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Individual Placement and Review Committee Process: Perceptions of Parents of Students Who Are Both Deaf and Autistic

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FONTBONNE UNIVERSITY
COLLEGE OF EDUCATION AND ALLIED HEALTH PROFESSIONS

INDIVIDUAL PLACEMENT AND REVIEW COMMITTEE PROCESS:
PERCEPTIONS OF PARENTS OF STUDENTS WHO ARE BOTH DEAF AND AUTISTIC

A Dissertation
SUBMITTED TO THE DOCTORAL FACULTY
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degree of
Doctor of Education

By
Elyza Polsky
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Individual Placement and Review Committee Process: Perceptions of Parents of Students Who are Both Deaf and Autistic

A Dissertation APPROVED FOR THE

COLLEGE OF EDUCATION AND ALLIED HEALTH PROFESSIONS

BY

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Acknowledgements

I dedicate this to my family. They kept me going, had faith in me and supported me, every step of the way. I am truly blessed and grateful. Sarit, Hudson & Barrett, I am so proud to be your mom. Thank you for standing by me and picking up the slack while I spent countless evenings and weekends studying and writing. Double Love. David, thank you for believing in me and taking on the extra load while I took on this extra load. Thank you for the countless hours you spent proofreading page after page, listening to me talk about my research, and most importantly convincing me to stay the course. I could never and would never have done this without you by my side. Thank you to my parents, who are always my biggest and loudest cheerleaders.

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Abstract

A paucity of research exists surrounding the area of children with the dual diagnosis of autism and hearing loss (Wiley et al., 2018). While research exists regarding the perceptions of parents of children with other disabilities and challenges, it has only just begun to extend to parents of children who are deaf/autistic (Perry et al., 2019; Starr & Foy, 2012). The purpose of this qualitative phenomenological case study is to achieve an understanding of the perceptions and experiences of parents of deaf/autistic students from a school board in Ontario, Canada, and their involvement in the Individual Placement and Review Committee (IPRC) meeting. The problem to be addressed by this study is that parents' perceptions about their participation in the IPRC process for their child who is deaf/autistic are not currently represented in the literature. Interviews were conducted with 3 parents of students who are deaf/autistic and have participated in an IPRC meeting. Data were also collected via surveys and a review of documentation. Understanding the perspectives of these parents revealed important information about barriers and facilitators to their participation. Although all parents participated in the meetings, their ability to collaborate with the IPRC team was hindered by factors such as language barriers, lack of knowledge and what appeared to the parents as pre-determined placement decisions. Based on the analysis of the data, an Organizational Improvement Plan was provided with suggestions for improving the IPRC process and developing and increasing the supports for the families, schools and, ultimately, the students.

Keywords: autism, deaf, hearing loss, parents, placement, decision-making, IPRC

Chapter One

"If you've met one person with autism,

you've met one person with autism."

-Dr. Stephen Shore

There has been a population of students within the education system who present with a unique set of strengths and challenges. They are a low-incidence group, yet each student, like all other students, is entitled to equitable access to education. Students who are both deaf and autistic do not receive consistent and comparable support across the school boards and Canadian provinces/territories (Parekh & Brown, 2018). Students who are deaf/autistic are considered low incidence because they have a low rate of prevalence and the disabilities are less common within the general population (Low Incidence, n.d.). The opening quote highlights how each individual with autism is unique, just as each individual with a hearing loss is unique, as is each individual without hearing loss or autism. By looking at each student as an individual with unique strengths, it is possible to use this lens to help break down visible and invisible physical, social and emotional barriers. Removing the barriers that stop or deter students and their families from accessing inclusive education is essential and a matter of law in Canadian schools (Lord, 2020). In the same way that this group of students is a low-incidence population, so too are their parents. "Students with low-incidence disabilities, as mentioned, are a much smaller group than the typical population of students and have unique specialized needs. Their parents consequently are a much smaller group with a small voice" (Brackenreed, 2019, p.101).

> Families are excellent resources for information regarding the day-to-day needs of their children. Information gained from families can help us identify appropriate research questions as well as guide clinical programs and educational settings. Without a clearer

> understanding of this dual diagnosis, it is challenging to move forward our understanding of appropriate interventions for the dual diagnosis. (Wiley et al., 2013, p.41)

This study focused specifically on the barriers faced by parents and caregivers of children who are both autistic and have hearing loss during the Identification Placement and Review Committee (IPRC) meetings. It was driven by the focus of exploring the complexities and the unique challenges created by the interaction of hearing loss and autism. There is a dearth of research regarding parents of students who are deaf and have additional disabilities, and even less information is available on their experience in the educational decision-making process (Singer et al., 2020). The following sections of this chapter will briefly introduce the issues of prevalence and the paucity of research in this field, both of which support the need for further investigation into this low-incidence population. A brief comparison between the special education processes in Canada and the United States will be reviewed. This chapter will also present the problem and purpose statements for the study. Finally, the chapter will conclude with the national and situational contexts related to this research topic as well as the personal context of the researcher.

Problem Statement

The problem to be addressed by this study is that parents' perceptions about their participation in the IPRC process for their children who are deaf/autistic are not currently represented in research and literature. Understanding the perspectives of these parents may reveal important information about possible barriers to parent participation for other families and administrators looking to improve parent participation in the IPRC process for children identified with both hearing loss and autism.

Purpose Statement

The purpose of this phenomenological collective case study was to describe the process involved in the identification, placement and review process for the parents of three students who are deaf/autistic and who attend a public school board in a metropolitan city in Ontario, Canada.

Disability Language and Definition of Terms

Addressing the use of language and terminology related to hearing loss and autism in children is essential prior to further exploring the subject of this study. This study focuses on parents of students who are both deaf and autistic. To clarify, the term *parent* is used to include parents and guardians.

Much of the discussion surrounding terms and phrases used related to hearing loss and autism concerns the juxtaposition of the medical versus social model and its implications on language. There is significant discussion among individuals and groups within the disabled communities about whether people-first or identify-first language is preferred (Canadian Autism Spectrum Disorder Alliance, 2020). People-first language puts the individual before the diagnosis, with the intention being to avoid the use of labels (Perry, 2021). Identity-first language places the descriptor first and it is more common among specific disability communities. In this view, disability is positioned as an identity (Perry, 2021). When discussing autism, this means referring to an individual as an Autistic person or a person with autism. The author acknowledges and respects that while this is a personal preference, for the purpose of clarity during this paper, person-first language will be used.

The terms autism, autism spectrum disorder (ASD) and autism spectrum condition appeared regularly throughout the researcher's extensive literature review (Bottema-Beutel et al., 2020). "While the Public Health Agency of Canada references the DSM 5 in classifying autism as a disorder, many autistic people prefer the terms neurological *difference* or *condition,* which removes the negative associations with the word *disorder*" (Autism Ontario, n.d.). With the move from a deficit model towards a model which views autism as a difference, many individuals have moved away from using the term disorder to using condition or even to using simply the term autism (Bell, 2020; Monk et al., 2022). As with other terms related to groups of individuals, it is advised to ask and respect each individual's preferences (Monk et al., 2022). For the purposes of this research and to maintain clarity, the term autism will be used, however, the author recognizes each individual's personal choice.

There are several terms used to refer to individuals with hearing loss. Most are born out of the medical view of hearing loss and describe the individual's hearing in relation to aspects such as the severity of the loss. The term hearing impaired can still be noted in older studies; however, due to its implication of a deficit, it is rarely used in formal, current research. Hearing-impaired or impairment appears in this paper only when referencing its use in another study. When referring to test results and medical assessments, the terms atypical hearing, hearing loss and typical hearing are often used. These terms represent a move from the deficit view of hearing to a psychosocial model view ("Recommended Terminology When Referring to Hearing Differences," 2023). The terms used throughout this paper will generally reflect the studies and articles from which they were taken. When the term Deaf is used with a capital D, it references members of the Deaf culture who use American Sign Language (ASL) as their primary method of communication. When the word deaf is used with a lowercase 'd', it is usually intended to refer to someone with little to no functional hearing (*Terminology*, 2015). Hard-of-hearing is often used to refer to an individual who communicates using spoken language and has a hearing loss anywhere from mild to profound (*Terminology*, 2015). Regarding the problem of practice and this current study, the terms *deaf* and *hearing loss* will be used throughout this paper to encompass all members of the Deaf community and deaf and hard-of-hearing individuals and to maintain consistency. The intention is to be inclusive and respectful of all individuals. However, the term deaf/autistic was chosen to represent the students being discussed in this study for the purpose of clarity.

Hearing Loss, Autism and Deaf/Hard-of-Hearing with Disabilities

Hearing Loss

There are several aspects to describing one's hearing status. It is not usually an all-or-nothing situation for individuals who experience hearing loss. There are three ways to categorize hearing loss: conductive, sensorineural and mixed (Lim & Goldberg, 2020). A sensorineural hearing loss involves damage to hair cells in the cochlea while a conductive loss is due to an issue with sound waves traveling to the inner ear. A mixed hearing loss is a combination of the two types of hearing loss (Tanna et al., 2023). Hearing thresholds are described in decibels from normal (ranging from 0-15 dB) to profound (ranging from 91-120 dB), and ranges often vary slightly from organization to organization (*Levels of Hearing Loss in Children*, 2015; Boys Town National Research Hospital, n.d.). An individual may experience hearing loss bilaterally or unilaterally, and the thresholds and configuration may be the same in both ears, or it may be different (*Hearing Loss in Children*, n.d.). Another way to report on hearing is by calculating the Pure Tone Average. "A Pure Tone Average (PTA) refers to the average of hearing threshold levels at a set of specified frequencies: typically, 500, 1000, 2000 and 4000 Hz. This value gives a snapshot of an individual's hearing level in each ear" (Lefrançois, n.d.).

Autism

In 2013, the DSM 5 was released with updates to the definition of autism (Hyman, 2013; Centers for Disease Control and Prevention, 2022). The new definition described autism spectrum disorder as “a set of atypical neurodevelopmental conditions (as opposed to the neurotypical conditions present in the general population) characterized by persistent impairment in social communication and interaction, as well as restricted, repetitive patterns of behavior, interests or activities” (Heifetz, 2022). Previously existing subtypes, which included Aspergers and pervasive developmental disorder, were integrated into the characteristics of the one label of autism. To meet the criteria of the new definition of autism, “a child must have persistent deficits in each of three areas of social communication and interaction plus at least two of four types of restricted, repetitive behaviors” (Centers for Disease Control and Prevention, 2022). Three levels of required support distinguish the degrees of autism. Each of the three levels of severity is defined by characteristics and features of social communication and restricted and repetitive behaviours. The third level, for example, includes individuals who ‘require very substantial’ levels of support, while level one includes individuals who are defined as ‘requiring support’ in their daily lives (Autism Speaks, 2013). “For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches” (Autism Speaks, 2013) is considered level three.

Both hearing and autism can be defined using two different approaches. The medical model presents both in a clinical manner, referencing terms such as disorder or impairment. The medical definition of autism is based on criteria from the DSM 5. Autism is a neurological condition which exists along a continuum, which means that individuals will experience differences in the characteristics and features in varying degrees and will need varying levels of support. The existence of an additional and co-occurring condition, such as hearing loss, will impact the way an individual experiences autism. Provincially, Ontario also discusses autism using a medical model perspective. “The Ontario Ministry of Education’s monograph on students with autism lists “learning problems” and “significant impairments” that students with autism face (Ontario Ministry of Education, 1990)” (Lord, 2020, p.337).

The medical model of hearing frames differences using a deficit view. Hearing loss and hearing impaired are terms often used to describe atypical hearing. Audiograms present a medical view of hearing loss, providing a technical description of an individual’s frequency and intensity thresholds. This model focuses on fixing the disability through the use of medical interventions or treatments.

The social model of disability views autism and hearing loss as conditions caused by the way society is structured (Grover, 2021). In a school setting, the social model views the environment as the issue rather than the individual (Stoyles, 2022). A student who is deaf/autistic would be challenged due to a lack of the necessary accommodations within the class to meet their needs. In this model, the term exceptionality is used as opposed to the more commonly used medical term, diagnosis. During the IPRC process in Ontario, the committee determines whether or not the student will be identified with an exceptionality. The IPRC process will be explained in further detail later in this chapter. “The categories of exceptionality are based on student learning needs and not diagnosis. For example, students with Autism Spectrum Disorders are identified under the Communication category as their learning needs are impacted by the disruption of their communication skills” (Morse, 2015, What is the link between a medical diagnosis and exceptionality? section).

Deaf/Hard-of-Hearing with Disabilities

Over the last several years, many different terms have been used to refer to students with hearing loss who have one or more additional disabilities. This population of students includes the smaller unique subset of students who are deaf/autistic. Terms and phrases found in the literature to refer to this population have included Deaf Plus, D/HH Plus, deaf with additional disabilities, deaf and diverse, and complex deaf (Borders et al., 2020; Bowen & Probst, 2023). Many educators and researchers now use the terms deaf/hard-of-hearing with a disability (DWD) or d/Deaf and hard-of-hearing with a disability/disabilities (DWD) to be more inclusive of individuals who identify as members of the Deaf culture (Guardino & Cannon, 2015; Paul, 2015). This study uses the term deaf/hard-of-hearing with disability (DWD) unless quoting directly from a source, in which case the author's original term is used.

The combination of hearing loss and autism can create situations which require unique and specific diagnostic techniques, educational strategies, educators, support systems, and possibly placements. The need for services and support extends to parents and caregivers in addition to the students who are deaf/autistic. As previously mentioned, the combination of hearing loss and autism is not additive (Bowen & Probst, 2023). Each individual is unique and differs in the manner in which they experience the characteristics of the neurological differences associated with autism, the support they require and their hearing thresholds. Due to their unique communication needs and other obstacles, such as the need to attend frequent appointments, students who are deaf/autistic are often challenged to fit into the traditional support programs intended for students with hearing loss only (Singer et al., 2020).

Determining prevalence data for students who are DWD has been extremely difficult. Prevalence estimates have ranged from 25-50% (Whicker et al., 2019; Bowen & Probst, 2023). It has been suggested that the reported rates may be low due to issues such as students receiving an exceptionality of multiple disabilities rather than the exceptionality of deaf/hard-of-hearing along with a second one (Musyoka et al., 2017). It may also result from a student receiving an exceptionality based on the primary disability (Bowen & Probst, 2023). Current knowledge of the number of DWD students across the United States almost exclusively is still derived from the Gallaudet Research Institute's final survey data suggesting that 40% of students who are deaf have at least one additional condition or disability (Gallaudet Research Institute, 2013). In their recent study conducted in 2023, Peterson et al. found close to 65% of students who are deaf/autistic had one or more disabilities.

The educational implications for students who are DWD extend to the parents as well. Whicker et al. (2019) discussed parents of children who are DWD and their relationships with pediatric audiologists. They noted that these parents “experience a significantly increased amount of stress compared to parents of children with hearing loss alone” (Whicker et al., 2019, p.5). A unique approach sensitive to the families' emotional needs may be required to create a successful and collaborative partnership to plan for DWD students (Whicker et al., 2019).

Contextual Background

National Context

The Canadian government sets out legislation regarding removing barriers and improving access for individuals with disabilities. Each province or territory is responsible for its governance specific to implementing education-related legislation (Brackenreed, 2019).

> The right to education of children with disabilities is protected by several pieces of international legislation: the International Covenant on Economic, Social and Cultural Rights (1966), the Convention on the Rights of the Child (1989), and the United Nations' Declaration of the Rights of Persons with Disabilities (2006). (Towle, 2015, p.8)

By presenting the overarching approach to disability rights, the Canadian government sets a tone for how each province should implement educational legislation for students with disabilities. The Federal government does not address education specifically, the interpretation is left up to each Ministry/Department of Education.

Concerning children with hearing loss, the most apparent difference between provinces/territories has been the implementation of the Early Hearing Detection and

Intervention programs (EHDI). The goal of the program is to address infant hearing issues proactively. As of 2019, seven out of the 13 provinces/territories in Canada were deemed 'insufficient' on the report card created and graded by the Canadian Infant Hearing Task Force (Speech-Language & Audiology Canada & Canadian Academy of Audiology, 2019). Each province/territory is graded on five different components. The goal of the EHDI is to focus proactively on infant hearing by concentrating on five different components. The five components are: “1) universal hearing screening of all newborns; 2) identifications of babies with permanent hearing loss; 3) intervention services which include support for technology and communication development; 4) family support; and 5) monitoring and evaluation of the program” (Speech-Language & Audiology Canada & Canadian Academy of Audiology, 2019, para.1). The provinces/territories have been graded, receiving either sufficient or insufficient, based on how successful they have been in having all five of the components available province/territory-wide. In a 2019 report card created by the Canadian Infant Hearing Task Force, the province of Ontario was found to be ‘sufficient’. Ontario was found to have 94%+ babies screened, all EDHI components province-wide, clinical protocols were implemented and monitored, and their database tracked and monitored outcomes. Overall, Canada received a grade of insufficient (Speech-Language & Audiology Canada & Canadian Academy of Audiology, 2019).

The variation between two Eastern provinces in their autism-related services was noted by Smith et al. (2020). In their study, they found that New Brunswick and Nova Scotia, two provinces adjacent to each other and have similar populations, had differences in autism services, including receiving a diagnosis, eligibility criteria for program placement, as well as wait times and variability in treatment programs.

Each provincial/territorial government is responsible for creating and implementing legislation related to special education. As a result, variations in the implementation of special education can be seen between provinces/territories. An example of this is the presence of the Individual Education Plan (IEP) in only select provinces/territories. Variations also exist in how students with additional needs are accommodated within the school system and how each province/territory defines inclusive education (Towle, 2015). "Despite, or perhaps because of, a lack of a national strategy for inclusion, boutique programmes have been introduced within various provinces that serve as exemplars of the innovation and creative ways Canadians approach academic and social inclusion" (Sokal & Katz, 2015, p.43). The provincial/territorial service variations are a result of various factors, including inconsistent eligibility criteria for intervention and specific treatment models (Smith et al., 2020). *Learn Canada 2020* is a framework established by the Council of Ministers of Education, Canada, which recognizes the federal government's role in education and the direct link between education and economic development. As part of the council’s pillars of lifelong learning, the provincial and territorial ministers of education who constitute the council recognize that children deserve inclusive learning environments (Council of Ministers of Education, Canada, 2008). Ontario, for example, a province in Eastern Canada, has a Ministry of Education which is “responsible for childcare and for administering the system of publicly funded elementary and secondary school education” (*Education in Ontario*, 2016, Ministry of Education section).

In Canada, it is impossible to locate federal data or any provincial data regarding the education of students with hearing loss. There are no readily available data, for example, which relay information about how many students are being educated in the general classroom or the number of trained teachers of deaf and hard-of-hearing students. “In Canada, the data does exist, but is located in disparate places with little coordination between the data collected by the fields of education and health care” (Millett, 2019, p.1). According to Millett (2019), the data being received by the Ministry of Education in Ontario is derived from the number of claims processed for assistive hearing technology used in the classroom for students who are deaf, and from the IPRC meetings where students receive their educational label of deaf/hard-of-hearing and their educational placement. However, there are students who have hearing loss who do not use assistive technology in the classroom, and there are students who do not have hearing loss who do use the technology. As such, the numbers do not accurately reflect the number of students with hearing loss in a particular board. There are also students who are deaf who may receive services from a school board but have not been brought to IPRC.

Prevalence of Autism in Canada

The most current data available on the prevalence of autism in Canada was collected in 2019 and indicates that 1 in 50 children and youth aged 1 to 17 had received a diagnosis of autism spectrum disorder (Public Health Agency of Canada, 2022). The same report also shared a breakdown of the prevalence rates by provinces and territories. Ontario's rate was 2.1%, just marginally above the 2.0% Canadian average (Public Health Agency of Canada, 2022). This report differs from an early statistic from the National Epidemiologic Database for the Study of Autism in Canada (NEDSAC), which found a 1 in 94 estimate for Canada (Fitzpatrick et al., 2014). One possible explanation for the discrepancy is the sample being documented. The data collected by Public Health Canada were based on youth ages 1 to 17, while the statistics compiled by NEDSAC focused on children between 5-9 years old. Beers et al. (2014), in their review of the literature surrounding autism and peripheral hearing loss, noted the increasing rates of autism in 2000 and referenced other studies which suggested the explanation might be due to both an increased awareness of autism as well as the broadening of the diagnostic criteria.

Prevalence of Hearing Loss in Canada

There are currently no definitive estimates of the prevalence rates of hearing loss using direct measures in the school-age population in Canada (Feder et al., 2017; Millett, 2019). The most recent statistics available from Statistics Canada were shared in 2015. While data disaggregated by age is available, it does not provide the school-age population in its separate category. Statistics Canada (2015) reported that 30.1% of men and women aged six to 79 had low-frequency hearing loss, 52.9% had high-frequency hearing loss, and 34.8% had speech-frequency hearing loss. This statistic does not provide information on the severity of the hearing loss. In 2017, Feder et al. conducted a cross-sectional population-based study to estimate the Canadian prevalence of hearing loss in children and adolescents. Their findings showed that 7.7% of Canadian youth between the ages of 6 and 19 had some hearing loss in one or both ears. “It is well known that hearing loss estimates for children/adolescents vary considerably across studies due to differing definitions of hearing impairment, variable age ranges, small sample sizes, selection bias, and inadequate sampling procedures (Bess et al. 1998; Lieu 2004; Mehra et al. 2009)” (Feder et al., 2016, p.14).

Collecting prevalence data on hearing loss, specifically for Ontario, has been slightly more successful than collecting national data but still challenging. “In Ontario, one might expect that the Ministry of Education has a count, but in reality, what data it possesses is flawed to the point of being unusable” (Millett, 2019, p.3). The information is collected via both the IPRC process and the claims process of the Specialized Equipment Amount (SEA). The SEA is a fund specifically allocated to the provision of equipment which is needed to accommodate students with special needs (Ministry of Education, 2022a). The collection of information via the IPRC and SEA data is not a comprehensive method, as there are deaf students who do not participate in either process and, as such, are not counted (Millett, 2019). Students who are deaf may receive services without being identified through the IPRC. Some may not use specialized equipment, such as a personal remote microphone system, so there would be no record via the specialized equipment claims process.

Prevalence of the Deaf/Autistic Dual Diagnosis in Canada and the United States

There are no definitive statistics regarding the number of children diagnosed with hearing loss and autism. Some researchers have suggested that autism is more prevalent within the deaf population (Do et al., 2017; McFayden et al., 2023). The difficulty in discussing prevalence and co-occurrence in these two populations is the challenge of diagnosing autism or hearing loss once the other has already been diagnosed (McFayden et al., 2023). Numerous studies have shown that autism is often diagnosed later in children with hearing loss than those with typical hearing (Fitzpatrick et al., 2014; Szarkowski et al., 2014).

There have been Canadian and American-based studies which have commented on the prevalence of hearing loss among individuals who have autism. In their Canadian-based studies, Beers et al. (2014) did not find any conclusive evidence that an increased prevalence rate exists, while Szarkowski et al. (2014) shared reports from other American-based studies regarding higher rates of autism diagnoses among students who are deaf as compared to the population with typical hearing. Szarkowski et al. (2014) note that there is minimal research on this population, making data very scarce. Fitzpatrick et al. (2014) conducted a retrospective chart review using a Canadian sample. They found results consistent with the Gallaudet Research Institute survey, which suggested a higher prevalence of autism in children with hearing loss (Gallaudet Research Institute, 2013). At one time, it was estimated that 9% of children who were deaf receiving special education services were also identified with autism (Young et al., 2019). However, it has been challenging to compile and report on these rates and gain consensus (Nelson & Bruce, 2019).

There are no current statistics on the number of children who are diagnosed both deaf/autistic in Canada or in the United States. The most recent numbers were published by the Gallaudet Research Institute (GRI), and according to their data, 1 in 59 children with hearing loss also have autism (Gallaudet Research Institute, 2013). Their 2013 survey published data suggesting a higher rate of autism within the deaf population (Gallaudet Research Institute, 2013). In December 2021, the Center for Disease Control (CDC) released new numbers reporting that 1 in 44 children were identified with autism, a change from the previous 1 in 54 in 2016 (Centers for Disease Control and Prevention, 2021). While there are no definitive rates of prevalence, it would be a reasonable hypothesis that as the rate of autism increases, the number of children who have both hearing loss and autism would also increase.

There is a dearth of general research regarding students who are both deaf and autistic This lack of research is even more pronounced when looking at information about how to support them and their families within the school setting (Wiley et al., 2018; Hansen & Scott, 2018). The absence of data specific to the Canadian context makes it necessary to generalize from studies conducted in other countries. Research into similar areas of education has extended to examining the parents' perceptions of students with various disabilities and challenges. However, the investigations have not yet been extended to include parents of students who are both deaf/autistic (Perry et al., 2020; Starr & Foy, 2012). The inconsistent and inequitable access to education, the absence of up-to-date and accurate prevalence data, and the lack of research to inform practice, combined with the increasing number of students who are deaf/autistic, make it imperative to focus on these Canadian students and their families.

Situational Context

The province of Ontario follows detailed legislation regarding special education procedures. In particular, Ontario implements a comprehensive set of guidelines concerning the identification and placement of students (Paré, 2015). The Ministry of Education (MOE) is responsible for overseeing all aspects of Ontario's public education system. School boards in Ontario follow the rules laid out in Ontario's Education Act (Government of Ontario, 2001). Within the Education Act are regulations and policy/program memoranda (PPM), as well as policy and resource documents which pertain specifically to special education. Regulation 181/98: Identification and Placement of Exceptional Pupils outlines the details and information regarding the IPRC process (Government of Ontario, 2001). This regulation ensures consistency in how the IPRC meetings are structured; however, no regulations address the follow-up once the decision has been made. "The IPRC is a legislated team that undertakes the task of formally identifying whether or not a student in the Ontario school system is considered exceptional, including students diagnosed with autism spectrum disorder" (Maich & Hall, 2016, p.247). PPM No.140 includes requirements for the use of applied behaviour analysis (ABA) methods in the support of transitions for students with autism (Ministry of Education, 2017). There are 72 school boards in Ontario, including 31 English public boards, 29 English Catholic boards, four French public boards, and eight French Catholic boards (How Ontario's Education System Works | Publicly Funded Education, 2017).

The Individual Placement and Review Committee Process

The Individual Placement and Review Committee (IPRC) process is mandated by the province of Ontario's Ministry of Education. The Ministry of Education sets the standards, laid out in regulations found in the Education Act (Government of Ontario, 2001). Parents have the right to request that an IPRC be held for their child. The school board must provide parents with a copy of their parent guide, prior to the meeting, explaining the IPRC process (Ministry of Education, 2023c). During the IPRC meetings, students may be identified by the committee as exceptional and receive one or more exceptionalities. There are five categories of exceptionality: behavioural, communicational, intellectual, physical, and multiple. Subcategories exist within the categories. Both Deaf and hard of hearing and Autism are subcategories within the Communicational category (Ministry of Education, 2023a). If the IPRC identifies a student as exceptional, then a discussion and decision about an appropriate placement takes place. When deciding on placement for the student, the regulations require that the committee first consider placement in a regular class with appropriate education services. Should they decide after considering all the information a regular placement is the most appropriate for the student, then a decision to place the student in a special education class is made. However, the committee must explain its reasons for the decision in writing. (Government of Ontario, 2023a).

There are five placement options from which the committee can select. The first three involve the student remaining in the regular class. The first placement option, a regular class with indirect support involves the student remaining in the regular class for the full day while the classroom teacher is supported with specialized consultative assistance. A regular class with resource assistance provides the student with specialized support either as part of a group or individually, within the classroom, from a qualified special education teacher. The third option, regular class with withdrawal support, provides the student with instruction from a qualified special education teacher outside of the classroom, for less than 50 percent of the day. The remaining two options require the student to be placed in a special education class. A special education class with partial integration placement requires that the student spend at least 50 percent of the day in a special education class with a low student-to-teacher ratio, as outlined in the standards of O. Reg. 298, section 31 of the Education Act (Ontario Education Act, 2023). The student must be integrated for a minimum of at least one instructional period into a regular class. In the final placement option, the student is placed and spends the entire day in a special education class with a low student-to-teacher ratio. This final placement is also referred to as a full-time special education class. Outside of these placements, a parent may explore the “Provincial Schools for students who are Deaf, blind or deafblind or a Demonstration School for students who have severe learning disabilities” (Government of Ontario, 2023a, the IPRC placement decision section).

A review of a student’s placement can occur any time after the student has been in the placement for a minimum of three months (Government of Ontario, 2023b). There must be an IPRC review at least once a year unless the parent chooses to waive the review, in writing. The purpose of the review meeting is to discuss and review the placement and identification decisions and determine if they are still relevant or if they require revision. The process and regulations of the yearly review meetings are similar to those of the IPRC meetings (Government of Ontario, 2023b).

In Ontario, students do not have to be identified to receive special education services. “An IEP may be developed for a student who has not been identified by an IPRC as exceptional, but the board deems to require a special education program or services to: attend school, achieve curriculum expectations, [or] demonstrate learning” (Ministry of Education, 2022c, The IEP Process section). Students who are working at the same educational curriculum level as their classmates but require accommodations to access the curriculum can receive an IEP without requiring an exceptionality. Approximately half of the students receiving services have obtained an exceptionality through an IPRC process (Ministry of Education, 2022b). By default, the other half who are receiving special education services have not obtained an exceptionality. For students who have not been identified as exceptional, the IEP “is developed [by] the principal, in consultation with members of the In-School Team (IST) or School Support Team (SST) (Toronto District School Board, 2023, p.169). The rules and regulations outlined in the Education Act, which apply to the IPRC process, require schools to provide information to parents regarding special education services (Government of Ontario, 2001). The same requirement is not in place for students not formally identified as exceptional. As such, parents of students who access special education services but have not been formally identified as exceptional may not have received information from the school board regarding the process or procedures involved in meeting their child's specific needs. In Ontario, a student can still receive special education services as listed in an IEP without having received a formal identification from the IPRC. Forty-four percent of students enrolled in special education programs in Ontario in 2012/13 possessed an IEP in the absence of a formal identification (Maich & Hall, 2016). In a 2016 report on special education services in Ontario, the rate noted by Ferenczy (2016) was 52% of students who had been identified, an increase of approximately 4%. Deaf/hard-of-hearing students do not require formal identification to receive special education services, including remote microphone systems through the specialized equipment claims program (Millett, 2019).

A student who has received a medical diagnosis of autism may not receive an identification of autism under the Communication exceptionality from the IPRC team if it is decided that it is not impacting their school performance (Maich & Hall, 2016). Clarifying the distinction between diagnosis and exceptionality is essential to better understanding the IPRC process. Maich & Hall (2016) explained that clinicians diagnose while the IPRC team identifies, and their roles "differ in process, purpose and outcome" (p.247). "There are two components to the definitions of the exceptionality. The first is the definitions provided by the MOE, and the second is the more detailed criteria used by each school board. The Ministry definitions are fairly broad, and the school boards have developed their own criteria to support the process of identification" (Morse, 2015, Where Can I Find the Definitions of the Categories of Exceptionalities section). Students receive an identification based on which area impacts their learning needs. For this reason, students with autism are identified under the Communication category (Morse, 2015).

The Ministry classifies 5 categories of exceptionalities, which are intended to encompass all of the conditions that impact a student's ability to learn and include all medical conditions (Ministry of Education, 2022b). A student can be identified in more than one area of exceptionality. Whether a student receives special education services is based not on a medical diagnosis but on determining a student's strengths and needs (Ministry of Education, 2022b).

Canadian / United States Frame of Reference

The IPRC process in the province of Ontario is similar to the Individualized Education Program (IEP) outlined by the Individuals with Disabilities Education Act, which is mandated federally in the United States (U.S. Department of Education, 2019a). The differences, however, extend beyond which level of government oversees the process (see Table 1.1). In Canada, specifically Ontario, the IPRC refers to the process and the IEP refers to the product. The IEP is a written plan that outlines the accommodations and services being provided for a student, by the school, as part of their special education plan (Justice for Children and Youth, 2021). In the United States the IEP is used to refer to both the process and the product created at the meeting. While there is variation between the provinces and territories in Canada, for this study, Ontario is referenced as the Canadian comparison to the Individual Education Program (IEP) in the United States.

The most notable difference is that in Ontario, the IEP is not completed at the time of the team meeting; instead, it is completed following the meeting by the teacher with input from the parent and any special education staff involved. In cases where students receive withdrawal of special education support, such as itinerant services from an itinerant teacher for students who are DHH, the IEP would be completed by that teacher with input from the parent and in collaboration with the classroom teacher (Ministry of Education, 2017). Other significant differences between the two countries are related to the members who are required to attend and the use of a case manager in the United States to coordinate the meeting and act as a point of contact for the parent. The term IPRC will be used throughout this study unless referring to a study or research that explicitly references the IEP meeting. A more detailed comparison of the IPRC process and the IEP meeting can be found in Table 1.1.

