Parents' Perceptions of Their Involvement in the Specialized Support Their Autistic Children Receive in Nova Scotia, Canada

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Abstract

The specialized support offered to autistic children during their early years, along with their families, has experienced considerable transformations over the past decade. The approach behind specialized support has shifted from a traditional paradigm rooted in biomedical knowledge to one emphasizing the family capacity-building paradigm. In practical terms, services are evolving from a professional-centered framework to a family-centered approach. This qualitative study aimed to explore parental experiences regarding their involvement in services that provide support to autistic children in Nova Scotia. A total of four parents of autistic children under the age of six participated in an online semi-structured interview. A reflexive thematic analysis was conducted, identifying four categorical themes: involvement in programming and decision-making, barriers experienced by families, and opportunities in specialized autism services. The findings provided valuable insights into the role of parents of autistic children navigating autism services in Nova Scotia. Parents described their experiences in navigating services with minimal involvement, wherein practitioners assumed the leadership and guidance of the decision-making process. Moreover, parents reported several challenges in accessing and navigating specialized services, which were particularly heightened for one parent living in a rural area of Nova Scotia. Parents shared significant insights and strategies for actively engaging in services to support their autistic children during early childhood. Thus, the perspectives of parents are crucial for the formulation of high-quality services tailored to the unique realities faced by each family with an autistic child.

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Finally, I want to take a moment to thank each parent who contributed to this research with your enthusiasm for sharing your invaluable experiences. Your voices brought crucial insights that will resonate with many families and service providers. I am confident that your perspective will be essential in fostering respectful approaches to autism services in Nova Scotia.

Language Statement

The term autism has evolved over the years, and the use of language has been crucial for understanding and supporting autistic people (Monk et al., 2022), also known as Autism Spectrum Disorder, which is the current terminology used for diagnosis in clinical contexts (American Psychiatric Association, 2022).

The author of this research holds in high regard the diverse language preferences of readers. I also want to share that my preferred language utilized throughout this study is identity-first language, which means autistic person or simply autists. Identity-first language recognizes individual strengths and embraces autistic characteristics as a part of the spectrum of human diversity.

Specialized support, specific support, and early care are terms that are preferred instead of early intervention. Intervention is a concept aligned with the traditional biomedical model, which depicts autism in terms of deficits or a lack of skills (Monk et al., 2022).

Chapter 1: Introduction

Autism, or Autism Spectrum Disorder (ASD), is a neurodevelopmental condition involving challenges in more than one development domain observed from early childhood; these domains include barriers in social communication and interaction across multiple contexts and patterns of behaviours focused on specific interests or activities which are restrictive and repetitive as a feature (American Psychiatric Association, 2022). Nevertheless, the expression of autistic characteristics varies for each autistic person, and the support required fluctuates across the lifespan (Lord et al., 2022). Specific support must be aligned with the needs and priorities of the child and their family; thus, parent involvement is essential during early childhood to ensure services that are relevant to their circumstances (Lord et al., 2022).

Recently, autistic people's needs and experiences were acknowledged and included in a national autism assessment with various stakeholders, such as researchers, policymakers, and health providers in Canada, to develop future public policies and customized programs (Canadian Academy of Health Sciences, 2022). The national autism assessment emphasized the crucial role of parents in fostering the well-being of their autistic children and family members. This enhancement is achievable when services adopt family-centered and strengths-based approaches, thereby facilitating parental empowerment and encouraging active participation in the attainment of their goals (Canadian Academy of Health Sciences, 2022; Government of Canada, 2021).

The national autism assessment also acknowledges the diversity, complexity, and needs that autistic people and their families face across Canada; for instance, a current worldwide debate involves different approaches and paradigms (Canadian Academy of Health Sciences, 2022). Historically, autism has been described as a disorder, and this concept was coined from the biomedical model, where autism is defined as a medical condition with the tendency to focus on deficits, impairments, and symptoms (Canadian Academy of Health Sciences, 2022). Consequently, autism is portrayed from a negative perspective, emphasizing the notion that there is something to fix or cure in the autistic person (Kenny et al., 2016; Monk et al., 2022). In this way, several models and approaches challenge the predominant biomedical model, acknowledging a broader perspective of human beings and embracing autists' experience in their interaction with the environment and the possibility of co-creating a realistic depiction of autism (Berghs et al., 2016).

The Canadian autism assessment report acknowledges the contribution of the biomedical model to supporting health conditions and navigation through the health system that autistic people may need; however, the language used to describe autism characteristics is centered on deficits (Canadian Academy of Health Sciences, 2022; Singer, 2017). So, in order to orient the development of policies and support services aligned to the well-being of autists, the social model of disability, conjointly with the neurodiversity movement, facilitates a holistic comprehension of autism (Chapman & Botha, 2023; McGreevy et al., 2024).

The social model of disability is a proposal that challenges the biomedical model by reframing the understanding of disability. This model shifts the focus from viewing disability as a personal biological issue based on impairments to recognizing the social barriers that restrict an individual's participation and empowerment (Barnes, 2022; Oliver, 1990). Furthermore, the neurodiversity movement was born from the co-construction of the autistic community, which also acknowledges neurological pluralism, viewing autism as part of human diversity with a distinctive identity (Botha et al., 2024; Orsini, 2012; Singer, 2017).

Regarding the updates on the specific support delivered during the early years to autistic children and their families, the traditional biomedical model is often aligned with professional-centered practices, whereas the family-centered approach recognizes each child and family's uniqueness (Dunst, 2002; Sukkar et al., 2017).

Aim of this Research

This research explores parents' perceptions about their role in services that provide specific support for their autistic children under six living in Nova Scotia. This research seeks to explore the following overarching question:

How do parents of autistic children describe their involvement in specific support provided to their children in Nova Scotia?

Specifically, this research will answer the following research questions:

1. How are parents of autistic children involved in the delivery of specific support for their child/ren?
2. How do parents of autistic children experience barriers in the specific support that is delivered for their child?
3. How could parents of autistic children be involved in the delivery of support for their children?

Researcher Positionality and Personal Connection

Autism research has primarily advanced within a framework and paradigm rooted in the biomedical model, which implies a deficit-oriented portrayal of autism. Furthermore, the understanding of autism has been developed based on a methodology driven by quantitative metrics. In contrast, qualitative research regarding autism has gained traction only in recent years in order to explore autists' experiences, potential barriers, combating stigma, and giving a voice to lived experiences (Grant & and Kara, 2021; Kaplan-Kahn & Caplan, 2023; van Schalkwyk &

Dewinter, 2020). However, it remains limited in its exploration of the experiences of parents with autistic children during their early developmental stages.

It is also relevant to mention that parents and caregivers were historically marginalized within the history of autism research, attributing the lack of affectivity as the cause of the characteristics of autism that their children presented (Courcy & des Rivières, 2017). In this context, I have confidence in a qualitative exploration regarding the experiences that families currently have in the province when seeking to access and navigate specialized services focused on autism.

My connection with autism is established through multiple avenues. As an insider, it is rooted in my educational qualifications and professional experiences, wherein I provided support to autists and their families in South America in my role as a clinical and school psychologist for over ten years. In this professional trajectory, I decided to specialize in family-centered models, also described as parent-mediated or caregiver-mediated models. These models focused on empowering parents and caregivers of autistic children and providing meaningful involvement in the process. My enthusiasm for this model called Paediatric Autism Communication Therapy (PACT) has intensified upon discovering that this approach demonstrates respect towards both parents and autistic children, emphasizing capacity-building while highlighting the parents' strengths (Carruthers et al., 2023; Conrad et al., 2024; Leadbitter et al., 2021).

I also experienced the benefits of parent-mediated approaches in my family, and observed how the parents of my autistic nephew and niece feel empowered and capable of advocating for respectful understanding of autism, as part of the spectrum of human diversity. The present research sheds light on parental involvement in autism services for children under six in Nova Scotia. I am an outsider in this context, considering I have lived for two years.

Literature Review

Parents' involvement in specific services to support autistic children has been evolving throughout the years (Courcy & des Rivières, 2017). To date, there are a variety of approaches and models to support autistic children and their families (Sandbank et al., 2020). The current focus is on tailored services (Lord et al., 2022), which consider a micro level of change, the heterogeneity of each autistic child and their family (Chen et al., 2022), and integrating the child and parents' priorities (Dunst, 2023; McGreevy et al., 2024). In this way, gathering lived experience through parents' voices whilst navigating specific services for their autistic child is crucial in order to co-construct the knowledge in the autism research (Green et al., 2022; Milton, 2017).

