When Mothers Disengage: Stories From Women Who Have Gone From Participants to Observers in Their Autistic Child's Education

By © Carly Sutherland

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Abstract

There exists a knowledge gap in our understanding of why some mothers of Autistic children resist engaging fully with their children's school-based teams, despite the body of research supporting the benefits of constructive family-school relationships. This thesis investigates the narratives of five mothers through the lens of Bronfenbrenner's ecological systems theory and the feminist theoretical framework of nonunitary subjectivity. The results were analysed for themes inductively using a constant comparative model. The qualitative data gained from this exploration finds that the participants disengage from their children's school teams after years of experience, intense efforts, discouragement, cumulative stress, and perspective shifts. School leaders should consider that any promotion of re-engagement needs to transpire through a culturally responsive, trauma-informed lens that prioritises relationship building, empathy, and suspended judgement. The research also suggests that more flexible hiring practices could be of benefit. Further research in this area exploring the perspectives of educators, fathers, and more marginalised groups is recommended.

General Summary

There is a gap in our knowledge about parents of Autistic children who cease or reduce involvement with their children’s schooling. A large body of literature exists to outline the value of positive parent-school relationships, and it is well-established that parenting Autistic children is a particularly challenging undertaking which is primarily led by mothers. This thesis connected these two concepts by conducting in-depth interviews with five mothers who self-identified as having withdrawn from interactions with their children’s schools, and examining their stories to uncover common themes. The results, which were analysed through a holistic lens, showed that the women interviewed reached a place of acceptance in their parenting journey after many years of struggling to balance significant, challenging demands related to their children’s care. In conclusion, school leadership should be aware of the individual circumstances of individual families navigating the complexities of Autism, and consider ways to be more accessible to families in crisis.

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Table of Contents

A Note on Terminology, Formatting, and the Exclusion of Autistic Voices

Throughout this thesis, I am following the lead of Autistic self-advocates and will be using the identity-first language “Autistic” instead of the person-first term “person with autism”. Semantics are powerful, and in the Autism community, being Autistic is as inherent to one’s identity as ethnicity or religion. Much like one would say a person is Muslim and not “someone who practises Islam”, gay instead of “person with same-sex preferences”, or “African-Canadian”, not “Canadian of African descent", *person with autism* suggests that Autism can be separated from who that person is. To quote Brown (2011), Autism “is an edifying and meaningful component of a person's identity, and it defines the ways in which an individual experiences and understands the world around him or her. It is all-pervasive.” They continue: “Referring to me as ‘a person with autism’, or ‘an individual with ASD’ demeans who I am because it denies who I am.” Therefore, this research will be using identity-first language to honour this perspective and to pay respect to the Actually Autistic community.

I have also chosen to capitalize Autism and Autistic. I noticed that self-advocates were using this formatting in much of their informal writing on social media and in blog posts. According to the Pittsburgh Centre for Autistic Advocacy [PCAA] (2024), the Autism community is following the lead of the d/Deaf community, wherein lowercase d (“deaf”) is used to describe a person’s ability to hear, and uppercase D (“Deaf”) refers to culture. The Autistic community “has moved towards capitalizing Autistic to reflect the unique children shared by Autistic people involved in disability rights and the Autistic Rights Movement” (PCAA). Reframing Autism (2004), an online community which supports the Autistic community “to achieve genuine acceptance, inclusion, and active citizenship,” capitalizes Autism and Autistic as per their “house style” and as a sign of respect and empowerment (Weller, 2023). I am doing the same throughout this thesis to pay respect to this perspective.

Finally, as an ally, I am always conscious of the “nothing about us without us” rule when speaking about disabled populations (Charlton, 1998). I am cognizant of the fact that I have not included Autistic voices in my research. This is a conscious choice, as the research is about mothers of Autistic children and their unique experiences. While their children feature large, this research is not about them.

Chapter 1: Introduction

The pressure in Western society to be a good mother can be a suffocating endeavour. Expectations are high for women and girls even before they become mothers, and certainly don't dissipate after they do. The "good mother ideology" suggests that women are naturally competent caregivers who should be fulfilled by the all-consuming task of mothering (Williamson et al., 2023). Failing to meet these expectations can result in "mum-shaming", wherein mothers are criticized for their choices in everything from feeding to sleeping.

When a woman is parenting a disabled child, one might expect a reprieve from this mentality, but instead, it is exacerbated. According to Brock (2014), society expects the "good mother of a child with a disability" to be a lifelong caregiver, place her child's needs before her own, not work outside the home, naturally possess the skills and qualities required to fulfil the role, and maintain a facade of normality all the while, as if there is nothing particularly special about what she is doing. This extends to the mother's involvement with her child's education. O'Hare et al. (2021) report that many mothers feel compelled to be highly involved in their child's schooling, embracing the "warrior-hero" identity (Sousa, 2011). Sousa describes the warrior-hero as an archetype, wherein the historical stigma and burden of blame for her child's disability becomes reframed in a new empowering role that goes to battle for resources and support.

All this getting involved requires an understanding of inclusion. Inclusion has been so well-established as the norm and best practice for serving students with diverse needs in our school system that outlining and discussing its benefits here seems superfluous at this stage. Its purpose, as defined by Nova Scotia's Inclusive Education Policy, is "to ensure every student has access to an equitable and high-quality education that is culturally and linguistically responsive, accepting, and respectful in supporting and valuing…learning and diverse abilities." (Government of Nova Scotia, 2019, p. 2). Inclusion, however, is not simply an interchange between schools and students. Parents are written into policy as the critical third partners required in this process. According to the same policy, parents are expected to:

> …engage in and support their child's learning, support their child in attending school, maintain ongoing, regular contact with teachers about their child's well-being, including their strengths, challenges, and interests…let the school staff know how they would like to be included in the discussion around their child's well-being and achievement, work with the teacher and the principal to seek clarification and collaborate on solutions when questions arise with respect to their child's education and to identify and eliminate barriers to their child's learning, promote and value student voice and choice and providing opportunities for them to speak to their strengths and challenges, [and] act as active members of their child's Student Planning Team. (p.5)

The Special Education Policy in Nova Scotia (Government of Nova Scotia, 2008) is both more succinct and more direct: "Parents have a duty and a responsibility to support their children in achieving success." (p.6) If this sounds exhausting and stressful for parents, it's because, as the subsequent literature review and results will demonstrate, it quite often is.

For mothers of Autistic children, these presumptions of competency and high involvement can seem elusive. Research shows that Autism is more stressful to parent than other neurodevelopmental disabilities, physical disabilities, and health conditions (Pottie & Ingram, 2008, Ingersoll & Hambrick, 2011, Hayes & Watson, 2013). In a rather sardonic response to the oft-circulated "Welcome to Holland" essay, which encourages parents with a child newly diagnosed with a disability to embrace the experience as unexpected (they had *planned* on

Italy…) but lovely in its own right (but wait, there are tulips!), one mother wrote an essay entitled “Welcome to Beirut” (Rzucidlo, 1996), which likens the experience of parenting an Autistic child with being dropped into a war zone. Unsurprisingly, this stress has a significant impact on mothers’ mental health. It is often cited that some mothers of Autistic children show post-traumatic stress disorder symptomology (Schnabel et al., 2020). While the findings may be validating for women who are struggling, they do not result in changing expectations of their role.

In this thesis, I examined the experiences of five mothers who eventually decided that they would not, and could not, continue aligning their actions with Sousa’s “warrior hero” identity. The author coined the “warrior hero” label after her examination of 33 memoirs written by women parenting children with disabilities, an archetype created in response to and in rejection of bearing the burden of blame and shame for their child’s difficulties. Such mothers wage “battle against social and political forces to gain medical and educational interventions for their children despite the high personal and financial costs to themselves and their families” (Sousa, 2011, p.220). Skinner et al. (1999) found that the mothers they researched consistently described the experience via a “quest” narrative, thus inspiring them to advocate, “struggling and fighting” (p.492). As Brock (2014) indicated, one may reject the intensive demands of this “good-mother-of-a-child-with-a-disability” (p.33) concept, but it is more difficult to escape the consequences it has on one’s sense of self.

As an experienced educator and parent of an Autistic teenager, I was aware from anecdotal observations, both personal and professional, that some mothers were struggling to fulfil the expectations set out for them. I sought to listen to their stories first-hand to understand the reasons for their struggles. I focused entirely on women in my research, because again, my anecdotal experience indicated that mothers were most often the primary caregivers, and therefore, also responsible for supporting their children's education. Research supported my observations. According to Houle et al. (2017) for Statistics Canada, date revealed that 65% of time spent on childcare fell to women in 2015, a decrease of only 7% from the previous 30 years. This was exacerbated and intensified by the COVID-19 pandemic, which resulted in women reporting they were primarily responsible for staying home with children and managing their schooling (LeClerc, 2020).

As the literature review will establish, while extensive research exists to support the stresses and challenges of raising an Autistic child, as well as the value of and challenges inherent in positive home-school partnerships, absent is the gestalt between those two established certitudes, as are the voices of mothers who stepped away. I posit that narrative research examined through an ecological systems framework (Bronfenbrenner, 1977, 1986, 1994) and feminist theoretical framework of nonunitary subjectivity (Bloom, 1998; Clark, 1999; Griffiths, 1995) is needed to add the voices of this group to the knowledge gap in the existing literature, and provide a previously unexamined perspective. Given the established benefits of a positive, constructive relationship between families and schools, there is a demonstrated need to hear the stories of those who have withdrawn from engaging with their children's school teams. Stories are not facts, but they are social constructs and lived realities of those communicating them. My goal is to use the research, with ecological systems and nonunitary subjectivity theories as foundations, to construct meaning from these narratives of experiences of mothers in this unique position to develop a frame of reference and understanding for stakeholders.

Theoretical Framework

Considering the complexity of interacting factors that can influence the interplay between mothers of Autistic children and their children's schools, it is helpful to frame this examination around Bronfenbrenner's ecological systems theory (1977, 1986, 1994). Bronfenbrenner (1977) defined the ecology of human development as such:

> The ecology of human development is the scientific study of the progressive, mutual accommodation, throughout the lifespan, between a growing human organism and the changing immediate environments in which it lives, as this process is affected by relations obtaining within and between these immediate settings, as well as the larger social contexts, both formal and informal, in which the settings are embedded (p. 514)

Ecological systems theory posits that the systems influencing the child are like a series of Russian nesting dolls, moving from those closest to the child to most distant, but all having influence on their child's development (1994). Importantly, the processes occurring in these settings do not operate independently of one another (1986).

The systems closest to the child, which they interact with directly, are the microsystems. Bronfenbrenner (1994) advances that ongoing forms of interaction in the immediate microsystem, which he coins proximal processes, are even more powerful than environmental contexts. The proximal process relevant to this discussion is that of mother-child interactions. As the quality of these interactions can be difficult and taxing due to their Autistic child's challenging behaviour, when viewed through the lens of Bronfenbrenner's (1994) assertion, we could infer that any environmental benefits the family may have – e.g. education, income, access to services, etc. - may not be able to compete with disadvantageous proximal processes within the home. The influence of these proximal processes is persisting and cumulative.

Bronfenbrenner (1994) states: “at each successive step, the same degree of active effort yields a somewhat smaller result” (p. 39).

The mesosystem is that which exists in between microsystems, and for the purposes of this thesis, much focus is on the mesosystem of the home-school relationship. Epstein’s (1983) study on the longitudinal effects of this joint involvement or lack thereof demonstrated that the effects of this mesosystem on student outcomes were in fact more powerful than socioeconomic status or race.

Bronfenbrenner (1986) warned that research focusing only on the “social address” or “environmental label” of participants risked creating limitations by ignoring context (p. 724). Therefore, examining “parents of Autistic children” and ignoring the environmental factors impacting the experiences of those parents can limit the scope of understanding. Better, according to Bronfenbrenner (1986), is the person-process-context model, which can yield richer results. This paradigm considers external influences on the developing child and family, as well as internal family dynamics.

Bronfenbrenner (1977, 1986, 1994) defines these external influences as the exosystem, macrosystem, and chronosystem. All three, as this research will show, have an effect on the home-school mesosystem being examined. The exosystem is the next layer outside the mesosystem and microsystem, and encompasses settings that do not include the developing child directly, but nonetheless serve to affect them. Examples of exosystems relevant to this thesis include parents’ places of work, their social and support networks, government policies, teacher training institutions, and the media. The macrosystem exists outside the exosystem, and comprises cultural norms and societal attitudes. These appeared in my research as expectations placed on mothers, stigma, and judgement.

The final system is the chronosystem. The chronosystem includes environmental events and changes that occur throughout a child's life - lifespan transitions, of a sort - but can also incorporate socio-historical events. Families that include an Autistic individual are no strangers to dramatic and recent socio-historical shifts, from the toxic legacy of Bruno Bettleheim's refrigerator mother theory in the 1960s, which opined (wrongly) that cold, distant mothers were themselves to blame for their child's disability (Sousa, 2011); to fraudulent research claiming that the measles, mumps, and rubella [MMR] vaccine caused Autism (Flaherty, 2011). These theories created mass panic and a public health crisis, as well as deep hurt within a community as many parents preferred their children be unprotected from life-threatening diseases than "suffer" with Autism. This precipitated the rise of the neurodiversity movement, which posited that Autism is a brain variation that should be celebrated, accommodated, and appreciated, not cured or seen as disabling (Jaarsma & Welin, 2012). The impacts of the chronosystem - these historical shifts on how society views and understands Autism - were all reflected in the discussions with participants and how they made sense of their personal experiences.

This research also has a poststructural feminist theoretical foundation, centred around the concept of nonunitary subjectivity (Bloom, 1998; Clark, 1999; Griffiths, 1995). According to Bloom, subjectivity is unitary in that it is "continually in the process of production within historical, social, and cultural boundaries" (p.4). As a subject is defined by their context, it can be difficult to ascertain what is socially constructed by one's experiences and perceptions thereof, and what originated within one's "untouched" self. As Clark explains, "we collectively make ourselves, but not in conditions of our own choosing" (p.3). Therefore, the concepts of self and subjectivity are so intertwined they are virtually inseparable. Given the centrality of motherhood in this research, it would be difficult to ignore how gendered social conditioning contributes to this nonunitary subjectivity, and thus the participants' perceptions of themselves. According to Flax (1987), “Feminist theorists have delineated many of the ways in which women's consciousness is shaped by mothering, but we often still see "fathering" as somehow extrinsic to men's and children's consciousness” (p.640). This research shows the intersection of the concepts of feminism and nonunitary subjectivity.