Table 1.1

Comparison of Individual Placement Review Committee Process and Individual Education Plan Meeting

Element	Initial Individual Placement and Review Committee (IPRC) Process (Canada)	Initial Individual Education Plan (IEP) Meeting (USA)
Purpose	To determine if a student is 'exceptional' or not based on 5 categories of exceptionality To decide appropriate placement To offer placement to parent (Government of Ontario, 2001)	To determine if the student qualifies for special education based on eligibility categories To discuss student's needs based on any recent evaluations To determine decisions about educational programs To develop the IEP
Attendees	Minimum of 3 people (1 of whom must be a principal or supervisory officer) Parent is entitled to attend Student's teacher, special education staff, board support staff may attend in addition to the 3 required individuals Representative of the parent may attend Interpreter for the parents must be provided if needed	School district representative (with power to approve services and resources) - required Parent or guardian– required At least one of the student's general education teachers -required At least one of the student's special education teachers – required

Element	Initial Individual Placement and Review Committee (IPRC) Process (Canada)	Initial Individual Education Plan (IEP) Meeting (USA)
	Other individuals whose presence is requested by either the parent or the principal of the student's school (subject to approval from the IPRC chair) (Government of Ontario, 2001)	Interpreter for the parents must be provided if needed An expert in the field who is able to interpret the student's evaluation results (this could be the special education teacher if that person is able to, or another member of the team who is qualified) – required Student (at age 16, or early if ready) Others may be invited (such as a health care provider invited by the parent, or an advocate or friend invited by the parent) If both parents and school agree, a member can be excused
Exceptionalities (CDN)[a]/ Conditions (US)	Behavioural Behavioural exceptionality Communicational Autism Deaf and hard-of-hearing Language impairment Speech impairment Learning disability Intellectual Giftedness Mild intellectual disability Developmental disability Physical Physical disability Blind and low vision Multiple Multiple exceptionalities	Specific learning disability Other health impairment Autism spectrum disorder Emotional disturbance Speech or language impairment Visual impairment including blindness Deafness Hearing impairment Deaf-blindness Orthopedic impairment Intellectual disability Traumatic brain injury Multiple disabilities

Element	Initial Individual Placement and Review Committee (IPRC) Process (Canada)	Initial Individual Education Plan (IEP) Meeting (USA)
Placement	When making placement decision, before deciding on a special education class, the committee first considers the option of a placement in a regular class (with appropriate special education services) If the committee decides to place the student in a special education class, the reasons for that decision should be stated	When making placement decision, before deciding on a special education class, the committee must first consider the option of a regular education classroom and if the IEP goals and objectives can be achieved with the help of supplementary aids and services If the team agrees this cannot be achieved satisfactorily, then they decide the route that allows for integration with peers without disabilities to the maximum extent possible and as close to his/her home school as possible
Decision	The statement of decision will note the decision of identification and placement and any recommendations regarding special education programs and services Parent may file a notice of appeal related to the placement or the decision to identify the student as exceptional or to NOT identify the student as exceptional	The product of the meeting is the IEP document which reflects the decisions of the meeting
Case Manager	Used inconsistently from school board to school and from province/territory to province/territory Not a mandated role in the IPRC process	Usually a special education teacher (may or may not be someone who works directly with the student) Ensures that services and supports are being implemented Parent’s first point of contact

Element	Initial Individual Placement and Review Committee (IPRC) Process (Canada)	Initial Individual Education Plan (IEP) Meeting (USA)
		May be responsible for coordinating assessments, future IEP meetings, collecting updates and information from staff
After the Meeting	IEP will be created by teacher(s) at the student's new school placement	

[a]categories and subcategories

Ontario Public School Boards

The Toronto District School Board (TDSB) is the largest of the school boards and is also the largest school board in Canada. The creation of TDSB on January 1, 1998, resulted from the amalgamation of six school boards from the Toronto region. Services for students with hearing loss and autism became centralized in one office, now serving a city that previously covered six school boards. Centralizing the services allowed for consistency in the procedures and routines followed and provided. A challenge, however, became and continues to be meeting the needs of the highly diverse population of families that spans this large board. Every school board in Ontario is required to offer special education services for those students who require them. Falling under the MOE's roles and responsibilities is determining categories and definitions for special education exceptionalities. Although these categories and terms are used primarily consistently across school boards in Ontario, the placement and learning conditions each board implements tend to vary (Parekh & Brown, 2018).

In 2022-2023 the Toronto District School Board published a fact sheet about students with special needs in the board. 40, 577 of the 236, 073 total TDSB student population were students with special needs (Toronto District School Board, n.d.). The Peel District School Board reports just over 153,000 students, with over 10,000 receiving special education services (Peel

District School Board, 2024). York Region District School Board serves nine municipalities, and as of October 2022, the school board reported 128,000 enrolled students (*York Region District School Board*, 2024). All three of these school boards are located within the GTA (*City of Toronto*, 2021). “The Greater Toronto Area is comprised of Canada’s biggest city by population, the City of Toronto, and 4 surrounding Regional Municipalities each of which have their own elected governing structure” (*Research Guides: Open Data Resources for Environmental Studies in the Greater Toronto Area: What Is the GTA*?, 2024, para. 1). Based on data regarding the average daily enrolment of pupils in the school board, from an Ontario Ministry of Education publication sharing projected board-by-board allocations of the Grants for Students’ Needs, a funding formula used by the Ministry of Education to determine grant allocations and other information for the 2023-2024 school year, these three boards, are considered to be the largest public English school boards in Ontario (Ministry of Education, 2023b). All three of these school boards are located within the GTA (*City of Toronto*, 2021). The results of the 2021 Census of Population brought attention to the cultural and linguistic diversity of this area of Ontario which is the home of its three largest school boards (Statistics Canada, 2022). Also reported in the 2021 Census of Population was data regarding the respondents’ language. Approximately half of the total 2, 772, 630 respondents from the GTA said that English was their mother tongue (Statistics Canada, 2022). In their phenomenological study, Wesely (2018) investigated the implications of a difference in the language of schooling and the home language and noted the impact on parent decision-making, parental communication, and collaboration with schools. Awareness of the cultural and linguistic diversity of the students and their families who constitute the student body and school community is important (Lasky & Karge, 2011).

Personal Context

Since beginning my career in deaf education, I have taught in both full-time special education special education classes and worked as an itinerant teacher for students who are DHH. In both roles, I worked with students who were engaging and eager to learn and who also had areas of challenge in addition to their hearing loss. In my current position as a special education itinerant teacher for students who are DHH in Ontario, Canada, I have witnessed the number of students on my caseload who are DWD grow from year to year. The specific population of students, however, which seems to be growing at a faster rate, are those who are both deaf/autistic.

As an itinerant teacher for students who are deaf, I have the unique opportunity to work with students from kindergarten to grade 12. I also often work with the same student(s) for multiple years, allowing me to build relationships not only with the student(s) but with their family and their non-school board support providers. The students on my caseload who are deaf/autistic are in a variety of class placements and receive a variety of support from the school board. Some students are learning in a general education class with no additional support, some receive one-on-one support for some amount of time during the day, while others learn in a full-time special education class with other students who have hearing loss and are taught by a teacher of the deaf. There are also students who are learning in a self-contained class for students with autism and are taught by a teacher who has some additional qualification courses in special education and autism. Finally, some students are learning in other self-contained classes, such as those for students with learning disabilities or mild intellectual disabilities. Full-time special education classes provide a low student-to-teacher ratio and specialized support offered by a teacher with additional qualifications in special education. Full-tine special education classes are organized by exceptionality.

Over the years, I have observed that not only is there a large variation in placements, but it is difficult to determine, based on observation, how the placement decisions were made. Having seen some of the student records, I have noted many students who moved from placement to placement, though their exceptionality category did not change. In some cases, the movement involved a change of school in addition to a change of class.

The placement of students who are deaf/autistic is an area which requires significant attention. The placement process is often the beginning of the education journey, and it is at this point where parents' input can be invaluable but is also overlooked. Unfortunately, parents have not been consistently involved in the decision-making process to determine the best educational placement for their child. I recognize the need to focus on research and expand our knowledge in this area.

Conclusion

The need to invest time and research into improving access to equitable education for students who are deaf/autistic is increasing as the population of students grows. The limited information currently available to guide the direction of administrators and educators makes it challenging for school teams to improve student outcomes based on best practices. Providing the best education for students involves ensuring that programming and placement opportunities are appropriate (Millett, 2019). To do this, it is necessary to understand the student, which includes their characteristics. Parents are vital in providing essential information about their children (Wiley et al., 2013). Focusing on the parents and exploring their lived experience of the IPRC process makes it possible to develop a more in-depth understanding of their child and their educational journey. This information is essential and helpful in planning and developing future educational opportunities.

The review of the literature in the next chapter will demonstrate the overall lack of data specific to students who are deaf/autistic. As such, research from other special education areas and other dual diagnoses will be examined in addition to the studies available in the field of students who are deaf/autistic.

Chapter 2

The previous chapter reviewed the prevalence of both autism and hearing loss in Canada with the most current and accurate statistics available. The need to delve deeper and invest time and energy researching the topic of students who are deaf/autistic and their families was examined. This chapter will provide a discussion of current issues in the education of students who are deaf/autistic, review the supporting research and synthesize them in order to provide a background for this phenomenological case study. The second section of the chapter includes the philosophical assumptions, which will present the grounding that influenced the framing of this research. As part of the philosophical assumptions, the methodological rationale is presented, followed by the theoretical framework. The methodological rationale provides an explanation and justification for the study's research design. The theoretical framework, which discusses the theories underpinning the study, provides a foundation upon which the information and research were built.

Research in the field of students who are deaf/autistic is still relatively new. "There is a significant lack of evidence guiding our understanding of the needs of families of children who are deaf/hard of hearing (Deaf/HH) with an autism spectrum disorder (ASD)" (Wiley et al., 2018, p.378). Due to the heterogeneity and low-incidence of the population, most studies involve small sample sizes. Both hearing loss and autism exist on a spectrum and so, finding a homogeneous sample upon which to conduct a quantitative research study is challenging. Most articles and studies found in peer-reviewed journals are examples of descriptive research. They tend to be either qualitative or mixed in their design. Audiologically focused studies which examine the relationship between hearing loss and autism, the relationship between hearing thresholds and severity of autism or prevalence rates have larger samples than other deaf/autistic-related research (Beers et al., 2014; Fitzpatrick et al., 2014; Feder et al., 2017).

Retrospective chart reviews, population-based studies, and descriptive/exploratory studies are common and often have a larger sample (Feder et al., 2017; Fitzpatrick et al., 2014; Scott & Hansen, 2018). The sample sizes continue, however, to be smaller than those seen in the general education research field. Samples are small regardless of whether the study focuses on the professionals or the families of the students because the population being examined is a low-incidence one. In their study, Scott & Hansen (2018) surveyed 70 teachers across 25 different states, working with students who were both deaf/autistic. The researchers commented on the size of their sample, acknowledging the small size, however pointing out that the Gallaudet Research Institute survey (2010) reported approximately 563 students total who were both deaf and autistic within the elementary and secondary school system (Scott & Hansen, 2018). Unfortunately, using a small sample made generalizing the results beyond the examined group difficult. Case studies are also extremely common in this area of research as the approach lends itself to the investigation of “a real-life, contemporary bounded system (a case) or multiple bounded systems (cases) over time...” (Creswell & Poth, 2018, p.96).

While the sample size made generalizing results challenging, there are other challenges besides this. The variation within characteristics in students who are deaf/autistic makes finding a homogenous group unlikely. Hearing loss can be bilateral or unilateral and sensorineural, conductive, or mixed (a combination of both) (Centers for Disease Control and Prevention, 2023). It can present in a range of hearing thresholds: mild, moderate, severe, profound, or a combination as the thresholds change from one frequency to another (American Speech-Language-Hearing Association, 2009). Students may use a variety of hearing technology or none at all. Some may use sign language, while others choose an oral/spoken communication modality (Gardiner-Walsh & Lenihan, 2017). For students who are autistic, three levels of support are described for both the domains of social communication and restricted interests/repetitive behaviours. The DSM 5 defines criteria for diagnosis by assessing performance in the two areas (Lovering, 2022). The variance in the criteria demonstrates the range of potential combinations, reinforcing that each student is unique. Regardless of the challenges posed by the heterogeneity of the population, investigators have examined various topics, including issues surrounding the diagnosis (Handelsman, 2016), the role parents play and their perspective on how professionals manage the identification (Myck-Wayne et al., 2011). Other studies have discussed the phenomenon of diagnostic overshadowing (Fitzpatrick et al., 2014), in which a child receives a first diagnosis of either hearing loss or autism, and this initial diagnosis overshadows the second one, causing a delay in its detection. Researchers have also focused on educational practices (Borders et al., 2016), teacher preparation (Guardino, 2015), placement decisions (Guardino, 2008), parents' involvement and their perspectives on the placement process (Whicker et al., 2019).

Parents and their involvement in school, including the decision-making process and collaboration with teachers, have garnered attention and focus among researchers investigating both the general special education and deaf/autistic populations (Banerjee et al., 2016; Correia et al., 2021; Love et al., 2017; Stephens & Duncan, 2020; Stephens & Duncan, 2022). In many cases, the studies that focused on the deaf/autistic population have drawn on findings from other studies, such as those about students with autism, students with hearing loss, and students with other co-occurring conditions (Beals, 2004; Dale & Neild, 2019; Stephens & Duncan, 2022; Wiley et al., 2013; Wiley & Innis, 2014). This has been because of the limited research available on the deaf/autistic population. Patterns and themes can be noted in comparable yet distinct studies, such as those investigating the same topic with similar yet differing samples, as has been the case in research such as Individual Placement and Review Committee (IPRC)/Individual Education Plan (IEP) studies. In their research, Zaidman-Zait et al.

(2016) attempted to better understand parents' lived experiences managing their child's disability. They touched on the issue of educational needs and placement in their discussion of emergent themes. Their research sample only included families with children who had a hearing difference. Regardless of the difference in populations, many of the emerging themes are relevant and can be used to direct inquiry. It becomes necessary to not only look outside of this small population of students, but it requires a deeper search into less recent research in order to find literature upon which to draw. Recognizing that prevalence rates and statistics are outdated, many findings can be synthesized to provide a background and foundation for current investigation.

While there is a need to further the research in all areas related to students who are deaf/autistic, the role that parents play in the educational system, specifically in the placement process, is a priority due to being largely overlooked. Parents are vital collaborators in their children's education and provide essential information for school staff when discussions are made regarding placement and intervention (Kurth et al., 2020). Another reason that this population of students and their families warrant focus and attention with respect to the placement and decision-making process is the impact that hearing loss, together with autism has on language acquisition (Borders et al., 2016). Each condition on its own makes access to language difficult. "Students with comorbid D/HH and ASD have two language impacting disabilities making access to language difficult" (Borders et al., 2016, p. 190). Together, the impact is more than just additive (Borders et al., 2016). In the IPRC discussion and when examining placement decisions, it is essential to be cognizant of the impacts and outcomes of the interactions of the two conditions. The undesirable behaviours, such as oppositional behaviour and violating social rules, may lead teachers to consider placements which address those needs rather than focusing on academics or communication (Barker et al., 2009; Borders et al., 2015). This is another reason why parental input in the IPRC decision-making process is vital in helping to provide a more holistic view of the student.

While Canadian-based researchers have begun to investigate the low-incidence population of students who are deaf/autistic, it remains a very limited field of study. Parents' perspective on the special education placement process has become an area which has received attention from Canadian researchers (Brackenreed, 2019) alongside their United States (Lalvani, 2012; Tucker & Schwartz, 2013) and other international country counterparts (Hebel, 2014). Outside of Canada, the research refers to the IEP meeting, while Canadian studies examine the IPRC process (see Table 1.1). The existing IPRC/IEP studies from Canada and abroad, which have not all been specific to students who are deaf/autistic, have investigated the collaboration between parents and the school and the barriers and facilitators involved in the interaction.

Given the limited research in the field, examining both studies that investigate the IEP process mandated by the IDEA (U.S. Department of Education, 2019) and the IPRC process outlined in the Education Act (Government of Ontario, 2001), is necessary when discussing the parents' perspectives of the meeting and decision-making process. It is also necessary to extend beyond the studies of students who are deaf/autistic. Drawing on similar research on other low-incidence populations is essential during this emergent stage of research. Prior research which focused on the parent perspective of the IPRC process examined several different key issues (Kurth et al., 2020; Lo, 2008; Love et al., 2017; Sanderson & Goldman, 2022). The following sections of this chapter will discuss and review some key issues presented in the literature: prevalence, power imbalance between the parent and school, collaboration, placement issues, barriers and facilitators to parental participation, and intersectionality. In order to provide a context for the discussion of parental perceptions of the IPRC process, a historical background of the special education system and the IPRC process from a Canadian standpoint will first be presented.

Historical Background

Within the research, there is discussion and debate surrounding Canada's success in creating and implementing disability legislation (McBride, 2013; Lord, 2020). In 1977, the Canadian Human Rights Act (Canadian Human Rights Act (R.S.C., 1985, C. H-6), 1977) was created and included in this act was the prohibition against discrimination based on various categories, including disability. The Canadian Charter of Rights and Freedoms (Canadian Charter of Rights and Freedoms, 1982), part of the Canadian Constitution, was enacted in 1982. Under the Charter, every individual is equal and has the right to equal protection under the law (Government of Canada, 2018; Canadian Human Rights Commission, 2021). In 2007, Canada signed the UN Convention of Rights of Persons with Disabilities. By signing this, Canada recognized the rights of persons with disabilities to an inclusive education (Convention on the Rights of Persons with Disabilities, 2006).

Canada has integrated legislation regarding inclusion and rights for disabled individuals into other areas of governance. In 2018, Bill C-81 (Government of Canada, Department of Justice, 2018) was passed, which focused on ensuring a barrier-free Canada. While the areas touched by this act include transportation, telecommunications, employment and more, it does not address education as this is a responsibility of the provincial governments (Employment and Social Development Canada, 2020). The mandate states that Canada will be barrier- free by 2040. The passing of Bill C-81 demonstrates the tone that Canada continued to set regarding inclusion and participation for all members of society.

Just over 50 years ago, the Commission on Emotional and Learning Disorders in Children released a report known as *One Million Children* (Laycock, 1970). This Canadian report written in

1970 was directed by several significant mental health and education stakeholders, and it put forth numerous recommendations. One of the issues it brought forward was the often-noted condescending attitudes between professionals, teachers and parents. The report recommended the creation of strong partnerships between all parties involved. While it may have been written more than five decades ago, the authors recognized the importance of building partnerships and the importance of including parents in the special education process. The findings from the *One Million Children* report further support the need to research and examine parents' role in the IPRC process. Including parents in this process and improving the partnership with administrators and teachers has been a recommendation for decades. Research has shown that including parents in the student's education, specifically the IPRC meeting, has beneficial and positive effects (Love et al., 2017; Myck-Wayne et al., 2011). Failing to include parents as collaborators in the IEP development and placement meeting creates barriers to inclusive education for the student (Lord, 2020).

> What is clear at this point is that there exists a good set of legislation, policies, standards and guidelines for special education across Canadian jurisdictions. What is less clear is the degree to which the practices are having the desired effect. (McBride, 2013, p.6)

Another highlight of the *One Million Children* report was the discussion regarding attitudes and labels in special education. The authors argued that children with disabilities should be viewed as a whole person rather than broken down in pieces by labels and diagnoses (Laycock, 1970). Labels, according to the report, did not emphasize a child’s strengths. Inclusion was advocated over segregation and isolation, with increased training and support for classroom educators to facilitate the process. These topics continue to be at the forefront of the special education debate in Canada.

Within Canada, the responsibility for education lies with the individual provinces and territories. Each province and territory have one or two departments/ministries in their government responsible for education. It is within the role of these departments/ministries to define the services provided as well as the policy and legislative frameworks (Council of Ministers of Education, Canada, n.d.). From province to province, school boards have varying degrees of local governance for which they are responsible. The decentralized nature of the responsibility for education, while beneficial in allowing each province and territory to focus on and meet the needs of its unique population, and also creates division between the provinces and territories in areas such as teacher training programs (Waddington, 2018). Special education services are part of the services covered under each province's domain. It is beneficial to understand a few historical events that shaped the current state of special education in Ontario.

In 1980, the Ministry of Education in Ontario introduced an amendment to the Education Act. The Education Act is the legislation within the province which governs public education. The amendment is commonly referred to as Bill 82, and it sets out requirements for publicly funded school boards to be responsible for the education of all students in Ontario, including those with special needs (The Council of Ontario Directors of Education, 2011). “The *Education Act* sets in law the powers and responsibilities of the Minister of Education and School Boards, the authority of principals and teachers, and the rights and responsibilities of parents and students” (*Education Law and Policy*, 2020). Regulation 181/98 of the Education Act is the Identification and Placement of Exceptional Pupils (Government of Ontario, 2001). This regulation lists the requirements on the school boards related to the IPRC process. The IEP was also introduced in this regulation, as well as addressing student placement in a special education class and the boards’ roles and responsibilities related to the early and ongoing identification of students.

The IPRC was introduced in 1981, formalizing the identification process for students and the subsequent placement protocol based on the findings. The IEP was also created, and educators had to create and implement the education plan following the IPRC meeting. Parents were recognized as part of this process, in particular through the mention of a parent guide, which had to be created by every board of education and also through the provision of an appeals process if a parent was in opposition to the outcome of the IPRC meeting (Brackenreed, 2019). Reid et al. (2020), in their review of the IPRC process in Canada, described an outdated practice which "relies on the logic of a medicalized approach to disability (Conner, 2013) …" (p.51) and is resource-heavy and inflexible.

Specific to the history and role of the IPRC process, two Canadian legal cases are often referenced regarding the perception of children who have disabilities and their parents' involvement and advocacy. Eaton v. Brant County Board of Education [1995] and Moore v. British Columbia [2012] both serve to reinforce the idea that all children, regardless of level of need or challenge, are entitled to an education (Towle, 2015). One of the most significant impacts to result from the cases was the response from the Supreme Court of Canada, in which they realized that there was no simple solution to placement that would work for every group of students (Towle, 2015).

Currently, a student may receive accommodations without being identified in an IPRC. An IEP can be developed, and accommodations can be listed regardless of whether the student has received an exceptionality from one of the 5 categories created by the Ministry of Education (Weston, 2019). This has led educators and researchers to ask why the IPRC process is still necessary if a student is able to receive accommodations in the regular classroom with an IEP but not having received an exceptionality. "It is clear that students are being 'identi-fied' and accommodated, at least by their teachers and schools, potentially years prior to engaging in the formal IPRC process” (Brown & Parekh, 2010, pp. 14-15). Weston (2019), in a blog post written for the Elementary Teachers’ Federation of Ontario, suggested that needed supports, such as educational assistants and specialized equipment, were not being provided to students if they had not been identified through an IPRC, regardless of having an IEP. Brown & Parekh (2013) argued that the fact that half of special needs students received support without having gone through the IPRC process was evidence of the declining need for and importance of the IPRC process.

Research Challenges in the Field of Deafness/Autism

Prevalence

Collecting data on the number of students who are deaf/autistic is not simple. Understanding the difficulties in determining the prevalence rate helps to understand the issues that surface in other areas, such as language, assessment, placement, and intervention. Due to the variability of characteristics, both autism and hearing loss manifest in different ways. Controversy exists in the literature regarding the prevalence of hearing loss among individuals with autism (Beers et al., 2014). In their 2014 study, Beers et al. (2014) found no conclusive evidence that children with autism were at an increased risk for peripheral hearing loss. They suggested that the various study methodologies and sample sizes, as well as subject inclusion criteria, could be the cause of the variability in prevalence reports. Fitzpatrick et al. (2014) conducted a retrospective chart review, which provided an estimate of the proportion of children with both permanent hearing loss and autism within a region in Canada. Their results were consistent with those of the Gallaudet Research Institute (2013), which suggested a higher rate of autism in children with hearing loss (Fitzpatrick et al., 2014). However, the data in this study were collected using medical chart documentation of a clinical diagnosis from a developmental specialist (Fitzpatrick et al., 2014). Scott & Hansen (2020) noted that children who were deaf were more likely to be diagnosed with autism than hearing children. They also noted that the reverse was that children with autism were more likely to receive a label of deaf/hard of hearing than their typically developing peers. To support their position, Scott & Hansen (2020) cited two studies, one of which was Beers et al. (2014). This was a misuse of the position stated in the Beers et al. (2014) study. Beers et al. (2014) noted, “among children with ASD there is no conclusive evidence that the prevalence of peripheral hearing impairment is elevated compared to the prevalence of hearing impairment within a general population” (p.98). Other factors which can influence the collection of data related to prevalence in the area is whether the co-occurrence of hearing loss and autism can cause one condition to be expressed differently as a result of the effect of the other condition (Young et al., 2019). This can result in delaying or masking one of the conditions, causing the identification to be missed. Additionally, there are reports of parents who do not pursue the assessment and evaluation for autism following a diagnosis of hearing loss or vice versa. This may be due to parents' difficulty when faced with having to accept and deal with a second, additional diagnosis for their child. As a result, a number of children may not receive a diagnosis, although they meet the criteria and require support in school.

Power Imbalance

There may be various reasons parents perceive an imbalance of power between themselves and the school IPRC team. Unfortunately, the result of the imbalance can make it difficult or even impossible to create a successful collaborative partnership (Friend & Cook, 2017). Kurth et al. (2019) shared a study in which fathers reported that their lack of legal background and special education knowledge made school meetings confusing and overwhelming. These fathers perceived themselves as unable to contribute to the decision-making process. Paccaud et al. (2021) noted that building trust between the parents and the school was vital in leading to a collaborative relationship in which the parties mutually recognized the other’s expertise. The building of trust serves to create some balance of power between the two. In some cases, it may go beyond failing to foster a collaborative relationship between the stakeholders. The imbalance can be created by a lack of awareness or cultural insensitivity on the part of the team members. There may be an actual hesitation and separation between the school and the families, maintaining the power imbalance. For example, parents come to the meetings potentially with different agendas and goals than the members of the school team. The two sides may not agree on the benefits and the long-term implications of the possible placement options. This differing opinion can lead to contention and adverse treatment from the school team towards the parents (Kurth et al., 2020). Paré (2015), in her chapter “Inclusion and Participation in Special Education Processes in Ontario, Canada,” and Reid et al. (2020) both looked at the structure of the IPRC process and how it creates an environment of power imbalance. Parents enter the meeting and are faced by a team of individuals consisting of school professionals. They are most often attending on their own, and this environment is not conducive for parents to speak on behalf of their children (Paré, 2015).

When comparing parents from within a higher socioeconomic status (SES) group and parents from a lower SES group who were part of the same sample, Lalvani (2012), in their review of the literature, noted differences in the parents’ perceptions of their home-school collaborative relationship. Some parents in the lower SES group shared that during the decision-making process, they had experienced a power imbalance in which they felt unable to make changes when they were dissatisfied with the placement outcome.

In their study, which examined how parents of children with disabilities were included or excluded from the educational decision-making process, Love et al. (2017) found several themes that emerged and could be shown to support the idea of power imbalance. Parents reported experiences in which the schools initiated the decisions without consultation. In one case, the author noted a parent shared their fear of not signing the IEP regardless of being unhappy with the content for fear of repercussions (Love et al., 2017). The same study discussed the barriers created by school hierarchies (Love et al., 2017). These hierarchies comprised the upper administration, which held the decision-making power and could pressure teachers and other team members to follow their decisions. Kurth et al. (2019) conducted focus groups with parents of children with an intellectual disability or a developmental disability. They found that in some cases, parents could not reach an agreement with the school regarding placement, while in the cases where they could agree, it was described as challenging. One parent in their study commented that there was no choice in the placement process (Kurth et al., 2019).

Collaboration

“Interpersonal collaboration is a style for direct interaction between at least two coequal parties voluntarily engaged in shared decision making as they work toward a common goal” (Friend & Cook, 2017, p.5). This definition of collaboration highlights the critical aspect of equality between members. As previously mentioned, an imbalance in power between members creates an immediate barrier to the collaborative process. Misunderstandings and miscommunications between parents and school staff can also impede the development of a solid collaborative relationship. Cultural factors which can affect the families’ perspectives, interactions and engagement levels can be perceived by the school team as uncaring or resistant (Olivos et al., 2010). The families maintain their cultural capital, which is infused into their interactions with the school. At the same time, the school staff transmits the dominant culture implicitly (Olivos et al., 2010). This difference in culture and resulting misunderstanding serves to undermine the collaboration process. Bourdieu’s theory of cultural capital (1977) provides a framework for the phenomenon of the clash of cultural capital between the school and family.

In their literature review, Kurth et al. (2019) noted that parents were appreciative when schools wanted their input and listened to their concerns and requests. Specific to IEP meetings, they highlighted another study, which “found communication, commitment, trust, and respect, among other qualities, as important in successful collaborative partnerships” (Kurth et al., 2019, p.108). A similar comment was noted by parents in another study, where they prioritized collaborative relationships with the school when making decisions but pointed out that they seldom experienced collaboration (Kurth et al., 2019).

Placement

Looking solely at students with autism in the United States, Kurth (2015), noted that once placement decisions were made for a child, they typically remained in that placement. This highlights the need to ensure that placements are done correctly from the start. It also brings forward the idea that the education system may not be properly meeting the students' needs if it is not periodically re-evaluating their strengths and challenges to determine if a change in placement is necessary. The study focused on the factors which were involved in determining placement. It gave additional information regarding how decisions were made. The author pointed out that some decisions were based on what was available in the area rather than the most appropriate factors, such as the child's needs. Child-specific factors and external factors such as teacher training and financial motivations were also cited as contributing to the placement decision. Findings from this study showed that environmental factors weighed heavily in the decision-making process and had a more significant impact than the child's characteristics (Kurth, 2015). Guardino (2008), in a literature review on the identification and placement of deaf students with multiple disabilities, noted that “students with multiple disabilities often are misidentified or identified late, and are placed in inappropriate educational settings and consequently receive inadequate services” (p.55). The educational placement decision-making can be challenging due to the differing opinions, goals and expectations that the different team members bring to the IEP meeting (Kurth et al., 2019).

Barriers and Facilitators to Parental Participation

Identifying the barriers to effective participation and communication is essential in order to be able to begin to work to dismantle them. Although there are differences between the IPRC process in Canada and the IEP meeting in the U.S., many issues concerning parental participation are similar. Parents have reported feeling excluded from the decision-making process for many reasons, such as decisions being more heavily weighted on assessments rather than parental input (Fish, 2008). "Despite theoretical and legislative support of shared decision-making in the IEP process, there are significant barriers to shared decision making and active parental participation." (Zeitlin & Curcic, 2013, p.6)

Although it is not explicitly discussed as an obstacle in the IPRC process, Papoudi et al. (2021), in their scoping review of parents of culturally and linguistically diverse children with autism, discussed some issues which could hinder the success of the team meeting. Specifically, they noted the variation between various ethnic groups regarding their understanding of autism. For example, different cultures have been shown to hold different views and beliefs, which would directly influence their understanding or approach to education regarding autism (Papoudi et al., 2021). More et al. (2013) addressed the issue of language interpretation for diverse families in their study and pointed out how cultural and linguistic barriers prohibit parents from meaningful participation in educational planning. In their conclusion, the authors commented that in addition to ensuring that parents' voices are heard, teachers, through the use of quality language interpreters, can ensure that their voices are valued in the decision-making process. Language barriers have been noted to create challenges for parents concerning their ability to comprehend the jargon and terminology related to IEP meetings (Fish, 2008).

Language barriers can also be caused by a lack of appropriate or adequate interpreting services (Love et al., 2017). Parents may be seen as passive as a result of language barriers or from poor interpretation services (Chang & Avila, 2022). Fish (2008) referenced several studies which found correlations between low socioeconomic status and cultural diversity, and challenges to collaboration in the IEP meeting. These factors could easily impact the parents' involvement or lack of involvement in the IPRC meeting. The gap in the literature around culturally and linguistically diverse families marginalized by their membership in the world of disability needs to be addressed.

Barriers in the form of implicit bias from the school staff can alienate and impede decision-making (Chang & Avila, 2022). “Implicit bias refers to unconscious attitudes, reactions, stereotypes, and categories that affect behavior and understanding” (Yale University, n.d.). When teachers focused on a student’s deficits rather than their strengths, parents reported feeling that the staff were not accepting their child (Kurth et al., 2019). The critical disability theory view of disability as a difference rejects the use of a deficit model. Kurth et al. (2019) shared a parent’s concern regarding the focus on their child’s deficit and their belief that it could potentially have been a cause of the failure to implement the IEP services. Parekh et al. (2018), in their exploratory study of teachers’ perceptions of learning skills, the skills evaluated on a report card separate from curricular achievement, found the presence of implicit bias toward special education students. Students who had been identified and had been in a full-time special education class were less likely to receive an ‘excellent’ on their learning skills. This study provided insight into the implications of implicit bias. Although it was focused on learning skills rather than its impact on the decision-making process, it illustrated the issue. “The consequences of presuming certain students do not embody the values and skills espoused in the Ministry’s Learning Skills is the marginalization through the exclusion from rigorous programming opportunities and venturing into precarious pathways through school" (Parekh et al., 2018, p.21).

Several studies have focused on the factors which facilitate collaboration and parental participation in the IPRC process (Fish, 2008; Whicker et al., 2019). Participants in one study noted that educating themselves proactively on the process and learning about special education law was one way to improve the quality of the meeting (Fish, 2008). The participants in this study had several suggestions, and the majority noted positive perceptions of the IEP meeting. Notably, the participants' demographics were 80% white, non-Hispanic, and the majority were from middle to upper-middle-class socioeconomic families (Fish, 2008). The use of case managers as a tool to help liaise with the school staff and other professionals during the collaborative discussions improved satisfaction levels for the families of children with dual sensory impairments (Whicker et al., 2019). Case managers are not utilized in the IPRC process in all school boards in Ontario.

Intersectionality

Many of the students who deaf/autistic and their families experience the intersecting and overlapping identities of disability and culture. Examples of these intersections have been noted in some of the previously discussed issues. The unique social identities experienced by families may impact positively or negatively, and they may change over time.

Culture has been shown to impact how a family reacts and responds to their child's disability diagnosis, and this reaction may differ between cultural backgrounds (Mohamed Madi et al., 2019). In a study by Ineese-Nash et al. (2018), the perspectives of some Indigenous families living in Canada were shared with respect to their views on early childhood disability services. According to the article, in some of the Indigenous languages, there is no word for disability. Some Indigenous Peoples feel that the use of labels can be limiting. Language, according to the participants in the study, is a very powerful thing and by speaking a word, life is brought into and can become real (Ineesh-Nash et al., 2018).

> While there is not always full participation in traditional life for individuals with disabilities, Indigenous communities hold the view that every individual has place and position and that there is something to be learned by each member of the community (Durst, 2006). (Ineesh-Nash et al., 2018, p.4)

How parents define or view their child's disability as compared to the school's views, assumptions and ideas about strategies and placement, can all be influenced by culture (Tamzarian et al., 2012). This can also lead to misunderstandings between the parties during discussions and decision-making meetings.

There are also culturally based biases, implicit or explicit, on the part of the families that may impact their involvement in the school. Parents react differently to school authority based on their cultural values, beliefs or expectations (Chang & Avila, 2022). For example, some families may view school personnel as experts and may not wish to question authority (Tamzarian et al., 2012). In their study on the perspectives of parents from culturally and linguistically diverse backgrounds regarding schooling and education found that some parents "felt unable to voice their concerns because of unfamiliarity with advocacy roles and fear of being branded as 'troublesome'" (Cardona et al. 2009, p.27). How families understand and define collaboration may be defined culturally and their expectations may not be compatible with that of the school (Lalvani, 2012).

Additionally, there are reports of parents who do not pursue the assessment and evaluation for autism following a diagnosis of hearing loss or vice versa. This may be due to parents' difficulty adjusting emotionally when faced with having to accept and deal with a second, additional diagnosis for their child. As a result, a number of children may not receive a diagnosis, although they meet the criteria and require support in school.