Autism History and Terminology

Eugen Bleuer, a Swiss psychiatrist, developed the term autism at the beginning of the 1900s to describe one of schizophrenia's symptoms in a group of people who demonstrated reduced social interaction as well as a tendency to focus on themselves (Kenny et al., 2016; Monk et al., 2022). Later, in the mid-1920s, Grunya Sukhareva, a Kyiv psychiatrist, described the clinical picture of schizoid psychopathy to explain the behaviours toward social avoidance that she observed in a group of children attending a program called hospital school, a center specializing in children who displayed developmental challenges (Sher & Gibson, 2023). Sukhareva decided that the term autistic psychopathy was a better fit than schizoid psychopathy to describe the autistic attitude demonstrated by this group of children (Sher & Gibson, 2023). In addition, Sukhareva described several characteristics that currently are within the autism diagnosis criteria in the Diagnostic and Statistical Manual of Mental Disorders fifth edition, for instance, significant variation in sensory profile, strong interests, and tendency to repeat some behaviours (Posar & Visconti, 2017; Rosen et al., 2021; Sher & Gibson, 2023). Sukhareva highlighted the relevance of the environment, family interaction, and the talents this group of children demonstrated in their hospital school program through sport, art, carpentry, and agricultural tasks (Sher & Gibson, 2023). Unfortunately, Sukhareva's works were overlooked until a few years ago, when researchers translated and published her work. They refer that Sukhareva faced several barriers in that decade, such as a Jewish origin, being a woman, and developing their work in the Union of Soviet Socialist Republics, which could have harmed the promotion of their work in a world facing World War II (Sher & Gibson, 2023).

Leo Kanner, an American-Austrian psychiatrist who, in the first part of the 1940s, described the picture of early infantile autism (Vicedo & Ilerbaig, 2021). Kanner emphasized his first patient's ability to perform memory tasks, but the psychiatrist observed a lack of emotional resonance, reduced intentional activity, and unwillingness to use the first pronoun; this child was Donald and has been acknowledged as the first autistic child who received a diagnosis of autism; likewise, early infantile autism was the first concept considered as the basis of autism research worldwide (Kenny et al., 2016; Vicedo & Ilerbaig, 2021). Contemporaneously to Kanner, in 1944, Hans Asperger, an Austrian psychiatrist, coined the term autistic psychopathy to describe a case report similar to the work developed by Kanner (Hosseini & Molla, 2023); although Asperger's description reported that the group of children showed a sophisticated language, better cognitive performance than Kanner's autism description, also this group of children usually developed an early language, but its use was restricted to one uncommon specific interest (Volkmar et al., 2014). Asperger Syndrome was incorporated as a new diagnosis in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM), and its removal in the next edition generated controversial debates related to the loss of people's identity who received this diagnosis (Rosen et al., 2021). In recent years, Asperger's research faced allegations related to his possible link with the National Socialist Child Euthanasia Program (Czech, 2018; Maher, 2021); however, there is no conclusive information that confirms those statements, even though it is reported that Asperger could not have information in advance about this program based on the fact that the military recruited Asperger between 1939 and 1943 (Tatzer et al., 2023).

In the late 1970s, Lorna Wing, an English psychiatrist, established the term Asperger's syndrome through a scientific paper where she identified differences between Kanner and Asperger studies; for instance, children under Asperger syndrome showed more verbal skills than children under Kanner's autism. So, children demonstrated significant differences in their behaviours. Later, Wing and her colleague Judith Gould, an English clinical psychologist, proposed that autism characteristics are within a spectrum and developed three main domains that usually challenge children: impairments in social communication, social interaction, and restrictive behaviour patterns (Wing et al., 2011). Thus, autism as a diversity within a broad spectrum resulted from Wing's and Gould's research, valid until today, reorganizing under subtle modifications in the last edition of DSM: social communication and interaction and restrictive, repetitive patterns of behaviours (American Psychiatric Association, 2022; Rosen et al., 2021).

Autism History in the DSM

In 1980, the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) included a new diagnosis called Infantile Autism, based on Kanner's study. This edition was updated years later, including autistic disorder as a new terminology (Rosen et al., 2021). Then, in the 1990s, the fourth edition of this manual was released, incorporating Asperger's disorder as a new category of autism, reporting a lower intensity of characteristics compared to

Kanner’s description of autism (Baron-Cohen, 2000). Later, in the fifth edition in 2013, based on Wing’s research, autism knowledge moved from categories of autism to a single broad dimension called Autism Spectrum Disorder (Baron-Cohen, 2000; Rosen et al., 2021; Wing et al., 2011). Nevertheless, people reported confusion about these changes, thinking that moving from Asperger’s to the autism spectrum could be a regression in their development (Wing et al., 2011). Hence, every update in autism terminology is not without controversy.

Neurodiversity and Autism

The neurodiversity movement started in the 1990s. It depicts neurological differences as intrinsically human variation, distancing itself from a pathological view frequently observed in the biomedical model (Kapp, 2020; Leadbitter et al., 2021; Singer, 2017). The neurodiversity movement is recognized as inherently part of the autistic community due to their co-constructed development (Botha et al., 2024).

The neurodiversity movement discourages early interventions or services which address changes toward reducing autistic characteristics or striving to meet normal parameters based on a neurotypical lens (Leadbitter et al., 2021; McGreevy et al., 2024). The provision of specific services in early childhood can significantly contribute to the well-being of autistic children when adhering to a respectful framework as promoted by the neurodiversity movement (Leadbitter et al., 2021). In this way, the appropriate use of language is crucial; for instance, employing terms such as “specific support” or “services” rather than “treatment” or “intervention” as the latter terms are often associated with deficit-based methodologies that seek to cure or normalize autistic children (Leadbitter et al., 2021; McGreevy et al., 2024; Monk et al., 2022). Moreover, services aimed at enhancing autism understanding facilitate interactions between the child and their immediate caregivers, promoting a respectful and enjoyable daily parenting experience to tackle everyday challenges (Conrad et al., 2024). As a result, the services should accept the child's characteristics, avoiding changing their nature (Leadbitter et al., 2021).

In the United Kingdom, autistic adults and family members showed a preference to use identity-first language, for instance, an autist or autistic person. In contrast, professionals preferred to use person-first language, for example, a person with autism (Kenny et al., 2016). On the other hand, Dutch-speaking autistic adults and parents showed a significant predisposition to use the person-first option (Buijsman et al., 2023), and other autistic communities were inclined toward identity-first language because it was perceived as less offensive (Bury et al., 2023). Similar results were obtained through a cross-cultural study that involved autistic communities from Australia, Canada, Ireland, New Zealand, the UK, and the USA (Keating et al., 2023). At the same time, other research revealed that professionals tended to be person-first (Taboas et al., 2023). Thus, several geographic locations showed that autistic adults and family members tend to use the term autistic or autistic person; nevertheless, health providers felt more aligned to use a person with autism as a preferred concept (Keating et al., 2023).

Researchers highlighted the relevance of language use, considering that terminology impacts psychological and emotional well-being and reduces stigma and social anxiety (Bury et al., 2023; Chahboun et al., 2022; Cooper et al., 2023). Consequently, future research initiatives ought to consider the linguistic preferences of the autistic community while minimizing language that may be deemed offensive in the context of autism research (Monk et al., 2022; Pukki et al., 2022).

Social Model of Disability and Autism

The medical or biomedical model has been the most predominant approach to conceptualizing autism across history, with a tendency to describe autism as a deviation, abnormality and pathology (Berghs et al., 2016; Monk et al., 2022). In this way, the biomedical model focuses on rehabilitating, fixing, and curing the autist's body, implementing deficit-based and potentially offensive language, triggering a negative portrayal of autism (Berghs et al., 2016; Canadian Academy of Health Sciences, 2022; Monk et al., 2022). Conversely, several models emerged as critiques of the biomedical model, shaping disability comprehension from different positionalities; the social model of disability is one of them (Berghs et al., 2016; Oliver, 1990; Oliver & Barnes, 2012). This model was born as an approach to establishing the foundation of disability equality through the awareness of social barriers to include disabled people, instead of individual characteristics of the person's body (Barnes, 2022). Therefore, disability is considered a social construction based on beliefs or attitudes promoting the participation of disabled people in different contexts (Oliver, 1990). In this way, the specific services should try to reduce or eradicate social environment limitations in a group of people historically considered worthy of charity or cure, such as autists (Barnes, 2022; Singer, 2017).

Autism and Specific Supports in Early Years

Early intervention or treatment terms have traditionally been employed for specialized support for families and children before age six. Nonetheless, this terminology is grounded in the medical approach, which tends to focus on identifying a cure or a target behavior that requires treatment; consequently, the terms "specific support" or "service" are advocated by the autistic community and promoted in the present research (Monk et al., 2022).

In the mid-1920s, Sukhareva described one of the first programs to support children who presented autism’s characteristics based on the strengths that autistic children demonstrated in specific interests such as nature, arts, or literature (Posar & Visconti, 2017; Sher & Gibson, 2023). Then, in the late 20s, Sukhareva reported that children were emotionally connected with some of their family members, such as a sister, whilst also emphasizing the importance of individualized support and the environment, such as education, offering them more opportunities to cope with autistic attitudes or autistic reactions, as she named (Sher & Gibson, 2023).

