

**INVESTIGATING NEWCOMER PARENTS' STORIES OF ACCESSING SUPPORTS FOR THEIR
CHILDREN WITH AUTISM SPECTRUM DISORDER**

By

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I. Introduction

Autism spectrum disorder (ASD) is defined as a life-long neurodevelopmental disorder, characterized by impairments in areas of social communication, patterns of behaviour that are repetitive and restrictive, and atypical sensory sensitivities (Zwaigenbaum et al., 2014). One percent of the world's population is estimated to have autism (CDC, 2014). Currently, in the Canadian population, the prevalence of autism in youth ages five to 17 years is one in 66 (Government of Canada, 2018). In a 2018 Canadian study, male children and youth were identified with ASD four times more frequently (23.9 per 1,000) than females 6.0 per 1,000) (Government of Canada, 2018).

The 2018 federal budget of Canada earmarked \$20 million over five years towards ASD. This included funding for a network to connect people with ASD and their families to information, resources and employment opportunities, and community-based projects to strengthen health, social and educational programs. Recently, Canada has recorded a larger influx of immigrants in more than a century. The country added 71,131 immigrants in the final three months of 2018, for a full year increase of 321,065, according to estimates provided by Statistics Canada (2019).

Early intervention has proven to be of significant benefit in the lives of children with ASD. However, timely access to health services and support requires equitable access, which is often a challenge for immigrant families (Sritharan & Koola, 2019). Barriers to equal access and support for immigrant families of children with ASD include

cultural beliefs about child development and ASD, delayed diagnosis, difficulty in accessing services, and negative perceptions of offered support (Sritharan & Koola, 2019).

There is a shortage of studies that explore how to increase understanding and collaboration among immigrant families and health care practitioners to address these barriers. The purpose of the study is to investigate, through the use of narrative methods, the stories and perspectives of newcomer parents related to accessing and receiving services and supports for their child with ASD.

II. Literature Review

Definition and Prevalence of ASD

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that affects communication and behaviour. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), a guide created by the American Psychiatric Association (2013) used to diagnose mental disorders, people with ASD have:

- Difficulty with communication and interaction with other people
- Restricted interests and repetitive behaviours
- Symptoms that hurt the person's ability to function properly in school, work, and other areas of life

Autism is known as a "spectrum" disorder because there is wide variation in the type and severity of symptoms people experience. ASD occurs in all ethnic, racial, and economic groups. Although ASD can be a lifelong disorder, treatments and services can improve a person's symptoms and ability to function.

Around one percent of the world's population is estimated to have ASD. Currently in the Canadian population, the prevalence of autism in youth ages five to seventeen years is one in 66 (CDC, 2018). Boys are almost 5 times more likely to be identified with ASD than girls. In the CDC report, about one in 42 boys and one in 189 girls were identified with ASD. This new estimate is roughly 30% higher than the estimate for 2008 (one in 88), roughly 60% higher than the estimate for 2006 (one in 110), and roughly 120% higher than the estimates for 2002 and 2000 (one in 150). Most children identified with ASD are not diagnosed until after age four, even though children can be diagnosed as early as age two (CDC, 2013).

Autism rates represent a global public health crisis; the costs are staggering and will continue to rise as prevalence continues to increase. Early diagnosis and treatment are critical in supporting the positive development of children with ASD. The investment made now will be essential in reducing the long-term costs of autism (Buescher, Cidav, Knapp, & Mandell, 2014; Buescher, Cidav, Knapp, & Mandell, 2014).

Access to Essential Supports: Newcomer Families

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by social, communication, and behavioural deficits. While early intervention has proved to be critical in the lives of children with ASD, timely and equitable access to health services is often a challenge for immigrant families (Khanlou et al., 2017). The literature highlights a range of potential challenges to service access for newcomer families inclusive of cultural perspectives regarding diagnoses and child growth and development, wait-list and wait times for assessment, and lack of familiarity and trust in health and

education services and supports (Freeman, Perry, & Factor, 1991). Furthermore, seeking out and obtaining appropriate health care and special education services and supports are especially problematic in the case of ASD (Millau, Rivard, & Mello, 2019). As a result, these families have been shown to exhibit higher stress levels than the families of children with other conditions (e.g., Down syndrome, cerebral palsy) (Rea-Amaya, Acle-Tomasini, & Ordaz-Villegas, 2017). Factors such as being of low socioeconomic status, going through the immigration process, or belonging to an ethnic minority group may amplify stress on the family. Stressful factors or circumstances may decrease families' ability to access and use available services, and increase potential risk for the emergence of emotional distress and diminished capacity to be resilient in the face of present stressors (Raspa et al., 2010).