Methodological Rationale

This research used a qualitative phenomenological case study approach to explore parents' perceptions of the IPRC process. More specifically, a collective case study approach, using purposeful sampling was employed to best illustrate the phenomenon that is the IPRC Process.

> Phenomenological studies seek to understand the experiences of a set of individuals who share a common experience. The purpose, then, of a phenomenological study is to describe the lived experiences of individuals in relation to an identified phenomenon (Creswell & Poth, 2018). (Burkholder et al., 2020, p.86)

The use of a case study methodology, particularly a multiple case study design, ensured a comprehensive exploration of the phenomenon. This blending of the two approaches, phenomenology and case study, avoided presenting a singular perspective and instead employed various lenses, thereby enabling the revelation and comprehensive understanding of multiple facets inherent in the phenomenon under investigation. Through the collection of multiple sources of information, which included interviews, surveys and document reviews, the collective case studies examined bounded cases within a real-life context (Creswell & Poth, 2018).

A deductive approach, also known as *a priori* and an emerging, inductive design were both used in this study in order to develop a rich understanding of the participants' experiences. The researcher began by deductively compiling a set of codes based on the research questions, the relevant research on the topic and the related theories (Burkholder et al., 2020). The inductive design was used in this study as this approach was aligned with the constructivist epistemological assumption that knowledge is evolving and “reality is constructed between the researcher and the researched and shaped by individual experiences” (Creswell et al., 2018, p.35).

Philosophical Assumptions

This qualitative study was guided by the four philosophical assumptions within an interpretive framework of social constructivism (Creswell, 2018). In the social constructivist paradigm, also referred to as interpretivism, “the researchers make an interpretation of what they find, an interpretation shaped by their own experiences and background” (Creswell, 2018, p.24). According to Takahashi & Araujo (2019), “there is no single objective truth to be discovered about the social world” within the interpretivism worldview (p.104). The phenomenological case study approach aligned with this framework as the goal was to rely on the views of the participants by listening through open-ended questions (Creswell, 2018). This study set out to examine the lived experiences of several parents of deaf/autistic children “with the intent of reporting the multiple realities” (Creswell, 2018, p.20). The ontological paradigm recognizes that there are multiple realities which interact and are all valid. The epistemological stance was based on the assumption that “knowledge is known through the subjective experiences of people” (Creswell, 2018, p.21). By definition, a phenomenological study focuses on the participant’s lived experience. The social constructivist approach provided a lens which supported the undertaking of the research within the participants’ natural environments. This not only fostered a closeness between the researcher and the participants but aided in providing the researcher with a context for the information the participants shared. The researcher’s axiological assumption was evident throughout the data collection process. Participants shared their perceptions through their responses to the interview and survey questions. The biases, implicit and explicit, of both the participants and the researcher were reflected on and acknowledged where relevant and appropriate. Interviews and surveys were conducted, and documents were reviewed by the researcher as part of this study. All of these methods allowed for the collection of rich and descriptive phenomenological case study data. The methodological assumption was based on an emergent, inductive approach thereby influencing the researcher's analysis of the data.

Theoretical Frames

Two theories served to support the framework of this research and helped to provide a richer understanding of the phenomenon experienced by the participants. Critical disability theory (Reaume, 2014) and Bourdieu's capital theory (1977) address different yet equally important aspects of the IPRC process for parents of students who are deaf/autistic. Both theories align with the researcher's social constructionist epistemological view.

"Critical disability studies view disability as both a lived reality in which the experiences of people with disabilities are central to interpreting their place in the world, and as a social and political definition based on societal power relations" (Reaume, 2014, p.1248). In this way, critical disability theory provided an interpretive framework with which to enact the researcher's epistemological assumptions. The theoretical framework complemented the methodological approach of this study, as reality, which is not rigid, became known by examining social structures, power and control (Creswell & Poth, 2018). Research can change reality (Creswell & Poth, 2018).

Critical disability theory builds upon disability studies' premise that disability is socially constructed (Eilers, N. 2020). Using the social model of disability rather than the medical model, disability studies view disability as a social phenomenon created by barriers constructed by society (Bilken et al., 2014). Although the focus of disability studies is the individual who is disabled, this phenomenological case study extended the theory and applied it to include the families. The social constructivist paradigm provided the framework for the inquiry into the phenomenon in order to gain knowledge about all aspects of the topic from multiple perspectives (Freedman, 2016). This would include how society and barriers impact the family as well as the individual with the disability. “Parents from culturally and linguistically diverse backgrounds face additional barriers to their participation that include access to adequate translation services, school personnel’s use of deficit perspectives towards diverse families, and a general lack of cultural responsiveness” (Love et al., 2017, p.158). The parents often experience a power imbalance during the IPRC meeting for their child, which can be exacerbated when parents are from culturally and linguistically diverse backgrounds. Parents can experience the oppression and lack of power created by the social structures of the IPRC meeting. This is the dynamic that the disability framework addresses, and therefore it serves to provide an interpretive framework for both the parents and the students.

Critical disability theory promotes a social justice discussion (Goodley et al., 2019). The purpose of research, from the perspective of the disability framework, is to seek a clearer understanding of the situation being examined, the situation in which there is an imbalance of power or barriers to access for individuals with disabilities. To do this, the researcher must sufficiently increase and improve understanding of the problem in order to effect social change. Researchers must interact with their participants as they co-create the understanding of reality. The case study approach and use of Interviews facilitated this interaction as they allowed the researcher to participate directly in the data collection process. “Disability studies researchers acknowledge that research is value-laden and influenced by the researcher from the framing of research to questions to methodological choices to interpretation of data” (Freedman, 2016, p.5).

Critical disability theory serves to highlight and provide a basis to examine the intersectionality between those marginalized as a result of being members of both disability and culturally and linguistically diverse groups (Kaplan & Celik 2023). This aspect brings together the two theories, and while disability theory presents a framework to discuss the marginalization of culturally and linguistically diverse families, Bourdieu's capital theory (1977) delves deeper and provides a frame of reference to explain the dynamic of the phenomenon of the IPRC process.

"The basic premise of capital theory is that people acquire and use information and knowledge (i.e., cultural capital) and social networks (i.e., social capital) similar to the ways in which they use economic capital (Bourdieu, 1974)" (Trainor, 2010a, p.35). Bourdieu (1986) extended his economic definition of capital and related it to other contexts. He used the term habitus to refer to the "mode of acting and making meaning in daily life" (Trainor, 2010b, p.248) and discussed the external field or social milieu, where connections and relationships occur (Yamauchi et al., 2016). This extended definition of capital theory provides a structure to better understand the parents' experiences in the collaborative process with the IPRC team.

"Cultural capital refers to valued ways of operating within particular social fields and the possession of certain competencies, skills and knowledge that provide access to resources and socially desirable ends" (Cardona et al., 2009, p.3). For parents to be able to read and understand the materials related to the IPRC process requires cultural capital (Trainor, 2010a). Other researchers have clarified and extended the idea of social capital as they applied it to schools and families. Applying it to special education, the involvement of parents in the decision-making process can be seen as "relying on their acquisition and use of cultural and social capital" (Trainor, 2010b, pp.245-246). Social capital encompasses the interpersonal relationships which allow individuals to improve and increase access to capital supplies (Trainor, 2010a). It can be explained as having two parts: the supplies and assets that are affiliated with group membership and one's social networks (Yamauchi et al., 2016).

Together, Bourdieu's capital theory and critical disability theory provide different yet supporting frameworks. Capital theory frames the dynamic between the parent and the school and explains many of the barriers which exist in the IPRC process. It provided a paradigm to examine and explore the barriers parents experience during the IPRC process. Using capital theory, factors such as race/ethnicity, culture, and language have been linked to status and, subsequently, unequal access in the school setting. It also explains the power imbalance which can be at the root of the inequality in educational opportunity (Trainor, 2010a). Reid et al. (2020) used critical disability studies as an instrument within their research to examine the IPRC process and to further the discussion on both system change and disability rights.

Conclusion

Parents can play a key and collaborative role in their child's education. The IPRC process often fails to capitalize on the valuable contribution that parents can offer. They are able to provide knowledge and information, as well as a unique perspective, which allows them to both question and provide insight into assessments (Greene-Woods & Delgado, 2019). This chapter provided a brief summary of some of the research related to parents of students who are deaf/autistic and the barriers and facilitators they face when participating in the IPRC process. The epistemological stance, methodological rationale and theoretical frameworks supporting this study were also presented. The next chapter will discuss the method of the phenomenological case studies, including the instruments and data collection procedures. The research study problem statement, purpose statement, as well as the research questions will all be shared.

Chapter 3

The previous chapter provided a brief overview of some of the research and discussions taking place in the field of education of students who are deaf/autistic. The epistemological stance, the methodological rationale, as well as the theoretical frames were provided to establish the study's philosophical and theoretical underpinnings. The current chapter presents information about the study setting, design and participants, the research study problem statement, the purpose statement and the research questions, data sources and collection procedures, analysis procedures, reflexivity and finally, threats to reliability and validity. There were two central research questions, along with supporting sub-research questions, which guided this research. The first central research question examined the lived experiences of parents of students with hearing loss and autism who participate in the decision-making process of the IPRC in Ontario. The factors believed to support or inhibit the collaborative family-professional IPRC partnership were explored through the second research question.

Study Setting

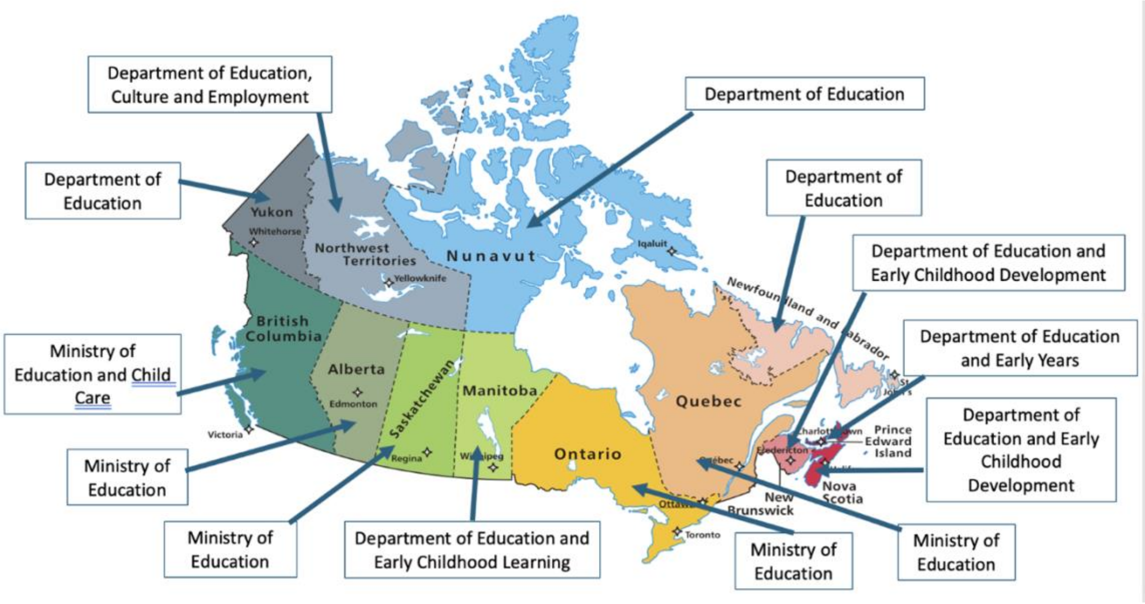
All case studies took place in the same province in Eastern Canada. All participants were parents of children who attended the same English public school board. Canada is comprised of 10 provinces and three territories. The Constitution Act of Canada is its supreme law, and it defines the roles and responsibilities of the executive, legislative and judiciary, the three branches of government (Department of Justice Canada, 2017). Under the Constitution, all ten provinces received equivalent legislative status. However, the territories were not recognized with constitutional status or legislative powers (Department of Justice, 2013). Yukon, Northwest Territories and Nunavut, the three territories, are therefore under the direct control of the federal government in many areas (*Ministries/Departments Responsible for Education in Canada*, n.d).

Under the Canadian Constitution, the 10 provincial governments are responsible for most areas of education, including elementary, secondary education and special education. There is no ministry or department of education at the federal level. Canada's three territories — Yukon (Yukon Act, S.C. 2002, C. 7, 2002, Northwest Territories (Northwest Territories Devolution Act, S.C. 2014, C. 2, 2014), and Nunavut (Nunavut Act, S.C. 1993, C. 28, 1993), were each granted legislative powers from the federal government which allows them to self-govern in the same way as the provinces. Education is one of the areas of responsibility which the federal government delegated to the territories (*Ministries/Departments Responsible for Education in Canada*, n.d.) (See Figure 3.1).

The parents who participated all had children who, at the time of the study, were placed in a full-time special education class, either for students with autism or for deaf/hard-of-hearing (DHH) students.

Figure 3.1

Ministries and Departments Responsible for Education in Canada



Study Design

A qualitative phenomenological case study approach, specifically a collective case study, using purposeful sampling was used, providing the opportunity to examine and explore the cases within a real-life context (Creswell & Poth, 2018). The student population who are both deaf/autistic is a low-incidence group. They have unique and diverse needs that run a spectrum of communication/language, social interaction, and behavioural (Szarkowski et al., 2014). Their families are also presented with unique challenges that merit investigation. As discussed in Chapter 2, there has been limited research into this low-incidence population. To gain a deeper understanding of students who are deaf/autistic, this researcher chose their parents as the foci of the case studies.

Purposeful sampling was used in order to select families for participation in the study (Creswell & Poth, 2018). As this is a low-incidence population, this type of sampling was necessary in order to seek out the families who would most likely meet the inclusion criteria for this study. This approach to sampling was also useful in allowing for comparisons to be made between the cases by providing the opportunity to highlight different aspects and factors of the phenomenon (Maxwell, 2009).

Participants

The group examined in this study were parents of children who are both deaf/autistic and who, at the time of the study, attended a public school within Eastern Canada. Participation in the study was voluntary and confidential. Participants were informed that they could withdraw at any point. Inclusionary criteria for parent participation required all of the following conditions:

Their child must have:

a) received an autism exceptionality from the school board.

b) a bilateral hearing loss of 30dB or more, calculated based on Pure Tone Average (500Hz, 1000Hz, 2000Hz and 4000Hz) (Calculator Academy Team, 2023). The child may or may not have received a deaf/hard-of-hearing exceptionality from the school board.

c) received a placement recommendation from the school board.

Parent/caregiver must have:

a) participated in the initial Individual Placement and Review Committee (IPRC) meeting at which their child received the exceptionality and placement was discussed.

According to the categories of exceptionalities in Ontario, the exceptionalities of Autism and Deaf/Hard-of-Hearing, are both listed under the category of Communication. The presence of additional exceptionalities did not exclude participant participation. Although participants' children were required to have a medical diagnosis of both hearing loss and autism, the student was only required to have a board-identified exceptionality of autism to participate. The Ministry of Education lists definitions for the five categories and the subcategories (Ministry of Education, 2022a). Their wording used in the definition of deaf and hard of hearing allows for interpretation on the part of each school board. Deaf and hard of hearing is defined as "an impairment characterized by deficits in language and speech development because of a diminished or non-existent auditory response to sound" (Ministry of Education, 2022a). As a result, there is variation between school boards in Ontario with regard to whether or not a student is required to have a deaf/hard-of-hearing exceptionality to receive certain levels of service from the Deaf & Hard of Hearing Programs.

One parent responded to the parent request letter (Appendix A) and was interested in participating but was excluded when it was discovered that although their child had received a medical diagnosis of atypical hearing and autism, there was no autism exceptionality listed on the student's Individual Education Plan (IEP). The parent had responded to the request to participate and was under the impression that their child had both exceptionalities on record with the school. The parent was not aware that the medical diagnosis that had been shared with the school and placed in the student's OSR (Ontario Student Record) was not sufficient on its own to identify their child as autistic. Based on the parent's understanding, having provided a medical diagnosis of autism to the school, and having had it placed in the child's school record was considered sufficient. The student had already received an exceptionality of deaf/hard-of-hearing at a previous IPRC, and the parent believed that the second condition would be added to the child's IEP and school record. As a result of being excluded from the study, the parent became aware of the oversight and requested that the school bring their child back to the IPRC meeting in order to add the second exceptionality.

Three participants responded and met the study criteria. The participants from the first and third case study had limited contact with the researcher prior to the study, as the researcher had worked in their children's classes on a periodic basis. The participant from the second case study had no contact with the researcher prior to the study, as the researcher only began working in their child's school a week prior to the start of the study. All parents were informed that their participation in the study or their decision to participate and, if necessary, withdraw from the study would in no way impact the relationship between the researcher and their child in the researcher's professional capacity as an educator in their child's school. There was no relationship between the participants in the study. Participants were given a gift card to a big box retailer as a form of appreciation for their time and effort.

All three participants were mothers, and all spoke English as a second language. In all cases, their child who was deaf/autistic was the only child in their family with an exceptionality.

Participating in the IPRC process was new for all the participants. In the first case study, the father was nearby during the interview and participated periodically to provide clarification or to supplement a response. All interviews were conducted in English despite it not being any of the participant’s first language. All three participants refused the option to have an interpreter present during their interview. The interview portion of the study was conducted at the homes of each of the participants. At the time of the interview, approximately eight and a half years had passed since the initial IPRC for the first participant, 20 months for the second and eight years for the third.

Research Study Problem Statement, Purpose Statement and Research Questions

The problem which was addressed by this study was that the parents’ perceptions about their participation in the IPRC process for their deaf/hard-of-hearing and autistic child were not currently being represented in research and literature. Understanding the perspectives of these parents may reveal important information about possible barriers to parent participation for other families and administrators looking to improve parent participation in the IPRC process for children dually diagnosed with hearing loss and autism. The purpose of this qualitative phenomenological case study is to achieve an understanding of the perceptions and experiences of parents of students who were deaf/autistic from within a province in Eastern Canada, and their involvement in the Individual Placement and Review Committee meeting. Based on the analysis of the data collected, an Organizational Improvement Plan is provided in Chapter 5, with suggestions for improving the IPRC process and the outcomes for the students and their families.

This phenomenological case study was guided by two central research questions and their related sub-questions. The first question was focused on exploring the lived experiences of parents of students with hearing loss and autism who participate in the decision-making process of the IPRC meeting in Ontario. The second question was aimed at examining the factors believed to support or inhibit the collaborative family-professional IPRC partnership. A full list of the research questions is presented in Table 2.1.

Table *2*.1

Research Questions

	Research Question
Central question 1	What are the lived experiences of parents of students with hearing loss and autism who participate in the decision-making process of the IPRC in Ontario?
Sub-question 1	What factors, if any, influence parents' satisfaction of the placement decision process in IPRC meetings for their deaf/hard-of-hearing and autistic?
Sub-question 2	What barriers, if any, do parents identify in regards to their participation in the placement decision making process of the IRPC for their deaf/hard-of-hearing and autistic child?
Sub-question 3	What facilitators, if any, do parents identify in regards to their participation in the placement decision making process of the IRPC for their deaf/hard-of-hearing and autistic child?
Sub-question 4	How do culturally and linguistically diverse families perceive their participation and language access in IPRC meetings?
Central question 2	What are the factors believed to support or inhibit the collaborative family-professional IPRC partnership?
Sub-question 1	In what way, if any, can collaboration be improved between parents and the members of the IPRC team?
Sub-question 2	What, if any, information, knowledge and understanding regarding hearing loss and co-occurring autism, do parents feel the IPRC committee should have, in order to make educated decisions regarding placement for their child?

	Research Question
Sub-question 3	How did the members of the IPRC team apply the exceptionality of both autism and deaf/hard-of-hearing to choose the most appropriate and effective placement for the student?

Data Sources and Data Collection Procedures

Institutional Review Board approval was granted by the researcher's educational institution prior to the start of the study (Appendix B). Ethics approval was also received from the school board where the participants' children attend. Following receipt of the school board's approval, individual school principals were contacted to gain their independent consent for participation. Principal consent was required before introductory parent letters were able to be sent home with students in their schools. The principals who were approached were selected based on a database search by an authorized board employee to determine which schools had students with both hearing loss and autism. This facilitated the process as the board's application approval included a limit of four principals who could be approached for participation. Requests were sent to four principals and approval was granted from all. Parent information letters, which outlined and included the purpose of the study, inclusion criteria, the study requirements and the researcher's contact information, were sent to parents (Appendix A). Interested participants were asked to contact the researcher. A total of eleven letters were sent home. This resulted in five responses, four of which met the criteria. The researcher provided the participants with an option of completing the consent form via an online JotForm or via a paper copy (Appendix C) which could be signed and emailed back. Of the four participants who com/pleted the consent form, three subsequently participated in the study. Participants were provided with an option between completing an online consent form or submitting a signed paper version.

Parents were offered the documents, specifically the consent form and the survey (Appendix D) translated and were also offered the option of having an interpreter present during the interview. The offer was made repeatedly during the exchanges with the researcher when initial contact was being made and later when interview scheduling was being done. Participants all declined, even though they all spoke languages other than English as their first language. One parent who used an interpreter during the initial IPRC meeting said, “I hate using interpreters”.

Each participant was asked to share documentation relevant to their child’s hearing/autism diagnosis and educational placement process. Parents were welcome to share any additional information they felt relevant. The documentation specifically requested by the researcher were: 1) an audiogram (preferably the most recent one), 2) an autism assessment, and 3) IPRC documentation (Appendix E). IPRC documentation included documentation from the initial IPRC and could include the referral package and parent statement of decision. The reason for having requested the audiogram was that this information was very relevant to the student’s hearing difference and the type of hearing technology being used. In the researcher’s experience, parents may not always be familiar with the technical terms related to their child’s hearing difference and are not always able to explain the hearing thresholds or describe their child’s type of hearing loss. They may or may not know the specific hearing technology that their child uses. All of this information is included in the audiogram and is very relevant to the impact on the child’s learning and likely on the placement. The request for the autism assessment was based on much the same rationale. In addition, it was interesting to note which professional conducted the diagnosis. The school board requires a medical diagnosis in order to identify a student with an autism exceptionality. Finally, the audiogram, the autism assessment and IPRC documentation were all important in helping to triangulate the data provided by the parent in the survey and interview. They were also helpful as a reference during discussions with parents, as for some, it may have been some time since the initial IPRC meeting. Parents were welcome to share any additional educational or assessment documentation. Prior to the start of each interview, parents signed an additional consent form permitting the researcher to record the interview (Appendix F).

Instruments

Data were collected by a semi-structured interview (Appendix G), a survey (Appendix D) and educational-related documentation shared by the parents. The documentation shared included their child's audiogram, autism assessment and initial IPRC paperwork. Due to the dearth of research in this area, it was necessary to create an original interview protocol. Both the interview questions and the survey used in this phenomenological case study were created by the researcher after a literature search of similar research, an action research mixed-methods pilot study test and consultation with professionals in the field of special education and deaf education. In addition, the researcher's own experience working as a teacher for students with hearing loss for more than two decades and having participated in many IPRC meetings was helpful in identifying significant topics and issues worthy of addressing in both the survey and interview protocol.

The Researcher. Although not an instrument in the traditional sense, the researcher was described by Denzin & Lincoln (2003) as "the primary conduit to data collection" (Billups, 2021, p.4). The importance of the researcher in the process of a qualitative phenomenological case study is significant in that the philosophical assumptions are grounded in the recognition of the multiple realities of the participants and the belief that knowledge is subjective, known and constructed jointly through the experience of the participants and the researcher (Creswell & Poth, 2018).

Survey. The survey consisted of three sections. The first and third sections were questions which required either a one-word fill-in response or a check selection response. The first section was related to the family, the child with hearing loss and autism, the language spoken in the home, and the participant's comfort communicating in English. The third section collected demographic data on the participants, such as age range, marital status, country of birth, highest educational level achieved, and employment status. The middle section contained 15 questions using a 5-point Likert scale questionnaire, 1 = strongly disagree and 5 = strongly agree, each with an optional follow-up question asking the participant to elaborate on their response. “Harry (2008) suggests that surveys provide a broad view of respondents’ perspectives, but do not necessarily provide the reasons or processes by which the respondents come to hold the specific view” (Zeitlin & Curcic, 2013, p.3). For this reason and to provide the participants an opportunity to expand on their perspectives, prompts were added to each Likert statement. This section included questions about the participant’s perceptions of the IPRC meeting. One such statement was, “The decision regarding my child’s exceptionalities and placement was made based on equal input from the IPRC team and from myself.” The prompt which appeared following the Likert statement was, “Can you explain more about why you feel this way?”

Interview. The semi-structured interview included 26 questions with prompts available if necessary. The questions were divided into four sections; information about the child and family, questions regarding events prior to the meeting, questions regarding the meeting and lastly, questions about ways to generate improvement. A script was read at the start of the interview to thank the participant and remind them that their personal information would be protected and that they could discontinue the interview at any point. One interview question which was asked regarding the meeting was, “How did you participate during the IPRC meeting?

For example, did you ask questions throughout the meeting, did you share your opinions on placement, did you talk about your child's strengths, etc.…".

Documentation. Documentation was collected for the purpose of supporting the other data collection tools, and to strengthen the reliability of the study by allowing for triangulation between instruments. Participants were asked to share documentation related to the assessment/diagnosis of their child's hearing loss/autism, and those related to the educational placement process. The documents were helpful in recreating the dates and details of events which in some cases had become difficult to recall due to the passage of time. In addition, the documentation served to provide some of the in-depth information related to the assessment and diagnosis.

Field Notes. Immediately following participant interviews, detailed notes were recorded regarding the researcher's observations. Field notes were helpful during the transcription process to clarify unclear details as they served to refresh the researcher's memory. The notes also allowed for annotations to be made about other relevant details, such as the setting and body language.

Memoing. As a method for data collection, memoing is often discussed in connection with the grounded theory approach (Creswell & Poth, 2018). In this study, the researcher used both inductive and deductive coding and as such, memoing proved to be a useful tool for data collection as the researcher's notes were able to guide the creation of codes during the analysis process.

Analytical Strategies for Data Analysis

The researcher met with the participants in person in their homes to conduct the interviews. Meeting in the participants' homes created a relaxed environment and aided in the development of a rapport between the researcher and the participant. It also provided additional information separate from the dialogue of the interview, which was derived from being in the participants' natural environment. The interview was transcribed using Microsoft Word and then manually checked by the researcher to confirm the accuracy of the transcription within the same day the interview took place. This was done so that the researcher's memory of the events and the conversation were as accurate as possible. Field notes and journaling conducted during the interview were used to clarify the transcription, as some of the audio was difficult to understand due to the participants' accents. The data were scrubbed, and all identifiable information was removed from the transcript.

Coding

The interview transcripts were read by the researcher twice before sending it to the participant for member checking (Burkholder et al., 2020). During the first and second read-through of the transcripts, the researcher created memos which made note of patterns, issues, or points of interest within the text. Once the transcripts were approved, the researcher began the process of data analysis. Both a deductive and an inductive approach to coding were used (Burkholder et al., 2020). During the researcher's extensive literature review, a codebook was created as a reference, which included themes and codes from studies which had investigated similar topics or similar populations (Hebel, 2014; Rossetti et al., 2018; Whicker et al., 2019). The transcripts were read for a third time and each transcript was coded using the Delve online software based on the collected list of descriptive codes as well as codes derived from the study's research questions. For example, the first sub-question of the first central research question, 'What factors, if any, influence parents' satisfaction of the placement decision process in IPRC meetings for their deaf/hard-of-hearing and autistic?' led to the creation of the code 'factors influencing parent satisfaction.' The codes from this deductive approach served as initial guides in reviewing the transcripts. An inductive coding approach was used during the second reading of each of the transcripts. Although the deductive approach was useful in providing direction, this area of study is new, and the paucity of research made it difficult to find a comprehensive list of appropriate codes. In addition, there were some new and original aspects to this phenomenological case study research, which required an inductive approach to coding. A code for 'sense of powerlessness' was created to represent statements made by the participants regarding their feelings throughout the decision-making process. The researcher created descriptions of each code for clarity during use (Creswell & Poth, 2018). A total of 23 codes resulted from the initial coding process. These codes were then refined and categorized into five themes. The themes were then ordered into a sequence which flowed to describe the parents' experiences, both outside the IPRC process and within the phenomenon.

Memoing

As a method for analysis, memoing was conducted throughout the entire duration of data collection. The researcher dated all memos so that changes and progress could be tracked and noted. Memos captured the researcher's thoughts in response to the topic or issue being addressed at that time. "Memoing, therefore, provides a mechanism by which the perspective of the researcher can be recorded for later critical review or confirmation" (Birks et al., 2008, p.71). In particular, the researcher used textual and observational memos to aid in the development of emergent categories (Burkholder et al., 2020).

Researcher Reflexivity and Positionality

The proximity of the researcher to the topic and to the participants, regardless of the indirect nature and of the acknowledged guarantee of no repercussions resulting from any points of view or perspectives shared, created a need to recognize any potential bias. Unknowingly, a researcher's point of view can impact the responses given by participants during interviews (Yin, 2018). Prior to the onset of the data collection process, the researcher made an effort to address their biases by self-reflecting on their positionality and identifying any preconceived beliefs regarding the research topic.

The researcher is a current doctoral student and a full-time itinerant teacher of deaf and hard-of-hearing students, where she has worked for more than 15 years. The researcher works with several students who are both deaf/hard-of-hearing and autistic and their families. The researcher acknowledges the bias towards the topic resulting from her current employment. In her role as an itinerant teacher, the researcher has participated in the IPRC process for students on her caseload, including students who are deaf/autistic and therefore has familiarity with the process. In addition, the researcher has participated in the IPRC meeting as a parent and, as such, has experienced the process from both sides of the process. The researcher holds no vested interest in the outcome of the research.

> The capacities to be reflexive, to keep track of one's influence on a setting, to bracket one's biases, and to monitor one's emotional responses are the same capacities that allow researchers to get close enough to human action to understand what is going on (Lincoln & Guba, 1985; Walsh, Tobin, & Graue, 1993) (Hatch, 2002, p.10).

The positionality of the researcher, informed by their reflexive practice, highlights the intricate relationship which exists between the researcher and the participant. "By facilitating the acknowledgment of the researcher's presence in the study, reflexivity acts to prevent distortion of the data" (Holloway & Brown, 2012, p.23). Although the researcher is employed in a capacity closely related to the subject matter under investigation, the primary focus was to conduct a study which shared a rich description of the lived experiences of the participants. As a result of the researcher acknowledging their positionality at the outset of the study, the process of being reflexive and examining biases, led the researcher to view the process with a more informed lens. Recognizing and acknowledging the potential for influencing data created an opportunity for the researcher to reflect prior to each interaction and during times of data analysis. “It requires an explicit self-consciousness and self-assessment by the researcher about their views and positions and how these might, may or have, directly or indirectly influenced the design, execution, and interpretation of the research data findings (Greenbank, 2003; May & Perry, 2017)” (Holmes, 2020, p.2).

As discussed in the philosophical assumptions’ section of Chapter 2, the epistemological stance of this study provided a lens to interpret the level of closeness which developed between the researcher and the participant, which then assisted the researcher in creating a frame of reference to understand the participant’s lived experience. This social interaction is necessary for the connection to develop and for the two to share and create their common view of reality. Therefore, although the researcher acknowledges her reflexivity, she also notes that her participation in the study is an unavoidable aspect. Regardless, all efforts were made to remain impartial and objective during the collection and analysis of the data.

Threats to Reliability and Validity

A qualitative phenomenological case study is a research approach which cultivates a subjective lens. “The empiricism and subjectivism of the researcher, namely through his/her emotional involvement with the field of work, means that the process of data collection and interpretation may be potentially biased” (Quintão et al., 2020, p.266). Several potential internal and external validity threats, as well as issues of content validity were noted by the researcher and were addressed.

Ricci et al., (2019) define content validity as the extent to which items of a questionnaire are designed to accurately test the construct for which it was created. To address the concept of content validity, the researcher conducted an extensive search of the literature related to both parental perceptions of the IPRC/IEP process and children who are both deaf/autistic. In addition, the researcher’s own experience as an educator of students who are deaf was helpful in guiding the development of the questions. In-depth discussion and review of both the survey and interview questions were conducted with senior members of the special education team from the researcher’s school board (Ricci et al., 2019). Feedback was provided and, where appropriate, was incorporated. Member checking and feedback from the pilot study conducted previously were also used to validate the value and quality of the questions used in the protocol.

Threats resulting from internal validity concerns were mediated as best as possible. Reflexivity was discussed in the previous section. The act of reflexivity is essential in qualitative studies because it serves to combat the possible effect of researcher bias. By recognizing their preconceptions and biases, the researcher was able to begin the iterative process of addressing the influence they may have on various aspects of the research (Johnson et al., 2020).

Additional potential threats related to internal validity were present and contended with, in this study. Maturation, history, and instrumentation threats all had some degree of influence over the implementation of the study and the analysis of the results. Triangulation of data between the interview questions, survey responses, documents, and field notes assisted in improving the validity of the study data. This was particularly useful to counteract the effect of maturation (Burkholder et al., 2020). In the first case study, just over eight years had passed from the first IPRC meeting to the interview. Recalling details in order to answer the study questions accurately may have become increasingly difficult as time passed. Having the documents from the earlier IPRC meetings to validate the information presented in the interview was helpful in ensuring the validity of the study.

Interactions with school administration, teachers, or other school processes in the time that passed since the initial IPRC may have served to alter the participant’s perspective of the IPRC meeting. Events that occurred during the extended period of time, whether they were positive or negative, may have served to alter the participant's memory in terms of having created a different feeling or association towards the school. Having multiple case studies allowed for a comparison which attempted to negate the effects of the threat of history. The use of rich descriptive data used in this study to support the findings also served to reinforce the validity by demonstrating trustworthiness.

Throughout the entire process of conducting this research study, the researcher engaged in peer debriefing with a colleague who was familiar with the topic being investigated. The colleague was able to provide information regarding the provincial Ministry's special education process, the school board process, the IPRC process and the education of students who are deaf. They served as a great resource to verify information and provide feedback on the instrument protocol. The ability to debrief and receive feedback from a colleague familiar with the topic was a useful tool in further combating the threats to the study's validity.