In the early 40s, the predominant belief about autistic children was that they could not learn (Bruinsma et al., 2019). Despite that, it was demonstrated that young autistic children could learn simple activities according to the conditions and arrangement of the setting (Ferster & Demyer, 1962).

In 1987, Lovaas reported the results of his study about intensive training with autistic children who received 40 hours a week implementing a behavioural approach named discrete trial training (DTT), which emphasizes three key components: antecedent, behaviour, and consequence (Lovaas, 1987); this study is the foundation of the traditional Applied Behavioural Analysis (ABA). Then, the Early Intensive Behavioural Intervention was developed following the same approach, frequently involving 25 to 40 hours per week to support autistic children under 6, reporting positive outcomes in the short term in cognitive and adaptive skills (Lovaas, 1987; Plavnick et al., 2020; Rodgers et al., 2020). However, a recent meta-analysis reported that behavioral interventions demonstrated some level of effectiveness, accompanied by risks of bias, insufficient information on long-term outcomes, and results that seldom address the well-being or quality of life of autistic children and their families (Rodgers et al., 2020; Sandbank et al., 2020). Furthermore, traditional services centered on behavioral strategies were considered highly structured (DTT), while children faced challenges in generalizing skills in new contexts, experiencing avoidance behaviors, showing reduced spontaneity, and exhibiting notable dependency on prompts; in that context the promotion of services that combine ABA and developmental strategies was encouraged to provide customized support to autistic children (Schreibman et al., 2015; Sherer & Schreibman, 2005).

As a result, a new group of specialized support in the early years for autistic children was developed under the Naturalistic Developmental Behavioural Interventions (NDBI) title, rooted in ABA principles and developmental science (Schreibman et al., 2015). Independently of the developmental domain that every model is centered, the NDBI approach spotlights core components, such as the nature of the learning targets across developmental domains, the nature of the learning contexts, implementing daily routines in their familiar setting, and the nature of the development-enhancing strategies based on motivating activities for children (Bruinsma et al., 2019; Schreibman et al., 2015). Some of the NDBIs promote the development of a plan of support based on children's interests and parent involvement within different formats; for instance, in parent-mediated support, parents have a relevant role from the planning until the implementation of strategies (Bruinsma et al., 2019). This program has been implemented online in recent years, and parents reported a positive perception of their child's achievement in social communication (Ingersoll et al., 2023). In contrast, other programs followed a community-based format, positively impacting parents' self-efficacy, quality of life, and satisfaction with the specialized service (Mirenda, Colozzo, et al., 2022).

A similar nomenclature was employed in a different report, Parent-Implemented Interventions (PII), a group of specialized support which facilitates outcomes in several developmental domains in autistic children from 0 to 5 years, such as communication, social skills, joint attention, play, cognitive, school readiness, adaptive, and challenging behaviours, among others (Hume et al., 2021). PII can also be known as parent-mediated support which are rooted in developmental principles, and they have shown significant long-term outcomes after six years. Once the support concludes, the adult-child synchrony and social interaction naturally enhance in autistic children (Carruthers et al., 2023; Green et al., 2010, 2017, 2018; Pickles et al., 2016; Segal et al., 2023). In parent-mediated support, caregivers engage with their autistic child by being sensitive to and observing the unique and subtle ways the child uses in daily activities (Cullinane et al., 2024). Parents also assume an active role in setting goals and designing programs to ensure alignment with their routines and needs, thereby fostering respectful support with parent's realities (Conrad et al., 2024; Cullinane et al., 2024; Divan et al., 2015)

Autism, Parents' Involvement, and Family-Centered Model

At the beginning of autism's history, parents were pointed out as responsible for triggering autistic characteristics of their child; for instance, Kanner's research reported that caregivers were the cause of the lack of affection in their child; then, Bettelheim went deeper into this proposal, which titled refrigerator mother, as an extreme manifestation of lack of mother-child affection (Bettelheim, 1967; Courcy & des Rivières, 2017; Douglas, 2014). Later, Bettelheim's proposal was debunked, although the negative impact persists today (Courcy & des Rivières, 2017).

Family involvement in specialized support in early childhood is highly recommended, and mothers usually assume this role (Benson et al., 2008; Woodgate et al., 2008). Thus, parents' depiction, and particularly the mother's portrayal, became guilty of differences in child development; even now, mothers are liable for following therapists' instructions, being co-therapists and engaging in programs of around 20 to 40 hours a week, under ABA approaches; as a result, mothers role moved from being the cause to the cure of autism (Blum, 2007; Courcy & des Rivières, 2017). Nonetheless, how parents play their role in early support will vary depending on the paradigms that underlie each specialized support (Bruinsma et al., 2019; Green et al., 2010; Leadbitter et al., 2021).

It is relevant to mention that autistic people and their families tend to distrust the health system, and healthcare workers' attitudes and beliefs were reported as one of the main barriers to access to specialized services (Canadian Academy of Health Sciences, 2022; Hemm et al., 2015; Tomczuk et al., 2022). Consequently, underrepresented groups based on their ethnicity or low income may face significant barriers to accessing support services, diversity in support services, and the stigma experienced in their communities (Mitter et al., 2019; Wallace-Watkin et al., 2023), and even blame parents for unexpected or negative child outcomes obtained in a specialized service (Milačić-Vidojević et al., 2014). Consequently, collaboration and community/home-based services rather than traditional clinical approaches could facilitate accessibility, parent involvement and reduced stigma (Pellecchia et al., 2018).

Indeed, Bronfenbrenner highlighted the active depiction of child development, involving a dyadic interaction and reciprocity between child and their close environment to promote human development, for instance, parents and caregivers (Bronfenbrenner, 1979). Bronfenbrenner developed a bioecological perspective on human development, which is built from a more specific system to a broader one (Bronfenbrenner, 2005). The microsystem is the first structure in Bronfenbrenner's model, involving a particular context with specific roles and routines that allow an active construction of the parent-child reality. Then, the mesosystem considers the interrelation between the child and other close settings. However, the child does not actively participate in the exosystem because it implicates a direct network with their parents, relatives, or friends. After that, the macrosystem includes ideologies, culture and belief systems (Bronfenbrenner, 1979). The chronosystem involves time and temporal events (Bronfenbrenner, 2005). Thus, experience, environment and interactions are crucial to understanding human development. Bronfenbrenner's model serves as a fundamental theoretical background for the family-centered approach developed by Carl Dunst, who advocates for family support from a systemic perspective (Dunst, 2002; Sukkar et al., 2017)

In order to understand family and parents' involvement, Carl Dunst developed a framework with a continuum of several family-oriented models usually implemented in early childhood (Dunst, 2002). The traditional paradigm included the treatment model, which focuses on remediating a disorder; the expertise model, where the therapist will solve the family's challenges; the deficit model, emphasizing the family's weaknesses; the service-based model, the support is established as a professional service; and the professionally centered model, the therapist decides by family members from their expert's perspective (Sukkar et al., 2017). In contrast, the capacity-building paradigm grouped the promotion model, facilitating a constructive performance; the empowerment model, which supports the development of new skills based on their current abilities; the strength-based model, highlighting the family's strengths; the resource-based model, facilitating the options available into the community; and the family-centered model, involving the family member actively with support based on their priorities and strengths (Dunst, 2023; Dunst et al., 2002; Sukkar et al., 2017). Thus, family-oriented models are frequently employed interchangeably as synonyms, although parents' involvement is entirely different from the traditional and capacity-building paradigm.

Parent-mediated and non-specialist support could benefit autistic children and adolescents who live in low and middle-income communities, considering that most of the traditional specialist support was developed in high-income contexts (Cherewick et al., 2023; Divan et al., 2015). Likewise, parent-mediated support could promote positive parenting and play a crucial role in the advocacy process, which means parents performing an active role in the specialized service will trigger children's empowerment during their childhood and develop caregiver advocacy as a first step. Later, children can move to self-advocacy following their interests. This approach was named the developmentally sequenced social-ecological intervention model by Cherewick (Cherewick et al., 2023). Thus, goals and outcomes in specialized services could be reframed, including quality of life, promotion of autonomy, and developing strategies to cope with daily tasks (Leadbitter et al., 2021). At the same time, research facilitates understanding how parents are involved in the specialized support for their children, what kind of characteristics they highlight, and how the services impact their lives (Leadbitter et al., 2020).