Women have historically encountered many contradictions about what being a woman entails (Ramazanoglu et al., 2002). As previously discussed, women, especially those parenting Autistic children, are concurrently surmised to be competent caregivers, a concept underwritten with domesticity and traditional female roles, celebrated for going to battle for their child while having been only recently absolved of blame in the public sphere for their child’s disability, and, in many cases, are dealing with their own mental illness. Approaching this research with the perspective that one’s model of self is nonunitary has the potential to capture a more complex view of the participants’ understandings of themselves and how they made sense of their experiences in this gendered social reality. The self, according to Griffiths (1995), is a fragmented being. To consider the question of - “How did I come to be myself?” Griffiths used the metaphor of a web, explaining:

> Spiders make webs which are nearly invisible until the dew falls on them. They are made with threads stronger than steel and take their shape from the surrounding circumstances and from the spider herself. Second, women have traditionally made webs: knitting, tapestry, crochet and lace. Their creations are constrained by the circumstances of their making but they bear the mark of the maker. (1995, p.3)

As the purpose of this research is to understand why some mothers disengage from the home-school mesosystem, the ecological systems theory serves as a blueprint for understanding the complex and interacting contexts which penetrate every aspect of this relationship. Moving from the smallest nesting doll to the largest, the mother-school mesosystem can be influenced by (among other things) proximal processes within the home; family dynamics; school programming; their child's therapies; parents' places of work, be it within or outside of the home; support and social networks; parents' access to social capital via education levels and income; access to services for parents and their children; relevant government policies around education, health care, and community services; recreational and respite opportunities; societal attitudes; and the ever-changing landscape of how we understand Autism.

Furthermore, the additional feminist framework of nonunitary subjectivity will inform interpretations of the participants' understandings of their various "selves" as they emerge throughout the narrative. Working within the frameworks of the ecological systems theory and nonunitary subjectivity allows researcher and participants to identify the many systems and processes that may be working collectively to intercept productive partnerships between mothers and their Autistic children's schools.

Research Question

My research seeks to develop a better understanding of what mothers of children with Autism experience in the context of being educational partners in the school system, in hopes of better appreciating why some mothers disengage from the process, and how school teams can facilitate re-engagement to better support families holistically using an ecological approach.

Chapter 2: Literature Review

Introduction

I undertook this literature review to uncover what research exists to contextualise the experiences of the participants in this study. As this chapter will show, much research exists delineating best practices to support Autistic individuals, the challenges specific to parents navigating the system to support their Autistic children, parent-school relationships, and the mental health of these parents. However, I sought to connect the dots between these realities and the assumptions of parent involvement as outlined in Nova Scotia's education policy, which has high expectations for their contributions to the School Planning Team and their child's education. Twenty years of anecdotal experiences as a learning centre, resource, and classroom teacher had made it clear to me that mothers were almost exclusively taking on these expectations, and not always fulfilling them. At times, I also heard the educational professionals involved blame these "failures" as a lack of interest or a form of programming sabotage on the part of the mothers (those who are responsible, after all, shoulder the blame when it is handed out). As a parent of an Autistic child, I was uncomfortable with these presumptions and felt confident there was more to the story than disinterest and/or hostility. I was unable to uncover research about parents who were/are *not* involved in their Autistic child's education, and wondered what their stories were. I knew there was a narrative to tell.

This literature review is organized by the themes that emerged in the conversations I had with the participants in this study through inductive analysis. The literature is ordered mostly chronologically to give the reader a sense of the mothers' journeys as they lead, ultimately, to disengaging from their child's school teams:

1. Characteristics of Autism Spectrum Disorder
2. The joy of parenting an Autistic child
3. Experiences with diagnosis
4. Early intervention
5. Transition to school
6. Persisting difficulties at home: challenging behaviour and mounting stress
7. The gap widens: disability in the family as a form of marginalization
8. Coordinating external support
9. Parent-school relationships
10. Conclusion

To begin this examination, I sought out exclusively peer-reviewed literature, using primarily OneSearch through Memorial University's library, and to a lesser extent, Google Scholar. Given the broad range of literature available - typing Autism into the search bar and limiting the search to peer-reviewed articles within the last twenty years yielded over 30,000 results, adding "family" only reduced it to just over 18,000 results - therefore, I used the pearl-harvesting methodological framework for information retrieval with Sandieson et al. (2010) as my guides, and refined my search accordingly in an attempt to keep the process broad yet relevant. I sought out Canadian and particularly Nova Scotian sources when possible and applicable. However, much of the theories and experiences around this topic come across in the literature as universal, many sources are international. I made every effort to find counter arguments to any potentially generalizable claims and included those here. In addition to peer-reviewed literature, I incorporated pertinent, local policy documents and information outlined on service providers' websites. These documents are the ones accessible to families on their quest to support their children, and in some cases, provide guidelines and expectations for families. In two cases, I used news articles from reputable media sources: one to illustrate information around waitlists, and the second to describe an extreme situation faced by one family in crisis. To summarize, I used a variety of sources from peer-reviewed and not peer-reviewed but reputable sources to guide this literature review and provide a framework to understand the stories of the participants in more depth.

Characteristics of Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder. Autism presents with impairments in social communication, sensory anomalies, and repetitive behaviours. Furthermore, Autism is frequently comorbid with other psychiatric or neurological disorders, including attention deficit hyperactivity disorder (ADHD), anxiety, depression, intellectual disability, and epilepsy. (Lord et al., 2020). According to Stewart et al.'s research (2020), studies show a range of 63-94% of Autistic children demonstrate challenging behaviours, which they define as behaviours that are socially unacceptable and/or dangerous, such as aggression, self-harm, elopement, and pica.

Statistics vary on Autism's prevalence, from approximately 1% of the world's population (World Health Organization, 2023) to 1 in 50 in Canada (Public Health Agency of Canada, 2022). The Diagnostic and Statistical Manual of Mental Disorders (2022) indicates that Autism is three to four times more common in males. Once considered a rare disorder, broadened diagnostic criteria and public awareness have resulted in increased diagnoses since Autism was first identified (Matson & Kozlowski, 2011).

The Joy of Parenting an Autistic Child

Although Autism is usually described (as above) from a deficits-based perspective, parents of Autistic children report many positive and enriching aspects of the experience (Broady et al., 2017), as well as altered worldviews and belief systems that recognize the child's positive contributions to the family unit (Woodgate et al., 2008). Adams et al. (2023) found positive meaning-making, benefit-finding, and resilience to be a consequence for some mothers of Autistic children and point to research which suggests that an Autistic child increases familial closeness. As the results section in this thesis will show, this was true for all participants in this research.

Experiences with Diagnosis

As of 2019, the median age of an Autism diagnosis in Canada is 3.7 years (Public Health Agency of Canada). According to Abbott et al. (2013), receiving an Autism diagnosis for one's child is a "momentous", "significant", and "anxiety-provoking" event, coupled with distress, whether or not parents were expecting it. However, Jacobs et al. (2020) indicate that a diagnosis can come with relief for some parents, as it provides an explanation for their child's difficulties, as well as access to support to which they would otherwise not be entitled, and removes concerns that their parenting might be to blame for their child's behaviour. In any event, diagnosis is a complicated and emotional journey for caregivers.

The process of receiving a diagnosis begins much earlier than the day parents are informed of the diagnosis. Concerns about their child's development can arise as early as 9 months, with most parents identifying a concern about development by age three (Wong et al., 2017). Bryson et al. (2007) indicate in their research that signs of atypical development can be evident as early as six months. Yet, many parents report that when bringing early concerns to their health care provider, they were met with dismissiveness, and suggestions that their child may “grow out of it”, leaving parents to grapple with confusion, stress, and self-blame while they continue to pursue answers (Goin-Kochel et al., 2006; Perlman & Howe, 2020). The Nova Scotia Health Authority (n.d.) concurs that a diagnosis does take time and often requires multiple evaluations, which “is due in large part because young children are all so different in the way they behave and develop.”

Early Intervention

Once parents finally receive a diagnosis, the next step involves connecting to services. The Izaak Walton Killam (IWK) Children’s Hospital in Halifax offers Early Intensive Behavioural Intervention (EIBI) for preschool-aged Autistic children, an evidence-based treatment founded on the principles of applied behaviour analysis (ABA). The main form of EIBI treatment is Pivotal Response Treatment (PRT) (Nova Scotia Health Authority, n.d.). Lynn Koegel (2014), the Stanford psychologist who developed PRT, points to myriad data concluding that early intervention is critical, and that outcomes are far less promising for children who receive treatment after the age of five. Koegel (2014) warned that the “wait and see approach…is likely to have significant negative consequences” (p. 51).

EIBI does not begin immediately following diagnosis, however. Media reported 225 children on the waitlist in Nova Scotia as of February 2023 (Hampshire, 2023). The current policy is to take the oldest children on the waitlist to ensure they can access the program before aging out at school entry (Nova Scotia’s Department of Health and Wellness, 2012). D’Entremont et al. (2022) report that the average age at onset of EIBI services is four and a half years old, nearly a year after the average initial diagnosis. This results in parents struggling with the difficult and potentially expensive decision to delay school entry, with a third of the aforementioned 225 waitlisted children having to either end EIBI early, or start school a year later should their family wish to complete the program (Hampshire, 2023).

Delayed EIBI services leave parents to either take the aforementioned warned-about wait and see approach, or seek out private service providers. While no research on parent experiences during this period exists specific to the geographical location of the participants in this study, the subsequent research suggests that accessing services to support newly diagnosed children is a stressful endeavour for parents. Milbourn et al. (2017) explain that understanding the importance of early intervention leads to significant pressure and a sense of urgency within families. As most primary health care providers are not specialists, and lack sufficient information to guide parents towards evidence-based interventions (McCormack et al., 2020), by default, the task falls on families to decide how to proceed until they move up in the queue. Significant time, energy, advocacy, direct participation and vigilance are required for this undertaking, with some parents going so far as to leave their jobs to take on the responsibility of securing services for their child (Lappé et al., 2018; Maich et al., 2019). Green et al. (2006) found that parents tried an average of seven different interventions for their children, with 10% of families surveyed trying 15 or more. While some of the interventions were evidence-based, such as speech therapy and ABA, some were not, such as chelation, holding therapies, and alternative diets. Schreck and Miller (2010) refer to these as “fad therapies” and caution that results can range from “blatantly ineffective” to harmful (p.307).

Frantic parents without a background in Autism interventions or research literacy, left to comb through options in desperation, are therefore vulnerable consumers. A study conducted found that in Nova Scotia, families spent an average of $2518 out of pocket on resources such as respite, learning materials, travel costs, and therapies to support their children in the time span between diagnosis and the commencement of EIBI (Ungar et al., 2018). This number does not capture time losses, a notable omission, as research indicates that parents of Autistic children work fewer hours and consequently earn less than parents of typically developing children or even children with other health conditions in order to meet their children's needs (Cidav et al., 2012; Maich et al., 2019). Maich at el. (2019) indicate that these adverse employment effects are particularly impactful on women, and tend to begin after diagnosis and throughout the preschool years. Tsiplova et al. (2019) place the figure capturing productivity losses alone as between $2719 and $9062 annually in Nova Scotia and New Brunswick.

To their credit, the IWK in Halifax has made an effort to expand public services for families during this waiting period. They provide an Autism Education Series to support families in building the skills needed to support their child (IWK Health, n.d.). Nova Scotia Hearing and Speech offers the "All Together Now" program to support parents in helping to address their children's social communication needs, and since the pandemic, has been offering this program remotely, which caregivers report has been more convenient and accessible (Hearing and Speech Nova Scotia, 2022). While this is certainly progress, these interventions are still limited, dependent entirely on parent coaching, and lack the ideal level of intensity and direct service many parents are clearly seeking.

EIBI itself is a year-long program that provides children with six months of direct intervention for 15 hours a week, three months of 10 hours a week, and the last three months for six hours a week. Parents receive monthly coaching and attend regular meetings. Treatment is based primarily on the PRT model and positive behaviour support (PBS). D'Entremont et al. (2022) indicated that the EIBI program in New Brunswick could be offered in the child's preschool or in their home, and while direct parent involvement was encouraged, it was not mandated. In Nova Scotia (as opposed to New Brunswick, the other province in the study) parents were expected to participate in monthly treatment planning sessions and explicit parent coaching.

Existing research indicates that EIBI results in meaningful gains for children. Reported gains include receptive and expressive language, adaptive functioning, and a reduction in challenging behaviours (Smith et al., 2015). However, other studies suggest that improvements are primarily limited to children with "normal" cognitive functioning at the onset of the program (Fernell et al., 2011). Although Smith et al. (2015) report the program results in reduced parental distress and increased parental self-efficacy, this does not come without burden to families (Tsiplova et al., 2019; Yingling et al., 2018). Yingling et al. indicated that parents expressed concerns such as the high turnover of interventionists, difficulty managing the household and other children during treatment sessions, and the "one-size-fits-all" model that assigns the same amount of intervention hours to all children regardless of symptom severity. All the above suggest that while EIBI has many benefits, it is not a perfect intervention to help families and Autistic children overcome their challenges.

Transition to School

As children in Nova Scotia age out of EIBI once they start school, the next stage is preparing for the transition to school. Atlantic Provinces Special Education Authority (APSEA), an interprovincial agency originally formed to support students with low incidence sensory impairments but since expanded to provide webinars, information papers, and research on Autism in education, wrote an information paper about school transition for Autistic students (2015), where the importance of "Ready Schools" is emphasized. Ready Schools, according to APSEA:

> proactively reach out to families and to early childhood service providers to establish strong connections in order to learn about the strengths and needs of the child and to make the necessary preparations to greet the child with the necessary planning and supports in place. (2015, p.4)

APSEA recommends the transition process begin 12 months prior to school entry, at which point initial discussions with the intaking school begin. Six months prior, focus should be on acclimating the child with visits, planning for supports and programming, making necessary referrals, and getting up to date on the child's profile.

Best intentions and guidelines aside, Autistic students are among the most vulnerable when issues emerge around school transition, which can create limitations for future success (Sefotho & Onyishi, 2021). Nuske et al. (2019)'s synthesis of research findings on primary school transition for Autistic children suggests that they experience adjustment difficulties such as anxiety, social pressure, and disorientation. Staff were often lacking in training and knowledge. Parents experienced worry, alienation, and discontent. Some parents found they no longer feel like the "partners in the therapeutic process" they once were (Atlantic Provinces Special Education Authority, 2015, p. 3). Conflict emerged around advocacy, over-reliance on external service providers, and unreliable communication (Atlantic Provinces Special Education Authority). Chen et al. (2020) echo Nuske at al.'s findings and note the importance of early intervention providers as a "critical" bridge to coordinate stakeholders, as not all parents are well-positioned to enable a collaborative transition, the absence of which has been linked to poorer outcomes for the children.

The nature of Autism means that difficulties with transition and the need for sameness and routine (a facet of repetitive behaviour), coupled with communication and social deficits, make the adjustment to school particularly challenging for this population (Fontil et al., 2020; Nuske et al., 2019; Sefotho & Onyishi, 2021). The same authors also indicate that positioning parents as the experts on their child and supporting and empowering them in their advocacy is linked to improved outcomes. The authors point to studies which suggest that often, the transition has the potential to be successful, with the right perspective and strategies.

Persisting Difficulties at Home: Challenging Behaviour and Mounting Stress

Once Autistic children age out of early intervention services and transition to school, successfully or not, the uphill climb is likely to continue. O'Nions et al. (2018) point to the "significant complexity" (p. 1281) of mitigating and managing problem behaviour at home, which they classify into four domains: irritability, non-compliance, challenging behaviour, and anxiety. The authors note the extreme lengths to which parents go to adapt the environment and the demands on their child to keep the peace in their homes. Survival mode might be a less careful description of this phenomenon.