Qualitative reliability indicates that the researcher's approach is consistent across different researchers and different projects (Gibbs, 2007, p.190). Threats to reliability can occur in studies with multiple researchers or in studies which are replicating protocols which are not clearly explained and described. The first inconsistency in the meaning of the codes used in the data analysis between case studies as well as variations in the specific procedures of the protocol, pose reliability threats to qualitative research (Gibbs, 2007). In this research study, threats to reliability were minimized by having the same individual conduct the interview, transcribe the data and conduct the data analysis. The researcher was responsible for all roles, and this eliminated the question of inter-rater reliability. Yin (2018) addressed the issue of reliability and suggested that in order to minimize biases and errors, it is important for the researcher to document their procedures in an explicit and detailed manner. Therefore, a detailed methodology and interview protocol attempted to address the reliability threat created by variation between the cases. However, effects of variability resulting from human interaction, such as potential differences in the administration of the interview by the researcher with the various participants, could still cause inconsistencies. Establishing reliability in phenomenological case studies is challenging (Burkholder et al., 2020). The interpretive epistemological view assumed by qualitative research relies on the participant's subjectivity in order to explore the constructs of their realities and lived experiences. "The interpretivist aims to achieve a deep understanding of the social phenomenon under study and recognizes the importance of participant's subjectivity as part of this process. Research participants use their own words while relating their experiences and beliefs" (Rashid et al., 2019, p.4). Each interaction between researcher and participant is different and unique regardless of consistency within the methodology and interview protocol. While this research study made efforts to adhere to both a consistent methodology and protocol among all case studies, reliability, specifically the ability to replicate this study, would be challenging.

Conclusion

The methods used to conduct this qualitative phenomenological case study were detailed in this chapter. Information regarding the setting, design, participants, data sources and collection, data analysis, researcher reflexivity and finally, the threats to the reliability and validity of the study were all presented. The goal of this chapter was to provide a clear picture of the process involved in the implementation of this study. Upon completion of the interview and survey, transcription of the interview and data analysis were conducted. The next chapter will discuss the reliability of the qualitative measures, data analysis results, and the answers to the research questions. Data analysis procedures were detailed. Finally, the chapter will share some additional factors and findings regarding the study's results.

Chapter 4

The preceding chapter provided a detailed overview of the study setting, design and methodology employed by this phenomenological case study. Information regarding the participants, the research study problem statement, the purpose statement, and the research question were also included. The data sources and their collection procedures were discussed, as well as the strategies for data analysis. The chapter also shared the threats to the reliability and validity of the study and the ways in which the researcher addressed them. Through the use of a qualitative phenomenological case study approach, the current chapter will focus on the data gathered and its analysis. A discussion of the rationale for the methodological approach will be followed by a presentation of the data. The data will be used to answer the following research questions; What are the lived experiences of parents of students with hearing loss and autism who participate in the decision-making process of the Individual Placement Review Committee (IPRC) in Ontario? What are the factors believed to support or inhibit the collaborative family-professional IPRC partnership?

Methodological Rationale

The problem addressed by this study, as mentioned in Chapter 1, is the paucity of research and investigation into the perceptions of parents of students who are deaf and autistic with regard to their participation in the IPRC process. Exploring their perceptions has provided information about barriers and facilitators which have the potential to improve the IPRC process for other parents of students who are deaf/autistic. In order to develop a deep and thorough understanding of both the phenomenon of the IPRC process for students who are deaf/autistic and gain a more in-depth understanding of the parents and their perceptions, a fusion of the phenomenological approach and the case study approach was used. “A phenomenological case study examines how different groups of people experience a phenomenon in a specific case bounded by time and location” (Burkholder et al., 2020, p.219).

Moustakas’s (1994) transcendental phenomenological approach was best suited to provide a framework for this research (Creswell & Poth, 2018). This approach “looks at how to transcend individual experience by reducing individual’s reported experiences into patterns and themes to find the commonalities people share about the phenomenon” (Burkholder et al., 2020, p.218). This served as a counterpart to the case study which was chosen to give voice to each unique participant. This approach allowed for their perspectives to be shared in an individual manner. Yin (2014) described case study research as involving “the study of a case (or cases) within a real-life, contemporary context or setting (Creswell & Poth, 2018, p.96). The IPRC process, while not a unique phenomenon, is one that is only experienced by parents who have children requiring certain levels of special education service. Parents of students who are D/HH/autistic are required to address two different conditions which affect their child’s learning (Szarkowski et al., 2014). For these parents experiencing it through the lens of a dual exceptionality has the potential to change the process. The opportunity to examine the IPRC process as a phenomenon in which parents of students who are deaf/autistic, allowed for insights into their lived experiences. It also provided the opportunity to explore challenges and strategies used by the participants which may be applicable in other situations.

Three data sources were used, and they all served to inform the case study descriptions and the phenomenological analysis. The data collected from the interviews (Appendix G), survey and documents will be shared and will answer the study’s research questions. Pseudonyms have been used to preserve the participants’ privacy and maintain confidentiality. All names of staff or other employees and all identifiable locations, such as schools or outside service providers, have been removed or changed. Participants were offered the opportunity to select their own pseudonyms. One participant offered to use their real names or have the researcher select the pseudonyms. The researcher selected pseudonyms on behalf of the other two participants as well. In an effort to honour and respect their cultural and linguistic background, the researcher selected names from within each of their home languages and attempted to select names with some meaningful significance.

By combining the two approaches and gaining a fuller, more complete picture of each participant via the case study approach, a potentially new and original perspective on the phenomenon of the IPRC process was exposed. In the following sections, the participants' lived experiences will be presented through the use of the case study approach followed by the phenomenological thematic analysis of their experiences as they went through the IPRC process.

Results

A thematic analysis generated five themes related to the perceptions of parents of deaf/autistic students with regard to the IPRC process; *parents' lived experiences*, *factors influencing parent satisfaction*, *factors supporting or inhibiting collaboration in the IPRC*, *IPRC process*, and *parents' suggestions to improve collaboration* (Table 4.1). The first theme, *parents' lived experiences*, while the essence of the case study, will also be reexamined using a phenomenological lens. This theme provides a rich background and appreciation of the participants' individual histories. Four codes were collapsed into and became part of this theme. *Diagnosis* was the initial code which referred to both the diagnosis of hearing loss and autism for their child. *Second guessing* was coded in the transcripts to signify both the experience of second-guessing the actions they had taken in an effort to pursue help and support for their child and the guilt of possibly having pursued the wrong choice. The *passage of time/forgetting* was coded and noted as part of the lived experiences of the participants. Finally, *access to service*s was coded as it was discussed repeatedly and impacted on the participants' experiences. The remaining four themes will be explored in the phenomenological data analysis section. They will each provide a greater insight into the participants' view of the phenomenon of the IPRC process. A visual depiction of the themes and subthemes can be found in Appendix H.

Table 4.1

Themes, Sub-themes and Descriptive Examples

Theme	Sub-theme	Quotation
Factors influencing parent satisfaction	Support from the school board Support from teachers Open and honest communication IPRC team knowledge	"And they do understand. And they you know, they explain to us, like OK, they will arrange somebody who will work with him for his behaviour or maybe his speech or something." (Basmah, case study 1)
Factors supporting or inhibiting collaboration in the IPRC	Parental factors facilitating or impeding participation Sense of powerlessness Following authority Perception of participation and language access Parents' lack of knowledge Barriers to participation Facilitators to participation Questioning exceptionalities/ies / school diagnosis	"They have to understand that I am not studying in Canada. I just came 2009. So I have no idea. So they should be explain me." (Labani, case study 2)
IPRC process	IPRC decision-making Placement decisions	"I think, like, every time when they meet, they already have an idea. But they just give the time for discussion for any questions or anything. I felt that they

Theme	Sub-theme	Quotation
		already had the plan in mind.” (Kiara, case study 3)
Parents’ suggestions to improve collaboration		“Then so they must, you know, like, first they themselves learn, like, what issues they are facing, and what are the priorities of the issues and how they keep working on those problems.” (Aariz, case study 1)
Parents’ lived experiences	Diagnosis Second guessing Passage of time/forgetting Access to services	“But now I’m thinking when I, now like I now, I backtrack it, I’m thinking like there might be signs that I didn’t pick up maybe? Because he doesn’t cry. He barely cries. And he’s always been, he’s independent in playing. There was sounds though. I take him outside, he was responding. There was music? But it’s just like how much was he engaged? Now I can think back, I’m like..how much did he hear? Or how much did he process?” (Kiara, case study 3)

Prior to the start of the data collection for this research study, the research questions were analyzed and examined based on their relationship to the data sources. The researcher determined not only which source(s) would provide data to answer the questions but, to aid in analysis, identified which questions/items within the sources responded to the research questions. The research questions were also used to provide codes which served to organize the statements made by the participants during the interviews. This deductive coding approach was helpful in ensuring that the focus remained on the research questions.

Case Studies

All interviews were conducted with the mothers, although during the first case study the father participated and contributed periodically throughout the interview as he was working in the adjacent room. During the second case study, the father arrived home shortly after the interview began and, after being introduced, excused himself to another room. All participants were born outside of Canada and spoke a language other than English as their first language. The researcher did not intentionally choose participants from culturally and linguistically diverse backgrounds. The interview excerpts are displayed in their unaltered form, maintaining their original grammatical structure and syntax. This approach aligns with the conventions of phenomenological inquiry, providing a deeper understanding of the participants and their linguistic ability in conversational English. All participants were offered an interpreter for the interview, and all declined. All participants were offered translated copies of all of the documents in their home language, and all declined.

Comprehensive timelines were created for each of the case studies based on information from the interviews as well as the surveys and additional documents provided. This was done in order to better understand the progression of the participants' children through the school system and IPRC process. It was also useful in validating the data as it provided the researcher an opportunity to triangulate the information collected from the interview, the survey and the various documents. This proved to be a very useful exercise given the complicated timelines which involved multiple agencies as well as movement between several educational settings.

An overview of the participants' characteristics, which share some of the demographics collected in the survey, is presented in Table 4.2. As mentioned, all parents were born outside of Canada and speak languages other than English. Only one parent responded that she is comfortable communicating in both her home language and in English. This is the only parent who works outside of the home. In all three of the cases, there is only one child in the home with hearing loss and autism. In fact, in the homes where there are other children (case study 1 and 2), there are no other exceptionalities or disabilities whatsoever.

Table 4.2

Participants' Characteristics

Survey question	Participant case study 1	Participant case study 2	Participant case study 3
Primary Language in the home	Urdu	Bengali (Bangla)	English / Tamil
Language most comfortable communicating in	Urdu	Bengali (Bangla)	Both
Interpreter required / preferred	No	No	No
Place of birth	Pakistan	Bangladesh	Sri Lanka
Interpreter used for initial IPRC meeting	Yes	No	No
Highest educational level achieved	University[a] (degree)	College[b] (diploma)	University[a] (degree)
Current employment status	Stay at home parent	Stay at home parent	Employed full-time
Age range	25 – 49 years	25 – 49 years	25 – 49 years
Number of children in the household	3	1	2
Number of children who are both DHH/ASD	1	1	1

[a] In Canada all universities grant undergraduate (bachelor's) degrees, and most grant graduate (master's/doctoral) degrees as well (*What Is the Difference between College and University in Canada?*, 2023).

[b] In Canada colleges offer full and part-time diploma and certificate programs, which tend to be more practical and hands-on than university programs. Some colleges also offer bachelor's degrees (*What Is the Difference between College and University in Canada?*, 2023).

Case Study 1

Basmah, a stay-at-home mother who was born in Pakistan and currently lives in Ontario with her husband Aariz and their three children. Their son Irfan is currently in grade 7 and attending a special education full-time autism class. He has both an autism and deaf/hard-of-hearing exceptionality listed on his Individual Education Plan (IEP) based on the decision from the IPRC meeting. Irfan is nonspeaking and uses some sign language and writing to communicate. The researcher was welcomed into their home to conduct the interview. While Basmah was the primary participant and it was her voice which was heard, her husband Aariz joined in and shared his thoughts and clarified details periodically since he was working in the adjacent room. Regularly throughout the interview, Basmah and Aariz switched from English to Urdu to confer with each other and remind each other about names, dates and times related to Irfan's diagnoses, and/or educational journey. The interview was conducted entirely in English, and it was necessary to repeat and paraphrase most, not all, of the questions for Basmah.

There are three children in the family. The oldest child is a son who, at the time of the interview. was in grade 11. The youngest child, a 4-year-old daughter, was in junior kindergarten. Neither of the siblings had any known learning challenges or disabilities. In their home, the family speaks primarily Urdu and uses some English; however, with Irfan, they speak entirely English. Their other two children speak and understand both languages. They communicate with Irfan mostly through the use of basic signs and by writing things down.

Irfan had been diagnosed at the age of 1 with hearing loss after his mom noticed at 6 months that “he don’t listen for my voice”. He had initially passed the early detection infant hearing screening conducted at the hospital at birth. Basmah explained that the process of confirming his hearing loss was long and slow. Aariz later explained that when they suspected that Irfan had a hearing loss, they took him to their family doctor, who referred them to an Ear, Nose and Throat specialist at the hospital. After conducting a hearing test, the specialist informed them that they needed to be seen at the children’s hospital and their office would send a referral. Basmah and Aariz were told that due to long wait times, it could be between 3-6 months before the specialist’s office would be notified of a date for an appointment and, in turn, notify the family. Despite their regular calls to follow up and check in with the specialist’s office, a year passed without any appointment notification from the children’s hospital. Aariz explained that it was not until he attended the specialist’s office in person, quite upset, to inquire about the delay that he discovered the appointment had been received by their office many months prior. The message had not been passed along to the family. Once sorted out, things moved along quickly and Irfan was seen at the children’s hospital and, shortly after, scheduled for bilateral cochlear implant surgery. He received bilateral cochlear implants at 3 years old.

Throughout the entire interview, Basmah searched for and collected documents related to Irfan’s schooling. She had difficulty locating many of them as they were in multiple locations in their home. Most documents, although open, were still in their original envelopes. As both Basmah and Aariz searched to locate an audiogram, the psychological assessment, and the IPRC documentation, it became clear that they were not familiar with what the documents looked like or the information they contained.

Prior to Irfan’s autism diagnosis, both Basmah and Aariz noticed that he did not make much eye contact, he vocalized more than normal and would play by himself a lot. When they started to figure things out, they went to an autism support centre in the city but were not able to offer an assessment. Instead, they provided Aariz with a 6-month parent training course to learn how to parent a child who has autism. Irfan received his autism diagnosis once he began to attend the deaf/hard-of-hearing preschool through the school board. A school board psychologist with a strong background in students who were deaf/hard-of-hearing and with a knowledge of sign language conducted the assessment. When the results of the psychological assessment were shared with Basmah and Aariz, an Urdu interpreter was present.

Basmah was eager to share Irfan's strengths and interests. She said how he loves technology, specifically computers, smartphones, and tablets. She also shared how he is extremely interested in geography, especially flags. Both parents talked positively about his educational experience and their plans for his high school and university future. At the time of the research interview, Irfan was in grade 7 and was in his fourth school placement. His current school was his first special education full-time placement in an autism class. Two of his previous placements were in a deaf/hard-of-hearing placement.

Both Basmah and Aariz expressed a sense of trust and gratitude toward the school board and the staff. They felt that the staff possessed the expertise to make the right decisions regarding placement for their son. They specifically commented on the IPRC team's understanding of the family's desires for their son. Aariz noted that the team even asked questions of the parents, such as things they might want to ask or need for their son. Although they were very pleased with the IPRC team and the outcome, Aariz chose not to sign the Statement of Decision accepting Irfan's most recent placement change to the full-time autism placement at the time of the meeting. He explained that, as a parent, he is always reluctant and always needs time to think things through, so he was not comfortable signing and accepting the decision on the spot without having a chance to review it. Their frustration and struggle were directed toward the agencies and services outside of the school board. Wait times, lack of services and programs, and funding were just a few of the concerns that were expressed.

Table 4.3

Irfan's Chronological Timeline

Timeline	Case Study 1
May 2011	Born, hearing screening passed at birth
April 2013	Initial hearing loss diagnosis
May 2014	Follow Up Audiology at children's hospital, profound bilateral hearing loss diagnosed, sent for cochlear implant assessment
2014	Received bilateral cochlear implants – 3 years old
Sept. 2014 – June 2015	DHH program preschool
April 2015	IPRC referral, already had DHH exceptionality, placement decision, DHH special education class full-time
Sept. 2015 – June 2017	JK-SK, received no support services
Sept. 2017 – June 2022	DHH special education class full-time (grades 1-5)
March – June 2019	School board psych assessment (age 7 years, gr. 2), autism diagnosis
Sept. 2022 - present	Autism special education class full-time (grade 6, 7 -present)
Sept. 2022 - present	Receives special education hearing itinerant services – 1 hour/week (withdrawal support)

Case Study 2

Labani was born in Bangladesh and arrived in Canada in 2009. Her husband, who is also from Bangladesh arrived in 2016. Their only child, a daughter, Aditi was born in 2018. Although a self-described stay-at-home mom, Labani had recently started taking classes and was about to finish a co-op placement which would earn her a diploma as an assistant working with preschool and kindergarten children. Her husband was employed full-time. At the time the interview was being conducted, Aditi was attending senior kindergarten in a special education full-time placement for deaf and hard-of-hearing students located in a neighbourhood public school. This was Aditi's second year at that school.

Although Labani was able to communicate in spoken English, it was challenging for her and speaking, reading, and writing were all significantly easier in her home language. The interview took place in Labani's home. When offered an interpreter for the interview in advance of the meeting, Labani declined and said, "I hate interpreters". The interview was conducted in English but required the researcher to explain and paraphrase most, if not all of the questions. Following the interview, the survey was returned with most of the sections incomplete and an explanation that Labani had filled in the questions she understood. Subsequently, the researcher had the remaining questions translated into Bengali and resent the survey. Perhaps the difficulty experienced reading the survey explained why Mom did not have any of the school documentation, such as IEPs, IPRC documentation, or assessment documentation such as audiograms or psychological assessments at home. She explained that she typically did not keep the documents. Instead, she had thrown most of them out after receiving and looking at them.

When pursuing the diagnoses for her daughter and having to deal with multiple professionals in the fields of both hearing and autism, Labani was faced with the additional challenge of overcoming the language barrier. She explained the difference between having to remember a name from her own language versus remembering one that was English. "But that time is beginning. Everything is too much pressure for me, and I can't remember". She said that if they were all names of people that were in her language, it would have been easier to recall all the people that she worked with, but because they were all names and places that were not in her language, it became that much harder to remember them.

At birth, Aditi weighed 5 lbs. and was placed in an incubator for the first four days of her life. Mom stayed in the hospital with her. For some reason unknown to Labani, her daughter's hearing was not tested when she was born, and so her hearing loss was not initially discovered. Aditi's hearing loss was diagnosed when she was 18 months old. When reflecting on that time, Labani shared a sense that things would have been different for her daughter had her hearing loss been diagnosed at birth. She talked about her regret and guilt of not pursuing the hearing test at birth. She was certain that had the test occurred, Aditi would have received her cochlear implants much earlier. Mom felt certain that had they tested her hearing in the hospital, they would have identified her hearing loss at that time and have received her cochlear implants much earlier. She received bilateral cochlear implants at the age of three. Mom believes that had she received her cochlear implants earlier, she would be talking. It was also very challenging helping her daughter adjust to wearing her cochlear implants. At first, she did not like them and cried every time they would be put on. Mom would put them on, and her daughter would take them off. Mom felt that this was because it was so much sound so quickly for her and it was too much of an adjustment. Again, she felt that if she had been implanted earlier, if they had known about the hearing loss earlier, then this would not have been an issue.

When Mom later asked why her daughter's hearing was not tested at birth, she understood the hospital to have said that hearing tests were conducted by Public Health, and they did not come to the hospital every day. Mom was unaware of the hearing testing that was done at birth, and so when her daughter was born, she did not know that she should have expected it. Since this was her first (and only child) and she had no relatives living in Canada, she had no experience with this and no one to ask. It was a very challenging time for Mom.

Managing both the diagnosis of hearing loss and autism affected Mom, and she reflected on how it was impacting her husband, "my husband is very introvert, so I don't know him properly, but I know he's sad. It is very hard for us because [our daughter] is my only child and she's both of them [autistic and deaf]. It is very hard to accept, you know." From the very beginning she did her best and listened to whatever she was told by the professionals. She followed their advice. "Whatever people say, I listen to them. I go everywhere". This included attending speech therapy and occupational therapy when she was told that it would help. After only a few sessions of occupational therapy, she was told that her daughter no longer needed to attend. She took advantage of any and all services that were available for her daughter.

Her daughter began attending a preschool program for children who are deaf/hard-of-hearing close to where they used to live. Mom found out about the program through who she initially remembered as being a social worker from public health, although later in the interview she corrected herself, commenting that it was likely the social worker from the children’s hospital where her daughter received her cochlear implants. Given the timeline of Aditi’s cochlear implant surgery and her start of school, it was unlikely to have been the hospital social worker. While this was a small and inconsequential detail, it highlighted the challenges posed by the passage of time and its effect on Labani’s ability to recall all the members of the multidisciplinary team. Labani also mentioned that at that time she received additional calls from other school boards, including the Catholic board, asking if she was interested in sending her daughter to their board. Mom had been invited, along with other prospective parents, to view the preschool program. She was very grateful for the teachers in the program who helped her through the process of learning about cochlear implants, including even going with her to the hospital during the initial appointments. The family then moved from one end of the city to the other, and her daughter transitioned to a deaf/hard-of-hearing preschool closer to their new home. It was at this preschool that the teacher suggested that Labani have Aditi assessed for autism because she was not speaking. With a very defeated sound in her voice, Labani shared, “They say because she is autism, that's why she's not talking. I don't know”. At the age of 3, Aditi received a diagnosis of autism from a developmental pediatrician. At the time of the interview, 3 years had passed since the conversation with the teacher and her daughter’s diagnosis, and it was still easy to hear Labani's sadness and sense of defeat at having received the autism diagnosis.

When she was ready to transition from the preschool program to kindergarten Mom was informed that her daughter could not attend the regular kindergarten at her neighbourhood home school because she was still not talking. They recommended another school that had a kindergarten for deaf/hard-of-hearing children. The school was very far from their home. She was told that there was nothing close to them. Mom agreed to send her to the recommended school despite the fact that her daughter was only in junior kindergarten and the bus ride to and from school was an hour and a half each way. At that time, it was also suggested to Mom to consider sending her daughter to the provincial school for the Deaf. Mom considered it, but in the end, she decided against it. She said that it was a difficult decision, but "you know from your heart." She felt that the school was too far away, and while the current school was also far, the drive to the school for the deaf would be on the highway and "I only have one kid." She was also apprehensive because she felt that if her daughter went there, she would not listen. She visited the school and "saw there is too silence," and she knew that she wanted her daughter to "hear sounds." At the time of the study, her daughter was attending the special education full-time deaf/hard-of-hearing kindergarten class and her primary method of communication was sign language. In Ontario there are three provincial schools for the Deaf for students from kindergarten to grade 12. The schools provide bilingual-biliteracy-bicultural education using American Sign Language and English and provide student lodging if necessary (*Provincial Schools for the Deaf*, 2024). Although only in senior kindergarten, at the time of the interview Aditi was already attending her third school placement.

When asked about Aditi's strengths and interests, Mom's demeanor changed, "I saw she interested in everything, like she's very curious. Or whatever she see she can remember. And she will curious girl and she liked to drawing. Yes. Whatever now I watch, she watch cartoon and she drawing, want to draw some like that. She's very interested about the study". It became clear that Labani was not convinced that her daughter was autistic. She said that she believed that the diagnosis was driven by the fact that her daughter wasn't speaking. When she reached out to a teacher who knew her daughter and she asked whether he thought she was autistic, he replied, "If she is autistic, then I am also autistic." Mom also observed that the autistic children at the school where she was completing her co-op did not demonstrate the same type of behaviours as her daughter. Mom's questioning of the autism diagnosis led her to feel that between the two exceptionalities, the hearing exceptionality required greater attention and focus.

Throughout the interview, Labani made several references to her lack of knowledge related to her daughter's exceptionalities and her inability to affect change. Most of the comments were tied to her limited command of the English language while some of it was due to her lack of access to information. Comments such as "What should I do?", "I didn't have experience," "They thought I know but I don't know", and "Who asked me?" all created a sense of helplessness.

When asked about ways the school boards could improve the IPRC process as well as ways parents could impact and improve the process, Labani immediately mentioned having the board explain things to the parents. Her suggestions for improvements that could be made by parents, all revolved around sharing their opinions and writing their reviews in an attempt to give their feedback to the school board.

Table 4.4

Aditi's Chronological Timeline

Timeline	Case Study 2
June 2018	Born, hearing screening passed at birth
18 months	Mom noticed that daughter was not talking or responding to loud noises

Timeline	Case Study 2
2 years	Hearing loss diagnosis
January 2021	Received bilateral cochlear implants (2 ½ years old)
Sept. 2021	DHH program preschool[a]
January 2022	Moved to alternate location of DHH program preschool
March 2022	Autism diagnosis (3 ½ years)
April 2022	IPRC review, autism exceptionality was added
May 2022	Parents accepted DHH special education class full-time placement for Junior Kindergarten[b] for Sept. 2022
Sept. 2022 – present (2023/2024)	DHH special education class full-time placement (Junior Kindergarten – Senior Kindergarten[c])

[a] Taught by specialist teacher of students who are deaf/hard-of-hearing, using spoken and visual language models, for students during the school year prior to junior kindergarten, not available at all school boards in Ontario

[b] In Ontario, children can attend in the calendar year they turn four, it is not mandatory (Ministry of Education, 2023; *Kindergarten*, 2024)

[c] In Ontario, children can attend in the calendar year they turn five, it is not mandatory (Ministry of Education, 2023; *Kindergarten*, 2024)

Case Study 3

Kiara conducted the interview with the researcher in English at her office without the use of an interpreter. At the start of the interview, she provided the researcher with all of the requested documents plus additional ones, which had been photocopied and prepared in advance of the meeting. All of Kiara’s own documents related to her son Hasik’s diagnosis and education were organized in a binder. Located at the front of the binder were all the business cards of the various professionals that the family had worked with over the years.

Kiara works full-time, is married, and has one son, Hasik, two older stepchildren who are half-siblings to her son and a dog. The younger of the two stepchildren, a boy, lives at home. Neither of the two older children has a hearing loss, autism or any other disability.

Hasik was born full-term. He was born with jaundice and spent the first week of his life in the neonatal intensive care unit. He passed the newborn hearing screening at birth. During the interview, however, as mom reflected on that time period, she recalled that when the nurse tested him, she repeated it a second time on one of his ears. Kiara was not sure what happened, but she recalled that something caught the nurse's attention. Kiara remembered the nurse saying, "he's so loud, there's no way he can't," and then the nurse did the test again. During the interview, Kiara said that sitting and thinking back on the events had her wondering if the nurse had noticed the hearing loss.

Hasik's hearing loss was not diagnosed until he was two years old. Kiara recalled that until Hasik was about 18 months old, he seemed fine and was responding. "He was fine, like ya, he was just being a normal kid". At 18 months, when they noticed that he was not talking they began to investigate. He has a bilateral severe-profound sensorineural hearing loss, and he was found to be ineligible for cochlear implants based on an assessment by the audiology department at the children's hospital. He wears two behind-the-ear hearing aids. Reflecting back on that time Kiara started to second guess and question whether there were signs that they missed. Kiara remembers back and noted that he barely cried, and he played independently. She said that he would make sounds, though and would respond to sounds when they would go outside. Once Hasik received his diagnosis of hearing loss, he started to receive services from the city's government-sponsored early years speech/language program. It was during those therapy sessions that they noticed that Hasik had some difficulties processing and understanding, and they advised Kiara to pursue further testing and assessment. Kiara shared many of Hasik's strengths and interests. According to Kiara, he is a visual learner with a strong visual memory. He follows routines, problem solves and can be independent.

Although not listed on his IEP, Hasik was diagnosed at the age of 3 with a global developmental delay. According to the Canadian Paediatric Society, the criteria for a global developmental delay are met when a significant delay (2 standard deviations below the mean) is noted in at least two developmental domains (Bélanger & Caron, 2018). Hasik's autism diagnostic assessment was conducted by a developmental assessment pediatrician. Initially, the pediatrician was hesitant to rush to a label because she thought that perhaps what they were seeing could be explained by his hearing loss. Hasik was formally diagnosed with autism at age 5.

Hasik is nonspeaking and uses some sign language as well as augmentative alternative communication and writing to communicate. At the time of the interview, Hasik was receiving Intensive Behavioural Intervention (IBI) and speech therapy services outside of the school system. IBI is covered by government funding, however this means that the funding dictates the number of hours that Hasik is able to receive per week. This has decreased over the years. Intensive behavioural intervention (IBI) is an intensive program which focuses on several developmental areas including communication, language, and behaviour management (Geneva Centre for Autism, 2023). It is conducted using a 1:1 ratio. It follows the principles of Applied Behaviour Analysis which uses various techniques to gain insight into a child's behaviour to modify it using positive reinforcement (Autism Speaks, 2021). Kiara shared that he had been on the waiting list for services for many years.

Kiara's experience with the diagnostic process and the services that followed have caused her to develop an interesting perspective on the dual diagnosis and the order in which they were identified. She believed that it was because Hasik was receiving hearing services that he was diagnosed with autism and set on a path at an early age. The individuals involved in his hearing programs were able to notice that he was not progressing the way they would have expected. She felt that having the hearing loss identified first was beneficial as it provided them with a framework to follow. Kiara also commented that the structure and system that exists between the city's early identification/speech-language program and the school board which supported her each step of the way, did not exist for his autism diagnosis. She had to search for all of the information on her own. Additionally, Kiara remarked that there were challenges of going the process of acquiring information for a child with a dual diagnosis of hearing loss and autism. "Like there wasn't too many people." "It's all like, box out, like this one for hearing, this one for ASD, this one for regular but there's no connecting. There's no correlations one or the other".

Table 4.5

Hasik's Chronological Timeline

Timeline	Case Study 3
May 2011	Born, hearing screening passed at birth
May 2014	Initial hearing loss diagnosis
July 2014 – Dec. 2015	Participated in preschool speech/language program offered through the city
July 2015	Received global developmental delay diagnosis from developmental pediatrician
October 2016	Started to receive services from speech language pathologist through the city, biweekly
Sept. 2015 – June 2016	DHH program preschool
2016	Received autism diagnosis
April 2016	IPRC, received DHH and autism exceptionality, recommended for DHH special education class full-time placement
Sept. 2016 – June 2018	JK, DHH special education class full-time placement
Sept. 2017 -?	SK, DHH special education class full-time placement (left mid way through)
2017-2019	Received IBI therapy full-time (outside of school board)
Jan. 2021 – Nov. 2021	Attended virtual school in school board with IBI therapist Mild Intellectual Disability (MID)[a] special education class full-time placement

Sept. 2022 – June 2023	Autism special education class full-time placement (grade 5)
Sept. 2022 – June 2023	Received special education hearing itinerant services – 1 hour/week (withdrawal support)
Sept. 2023 – present (grade 6)	Autism special education class full-time (grades 6-present)
Sept. 2023 - present	Receives special education hearing itinerant services – 1 hour/week (withdrawal support)

[a] According to the Ontario Ministry of Education it is characterized by: "an ability to profit educationally within a regular class with the aid of considerable curriculum modification and support services, an inability to profit educationally within a regular class because of slow intellectual development, a potential for academic learning independent social adjustment and economic self-support" (Ministry of Education, 2022, Mild Intellectual Disability section).

Phenomenological

The information gathered from the interviews, along with the supporting documentation collected was used to help create comprehensive timelines to better understand the educational journey of the participants' children through the school system and the IPRC process. The timelines presented the changes and additions to exceptionalities and placements. For each of the cases, there were multiple placements which led to multiple meetings and interactions with the school team.

To address this dearth of literature and add to the research in the field of education of students who are deaf and autistic, data were collected to answer the following two central research questions:

1. What are the lived experiences of parents of students with hearing loss and autism who participate in the decision-making process of the IPRC process in Ontario?

2. What are the factors believed to support or inhibit the collaborative family-professional IPRC partnership?

The four remaining themes, *factors influencing parent satisfaction*, *factors supporting or inhibiting collaboration in the IPRC*, *the IPRC process*, and *parents' suggestions to improve collaboration*, have been explored and discussed using a phenomenological approach. These themes provided both textural and structural descriptions of the participants' perspectives on the IPRC process (Creswell & Poth, 2018). The textural descriptions created a representation of the participants' views on what they experienced during the IPRC process and the structural descriptions "reflect[ed] on the setting and context in which the phenomenon was experienced" (Creswell & Poth, 2018, p.201). The "essence" of the experience, described by Creswell & Poth (2018) as the composite description, incorporated both the textural and structural descriptions to visualize the voices of the participants, creating a richer description of their experiences. The theme of *parents' lived experiences*, although addressed in the case study portion of this chapter, is also discussed from a phenomenological thematic approach as there were statements made by the participants which contributed to both the textural and structural descriptions of the phenomenon.

Factors Influencing Parent Satisfaction

Three codes were collapsed and merged into the theme of *factors influencing parent satisfaction*. *Support from the school board, open and honest communication*, and *IPRC team knowledge* were all coded as factors which were seen as impacting on parent satisfaction with regard to the IPRC. *Factors influencing parent satisfaction* and *IPRC team knowledge* were both deductive codes which resulted directly from the research questions. Sub-question one of the first central research question was aimed at identifying the factors which influenced parents' satisfaction with the placement decision process.

Support from the school board and *open and honest communication* were coded inductively during the analysis of the data. Significant statements were noted in the interviews with the participants about *support from the school board* and *support from teachers*. These statements were inductively coded and categorized into *support from the school board* code. *Open and honest communication* was another factor which was inductively coded and appeared in all three of the interview transcripts.

Support From the School Board/Teachers. Support provided by the school board directly impacted the parents' feelings of satisfaction related to not only the IPRC meeting but to the process of assessment, decision-making and placement. Basmah and Aariz commented on the support provided by means of communication. "For us is easy, like communication is very good. Like if we call them, we email them, they respond very quickly, so we never had any complaints". They also shared that early on a board employee (whose role we were unable to identify) worked with the family to arrange and engage all the necessary requirements that Irfan needed for school. They referred to this person multiple times throughout the interview, as he had clearly been a significant individual at the start of their son's educational journey.

Kiara shared an interesting insight regarding the support she received from the school board. She compared the support provided by the members of the hearing support team versus those of the autism support team. "When I went with his hearing loss, I had multiple resources being given to me, like hey this is how it happens, this is what it is". The framework that existed started at an early age from within the hearing services and provided support that included guidance on seeking services outside of the board such as audiology. It was particularly challenging since the school board did not have any support geared specifically for students with the dual exceptionality. "In the school board system I think, it's all like, box out, like this one for hearing, this one for ASD, this one for regular. But there's no connecting. There's no correlations one or the other".