Parent-Mediated Services Across Canada and Nova Scotia

In Canada, there are several initiatives aligned with parent-mediated supports that shed light on their impact on the parents of autistic children. For instance, a community-based program called Parent and Child Early Coaching (PACE) was implemented in sixteen community agencies across British Columbia, not affiliated with university settings (Mirenda, Smith, et al., 2022). PACE was a modified version of the Parent-based Early Start Denver Model (P-ESDM), a manualized program that addresses several developmental domains included in a broad curriculum aged 12 to 48 months, and the results of this study reported that parents achieved high scores in quality of life, satisfaction, and self-efficacy while children increase their word comprehension (Mirenda, Colozzo, et al., 2022; Mirenda, Smith, et al., 2022). PACE was a relevant study in terms of including parents of young children aged 15-36 months, with no formal autism diagnosis, living in British Columbia (BC). Parents were only required to possess basic proficiency in spoken and written English. Furthermore, the research showed that about one-third of parents could complete the parent coach program, regardless of the challenges they experienced, such as low household annual income (based on BC population statistics), mental health challenges, or living outside urban centres (Mirenda, Colozzo, et al., 2022). Upon completing the program, children exhibited enhanced word comprehension, whereas parents reported elevated scores in quality of life, satisfaction, and self-efficacy measures (Mirenda, Colozzo, et al., 2022). Similarly, a community-based program called QuickStart in Ottawa – Ontario, reported that children improved their social, language and communication skills, the therapist developed a collaborative and flexible approach to cover the child's needs, and parents obtained a better comprehension of their child with strategies that were easy to implement in their daily routines (Gaines et al., 2022). Nevertheless, services based on ABA, such as Early Intensive Behavioural Interventions (EIBI), are frequently implemented in clinical settings as a primary alternative, involving intensive hours per week across Canada instead of family-centered approaches (Canadian Academy of Health Sciences, 2022).

Nova Scotia also has a QuickStart program, which was launched in 2019 and is delivered by Autism Nova Scotia; this parent-coach program is based on the Early Start Denver Model (ESDM), which is rooted in ABA and developmental approaches (Autism Nova Scotia, 2019, 2022). The QuickStart program has witnessed a substantial increase in the number of families supported in the province and its implementation across Nova Scotia in recent years (Autism Nova Scotia, 2024).

Health system in Nova Scotia implements an EIBI program for autistic children as a gold standard, including programs intrinsically associated with a biomedical standpoint, such as

Pivotal Response Treatment (PRT), Picture Exchange Communication System (PECS), and Positive Behaviour Support (PBS), most of which are rooted in ABA principles (IWK, 2023). Nevertheless, the principles of these programs are aligned with the traditional biomedical model, which addresses the reduction of characteristics associated with autism.

A quantitative study was carried out in two Atlantic provinces of Canada: New Brunswick (NB) and Nova Scotia (NS). This research indicated a reduction in family distress and increased parent self-efficacy from the start of the intervention to one year later (D'Entremont et al., 2022). However, in NS, the autism program implementation explicitly included parent coaching strategies based on Pivotal Response Treatment at the beginning of the program, and parents had the option to select where to implement the program, such as their home. In contrast, while parents' involvement in NB was encouraged, it was not mandatory, and professionals chose the location of service delivery (D'Entremont et al., 2022).

The EIBI program for autistic children is publicly funded in Nova Scotia and other Canadian provinces, such as Quebec, Newfoundland and Labrador, New Brunswick, Manitoba and Saskatchewan (Tsiplova et al., 2019). This situation may create confusion among practitioners who view parent involvement through family-centred approaches as an alternative rather than the primary method for delivering specialized services.

The social ABC program, a parent-based model, reported results from caregivers in Ontario and Nova Scotia, which showed positive parent satisfaction and high scores in the fidelity of the strategies included in this program (Brian et al., 2016). Children improved language and communication skills, positive affect, and social orienting (Brian et al., 2016). Recently, the social ABC program reported being feasible, acceptable, and appropriate in community services delivered in Ontario, implementing a parent-coaching format, with adults demonstrating significant adherence to this kind of programming, where the social ABC is one of the parent-mediated options available in Ontario (Drmic et al., 2024).

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Chapter 2: Manuscript

Families of autistic children frequently assume the primary responsibility for caregiving and serve as crucial intermediaries among a range of services, encompassing educational institutions, healthcare providers, and community resource programs (Lord et al., 2022). Families may also face numerous challenges when seeking specialized services for their autistic children, such as programs that inadequately address their needs, limited access to services, financial burdens, and social isolation (Divan et al., 2015; Lord et al., 2022; Sharpe & Baker, 2007). Thus, involving parents or caregivers is crucial when designing and delivering support services targeting autism in early childhood (Canadian Academy of Health Sciences, 2022; Dunst, 2023; Green, 2019; Green et al., 2022; Lord et al., 2022; Shattuck et al., 2018). Parent-mediated approaches are considered family-centered support that promotes early social relationships among autistic children, focusing on the caregiver-child dyad in natural contexts (Bearss et al., 2013; Canadian Academy of Health Sciences, 2022; Green et al., 2018, 2022; Prata et al., 2018). In contrast, when traditional support in early childhood is implemented, the practitioner directly assists the child in teaching specific strategies (Bearss et al., 2013; Dunst, 2002; Roggman et al., 2008).

The approach and pathways to actively include family members in the specialized support for autistic children respond to the features of two paradigms; the traditional paradigm views children and their families as having deficiencies and lacking skills, emphasizing the remediation of a disorder and requiring the involvement of an expert with specialized knowledge (Dunst, 2002, 2023; Dunst et al., 2002; Sukkar et al., 2017). In contrast, the capacity-building paradigm highlights the importance of recognizing talents and strengths while developing competencies and opportunities within the community where families and children reside (Dunst, 2023; Dunst et al., 2002). The family-centered model widely depicts the capacity-building paradigm given its focus on addressing the needs and priorities of families (Sukkar et al., 2017). Services that encompass and support the entire family in order to enhance their quality of life and overall well-being were suggested by national reports and research studies (Canadian Academy of Health Sciences, 2022; Conrad et al., 2024; Government of Canada, 2021; Ooi et al., 2016; Tint & Weiss, 2016).

Thus, this study explores how parents are involved in the specialized services for autistic children in Nova Scotia. Parents' experiences offer valuable insights regarding into service features and their implementation.

Literature Review

Parents' Involvement in Specialized Autism Services for Early Childhood

The role of parents of autistic children in early childhood services has significantly evolved over the years. Initially, parents were unjustly held accountable for a perceived deficiency in emotional connection with their children, which was erroneously believed to cause their child's autistic characteristics (Courcy & des Rivières, 2017). Mothers were identified as the primary individuals accountable for eliciting autistic characteristics in their children under the "refrigerator mother" concept, which depicted women as exhibiting a marked deficiency of affection towards their children and displaying a cold demeanor in this interaction (Bettelheim, 1967; Courcy & des Rivières, 2017; Douglas, 2014). Nevertheless, this hypothesis has been debunked due to advancements in neuroscience, which have enhanced the understanding of autism as a neurological condition and also as part of the broader human spectrum of experience rather than attributing it to the personality or parenting style of the parents (Courcy & des Rivières, 2017; Farrugia, 2009; Murray et al., 2023).

Parental involvement may differ according to the orientation of early childhood services; for example, the traditional paradigm perceives families as lacking skills, thereby necessitating that professionals adopt an active role (Dunst et al., 2002; Sukkar et al., 2017). In contrast, when families are viewed as capable, parents are motivated to engage actively in program practices, fostering the communication of their priorities and needs (Dunst et al., 2002; Lord et al., 2022). Parents may regard their children's attainment of developmental milestones as their duty, shaped by the responsibility assigned as co-therapists in rigorous weekly programs, and feeling guilty while attempting to manage work-life balance demands and interactions with their other children (Courcy & des Rivières, 2017). When service providers comprehend and address parents' experiences, they may enhance the navigation and involvement through specialized autism services (Gentles et al., 2019; Lord et al., 2022). This trajectory of engagement may encompass three significant processes for parents: initially coming to understand their child is autistic, then a sense of urgency and being involved in required services (Gentles et al., 2019, 2020). After that, parents transition to a measured approach where are able to understand autism as a lifelong condition and, consequently, adjusting their lives while seeking support required at this new developmental stage (Gentles et al., 2019, 2020). In contrast, when service providers focus on their views regarding parents' and families' capability to engage in the parent program, it leads to increased obstacles in accessing specialized autism services (Tomczuk et al., 2022). Families with restricted financial resources, complex family dynamics, and those identified as part of minority groups are often seen as ill-equipped to take part in family-centered services (Tomczuk et al., 2022).

A collaborative framework between service providers and the parents of autistic children is advised as families navigate the stages of pre-diagnosis, diagnosis, post-diagnosis, and long-term support in autism (Green, 2019; Green et al., 2022). This active parent involvement and the reciprocal relationship between families and professionals become evident when parents can establish their own goals (Green et al., 2010; Leadbitter et al., 2020; Pickles et al., 2016). Parents observe enhancements in their interactions with their children, and increased sensitivity to their children's characteristics experienced during daily routines (Conrad et al., 2024). Involving parents in specialized autism services during early childhood may foster self-advocacy in adulthood (Cherewick et al., 2023). This implies that advocacy is predominantly supported initially by parents or caregivers (Cherewick et al., 2023; Leadbitter et al., 2021).