Population-based surveys indicate that access to health care is influenced by ethno-cultural factors. However, limited research is available related to the service experience of immigrant and refugee families who have a child with a chronic health condition (physical disability or illness), mental health disorder, or developmental disability (hereafter referred to as "disability conditions" or "disabilities"). Areas of needed research should consider newcomer family experiences pertaining to health and social service access, utilization, and care experience (Newacheck, Stoddard, & McManus, 1993; Sritharan and Koola, 2019). In a 60-page report and literature review on the experiences and needs of refugee and asylum-seeking children in the United Kingdom, a single paragraph is devoted to those with disabilities (Hek, 2005). Given the growing number of immigrant families residing in North America and Europe, more information is

needed to guide service providers and inform policymakers about the best ways to meet the needs of newcomers whose children have disabilities (Cho, Singer, & Brenner, 2003). Immigrants and refugees experience complex issues affecting their access to and utilization of services (Thomson, Chaze, George & Guruge, 2015).

Research indicates that immigrant mothers of children with ASD are in need of essential system support services that include a range of specialties; however, these mothers often experience barriers to accessing services when care is most needed. This issue may continue to be exacerbated through the ordeal of stressors such as learning to navigate unfamiliar environments through sectors such as health care, education, and social services (Rivard, Millau, Magnan, Mello, & Boulé, 2019). To alleviate these stressors and promote greater awareness and urgency regarding ASD for newcomer families, the provision of equitable services requires the recognition of the challenges they face in accessing support and services for their children with ASD.

Evidence for the role of social support in facilitating improved outcomes for both newcomer parents and children is consistent (Hendricks, DeMoor, Oud, & Franken, 2000). In addition to accessing services, newcomer families of children with ASD require social support. Social support has been recognized as an important positive influence on the health and wellbeing of parents (Pelchat, 2007), and as a way to reduce family burden for parents of children with disabilities. Social support has also been linked to the timeliness and effectiveness of the outcomes of ASD interventions (Osborne et al., 2008; Weiss et al., 2017). Both perceived and actual social supports have been reported to reduce

parental stress, increase coping skills, and prevent parents from developing conditions such as depression and anxiety (Cachia, Anderson, & Moore, 2016).

Barriers to Social Support and Early Access to Services

Considering that timely diagnosis and optimal intervention effectiveness rely partially on social support, pathways for connecting to or accessing services for ASD must also take into account the supplementary support for newcomer parents that is received from other people or helping organizations. Community support experienced by newcomer parents with varying levels of social support and access to services may influence newcomer families' intention to proceed or delay accepting services associated with an ASD diagnosis or intervention (Becerra et al., 2014).

In Canada, the levels of immigration have been significant in recent years. In 2012, immigrants accounted for two-thirds of Canada's population growth (Statistics Canada, 2019). About 49% of Toronto's population identify themselves as immigrants, one-third being newcomers having arrived in Canada between 2001 and 2011 (Chakraborti, 2013). It is estimated that 56% of these families are refugees with children younger than 14 years of age who have not had access to either educational or health services for several years, and with parents who possess low literacy and language skills (GOC, 2016).

In light of increased ethnic diversity in Canada, it is critical that system efforts ensure the existence of equitable social, educational and health services for all, both in terms of access and provision. Immigrant families tend to leave behind strong social networks such as relatives and neighbours. In their communities, they continue to rely on their cultural perceptions, beliefs and traditions from their countries of origin. Views

related to child development and areas of health concern pertaining to their children may vary among newcomer families, as well as from perspectives held within the communities and regions in which they are now living. In this regard, they may have difficulty in navigating a different system for children which comes from cultural perception, and especially regarding neurodevelopmental conditions such as ASD (Shepherd & Waddell, 2015).