Teacher support and the relationship that ensued in some cases between the family and the teacher impacted the parents' sense of satisfaction. Teacher support took many different forms including diagnostician, family advocate, and referral source. All of the study participants commented on how the teachers helped not only their children but them as well. Labani shared an instance when the teachers in the DHH program preschool assisted her just after her daughter received her cochlear implants.

> I found it when Aditi get the implant it was like two and a half. It was very challenging for me. That time his [sic] teacher is very helpful. They're very nice and they're very helpful. Now, the teacher just because she's very hard worker, even she go with me the children's hospital. Yeah seriously, she is amazing. I love her. Still I miss her.

Open Honest Communication. All three of the participants addressed the topic of open and honest communication between themselves and the teachers and/or school administrators. Two different types of meaningful statements were coded by the researcher. The first group of statements was made by Kiara regarding the need for transparency by the school board during the decision-making process. The second type of statement highlighted the parents' preference to receive direct and honest information from the school staff rather than simply being told that things are going well. Open, honest communication was also coded, however, again when parents were asked about suggestions to improve collaboration.

For Kiara, the lack of transparency negatively impacted her satisfaction with the IPRC process. She commented on the absence of open, honest communication when the discussion of placement options was being addressed. At the initial IPRC, when they were attempting to decide the most appropriate placement, Kiara shared information about Hasik and the fact that he has both hearing loss and autism. At the time, she was unaware of the various placement options, specifically, the types of classes available and where they were located. During that meeting, a placement offering was made for a full-time special education class for students with mild intellectual disabilities. Only one placement was offered, and Kiara was not aware of any other more appropriate ones. There was no transparency on the part of the board. Rather than agree and send Hasik to that placement, Kiara withdrew him from the board and sent him to private IBI therapy for the next several years. Upon returning to the board and participating once again in an IPRC, Hasik was offered a placement in a full-time special education class for students with autism. This placement was much more suitable than the one offered previously. "Why didn't they offer me [the autism special education class] at the time [at the initial IPRC]"? "Because if I knew [the autism special education class] was there years ago when they offered me [full-time special education class for students with mild intellectual disabilities] I would have had him back in the system years ago". "So if you already, if this information, the supporting information, this system has everything, you do have a program, why didn't, why wasn't that offered before"?

Two of the participants discussed the extent to which they appreciated receiving open, honest communication from their children's teachers. Being given the facts and told what the teachers were really thinking was reassuring to the parents and eliminated any second-guessing or miscommunication. This had a direct correlation to their feelings of satisfaction and contributed to their understanding of the school's reasoning for decision-making regarding placement.

IPRC Team Knowledge. Sub-question two of the second central research question was the source of the code focused on the IPRC team knowledge. Throughout the interview, Basmah and Aariz, the parents from the first case study, made their feelings very clear regarding the knowledge of the IPRC team members. They expressed their full faith in the team members' awareness and understanding of Irfan's disabilities and learning needs. "So we actually had to ask them, like, ok we want Irfan to be in that…or like we want to, you know, somebody to work for him on his behaviour. And they do understand. And they, you know, explain to us, like ok, they will arrange somebody who will work with him for his behaviour or maybe his speech or something like…".

Both Labani and Kiara shared that throughout the identification process for their children's exceptionalities and the decision-making process for their placements, members of the deaf/hard-of-hearing staff assisted and participated. The presence of the staff from deaf/hard-of-hearing department during the IPRC meetings provided a perspective and understanding of the needs of the deaf/hard-of-hearing exceptionality. They made no mention at all of anyone who offered knowledge specific to autism or specific to the combined exceptionality.

Factors Supporting or Inhibiting Collaboration in IPRC

The second central research question investigated the factors believed to support or inhibit the collaborative family-professional IPRC partnership. Four codes and four sub-codes were collapsed into the theme of *factors supporting or inhibiting collaboration in IPRC* (Table 4.5). This theme directly responded to the second central research question.

Parental Factors Facilitating or Impeding Participation. Four sub-codes were collapsed into this larger code during the researcher's third read of the transcripts. *Sense of powerlessness*, *following authority*, *perception of participation and language access*, and *parents' lack of knowledge* all became sub-codes within *parental factors facilitating or impeding participation*. In their literature review, Cavendish & Connor (2018) also identified knowledge barriers and communication challenges as well, when investigating barriers to involvement in the IEP meeting.

When asked about steps that parents took to access information and become proactive, the topic of parent support groups was mentioned. Parents shared that it was difficult to access information about deafness and autism and how best to support their child and this included accessing information via parent groups on social media. Their experiences were similar to those of the families discussed by Wiley et al., (2022) in their chapter, Children Who Are Deaf/Hard-of-Hearing PLUS. They found that because “their children do not ‘fit’ into a traditional group where they can find support” (p.4), they can struggle with challenges of isolation and financial strain. They also mentioned the emotional toll experienced by parents resulting from healthcare providers not being aware of the difficulty of their situation.

The following snippets, both from the same participant, illustrated the sense of powerlessness experienced during the decision-making process. “So I just sign it. Because, first of all, I don’t want to send her that that far [referring to the provincial school for the deaf which would require an hour bus ride on the highway], because [the other school] is so far from here too, what should I do”? “So what I’m gonna do”? Several times throughout the interview, Labani commented that she accepted decisions made by the school and the IPRC team. “What can I do? My position? Like what can I do? So what should I do? I listened what they said”.

According to her survey response, Labani did not use an interpreter during the IPRC meeting, however, when asked whether or not she felt that the meeting was properly and accurately interpreted, she responded yes. There was clearly some confusion in the understanding of the question. This survey question spoke to her language access as observed by the researcher. Throughout the interview, however, Labani made multiple references to challenges she faced when trying to participate resulting from her lack of English knowledge.

Kiara said that during the meeting there were points where the IPRC team stopped to explain various terms to her. Labani did not seem to experience the same support from the IPRC team with regard to the explanation of terminology. “Like they should explain like, the IPRC, for example, mean this, this, this. No. Because they thought I know but I don’t. They should explained.”

Throughout all three interviews, comments were made that illustrated different ways the parents followed authority. In Basmah and Aariz’s situation, they suggested that they followed the recommendations and suggestions of the school board personnel because they trusted them. They felt that they were the experts. Labani and Kiara both complied with the school board’s recommendations, yet they presented a sense of powerlessness. They both followed the school board’s authority because they felt that they had no other option.

Comments were made by both Kiara and Labani suggesting that they sought out information so that they could increase their knowledge and participate more. Difficulty locating information about children with both autism and hearing loss was very difficult for the parents to find. Parents mentioned trying to access information via the internet or through social media. They found that there was little information to be found, and in Kiara’s case, when she connected with others on social media, she found that she had already searched and researched on the internet and so she was a source of support and information for others rather than receiving assistance.

The following comment illustrates the barrier presented by the parents’ lack of knowledge related to the IPRC process. “Yeah, that time I asked question but not that much because I don’t have any experience”. The lack of knowledge and limited ability to ask questions may be experienced by the parent as a feeling of inadequacy. These feelings could “constitute a tremendous obstacle to facilitating parent-school collaboration” (Burke, 2013, p.227).

Barriers to Participation/Facilitators to Participation. Factors outside of the parents’ control and not directly caused by their actions were coded separately as barriers and facilitators to participation. Parents acknowledge their lack of knowledge in the areas of both their children's exceptionalities and the IPRC process. While this barrier is a product of the parent's actions or lack thereof, it can also be looked at as a barrier that is imposed upon them. Throughout the interviews parents remarked about terminology which was not explained during the meetings. Labani commented, "No, like they should explain like the IPRC, for example, mean…"

When asked whether they received any of the documents translated into their home language or if anything was presented to them in the IPRC meeting in their language, Aariz responded, "only in English." In addition, all of the parents commented that they did not have interpreters present during their meetings, aside from a meeting Basmah and Aariz had with the school board psychologist.

Another barrier that made the parents feel hesitant to participate was the sense that the decision had already been made. Kiara discussed the fact that she felt that everything had already been decided before she entered the meeting. "It kind of seems like a pre-defined, non-communication decision, kind of thing."

Questioning Exceptionality/ies / School diagnosis. In all three of the case studies, the children were diagnosed with hearing loss first. Their children's autism diagnosis resulted from the recommendation of a school board employee, usually a teacher, to seek an assessment. On three separate occasions during the interview, Labani's statements were coded as questioning exceptionality/school diagnosis. In her case, the pursuit of a developmental assessment was a result of being told that perhaps her daughter was not speaking because she had autism. "Yeah, and they say because she is autism. That's why she's not talking. I don't know." Although the developmental pediatrician diagnosed autism, and autism was added as an exceptionality on Aditi's IEP, Labani continued to question the diagnosis. "Yeah because yes, like I said, 'why you

Aditi not talking?' They say 'autism, that's why maybe she is not talking'. It's not a good answer. I think so. When I asked everybody they say, 'ok, maybe that's why'."

IPRC Process

Of the five themes, *IPRC process* was the most frequently coded theme in the data. There were two aspects to the decision-making process in the IPRC for the parents. The first was whether or not they felt that they had contributed to the process and whether their opinions and information had been considered. The second was whether or not the parents were satisfied and/or pleased with the decision, regardless of whether they had equal or even partial input.

IPRC Decision-Making/Placement Decisions. Basmah and Aariz had very positive views of the entire IPRC process. "Always you can give them suggestions or anything. They listen to the parents, so we never had any complaint or anything like we said. Like even they are professionals they know a lot of things. Before because they deal with different kinds of problems. Or maybe our problem is just not focused on this, so they ask us like so many questions or different things from different areas that we don't, we are not aware of."

Kiara felt that although the team allowed her time to ask questions, and heard what she had to say, she was not equipped with the necessary information to ask the proper questions. At that time, she did not have the knowledge or the information to understand the implications of her son's exceptionalities on his education. Research conducted with parents of children with learning disabilities in the United States documented similar results, with one parent commenting that their voice was heard but members of the team were not really listening (Cavendish & Connor, 2018). Labani noted that she was able to and did ask questions during the meeting. However, they were not productive. "Yeah, that time I asked question but not that much because I don't have any experience."

Sub-question three of the second central question addressed the topic of the IPRC team's selection of an appropriate and effective placement for the student and how they applied the student's exceptionality in order to make the placement decision. The issues related to this were not particularly prominent in the interview data. The parents' responses did not address the IPRC team's application of the students' exceptionalities. Brief comments were made suggesting that it was unclear how the decisions were made.

All three participants experienced different levels of satisfaction related to the decision in the IPRC. Although Kiara commented that she was satisfied with his most recent placement in a full-time special education autism class, she was unaware that there may have been full-time placements in a deaf/hard-of-hearing class. The comment below illustrates her confusion regarding why the IPRC team chose an autism placement.

> I think, like, every time when they meet, they already have an idea but they just give the time for discussion for any questions or anything. But I felt that they already had the plan in mind and then it was, if I declined anything, then maybe there might be options. But it kind of seems like a pre-defined, non-communication decision kind of thing, I guess.

While Kiara felt that the decision was pre-made, she also noted that "there was no defined clear placement". She did not have enough information to know if there were better, more suitable options for placement. Looking back at previous placements, Kiara shared that Hasik went to a junior and senior kindergarten class in a full-time special education deaf/hard-of-hearing placement because there were no autism full-time classes. Although only one placement option was offered, Kiara talked about the opportunity she was later given to visit the class. "But they asked me to go to the classroom, to check the classroom, to see if I think it's fine. But looking at the classroom is, yes, you can assume. But the function at the level of functional abilities, we don't know. So I didn't decline it. That's when I always try, 'OK let's try it', if not let's go back."

In a review of the research conducted by Guardino (2008) regarding the identification and placement of students who were deaf/hard-of-hearing with multiple disabilities, the challenge of determining the primary disability for students who were deaf/autistic was discussed.

> They found that if autism were considered the primary disability, the child would be placed in an educational system for autistic children. In contrast, if the child were labeled 'autistic-deaf,' programs designated for children with deafness would be the legal placement. (Guardino, 2008, p.58)

Although considerable time has passed since this review took place, the struggle to determine an appropriate placement for students diagnosed with both hearing loss and autism persists. Both autism and hearing loss impact language development and communication, making the placement decision a difficult one (Guardino, 2008; Scott & Hansen, 2020). Labani's comment on being offered only one placement continues to highlight the struggle faced by parents during the decision and placement process. "Did not give me too much option. They always give me one option. This is school. This is school. This is school. Even I don't know how many this program have any around my home or no, [wondering if there were any similar type programs near her home] they're not explain me anything. So they don't give me any choice. Just the one." Labani's focus was largely on the actual school and its location rather than the type of placement. She wanted to find a placement in a school that was closer to her home. Her frustration came from being unaware of the location of full-time special education programs within her neighbourhood and the surrounding area. It was the lack of access to this information that she found frustrating.

Parents' Suggestions to Improve Collaboration

Several interview and survey questions were aimed at eliciting responses to the research question exploring ways in which collaboration could be improved between parents and members of the IPRC team. Friend & Cook (2017) define collaboration "as a direct interaction between at least two coequal parties voluntarily engaged in shared decision making as they work toward a common goal (p.5). They point out, however, that school professionals need to take into account the needs of the families and potentially adjust expectations related to the collaborative relationship. "Despite the strength of your collaboration, your primary responsibilities in working with families are to understand the family needs and to facilitate family participation in decision making about the education of the family member with a disability" (Friend & Cook, 2017, p.265).

Open and Honest Communication. Being prepared to hear the truth about your child's progress and development was mentioned by all of the parents as an important factor in improving collaboration. Parents needed to be able to accept the honest messages from the school staff and listen. Aariz commented that "parents need to be ready to listen, have a consciousness about what they are dealing with." At the same time, the school staff needs to share honest information and avoid glossing over the hard parts of the message. Labani related her frustration with not being told honest, actionable information about her daughter's ability, functioning and strengths.

> Yeah, I don't like that. I want to hear is Aditi needing… What is Aditi like? I know she is shy, they don't say anything but I know Aditi shy. What is her problem? I want to know. How it is overcome? She overcome the shyness.

Kiara addressed the issue of parents who do not want to acknowledge that there might be an issue with their child. She had spoken with other parents and had experienced situations where parents did not want to pursue assessment or accept an exceptionality. “They should understand that you’re not the one going to suffer after, at the end of this. And you can access certain services only if you do it.”

Lived Experiences

The participants’ lived experiences were explored within the context of the case studies previously shared. There were, however, additional meaningful statements made by the parents which were coded and were more aligned with the phenomenological framework of this research study. The following four codes were included in the theme of *lived experiences*: diagnosing, second-guessing, passage of time/forgetting and access to services.

Diagnosing. Parents shared multiple issues surrounding both the diagnosis of hearing loss and the diagnosis of autism which impacted the children’s educational experience and interactions with school staff. As mentioned earlier in the results, all children were diagnosed with hearing loss prior to their autism diagnosis. For all three of the participants, it was either their child’s preschool teacher, speech therapist or a combination who initially suggested that there were indications of autism. Basmah and Aariz, as well as Kiara told the researcher that they had seen signs, specifically concerns related to eye contact, prior to being notified by the teachers/therapists. In all cases, the parents listened to the recommendations and pursued an assessment.

Kiara’s experience pursuing an assessment for Hasik was slightly different than the other two cases but demonstrates the effects that could be seen as a result of diagnostic overshadowing. McFayden et al., (2023) defined diagnostic overshadowing in relation to hearing loss as “explaining the behaviors as related to Deafness and ignoring the possibility of another etiology or contributing diagnosis” (p.2). Kiara shared that the developmental pediatrician was initially hesitant to definitively diagnose autism and suggested that they wait, explaining that perhaps what they were observing was a result of Hasik's hearing loss. This is not reflected in the developmental report. Kiara realized the value of obtaining the diagnosis. "It was delayed [beginning access to autism services] because the diagnosis delayed. They don't want to label it right away. I had to kind of push them to like, 'no it's fine, just do it'."

Second Guessing. For the parents, participation in the decision-making process was impacted by their own lived experiences having dealt with the guilt associated with second-guessing themselves and questioning if there were things they could have done differently for their children. Kiara expressed her sense of reflection, "When I see him now I feel like, 'oh I should have'. I always think that one. Like I should've inputted more in him, even more. But you never know what you would have done or wouldn't have done." She looks back at the time in Hasik's education when she made the decision to remove him from the school board entirely and placed him in private IBI therapy. "Yeah but again that was the best decision I thought I could able to take at that time 'cause his, that point his hearing services were up but his autistic support were very low." She continued to say that she still did not know if that was the right decision.

As discussed previously, Labani also shared her upset and second-guessing about the delay in Aditi's hearing loss diagnosis and the impact it had on her speaking. She commented repeatedly throughout the interview that because Aditi did not have a hearing screening at birth and therefore her hearing loss was not identified, she was not implanted until age three. Labani connects the late age of implantation to Aditi's delay in speaking. She wondered what would have happened had she known about the hearing screen and had she requested that it be done. This second-guessing and sense of guilt has led to Labani's questioning of the autism diagnosis as she strongly feels that Aditi's delayed speech is more likely a result of the delayed hearing loss diagnosis rather than autism.

Labani also questioned her role in Adriti's speech and language delay. Although she had been told that she was not responsible, she still wondered if she was confusing Adriti and causing her language delay by speaking to her and exposing her to Bengali in their home. "Maybe that's why she not take any language."

Passage of Time/Forgetting. Of all the participants Labani had experienced the shortest amount of time between the initial IPRC and the interview conducted for this research study. At the time of the study, her daughter was 5 years old. A total of 20 months had passed between the time of the interview and the IPRC. Labani frequently mentioned the difficulty she had recalling information and details related to her daughter's exceptionalities. Statements such as "I don't remember the name of the school also" and "I don't know, forgot. Maybe they give me and I forgot" were made frequently throughout her interview. Labani explained that for her memory was tied to language. She could not recall the details because they had been presented to her in English and they were not familiar to her.

Basmah experienced the greatest amount of time between the interview and the initial IPRC. Although she did not mention it, language was likely a factor for her as well. She explained the difficulty recalling the details related to the IPRC with the following statement: "so many thinking, so many thing is so many meetings." She found it challenging to remember which meeting was for which purpose.

Access to Services. Services outside of the school board provided support for all of the families. Based on statements from the participants and a review of the documents shared, there was a range of collaboration between the outside service providers and the school board. Reports from other support services such as IBI therapy, speech therapists, developmental assessments and audiological assessments, were shared and included in the IPRC meetings.

Each of the participants expressed difficulties accessing services. Issues that were mentioned included long wait times, lack of programming specifically geared for children who are both deaf and autistic, and having no knowledge of the quality of the various services when selecting from lists on websites. Again, the barriers related to language access and having limited knowledge in this area created additional challenges for the families when accessing services. When outside services and school personnel worked collaboratively, the result was not only beneficial for the child but also beneficial for the parent and impacted the parent's perspective of the educational process.

Factors to Consider

The intended focus of this research study was the phenomenon of the initial IPRC meeting for parents of deaf/autistic students; it quickly became clear that part of the phenomenon was that, for the parents, this initial IPRC repeated itself. The deaf/hard-of-hearing exceptionality was not identified at the same time as the autism exceptionality, and the students' placements changed more than once. The subsequent meetings, while not officially referred to as the initial IPRC, included parent participation and collaboration with the school team. The facilitators and barriers which impacted parent satisfaction were the same. It became clear from the interviews with the parents and from the documents they shared, that it was difficult for the parents to distinguish between the initial meetings and the IPRC review meetings.

Conclusion

This chapter presented an explanation for the researcher's choice of a phenomenological case study approach. The data were presented using descriptive case studies, followed by the phenomenological framework of thematic descriptions. The data were analyzed and used to answer the study's research questions. The final chapter of this dissertation will integrate the results with the relevant research and theoretical frameworks. The study limitations will be shared. The potential impact the study findings might have on practice in the field of deaf/autistic education will be discussed by way of an Organizational Improvement Plan (OIP).

Chapter 5

The previous chapter focused on the analysis and results of the phenomenological case study. Based on the results of the qualitative data, the following research questions were answered: What are the lived experiences of parents of students with hearing loss and autism who participate in the decision-making process of the IPRC in Ontario? What are the factors believed to support or inhibit the collaborative family-professional IPRC partnership? Finally, some additional factors regarding the results were shared.

The final chapter of this study will conclude with an overview of this dissertation, followed by a discussion of the connections between the findings and the extant literature and theoretical frameworks discussed in Chapter 2. The study's limitations will be analyzed and potential implications on current practice and future research in the field of deaf/autistic education will be presented. Finally, an Organizational Improvement Plan directly connected to the findings will be delineated.

The participants in this research study all shared their experiences openly with the researcher throughout their interviews. While they all had children who were deaf/autistic and all three children attended full-time special education classes, their experiences, although occasionally similar, also demonstrated the uniqueness of each individual child and family. Commonly found across the three participants was the belief regarding their child's ability to succeed and their absolute desire to assist in and enable that success.

Due to challenges resulting from the participants trying to express themselves in their non-native languages, some of the information shared during the interviews was not in chronological order. The researcher was required to repeat and rephrase some of the questions in order to enhance clarity for the participants. An interesting note was that the parents' responses on the Likert-scale survey were more positive than their responses during the interview with the researcher. This finding was also noted by Zeitlin & Curcic (2013), in their literature review of parent satisfaction regarding IEPs. They found that responses collected via surveys were more positive than the reports of parents' perceptions and satisfaction shared in interviews. This finding as well as that of the current dissertation finding, supports the researcher's selection of a survey, an open-ended interview and collection of documentation to provide a fuller and more comprehensive understanding of the participants' perspectives and lived experiences.

Examining Study Findings in Context: Building on Extant Research

When reviewing and connecting the findings of this study to extant literature, it is necessary to recall that research in the area of deafness and autism is just beginning to emerge. As a result, similar studies in other areas of special education have guided the investigations and helped direct research. Much of the literature reviewed in Chapter 2, while not having been conducted on the same population, has been informative in its presentation of the parents' experiences of the identification and placement process for students with exceptionalities. Some of the comments made by the parents were not found in the extant research. This could be explained by the uniqueness of this small sample. The participants in this study were not only parents of children who were both deaf and autistic and lived in Ontario, Canada, as were the criteria for the study, but they shared many other similarities as well. All of the participants had been born outside of Canada, and all spoke a language other than English as their first language. In all three families, they each only had one child with a disability. Finally, all three children discussed in this study used non-verbal communication and did not use spoken language. All three had received their hearing diagnosis prior to their autism diagnosis and were being educated in full-time special education placements. The experiences were and continue to be very specific to this low-incidence group. Although there may not have been a significant amount of pre-existing research from which to draw, the insights from the participants provided rich descriptions of their lived experiences which will serve to support future investigation in the field.

Factors Influencing Parent Satisfaction

Support from School/Teacher

Although this phenomenological case study represents the experiences and perceptions of three participants, the data and results reflect much of the existing literature reviewed in Chapter 2. Kurth et al. (2020) conducted their study focusing on parents of children with autism. One of their findings was centered around the behaviour, skills and knowledge of the school personnel. They noted that these factors were consistently connected to parents' satisfaction, which directly impacted their ability to have input and, therefore, affected their participation (Kurth et al., 2020). The participants in this current qualitative study mentioned the same factors as barriers to participation throughout the interview.

Support from the school board was reported on by the participants in this study in multiple ways. The parents referenced specific actions and services they received or, in some cases, did not receive and they discussed information provided or not provided related to the IPRC. They also shared multiple examples of the support they received from their children's teachers. The sense of satisfaction, either positive or negative, impacts the quality of parental participation, which has direct bearings on the collaboration between the family and the school (Paccaud et al., 2021).

None of the three participants recalled having received the board-created parent guide which the school board is required to send prior to the IPRC according to Ontario Regulation 181/98 (Government of Ontario, 2001). "Once an IPRC has been requested, parents must be provided with a copy of the guide, which contains information on the IPRC and the decision-making process” (Government of Ontario, 2024a, The Parents’ Guide section). When reviewing the additional documentation supplied by Kiara, the researcher discovered a cover letter from the school board mentioning the “attached parent guide”. Kiara’s lapse in memory regarding the receipt of the parent guide could be explained by the amount of time that had passed since the guide had been sent to her or perhaps, she had not acknowledged the guide when she received it and had not read it. There are no requirements for the school boards to make the parent guide available in multiple languages or to include any other accessibility features. A review of several school boards in the GTA revealed the variety in the level of language and disability access offered in the parent guides. The Toronto District School Board’s parent guide is accessible online and is available both as an audio download and as a Word document (Toronto District School Board, 2023). York Region District School Board offers their guide in braille, large print or in an audio version (York Region District School Board, n.d.). The Peel Region District School Board offers the guide translated into 13 languages other than English as well as braille, large print or an audiocassette (Peel District School Board, 2024). Brackenreed (2019) found similar results when examining parent and caregiver perspectives on barriers to providing care for their children with low-incidence disabilities. The phenomenological study was conducted in Ontario, Canada and, as such, “a parent guide for the IPRC process was to be made available to parents as a result of Ontario Regulation 181/98 (1998)” (Brackenreed, 2019, p.105). Brackenreed revealed that the participants had no recollection of receiving the parent guide from the school. It is important to note, however, that the participants in the study were discussing their children who were now adults. The events they were discussing had occurred years, possibly decades prior. While memory may have been a factor, this is still worthy of mentioning given that none of the participants could recall receiving the guide.

The school board offered support, which positively influenced parent satisfaction. Parents specifically noted having received this support through the provision of school psychologists and the existence of a strong framework within the hearing department. Parents in this study commented that when meeting with the psychologist there was an interpreter present to ensure that everything being said was understood. In addition, Basmah and Aariz recalled that when Irfan received his autism diagnosis from the school board psychologist, she was able to communicate with him in sign language as well as spoken English. They were grateful for her understanding of his hearing challenges and how best to accommodate them during the assessment.

All three of the participants mentioned teacher support, specifically received from the teachers within the DHH preschool. This was a significant factor related to parent satisfaction. The support provided by the teachers occurred during times when all of the participants were negotiating through the assessment process and adjusting to the autism diagnosis for their child. Parents also mentioned the extra effort made by the teachers in the full-time special education classes. Basmah and Aariz reflected on how passionate and hard-working they felt the teachers were and how satisfied they were with the work that the teachers were doing with their son.

Open and Honest Communication

"Like so many parents in so many similar situations, I can only wish that everyone who suspects additional problems would be as direct with me as others were about deafness" (Beals, 2004, p.288). Labini and Kiara were very clear in their desire to have open and honest exchanges with their children's teachers. Both shared examples of that type of relationship with the teachers in their child's preschool program. They found that regular communication and clear, direct updates and information were both helpful and reassuring. These findings are similar to those found in Hess et al. (2006), in their discussion on the relationship between parents and teachers. “When teachers care about children, communicate openly and perform their job in a professional manner, parents appreciate these efforts and are satisfied with their child’s education” (Hess et al., 2006, p.154).

IPRC Team Knowledge

None of the participants in this study commented about the IPRC team members’ knowledge or understanding of their children’s disabilities. This did not seem to be a factor which impacted on the parents’ relationship with the team. Kiara briefly touched on the topic when she mentioned the uncertainty she experienced when trying to decide about the best placement for her son. She recalled that, similarly, the IPRC team was slightly tentative since the dual exceptionality presented a unique uncharted path. There were no specific comments made by any of the participants about a lack of awareness or knowledge of hearing loss or autism on the part of any of the IPRC team members. Perhaps this is not an important factor in the decision-making process, or the possibility exists that the interview questions did not elicit the proper information. The parents’ impressions about the IPRC team’s knowledge and its impact on decision-making were in direct response to the second sub-question for the second central research question; What, if any, information, knowledge and understanding regarding hearing loss and co-occurring autism, do parents feel the IPRC committee should have in order to make educated decisions about placement for their child? A review of the extant research in the field also did not reveal a discussion on the topic of the expertise or knowledge base of the IPRC team members, the impact of their expertise on decision-making or the collaborative relationship with parents.

Factors Supporting or Inhibiting Collaboration in IPRC

Parents shared factors which impeded the collaborative process in the IPRC as well as those which facilitated it. Collaboration was essential for full parent involvement. Cook & Friend (2010) provided a definition of collaboration in their article regarding students with disabilities.

> The definition that we developed nearly two decades ago still applies: Collaboration is the style professionals select to employ based on mutual goals; parity; shared responsibility for key decisions; shared accountability for outcomes; shared resources; and the development of trust, respect, and a sense of community (Friend & Cook, 1990, 2010). This definition recognizes that many school activities, including consultation and team interactions, may be collaborative but are not always. (Cook & Friend, 2010, p.3)

Several sub-themes were collapsed into the theme of *factors supporting or inhibiting collaboration in the IPRC*. A list of the themes and sub-themes can be found in the previous chapter (see Table 4.5). In the previous chapter quotes were shared from the participants to highlight the various sub-themes.

Parental Factors Facilitating /Impeding Participating

In the earlier review of the literature, the effect of power imbalance was presented as a barrier in several studies. Love et al. (2017) noted that in their study a parent feared signing the IEP documents regardless of the fact that they were not pleased. Their fear was out of concern for repercussions. The findings from this current qualitative phenomenological case study are consistent with Love et al. (2017), specifically Kiara's hesitation to refuse the placement for her son for fear that the alternative she would be presented with would be worse. Parents are only presented with one placement option; a second option is only provided once the initial option has been rejected. Labani commented frequently throughout the interview that she felt she had no choice, suggesting a clear imbalance in power between herself and the decision-making team. Both Kiara and Labani's experiences further support the results reported by Hess et al. (2006) regarding the imbalance of power between culturally and linguistically diverse families and school personnel. This imbalance of power can be connected to both the theme of a sense of powerlessness and following authority. They are examples of the imbalance experienced by the participants, which impeded their participation. McLeod (2022) explored the challenges that CLD families face during partnerships with educators when navigating the special education system. One of the factors reported by the parents in the study was a sense of powerlessness. "Often they saw themselves as powerless and afraid to challenge educator's and service providers' authority in critical decisions about their children" (McLeod, 2022, p.34). This study provided a second perspective, however, that of the educator. The educators perceived the parents as being minimally involved, a direct result of the parents' fear and sense of powerlessness on their behaviour.

When asked about their interactions with the school board and their perceptions related to the administration, Basmah and Aariz consistently had only positive things to share. They had no negative or constructive comments to share regarding the school board or the IPRC members. Perhaps this was because they were concerned that it could reflect on their child despite all of the reassurances. Throughout the entire interview, their attitude and response towards the school were enthusiastic. While they repeatedly commented that they were asked to contribute during the meeting, they also noted that they participated in a limited way and were happy to accept the advice and decisions provided by the IPRC team. Aariz expressed repeated gratitude for the guidance and knowledge that the school administration and teachers had offered and shared. Of note was his choice to not sign the Statement of Decision for Irfan's placement at the time of the IPRC meeting. Although Aariz was in agreement with the IPRC team and respected their knowledge, it seemed based on how he expressed himself, that by not signing and taking the time to think about it before making the decision, he was maintaining his own power within the process. McLeod (2022) found that although most of the parents in the study, which focused on CLD families, reported negative perspectives on the parent-educator partnership, there were some that felt there were positive interactions. Similar to Basmah and Aariz, parents reported that “They listen to what I have to say, and we take it from there” (McLeod, 2022, p.30).

In the study’s results, McLeod (2022) found that parents felt powerless, and they discussed the negative manner in which the educators exerted their authority. While this was not the position of all the participants in the study, those who expressed that view shared a sense of having their rights as parents overridden. In one case even describing the actions of the educators as “victimizing the victim” (McLeod, 2022, p.30). In comparison, the participants in the current study used similar terms and phrases to express their feelings of powerlessness and reaction to following the authority of the school but they did not portray themselves in the role of victim.

Findings in the current study regarding parents’ perspectives on language access and barriers resulting from technical language and jargon are consistent with those of Childre & Chambers (2005) and Papoudi et al (2021). “Another way educators alienate families in planning is through the use of educational and medical jargon” (Childre & Chambers, 2005, p.224). In their article about the IEP process, Lo discussed some of the challenges facing CLD families, as well as ways in which professionals can best work with and support the families. Lo pointed out that the meeting documents may not be written in the parents’ home language, and they may not be written to match their reading and comprehension levels (Lo, 2012). This was a barrier which impeded the participation and collaboration of the families in this phenomenological case study. Basmah and Aariz searched through years’ worth of documents sent home by the school, and as they shared them with the researcher it was clear that they were unfamiliar with the content and purpose of the documents.

> The parents described three components of language accommodation necessary to access IEP materials and meetings. These included live interpretation during IEP meetings, translation of IEP materials into their preferred language, and recognition by school personnel of the difficulty of participating in IEP meetings with limited English proficiency. The absence of these components prevented their meaningful engagement in IEP meetings by limiting their access to necessary information and modes of participation. (Rossetti et al., 2020, p.251)

The theme of limited knowledge and its role as a barrier for parents of children with disabilities was also present in a study by Wallace-Watkin et al. (2023). Focusing on parents from underserved populations with children who were autistic, the study reported that the lack of knowledge included a limited understanding of autism and a lack of relevant information needed to access services.

Similar to the findings in the current phenomenological case study, the participants in Wallace-Watkin et al. (2023) noted that they had attempted to educate themselves via parenting classes and internet searches. Gaining knowledge was both empowering and, in some cases, allowed them to feel more equipped to advocate for their child.

Barriers to Participation

Rossetti et al. (2020) conducted focus group interviews with CLD families to explore their perspectives regarding participation in IEP meetings. Their study used Trainor's (2010a) interpretation of Bourdieu's (1977) capital theory in their discussion to explain the perspectives of the parents. They found that the parents "utilized their social capital (i.e., social networks) to gain valuable forms of cultural capital (i.e., knowledge of rights and importance of IEPs) within the context of IEP meetings” (Rossetti et al., 2020, p.254). Furthermore, the CLD parents used their social networks to help them develop the necessary skills and knowledge to overcome barriers and participate in IEP meetings (Rossetti et al., 2020). The results of the current phenomenological case study did not find examples within the parents’ statements which suggested that they accessed their social capital in this manner. In fact, only one parent, Kiara, shared that she connected with other parents of children who were deaf/autistic via social media groups to gain information. However, she found that her understanding, and knowledge of the processes involved with accessing services were more robust than other parents.