Parent-Mediated Services Throughout Canada and Nova Scotia

In Canada, several research initiatives aligned with parent-mediated supports that shed light on their impact on the parents of autistic children; for instance, a community-based program named Parent and Child Early (PACE) Coaching was implemented in sixteen community agencies across British Columbia, not affiliated with university settings (Mirenda, Smith, et al., 2022). PACE was a modified version of the Parent-based Early Start Denver Model (P-ESDM), and the results of this study reported that parents achieve high scores in quality of life, satisfaction, and self-efficacy while children increase their word comprehension (Mirenda, Colozzo, et al., 2022; Mirenda, Smith, et al., 2022). PACE was a relevant study in terms of including parents of young children aged 15-36 months, with no formal autism diagnosis, living in British Columbia (BC). Parents were only required to possess basic proficiency in spoken and written English. Furthermore, the research showed that about one-third of parents could complete the parent coach program, regardless of the challenges they experienced, such as low household annual income (based on BC population statistics), mental health challenges, or living outside urban centres. Similarly, a community-based program called QuickStart in Ottawa – Ontario, reported that children improved their social, language and communication skills, the therapist developed a collaborative and flexible approach to cover the child's needs, and parents obtained a better comprehension of their child with strategies that were easy to implement in their daily routines (Gaines et al., 2022). Nevertheless, services based on ABA, such as Early Intensive Behavioural Interventions (EIBI), are frequently implemented in clinical settings as a primary alternative, involving intensive hours per week across Canada instead of family-centered approaches (Canadian Academy of Health Sciences, 2022).

Nova Scotia also has a Nova Scotia QuickStart program, which was launched in 2019 and is delivered by Autism Nova Scotia; this parent-coach program is based on the Early Start Denver Model (ESDM), a manualized program that covers several developmental domains, and is rooted in ABA and developmental approaches (Autism Nova Scotia, 2019, 2022). The QuickStart program has expanded families' reach in recent years. However, there's still a need to include qualitative data that captures children's, parents', and practitioners' perspectives (Autism Nova Scotia, 2024).

The health system in Nova Scotia implements an EIBI program for autistic children, including Pivotal Response Treatment (PRT), Picture Exchange Communication System (PECS), and Positive Behaviour Support (PBS), most of which are rooted in ABA principles (Canadian Academy of Health Sciences, 2022; IWK, 2023).

A quantitative study was carried out in two Atlantic provinces of Canada: New Brunswick (NB) and Nova Scotia (NS). This research indicated a reduction in family distress and increased parent self-efficacy from the start of the intervention to one year later (D'Entremont et al., 2022). However, in NS, the autism program implementation explicitly included parent coaching strategies based on Pivotal Response Treatment, and parents had the option to select where to implement the program, such as their home. In contrast, while parents' involvement in NB was encouraged, it was not mandatory, and professionals chose the location of service delivery (D'Entremont et al., 2022). Additionally, the methodology used may not fully capture the depth of parents' experiences.

The EIBI program for autistic children is publicly funded in Nova Scotia and other Canadian provinces, such as Quebec, Newfoundland and Labrador, New Brunswick, Manitoba and Saskatchewan (Tsiplova et al., 2019). This situation may create confusion among practitioners who view parent involvement through family-centred approaches as an alternative rather than the primary method for delivering specialized services.

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In Nova Scotia, there is a gap in local research concerning parental involvement in the specific services that support autistic children and their caregivers. Qualitative research has the potential to provide insights into parents' experiences as they access and navigate services tailored to autism within the province. Thus, this study set the following overarching question: How do parents of autistic children describe their involvement in specific support provided to their children in Nova Scotia? Three sub-questions were explored: (1) How are parents of autistic children involved in the delivery of specific support for their child/ren?; (2) How do parents of autistic children experience barriers in the specific support that is delivered for their child?; and (3) How could parents of autistic children be involved in the delivery of support for their children?

Method

Research Design

This qualitative research is conducted under an interpretive paradigm, meaning that reality is socially constructed, and knowledge is co-created in individual interaction (Tracy, 2020) . Thus, this is a self-reflective and iterative process that facilitates in-depth answers from parents of autistic children who will share their experiences about their involvement in the specialized services focused on autism in Nova Scotia, facilitating a contextual understanding of their reality (Clark et al., 2021).

Theoretical Framework

This study grounded in a family-centered approach, which emphasizes the needs, strengths, and social support system of families to promote child and family well-being (Canadian Academy of Health Sciences, 2022; Dunst, 2002, 2023; Dunst et al., 2002). A family-centered perspective recognizes parents as capable partners who play an active role in setting goals and shaping programming. This reflects a capacity-building paradigm, which contrast with traditional models, where professionals are seen as the primary experts and parents are viewed as adjuncts-or even obstacles-to care (Dunst, 2002; Leadbitter et al., 2020, 2021; Sukkar et al., 2017). This framework informs the current study by shaping its focus on how parents engage with early childhood programs and autism – specific services, highlighting the importance of empowering families rather than positioning them as a passive recipients of care.

Participants

Four parents (n=4) based in Nova Scotia participated in this study. A snowball recruitment was conducted in order to engage self-referred parents who can also recommend other caregivers. This method aimed to reach families living in more rural regions of Nova Scotia, where traditional recruitment may be less effective. Snowball recruitment was chosen because it enables a non-invasive and participant-driven approach to identifying additional caregivers, allowing new participants to be connected through trusted social networks (Braun & Clarke, 2013; Tracy, 2020).

Three mothers and one father, all parents of autistic children. Given this study's focus on gaining deep, experiential knowledge of how parents navigate specific supports and services for their autistic child, a small and specific sample was appropriate (Braun & Clarke, 2021).

Table 1

Family Characteristics

	Parent 1	**Parent 2**	**Parent 3**	**Parent 4**
Participant's role	Mother	Mother	Father	Mother
Child's age	4 Years	6 Years	5 Years	5 Years
Residence area	Urban	Urban	Urban	Rural
Time accessing services in NS*	3 Years	4 Years	3 Years	2 Years

Note: NS*= Nova Scotia

Procedure

Participants were recruited through posters disseminated via electronic mail and social media platforms. Eight parents expressed their interest in participating in this study. However, we were only able to schedule interviews with four participants (n=4). One mother disclosed a challenge related to her work schedule, whereas three other refrained from providing additional details.

Participants who successfully scheduled an interview were provided with the informed consent form and received the interview questions (Appendix A) so they could prepare for the interview. The interview reviewed their particular context, followed by questions about the participant's experiences navigating services for their autistic child. Interviews averaged fifty-five minutes and were automatically transcribed using the Teams platform, then cleaned by the researcher. Initial themes were generated in relation to the research questions, theoretical framework and data reported by participants. Participants' quotes and initial themes were compiled into a summary chart to facilitate participant review. The summary chart was shared with participants before the mutually agreed-upon follow-up virtual meeting. During the follow-up meeting, which lasted an average of thirty minutes, participants were given the opportunity to review the summary chart and transcript, if requested, and to make necessary additions, edits, or deletions, with a deadline of one week after the follow-up meeting. This research received Research Ethics Clearance from the Mount Saint Vincent University Research Ethics Board (#2023-273).

Analysis Strategy

Data was analyzed through a reflexive thematic analysis strategy (Braun & Clarke, 2006). I began by familiarizing myself with the transcripts from each interview. After that, I began the coding process, capturing semantic (participant-driven) and latent (researcher-driven) codes for each interview individually before synthesizing insights across them. Orientation to data involved an iterative process of inductive and deductive analysis, meaning coding and team generation were driven by data content and a theoretical framework informed (Braun & Clarke, 2022). Next, the codes were organized into initial categorical themes and potential sub-themes, which were discussed with participants in the follow-up meeting (Braun & and Clarke, 2023). Finally, themes and sub-themes were developed and reviewed to identify final names and define them clearly in response to the research questions, following a sequence proposed by qualitative researchers (Braun & Clarke, 2006; King et al., 2019). The 24th version of MAXQDA software was implemented to analyze data (Kuckartz, 2023)