There are many facets of challenging behaviour. One study found that 25% of Autistic children engage in aggressive behaviour, but indicated that this number could be as high as 68% depending on the parameters of one's definition of thereof (Hill et al., 2014). Aggression can include that which is directed towards others and/or towards property. Hill et al. (2014) go on to state that aggression is often the primary reason for residential placement, and a source of great parental distress. Self-injury, such as self-hitting/biting/hair-pulling/scratching is another purportedly common challenging behaviour, with researchers estimating a 42% prevalence rate of self-injury among Autistic children (Steenfeldt-Kristenson et al., 2022). One study found nearly half of the Autistic children in the families they examined eloped (left their caregiver without notifying them), putting them at risk for drowning, a collision with a vehicle, and more, causing great anguish for their families (Anderson et al., 2012).

Although those behaviours are certainly among the most immediately dangerous, others can be equally challenging and deeply distressing for parents. Sleep difficulties, although not part of the diagnostic criteria, are common and a source of high levels of stress for mothers (Hoffman et al., 2008). Feeding challenges, such as highly restrictive eating, gastrointestinal issues, and pica are frequently present (Leader et al., 2020; Rogers et al., 2012). Autistic individuals are more likely to develop depression and anxiety than the rest of the population (Derguy et al., 2015), and have a high-risk profile for suicide (Richa et al., 2014). General irritability and disproportionate reactions to frustration (often described as meltdowns) were also noted in all the above literature as causes of discord in the home.

Unsurprisingly, the challenging behaviours of their children can lead to levels of stress so extreme that some parents report being unable to cope (Derguy et al., 2016; Hoffman et al., 2009; Silva & Schalock, 2011; Steijn et al., 2014). As mentioned in the introduction, Autism is commonly noted as more stressful to parents than other disabilities, which has no small impact on parental mental health. According to Schnabel et al. (2020), nearly one in five parents of children with Autism met the criteria for post-traumatic stress disorder. Parents also had higher rates of depression symptoms than that of the typical population, and more symptoms than parents of children with other disabilities (Steijn et al., 2014).

Mothers of Autistic children, however, are at particular risk for compromised mental health (Zablotsky et al., 2014). As mothers frequently end up being the default primary caregiver, given societal expectations (Brock, 2014; Dudley-Marling, 2001), coordinating supports and navigating siloed services take a toll, leaving mothers feeling exhausted, overwhelmed, and stressed. Seltzer et al. (2010) found in their longitudinal study of mothers parenting Autistic children that those whose children consistently engage in challenging behaviours have a physiological profile characteristic of those dealing with chronic stress, and likened their profile to that of combat veterans, Holocaust survivors, and parents of children with cancer. The lower cortisol levels found in the women studied are a biological marker of burnout and post-traumatic stress disorder (PTSD) and can lead to fatigue and attentional problems. According to Hodgetts et al. (2017), minimal research exists to examine how interactions with service providers can impact mothers' psychosocial wellbeing, an assertion that I can agree with based on the lack of research I was able to uncover on the topic, and noted in their research that there was a connection between wellbeing and continuity of services.

In addition, parents of Autistic children can be at risk for lower marital quality than the typical population (Harper et al., 2013), although other studies indicate that the collaboration required to parent their children can in fact bring couples closer together (Sim et al., 2019). Parenting their other, typically developing children is another sensitive task that requires careful navigation. Some research has shown that typically developing siblings are at risk for adjustment difficulties (Jones et al., 2019). Other large-scale studies suggest that this may not be the case, and that any negative impact on siblings may be assumed, but not well-supported by the evidence (Hastings & Petalas, 2014). In any event, effort beyond what they may have expected is needed to manage a healthy balance with their partners and their typically developing children (Woodgate et al., 2008).

Kabashima et al. (2020) suggest that promoting self-efficacy, or one's sense of their own ability to be successful, may be helpful to parents struggling with their children's challenging behaviour, and by extension, their own well-being. The authors describe parents with increased self-efficacy as better positioned to manage their children's difficulties. However, self-efficacy, according to the authors, comes from having experienced past success with strategies, thus creating a rather disempowering catch-22 for parents if they are not in fact managing well. Kurzrok et al. (2021) indicate that increased involvement with their child's interventions can increase parental feelings of self-efficacy.

The Gap Widens: Disability in the Family as a Form of Marginalization

While the experience of living with a disability is marginalizing, the associative marginalization of family members is not as well-documented. Parents of Autistic children report feeling isolated and excluded, due to reasons such as needing to bow out of social and family events, and/or reduce time spent at work and therefore in the company of colleagues, due to their child's difficulties (Kinnear et al., 2016; Woodgate et al., 2008). Experiencing stigma was reported by 95% of parents in Kinnear's study. While Gray (1993, 1997) suggested in a series of studies conducted in Australia that isolation was mostly self-imposed due to embarrassment caused by their child's behaviour and the subsequent judgement of others, a Canadian study conducted more recently found that parents were more likely to blame this isolation on a general lack of societal understanding (Woodgate et al., 2008). Broady et al. (2017) posited that since Autistic people lack obvious physical characteristics, and their disability is even less obvious when they are verbal, socially unacceptable behaviours such as meltdowns could be attributed by an uneducated bystander to simply bad parenting and/or behaviour. Regardless, it would seem that all possible scenarios and thus the exosystem that comprises societal perspectives and judgments on Autism has the potential to isolate both the child and the family. This may widen the perceived gap between the day-to-day reality of the lived existence of families with Autistic children and that of families with typically developing children.

Coordinating External Support

Despite the end of EIBI and the onset of public school, the need for additional services to support Autistic children continues. Furthermore, many services provided outside of school are home-based, which leaves mothers feeling intruded upon and often left with “homework” that infringes upon their already scarce time (Hodgetts et al., 2017).

Woodgate et al. note parent reports that service providers can be inaccessible, and at times unsupportive. The tendency for Autistic individuals to have co-occurring diagnoses results in increased need to access health care services, yet, parents report difficulty accessing services, thereby resulting in unmet physical and mental health care needs (Kogan et al., 2008). Care coordination is another challenge, given the multitude of services that Autistic children may access, and parents of Autistic children report this as a problem more often than parents of children with other developmental disabilities or mental health conditions (Vohra et al., 2014). While the IWK does have a complex care program, the criteria shut out Autistic patients without comorbid physical challenges (IWK Health, n.d.). Parents, therefore, become de facto care coordinators, navigating a complicated system, and quite likely without any education or training to do so effectively.

Coordinating respite care is another difficulty parents face. A Nova Scotia study conducted by Hutchinson (2010) found that many typical childcare arrangements and programs, such as summer camps, that free up parents are not accessible for parents with Autistic children. Respite care is critical, according to Hutchinson, be it for self-care, employment, time to focus on their other responsibilities and relationships, and/or simply take a break. Yet, all the participants in Hutchinson’s roundtable shared struggles involved with finding, training, and paying respite workers, an undertaking which falls on families to arrange. Nova Scotia’s

Department of Community Services does offer Direct Family Support, a program which funds respite care, but it is income dependent, and furthermore, requires the dependent to have an intellectual disability, long term mental illness, and/or a physical disability to qualify (Department of Community Services, 2024), thus excluding many Autistic participants.

Parents are also responsible for seeking out recreational opportunities for their children. In Halifax, inclusion support for summer camps and recreation programs through Halifax rec ends when children turn 12 (Halifax Rec, n.d.). This coincides with research indicating that participation in recreation, social, and leisure activities declines sharply for Autistic children at age 11, despite evidence of its importance for long term physical and mental health outcomes (Ratcliff et al., 2020).

In extreme cases, access to appropriate services may not even exist. While typically, literature reviews do not reference one's personal experience, this researcher personally experienced the limitations of services when my then-nine-year-old son was hospitalised for seven weeks after six months of extreme violence to himself and others, unable to attend school or any other supportive programming due to his behaviour. When he was set to be released from hospital, virtually unchanged and waitlisted for follow-up behavioural consultation, the only remedy suggested was to relinquish care (Leeder, 2017). Ultimately, after holding a press conference and going so far as to speak on camera to the prime minister, I was able to secure additional "enhanced family support" from the Department of Community Services to the tune of just over $4000 a month, every penny of which went towards hiring support workers which I personally trained to provide care and programming in our home. While I can report that my son is much improved, this level of support, which I personally manage, is ongoing. The extreme nature of my own son's case, which received significant media coverage, illustrates the extent to which some families must go to coordinate this often-elusive external support, and merits mentioning in this section.

Parent-School Relationships

As previously mentioned, enlisting parents as partners in education is a mantra, if not a fundamental value, of many education systems. Indeed, schools no longer operate within the mechanistic ideals of the past wherein school and home operated in separate silos (Price-Mitchell, 2009). Epstein (2010) refers to these silos as “spheres of influence” (p. 2). When the spheres of family, school, and community overlap, with the student (or better, according to Epstein, the *child*) at the centre, these partnerships strengthen and result in better outcomes for the child. However, despite the current research on parent engagement in schools being extensive, it is also mixed, as is the extent to which theory is put into practice.

Bourdieu was concerned with how education can perpetuate pre-existing inequalities (Rawolle & Lingard, 2008). Schools are infused with certain assumptions and expectations regarding what students bring to the table, and these implicit assumptions are frequently extended to families; in this case, that families possess the skills, knowledge, and capacity to fulfil their partnership role. Many families that are struggling to cope, let alone “engage in and support their child’s learning…work with the teacher and the principal to seek clarification and collaborate on solutions when questions arise with respect to their child’s education…[and] act as active members of their child’s Student Planning Team” (Government of Nova Scotia, 2019, p.5) are not meeting these expectations.

While much research indicates that parent engagement in schools is closely linked to better student behaviour, higher academic achievement, and enhanced social skills (Cheung & Pomerantz, 2012; Barnard, 2004), this is not a universal benefit. Parents at the higher end of the socioeconomic spectrum, who also tend to be those with the most cultural capital, are the most comfortable engaging with their children's education, according to Aurini et al. (2016). Those on the other end of this spectrum, however, do not feel as empowered to challenge authority and advocate on behalf of their children. Furthermore, children whose parents are less involved are more likely to face consequences for rule-breaking, unfinished work, and the like, presumably because their parents are less likely to intervene and make life difficult for the teacher (Calarco, 2020). This suggests that problematic inequities can emerge depending on the level of parent involvement.

If this issue is prevalent for typical students, it becomes exacerbated significantly when families are marginalised by association with their child's disability. Research indicates that parents of children presenting with behavioural and/or academic challenges are less involved than the parents of typically developing children (Aurini et al. 2016). Gwernan-Jones et al. (2015) report mothers of children with ADHD feeling "silenced and criticised", and Valle's (2011) research describes parents (again, mothers in particular) of children with learning disabilities being treated paternalistically, and in possession of perspectives too subjective to be valuable in the development of their children's IEP (Individualised Education Plan) goals.

Parent-school conflict in special education is well-researched and has become such a regular occurrence that in the United States, at least, there is an established federal procedure for dispute resolution (Mueller, 2015). More locally, Ontario has a published guide to resolve conflicts in special education (Ontario Ministry of Education, 2007), and the Halifax Regional Centre for Education has a Parent/Guardian Concern Policy (2021), albeit not specific to special education. Factors that escalate parent-school conflict in special education include the perception by parents that schools viewed their children from a deficit rather than a strengths-based viewpoint, an imbalance of power and knowledge, poor communication, excessive use of jargon, and disputes over resources, wherein the school's limited budget clashes with the parents' advocacy for the child's needs (Lake & Billingsley, 2000; Nowell & Salem, 2007).

When conciliation and collaboration fail, broken-trust relationships ensure. According to Lake and Billingsley, parents in broken-trust relationships "no longer maintained hope that the parent-school relationship had value in and of itself or provided benefit to the child" (p.248). Hoy and Tschannen-Moran (1999) define trust as "an individual's or group's willingness to be vulnerable to another party based on the confidence that the latter party is benevolent, reliable, competent, honest, and open" (p.189). Trusting relationships exist when school personnel suspend judgement, focus on successes, and show empathy and understanding for the parents' struggles. Distrust emerges when parents perceive the school is not meeting their children's needs, following recommendations, providing appropriate programming and accommodations, and/or failing to maintain confidentiality (Angell et al., 2009).

The pattern of these issues being exacerbated for families dealing with Autism continues to appear in the research. As this review of the literature has outlined, socioeconomic status is closely correlated to positive parent involvement, and families with Autistic children are often at an economic disadvantage (Santiago et al, 2022). Indeed, Santiago's research asserted that the socioeconomic status of a family was a factor in positive relationship quality between home and school, which suggests that when issues arise, parents in an economically disadvantaged position may not be able to address them constructively. In addition, Spann et al. (2003) noted comments from frustrated parents describing disagreements over such issues as how to address a behaviour problem; being "presented" with their child's IEP instead of being invited to collaborate on it; a lack of timely communication; and perceived insufficient efforts of the school in addressing IEP goals. Discouragement over these and other difficulties with the system results in parents "fighting for support", which unfortunately leads to declining trust on both sides (Stoner et al., 2005). Stoner and Angell (2006) found that when trust in educational professionals supporting their Autistic children declined, parents in their study were more engaged in negotiating for desired supports and close monitoring. Furthermore, those same parents demonstrated caution in expressing their trust, citing past negative experiences with professionals, and suggested they likely know more about Autism than the educational professionals.

It is important to note that not all families have a relationship with their Autistic child's school that is fraught with conflict. Parents have expressed appreciation for competent, accessible, trustworthy, and caring teachers who have their child's best interests at heart. (Boshoff, 2018). In Spann et al.'s study, despite the issues noted above, 80% of the parents reported high to moderate satisfaction with their child's education, and Stoner and Angell (2006) indicate that so long as trust is present, parents are happy to take on a more productive supporter/advocate role in tandem with the school team.

Conclusion

Autism is a complex, lifelong neurodevelopmental disorder which impacts most areas of functioning. Educational professionals seeking to support their Autistic students' education are responsible for only as long as the students are in their classes or schools. Mothers have been on the front lines since they first noticed something was different about their child. While the journey can bring love, joy, and new meaning and perspectives, it can also be a tireless endeavour, and one which is led primarily by mothers. Seeking a diagnosis, navigating early intervention services, and transitioning their children into the public school system is only the beginning. Challenging behaviour, often to the extreme, is ongoing at home, and mothers continue advocating for services and programming at school and externally. As the years go on, families can become increasingly marginalised and isolated from their various communities, and mothers, more so than fathers, are particularly susceptible to impacts on their mental health.

Balancing the many possible roles a mother of an Autistic child can have, as outlined here - among them, caregiver, advocate, negotiator, master planner-coordinator, co-therapist, recipient of stigma and exclusion, spouse, employee, parent - can lead to burnout (Kütük et al., 2021). Lin et al. (2023) defined burnout as "extreme exhaustion related to childcare, emotional distance from children, loss of enjoyment and efficacy in the parenting role, and comparison between past and present parenting selves" (p. 2). These authors suggested that mothers were more susceptible than fathers to burnout. Weiss (2014) sought to define crisis in this context, and described it as:

> an experience arising from an imbalance between the cumulative impact of numerous types of demands in one's life (e.g. child behaviour, family problems, and health problems) and the availability of external resources available to meet these demands (support, emergency services, and finances) (p.991).