In an effort to further explore the barriers to parent participation, parents were asked about their perspectives on the IPRC team members’ understanding of hearing loss and autism. Responses from the parents suggested that it was not about the knowledge of the IPRC team, with regard to the students’ exceptionalities. Rather, it was about other factors, such as the IPRC process and how the team members included the parents.

Although legislation is in place to ensure parents’ right to participate in the decision-making process for their children’s special education placement, as well as guidelines outlined in each Ontario school board’s special education plan, there continue to be challenges and barriers for parents attempting to advocate for their child with disabilities. Lack of parental involvement leaves children “with disabilities vulnerable to receive inadequate and inappropriate services” (Burke, 2013, p.225).

Facilitators to Participation

The parents were all in agreement with the decisions the school board made regarding their children’s exceptionalities. All three participants agreed with both the deaf/hard-of-hearing and the autism exceptionality. At various points in the interviews, the parents mentioned the need and recommendation for all parents to be open and accepting of their children's disability and, as such identification and exceptionality. Focusing on the habitus of perspectives and actions of parents of children with disabilities, Trainor (2010b), discussed two different points of view on the use of labels. The first viewed labels as a positive source of capital. Parents felt that using a label to name a disability allowed them to gain access to professionals to support their child. Some parents felt that this was not the case for all labels, but in the situations where it was beneficial, it helped maximize access to special education services. Parents noted that the label, a result of a definitive diagnosis, became a form of capital as it allowed the parent to use it to qualify for eligibility for services for their child.

Questioning Exceptionalities/School Diagnosis

Disagreeing and questioning school authorities openly may be viewed negatively by some CLD parents. For this reason, parents may remain silent or appear accepting of a decision while at the same time questioning or disagreeing with it (Tamzarian et al., 2012). It is important to consider the extent to which the concept of special needs is influenced by society and culture (Tamzarian et al., 2012). This is particularly true when working with families from CLD backgrounds as "cultures differ in what is considered an appropriate range of behaviour and development (Tamzarian et al., 2012, p.5). Difficulties can also occur resulting from the differing views of disability between Western societies and other non-Western cultures. "…most Western societies have a deficit view of disabilities, acting on the assumption that it is best to identify the disability and whenever possible correct or remediate the associated deficits" (Tamzarian et al., 2012, p.6).

IPRC Process

IPRC Decision-Making

In research conducted with parents of children with intellectual and developmental disabilities, Love et al. (2017) found a slightly different response in their data. Their findings were based on the parents' exclusion from the decision-making process resulting from "pre-IEP staff meetings" (Love et al., 2017, p.167) where school personnel had already made unofficial decisions. This research does not stand in contradiction to the data collected in the current research study. While the issue of the school personnel having meetings prior to the IPRC without the parents present was not a topic raised by the participants, Kiara believed that the team "already had an idea" about placement. If, in fact, the meetings did occur, the parents were unaware. To answer questions such as this, future research could include members of the IPRC team to draw on their perspectives.

Whicker et al. (2019) conducted a comprehensive review of the literature regarding the challenges and perspectives of parents of children who were deaf and hard of hearing with other disabilities. In their summary of the studies of parents of children with hearing loss and autism, they found that with regard to decision-making, parents reported using a trial-and-error approach to determining whether to select services for hearing or autism. This approach was specifically mentioned by Kiara when discussing the challenges she faced in determining the most appropriate placement for her son.

"Because which classroom is he gonna benefit more? We don't know. I think that's also part of the trial-ing when he started the special education full-time autism class [primary]".

"And that's when I was thinking, he's already getting the behavioural half and then half and half… but again that was also still in trial".

"That was like unclear for everybody I think, in his case. That's probably more of a system issue in my opinion, 'cause I was also, couldn't able to decide completely, should he be the right fit for the autism class? We don't know that. It was the trial before we landed in the special education full-time autism class".

Placement Decisions

The participants in this study all expressed a similar sense of acceptance and uncertainty in addition to their agreement with their child's placement decision. Each parent signed the Statement of Decision and accepted the full-time special education placement. It did not seem at any point that a full-time placement was in question for any of the students discussed in this study. The discussion for Basmah and Aariz, as well as for Kiara, was based on whether an autism full-time placement was most appropriate versus a DHH placement. In Kiara's case, there was earlier discussion about a placement for Hasik in a full-time special education class for students with mild intellectual disabilities (MID). Another factor in the decision was a logistical one resulting from access to services for Hasik's hearing and autism exceptionalities. When Kiara reflected on his most recent placement in an autism class, she began to realize that this afforded him the opportunity to receive services from the Special Education Hearing Department in the form of weekly itinerant services. This placement, therefore, gave focus to both of his exceptionalities. The school board did not offer similar autism itinerant services had they chosen a full-time DHH placement instead. Basmah and Aariz, and Kiara agreed to follow the decision of the IPRC team. They shared during their interviews that they were uncertain at the time they agreed if the placements were the correct ones. For Labani the decision was whether or not to send her daughter to the full-time special education DHH class or to send her to the provincial school for the Deaf. Ultimately her decision was made based on distance and on the fact that the provincial school uses American Sign Language as the language of instruction.

Extant research addressing parents' perspectives on placement decisions focuses on the issue of inclusion versus full-time special education classes. "Parents' decisions about placements often reflected an inner conflict between positive beliefs about inclusion and the realities of teacher preparation and service provision. Several parents felt that schools did not understand what inclusion means or did not prioritize it" (Love et al., 2017, p.165).

Parents' Suggestions to Improve Collaboration

Although this was not a topic present in the extant literature, all three parents referenced the need for families to understand the needs of their children and fully accept their children's diagnoses and/or exceptionalities. All three parents referenced the need for families to understand and fully accept their children. Aariz explained it as having a consciousness about the problem they are facing, and their child is facing. Labani and Kiara discussed their recommendation that parents need to be ready to receive and listen to honest information about their child from the school. This open communication was a key factor for all three participants when asked about improving the collaborative process. According to the parents, open lines of communication need to exist in order to improve the relationship and ultimately improve collaboration.

Lived Experiences

Diagnosis

Several studies have shown that for children who have both hearing loss and autism, there is a higher likelihood that hearing loss is diagnosed first (McFayden et al., 2023; Myck-Wayne et al., 2011). In addition, the age of autism diagnosis is usually delayed as compared to children with typical hearing (Szarkowski et al., 2014). Researchers have often explained that the reason for the delay may come from the overlap in characteristics related to both hearing loss and autism (Dale & Neild, 2019; Jamieson & Mason, 2019; McFayden et al., 2023). This was the case for all three of the participants' children. Autism was identified after they had received a diagnosis of hearing loss. The 2019 Canadian Health Survey on Children and Youth collected data on autism. In their autism highlights report, they shared their results which found just over half of the respondents were diagnosed before the age of five (Public Health Agency of Canada, 2022). These results reflected children and youth who did not have hearing loss. “Children and youth with autism spectrum disorder were diagnosed with a median age of 3.7 years” (Public Health Agency of Canada, 2022, p.10). “Visible minorities were diagnosed at a younger age (median age of 2.7 years)” (Public Health Agency of Canada, 2022, p.10). For all three case study participants, the age at which their child received their autism diagnosis (4 years, 3.5 years, 4 years) was later than the median age of the respondents from the Canadian health survey who were visible minorities. In their study, Szarkowski et al. (2014) found that among the 30 deaf/autistic children in their sample, the average age of their preliminary diagnosis of autism was 4.5 years. Kiara shared that she believed her son’s hearing diagnosis interfered with his autism assessment. She felt that it may have caused the pediatrician to hesitate before confirming an autism diagnosis. This experience of diagnostic overshadowing is discussed in the research, both within deaf/autism literature (Dale & Neild, 2020; McFayden et al., 2023; Young et al., 2019) and in other fields, for example, learners who are deaf with a learning disability (Goldsmith & Schloss, 1986), and learners with intellectual disabilities and mental health disorders (Jopp & Keys, 2001). Although the other two participants in the study did not specifically mention challenges to obtaining an autism diagnosis for their child or issues surrounding the identification of autism, the delayed age at which they both received it could potentially be a result of overshadowing from the hearing-related behaviours. Parents can also experience the effects of diagnostic overshadowing such that the “deafness obscured the recognition of autistic behaviours” (Roper et al., 2003, p.250). In their study comparing participants from three groups, deaf autistic students, hearing autistic students and deaf learning-disabled students, Roper et al. (2003) found that although a later age of autism diagnosis was noted in the deaf autistic group as compared to the hearing autistic group, the age at which the parents noticed concerning behaviours were the same between the groups. This suggests that the parents noticed the behaviours; however, in the group of deaf autistic students, they did not pursue assessment and/or diagnosis as early. This finding might perhaps support and explain the delay in pursuing an autism diagnosis for the children in the first two case studies. In addition, in all three case studies, the suggestion to seek out an assessment was from a teacher or therapist and not initiated by parental concern.

In a review of the literature surrounding the diagnosis of autism in children with hearing loss, Dale & Neild, (2019) found that one of the themes noted was that of frustration while seeking a diagnosis as a result of the lack of coordination between the autism and hearing avenues of service. The findings from this study regarding access to services aligned with those of Resch et al. (2010). In their study of parents of children with disabilities, they discussed the need for parents to fight for access. “Access, or more pointedly lack of access to important information and needed services was the most salient and overarching area of concern for the participants in our study” (Resch et al., 2010, p.142). Coordination of services between agencies geared toward children who are deaf and children who are autistic is one aspect of the challenge while lack of services for children who are both deaf and autistic is another. The participants from this phenomenological case study all shared their challenges and the significant frustration caused by long wait times, limited collaboration between schools and outside service agencies, and lack of deaf/autistic-specific programming.

Second Guessing

In all of the recounts of their experiences receiving the diagnoses of hearing loss and autism for their children, it was only the autism diagnosis which brought with it doubt and second-guessing for the parents. Based on the literature review conducted for this study, there appear to be two factors related to the difficulty with accepting the autism diagnosis. The known presence of hearing loss creates uncertainty and makes it difficult to parse out the characteristics of autism from the effects of hearing loss (Borders et al., 2020). The second factor involves the lack of definitive assessments available to identify autism in children who have hearing loss. The diagnostic tools used for autism assessment have not been validated for use with children who are deaf/autistic (Wiley et al., 2018). As such, diagnosticians, in their assessments of children with known hearing loss, are typically careful to include statements which acknowledge that the child may meet criteria or reference to the possibility of the confounding effect of hearing loss. Parents, in this case, may be left with the thought that there is a possibility that, in fact, it is not autism. They may believe that hearing loss is the only issue and that as their child grows and improves and develops their communication and language skills, the behaviours which appear to be autistic-like will fade.

Passage of Time/Forgetting

"Recall bias may have affected parents recounting of their decision-making experiences. Overwhelmingly, parents recalled extreme examples of negative or positive interactions. Moreover, decision outcome could color parental perception of decision-making" (Lin et al., 2020, p.9). Determining the factors which caused the parents' difficulties in recalling details regarding their children's educational journeys is not possible. There is a paucity of research which addresses this issue. Based on the experiences shared by the participants, it is possible to speculate about potential influences which may have affected their reflection and review of the parent/school relationship. The two aspects which are most connected based on the frequency of parent comments are the number of class placements and individuals involved in the child's support and the challenge posed by language access. During the interviews with the researcher the parents struggled to recall the names of the various schools as well as whether they were DHH or autism classes. They also had difficulty recalling the sequence in which their child attended the different classes. Although they could recall the impact that certain individuals had on their journey, remembering their names and their role was usually difficult. This could be explained by the fact that it was simply too hard to recall the large number of names and places. All three participants in this study experienced the added challenge of a language barrier. Labani explained the challenge she faced when trying to remember the names of individuals she encountered over the years working with her daughter. The difference between hearing and remembering a name in her own language versus a name in another language, in these cases, English, was very difficult for her. “And this is not my first language, so everybody that is easy, like my Bengali people’s names, I can remember.” She continued to explain that recalling the researcher’s name was much more challenging. “I feel I remember hard your name. I can’t remember. So that’s why. Seriously.”

Another issue which impacted the participants was the COVID-19 pandemic. As a result of the pandemic, many of the IPRC meetings took place over Zoom. Parents mentioned that it was different to meet with the school team in this way. As compared to previous face-to-face parent teacher interviews, meetings over Zoom, especially with multiple individuals, many of whom were unfamiliar, were more challenging. Since the initial IPRC meeting, and since the end of the pandemic, many of the school IPRC review meetings have returned to in-person meetings. Labani commented that the first time she met the teachers was at the meeting on Zoom and she could not recall who else attended.

Access to Services

Overall, the parents in this study voiced their disappointment as well as the difficulties they faced when interacting with the service agencies outside of the school system. The agencies mentioned by the families were either government organizations, not-for-profit agencies or medical offices. There were some neutral comments made in which the families recounted the programming received such as sessions of IBI therapy. Other comments were more specifically negative resulting from frustration experienced by the families. Long wait times, limited programming options, and being turned away for service due to an inability to provide appropriate care were just a few of the examples touched on by the parents. These issues are similar to those found in the research by Charlton et al. (2017) which was conducted in two Eastern Canadian provinces. They created three main barrier categories based on the results from their participants. Barriers to service availability included issues such as gaps in available services, while barriers to organizational availability referred to issues connected to policies and processes and barriers to financial availability encompassed both challenges on the part of the families and the systems (Charlton et al., 2017). The families in this phenomenological study mentioned barriers they had encountered related to both service and organizational availability but had not shared any challenges they may or may not have had with financial availability.

Another aspect related to access of services is the coordination and collaboration between the outside agencies and the school. “Key stakeholders in the education of students with disability and potential members of a collaborative team extend beyond education staff (principals, teachers and teacher assistants) to include allied health professionals and parents (Iacono et al., 2020; Vlcek et al., 2020)” (Garcia-Melgar et al., 2022, p.2). Parents shared that during the IPRC meeting documents and reports from outside agencies were presented to the committee. Specifically, parents mentioned audiology reports and assessments from developmental pediatricians. When discussing Hasik’s various placements, Kiara mentioned that she had coordinated meetings between his therapist at the Intensive Behaviour Intervention (IBI) centre and his teachers in the past to help coordinate consistency in his instruction. The coordination and collaboration of services is discussed in the literature and is emphasized specifically in relation to its impact on transitions. “No one person or agency can meet the needs of all transitioning students; transition planning requires shared expertise and a wide range of services” (*How Can School and Agency Personnel Work Together to Support Smooth Transitions for These Students?*, n.d., para. 1). The topic of transitions was not mentioned by the parents in this study as none of the parents’ children had entered high school at the time of the data collection.

Theoretical Frameworks

The researcher selected the critical disability theory (Kaplan & Celik 2023) and Bourdieu’s capital theory (Trainor, 2010b) as theoretical frameworks to inform the study. Both theories provided a lens with which to frame the questions and discussions, and they both serve well to explain the results of the study. Using the critical disability framework to examine how the administrators, teachers and parents define inclusion, as well as how they examine their own biases with respect to disability, significantly impacts the decision-making process (Creswell & Poth, 2018). The interdisciplinary approach of critical disability theory builds on the perspectives of disability theory. It focuses on the disability from the point of view of the barriers that hinder an individual with a disability, and potentially impact on their families, and instead focuses on changing the association which often exists between disabilities and deficits. This view helps provide insight from the perspectives of the parents, into the barriers which may exist in the special education environment for their children with low-incidence disabilities. In application to this study, the removal of barriers can also pertain to the barriers to parent participation. The disability framework can be used as a lens for examining how all parties, including administrators, teachers and parents of children who have disabilities define inclusion. This theory complemented the data collected in this study. By removing the barriers for parents to participate and collaborate, specifically, parents from culturally and linguistically diverse backgrounds, an environment can be created in which their social and cultural capital can be recognized and valued. By implementing family-centered supports, a connection can be made between critical disability theory and Bourdieu's capital theory. By empowering parents of children with disabilities, such as the parents in this study, and removing the barriers to participation through the implementation of family-centered supports and family empowerment strategies" (Fielder et al., 2008, p.231) they have the opportunity to increase and further develop their social and cultural capital in the eyes of the school. Specific supports and strategies will be discussed further in the organizational improvement plan section of this chapter.

Bourdieu's capital theory provided a reference for explaining the phenomenon of the collaborative process of the IPRC meeting. "The basic premise of capital theory is that people acquire and use information and knowledge (i.e., cultural capital) and social networks (i.e., social capital) similar to the ways in which they use economic capital (Bourdieu, 1974)" (Trainor, 2010a, p.35). The interactions between the parents and the IPRC team can be affected by social capital. Trainor (2010b) suggested that by placing parents in the collaborative environment of the IPRC meeting, the inequity of the social capital between the groups could be highlighted. It could, however, be argued that by placing parents into this collaborative environment the inequity that exists between families is highlighted (Trainor, 2010b). Comments made by the parents in this phenomenological case study expressed their feelings about the decision-making process in the IPRC meeting. Kiara and Labani both sensed that the decision had already been made prior to the meeting by the school staff. Love et al. (2017) found similar results in their study and noted that by excluding parents from the decision-making process and thereby "limiting parents' ability to direct their child's placement and services," (p.167) access to their cultural capital was being denied. Teachers' interactions with parents can be influenced by the family's social and cultural capital. While the inequity between the parents and the teachers or the school administration is clearly more evident in this situation, it is not possible to determine or discuss the influences on the teachers' interactions in this study given the study's focus strictly on the parents' perspectives. It is equally possible that parents experience a sense of inequity, and it further impacts their actions. "Capital, which, in its objectified or embodied forms, takes time to accumulate and which, as a potential capacity to produce profits and to reproduce itself in identical or expanded form, contains a tendency to persist in its being, is a force inscribed in the objectivity of things so that everything is not equally possible or impossible" (Bourdieu, 1986, p.15). Parents of marginalized groups may be more likely to withhold their true thoughts and perspectives and only share them with those they trust (Trainor, 2010b). Ultimately, addressing the imbalance and supporting both the parents and the school to improve the collaborative, equitable relationship, is in the best interests of the students (Trainor, 2010b).

"Bourdieu (1977) argues that public schools transmit and legitimize the cultural capital of the dominant culture through their explicit and implicit ideologies and practices. It is transmitted through classroom and social discourse, through subject matter, through interpersonal relations, and through educational policy and practice that emphasize assimilation and mainstreaming as their goal. This institutional bias may provide scant room for a culturally and linguistically diverse existence or for individuals with disabilities" (Olivos et al., 2010, p.34).

> Within a social systems perspective, empowerment recognises that all families have a degree of competency, but that it is the social system that prevents this competence from being displayed (Dunst et al., 1988). Within a family's social system it is the degree to which the family is supported to display competency and recognised as being

> competent that empowers the families to be an active partner in the decision making. (Rouse, 2012, p.19)

The critical disability theory and Bourdieu's critical theory were both appropriate choices to explain and support the focus of this study. By combining the two theories, a unique perspective was created in which the process of removing social barriers to participation and collaboration for parents of children who are deaf/autistic could be discussed. Supporting and recognizing the social and cultural capital (Bourdieu, 1977) of parents of children who are deaf/autistic begins the process of removing the social barriers which stand in the way of participation and collaboration. The support and recognition of parent's social and cultural capital (Bourdieu, 1977) can further empower parents and increase their participation in decision-making (Rouse, 2012). Both theories not only provided a basis and framework to view the methodology and implementation, but they were able to support the results and contribute to the discussion.

Study Limitations

There are inherent limitations when conducting a case study. The most obvious limitation which resulted from the study design was the small sample size. This is often the challenge in studies involving students who are deaf and/or autistic due to the low-incidence of the population. "One limitation of this study is the relatively small sample of children available for study due to the relatively low incidence of permanent hearing loss (Fitzpatrick et al., 2014, p.584)". Fitzpatrick et al. (2014) explained that although they were limited due to the small sample, the results of their study examined the characteristics and audiological management of children who were deaf/autistic and could potentially help guide families and help establish expectations for children with autism and hearing loss. The current phenomenological case study acknowledges the limiting effect of the small size; however, the intention was not to generalize the results but rather to add to the limited body of research by providing an in-depth view of the lived experiences of the parents of children who are deaf/autistic as well as a richer understanding of a unique phenomenon.

Due to how the sample was recruited and the fact that all three families were from the same school board, it cannot be considered representative of all parents of children with hearing loss and autism throughout the province of Ontario or throughout Canada. While the sample created limitations such as an inability to generalize the results beyond the one school board, it enhanced the richness and in-depth view, which became possible as a result of investigating within one area. This same juxtaposition was seen in similar research studies (Childre & Chambers, 2005).

The effect of maturation may have affected the participants’ ability to recall the details of all the IPRC meetings (Creswell & Poth, 2018). The documents shared by the participants were helpful in counteracting the effects of maturation. This was discussed in greater detail earlier in the chapter. The researcher was able to create timelines and fill in many of the gaps which the participants had difficulty recalling through the use of the documentation shared.

The Canadian context of the study does not limit the relevance of the perspective shared by the participants however, it should be taken into consideration as the regulations of the IPRC meeting differ in some ways from the IEP meeting in the United States. The perspectives of the parents, the challenges posed by a dual diagnosis and the difficulties arising from the language barrier are all issues which concern the stakeholders in both the Canadian and American educational systems. It should also be noted that as explained in Chapter 3, each province/territory in Canada operates independently with regard to education and as such, the IPRC process is not a common process. Regardless, there are similar structures in place and the barriers and facilitators shared by the parents are ones which would be applicable to other special education decision-making processes.

Due to the design of the study and time limitations, there was no opportunity to circle back and go through the survey questions with the participants. Being able to do so would have potentially offered some additional insights into the participants' perspectives and may have allowed for clarification of other ambiguous statements. Another limitation resulting from the design was that the parents did not respond to the write-in section of the Likert-scale survey. Although they were also given the option of completing the survey electronically, all three chose to use the paper copy. There were no constraints on the paper survey forcing participants to complete the write-in response before proceeding to the next question. This was an unforeseen limitation of the paper format.

Although interpreters were offered to the participants for the interviews, all three refused. As a result the researcher conducted the interviews in English but was required to adapt and paraphrase the questions to match the language level of each of the participants. While there was consistency between the interviews, in that the same researcher conducted all three, it was impossible to guarantee the use of the exact same phrasing due to the need to go off script and reword to ensure clarity. The researcher made every effort to maintain the integrity of the questions and to ensure that the content validity of the questions was not altered.

Implications for Practice and Future Research

According to the rates reported, the number of children being diagnosed with autism continues to increase (CDC, 2021). As mentioned in Chapter 1, the rates of hearing loss in children are harder to confirm. However, it is possible to extrapolate that given the rise in autism, the number of children who have hearing loss and also have autism will increase as well.

This qualitative phenomenological case study directly focused on addressing an issue within this community and attempted to illuminate the need for change. Several potential implications resulted from the implementation of this study. This study brings to light issues and inequities which exist within a process central to the education of students within the special education program.

Although not a focus of this research study, a theme which was shared among all three case studies was the frequent transitions between placements. In the first case study, since starting in the DHH preschool, the student had experienced a general education placement, a DHH full-time special education placement and an autism full-time special education placement as well as having received withdrawal support from an itinerant specialist teacher of students who are deaf/hard of hearing. The parent mentioned the shift in need between their child's exceptionalities. One exceptionality takes more priority at a given time than the other, leading to, in their opinion, the possible reason for the change in placement. They also discussed the move from elementary grades to middle school grades being responsible for the placement change. In the third case study placement moves also included DHH classes, autism classes, itinerant withdrawal support, online virtual MID class, as well as the parent choosing to withdraw entirely from the school board to pursue private IBI therapy. In case study two there had already been three different schools, two DHH preschool placements and a DHH kindergarten placement, in a total of three schools. The researcher did not have the opportunity to investigate the social impact this had on the student with regard to making friends or having the chance to become familiar with a school, the impact it had on developing collaborative relationships between the parents and the school or on the student's academic development. In case study two we discussed the lengthy bus ride that was necessary in order to get to the only available placement. Borders et al. (2020), in their chapter in Preparing to Teach: Committing to

Learn, discussed this concept of a movement back and forth between placements and referred to it as the *zipper trajectory*. The effect of the zipper trajectory can be a limit on the “amount of academic language and behavioral growth over time” (Borders et al., 2020, p.6). There are multiple factors involved in addition to the academic and behavioural such as the social and emotional which clearly impact the students and their families as a result of the multiple placement transitions. The impact a placement has on a student needs to be recognized and acknowledged by the IPRC team members. The decisions are not simple transactions as illustrated by the stories shared by the parents in this study.

Organizational Improvement Plan

While the focus of this Organizational Improvement Plan (OIP) is on the Canadian, specifically the Ontario educational system, several of the research articles referenced and cited are from the United States and other countries. As was explained in Chapter 1, in Canada the special education meetings at which decisions are made regarding student placements are referred to as IPRC meetings. The IPRC process in Ontario is similar to the IEP process outlined by Individuals with Disabilities Education Act, which is mandated federally in the United States (U.S. Department of Education, 2019a). While there are some differences in the process, they are similar enough and serve the same function closely enough that the terms IEP and IPRC will be used interchangeably throughout this OIP and the suggestions will have application for other provinces/territories as well as the United States.

The OIP is divided into two separate components, each framed by the principles of a different organizational theory. The research approach used in this study followed a fusion of the phenomenological and case study methodologies. While one approach was centered on the phenomenon of the IPRC process, the other explored the lived experiences of the parents of students who are both deaf and autistic. The OIP, which was developed as a result of this study’s findings addresses areas of improvement for the IPRC process and a second set of recommendations directed towards parents. Although this is a two-pronged approach which is intended to operate simultaneously, there must be an acknowledgement that because of the existing institutional and organizational structure, the school is tasked with creating some of the initial framework for the parents' initiatives. The role that schools play in creating barriers for parents is also necessary to recognize. "Barriers limiting family involvement place the locus of control in educational planning firmly with professionals" (Childre & Chambers, 2005, p.217).

Perspectives

There are three main factors which have shaped and significantly informed this problem of practice and, as a result, directly affected the development of the Organizational Improvement Plan. The first and over-arching factor was the fact that the needs of this group of students and their families have not been given the focus and attention they deserve or require. Recognizing that the students present with a unique, varied and more complex set of learning needs, the families may need a higher level of support from the schools. A second factor, which is likely a consideration in all school boards but given the demographics in the area in which the qualitative study was conducted, was the significant cultural and linguistic diversity within the population of the Greater Toronto Area (GTA) and therefore among the families of the school boards located within the GTA (City of Toronto, 2019). Finally, legislation in Ontario specifies the inclusion of parents in the decision-making process for their child with exceptionalities (Government of Ontario, 2024).

While there are numerous groups and organizations for families with children who have hearing loss or who are autistic in Canada, there are no such groups for families with children who have both hearing loss and autism. It can be particularly difficult to locate medical professionals with the expertise necessary to conduct diagnostic testing for children who are deaf/autistic. Both assessing a child with autism for hearing concerns and assessing a child with hearing loss for possible autism can be difficult. It can be a frustrating task for parents to find a professional who can help them with diagnostic and assessment support. Once they receive an identification for their child, parents are often left with questions about how to determine the best method of communication and the most appropriate educational placement. In addition, many parents are not familiar with the process of determining placement within the school and how the decision-making process works.

While parents are facing challenges and attempting to learn a new set of skills, many of them are doing so with the additional struggle of a language and cultural barrier. Toronto, the capital city of the province of Ontario, is ranked by multiple websites as the most diverse city in the world (Most Diverse City in the World, 2023). In a post on the World Atlas website, Toronto was noted as the most multicultural city in the world, where approximately half of its roughly three million people are born outside of the country (Fleiszer & Ahmed, 2019). There are more than 200 languages spoken in Toronto and in 2016, 44% of the population had a mother tongue other than English (Fleiszer & Ahmed, 2019). While this adds to the diversity which makes the city unique, it can also lead to barriers when accessing healthcare, education and many other economic and social situations/domains/circumstances. Many of these parents, who are part of the 44% of the population, may face significant barriers when participating in school meetings. The involvement of parents in the decision-making process can be seen as "relying on their acquisition and use of cultural and social capital" (Trainor, 2010b, pp.245-246).

Vision for Change

Reflecting on the findings from this research study the researcher determined several areas of change worth focusing on to improve outcomes for students who are deaf/autistic. The areas were determined based on the number of times they were mentioned and subsequently coded in the interviews with the participants. It was also necessary to take into account the ease with which they could be implemented, the cost, the number of people involved, and whether the change could be affected within a reasonable amount of time. The main concerns reported by the participants were access and lack of equity in the IPRC process. Responsibility for improving access and equity falls to both the school and the parents. The suggestions were divided into two separate but parallel modules and then prioritized for further description as part of the OIP. The two modules which will address the changes in the OIP are the school level and the parent level. A needs assessment, as well as a timeline with checkpoints and a rubric, will be suggested as a method for measuring the success and progress of the OIP.

Two underlying beliefs support this OIP and will ostensibly lead to improved outcomes for the student. The first belief is that providing parents with the knowledge and therefore the ability needed to participate in the IPRC process will increase the quality of their involvement (Hebel, 2014). The second belief is that involving parents in the decision-making process is a key variable to school success (Childre & Chambers, 2005).

While this OIP contributes to the various Ontario school boards' already existent focus on equity, it fills a gap resulting from the disconnect which continues to persist between the stated goals of the organization and the reality of what, in fact, is occurring or perhaps what is being perceived by families. Although the school boards have made gains in the area of parent-professional collaboration as well as having conducted research into special education (Parekh & Brown, 2018), the specific study of parents and their role in the IPRC process has not been examined. More specifically, parents of students who are deaf/autistic have not been the focus of the investigation. Their specific needs resulting from having a child with complex challenges coupled in many cases with the barriers they face from being culturally and linguistically diverse have not received the needed attention and assistance.

Currently, the focus within many school boards, and within the field of education in general has been on equity, anti-racism, and anti-oppression. This practice encompasses family income, race, gender, ethnicity, sexual orientation, and disability (Peel District School Board, 2024a; Toronto District School Board, 2023). The specific vision for change of this OIP is to continue to close the opportunity gap and put the attention directly on parents supporting their children in the IPRC process. "…equity efforts rely on parents being informed about the decisions that are being made about their children, especially when it comes to school and classroom placement" (Smith et al., 2017, pp.100-101).

The intention, although placing a significant responsibility on the school boards, is to identify the role that parents play and provide opportunities for them to become active in narrowing the gap. Mapp et al. (2017) in their book *Powerful Partnerships*, identify the school as being primarily responsible for facilitating and managing the relationship. This view is supported by Tamzarian et al. (2012). "It is a school site's responsibility to mitigate barriers that inhibit parents' active contribution to the children's education" (p.1). However, by taking ownership and developing a sense of control over their circumstances to the best of their abilities, parents can become advocates and increase the quality of their involvement. It is also important to acknowledge that a truly collaborative relationship between the school and families will not be fostered and fueled within the boundaries and constraints of a brief process such as the IPRC meeting. In order to develop an equitable and collaborative relationship which encourages participation by the parents, effort and planning must take place outside of the IPRC.

Theory for Framing Change

Implementing change in the IPRC process involves making changes from two different angles. By approaching from both sides, that of the parent/family, also referred to as the individual level, and from the school, also known as the organizational level, the intention would be to increase the likelihood of improving the family-school collaboration. Several options to improve upon the status quo are suggested at the family level and participation can be determined based on individual circumstances. The recommended organizational level changes are all presented with the intention that they all be implemented, however, over a span of three years. Change at this level involves organizational processes, policies and practices as well as more than one layer of school board staff. For this reason, the change at this level may require more coordination, time and effort.

Change Management Theories

Two different theories of change management were used to facilitate the two different levels of change. The ADKAR model by Prosci (Prosci, n.d.), has a stronger focus on people and how to get them to change. Lewin's three-stage change management model (Burnes, 2020) is beneficial for understanding and managing change at an organizational level, providing a high-level view of change.

ADKAR Model

The ADKAR model is a five-step process: awareness, desire, knowledge, ability and reinforcement. This model can be used to provide a structure and process for the adoption of the programs and changes which pertain to the families. Each stage of the model builds on the next, the process can be an iterative one when dealing with the implementation of change with regard to the IPRC process. Once awareness and desire are established, knowledge, ability and reinforcement may continue to repeat as families need updates to information, or changes are introduced in school procedures.

Awareness Stage. In the awareness stage of the process, families need to be alerted to how the change, in this case the changes to the IPRC process, will benefit their child and why the change is necessary. Although parents may believe that they should be involved, they may not have an awareness about the important role they play. One would think that parents would be aware of the need for change because it involves them and benefits their children. They would be aware of the issue and the problem that would be addressed by the change. This might not be the case, for two reasons: 1) they might not make the connection between the changes and the end result of an improved outcome for their child and increased participation from them in the IPRC process, and 2) they may never have thought about changing the status quo because they did not think of it as an option. In some cultures, it would not have been considered an option to have participated in a decision-making capacity within the school. Questioning the authority of the school would have been seen as rude by some parents. “For example, cultural beliefs might result in a parent indicating agreement with a team decision out of respect for professional educators rather than conviction” (Dabkowski, 2004, p.37). For these reasons it may be necessary to build awareness for many parents. It is important to think about who the message is coming from when raising awareness. The credibility of the person sending the message is important. This is another reason that having parents build awareness among other parents would be more likely to have success.

Desire. The next step in the process involves developing a desire to participate in the change. Providing parents with an understanding of the effect of their involvement and its value can help to foster a desire. This could be created by the sharing of success stories of other parents. These stories could be shared by both families and by members of the school administration to demonstrate the benefit to student outcome which results when parents are involved.

Knowledge. Families need access to the necessary knowledge in order to change once the desire is created. Without the knowledge, families cannot participate effectively in the IPRC process. Regardless of whether they are provided with support during the process, they still require knowledge such as how to access services. Knowledge informs parents of their rights, it explains the process of the IPRC, and can lead them to further support the outcome.

Ability. Equipping families with skills and behaviours they need so that they have the ability to change is the next step in the ADKAR model. The focus in this step is on their ability and using the resources and information obtained in the previous stage to give them the ability to become active participants. At this stage it is more about skills building, such as improving on communication or negotiation.

Reinforcement. The final step in the ADKAR process but not the last one, as it is an iterative process, is reinforcement. By providing ongoing support, continued resources and conducting regular check-ins with families, issues can be addressed as they arise and dealt with in a timely manner. This regular reinforcement of efforts increases the likelihood of participant retention. Celebrating achievements is a key motivator and an important part of this stage.