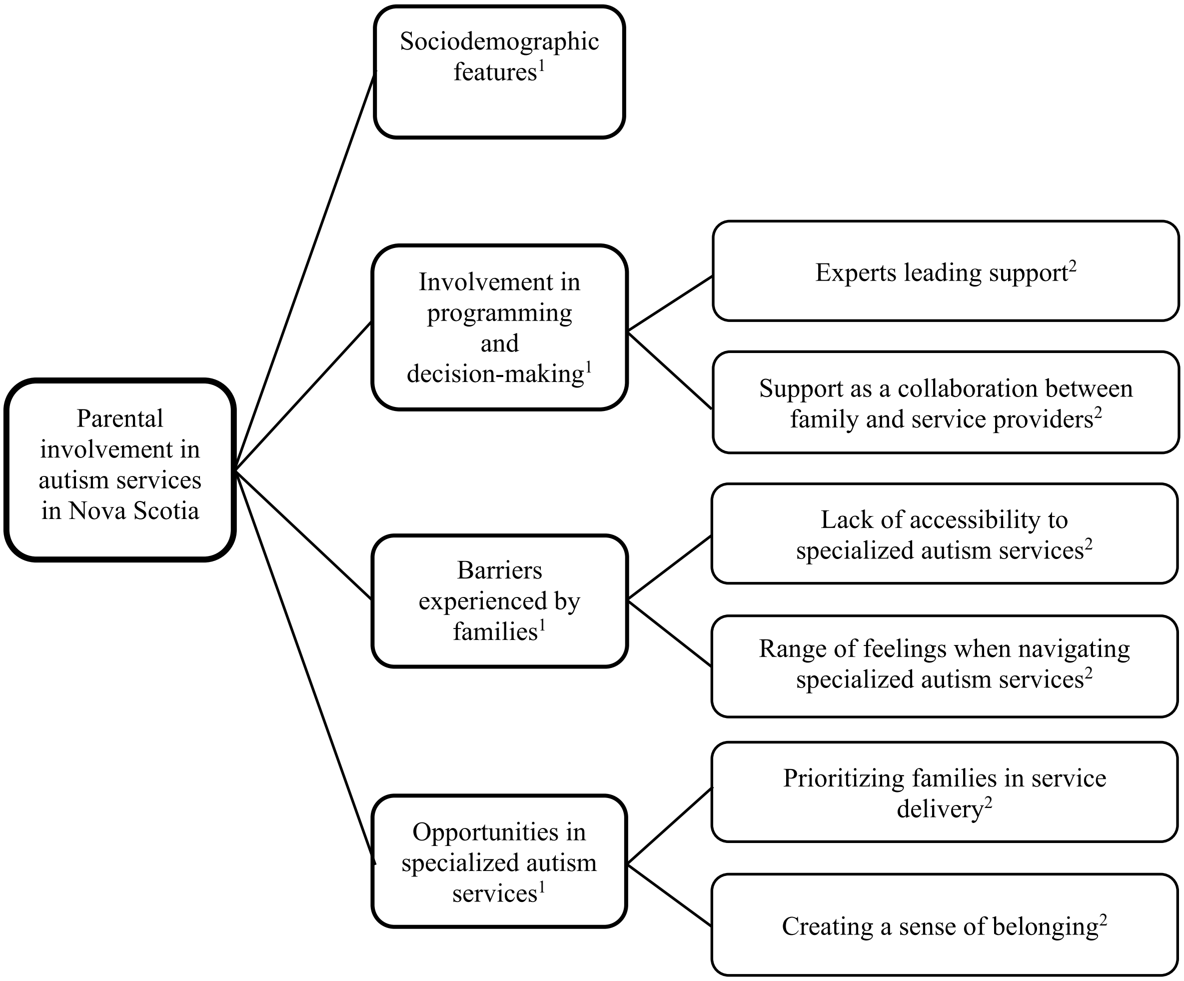
To develop and maintain rigor in qualitative research, I applied eight criteria proposed by researcher Sarah Tracy, known as the big tent: worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethical considerations, and meaningful coherence (Tracy, 2020). The criteria were utilized as a reflexive guide throughout the iterative process across study development (Tracy, 2010). Worthy topic involved initial reflection on its relevance and a significant research subject. Rich rigour included reporting the theoretical framework, an analysis of the literature review, and data collection and analysis processes. Sincerity involved an iterative, self-reflexive approach and transparency about the methods and challenges encountered. Credibility was established by including thick descriptions and participants' quotes. Resonance involved a reflexive process that develops meaningful knowledge for the audience, impacting and creating opportunities for transferring findings into their own contexts. Finally, significant contribution, ethic, and meaningful coherence captured the contribution of finding, interconnected with the literature available within ethical procedures (Tracy, 2010; 2020).

Results

Through thematic analysis, I identified four principal categorical themes. Three of them were supported by two sub-themes, which significantly enhanced our comprehension of parental involvement in autism services in Nova Scotia (see Figure 1).

Figure 1

Categorical Themes[1] and Sub-Themes[2]



Note. Four main categorical themes describe parental involvement in autism services in Nova Scotia: sociodemographic features, involvement in programming and decision-making, barriers experienced by families, and opportunities in specialized autism services. The last three categorical themes unfold into two sub-themes.

Sociodemographic Features

The theme delineated the characteristics of the participants that influence the findings, including factors such as residential location, attainment of post-secondary education, and work schedules. Three parents reside in the Halifax area, while one lives in a rural community in Nova Scotia. The number of family members ranged from four to five. Four parents reported speaking English at home; one parent indicated that they also speak French, and another speaks Bangla. Participants shared thoughts on the benefits of their parental post-secondary education. All parents acknowledged that their formal education has significantly contributed to securing their current employment, which includes insurance benefits that have reduced out-of-pocket expenses related to private autism services. Parents viewed the employee insurance plan they accessed through their job as an opportunity to pursue and provide private services for their autistic children, especially given the lengthy waiting lists associated with public autism services in the province. A mother living in a rural community shared her experience based on significant challenges to seek specialized autism support for her child, and how the insurance benefits, although limited, allowed them access to private autism services:

> *"I have him in soccer and other extracurricular activities, like hockey, we pay a lot of money to have extra support for him in those situations […] my husband and I have very good health insurance from our work. So, we can afford to hire Speech-Language Pathologists and different Behaviour Therapists. However, not all families have access to that. […] I'm lucky; I have access to privatized services, a lot of families do not, especially in rural communities, because for you to get a job like my husband and I both have health benefits, and that is extremely lucky."*

Four parents indicated that they received their child's diagnosis and subsequently accessed and participated in at least one program or service offered by public services related to autism during early childhood. In addition, three parents engaged in private services; one parent actively seeks such services. Participants also reported workload challenges, which are viewed as a concern when seeking specialized support, regardless of whether it is from the private or public sector.

Involvement in Programming and Decision-Making

The theme uncovered how parents were involved in receiving specific support. The characteristics of program planning and goal setting shed light on this matter. All parents described that decision-making typically rested with the practitioners. One mother recounted her experience with a new program in the province, where she and her husband had the opportunity to take an active role. Two sub-themes provided a deep understanding of (1) experts leading support and (2) support as a collaboration between family and service providers.

Sub-Theme: Experts Leading Support

Four parents described their involvement—either directly or indirectly—as following the direction of therapists or service providers. One mother described her experience with a program implemented at home where the service was primarily directed by the practitioner, who also selected the type of toy her son was able to use during the specific support. As such, the program was designed without including her reality and child's preferences:

> *"Talking and giving instructions and things like that, it was difficult. I also didn't like the program; it was very… I found it very rigid, and as far as they came in, they're like, ok, well, we want him to play with this toy."*

The same mother further indicated that when the service excluded her perspective, it became evident that the program was primarily concentrated on tracking developmental milestones rather than providing the support they needed:

> *"I found it very rigid [behavioral program], a lot of tracking outcomes and numbers of times he did this. It was like trying to reach this certain level of achievement […] I feel like you constantly…I have to be observing him all the time because every time somebody comes [to home], they want an update. They're like, what's he doing here, How's this going? How's he sleeping? How's he eating? What? How's this behaviour? [...] I feel like we're overanalyzing him all the time."*

Another mother promptly observed that her participation in the program's delivery was restricted. The practitioner predominantly directed the topics and goals throughout most of the sessions. The mother indicated that the program lacked organization, and certain interactions were primarily aimed at verifying general matters:

> *"We haven't been involved in the program planning…It is mostly just like… We're gonna talk about…, the goals are…and even like they're going to contact us. I believe in another three weeks to say how everything's going if we need to change anything […]stuff like that."*

In contrast, another parent indicated they positively value the opportunity to follow the guidance of practitioners. She mentioned that learning from a qualified practitioner is beneficial, articulating her experience of entering the session room to observe the therapist while providing support for her autistic child:

> *"I'm present during [the behavioural analyst's] sessions. So, I'm able to see what she's doing and learn."*

Three parents emphasized the challenges of navigating services when their perspectives, needs, and interests were omitted from the program design. One parent found it beneficial when the practitioner facilitated the session, directly supporting her child and providing her with the opportunity to learn the strategies.

Sub-Theme: Support as a Collaboration Between Family and Service Providers

Additionally, parents described their involvement as a process of making decisions, participating in a new program, or collaborating with a team:

"In this [new program] what I like is that they are offering us what the goals are, and they really took a deep dive into my son [...] We are involved pretty much just with setting the goals, and meeting to find out whether or not the goals are important to our family."

Another mother emphasized her experience navigating educational support as part of a team and the decision-making that arose from collaborative work:

> *"[...] and once I made that decision, I felt really good about it. And then we just built his team up [...] as a team… I felt like it was a team. I had those three: the private therapist, the inclusion coordinator, and the teacher; we were meeting, we were talking about what was working, what was it working. We were problem-solving, and it was just very collaborative."*

Parents who engaged actively in programming and decision-making processes felt acknowledged, and the service is regarded as genuine support for their autistic child and family members.

