to help support them in anticipating questions or concerns parents may have when attending meetings. This constructive approach allows teachers to be solution oriented and student centric so that—in the event of a disagreement, heightened emotion, or an impasse—teachers are able to stop and reconvene at another agreed upon time. Practice informed resources, such as Shared Solutions and Learning Support Services, can also help parents and teachers prevent and resolve conflicts regarding programs and services for students with exceptionalities.

Suggestions for Future Research

The purpose of this study was to explore how parents of children with ASD, from a South Asian background, understand, perceive and experience their role in a collaborative relationship, between special education personnel and themselves. To help fill gaps identified by this research, a future study should include the narratives of both the South Asian

demographic, as well as the special education professionals with whom they interact, so that both reflexive and interactive positioning can be analyzed. This will allow for potential clarification of perceived importance that habitus plays in parent participation. Future research should consider analyzing the narratives of South Asian special education professionals who work alongside South Asian parents to determine if there is a change in parental perception of the process. For example, such research could help determine if common cultural background leads to a more concessionary view of the process or if it leads to more scrutiny. While this study recruited South Asian parents of children from various school boards across Ontario, a future study may focus on schools within one school board, to see how schools appropriate board guidelines, and the impact this has on parent participation.

To better understand the role of power and privilege, future studies could also explore and compare how CLD families, from different cultural and socio-economic backgrounds experience IEP meetings, within the same grade and the same school. With all other variables being equal, it would be interesting to develop a more comprehensive understanding of how a parent's habitus influences, or does not, the type and level of power exerted by professionals on the direction of the process. To this end, a longitudinal study, exploring the relationship between teachers and various CLD communities, within the same parameters, may shed a different light on how teachers perceive parents as partners. It is important that future research differentiate between experienced and novice teachers. This could help determine whether teachers' experiences provide them with a larger breadth of knowledge that enhances the support they provide or whether their past experiences and frustration create the potential for unconscious bias. It can also help

determine whether novice teachers' relative inexperience makes it easier to adapt to new challenges and what kind of guidance and support they need.

Concluding Remarks

Research demonstrates that parent engagement and successful parent-teacher partnerships result in improved educational and non-educational outcomes for students, particularly for students with exceptionalities (OME, 2010). Research also demonstrates that the level of collaboration that exists between educators and CLD families of children with exceptionalities is marginal at best (Cohen, 2013; DeRoche, 2015; Esquivel et al., 2008; Fish, 2008). This study had as its primary aim the explorations of the lived realities of South Asian families as they navigated the special education process in the province of Ontario, so as to better understand why lower levels of parent-teacher collaboration were observed amongst this population. To this end, this qualitative study examined the varying narratives of five Indian and Pakistani families of children with ASD to better understand how parents comprehend, perceive, and experience their role in a collaborative relationship between special education and school personnel and themselves before, during, and after the IEP meeting.

The findings suggest that Indian and Pakistani parents face a number of barriers that prevent meaningful participation in their child's special education. These barriers range from unfamiliarity with the schooling system in the province, to lack of knowledge regarding special education services and legislation. While they showcased varying levels of capital, which in some cases allowed parents to secure the provisions they deemed necessary for their child's development, most CLD parents frequently found themselves in subordinate positions as they navigated the special education processes, be it in the public

or private setting. This study also highlighted the varying power dynamics at play in parent-teacher relationships, be it from the bottom-up or top-down, and the many tensions, constraints, and restrictions experienced by CLD parents, as they negotiated the power differentials between teachers and themselves.

To help create and sustain stronger parent-teacher partnerships, school professionals should first and foremost, familiarize themselves with the child and their family, provide relevant information for parents to learn about their child's disability, related education processes, provisions and services to which they are entitled, and where possible, community resources related to both disability and educational supports.

When parents are given the appropriate assistance in navigating the education system, their satisfaction levels increase, resulting in important gains for their child. It is hoped that the parental stances shared in this study, together with other educational literature highlighting the challenges faced by CLD communities, can provide educators with insights on how to better foster collaborative and productive relationships with CLD families. This is vital as collaboration is critical to the development of effective IEPs, that in turn, may provide comprehensive education for all students.

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