Lewin Three-Stage Model

The process for implementing change at the school level begins by having the members of the school team recognize the need for and then accept the change. The Lewin three-stage model (Bridges, 2019) is an easy-to-understand approach, and it is structured for a slower transformation which works well with the manner in which change should be implemented at the organizational level. Time needs to be allowed for members at the various levels of the school, from the administration to the teachers, to buy-in to the need for change. The model is also known by the names of the three stages, Unfreeze, Change, Refreeze.

During the initial Unfreeze stage, the school begins by identifying what needs to change and why. By connecting with parents, teachers and administrators, schools would recognize and acknowledge the lack of, or limited parental involvement and the need to change that status. In order to create a climate that encourages change, schools could highlight the benefit of parental involvement supported by data such as information on student outcomes and parent attendance at meetings. The data would support the recognition of change and would also serve as a baseline for later comparison when attempting to determine whether progress has been made. Another benefit served by the data is that it would help garner support from other members of leadership and management. Determining the change readiness of the group is important at this point as it provides an opportunity to discuss concerns and it also provides an opportunity to reinforce the reasons for implementing the change. Implementation follows in the next stage known as Change. It is at this point that new policies and practices to facilitate parental involvement will be introduced. As the changes are being implemented the administrative team needs to provide feedback on the progress and benefit resulting from the new systems. Finally, the changes are reinforced and enter a stage of Refreezing. At this point, they are being used on a regular basis and have become a part of the regular IPRC procedures. During this phase, communication is key and policies and processes are changed. Support and feedback need to be provided to the school team and successes need to be celebrated to maintain motivation.

Change Readiness

Change readiness is the individual's or the group's willingness to engage and participate in the process of change. According to the ADKAR model, change readiness can be determined by looking at the gap between the awareness of the need for change and the desire for change. The smaller the gap between the two, the higher the change readiness measurement. Determining change readiness is an essential step in the process and requires regular monitoring as it can be affected by various factors. Surveys, interviews and/or focus groups with the stakeholders would provide a sense of where they are positioned with regard to their awareness of the need for change and their actual desire to embrace it. This approach is effective with both the parents/families and the schools. Feedback collected in the pilot study conducted by this researcher demonstrated an awareness of the need and a desire for change.

Determining change readiness at the school level can be conducted in much the same way. Data collected from surveys, interviews and focus groups done with members of the administration and teaching staff would provide important feedback about the status of their readiness and feelings towards change. Understanding the distance between their awareness and desire for change and more importantly the specific areas where the gaps are larger and smaller, would allow for targeted intervention. In keeping with the Lewin change theory, the force field analysis by Kurt Lewin (Connelly, 2020) presents a model for conceptualizing the two opposing forces of change.

Determining change readiness and establishing buy-in within the parent population is likely an easier endeavour. Parents have a more vested interest in the process and while they may require some encouragement and support throughout the process, creating desire will likely be the easiest stage. This may not be the case with the implementation of change in the school board.

Creating the initial buy-in is a task which requires a trickle-down effect. For those at the administrative level, buy-in is already required to some extent as part of their already existing provincial and school board mandate to increase equity (Ontario Ministry of Education, 2010; Ontario Ministry of Education, 2014). The question becomes, why would they want to focus specifically on students who are deaf/autistic and their families? The reality is that the schools do not need to focus on these families specifically. These practices will apply to and benefit the larger group of special education parents. However, during the implementation process, it may be beneficial for the school board to use this low-incidence population to begin the process so that they can roll out the change slowly and ensure attention to detail. In order to garner support and establish change readiness from teachers, it would be necessary to demonstrate that by improving collaboration with parents, they will receive, in turn, improved support from parents which will lead to better outcomes for students. Ultimately it is necessary to demonstrate how this will benefit the teachers.

The Ontario Ministry of Education's *Equity and Inclusive Education in Ontario Schools (2014)* is a document which includes guidelines for policy development and implementation for school boards within the province. Action items are laid out for both boards and schools to achieve further implementation of its equity and inclusive education program. The Ministry of Education's mandate supports the buy-in of the initiatives suggested in this OIP, as evidenced by the one of the action items listed in the first area of focus, "develop and implement strategies to engage students, parents, and the broader community actively in the review, development, and implementation of initiatives to support and promote equity and inclusive education;" (Ontario Ministry of Education, 2014, p.17). Ensuring parental involvement in the IPRC process would support the action item outlined in the document and as such the buy-in for creating change would be impacted.

Another government influence on the school buy-in for change regarding parental involvement is a result of the Ontario Education Act. Ontario Regulation 181/98 Identification and Placement of Exceptional Pupils of the Education Act, part three specifies that school boards "shall prepare a guide for the use and information of parents..." (Ontario Ministry of Education, 2017). Outlined in the regulation are points about what should be included such as explanations of the function of the IPRC committee, its duties, the function of the appeals board and the fact that decisions made by the committee cannot be implemented without parental consent. Although certain content is mandated by the regulation, the variety between the boards' parent guides is vast. Some boards provide information beyond that which is required and offer the information translated into other languages while others do not meet the requirements outlined in the Education Act. This provides a minimum level of content which the school board must produce, thereby creating some level of buy-in regardless of whether it is initially imposed. Buy-in may increase as staff is able to witness the benefit of the initiatives.

Identification of Potential Solutions

Changes continue to be made in special education and specifically in the IPRC process. School boards are focused on ensuring that equity, inclusion, and diversity are all terms mentioned in their documentation and program planning. In many cases, the policies and procedures have started to materialize into action in the form of changes in the IPRC and parent involvement. Unfortunately, the changes in Ontario and across Canada are not widespread, and they are certainly not all-encompassing regarding parents of children who are deaf/autistic as well as those families who are also CLD. If specific outlined changes are not implemented and attention is not brought to this issue, then groups of parents will continue to be marginalized and excluded from participating in an equitable and valuable manner in the IPRC process. If this were to continue, then the message received by some parents would be one of an unwillingness to collaborate on the part of the school. Parents who already feel that there is an us/them dynamic between the home and school may see the lack of positive action as validation of their belief. In addition, by not fully including families in the process, the students' best interests are not being served. For students with both hearing loss and autism, this could result in an inappropriate placement or educational goals which do not reflect the students' strengths and needs.

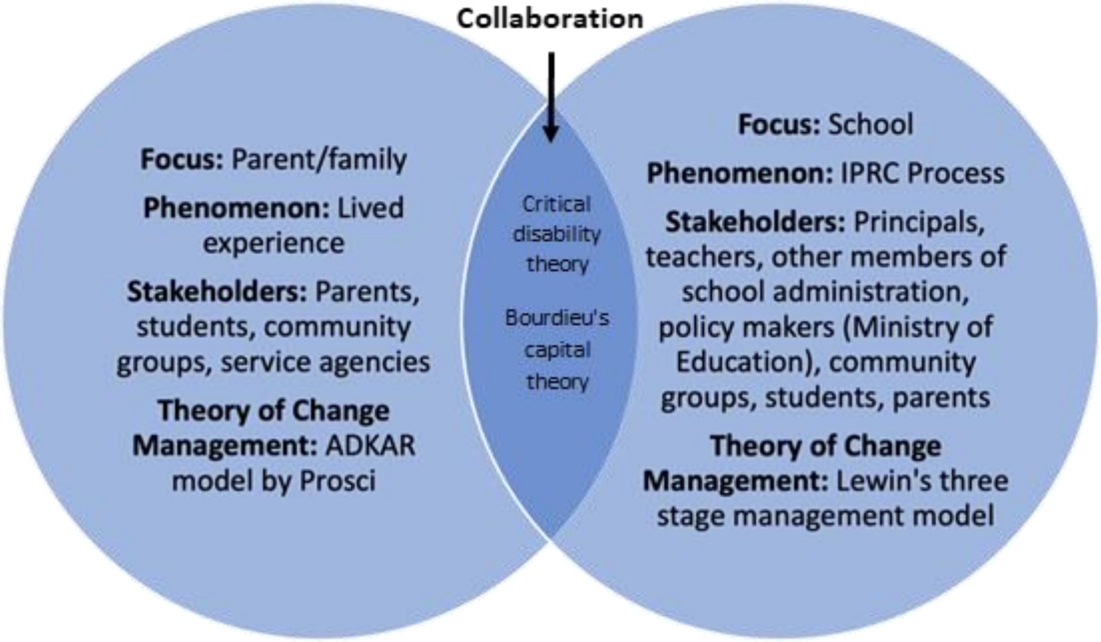
As previously discussed, this OIP proposes a two-pronged approach. An overview of the main components of the OIP is presented in Figure 5.1. A suggested method of implementation follows the introduction of the change to the parent group initially, followed by the introduction at the school board level. A simultaneous and interconnected implementation would then continue in iterative cycles as part of a slow roll-out of the various pieces to avoid overwhelming either group. The bulk of the responsibility in this OIP, however, falls to the schools, so that they can help maintain the change in order to support the students and their families. Anonymous surveys throughout the process would provide the stakeholders with feedback to be responsive and adaptive.

Figure 5.1

Overview of Organizational Improvement Plan

Factors affecting the development of the OIP:

1) The needs of students who are deaf/autistic and their families have not been given the focus and attention they deserve or require. Recognizing that the students present with a unique, varied and more complex set of learning needs, the families may need a higher level of support from the schools.
2) There is a significant cultural and linguistic diversity within the population of the families in the Greater Toronto Area (GTA) and, therefore, among the families of the school boards located within the GTA (City of Toronto, 2019).
3) Legislation in Ontario specifies the inclusion of parents in the decision-making process for their child with exceptionalities (Government of Ontario, 2024).



Underlying beliefs supporting the OIP and leading to improved outcomes for the student:

1) Providing parents with the knowledge and therefore, the ability needed to participate in the IPRC process will increase the quality of their involvement (Hebel, 2014).
2) Involving parents in the decision-making process is a key variable to school success (Childre & Chambers, 2005

The Individual Level/Parent Level

As discussed earlier in the analysis, the findings of this study, supported by multiple findings in the extant literature (Wallace-Watkin et al., 2023), highlight the importance of parents participating in educational programming. Through their engagement in programming, parents will gain knowledge and skills related to advocacy and increase participation in the educational placement and decision-making process for their child who is deaf/autistic.

Parent Mentors/Network. While there are multiple solutions which could be implemented to improve the current situation, it is important to prioritize and focus on selecting a few programs which can serve as a basis for future growth. Wiley et al. (2018) discussed the researchers' own clinical experience pertaining to families with children who were both deaf and autistic. They shared the families' struggles of not being able to fit in with either the networks for parents of children with hearing loss or the networks for parents of children with autism. As such, it is important to create a parent network in which parents of children who are deaf/autistic are able to connect with one another for support, resources and information. This network will help establish the future frameworks for other programs and workshops, such as educational programs and parent advocates/mentors. Initially the start of the network may require support from the school board to facilitate the process. School staff, specifically classroom teachers and/or special education teachers who may be familiar with the parents, might be in a position to help initiate the parent mentor program by identifying parents who would be able to lead others and have the skills, knowledge and desire to be involved. Once a core group of parents are identified, they would then be able to continue the efforts on their own. The group can then grow via social media and would have the benefit of being able to connect parents who are not geographically close together. "Families participating in a focus group on issues related to the dual diagnosis noted the internet as a way to combat this barrier and found this mechanism helpful in connecting to other families and identifying resources" (Wiley & Innis, 2014, p.262). There is no cost to creating a group via social media, and the only limitation would be locating the initial group of parents to operate as a volunteer board to oversee the group. This parent network will have the potential to help create a group of parent advocates/mentors who can function both in person and virtually. There are similar groups which already exist for parents of children who are deaf/hard of hearing and for parents of children who are autistic as well as for parents of children with other disabilities. There is potential to create this as an offshoot of an already existing network.

Parent Education. Another important starting point for parents and families is the creation of workshops specifically about the IPRC process. Parents need to be aware of the process, their rights, and how to build their self-confidence in participating. "Studies have revealed that parents who are familiar with special education procedures and who understand the formal requirements of parental involvement in the IEPs experience less frustration and become more involved in the process" (Hebel, 2014, p.59). Workshops could be offered in conjunction with the school board, other special needs advocacy groups or service agencies. The challenges faced by this initiative would be the logistics of where and when the workshops were offered and the language in which they were conducted. Ensuring access for parents in as many languages as possible is exceptionally important. Participants in one study noted that educating themselves proactively on the process and learning about special education law was one way to improve the quality of the meeting (Fish, 2008).

The Organizational Level/School Level

Changes at the school level require greater input and effort from members of the school team. While the school team can appreciate the benefit of the change, the parents and students are still the greatest recipients. It is important to remember and continue to circle back to the school team’s change readiness as the implementation begins given that they are not the direct recipients of the change and will likely require additional motivation.

IPRC Modification. Many of the changes involve altering various aspects of the IPRC process to create a more inclusive environment. The first change takes place before the meeting begins. A pre-meeting between parents and their child’s teacher in advance of the IPRC would serve as a way to begin the collaborative partnership. Forms which would be used or presented in the IPRC could be given during this pre-meeting so that parents have the opportunity to read and review them at their own pace. This would also give parents the chance to prepare any questions that they might have based on the documents.

Another extremely important change that the board can implement is to improve interpreting and translation services. This is a topic commonly addressed in other studies such as Rossetti et al. (2020), where the focus was on CLD families and the IEP process. “Language access consisted of two components: (a) live language interpretation during the focus group interview and (b) translation of the consent form and demographic form into the participants’ preferred language” (Rossetti et al., 2020, p.246). Providing parents with properly trained interpreters allows them to participate in the IPRC meetings in a more meaningful capacity. This means, however, that the interpreters must be trained and familiar with the terminology used in the special education discussions. Throughout the interviews, each of the participants shared experiences in which they faced a barrier when attempting to participate or collaborate with the school due to difficulty comprehending fully in English. When Labani shared that she did not know what an IPRC was or what it stood for, she was frustrated and explained that it was the responsibility of the school team to explain it to her. “Because they thought I know but I don’t know. They should be explained. They just send every year the paper home.” Her experience was not uncommon. Participants from a research study conducted on CLD parents regarding their perceptions of the decision-making process reported similar experiences. They "complained that they were unprepared because they were unaware of the purpose or structure of the meeting, had little knowledge of the logistics of the special education system" (Wolfe & Durán, 2013, p.11). Implementing this change will create additional costs for the schools. However, there is no opportunity for equitable participation when parents cannot understand the language being used. "Families need to be given access to information about their children's educational options and their rights in a language they can understand" (Hess et al., 2006, p.156). It is also equally important to present the families with the relevant documents translated into the language in which they are most comfortable reading. If parents are presented with documents in English and are not able to read them, then they cannot be expected to sign them.

Creating a warm welcoming environment is an essential part of the IPRC meeting and its impact is significant. For example, on the day of the meeting, the tone and sense of inclusivity are easily created by assigning someone to greet parents, escorting them to a waiting area and having water available. The physical structure of the meeting also sets a tone is important, and it can be exceptionally intimidating when a parent is brought into a room to face a group of individuals already sitting around a table with their computers open. Once ready to begin, understanding how appreciative parents can be when staff take a strength-based approach, and avoid discussing their child in ways that suggest that he/she is defined by his/her disability (Reiman et al., 2010). "Families discussed how negative expectations alienated families from planning, destroying family-professional trust, but more importantly how these statements can inflict wounds that families must struggle to overcome emotionally" (Childre & Chambers, 2005, p.224). Members of the IPRC teams also need to remember that when engaging with parents, whether they are CLD families or not, it is essential to speak in simple, clear, jargon-free language. The IPRC process can be a stressful time for many parents and whether English is their first language or not and whether they are familiar with the terminology or not, the process can be overwhelming.

IPRC Guide Update. Ensuring that the parent guide is easily accessible, available in a multitude of languages and written in a simplified language level are all extremely important elements to address. If parents do not recall receiving the guide, whether they did actually receive it or not, then it did not serve its purpose. The school board needs to examine the possible reasons that parents might not be accessing the IPRC guide. Receiving feedback from the consumers of the guide, that is, the parents, would be essential in creating an improved and useful tool.

Professional Development. *Powerful Partnerships* is an excellent resource for professional development within the schools to support the implementation of the OIP and improve the collaborative relationship between the families and schools. This book has application not only those involved in the IPRC process, but it is extremely beneficial for classroom teachers who are interested in improving their partnership with parents. The focus of the book is on developing the foundations for effective and respectful relationships with families which will continue to grow with the goal of supporting student success. Improving family/school conferences and IEP meetings is a key goal of the authors. The book is based on four essential core beliefs which are also fundamental to this study's OIP. They are:

1. All families have dreams for their children and want the best for them.
2. All families have the capacity to support their children's learning.
3. Families and school staff are equal partners.

4. The responsibility for cultivating and sustaining partnerships among school, home and community rests primarily with school staff, especially school leaders. (Mapp et al., 2017, p.20)

The second core belief brings together critical disability theory and Bourdieu's capital theory (1977). In their explanation of the belief, the authors make clear that families have the capacity to support their children. The responsibility is upon the members of the school staff to examine their implicit biases and assumptions when engaging with families (Mapp et al., 2017). When discussing families, schools can change the way they view their social and cultural capital by shifting from a deficit-based lens to a strength-based one (Mapp et al., 2017). The shift from a deficit-based framework with regard to families and communities demonstrates the removal of barriers to parent participation and collaboration. In this case, as was explained earlier in the chapter, critical disability theory provides a framework for understanding the removal of social barriers for the families of children with disabilities rather than the students with disabilities directly.

Measuring and Communicating Change

This OIP focuses on the parents and the school as the primary stakeholders of this change process. Change for both is intended to be iterative processes which continue to improve and grow as feedback is provided and stakeholders begin to adjust to and adopt change. However, this situation involves more than just the two groups of stakeholders and there are many individuals within each group. For this reason, the implementation and feedback process need to be organized in order to achieve successful change. "Change efforts must draw a sufficient connection to the impact that will be realized by students, the ultimate beneficiary of education reform" (Edney & Baker, 2019, p.6). As such, a tool which both provides feedback about the success of the IPRC interaction at the moment and how it could continue to improve is essential.

The school level implementation requires a different method of assessment than the parent level change. At the school level, feedback on progress needs to be collected from multiple sources. A survey collecting data from parents after the conclusion of an IPRC meeting is a necessary tool for feedback. The tool must be available in the language in which they are most comfortable reading and writing. Understanding whether or not the efforts made by the school team have had any impact and been felt by the parents is significant. All members of the IPRC meeting should also complete a survey following each meeting, reflecting on the particular meeting and its process. Questions would reflect the aspects of the meeting which were being focused on and which were being targeted for improvement. For example, identifying the key indicators such as whether the parents were provided with the documents in the language of their choice. For example, *Did the meeting begin with a discussion of the student's strengths?* Each member of the IPRC team would have the opportunity to reflect on the meeting and determine how they did to reach their goal.

Change implemented at the parent level also needs to be tracked and assessed. Given the types of changes being suggested, it is difficult to monitor gains. Feedback given to parent mentors can be recorded and reviewed, social media statistics can be tracked (e.g., interactions with posts) and visits to websites can be noted and chronicled.

Limitations of the Organizational Improvement Plan

The various pieces of the OIP may move forward at varying rates due to their complexity and the fact that they will not all be starting at the same time. This may create a challenge for developing buy-in given that the groups may not be participating in or become invested in the projects at the same time. Smaller groups of stakeholders may not see the incremental values given their pre-disposed view. This has the potential for limiting and minimizing the change readiness experienced by some.

Another limiting factor is the costs associated with driving change. Creating, organizing, and running programs require a staffing level, staff training, allocations of time and an organizational commitment that includes professional development. Further costs can be found in creating the buy-in, essentially marketing the change to stakeholders. Operational costs will also exist for things such as interpreters and document translations.

Given the culturally diverse population, the possibility exists that some families may be held back by what they perceive to be a stigma associated with either hearing loss, autism or both together. Regardless of whether it is just perceived, it can cause hesitancy when stepping forward to participate in the IPRC process. In a study examining barriers to parental involvement, researchers commented on the effect of stigma, noting, “persons with intellectual disabilities in most African countries are subjected to discrimination ultimately resulting in the lack of parental involvement in their education” (Oranga et al., 2022, p.417). Ensuring that the members involved in the IPRC team are not only practicing cultural humility and educating themselves on equitable practices, but they also need to familiarize themselves with the various cultural groups within their schools.

Empowering Collaboration: Conclusion and Future Directions for Enhancing Support for Children Who are Deaf/Autistic

The lack of information and data regarding parents of children who are deaf/autistic is an issue which will require time to address. Hearing loss and autism are both low-incidence disabilities, and as such, sample sizes will continue to be small and locating participants will be challenging. Regardless, the difficulty does not make this population a group unworthy of investigation or one which will not produce results of benefit to education research.

While the sample of this research study resulted in an even more niche group due to the fact that all three of the participants were CLD families, the recommendations presented in this OIP will still offer solutions for all stakeholders who participate in the IPRC process. This OIP recommended initiatives which, while benefiting this niche group of families, have application to a larger population. Some of the discussion and research were targeted toward supporting families who might experience language or cultural barriers and they resulted in specific suggestions such as interpreters and translations of documents. All other suggestions, including those related to language access, such as the reduction of jargon and technical terminology, will benefit all families. Through the use of data collection and record keeping, information gathered during the implementation will serve to not only extend programming for parents of deaf/autistic students but also support the development of other similar projects.

This qualitative phenomenological case study provided a glimpse into the perspectives of a small group of Canadian parents of children who are both deaf and autistic with regard to the IPRC process. The Canadian perspective is unique in that it is legislated provincially and not federally. The focus of this study was even more distinctive in that it discussed a low-incidence population of students who are both deaf and autistic. The researcher demonstrated the need for investigating this group of students and their families, supported by the national and situational context as well as the existing literature. “Even less is known regarding family needs for these children who do not fully fit into the D/HH community or the autism community (Beals, 2004; Myck-Wayne, Robinson, & Henson, 2011)” (Wiley et al., 2013, p.2). The researcher’s personal context was shared as a form of support for the need to explore the topic, as well as their reflexivity. The research study’s methodology was outlined, and the results were shared. Both central research questions and their sub-questions were reflected upon and answered through the analysis of the results. Ultimately the main goal and focus of this study was achieved. Having interviewed and collected data from parents of students who were both deaf and autistic and who had participated in the IPRC process, the researcher was able to use the feedback and information to develop an organizational improvement plan.

Students who are both deaf and autistic experience challenges over and above students who are deaf or students who are autistic (Borders et al., 2020). While the population of students who are deaf/autistic is smaller than those of other disabilities, they have continued to grow over the last several decades and they require unique and specific teaching strategies. “Rates of autism in children who are D/HH are higher than rates of autism in the general population at comparison rates of 7% to 9% (compared with ≈1.7% - 2%; Kancheerla et al., 2013; Van Naarden Braun et al., 2015)” (McFayden et al., 2023, pp.1-2). To date, there has been limited research in the field of deaf/autistic students, and as such developing teaching strategies and determining the best educational placement have been difficult. “Without studies designed to investigate educational problems thoroughly, students who are deaf and autistic will not be adequately served” (Guardino, 2008, p.58). Therefore, it is necessary to focus greater attention and research in order to develop a deeper and more complete understanding of this small but growing population of students. Additionally, research in the area of parents of children with disabilities has shown that parental involvement benefits not only the student but the family as well (Myck-Wayne et al., 2011).

For many, the IPRC is the first piece, the entry into the educational system. It is where the school determines if the student meets or does not meet the requirements for an exceptionality. It is at this encounter that the determination for the best placement is made. Through the use of the IPRC process, this research study presented a rich and in-depth look at the parents of deaf/autistic students. By gaining a deeper understanding of the lived experiences of the families and of the educational journeys of their children, information was gathered and added to the growing catalogue of research regarding deaf/autistic students.

Appendix A

Parent Information Letter

December 1, 2023

Individual Placement and Review Committee Process: Perceptions of Parents of Students Who Are Both Deaf/Hard of Hearing and Autistic

Researcher: Elyza Polsky, epolsk03518@fontbonne.edu, [redacted]

Purpose of the Research:

The purpose of this qualitative phenomenological case study is to achieve an understanding of the perceptions and experiences of parents of deaf/hard of hearing (DHH) and autistic (ASD) students from Ontario Canada, and their involvement in the Individual Placement and Review Committee (IPRC) meeting. Based on the analysis of the data collected, an organizational improvement plan will be provided with suggestions for improving the IPRC process and the outcomes for the students and their families.

The inconsistent and inequitable access to education, the absence of up to date and accurate prevalence data, along with the lack of research to inform practice, combined with the increasing number of DHH/ASD students, make it imperative to focus attention on these Canadian students and their families. There is a dearth of general research regarding students who are both DHH and ASD. This lack of research is even more pronounced when looking at information about how to support them and their families within the school setting (Wiley et al., 2018; Scott & Hansen, 2020). The absence of data further specific to the Canadian context makes it necessary to generalize from studies conducted in other countries. Research into similar areas of education have extended to examining the perceptions of the parents of students with various disabilities and challenges, however, the investigations have not yet extended to include parents of students who are both DHH/ASD (Perry et al., 2020; Starr & Foy, 2012).

Understanding the perspectives of these parents may reveal important information about possible barriers to parent participation for other families and administrators looking to improve parent participation in the IPRC placement process for children identified with both hearing loss and autism.

What You Will Be Asked to Do in the Research:

Participants (parents) will be directly contacted via letters sent home / emails asking them to participate. Participants will be provided with the survey in advance so that it can be returned to the researcher for review prior to the interview. This will enable the researcher to discuss their responses and clarify any questions which may have come to light upon the researcher's review of the completed survey. Following the interview, a transcription will be provided to the participant for member checking to ensure that the content is accurate and to allow for clarification of details or discrepancies. If willing, you will also be asked to share some documentation, including your child’s audiogram, autism diagnosis and IPRC documentation from the initial IPRC (this may include the referral package and/or the parent statement of decision).

Risks and Discomfort:

The risks may be that the parent may be inconvenienced or may feel uncomfortable answering questions. The mitigations for these risks are the researcher will be as flexible as possible in accommodating the schedule of the parent, further, the researcher will conduct the interview in a familiar setting. Questions for both the survey and interview are structured and presented in a manner such that the participant may decline to respond if they are uncomfortable.

Benefits of the Research and Benefits to You:

There are certain potential benefits associated with parent participation in this research. A benefit of participating is that their unique voice will be added to those of other parents of children who are both deaf and autistic. Another benefit is that their experiences will contribute to this area of emerging research and help build knowledge about this topic.

Voluntary Participation and Withdrawal:

Your participation is completely voluntary and if you choose not to participate it will not impact the relationship between the primary researcher, Elyza Polsky, who serves as an itinerant hearing teacher, and you or your child. It will also not impact any relationship with Fontbonne University or the Toronto District School Board. The research has been reviewed and approved by the Fontbonne Research Ethics Board. In the event you withdraw from the study/research project, all associated data collected will be immediately destroyed.

Confidentiality:

All information collected will be strictly confidential and protected in accordance with all applicable privacy laws, including Municipal Freedom of Information and Protection of Privacy Act, R.S.O. 1990, c. M .56 (“MFIPPA”) and Toronto District School Board (“TDSB”) policies and procedures. The researcher, and no one else, is responsible for ensuring the confidentiality of any information collected during the study/research project.

All data collected will be stored in a password protected file and paper copies will be locked in a storage box. Any information obtained in connection with this study that can be identified with you will remain confidential and will be disclosed only with your permission. In any written reports or publications, you will not be identified or identifiable. Data will be collected via email survey, audio taped interviews and collected documents. All identifiable information will be removed from the survey and interview and wherever necessary, a pseudonym will be used. All identifiable information, including names, addresses, school/business names and locations will be redacted from all documents.

Data files will be stored in password protected files and where necessary, secure lock boxes. Only the researcher will have access to the original data. The results will be disclosed as part of the researcher’s doctoral dissertation and will be available upon request to the Toronto District School Board. The dissertation will incorporate an organizational improvement plan which will reflect the results of the research. The data will continue to be held in a secure encrypted fashion for a period of 3 years following the completion of the research, after which it will be permanently deleted. Any non-digital documents (i.e. paper) will be shredded.

Reporting of Results:

The result of this research study will be a doctoral dissertation which will be made available to participants, the TDSB, Fontbonne University, as well as the general public as it will be published in the publicly accessible University's library.

Conflict of Interest:

As the primary researcher for this educational research study, I am also employed by the institution where this research is conducted. It is important to note that I do not receive any financial benefits or incentives from the outcomes of this study. Furthermore, I hold no personal vested interests in the results of this research. While I am employed in a capacity closely related to the subject matter under investigation, my primary objective is to conduct an unbiased and impartial study to contribute to the field of education. I am committed to maintaining the integrity and objectivity of this research, and any potential influence from my professional role will be rigorously managed to ensure the study's impartiality and accuracy.

Questions About the Research?

If you have questions about the research in general or about your role in the study, please feel free to contact Elyza Polsky at epolsk03518@fontbonne.edu or [redacted].

This research has received ethics review and approval by Fontbonne University, IRB #

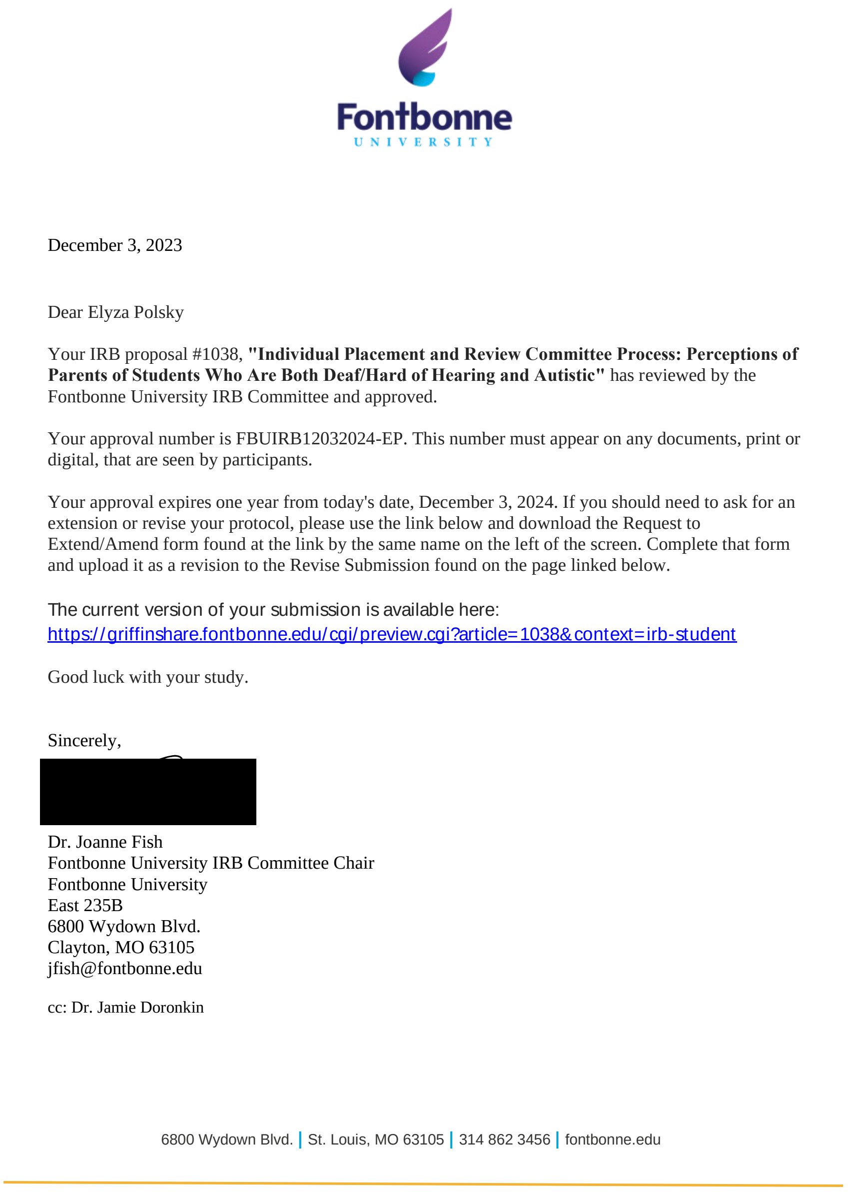
FBUIRB12032024-EP. TDSB External Research Review Committee has granted approval for this study/research project, file no. 2023-24 5197385

Researcher Full Name: Elyza Polsky

December 1, 2023

Appendix B

IRB Approval Letter



Fontbonne
UNIVERSITY

December 3, 2023

Dear Elyza Polsky

Your IRB proposal #1038, **"Individual Placement and Review Committee Process: Perceptions of Parents of Students Who Are Both Deaf/Hard of Hearing and Autistic"** has reviewed by the Fontbonne University IRB Committee and approved.

Your approval number is FBUIRB12032024-EP. This number must appear on any documents, print or digital, that are seen by participants.

Your approval expires one year from today's date, December 3, 2024. If you should need to ask for an extension or revise your protocol, please use the link below and download the Request to Extend/Amend form found at the link by the same name on the left of the screen. Complete that form and upload it as a revision to the Revise Submission found on the page linked below.

The current version of your submission is available here:
https://griffinshare.fontbonne.edu/cgi/preview.cgi?article=1038&context=irb-student

Good luck with your study.

Sincerely,

[redacted]

Dr. Joanne Fish
Fontbonne University IRB Committee Chair
Fontbonne University
East 235B
6800 Wydown Blvd.
Clayton, MO 63105
jfish@fontbonne.edu

cc: Dr. Jamie Doronkin

6800 Wydown Blvd. | St. Louis, MO 63105 | 314 862 3456 | fontbonne.edu

Appendix C

"Schedule B"

PARENTAL/GUARDIAN CONSENT FORM

Individual Placement and Review Committee Process: Perceptions of Parents of Students Who Are Both Deaf/Hard of Hearing and Autistic

Please note that this study/research project is conducted by a third party and is not a [redacted] study/research project.

NOTE:

- Signed Parental/Guardian Consent (Schedule "B") is required for all students under 18 years of age.
- Children under 18 years old are not required to provide signed written consent in addition to their parental/guardian consent.