It would appear based on what the literature tells us about the chronic and acute demands on mothers raising Autistic children, reaching the point of burnout or crisis seems like a strong possibility.

If there is a need to understand families holistically to establish trust (Summers et al., 2005), there is a need to acknowledge this reality. Yet, school systems and our society expect parents - mothers, in particular - to be heavily involved with their children's schooling, and possess the capital and skills to do so effectively and collaboratively. Herein lies the conflict. It merits restating what is written into Nova Scotia’s inclusion policy (2019), now that context has been provided:

> [parents will] engage in and support their child’s learning, support their child in attending school, maintain ongoing, regular contact with teachers about their child’s well-being, including their strengths, challenges, and interests…let the school staff know how they would like to be included in the discussion around their child’s well-being and achievement, work with the teacher and the principal to seek clarification and collaborate on solutions when questions arise with respect to their child’s education and to identify and eliminate barriers to their child’s learning, promote and value student voice and choice and providing opportunities for them to speak to their strengths and challenges, [and] act as active members of their child’s Student Planning Team (p.5).

It would appear that a gap exists between expectations and reality. The methodology chapter which follows will outline how I sought the perspectives of women who self-identified as reaching a point where they no longer met the gamut of assumptions, nor could they fulfil the breadth of responsibility heaped upon them. These stories are absent from the literature, which instead feature parents either meeting the expectations or encountering conflict. Who are these women, and why did they no longer identify as active participants in their children’s education? Understanding these questions, I believe, will lead school leadership to better engage all families in a constructive, holistic, and compassionate manner.

Chapter 3: Methodology

Introduction: Using a Qualitative Research Design

This thesis utilizes a qualitative research design to inform the chosen methods. Whitt (1991) argues that qualitative research is a holistic undertaking. Phenomena exist within a complex system, not in isolation. Approaching phenomena with pre-existing hypotheses runs the risk of inhibiting what a researcher may uncover as meaningful. As Eisner (1998) put it, we "seek what we know how to find" (p.186). Yilmaz (2013) defines qualitative research as:

> …an emergent, inductive, interpretive and naturalistic approach to the study of people, cases, phenomena, social situations and processes in their natural settings in order to reveal in descriptive terms the meanings that people attach to their experiences of the world (p. 312).

Given this is qualitative research, I made an effort to avoid approaching the research with preconceived notions of what it would uncover. Instead, I sought rich descriptions of the participants' lived experiences to derive meaning (Englander, 2012) and understand the subjective truths held by participants.

A positivist approach, which is dependent on observable facts, would not suffice to capture the complexity of the phenomena being examined. Maykut and Morehouse (1994) indicate that a positivist approach understands relationships as mechanical - "a one-way flow chart" (p.14) - in contrast to the alternative, which they describe as a holographic perspective: the webs of interconnection mean that if one aspect of circumstances is altered, the entire relationship is affected. The choice of research genre came down to the problem and the theoretical frameworks through which it is being explored. In this case, the problem is that some mothers of children with Autism are reluctant to engage fully with the education system, in conflict with the expectations of provincial policy and school personnel, and potentially to the detriment of the children's success. Reasons uncovered for this were expected to be manifold, and complicated. The exploration of the issue is framed by theories on ecological systems and nonunitary subjectivities. Qualitative research is therefore fitting for this topic as it comes from the epistemological philosophical tradition wherein meaning is subjective and co-constructed with participants, and causes are complex, intertwined, dynamic, and contextually dependent (Matta, 2022).

Using the Narrative Tradition

This qualitative research is carried out in the narrative tradition. Narrative research is concerned with meaning making from the telling of personal experiences (Casey, 1995; Riessman, 2005). "The main claim for the use of narrative in educational research," according to Connelly and Clandinin (1990), "is that humans are storytelling organisms who, individually and socially, lead storied lives" (p. 2). Indeed, the goal of qualitative research is not to provide a generalizable truth, but rather to tell a story within a particular context to uncover rich understanding. Certainly, different formats of information have their place in imparting knowledge, but the story is a powerful means of doing so. Stories are immersive and convincing, can influence a debate, and generate empathy in those who possess alternate viewpoints (Bortolotti & Jefferson, 2019). This research is a holistic undertaking in search of meaning through stories; hence, narrative inquiry fits the bill as the methodology of choice.

Moreover, the understanding I am seeking is unlikely to be uncovered in a linear fashion. There are no anticipated straight paths, narrow plotlines, or tidy conclusions here. Clandinin et al. (2007) encourage researchers to consider their narrative inquiry as taking place in a "multidimensional, ever-changing life space" (p.27). I suspected, based on the questions I was posing, that the stories would be a series of anecdotes in need of representation within a larger context. Narrative research satisfies this condition.

Clandinin and Connelly (1996) categorised stories as secret, sacred, and cover. While their research was centred around teachers' professional knowledge, the concept can apply to all the stories we tell. Secret stories are those we tell those closest to us, perhaps in confidence. Cover stories are how we present ourselves. Sacred stories are a bit more elusive, having their basis in theories and concepts which may be assumed but not necessarily articulated. The narrative tradition is a way to get past the cover stories, which are featured prominently in most of the research I examined, to reach the secret stories, and through analysis and evaluation of the results, uncover the sacred stories underwriting both. According to Polkingholme (2007), "personal descriptions of life experiences can serve to issue knowledge about neglected, but significant areas, of the human realm" (p.472). A significant body of literature exists on family-school relationships, Autism, and parental stress, as indicated in Chapter 2. My hope is for the stories here to fill the spaces in between, and for the stories have the power to construct new knowledge and understanding, thus adding value and depth to this ongoing conversation about how to best holistically support families.

Interdisciplinary Angles: Feminist Research

Feminist research is shaped by feminist theory and grounded in women's experiences (Ramazanoglu et al., 2002). Feminist research is also concerned with examining dominant discourses, so is therefore inherently political and concerned with inequality and emancipation (Bloom, 1998; Griffiths, 1999; Ramazanoglu et al., 2002).

Power imbues dominant discourses and informs knowledge throughout the macrosystem, and the dominant discourses relevant to this discussion are those which compel mothers, and not fathers, to assume the majority of caregiving duties, and embrace the role in the process, as the introduction and literature review outlined. Clandinin et al.'s (2007) aforementioned "multidimensional, ever-changing life space" as captured by narrative inquiry, coupled with the theoretical framework of nonunitary subjectivity, adds a feminist slant to the methodology. While the research here doesn't endeavour to dismantle any oppressive structures, the feminist interdisciplinary angle is an additional mechanism to highlight the participants' nonunitary subjectivities as they exist within a gendered social reality, as well as deepen and extend meaning assigned to any knowledge claims.

Methods

Sampling, Recruitment, and Informed Consent

This research uses extreme sampling (Creswell & Guetterman, 2019). The population I examine varies greatly from the norm. From least specific to most specific, this group is parents of children with Autism, then mothers of children with Autism, and finally, mothers of children with Autism who self-identified as having disengaged from their child's schooling. Creswell and Guetterman indicate that extreme case sampling is purposeful in that it focuses on outlier cases. Typically, this would be a difficult population to access, considering they may have already pulled away from institutions that may have broken their trust, as the literature review indicates, but I was fortunate. I indicated in my ethics application that I would recruit participants by various means: first via social media (posting on a local Autism parent support group) and then by reaching out to Autism Nova Scotia. I was prepared to go out of the community if needed. Social media followed by word of mouth turned out to be sufficient, and the participants were recruited with relative ease. Criteria were that participants had an Autistic school-aged child, and had either reduced or ceased interaction with their child's school team at some point. I forwarded recruitment letters and informed consent forms to the participants for their review, invited questions and concerns, and reminded them of their right to withdraw at any time.

Procedure

I collected data by corroborating two methods of data collection for purposes of triangulation, with the intent of increasing the credibility and strength of the research (Creswell & Guetterman, 2019). Carter et al. (2014) define triangulation as “a qualitative research strategy to test validity through the convergence of information from different sources” (p. 545).

First, I held a focus group with the participants. My hope was that a guided group discussion could feel less intimidating than a one-to-one interview, the interactions could stimulate new opinions and unexpected topics, and solidarity in circumstances could increase comfort levels, with the added benefit of collecting rich data in a short time period (Creswell and Guetterman). I also had the aim of capturing the interactions between the participants based on the topics brought up. The focus group, which was held virtually, was scheduled to last two hours. I was prepared to stop once saturation, or the point when little or no more relevant information was being revealed (Weller et al., 2018) had been reached, although conversations of substance continued until the last minute. Questions that guided the focus group can be located in Appendix C.

I then conducted one-on-one interviews with the five mothers, each of which averaged an hour in length. I first reviewed the transcript from the focus group to note the most intriguing comments that weren’t expanded upon in the focus group, and developed questions based on these insights to obtain more individualised perspectives and allow for elaboration on discrete experiences. The focus group and the interviews were audio-recorded and transcribed for later analysis.

Setting

The focus group and four of the five individual interviews were held virtually. All the interviewees noted the difficulty of coordinating childcare and other responsibilities to be present in person. It was challenging to find a time that accommodated all five of the female participants who agreed to take part in this study. The back-and-forth group email communications used to establish the focus group meeting served the unexpected benefit of bonding the participants over their shared, self-described "chaos". The fifth individual interview was held in person.

Data Analysis

I analysed the data by inputting transcripts from the focus group and interviews into Delve, a qualitative software program. I verified the transcripts for accuracy by re-listening and member-checking when I was still unsure of what was said. I then coded the raw data inductively by noting trends that emerged, noting these trends as themes, and coding accordingly. I used a constant comparative model for this process (Maykut & Morehouse, 1994) by grouping units of meaning and combining themes that overlapped, noting positive and negative instances thereof and eliminating any non-sequiturs. Focus group interview transcripts were further analyzed using interaction analysis (Keyton, 2018), as I positioned myself as an interpreter of what was being said, taking into account nonverbal communication such as tone and emotion, rather than simply transcribing the accounts, which is reflected in my description of the results. I developed a protocol prior to the meetings/interviews, but was flexible, because as expected, emergent design dictated which themes of interest appeared. The themes were then organized chronologically around significant life transitions that all mothers held in common, my focus being on interpreting the meaning of the experiences shared and tying them to larger exosystems, macrosystems, and chronosystems.

Clandinin et al. (2007) outline what they call the three commonplaces of narrative inquiry: temporality, which presumes that people, places, and events are always in transition; sociality, which is concerned with each individual's context (thus linking to Bronfenbrenner's ecological systems), and the physical place in which those stories take place. I used these commonplaces as touchstones in my analysis, a lens through which to see past the words being said, and as a means of guiding my focus through the rich descriptions provided by the participants.

My Role as a Researcher

My role in the research is to first acknowledge the multiple subjectivities I bring to my research due to my personal and professional experience. First, I am the mother of a profoundly Autistic teenager and truly understand the challenges that other mothers experience. As outlined in the literature review, I publicly led my family through navigating a crisis of our own. This established an innate connection to the experiences of the mothers I interviewed. However, I believe that this did not necessarily create a bias, but rather gave me an advantage, as it allowed me to be authentically empathetic, which Leake (2019) says is valuable to research for its role in helping to understand the perspectives and experiences of others. It minimised asymmetry, which helped me to gain access to the outlier population I needed to interview. Furthermore, according to the literature, many of these mothers lost trust in the "system" and can have faith that despite being part of it, I am also a safe person who "gets it" and is unlikely to judge any of the participants' experiences, choices, and/or confessions. In fact, this was reiterated more than once during the focus group and interviews I held.

My second subjectivity, and the primary inspiration for doing this research, is that I have been a teacher for twenty years, eight of which I spent as a learning centre and resource teacher.

A central part of this role was ensuring behavioural supports were in place in the classroom, given our inclusion policy dictates that students should be in the classroom to the greatest extent possible, and much of the supports and accommodations needed would have to be implemented by the classroom teacher. This involved a lot of coaching, and often, I would hear teachers' frustrations with the students' parents being vented and was present at many meetings where I bore witness to tensions between the teachers, administration, and mothers. Notably, I found this aspect of the job so stressful, and often felt so caught in the middle, that eventually I requested a move back to a classroom teaching position to escape it. This experience lends well to keeping an open mind regarding the perspectives of both sides.

My third subjectivity is that I have been a vocal advocate in the past in the Autism community, and have often been in the media, but want to be clear to readers and participants that this research is not connected to any of my advocacy efforts. Kemmis (2013) indicates that one of the features of critical action research is that it aims to empower participants to make improvements in their circumstances. This is not a goal of the research here. I made attempts to mitigate any misconceptions by indicating to participants in both the consent and debriefing script that this is not critical action research, nor was the research conducted for advocacy purposes, but rather conducted to gain insight into mothers' experiences.

Ethical Considerations

Ethical considerations are a primary consideration in this research, not an afterthought. I designed this research to maximize good outcomes for the participants and minimize any risk. There is a risk that the stories, which are unlikely to be entirely positive, could have long-lasting negative implications for the participant (Creswell & Guetterman, 2019), particularly if there is trauma involved in the retelling and reading of potentially painful experiences. Clandinin et al.

(2007) suggest that ethics need to be considered with particular care in narrative inquiry, as there is vulnerability inherent in reading one's own descriptions of difficult circumstances. My hope is that by gathering data firstly via a focus group and secondly in a 1:1 setting, I prioritized relationship building and established a safe space for participants to share their stories. All names used throughout this research are pseudonyms.

Limitations

Given this is qualitative research, I am not attempting any generalizable claims. However, I intend for the research to be credible by triangulating my data collection, rigorous and dependable by using multiple data analysis tools, confirmable by acknowledging my biases and subjectivities, and transferable by providing detailed descriptions of procedures and findings. I also used member checking by asking the participants to check the accuracy, fairness, and representativeness of my accounts, a request that all participants agreed to and proceeded without finding any conflicts with their memories.

The research is limited to the perspective of mothers and is intentionally context-specific. Father and teacher perspectives are not explored; however, this exclusion was intentional. I am interested in the unique experiences of caregiving mothers, which is separate from that of teachers, whose caregiving duties to their students are not lifelong, and separate from fathers, who have differing roles and expectations, as indicated in the literature review.

Perhaps the greatest limitation of this research is that none of the five participants fit any minority and/or marginalised category, beyond gender and that which occurs by association with their child's disability. None was of colour, a single mother, low income, LGBTQ2+, neurodivergent, or physically disabled. All were educated. The fact and possible implications of the participants' privilege, which they themselves acknowledge, as the results will show, is followed up on in the discussion and conclusion sections.

Chapter 4: Results

Pseudonyms

The five women recruited for this study and their children are referred to throughout with the following pseudonyms to protect their anonymity:

- Anna, son Harry
- Lucy, son Michael
- Mary, daughter Lily
- Sadie, son Owen
- Stella, son Theo

Organization of Results

Themes throughout this chapter are organized chronologically around significant life transitions that all mothers held in common. For further details on how themes were extracted, refer to the section on data analysis in the methodology chapter.