Barriers Experienced by Families

The parent-participants described their encounters when accessing and navigating early childhood autism services in the province. The theme encompasses two sub-themes: (1) lack of accessibility to specialized autism services, and (2) range of feelings when navigating specialized autism services.

Sub-Theme: Lack of Accessibility to Specialized Autism Services

All parents indicated that they encountered challenges while seeking specialized services in Nova Scotia. One mother recounted that an intensive program was implemented at home. The program concluded abruptly upon completing the sixth month, despite being outlined for one year by the public health system:

> *"Who was in certain years was only gonna get half the program and six months of the program? So, we are on the fast-track program, so that was disappointing, especially having waited for so long to go into this program that everyone was talking about [behavioral program] It's really hard to go from getting 15 hours a week of one-on-one attention and then like being finished and up. And I'm like, well, I can't give him that. Unfortunately, I work full time, and my husband works, and I can't quit my job."*

Another mother shared her experiences concerning the extended waiting periods for autism services in Nova Scotia. She communicated her decision to keep her son in preschool education, observing that children who enter elementary school do not meet the criteria for services and programs tailored for autistic children under the age of six:

> *"For instance, our son, to qualify for this program, we had to hold him back in school because he did not, we were still on the waiting list [...] However, access to the programs is our biggest issue. The wait times was incredibly long, and no one really could ever give us an answer on anything. For instance, when we were trying to make the decision on whether or not to hold our son back in school so that he could receive services. No one could actually tell us, even if he would receive them within the next year [...] So, we made the decision to change his school so that wasn't an issue, but all of these big decisions had to be made and still have absolutely no clue what was actually going to come of it."*

A parent expressed her concerns regarding the eligibility criteria for accessing specific support services for autistic children. Her child remains on the waiting list, and they have subsequently transitioned to private services:

> *“I don’t even know if my son’s gonna be eligible for it because I believe my understanding is based on needs, and if I look at my son… as a whole, the spectrum is huge, but in my opinion, he has lower needs.”*

In a similar situation, a mother living in a rural area described her apprehensions regarding the accessibility of specialized support within the educational system. She observed that, as parents, they provide their autistic child with private assistance; however, public schools decline to engage in communication with external practitioners:

> *“They have to have their own; for example, a psychologist has to be a school psychologist. I can’t have somebody from the outside go in; even occupational therapists […] There are a lot of families… I've been told by a few of our support people that these schools, typically kids, will start in them, but they never finished there, they get moved to another school board because the service is just not there.”*

In light of the challenges faced by autistic children and their parents in navigating the health system, they decided to switch to private services as a means to secure timely access to specialized assistance. One parent expressed her concerns regarding the limited coverage provided by insurance:

> *“I started going private, and that’s kind of the journey I've been on for the last several years, finding different people. I think we started with Speech [Language Pathologist] and finding a private speech person […] Some people have very little coverage, and it might only be a few sessions a year. Then, depending on your coverage, like my sessions, I have about 20 covered […] I realize how difficult it would be for a family that couldn’t*

> *have. That doesn't have the resources to do that, and I can't imagine how scary that must be for other families."*

Another parent described his first contact browsing private services and insurance coverage. He described his concerns in this way:

> *"One thing that we were exploring the private sector services [...] I don't think the insurance company would cover everything because it can be very costly depending on the type of insurance or where you work [...] So, while you are waiting, I mean you also cannot access private services because you have to pay out of your pocket and it's not cheap."*

All parents indicated that they faced challenges in accessing specialized support for their autistic children. When the service is publicly funded, parents encounter prolonged waiting lists, whereas private services are costly, and insurance coverage is often limited.

Sub-Theme: Range of Feelings When Navigating Specialized Autism Services

The sub-theme highlighted the parents' need to be heard, along with the feelings they experience when insufficient information is provided regarding autism support. Parents go through a range of emotions while navigating specialized services, a field rarely addressed by specific programs for autistic children. In this context, accessing adequate support is often difficult for parents. One participant recalled her experience in navigating specialized support through the provincial health system:

> *"I remember we would get phone calls for intake and then they'd be like, OK, well, we're gonna call you in a month to give you an update. OK, call us back in a month. Well, we have nothing to update you on. We'll call you again in another month. And I was like, listen, this is getting a little bit irritating because the length of this in between is hard. It's*

very hard."

A mother shared her rationale for selecting private services, accentuating the considerate deliberation that motivated their decision to pursue timely support:

> *"I did not feel supported by the provincial. Like the provincial programs at all [...], We also are on a waitlist for EIBI through the IWK, which there's a lengthy waitlist, and it's offered to the oldest child before they hit the school. However, his brain is developing now, so we sought out private."*

When parents embark on the journey of accessing services, they frequently encounter substantial challenges. However, if practitioners fail to address the emotional needs of parents, this may be considered a significant challenge. A parent reflected on the program her child was referred to, sharing her feelings about how service providers often struggle to understand the realities of parenting an autistic child and the uncertainties that come with a diagnosis:

> *"I hate to say this, but they were all younger, people who may not have had the world like the experience of being a mother or running a household with children, and that it just felt like that was coming through, like as far as a factor as some of the recommendations and things they wanted me to do. I mean, it was our first experience, and we were scared, and we were like, oh, we're gonna do whatever."*

And another similar experience, reported the reality of the province, going through updates in the programs focused on autism. But this situation is not without stress:

> *"I noticed that the province is also going through some changes with the programming. So as a parent, at times it can be overwhelming [...] So, it can be confusing, overwhelming and navigating these services like so you feel like, for example, feeling up different forms for the assessment you have like they will send you a package home and*

> *bunch of questions like it took me few days to fill this out."*

Occasionally, when parents gain access to the long-awaited support, the lack of reliable information provided to them may generate feelings of uncertainty and distrust:

> *"I know it's a new program in Nova Scotia. Apparently, my son is one of the first children to receive it. It was really difficult for us; it was kind of that feeling that he's the Guinea Pig in this situation. I like the idea of tried and trusted approaches to things, and I get that we're in a moment of change, but we're also concerned sometimes like this. Are they just trialling it with him like that? Kind of thing it was more of a fear on our side." (P4)*

The transition to elementary school was described as eliciting a blend of emotions among parents. A mother disclosed her feelings regarding her upcoming shift to elementary school, drawing upon her professional experience within the public education system:

> *"We know the schools are underfunded and don't have the resources to provide the support, so it's just unfortunate that that happens because our kids are missing out […] So I feel he would be lower on the list and again it's just unfortunate because I don't think my son deserves that service any less than anybody else […] It's extremely sad in my professional life. I work in schools with children as well, and I see the gap because and I know now living this life with my own son […] I'm nervous about that because I know a speech and language pathologist who works at the six different schools and she literally has said to me I can give this child they work with. Like I can give her 20 minutes every two weeks. What it what is that doing? […] They have the school program. It's not sufficient."*

Opportunities in Apecialized Autism Services

This theme outlines the potential opportunities that services oriented towards autism in early childhood could leverage. The theme consists of two sub-themes: (1) prioritizing families in service delivery, and (2) creating a sense of belonging.

Sub-Theme: Prioritizing Families in Service Delivery

Parents have both explicitly and implicitly expressed the importance of their priorities in influencing the tailored support developed for their autistic children and their families. The consideration of these priorities significantly enhances the quality of life and well-being of parents, particularly when their priorities are acknowledged in the workplace, as this mother reflects on it:

> "*We're fortunate that my work has been lovely in allowing me to have a day off weekly because it is my son's therapy day, so I pick him up in the afternoon, and I have this time to do what I need to do for him. So, we've been fortunate in that way."*

The flexibility of parents' schedules is significant when parents wish to be involved in specialized support. For instance, this mother indicated her decision to reduce her workload in order to engage with the support her child required:

> *"I was very involved to the point where I gotta leave of absence from work for like part time. So, I got two mornings a week so that I could be involved. So, I was in the sessions two of the five days a week. I was right here they were happened in my home. Then, the other days, they happened at school. I was very involved. I was watching everything that was going on."*

Parents possess considerable information and insights to share and communicate with practitioners, irrespective of whether the discussion pertains to educational, health, or community support matters. Thus, their priorities are a crucial element in fostering tailored services.