Your signature on this form means you agree with the following:

- I/We have read the **Information Letter for Individual Placement and Review Committee Process: Perceptions of Parents of Students Who Are Both Deaf/Hard of Hearing and Autistic (attached hereto as Schedule "A")**. I/We understand that I/We can ask questions about the study/research project if I have any. I/We understand that the study/research project has been approved by [redacted] External Research Review Committee.
- I/We understand that this study/research will explore the lived experiences of parents of students with hearing loss and autism who participate in the decision-making process of the IPRC in Ontario and the factors believed to support or inhibit the collaborative family-professional IPRC partnership.
- I/We understand that, if I/we wish, I/we can participate in an interview which will take approximately one hour to complete and will be audio recorded via a hand-held recorder and transferred to an MP3 format on to a password-protected laptop, a survey which will take approximately 15-20 minutes and be sent via email to be completed and returned to the researcher prior the interview, and share some basic diagnostic and assessment information/documents regarding my child, all of which will have identifiable information, including names, addresses, school/business names and locations will be redacted from all documents.
- I/We understand that I/we am/are free to withdraw from the study/research project until the results are analyzed in February 2024 at any time without any reason.
- I/We understand that if I/we withdraw from the study/research project, any data collected from me/us will be immediately destroyed.

- I/We understand that the data I/we provide will be confidential and protected in accordance with all applicable privacy laws, including the Municipal Freedom of Information and Privacy Protection Act ("MFIPPA") and TDSB policies and procedures. I/we understand that my/our personal information will not be disclosed to any third party without my/our written consent/permission.
- I/We understand that data collected during this study/research project may include demographic data, participant opinions and perceptions, some basic diagnostic and assessment information/documents regarding my child (i.e. audiograms). However, for research purposes, only de-identified data will used.
- I/We are aware of the potential conflict of interest on the part of the researcher and understand that the researcher is committed to maintaining the integrity and objectivity of this research. We understand that the researcher's primary objective is to conduct an unbiased and impartial study to contribute to the field of education.
- I/We understand that the researcher, and no one else, is responsible for ensuring the confidentiality of any information collected during the study/research project.
- I/We understand that I/we can keep a copy of the signed and dated consent form.
- I/We understand that I/we can contact the Institution Review Board Committee Chair from Fontbonne University, Joanne Fish at jfish@fontbonne.edu, if I/we have any concerns about the ethical conduct of this study/research project.

Legal Rights and Signatures:

I/We (student/staff/parent/guardian name), consent to participate in Individual Placement and Review Committee Process: Perceptions of Parents of Students Who Are Both Deaf/Hard of Hearing and Autistic conducted by Elyza Polsky. I/We have understood the nature of this study/research project and wish to participate. I/We am/are not waiving any of my/our legal rights by signing this form. My/our signature below indicates my consent to participate in this study/research project.

Name of Parent/Guardian:____

Signature: _______________________ **Date:** _____________________

RESEARCHER ACKNOWLEDGEMENT I hereby acknowledge receipt of this Parental/Guardian Consent Form

Name of Principal Investigator/Researcher: ____________________________

Signature: _______________________ **Date:** __________________________

IRB#FBUIRB12032024-EP

Appendix D

Caregiver Survey

Name: _____________

Date: ______________

The following survey is about your child and their special education placement in school. The IPRC process mentioned in the survey refers to the **I**dentification, **Pl**acement and **R**eview **C**ommittee meeting at which the school board officially determined the exceptionalities which apply to your child, as well as their school placement. Following the first IPRC meeting, there are yearly IPRC review meetings to which you are invited to attend to review and discuss your child's placement. Questions in this survey are specifically regarding the **first** IPRC meeting. Please read the questions carefully before answering and respond as honestly as possible. You may skip any questions you do not wish to answer. Your responses will be confidential.

Thank you for taking the time to complete this survey.

The purpose of this section is to gain information about your child and your family. Please fill in the responses to the best of your ability and recollection.

What is your relationship to child? ___________

What is the primary language in your home? __________________

What language are YOU most comfortable communicating in? ________________

Do you require / prefer to have an interpreter? _____ yes _____ no

Did you use an interpreter in the initial IPRC meeting? ___yes ___ no

If yes, did you feel that the meeting was being properly and accurately interpreted? _____ yes _____ no

Number of children in your household: ____

Number of children in family who are both deaf/hard of hearing and autistic: ___

If you have any other children with hearing loss or autism, or have other children with exceptionalities who have brought you to the IPRC process before, please list: (For example: **Behaviour**, **Communication** (autism, deaf and hard of hearing, learning disability, speech impairment, language impairment), **Intellectual** (developmental disability, giftedness, mild intellectual disability), **Physical** (blind and low vision, physical disability), **Multiple exceptionalities)**

Exceptionality ____________

Exceptionality_____________

The following questions are about your child who has both hearing loss and autism:

What grade is your child currently in? _____

What is your child's gender? ___male ___female ___non-binary ___ prefer not to say

At what age was your child diagnosed with hearing loss? _____

Does your child use hearing aid technology (HAT)? Yes No

If yes, what type of HAT does he/she use?

___hearing aids (1__ 2__)

___cochlear implants (1__ 2__)

___bone conduction aids (1__ 2__)

Please describe your child's hearing loss (e.g. mild, moderate, severe, profound, other)

____

Indicate the communication modalities your child uses (Check all that apply): ___ spoken language ___ sign language ___ gestures ___ AAC (augmentative & alternative communication) device ___ PECs (picture exchange)

___ written communication ___________ other (please specify)

List in order of preference the communication modalities your child uses:

1) ______________ 2) _______________ 3) ________________

At what age was your child diagnosed with autism? _______

Who diagnosed your child? ___ family doctor ___ pediatrician

___psychologist ___other (please specify) _____________________

What year/grade was your child's initial IPRC (the meeting which determined his/her

exceptionality and school placement)? _________

What is your child's current school placement? (please check one)

__**Regular Class with Withdrawal Assistance-** placement in a regular class but also receives instruction outside the regular classroom **for less than 50%** of the school day from a special education teacher (this can include support from a hearing itinerant teacher or from a special education resource teacher in the school)

__**Regular Class with Resource Assistance-** placement in a regular and receives direct, specialized instruction, individually or in a small group from a special education teacher *within the regular classroom (*they do not leave the class to receive the extra support from the special education teacher)

__**Regular Class with Indirect Support-** placement in a regular class for the entire school day and receives direct instruction from the regular classroom teacher. The classroom teacher receives specialized consultative services from a special education teacher in order to support your child.
__**Special Education Class with Partial Integration-** placement in a special education class and is integrated with a regular class for part of the student's instructional program (a minimum of one instructional period daily).

__**Special Education Class Full Time-** placement in a special education class for the entire school day. This placement is also known as an Intensive Support Program (ISP).

Please list any additional services that your child receives at school (e.g., speech language services, hearing itinerant services, occupational therapy):
____

____

The purpose of this section is to gain additional information about your perceptions of the IPRC meeting. For each statement below, indicate the strength of your **agreement** or **disagreement** by circling the number on the five-point Likert type scale that matches with your thoughts on each item. Please circle one response for each of the statements below using the following answer guide:

1 = Strongly Disagree, 2 = Disagree, 3 = Neither Agree nor Disagree, 4 = Agree, 5 = Strongly Agree

There is no right or wrong answer

Questions					
1. **I felt comfortable asking questions during the IPRC meeting.**	① **Strongly Agree**	② **Agree**	③ **Neither**	④ **Disagree**	⑤ **Strongly Disagree**
Can you tell me more about why you feel this way?					
2. **The IPRC team members were knowledgeable about hearing loss.**	① **Strongly Agree**	② **Agree**	③ **Neither**	④ **Disagree**	⑤ **Strongly Disagree**
Can you tell me more about what made you think this way?					

3. **The IPRC team members were knowledgeable about autism.**	① **Strongly Agree**	② **Agree**	③ **Neither**	④ **Disagree**	⑤ **Strongly Disagree**
Can you tell me more about what made you think this way?					
4. **The IPRC team tried to understand my child as a whole and learn about his/her strengths.**	① **Strongly Agree**	② **Agree**	③ **Neither**	④ **Disagree**	⑤ **Strongly Disagree**
Can you tell me more about what led you to feel this way?					
5. **I was an active participant in the decision-making discussion at my child's IPRC meeting.**	① **Strongly Agree**	② **Agree**	③ **Neither**	④ **Disagree**	⑤ **Strongly Disagree**
Can you explain more about why you feel this way?					
6. **The decision regarding my child's exceptionalities and placement were made based on equal input from the IPRC team and from myself.**	① **Strongly Agree**	② **Agree**	③ **Neither**	④ **Disagree**	⑤ **Strongly Disagree**

Can you tell me more about what made you think this way?					
7. **The placement offered to my child was the most appropriate and best suited to his/her exceptionalities, strengths and challenges.**	① **Strongly Agree**	② **Agree**	③ **Neither**	④ **Disagree**	⑤ **Strongly Disagree**
Can you explain more about why you feel this way?					
8. **The IPRC meeting was a collaborative process where I felt involved and like an equal member of the team.**	① **Strongly Agree**	② **Agree**	③ **Neither**	④ **Disagree**	⑤ **Strongly Disagree**
Can you tell me more about why you feel this way?					
9. **Materials were provided by the school or made available in advance of the meeting which helped explain the IPRC process.**	① **Strongly Agree**	② **Agree**	③ **Neither**	④ **Disagree**	⑤ **Strongly Disagree**
Can you tell me more about why you feel that way?					

10. **Information provided to me in advance of the IPRC meeting was helpful in allowing me to properly prepare for the meeting.**	① **Strongly Agree**	② **Agree**	③ **Neither**	④ **Disagree**	⑤ **Strongly Disagree**
Can you tell me more about why you feel that way?					
11. **The atmosphere of the meeting was welcoming.**	① **Strongly Agree**	② **Agree**	③ **Neither**	④ **Disagree**	⑤ **Strongly Disagree**
Can you tell me more about what made you feel that way?					
12. **I did not feel intimidated by the IPRC team during the meeting.**	① **Strongly Agree**	② **Agree**	③ **Neither**	④ **Disagree**	⑤ **Strongly Disagree**
Can you tell me more about what made you feel that way?					

13. **All the members at the IPRC meeting introduced themselves and explained their job/role.**	**①** **Strongly Agree**	**②** **Agree**	**③** **Neither**	**④** **Disagree**	**⑤** **Strongly Disagree**
Can you provide more detail about your response?					
14. **I was satisfied with the outcome of the IPRC meeting.**	**①** **Strongly Agree**	**②** **Agree**	**③** **Neither**	**④** **Disagree**	**⑤** **Strongly Disagree**
Can you explain more about why you feel this way?					
15. **I understand how my child's hearing loss and autism, together, impact on his/her learning.**	**①** **Strongly Agree**	**②** **Agree**	**③** **Neither**	**④** **Disagree**	**⑤** **Strongly Disagree**
Can you provide more information, such as examples, to explain your response?					

If you are comfortable, please respond to the following personal questions to help provide a better understanding of how different groups are affected by this issue. This will potentially support future focus on equality, diversity and inclusion.

What age group are you in?

___18 to 24 years

___25 to 49 years

___50 to 64 years

___65 to 79 years

___Prefer not to say

How would you describe your marital or partnership status?

___Single

___Cohabiting

___In a civil partnership

___Married

___Separated

___Divorced / Dissolved civil partnership

___Widowed

___Prefer not to say

Gender

___Male

___Female

___Non-Binary

___Prefer not to say

Place of Birth

___Canada

___Outside Canada

If you have selected ‘Outside Canada’, please specify where:

____

How well can you understand, speak, read and write English?	***Not at all well***	***Not well***	***Well***	***Very well***	***Unsure or don't know***
I understand spoken English					
I speak English					
I read English					
I write English					

If English is not your home / first language, which language do you use to:	__________*Communicate* __________*Read* __________*Write*

If you communicate in a language other than English as your primary language, please specify: ___________________________________

What is the latest educational level you have achieved?	___*None* ___*Primary, grades 1-5* ___*Middle school, grades 6-8* ___*High school or equivalent, grades 9-12* ___*Post-secondary vocational/ technical* ___*College (diploma)* ___*University (1st degree)* ___*Postgraduate (2nd or further degree)* ___*Not known* *Prefer to self-describe (please specify)* ___________________________________

Which of the following best describes your current (main) employment status?	*____Working full time (employed or self-employed)* *____Working part-time (employed or self-employed)* *____Unemployed and looking for work* *____Unemployed and unable to work (health issues/ disability)* *____Retired* *____Stay at home parent* *____Carer to a member of the household with additional needs* *____Student* *____Doing unpaid work/ volunteering* *____Shift work* *Other (please specify)__________________________________*

Do you identify as a racialized person? * We use "racialized persons" instead of "race" to acknowledge the social impact of racialization in Canada.	*____Yes* *____No* *____Prefer not to say* *My race / ethnicity is:______________________* The following are some examples of ethnic and cultural origins referenced in the 2021 Canadian census: American, Armenian, Bahamian, Canadian, Chinese, Filipino, Iranian, Israeli, Nigerian, Syrian, African Canadian, Arab, Asian, Caucasian (White), East Asian, Hispanic, Middle Eastern, Persian, Roma, Tamil, West Indian For the complete Statistics Canada list: **https://www12.statcan.gc.ca/census-recensement/2021/ref/98-20-0002/982000022020001-eng.cfm#a7**

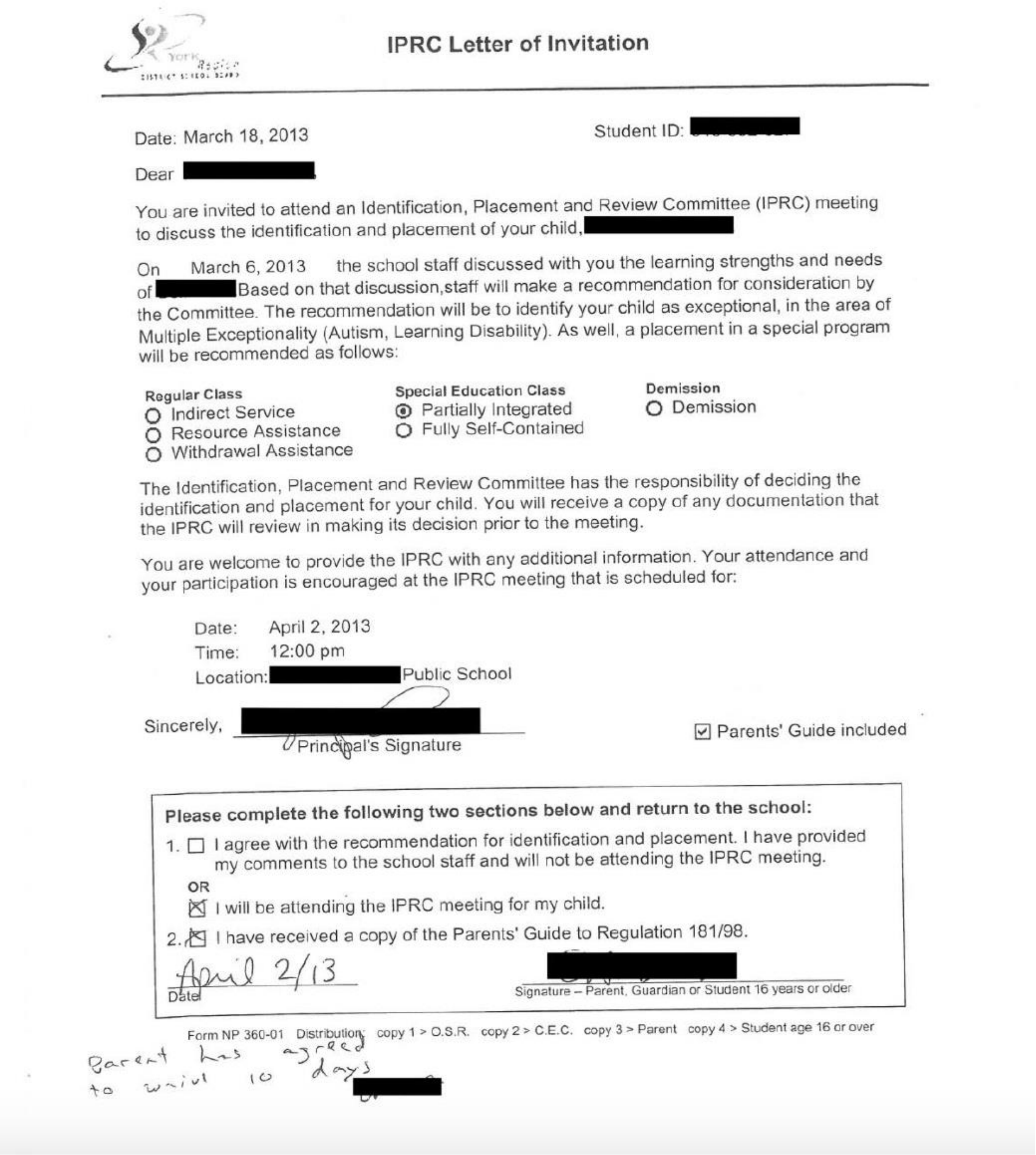
Thank you for your time!

If you have any questions, please contact

Elyza Polsky at epolsk03518@fontbonne.edu

Appendix E

*Sa*mple IPRC Letter of Invitation



York Region District School Board

IPRC Letter of Invitation

Date: March 18, 2013

Student ID: [redacted]

Dear [redacted]

You are invited to attend an Identification, Placement and Review Committee (IPRC) meeting to discuss the identification and placement of your child, [redacted]

On March 6, 2013 the school staff discussed with you the learning strengths and needs of [redacted] Based on that discussion,staff will make a recommendation for consideration by the Committee. The recommendation will be to identify your child as exceptional, in the area of Multiple Exceptionality (Autism, Learning Disability). As well, a placement in a special program will be recommended as follows:

Regular Class
○ Indirect Service
○ Resource Assistance
○ Withdrawal Assistance

Special Education Class
● Partially Integrated
○ Fully Self-Contained

Demission
○ Demission

The Identification, Placement and Review Committee has the responsibility of deciding the identification and placement for your child. You will receive a copy of any documentation that the IPRC will review in making its decision prior to the meeting.

You are welcome to provide the IPRC with any additional information. Your attendance and your participation is encouraged at the IPRC meeting that is scheduled for:

Date: April 2, 2013
Time: 12:00 pm
Location: [redacted] Public School

Sincerely, [redacted]
Principal's Signature

☑ Parents' Guide included

Please complete the following two sections below and return to the school:

1. ☐ I agree with the recommendation for identification and placement. I have provided my comments to the school staff and will not be attending the IPRC meeting.

   OR

   ☒ I will be attending the IPRC meeting for my child.

2. ☒ I have received a copy of the Parents' Guide to Regulation 181/98.

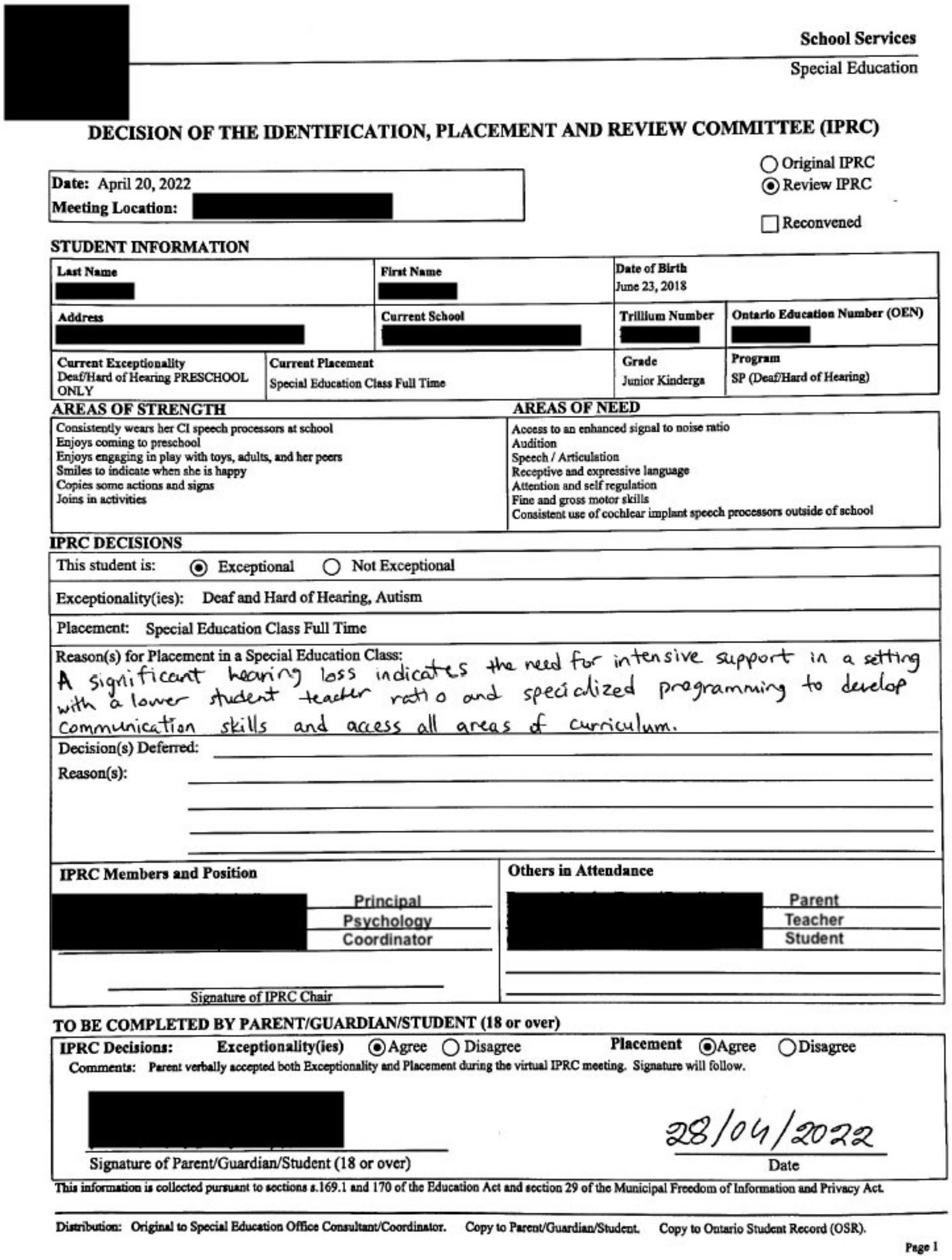
April 2/13
Date

[redacted]
Signature – Parent, Guardian or Student 16 years or older

Form NP 360-01 Distribution: copy 1 > O.S.R. copy 2 > C.E.C. copy 3 > Parent copy 4 > Student age 16 or over

Parent has agreed to waive 10 days [redacted]

Sample Statement of Decision



[redacted]

School Services
Special Education

DECISION OF THE IDENTIFICATION, PLACEMENT AND REVIEW COMMITTEE (IPRC)

Date: April 20, 2022
Meeting Location: [redacted]

○ Original IPRC
● Review IPRC

☐ Reconvened

STUDENT INFORMATION

Last Name [redacted]	**First Name** [redacted]	**Date of Birth** June 23, 2018	
Address [redacted]	**Current School** [redacted]	**Trillium Number** [redacted]	**Ontario Education Number (OEN)** [redacted]
Current Exceptionality Deaf/Hard of Hearing PRESCHOOL ONLY	**Current Placement** Special Education Class Full Time	**Grade** Junior Kinderga	**Program** SP (Deaf/Hard of Hearing)

AREAS OF STRENGTH	**AREAS OF NEED**
Consistently wears her CI speech processors at school Enjoys coming to preschool Enjoys engaging in play with toys, adults, and her peers Smiles to indicate when she is happy Copies some actions and signs Joins in activities	Access to an enhanced signal to noise ratio Audition Speech / Articulation Receptive and expressive language Attention and self regulation Fine and gross motor skills Consistent use of cochlear implant speech processors outside of school

IPRC DECISIONS

This student is: ● Exceptional ○ Not Exceptional

Exceptionality(ies): Deaf and Hard of Hearing, Autism

Placement: Special Education Class Full Time

Reason(s) for Placement in a Special Education Class: A significant hearing loss indicates the need for intensive support in a setting with a lower student teacher ratio and specialized programming to develop communication skills and access all areas of curriculum.

Decision(s) Deferred:

Reason(s):

IPRC Members and Position		**Others in Attendance**	
[redacted]	Principal Psychology Coordinator	[redacted]	Parent Teacher Student

Signature of IPRC Chair

TO BE COMPLETED BY PARENT/GUARDIAN/STUDENT (18 or over)

IPRC Decisions: **Exceptionality(ies)** ● Agree ○ Disagree **Placement** ● Agree ○ Disagree

Comments: Parent verbally accepted both Exceptionality and Placement during the virtual IPRC meeting. Signature will follow.

[redacted]
Signature of Parent/Guardian/Student (18 or over)

28/04/2022
Date

This information is collected pursuant to sections s.169.1 and 170 of the Education Act and section 29 of the Municipal Freedom of Information and Privacy Act.

Distribution: Original to Special Education Office Consultant/Coordinator. Copy to Parent/Guardian/Student. Copy to Ontario Student Record (OSR).

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Appendix F

Audio Recording Consent Form

“Schedule C”

1. Audio recording of Parent Interview

☐ I consent to the audio-recording of my interview(s).

Name of Parent/Guardian:____

Signature:________________________ **Date:**____________________

_

RESEARCHER ACKNOWLEDGEMENT: I hereby acknowledge receipt of this Consent Form

Name of Principal Investigator/Researcher:______________________________

_

Signature:________________________ **Date:**____________________

IRB#FBUIRB12032024-EP

Appendix G

Interview Questions

Name: ______________________ Date: ________________________

Individual Placement and Review Committee Process: Perceptions of Parents of Students Who Are Both Deaf/Hard of Hearing and Autistic

Researcher: Elyza Polsky

Script: I'd like to thank you again for being willing to participate in this interview and for taking the time to complete the online survey. As you are aware, the purpose of my study is to examine parents' perspectives of the Individual Placement and Review Committee process, specifically parents of children who are both deaf/hard of hearing and autistic. Our interview today will last approximately an hour, during which I will be asking you about your child, and the first IPRC meeting where the school placement decision was made for your child. Your responses will all be kept confidential. Your personal information as well as any other identifiable data such as your child's name, the school's name, etc.. will all be changed. I will be audio recording this interview to help me when reviewing the data afterwards. I would like to begin by asking if you have brought any diagnostic or assessment documentation related to your child's educational placement to share?

I would like to take a few minutes before we start the interview questions to review and clarify a few of your responses on the survey. This just allows me to make certain that I understand what you meant and your intention in your responses.

Please know that you may discontinue the interview at any time.

Interview Questions

1. Please tell me about your family.
2. Can you share with me some information about your child specifically, in particular his/her hearing loss and ASD. This can include your child's strengths, interests, age, disability, diagnosis, and challenges or needs. • What are your child's areas of strength? • Which one is your child's primary learning challenge (dhh or asd)?
3. How has the diagnosis of autism paired with hearing loss impacted your family?

4. How has the dual diagnosis impacted the way you communicate in your home? How does it affect your communication decisions and the strategies you use with your child? • (If English is not their first language..) Has your child's diagnosis impacted the language you speak regularly at home?
5. Please think back to your child's first IPRC meeting. Was it requested by the school or did you ask for the meeting to be called? • (If they can't recall the details prior to the initial IPRC..) What information or details are you able to recall from the time when your child was first being identified by the school and the discussion of placement was occurring?
6. How did you prepare or get ready for the IPRC meeting (i.e. collect documents to bring)? • (If necessary..) Do you know other parents who have gone through the IPRC process and who were able to guide you and offer advice? Have you connected with any online social media groups for parents? Did you learn anything about the IPRC process through your own online research?
7. Did you receive any materials or information from the school in advance of the meeting? • (If necessary..) Were the materials made available to you in your native language?

8. What did you find to be the most helpful? What was the least helpful?
9. When you went to the meeting, did you bring anything with you, such as reports, assessments or other documentation to share with the IPRC committee? • (If yes..) During the meeting, did you have a chance to share your reports? • Did the members of the team have a chance to familiarize themselves with the content?
10. How did you participate during the IPRC meeting? For example, did you ask questions throughout the meeting, did you share your opinions on placement, did you talk about your child's strengths, etc… • (If necessary..) Was an experienced interpreter present? Tell me about the interpreting services.
11. Did you feel that you were listened to during the meeting?
12. During the discussion in the meeting, did the team members / school personnel use a lot of technical language / educational jargon? • (If so..) Did they explain themselves clearly? • (If using an interpreter..) Did the interpreter seem comfortable translating the terms being used?
13. Were any assessments or reports shared by the IPRC team with you during the meeting regarding your child's progress in school, their exceptionality or any assessments completed by the school?

• (If so..) Were the documents explained to you?
14. Did you ask questions or seek clarification for any information that may not have been clear during the meeting? • (If so..) Could you describe your comfort level in asking questions?
15. Did you have enough time to discuss everything you wanted to discuss?
16. During the discussions, did you get a feeling that the members of the IPRC team (all or any of them) were familiar with your child's exceptionalities? • Were they familiar with the terminology related to hearing loss and ASD? • Did they demonstrate an understanding of your child's communication needs?
17. Can you tell me what you remember about where the committee's focus and attention was during the meeting? Specifically, did the give equal focus to both the deaf/hard of hearing exceptionality as they did to the autism exceptionality?
18. Do you feel that your child has one exceptionality that requires more attention or focus in school?
19. Did you agree with the exceptionality/ies / designation(s) given by the committee?
20. Before giving you a specific placement option, do you recall the IPRC team presenting you with other possible placement options?

21. Before giving you a specific placement option, do you recall the IPRC team asking you what you thought and which option you felt was best suited to your child's learning needs?
22. How did you feel about the placement option(s) offered?
23. Did you sign the Statement of Decision at the time of the meeting?
24. How can the school boards improve the IPRC meeting process?
25. What can parents do to improve the IPRC meeting?
26. Before we finish the interview, is there anything else that you would like to share about the IPRC placement process, your participation or the outcome for your child?

Documents:

Audiogram

Autism assessment

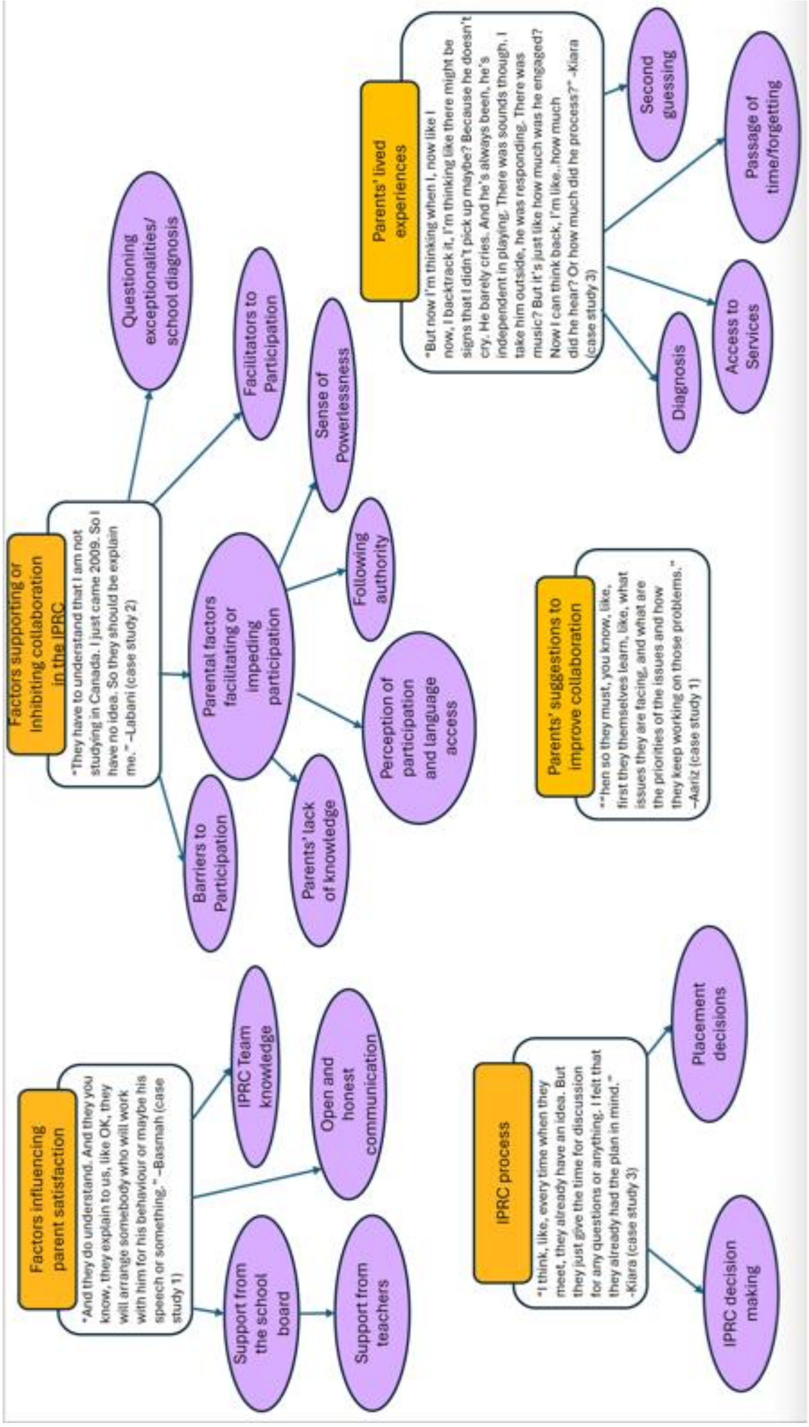
IPRC documentation

Other ____

____

Appendix H

Themes, Sub-Themes and Quotations



"And they do understand. And they you know, they explain to us, like OK, they will arrange somebody who will work with him for his behaviour or maybe his speech or something." –Basmah (case study 1)

"I think, like, every time when they meet, they already have an idea. But they just give the time for discussion for any questions or anything. I felt that they already had the plan in mind." -Kiara (case study 3)

"They have to understand that I am not studying in Canada. I just came 2009. So I have no idea. So they should be explain me." –Labani (case study 2)

""hen so they must, you know, like, first they themselves learn, like, what issues they are facing, and what are the priorities of the issues and how they keep working on those problems." –Aariz (case study 1)

"But now I'm thinking when I, now like I now, I backtrack it, I'm thinking like there might be signs that I didn't pick up maybe? Because he doesn't cry. He barely cries. And he's always been, he's independent in playing. There was sounds though. I take him outside, he was responding. There was music? But it's just like how much was he engaged? Now I can think back, I'm like..how much did he hear? Or how much did he process?" -Kiara (case study 3)

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