The Early Years

As initial conversations began in this research, and participants were first asked about their children, they led with their children's many wonderful qualities, and the deep love they felt towards them. They talked about their children's strengths, their special interests and hobbies, and the delight the children brought to their lives. Mary's daughter Lily loves to cuddle, and can replicate any song she hears on her piano by ear. Sadie's son Owen loves to swim. Anna describes her son Harry as resilient in the face of the many challenges he has, often masking to get through the day. Stella's son Theo has a great sense of humour and is very affectionate. Lucy describes her handsome son Michael as generally easy going.

There was an initial reluctance to share the less than positive aspects of their lives, and initially, the participants were quick to preface any comments on the difficulties they had experienced over the years with a qualifying “but I love him/her”, to which Sadie was quick to point out to the focus group:

> We can't say those struggles without having to follow it up with “but I love him”… even in this group where you know we all get it…we all know you love your child…but it's like when you need to talk about anything that you're struggling with, that you feel like you have to follow it up with but I [would] do anything for him, or…like you still have to justify that you still love them…I can't talk about [when] I'm having a hard time without saying… it could be worse, or you know, we're thankful for this….we shouldn't have to say that [when it’s what] a normal parent [does] when their kid has a tantrum…It feels like there's this different…tone. Where we can't. We can't fully express how we're feeling, because we feel like we would be judged.

Mary responded later, with (comedic timing omitted):

> I have a funny feeling. I’m not going to be judged.

Anna admitted:

> There’s this aspect…not knowing where you can ask for help and talk about it and be safe in doing so, you’re just supposed to celebrate everything. And you know what? I don’t want to celebrate everything. Some of this is very, very, unfair.

She added:

> I don’t know if other parents relate, but I often struggle with the political correctness around talking about parenting [my] child.

The other participants wholeheartedly agreed, and once it was clear that participants had a safe space to share their struggles, the floodgates opened, and participants were eager to share. All five children of the participants were diagnosed in the preschool years: three at two years of age, and two at four. While I was expecting the early part of our conversations to be more of a discussion about challenging behaviour and grappling with the emotions around a diagnosis, what dominated the conversation was the incredible pressure all participants felt to provide the best possible support for their children in the early years, and stress over the messaging from specialists about the imperative nature of early intervention. Rather than motivate the participants, this information appeared to set off tremendous anxiety. When asked about receiving her son's diagnosis, Anna recalled:

> It brings back so many bad memories of that, like [that] windowless room at the IWK and…[the] sick feeling of being told like you have like this bare minimum of time, because he's already 4…so you're like panicked…and it was up to the moms, like it was up to the moms.

Mary added:

> If you don't do this, you don't do [that]...their odds of, you know. Being able to develop and…have any gains in life, or [is] the window going to close?...I think I've just felt guilt all along. I'm…a failure.

Stella chimed in:

> I felt this incredible responsibility to make sure that I did everything right...[and that] I didn't miss anything. I felt like it all came down to me. And if I missed this crucial thing that was going to make [a] big difference for Theo or this one therapy that was gonna make him talk, or something like that, you know…and so I would stay up until 3 and 4 in

> the morning like researching because that's who I am. I research things and…I think back on the incredible pressure I put on myself to make sure that I didn't miss anything, or that, you know I didn't let him down. And I was trying to do every therapy, like we're doing physio and OT [occupational therapy] and speech, and we're paying for private services because he was on waiting lists for things. And you know…it's like you gotta do it before they're 5, because otherwise you [miss] your window. It's too late. And so there is this like incredible pressure. And we did everything.

This led to a discussion about their memories of the hospital's then-recommended reading for parents of newly diagnosed children, *Overcoming Autism: Finding the Answers, Strategies, and Hope That Can Transform a Child's Life* by Koegel and LaZebnik (2005). While Koegel et al. (1999) assert that "The ultimate goal of our pivotal response model [as used in EIBI] is to provide individuals with autism with the social and educational proficiency to participate in enriched and meaningful lives in inclusive settings" (p. 174) it appeared that this was not the interpretation of the participants. A reminder of the book hit a nerve. Sadie said:

> So think about that. Think about that title, and that's what they hand [you]....you're on the waitlist for EIBI now. And you're going to overcome autism. Right? You're gonna fix it. You're gonna get him over the hump…The goal is to not have Autism….to make them as normal as possible…not with my kid, not with my kid. No, absolutely not.

She later added:

> They know the theory, and they know what the textbook says works for the majority of people. But the arrogance from, you know, SLPs [speech language pathologists] that don't have children at all who are like, well, this, this will work. Do it this way, and then you know you do it that way. And then… it causes everyone stress, and it doesn't

> work…and it's too bad cause that kind of sets you up, right? That's like your first thing, and that's [where] they point you there like this is your saving grace. This is what's gonna help change direction. You put all this, all this emotion, feeling, into seeing a light, and then you do it, and it's like, what's the point of that.

Exacerbating the stress of managing the care and support of their newly diagnosed children was managing and attempting to find balance with typically developing siblings. Of participants' children, only Lily is an only child. Michael is one of three. Lucy said:

> [Michael's sister] was doing things at 2 that Michael wasn't doing at four…we're a busy family and I'm dragging the kids everywhere and taking [Michael's brother] to school…he was having…problems…yeah, I was very busy.

In Stella's family:

> One of the biggest challenges has been the balance…with our daughters, and I know some of you go through that, too, trying to find the space and the energy for them.
> So much of it is tied up in him like, and it's in a way that's quite different from our daughters…[Theo's sister] was only a year and a half older, so she just sort of [got] dragged around for appointments, her entire first 5…6, 7 years of her life. And she just talked to adults all the time because…that's all she did was go to appointments.

Anna added:

> I also have a daughter, and I try…[but] it's not enough time.

School: A Hopeful Beginning

It was clear that by the time the participants' children started school, it had been a long five years. Nonetheless, all of them described the initial transition to school as a source of cautious optimism, and I sensed a mild relief at the hope they could hand over at least one of the reins. My research showed that the early school years were a bright spot. Mary’s story is particularly poignant:

> Her learning centre teacher called me two days before school started, and she said, Mary…I'm going to be honest….I have worked with a child with cerebral palsy, who is fully functioning in the classroom, and I've worked with one person with Asperger's…I've never worked with anybody like Lily ever before…but I'm willing to learn. And if you're okay with this, I'd love to learn right alongside you, and I'm like, we're gonna be great friends. I cannot say enough about this learning centre teacher. She started with Lily in Primary and she left when Lily left Grade 6…She's actually just taken her first Autism specialist job this year…she's [designated in my will as] Lily's legal guardian.

Stella described Theo’s first introduction to school as similarly positive:

> I was so so over the top, like protective and involved when he started primary… I would go to school with him, and I would sit on one of the couches in the hallway like I wouldn't leave, and they wouldn't make me leave. They were so patient with me. I look back now and think I probably drove them crazy. But they were really kind.

The positives described by the participants involved a caring, flexible relationship with one or more staff members, and staff recognizing the needs of both child and family. In describing the relationship with one of Owen’s learning centre teachers, Sadie said:

> We had very open communication. She texted me throughout the day, if things were going on…We talked about his goals. And just when you get along with somebody, take an interest in the person, [it] just makes it just flow better, like the level of care.

All the women had entirely positive feedback about the educational programming assistants (EPAs) their children had over the years. Lily’s same-age peers graduated last year, while she stayed back. To this, Mary said:

> I am on like speed dial with her. EPA. We were texting tonight. [She] wanted to come over to the house on Thursday after the…graduation…She was working with Lily to go down with her [mortarboard] to try to have some sort of something for her. And so she was gonna come over and decorate and throw a little party. What her EPAs have done. They're the human face of all of this, at least in our experience…they get paid nothing. And yet they've had the most accountability, like in terms of actually wanting to deliver service in and outside of school for not just Lily, but for her family, too.

Sadie added:

> [The learning centre teachers are] not really the ones that implement anything…The EPAs are the ones that are there [on] the front lines. They're the ones that know our kids the best. And then you're not supposed to talk to them…I'm Facebook friends with our old EPA…like, I've had their phone numbers…It's so silly that the school thinks that you can put a person in your kid’s life that's like the most important person in the school, and then think that there should be no relationship at all, [it] baffles me.

Anna agreed:

> Exactly. They are the people that I feel are the most important to communicate with, but yet there are boundaries put in place.

She added:

> I don't know what the statistics are [but the EPAs] are vastly women, many who have a child who has a disability. Those are the people who get it.

Flexible administrators were praised as well. Stella:

> If I was going to pick out a bright spot, it would be some principals who definitely bent a lot of rules for us. Like most schools won't let you send in your own experts. And we [had] principals who did so. I appreciated that.

Persisting Difficulties at Home

Despite the challenging preschool years being over and their children having made a relatively smooth initial transition to school, difficulties at home persisted for the participants. In defiance of the intensity of what the participants described, they talked about their daily challenges calmly and objectively, even with humour at times, and with great compassion and understanding for their children. Lucy described the daily struggle of ensuring Michael is set up for success:

> I am the one trying to figure out what to do. All the time, constantly, second-guessing everything. And always make allowances for him, setting up so we could do things. And I just get really tired of doing that. I always have this like, background of planning. Well, we need an hour to get him ready for this. Yeah. So we need to be home by this time. And then we need to leave here. I can’t just grab him and say let's go, no, never.

Mary:

> The frustration out of not being able to communicate the way that she would like to be able to, and people not understanding what it is that she needs or she wants, she gets really frustrated, and that can result in a lot of self-harm or [harm] towards others. She's also super rigid…when she gets frustrated she can become very violent.

She described how this behaviour manifested during a failed attempt to visit family at Christmastime:

> Lily is 4 foot 10, [but] she can take down 2 or 3 adults like no problem…she took both of *us* down. She keeps [saying], "Montreal airport on the floor." I'm like, yep. We were all on the floor, girlfriend…I don't know, I think, unless you've lived it, you don't really, truly understand.

The caregiving burden at home is high for 18-year old Lily. She continued:

> It's hard to get to the regular laundry, because there's so much pee laundry that has to be done…so you're like stripping the bed and the mattress pad things…the rug was a poop place. Toileting is still a huge issue. We're having an OT come in hopefully in the next few months to kind of help us, because, like, you know, I'm still changing her diapers every night.

Anna's son Harry is the most verbal of the participant's children.

> I have a very, very verbal child. who also is OCD, so he's constantly asking you reassuring questions. And sometimes I feel like I can't breathe.

Sadie:

> He [does] not like other children, which has been a very big challenge for us throughout his entire life, because now we have a 2-year-old which has been quite interesting…we parent the kids in separate rooms. Honestly, there's never been a day…that they've been in the same room together for longer than like 2 minutes ever…We can't have one babysitter. We have to have 2…only we don't do that. Like the 2 babysitters for, like what? Going out to dinner? No, no. So it's challenging. It's our normal. It doesn't feel that weird.

Stella's son Theo presents with the highest support needs of all the participants' children.

> When he was 5 or 6, he was diagnosed with a genetic deletion on chromosome 10 that's

> super rare. And there was no one else out there with the same deletion…and then in 2020, with advances in genetic research, they did…some testing, and discovered that he has GRIN 2A, which is one of about 9 different GRIN disorders…and it turns out there are about 400 kids out there in the world with GRIN 2A.…Theo has developed just this year seizures on top of everything else.

She said later:

> It takes three people to get him to go anywhere…Theo became more and more challenging behaviorally as the years went on. And by the time he [was in] grade 4, grade 5 he was quite self-harming and [had to] have a helmet.

The Gap Widens

It appeared that as the years went by, and gaps between the children and their typically developing peers widened, the difficulties experienced by the participants seemed highlighted in comparison, and feelings of isolation, hurt, and exclusion increased.

Mary:

> Some of the things that they [talk about], you know, my son didn't make the triple A team. Whatever. And we're just…dealing with this in the house right now, [but] I get it, everything is relative.

Stella:

> My friends who have neurotypical kids… just don't get it, and like the things that they think are hard…I have a hard time not being really frustrated sometimes…sometimes the things that seem kind of mundane, and I know they are big deals in their lives. But even the people who are closest to me, [even] my closest friends and my closest family don't really get what we live. I don't feel like anybody really gets my kid, or really gets what's

> going on in our house.

Anna:

> I did not feel included by the other parents. I did not feel that the activities planned at the school, were inclusive of our son or our family.

Sadie talked about these feelings in the context of a recent EPA strike, when her son was unable to attend school.

> When the strike was on and Owen wasn't allowed in school [the] teacher was still sending out mass emails to all the kids in the class saying, oh, the kids had such a great day. Today we learned about this. We learned about that…we're getting ready to go on a field trip on Friday…I was so mad…even though I know she meant no harm. But it's like all these normal kids are getting to have their regular fun education.

Mary added, in a discussion about how summer and social media can sometimes make things more difficult:

> [Social media is] a little added layer. I try to stay off it some, because all this I'm scrolling through, and it's this fab beach day, [or] everyone's at the busker's festival. I'm so bitter and resentful.

Coordinating External Support

In addition to the challenging behaviours the participants were managing at home, bound up in complicated emotions, the women were all trying to coordinate external support and their children's health care needs. Frustration and guilt were dominating themes. Sadie talked about trying to get the right medication to help Owen. Notably, her insights were not considered until a third party joined the conversation:

> I always pushed for anxiety medication. But then the paediatrician's like well, we start

> with ADHD meds…They were awful, and it didn't work for him. And then our learning centre teacher talked to our paediatrician [and said] we really see a lot of anxiety in Owen, and then the paediatrician's like, oh, well, let's try anxiety medication. I'm like, I've been telling you this [for] like 2 years…The anxiety medication was a big, a big shift for him just because he was able tolerate so much more…if anything, I'm mad that it took so long to start it, because we could have made progress during those 2 years.

Lucy discussed trying to find recreational and respite opportunities for Michael.

> Respite workers move on all the time…It's hard…and now that he's well into the teens he outgrew the elementary age camps that he was doing. And I haven't made that transition to a lot of teen things that he had been doing. And I probably should.

Anna brough some levity when talking about finding Harry the right medication, after his primary teacher hinted at ADHD medication:

> We called him Donald Trump's Twitter account. I remember this little girl Sophie walked by and he was like, "Hi! Stupid hat, Sophie"…I was the one to go to his paediatrician…[and say] I think he has anxiety like, I don't think this is ADHD. I think he's so anxious. He's perseverating on things …[so] they were like, Oh, hmm!...Then he gets put on Zoloft, and like he's immediately [better].

Challenges at School

As difficulties mounted outside of school, it didn't take long for the school to stop being the saving grace the mothers hoped it would be. Mary's comment below framed much of the discussion:

> They one hundred percent do not understand the stress that special needs parents are under. They just don't get it. They see what's in front of them. They do not see the family

> as a whole.