Sub-Theme: Creating a Sense of Belonging

The sub-theme focused on the perceptions of parents regarding their active involvement in available services. The experience of being a parent of an autistic child is distinctive, prompting a desire and necessity to engage within a community. Parents seek to share their insights on developing supportive environments conducive to autism. One mother articulated her views as follows:

> *"That community piece, I think is really missing in the system right now. A place for parents to get together, share ideas, resources and experiences. I haven't really ran into any of that yet."*

Another parent emphasized the parenting journey positively, recognizing the daily efforts they make to enhance their child's development:

> *"I think cause parents that I'm sure every parent out there are trying to help their kids as much as they can [...]"*

A noteworthy perspective was presented by a mother who emphasized the significance of parental support commencing from the point of diagnosis. She underscored the importance of incorporating parents of autistic children into formal services, identifying this as an essential form of support following the confirmation of diagnosis. A sense of belonging from the first moment:

> *"That's accessible, and maybe it's somebody setting like when there's a diagnosis, maybe it's setting someone up with a parent that's maybe a few years down the road. And you know what I mean, matching them up and saying, you know, what, like, why don't you guys have a chat so that it, it helps all the scary. You know what I mean? The scary part of just getting that diagnosis and being like, what does this mean, and where am I going? Where do I go? Who do I? You know what I mean?"*

A parent also expressed his perspectives regarding the ways in which services can foster a family-friendly environment, thereby facilitating easier access to specialized services:

> *"So, I was thinking then to make it a little bit easier for the parents, whether the intake can be central, like once you want to like once they're spending done."*

In conclusion, it is imperative to emphasize the importance of granting parents the opportunity to make decisions concerning the services provided. A parent emphasized the relevance of transitioning towards a pathway of service that is both respectful and thoughtfully constructed with autistic children and their families:

> *"It could be helpful [...] so I think it's parents' choice. So, whether it's evidence-based or not, you give the parent the information and let them make the choice. It's best for the family."*

Discussion

This qualitative study, employing reflexive thematic analysis, offers insights into parents' perceptions about the characteristics of their involvement in early specialized services for autistic children in the Canadian Province of Nova Scotia. It also emphasizes the challenges parents face in accessing these services and outlines key features that should align with their priorities.

Sociodemographic Characteristics of Families

The parents participating in this study live in Nova Scotia, Canada. Most resided in urban areas, whereas one parent was based in a rural community. According to the duration that the last parent indicated for accessing specialized autism services (Table 1), her child received specific support one year later than those living in urban areas, reflecting similar challenges in accessing specific autism services that other families with autistic children encounter in rural areas across Western Canadian provinces (Canadian Academy of Health Sciences, 2022; Hoogsteen &

Woodgate, 2013; Young et al., 2019). Barriers are usually associated with the lengthy waiting list for the diagnostic process, as documented in prior studies, where some families may cope with a total waiting period of nearly two years from the initial referral to diagnosis (Penner et al., 2018).

The majority of parents involved in this study indicated they switched to private service providers, resulting in out-of-pocket costs, occasionally mitigated by minimal insurance coverage (Lord et al., 2022; Tsiplova et al., 2019). Parents observed that the completion of their post-secondary education facilitated the attainment of enhanced employment opportunities, which subsequently provided insurance options for private services coverage for their autistic children. Parents also recognized that many families with autistic children might not have the financial resources to obtain this private support, which can be overwhelming.

It is essential to acknowledge that parents who participated in this study reported having a busy schedule. Consequently, they used their days off, office hours, or lunch breaks to voluntarily participate in this study, hoping to share their experiences and support other parents navigating specialized autism services in Nova Scotia. One of the parents interested in participating but unable to schedule a meeting in this study communicated challenges regarding her busy schedule, which hindered her ability to find time for a virtual interview. The complexities faced by Canadian families with autistic children may vary across provinces and territories; however, there exists a notable gap within the Canadian health system in addressing the potential challenges these families encounter (Canadian Academy of Health Sciences, 2022). Autistic children and their families have the right to access evidence-based services, regardless of where they live (Smith et al., 2021).

Involvement in Programming and Decision-Making

The majority of services provided for autistic children during early childhood in Canada and Nova Scotia are based on methodologies deeply rooted in traditional paradigms such as Early Intensive Behavioral Intervention (Canadian Academy of Health Sciences, 2022).

The traditional standpoint of specialized support typically focuses on the child's unique characteristics, emphasizing the alleviation of deficiencies or symptoms rather than acknowledging the strengths and abilities of both the child and their parents, as indicated in family-centered approaches (Dunst, 2002, 2023; Dunst et al., 2002; Sukkar et al., 2017).

When parents characterized the services as inflexible or inadequately aligned with familial circumstances, they experienced heightened pressure in their daily routines. Paradoxically, the service designed to support autistic children and their families may inadvertently become an additional burden for those families (Courcy & des Rivières, 2017; Divan et al., 2015; Lord et al., 2022).

Barriers Experienced

Parents in this study have indicated that the process of accessing and navigating early specialized support for autism has been both overwhelming and a source of considerable stress. This observation aligns with findings presented in the national report regarding the experiences of autistic people and their families throughout Canada (Canadian Academy of Health Sciences, 2022). Stressful parents' experiences can be addressed when parents play a crucial role from pre-diagnosis to the therapeutic support moment (Carruthers et al., 2023; Conrad et al., 2024; Green et al., 2022; Leadbitter et al., 2020, 2021). Thus, it is essential to transition to an autism care system, where parent-mediated support evolves across the autist lifespan, instead of focusing all the services on waiting for a diagnosis to provide specific support (Green et al., 2022).

Developing New Autism Specialized Services in Early Years

Parents shared their insights on how their children can succeed and thrive by appreciating their unique traits and encouraging self-advocacy. These perspectives reflect modern beliefs about parents' crucial role in early childhood, primarily through parent-mediated supports. In this supportive role, parents act as advocates, helping their children develop self-advocacy skills as they mature into adults (Cherewick et al., 2023; Leadbitter et al., 2021). Therefore, caregiver advocacy is essential for attaining self-advocacy in adulthood.

Limitations & Future Directions

It is important to note the limited sample in this research. The recruitment issues experienced in this study further shed light on the challenges parents of autistic children may face in Nova Scotia. Half of the initially interested participants were unable to schedule an interview date, while the parents who were involved in this research reported they used lunch time, a day off or breaks in their work. When conducting research involves parents of autistic children or autistic individuals, it is advisable to consider offering financial assistance to facilitate their involvement and reduce barriers in this context.

Most participants in this research reported living in urban areas of Nova Scotia, whereas one parent mentioned residing in a rural community. Future studies might concentrate on families with an autistic child living in rural areas of the province. This could offer greater insight into the potential barriers that autists encounter when accessing and navigating specific support services.

The present research explored parents' perspectives of their involvement in services aimed at children under six. However, the support needs for autistic people and their families can vary greatly throughout their lifespan. Research focusing on different age groups may provide further insights into the adjustments needed for autism support throughout the lifespan in Nova

Scotia.

Parents’ experiences with their involvement in services focused on autism during the early years offered valuable insights into both service features and the traditional or family-centered approaches that shape specific support. Additionally, other forms of qualitative research could greatly enhance our understanding, guiding the development of meaningful policies and action plans for autism across the lifespan. For example, grounded theory might allow for a distinctive conceptualization of tailored autism services in Nova Scotia.

Conclusion

Overall, this study reported the realities faced by some parents with autistic children under six when accessing and navigating specialized services for autism in Nova Scotia. While parents demonstrated resilience and commitment, they continue encountering significant barriers related to accessibility, flexibility, and financial burden. These challenges might be particularly pronounced when families are based in rural areas, further emphasizing existing service inequities.

The findings highlighted the importance of further research into family-centered autism services, especially from a capacity-building viewpoint. By supporting parents as engaged partners instead of passive recipients of expert advice, we can help alleviate stress and create better outcomes for children and families regarding well-being and quality of life. It’s crucial for future service models to prioritize equal access throughout the province and genuinely include parental voices, ensuring that services reflect the everyday experiences of all kinds of families.

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Appendix A: Interview Guide

The following questions will be presented in standard order. The response to each scripted question will include a follow-up to clarify ideas or comments during the interview.

Initial instruction: “In this first part, I would like to know general information about you and ***your*** child.”

A) Initial/demographic questions:

1. How old is your child?
2. What is the gender identity of your child?
3. What is your relationship with the child?
4. What was the last educational course or program you completed?
5. What is the gender which you self-identify?
6. Who lived with the child in the last year?
7. What language/s is frequently used at home?
8. Do you belong to the First Nation community, or do you self-identify/belong to an Indigenous community? Do you care to share:
9. How long have you and your child been living in Nova Scotia?

How long have you attended the current program, support, or services for autistic children with your child? Note: “During the next part of the interview, I will use the word *support* interchangeably with the words *services* and *program.*”

Second instruction: “In this second part, I would like to ask some questions related to your experience in the current autism support you and your child receive here in Nova Scotia.”

Interview Questions:

1. How do you describe the specific support your autistic child and your family are currently participating in?

Follow-up questions:

1.1) How is the support implemented?

1.2) What are the strengths of this support?

1.3) What are the drawbacks of this support?

2. How are parents engaged in the specific support?
3. How are parents involved in program planning and goal setting?

4. How would you like to be involved in the specific support?
5. What barriers did you or your autistic child experience participating in the specific support?
6. What is the most effective way to involve parents in specific support?

Final questions:

7. Is there any additional idea you would like to mention?
8. Do you have any concerns or questions you would like to ask me?