Communication with school was a source of frustration for parents when they felt they were on the receiving end of only negative information, as well as too-frequent non-emergency communication. Anna said:

> If you are really engaged with the school, then there is more of a tendency in our experience to [be in] constant contact…like Harry did this today. Harry did that today…I would be getting 2 to 3 calls a day…like, Hey, do you have a minute?... It's like, no, I do not have a minute. I do not have a minute. He is your problem for the day, please fucking deal with it, and call me outside of school hours, because I am working…you know how many calls [my husband] got?...Zero.

Mary, a teacher, said:

> I get called a lot. You need to come get Lily. You need to get her. So…I'm like, do I even bother working anymore…? Or do we take her out and have respite for her?

She later added:

> When I'm in the middle of teaching a lesson, and I see my phone going…I have this complete psychosomatic-like reaction.

On the flip side, other participants felt that there were times when communication was far too minimal. Lucy said:

> I don't feel the school is in very much communication with me unless there's a problem.

Sadie often felt at a loss when communication was lacking:

> How else am I supposed to know what's happening in [Owen's] day, where he is at school for 5 or 6 hours…when he comes home, and he's in a bad mood, or he's really happy. I don't know. I don't know why. I have no idea why, and I've just kind of accepted

> that I'm not going to know, like not with this teacher…I'm not going to know.

Another significant problem faced by the majority of the women was the high turnover of learning centre teachers as well as the inexperience of staff. Sadie:

> [Owen had] 3, 4 Learning Center teachers in the last 5 years and only one of them ever really took interest in…kind of figuring out our life and that…made all the difference. She's a really good person. She really liked her job. [The kids] know when you're just doing your job as opposed to like really caring.

When Mary’s daughter was in junior high:

> Her learning centre teacher, who tried so hard, ended up getting bumped. And she had a learning centre teacher who just wasn't into it.

High school wasn’t much better:

> [Lily’s learning centre teacher] wasn't interested in being a learning centre teacher, but she didn't want to make a switch. She only wanted the kids that were higher functioning…[the high school] has literally been a dumpster fire, like so many learning centre teachers in and out, stressed. It's not a job for the faint of heart, there's no question, but they're just not getting the right people in for the kids that they've got…And I know that doesn't even matter, because it's all based on seniority…she ended up having 3 different learning centre teachers within 3 months in grade 10.

Lucy said the same:

> The school staff keep changing as well. Like maybe someone is really good. But then they leave. That happens. I understand. Inconsistency is a big problem…there were two full-time learning centre positions [at Michael’s junior high]…they were both doing full-time because there's quite a few kids. And they both said to me like this is not a good

> setup. Like they did not like it and they're both leaving. So they are moving to other schools next year after only a year. Yikes.

Theo’s experience in elementary school was perhaps the most extreme in this regard:

> We were just super unlucky. So from grade primary to grade 5, Theo had 9 different learning centre teachers…And every one of them had never been a learning centre teacher before…they’d come, and then they'd be gone by Christmas, and then we’d have another one. And so we felt like the entire time he was there the learning centre teacher didn't know him.

Sadie agreed with the importance of consistency, particularly when dealing with her nonverbal son:

> It's so important to get to know him. You just pick up on his little cues, and once you get them they're loud like, you can't miss the cues once you know them…now, because our learning teacher just said she's leaving..it's like, well, who are we going to get next year? They get better or worse. Now we have to tell them about Owen all over again. There's no stability at all.

Given staffing inconsistencies, cracks began appearing in the foundation of the programming the children were receiving. Stella:

> [His goals] were things that it was easy to say he did…it was like he participated in a group thing every day…but they weren't actually things that were moving him forward. They were time fillers, or they were accommodating comfortable schedules for them…And I'd say at the [meeting] hey, you know, he's used to using a visual schedule, could we do that? “Oh, that's a good idea.” And then the next IPP [individualised program plan] meeting, “Oh, yeah, we didn't do that.”

Lucy started to question some of Michael's programming:

> And when we had little meetings, I noticed that a lot of the skills and things that he was doing were like sorting things and bins, right? Matching things. But a lot of it was still paper, paper, paper. And when I talked to [his external support worker] she was kind of wondering, why is he doing all this paper stuff, which is a really good point, because I never thought about that before.

Specialist support, if and when it appeared, was also perceived as ineffective. Sadie said:

> The school dangles all these little things like, you know…speech therapy and OT… but you never get it. You never get it. And if you do, it's like once a year, and it's like a fake, inclusive world. There's nothing actually there. Window dressing.

Lucy agreed:

> I feel like the specialists have only limited availability to talk to me. Yeah, [they] hardly see Michael. The Autism specialist is hardly ever in the school. So it's not even like a recurrent meeting that we have. It's like twice a year you have this big discussion about things you're supposed to be doing [and I] don't feel like there's any follow up…so what's going on with that?

Stella:

> Even the speech language pathologist that was assigned to work with him did not do PECS [Picture Exchange Communication System] training. So she didn't know anything about PECS, and I had done the training twice, so I was literally going in there and trying to teach her about PECS. So…the speech-language pathologist couldn't teach the learning centre teacher how to do it. And then the learning centre teacher couldn't teach the EPAs. And so…we were paying people to go in. And I'm thankful that we have principals who

> allowed us to do that. But I think they recognized how desperate it was. We were just fortunate, I guess, but you know, we paid behaviour analysts…and various other people just to go in and work directly with the EPAs and teach them what we were doing at home and then, of course, after we invested all that time and money they just pull the EPA.

Navigating Difficulties

Despite building frustrations, the participants were determined to maintain a positive relationship with the school team. This involved pushing outside their comfort zone.

Sadie:

> I've learned to get a little bit louder. Get a little more pushy, and I hate that cause that's not me. It's not my personality at all.

Stella echoed this sentiment:

> I've struggled a lot because I care a lot about what people think of me, and…I'm very aware of those things and I'm quite intuitive. So I read people really well, and I don't like it when I feel like I'm being irritating or annoying. I have to be irritating and annoying a lot, and that's something that I find is really hard for me as a parent in this role.

To mitigate what the women perceived as risking their children being penalised for their pushiness, Anna took on an active role within the school.

> I wanted people to like me…I wanted teachers to like me. I wanted EPAs to like me. I wanted the school to like me so that…they would be nicer to Harry. So like I was like, [I'll] be on the SAC [school advisory council]. I will advocate for anything you want, because I want you to like me.

At times, the mothers accepted decisions they did not agree with and that were hugely inconvenient to keep the peace. Sadie's son was on a reduced schedule for a year, and in her words:

> I was just like, okay, what's gonna make everyone else happy like, instead of pushing for what can we do to keep him in school for the rest of the day, he went a whole year of coming home at 12, because we wanted to make things easier for everyone else.

The participants also shared frequently feeling negatively judged by the school team for some of their parenting decisions, as well as blamed for their child's difficulties and lack of progress. This took a toll on them. Lucy:

> I feel like I'm a failure for not being consistent…I don't even really understand how [the speech app] works myself. How can I expect to do it?...part of me would love for him to be better at that [but] I feel like this is another project for me…there's a huge amount of guilt. Yeah. So then if the child is not successful, it's easy for them to say well, the reason he's not using this is because you're not doing it at home…fine. But I would rather just cut up his food [for him].

Anna was blunt in describing how comments and questions feel loaded with judgement:

> Moms of Autistic kids. We can't fucking get it right? We just cannot. We are like pariah[s]…They're clearly not doing this, or like, maybe if [he was] on this [medication]...and does he get enough sleep? I hate that fucking question. You know, what time does he go to bed? He goes to bed at 7 o'clock. Typically, it's just these questions that nobody would ask typically developing kids' parents, never.

Mary added:

> Oh, yeah, they just let him do whatever he wants at home. It's like, you know what you

> trade places for a week and see if you're super skilled at this right?...I'm just like, you don't have a sweet clue what you're talking about.

Anna continued, bringing light to how the child might be at the receiving end of this friction:

> [I felt judged for] not doing what I should be doing at home to manage these behaviours. I felt as though the onus was on me to figure it all out…why is he doing this, like, why?...I'm so sorry, like the number of times I said. I'm so sorry, I'm so sorry that he did that…and then I'd be angry like he would get off the bus, and I'd be like, how did you do this; you know better?

When asked later what people might not know about her parenting experience, Anna said:

> How vulnerable you feel, the judgement you feel, the judgement, from teachers, from administration.

Despite their feelings of vulnerability and the pressure to maintain a positive relationship with the school team, all the women described themselves as reluctant advocates as the years went on. Assuming this role happened simultaneously with growing confidence. Sadie:

> We just started doing stuff that worked at home. And then I just kinda saw the progress at home. And I'm like, well, maybe they don't know everything. I don't know. It's just like a switch where…you get the confidence after being a parent for so long. Like okay, I've been an Autism mom for, you know, 7 years now, like maybe they don't know everything…I guess it was just more confidence…realising that…I do know my kid best.

Speaking up did not always come naturally to Stella, but it did come with emotional baggage:

> Sometimes I'm just so angry and fiery that I really don't care. And you know, other times it bothers me more.

There was also the pressure to remain dignified in the process, regardless of the inner turmoil the participants were experiencing. Anna:

> I put on a facade. I put on a show and wanted every[one] to think that it was all okay, that I seamlessly like, morphed into this role of parent advocate. I had it all together, like this was my journey, and, God, wouldn't give me anything I can’t handle, like all of the tropes, because I couldn't bear the pity.

Burnout and Declining Mental Health

As the years went on, four of the five participants admitted to a significant decline in their mental health. Anna used the word “profound” as a qualifier. One of the participants had been on medication for mental health challenges prior to having children, but three more confessed to starting antidepressant and/or anti-anxiety medication to help them cope. Sadie said:

> [My husband I have] had to do it because it was getting to the point where we both couldn't function. There were days where I was like, I'm just done, like I'm done….I'm not going to do it anymore.

Stella struggles with depression:

> My mental health has been poor…I've been depressed the last few years, and it's kind of forced me to step away a bit more and look at it. Therapy's been incredibly helpful, and it's been a way that I have taken care of myself…and I do think that it's been an important part of my journey. But I think I'm honestly still learning how to value myself…and not make Theo the centre of the universe…I definitely took on the project of Theo in full force. I'm recognizing in recent years that hasn't been so good for me.

Anna developed a substance abuse disorder. She was initially reluctant to talk about it for fear that she would be perceived as blaming her child for causing it:

> It is not my child's fault in any way, shape or form that my stress and anxiety [got] to such a point that I sought out unhealthy coping tools…[Nonetheless] the stress and the pressure and the stigma from external sources, all a hundred percent contributed to me abusing alcohol.

Mary experienced suicidal ideation:.

> I've been on the edge, like at different times, where I thought, today's the day. Yeah, I'm doing it today. Like, I'm I don't. I'm not doing this anymore. I'm not doing this life. I will get to see my mom and dad again. I'm just like I'm over it. I'm done, and then I'm like, Nope, I can't do that to [my husband], and I can't do it to Lily…But then I think about my privilege and about those families, those moms in particular *moms* [emphasis added]…I don't know how some of them are hanging on.

She added later:

> I just, never, ever, ever for the life of me thought that, being a parent I would struggle so deeply with mental health, like depression, suicidal ideation. And again, I don't know if it's just me, and I just have poor coping strategies, that I should really just be able to [handle this].

Anna experienced advocacy burnout. She explained:

> Throughout public school, we have been very vocal advocates for inclusive education, and it was exhausting…to have to advocate day in and day out for support for him.

Later, she added:

> There were moments where, like I almost broke…I have compassion for the parents who broke.

Participants danced around the topic of trauma. When asked, Mary said:

> I think I feel trauma every single day…even on the good days. Because I know what can happen, I know what has happened. And I'm never quite at ease.

Anna chimed in:

> What I'm starting to unpack in this whole process is that a lot of trauma has come out of this for a lot of us.

Follow-up Email and Member Checking

I sent a follow up email after the participants had a chance to review the results, asking them, as a means of extending my member checking: "Why are you less involved in your child's education than you were when they started in the public school system? I guess I am looking for your gut reaction to this question, not a well-thought-out response." Highlights from their responses are as follows.

Lucy:

> I don't have to micromanage school life and routine for my other kids, so why should I do it for Michael?...I feel like the more I engage with school staff, the more follow-up work I will have to do at home. No news is good news.

Anna:

> I am less involved in my child's education because I am burnt out and demoralised by the years of advocacy. Also, we are in the very privileged position to be able to send my son to a private school that accommodates his needs.

Mary:

> I am less involved in my child's education due to my own personal burnout over the years. I am also less involved because I feel there is no real planning for her - and I am tired of fighting the fight. They are warehousing her. However, my husband and I need

> her to attend so that we can both continue to work full time.

Sadie:

> Because I'm tired. Tired of having to beg for basic rights. Tired of the constant meetings and talks in which I'm told how bad my child is. Tired of feeling like an inconvenience. Because at the end of the day nothing ever seems to get better. The public school system is NOT set up for my son and all the kids like him. He will never thrive in a setting where the goal is to "make him like the others".

Stella was the only participant who didn't respond, but she had pulled Theo from school a decade ago. Her description of how she reached this point was one of the more intense moments in the research focus group discussion:

> We [were] having a meeting to discuss Theo. And he obviously had gotten into a behaviour situation and we watched him be dragged dead weight by his arms into the learning centre. Like he could have dislocated his shoulders for sure. And everybody just kind of stood there and watched it happen, and then they kind of dragged him into the corner…It was a corner with cement block walls…and he proceeded to sit there and smash his head against the cement wall…they all just kind of backed up and stood there and they were treating it like a you know, behaviour for attention, I guess, so [they] just ignore it…And I said, this is what you're gonna do…so I went over and sat behind him, because this is what I could do back then, because his head just kind of came to here [indicating chest height], and I sat behind him and wrap my arms around and…he flailed it and pulled my hair a bit, but that was pretty normal for us…and gradually it ended and he calmed down. But the entire time I was sitting with him…the behaviour specialist was saying, "somebody needs to get her to leave. This is not helping, you need to leave," and

> I was just ignoring her…and EPAs came and took him away. I was shaking…The vice principal met up with me in the hallway as I was leaving, and [asked], "So, how was the meeting?" I said, "I'm so angry I can't talk right now, but I will be in touch," and that was really the beginning of the end. I watched my son be physically abused at school, and then the people who are supposed to be the experts [told] me that I had no place.

Stella escalated her concerns as high as the Department of Education and Early Childhood Development, who suggested switching to another local school. When asked what would be different, the official was unable to give a satisfactory response, and suggested homeschooling as an option. Stella:

> I wouldn't be homeschooling Theo. He'd just be home, because he really wasn't doing academic work anyway. And so he just never went back. And no one ever looked for him.

Conclusion

The themes throughout this results section were organized chronologically around significant life transitions that all mothers held in common, and emerged as follow:

- The early years
- School: A hopeful beginning
- Persisting difficulties at home
- The gap widens
- Coordinating external support
- Challenges at school
- Navigating difficulties
- Burnout and declining mental health

In the next chapter, I endeavour to interpret the meaning of the results by tying them to larger exosystems, macrosystems, and chronosystems, with a feminist interdisciplinary angle as an additional mechanism to highlight the participants' nonunitary subjectivities as they exist within a gendered social reality.

Chapter 5: Discussion and Conclusions

Overview

This research sought to develop a better understanding of what mothers of children with Autism experience in the context of being educational partners in the school system, in hopes of better appreciating why some mothers disengage from the process. Exploration of this perspective was a gap in the current research. This chapter will discuss the findings in further detail.

Description of Findings

All five participants were adamant about protecting their children's dignity and approaching any discussion from a respectful, strengths-based perspective. They did not see themselves as victims, nor did they appear to view their children as a burden. The women threw themselves headlong into securing the best possible supports and interventions for the child from the moment of diagnosis. Despite some seeds of doubt being planted around the nature and motivation of some of the therapeutic strategies and philosophies, they persisted in trusting the professionals, often at the expense of their own well-being and quality time spent with their other children.

By the time the children started school, the participants remained mostly willing to trust, recalling many positives early in the experience, and a cautious optimism emerged. However, the challenges faced by the participants' children, and by default the families, continued to grow, and evolve. Sadness crept in as milestones passed unmet, and the gaps between the children and their typically developing peers were exacerbated. The women continued to struggle navigating the many silos required to support their children, juggling health care, recreational opportunities, and respite care. Simultaneously, cracks appeared in the foundation of the children's education, as participants experienced mostly good intentions but also inconsistent staff, a lack of understanding and training, communication conflicts, and questionable programming. Their own acculturation as people pleasers resulted in an avoidance of appearing “difficult”, and they often tiptoed around concerns while feeling blamed and judged. Nonetheless, they learn to speak up, albeit gently most of the time, and advocate for their children’s needs. Rather than engage in conflict with the school, these mothers appeared to ultimately withdraw out of self-preservation.

Eventually, stress and burnout got the better of the majority, and out of deep respect for their children as well as the taboos, they hesitated to confess, even in safe company, that their own children may have played a role in their mental health difficulties.

Synthesis of Findings

The above results corroborate what the literature already described, but added to this conversation and body of knowledge by bridging the space between maternal stress in families with Autistic children, and what we know about family-school relationships.

Returning to Bronfenbrenner’s ecological systems framework (1977, 1986, 1994), every layer thereof impacted the participants’ perspectives and journeys, both physical and psychological. The historical shift in the chronosystem created conditions for the participants where they felt pressure to celebrate their children at every turn. This was evident in the way that any difficulties the participants shared were, most of the time, carefully phrased and quantified to be respectful and positive about their children, in defiance of the incredible challenges they described. The macrosystem imposed gendered cultural norms that expected them, as women, to be the primary contacts, caregivers, and coordinators to manage their children’s needs, far beyond the expectations placed on their husbands. The macrosystem also socialised the participants to do so gracefully and courteously, regardless of how frustrated they were, and left them vulnerable to judgement from others and from themselves. The exosystem put up barriers in the form of government policies in health care, community services, and recreation mandating exclusionary and/or difficult to access services, requiring them to navigate complicated systems themselves; inadequate teacher training, which led to the mothers having to take the lead at times with their children's programming at school; and education and union policies that informed the distribution of school supports and staffing procedures, thus directly impacting the support their children received. The exosystem of the participants' workplaces were also impacted, as meeting their children's needs either caused frequent interruptions or required them to step away altogether. Their social groups were similarly affected, as they lamented that no one really understood what their day-to-day reality was like, and as years passed and contrasts between the children and their same-age peers were heightened, it became more difficult for them to relate to others and vice versa, thus pushing them further away from the shared experiences that bond networks of people. At the very centre sat the microsystems of their child's school and their home life. School often proved to be inconsistently supportive, with staff turnover, insubstantial access to specialists, and bureaucratic barriers limiting authentic interactions with frontline support staff clouding the experience. Expectations and goals were frequently misaligned with the reality of the family's circumstances as well as their own priorities for their children. The participants also sensed judgement from the school teams. Finally, the microsystem of home life was a day-to-day struggle of managing challenging behaviour that ranged from rigidity to violence: a struggle they oversaw while also attempting to manage their own mental health.

Viewing the results through the lens of post-structural feminist theory, and how the framework of nonunitary subjectivity informs how the participants came to understand their various "selves" (Bloom, 1998; Clark, 1999; Flax, 1987; Griffiths, 1995; Ramazanoglu &

Holland, 2002) provides deeper layer of understanding. The “selves” that emerged from and came to be defined by the participants’ various contexts within the ecological systems in which they found themselves – advocate, researcher, navigator, people-pleaser, martyr, et cetera - were ultimately the selves which were rejected. As the women progressed in their journeys, they became increasingly critical of these expectations, and evaluative of their sustainability.

Upon examination, mothers of Autistic children disengaging from the mesosystem that comprises the home-school relationship cannot be reduced to a singular cause. If considering the results within the framework of Clandinin et al.’s first commonplace of narrative inquiry - temporality - it becomes clear that while the fact of their unending love and devotion remained static, the participants’ outlooks, actions, and psychological well-being unfolded in the narrative as dynamic entities.

Most notably, experience gained from years manoeuvring through the web of ecological systems transitioned them from a nearly panic-stricken desire to “fix” their children and do everything right to a place of acceptance: acceptance of their children as they are; acceptance of a school system that seems unlikely to meet many of their needs; acceptance of the perceived futility of their efforts in all realms; acceptance that they would not necessarily be welcomed as valuable resources; acceptance of the impracticality of hyper-involvement at every turn; and acceptance of what was required for them to protect their own mental health. It can be claimed, however, that the narrative uncovered that disengagement was, counterintuitively, not on the opposite end of the spectrum from deep involvement, caring, proactivity, and commitment, but rather a result of the perspectives gained in the process, as well as the impact the journey had on the participants’ mental health. Acceptance, while it was not necessarily synonymous with inner peace, led, ultimately, to disengagement.

Implications for Practice

The current study highlights a number of relevant discussion points with implications for how educational professionals approach their expectations of mothers of Autistic children as members of school teams. Gloria Ladson-Billings first coined the term culturally responsive pedagogy (CRP) in 1995 as a framework to re-imagine educating and supporting students of colour and their families, but has since encouraged fluid interpretations of the concept (Ladson-Billings, 2014). CRP can serve as a lens through which educators can better understand the circumstances of mothers parenting Autistic children. According to Brion (2022), a lack of cultural proficiency within schools results in alienating families who are not part of the dominant culture. Our dominant culture is that of neurotypical families, one to which the participants do not belong. Much like colour blindness, once considered an enlightened view, is now well-established as a form of racism denial, ignoring the incredible difficulties inherent in raising an Autistic child limits the understanding necessary to forge a productive relationship based in consideration and compassion. This requires educators to prioritise developing authentic relationships, and being vulnerable to parents by acknowledging limitations in their scope of knowledge about Autism and the impact it has on families. Lavín et al. (2021) stated:

> …we tell our teachers that relationships matter, yet we often fail to outline a rationale for why they matter, or how to build, develop, and leverage those relationships for the betterment of children and families. (p.11)

The same researchers also encourage reflexive practice, wherein educators reframe dominant narratives such as “This mom clearly does not care,” by considering, “Am I understanding the situation this family is going through? Is the school supporting this student and their family’s needs?” (p.13). As the results of this thesis showed, the participants did not feel that all educators were engaging in this practice, a relatively simple yet effective cognitive exercise that suspends judgement in order to seek understanding through empathy. Perhaps instead of assuming a mother can't be bothered to reinforce an IPP goal at home and viewing her as an obstacle to progress, it would be better to consider if the goal is aligned with her family's priorities and values, if she trusts that the goal was suggested by a someone who knows her child well, or maybe, if a simple and reassuring positive email about her child's progress is in order.

The Centre for Addictions and Mental Health defines trauma as "the lasting emotional response that often results from living through a distressing event" (2024). The participants in this study used the word traumatic as a descriptor for their experiences. Nova Scotia promotes a trauma-informed approach in public school classrooms (Nova Scotia Department of Education and Early Childhood Development, n.d.) as a means of better supporting students. However, this same lens is not applied to families, at least not in writing. Venet (2023) proposed a new definition of trauma-informed practice within the context of education as such:

> Trauma-informed educational practices respond to the impacts of trauma on the entire school community and prevent future trauma from occurring. Equity and social justice are key concerns of trauma-informed educators as we make changes in our individual practice, in classrooms, in schools, and in district-wide and state-wide systems (p.10).

Individual teachers, school leaders, and policy makers should be aware of the ecosystems, macrosystems, and chronosystems that have cooperated to impede the wellness of some parents in their school community, and if they are not in a position to dismantle these systems and rewrite policy to make it more accessible, they should at a minimum remove any barriers they may have inadvertently set up within the microsystem, such as judgement, unreasonable expectations, and imposed values.

School leadership should consider how their expectations of parental involvement may require readjustment for parents of Autistic children. Epstein and Sanders (2006) identified six types of parent involvement: “parenting, communicating, volunteering, learning at home, decision making, and collaborating with the community” (p.87). It merits consideration that these types of involvement may not be inclusive or practical for parents in similar circumstances to the participants in this study, and that this actuality is not indicative of indifference. It can be difficult for families to bring an Autistic child to their school’s Spring Fling, Family Bingo Night, prom, holiday concert, and other such noisy, chaotic, and unpredictable events. Exclusion from these types of events, while it was not explicit, was nonetheless sensed by the participants. Parents ascribe importance to the role school leadership plays in setting the tone for school-family relationships, the building and maintaining of which has particular importance for vulnerable families (Barr & Saltmarsh, 2014). School leaders should make every effort to understand the individual situations of families, and think creatively and inclusively about how to ensure all families feel connected to, included, and supported by their child’s school community.

Overall, school leadership should reflect on whether they are cultivating a school culture of simple balance and compromise, thus maintaining the status quo, rather than an accommodating culture that yields and supports (Gorton & Alston, 2009). An accommodating culture may require transformational leadership. Transformation leadership is about using leadership skills to bring about positive change and reforms (Berkovich & Eyal, 2017; Day et al., 2016; Wilson Heenan, 2023). By helping their school commit to reframing their understanding of and empathy for families managing Autism, and transform this into action, school leadership will need to be transformative.

A challenge that arose on multiple occasions during discussions was the high turnover of learning centre teachers, which had an impact on the ability of staff members to develop relationships of substance with both the participants and their children. It is worth noting that Nova Scotia's most recent teacher collective agreement (2019) allows for 38 positions within the regional centre known as "10.04" contracts. These contracts require a three-year commitment to the position accepted in order to provide consistency in schools known for high rates of turnover (25% and above) and "high needs" schools, where a large number of families have lower socioeconomic status, and are not filled according to seniority, thus allowing more flexibility with hiring practices. The current research suggests that it would be ideal to consider similar contract parameters for all learning centre teachers, regardless of school.

The participants noted similar frustrations around consistency with EPAs, whose positions were correspondingly unstable. Furthermore, the participants frequently noted feeling blocked in an official capacity from communicating openly with their children's EPAs, and usually found a way to circumvent this. The EPA job description on the Halifax Regional Centre for Education's website (Halifax Regional Centre for Education, 2022) indicates that the position requires little in the way of qualifications, beyond high school graduation and first aid. Notably absent from the specific job components is any mention of parent communication, a task which falls to the classroom and learning centre teachers. While teaching assistant programs do exist in Nova Scotia, it does not appear that completion of such programs impacts pay or scope of responsibility, only that such a program would be considered an "asset" (Halifax Regional Centre for Education, 2022). This raises questions about whether professionalizing the career of teaching assistants would serve to increase the scope of responsibility, thus allowing for greater parent contact, and potentially stabilize the occupation. While I acknowledge that these would not be simple policy changes to implement, they could serve to provide more consistency and positive conditions for relationship building, which this research suggests is needed.

Conclusions, Limitations, and Future Research Directions

The current research found that the mothers of Autistic children examined here disengaged from their children's school teams after years of experience, intense efforts, discouragement, cumulative stress, and perspective shifts. School leaders should consider that any promotion of re-engagement needs to transpire through a culturally responsive, trauma-informed lens that prioritises relationship building, empathy, and suspended judgement.

While the research highlighted valuable points about how school teams can support families in such challenging circumstances, there are limitations to consider. The first is the small sample size. While every effort was made to make the research confirmable, credible, rigorous, and transferable, the sample size, in combination with the nature of qualitative research, means that these claims are not meant to be generalizable. Secondly, this research did not consider the perspectives of educators struggling to re-engage families. Including these perspectives could provide an evidence-based foundation from which to proceed with future research in this area. Thirdly, as Ramazanoglu & Holland (2002) noted, "knowledge from a feminist standpoint is always partial knowledge" (p.66). Research centred on the perspectives of fathers is limited in scope, and if conducted, could add to the body of knowledge in this domain, as well as provide a potentially contrasting - or confirming - point of view. Finally, as noted in the methodology chapter, this sample featured five women who were white, cisgender, heteronormative, neurotypical, able-bodied, educated, financially stable, and in long-term partnerships with the fathers of their Autistic children. The participants regularly checked their privilege throughout the discussions we had. While this may be a shortcoming in the research, it could also be viewed as highlighting that even in the absence of systemic marginalisation (excluding the disability in the family unit), this journey is a challenge even in the most ideal of situations, and we can infer that with other challenges present, the hardship could be yet more extreme. Future research should consider examining the experiences of women without the advantages of the participants featured here.

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Appendices

Appendix A: Informed Consent Form

Title: When mothers disengage: stories from women who have gone from participants to observers in their Autistic child's education

Researcher: Carly Sutherland, Memorial University, Graduate Department of Education. cjsutherland@mun.ca / 902-430-3928

Supervisor: Dr. Sharon Penney, Memorial University, Faculty of Education. scpenney@mun.ca

You are invited to take part in a research project entitled *When mothers disengage: stories from women who have gone from participants to observers in their Autistic child's education*. This form is part of the process of informed consent. It should give you a basic idea of what the research is about and what your participation will involve. It also describes your right to withdraw from the study.

In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is the informed consent process. Take time to read this carefully and to understand the information given to you. Please contact the researcher, Carly Sutherland, if you have any questions about the study or would like more information before you consent.

It is entirely up to you to decide whether to take part in this research. If you choose not to take part in this research or if you decide to withdraw from the research once it has started, there will be no negative consequences for you, now or in the future.

Introduction:

I am a graduate student at Memorial University, working towards my master’s degree in educational leadership. As part of my Master’s thesis, I am conducting research under the supervision of Dr. Sharon Penney.

Purpose of study:

The purpose of this study is to develop a better understanding of what mothers of children with Autism experience in the context of being educational partners in the school system, in hopes of better appreciating why some mothers disengage from the process, and how school leadership teams can facilitate re-engagement to better support families.

What you will do in this study:

If you decide to participate in this study, you will participate in a focus group and a one-to-one interview to discuss your experiences with the school system. The focus group and interview are each expected to take approximately one to two hours, depending on the group and the nature of the conversation.

Compensation:

As an incentive for participating in this study, a $50 donation will be made to Autism Nova Scotia in your name.

Withdrawal from the study:

You have the right to withdraw from the study at any point without explanation or penalty.

If you withdraw consent, you can request within the next 30 days in writing that your data be destroyed.

Possible benefits:

Participants in this study have the opportunity to reflect on the broken-trust relationships with their child's school team, as well as hear and share stories from others in similar situations to reduce feelings of marginalisation.

There is currently a gap in the existing literature that features voices from this group. I hope the research will construct meaning and understanding about mothers in this unique position experience. Ideally, school leadership facilitating the home-school partnership will be provided with a frame of reference centred around compassion and trauma-informed practice to apply to future interactions and relationship-building opportunities.

Possible risks:

There is a risk that the stories, which are unlikely to be entirely positive, could have negative implications for the participant, particularly if there is trauma involved in retelling and hearing difficult experiences.

Throughout the research, I will ensure informed participation and make every reasonable effort to ensure anonymity to establish a safe space for participants to share.

Before the focus group and interview, you will be provided with information on where you can access mental health support should the experience is distressing.

Confidentiality:

The ethical duty of confidentiality includes safeguarding participants' identities, personal information, and data from unauthorised access, use, or disclosure.

By signing this consent form, you agree not to share the stories of other participants outside of the group, and this is outlined in the consent form. Although I will safeguard the confidentiality of the discussion to the best of my ability, the nature of focus groups prevents me from guaranteeing that other members of the group will do so. Please respect the confidentiality of the other members of the group by not repeating what is said in the focus group to others, and be aware that other members of the group may not respect your confidentiality.

The only situation where confidentiality has limitations is in cases where there are concerns of abuse and/or neglect. Every individual in the province of Nova Scotia has a legal obligation to report concerns of abuse or neglect of a child under the age of 19 in order to ensure children are protected from harm. Failure to report is a criminal offence.

Anonymity:

Anonymity refers to protecting participants' identifying characteristics, such as name or description of physical appearance. Your identity will be known to others in the focus group; however, pseudonyms will be used in the thesis and when inputting into data analysis software, no identifying characteristics will be used.

Please note that because the participants for this research project have been selected from a small group of people who may be known to each other, it is possible that you may be identifiable to other people based on what you have said.

<u>Every reasonable effort</u> will be made to ensure your anonymity.

If you prefer not to remain anonymous in the reporting, this is an option so long as it does not negatively affect or identify other participants who wish to remain anonymous in the reporting. You will not be identified in publications without your explicit permission (see the last page of this consent form).

Use, access, ownership, and storage of data:

All focus groups and interviews will be audio recorded. Data will be stored in a password-protected computer within a password-protected data analysis software program. Any handwritten field notes will be kept in a locked filing cabinet in my home office until they are transcribed electronically, after which they will be destroyed.

The data will be converted to print and safeguarded for five years after the research is complete as required by Memorial University's policy on Integrity in Scholarly Research. It will be kept in a locked filing cabinet in my home office and the only individuals with access to the data are the researcher and supervisor.

Third-party data collection and/or storage:

Data collected from you as part of your participation in this project will be stored electronically by the qualitative software program *Delve*, and is subject to their privacy policy, and to any relevant laws of the country in which their servers are located. Therefore, anonymity and confidentiality of data may not be guaranteed in the rare instance, for example, that government agencies obtain a court order compelling the provider to grant access to specific data stored on their servers. If you have questions or concerns about how your data will be collected or stored, please contact the researcher and/or visit the provider's website for more information before participating. The privacy and security policy of the third-party hosting data collection and/or storing data can be found at: https://delvetool.com/privacy-policy

Any interviews or focus groups conducted virtually will be recorded via Webex. Recordings will be deleted after transcription. Webex's privacy policy can be found here: https://trustportal.cisco.com/c/dam/r/ctp/docs/privacydatasheet/collaboration/cisco-webex-meetings-privacy-data-sheet.pdf

Reporting of results:

The data will be aggregated and summarised in a thesis, which will likely have direct quotations from participants. The thesis will be available at Memorial University's Queen Elizabeth II Library, and can be accessed online at: http://collections.mun.ca/cdm/search/collection/theses.

Findings may be shared at teaching conferences or with other stakeholders.

Sharing of results with participants:

Participants will be provided with an electronic copy of the thesis upon completion and will be advised of any additional future instances when findings will be shared (e.g. conferences).

Questions:

You are welcome to ask questions before, during, or after you participate in this research. If you would like more information about this study, please contact the researcher, Carly Sutherland, at cjsutherland@mun.ca or 902-430-3928, or the supervisor, Dr. Sharon Penney, at scpenney@mun.ca.

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research, such as the way you have been treated or your rights as a participant, you may contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at 709-864-2861.

Consent:

Your signature on this form means that:

- You have read the information about the research.
- You have been able to ask questions about this study.
- You are satisfied with the answers to all your questions.
- You understand what the study is about and what you will be doing.
- You understand that you are free to withdraw participation in the study without having to give a reason, and that doing so will not affect you now or in the future.

Regarding withdrawal <u>during</u> data collection:

- You may stop or withdraw your participation during the focus group and/or interview at any time.
- You understand that if you choose to end participation during data collection, any data collected from you up to that point can be removed from the study within 30 days.
- A donation will still be made to Autism Nova Scotia in your name.

Regarding withdrawal <u>after</u> data collection:

- You understand that if you choose to withdraw after data collection has ended, your data can be removed from the study within 30 days after your data collection is complete.
- A donation will still be made to Nova Scotia in your name.

I agree to the use of direct quotations Yes No

I allow my name to be identified in any publications resulting from this study Yes No

By signing this form, you do not give up your legal rights and do not release the researchers from their professional responsibilities.

Your signature confirms:

I have read what this study is about and understood the risks and benefits. I have had adequate time to think about this and had the opportunity to ask questions and my questions have been answered.

I agree to participate in the research project understanding the risks and contributions of my participation, that my participation is voluntary, and that I may end my participation.

A copy of this Informed Consent Form has been given to me for my records.

Signature of Participant	Date

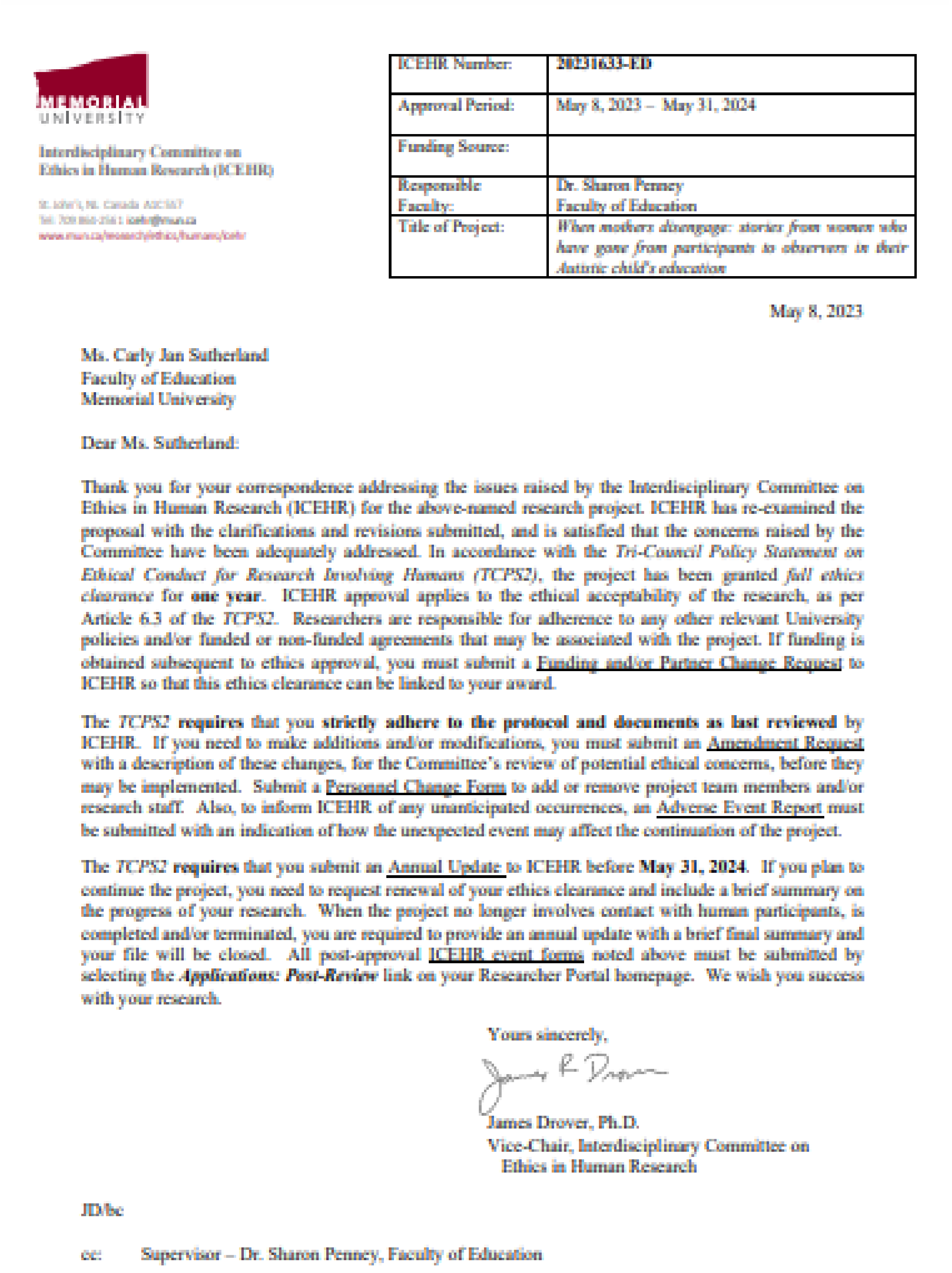
Researcher's Signature:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

Signature of Principal Investigator	Date

Please retain a copy of this consent information for your records. A PDF copy of the consent form will be emailed to you.

Appendix B: Ethics Clearance



MEMORIAL UNIVERSITY

Interdisciplinary Committee on
Ethics in Human Research (ICEHR)

St. John's, NL Canada A1C 5S7
Tel: 709 864-2561 icehr@mun.ca
www.mun.ca/research/ethics/humans/icehr

ICEHR Number:	**20231633-ED**
Approval Period:	May 8, 2023 – May 31, 2024
Funding Source:	
Responsible Faculty:	Dr. Sharon Penney Faculty of Education
Title of Project:	*When mothers disengage: stories from women who have gone from participants to observers in their Autistic child's education*

May 8, 2023

Ms. Carly Jan Sutherland
Faculty of Education
Memorial University

Dear Ms. Sutherland:

Thank you for your correspondence addressing the issues raised by the Interdisciplinary Committee on Ethics in Human Research (ICEHR) for the above-named research project. ICEHR has re-examined the proposal with the clarifications and revisions submitted, and is satisfied that the concerns raised by the Committee have been adequately addressed. In accordance with the *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (TCPS2)*, the project has been granted *full ethics clearance* for **one year**. ICEHR approval applies to the ethical acceptability of the research, as per Article 6.3 of the *TCPS2*. Researchers are responsible for adherence to any other relevant University policies and/or funded or non-funded agreements that may be associated with the project. If funding is obtained subsequent to ethics approval, you must submit a Funding and/or Partner Change Request to ICEHR so that this ethics clearance can be linked to your award.

The *TCPS2* **requires** that you **strictly adhere to the protocol and documents as last reviewed** by ICEHR. If you need to make additions and/or modifications, you must submit an Amendment Request with a description of these changes, for the Committee's review of potential ethical concerns, before they may be implemented. Submit a Personnel Change Form to add or remove project team members and/or research staff. Also, to inform ICEHR of any unanticipated occurrences, an Adverse Event Report must be submitted with an indication of how the unexpected event may affect the continuation of the project.

The *TCPS2* **requires** that you submit an Annual Update to ICEHR before **May 31, 2024**. If you plan to continue the project, you need to request renewal of your ethics clearance and include a brief summary on the progress of your research. When the project no longer involves contact with human participants, is completed and/or terminated, you are required to provide an annual update with a brief final summary and your file will be closed. All post-approval ICEHR event forms noted above must be submitted by selecting the ***Applications: Post-Review*** link on your Researcher Portal homepage. We wish you success with your research.

Yours sincerely,

James R Drover

James Drover, Ph.D.
Vice-Chair, Interdisciplinary Committee on
Ethics in Human Research

JD/bc

cc: Supervisor – Dr. Sharon Penney, Faculty of Education

Appendix C: Guiding Questions for Focus Group

- Tell me about your child.
- Tell me about your experience as a parent.
- In what ways do you believe the education system has served your family's needs?
- In what ways has the education system failed to serve your child's needs?
- Under what circumstances would a more collaborative relationship with your child's school be more likely?
- In what ways could leadership within our education system better serve families like yours?

Appendix D: Recruitment Letter

My name is Carly Sutherland, and I am a graduate student in the Department of Education at Memorial University of Newfoundland. I am conducting a research project called *When mothers disengage: stories from women who have gone from participants to observers in their Autistic child's education* for my master's degree under the supervision of Sharon Penney. The purpose of the study is to develop a better understanding of what mothers of children with Autism experience in the context of being educational partners in the school system, in hopes of better appreciating why some mothers disengage from the process, and how school leadership teams can facilitate re-engagement in order to better support families.

I am contacting you to invite you to participate in a focus group and an interview, in which you will be asked about your personal experiences as partners with your child's school team. Sessions will be held in person at a local community room or virtually, depending on the needs of the participants, and will be recorded.

The focus group is expected to be 1-2 hours in length, and the interview approximately one hour.

Participants should have a school-aged child with Autism, and have reduced or ceased interaction with their child's school team at some point in their educational career.

If you are interested in participating in this study or have any questions about this project, please contact me via phone or email: cjsutherland@mun.ca/902-430-3928.

If you know anyone who may be interested in participating in this study, please give them a copy of this information.

Please note that this study is not a requirement of any organisation(s) distributing it on my behalf.

Thank you in advance for considering my request,

Carly Sutherland

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research, such as your rights as a participant, you may contact the Chairperson of the ICEHR at icehr.chair@mun.ca or by telephone at 709-864-2861.

Appendix E: Debriefing Script

Thank you for taking the time to participate in this study. The purpose of the research is to to develop a better understanding of what mothers of children with Autism experience in the context of being educational partners in the school system, in hopes of better appreciating why some mothers disengage from the process, and how school leadership can facilitate re-engagement.

Given that you may be discussing your own difficult experiences and listening to those of others, the subject matter has the potential to trigger emotional reactions. Oversharing is always a possibility. Please know that you have the right to withdraw at any point without needing to provide an explanation.

Although the researcher will safeguard the confidentiality of the discussion to the best of his/her ability, the nature of focus groups prevents the researcher from guaranteeing that other members of the group will do so. Please respect the confidentiality of the other members of the group by not repeating what is said in the focus group to others, and be aware that other members of the group may not respect your confidentiality.

If you find the experience of sharing and hearing these stories distressing, the Provincial Mental Health and Addictions Crisis Line can be accessed 24/7, toll-free, at 1-888-429-8167. Crisis is self-defined by the individual calling for support.

Thank you again for your time and valued contributions. My hope is that the information you share will be used to inform school leadership and teams about how to better support the challenges facing families like yours.