Studies have demonstrated that newcomer children with ASD have reduced access to resources, early intervention and, therefore, to positive outcomes (Chiao & Blizinsky, 2013). Immigrant parents are often unable to access needed supports due to language barriers, low income, and transportation limitations (Luther, Canham, & Young Cureton, 2005). Additionally, inflexible service offerings by the host community, reduced social networks, lower employment and marginalization have also been reported as interfering with service access (Greenwood, Holley, Ellmers, Bowling, & Cloud, 2017). Furthermore, the ways in which immigrant parents understand and approach childhood disability, parental acculturation levels, knowledge about child development and awareness of the availability of services have been found to affect access to services among immigrant families (Porche et al., 2011; Magana et al., 2013). This, in turn, has contributed to their experience of social isolation, guilt and shame (Sorheim, 2006).

Through these findings, it is apparent that parents who struggle throughout these situations may have a harder time understanding how to navigate the different service sectors in relation to raising their children with ASD. For immigrant and non-immigrant families from varying ethnocultural and racial backgrounds, the process required to

receive a diagnosis of ASD may serve as a barrier to accessing further services. In the United States, the literature indicates that families from diverse racial or cultural backgrounds often receive a later diagnosis for their children. The average mean age of diagnosis within these groups is reported to be 88 to 89 months (Daniels & Mandell, 2014). Canadian-born children are generally diagnosed between the ages of 39 and 55 months, depending on the region in Canada where these children reside (Ouellette-Kuntz et al., 2010). The trend is particularly striking in the United States where autism diagnoses of mild and moderate levels of severity are more likely to be identified at significantly later ages for minority groups (Heejoo et al., 2015; Monz et al., 2019). This delay in diagnosis has been attributed to several clinical, sociodemographic and geographic factors (Daniels & Mandell, 2014).

Cultural Considerations

Culture may be viewed as a continuously developing interrelated set of common goals, beliefs, and attitudes that are supported by specific groups or communities. These sets of values are passed from one generation to another within any social group (Ravindran, & Myers, 2012; Lai & Weiss, 2017). Research has shown that the way in which culture perceives ASD is dependent on what is socially typical or atypical in that culture (McDermott & Varenne, 1995). According to Daley's (2004) study, an actual diagnosis requires not only the knowledge of symptoms but also a belief that specific symptoms are problematic. Cowden and Kreisler (2016) emphasize the difficulties of screening for ASD in immigrant families. They agree that ASD requires interpretation within cultural contexts; therefore, the challenges to diagnosing and treating ASD are inevitable.

Daley (2004) found that parents in India tend to identify delays in social difficulties first. Conversely, other studies have shown that American families detect general developmental delays and difficulties in language first (Mandell et al., 2002). Other researchers have noted that Asian/Pacific Islander families were less likely than European families to agree that their children's behaviour was related to a disorder (Putnam-Hornstein, Needell, King, & Johnson-Motoyama, 2013). Asian cultures may consider it disrespectful to maintain eye contact or imitate adult gestures, which is a product of societal and cultural interpretation. However, such socialized behaviours may be misinterpreted as manifestations of ASD in the Western world (Welterlin & LaRue, 2007).

Families who hold Western beliefs have generally accepted an assortment of Western treatments for their children (i.e., speech therapy, behaviour therapy, occupational therapy) and rejected spiritual beliefs such as that destiny and/or their parental mistakes were the cause of their children's ASD. On the other hand, parents who held Indian beliefs combined both Western treatments and traditional treatments such as the Indian system of medicine called Ayurveda. These parents were prone to label ASD as the result of parental mistakes, karma, and destiny. This finding is consistent with other research that shows that some Native Americans, Latinos, and Asians believe that family members are responsible for their children's disabilities (Welterlin & LaRue, 2007).

Somali parents who have children with ASD have been hesitant to adopt the idea of a genetic explanation for ASD. They lean towards the perspective that their children's ASD is an acquired disorder, and they tend to adopt the idea that environmental factors cause ASD rather than genetics. Given this understanding, both Somali and non-Somali

parents have turned to alternative therapies for their children (Decoteau, 2017; Miller-Gairy & Mofya, 2015).

In trying to achieve early diagnosis, many fail to realize the variables that need to be considered in the process. Culture is among the many factors that allow for a deeper insight into individuals' behavioural and thought patterns. This is encompassed in the definition of culture: A group of people's ways of life, consisting of predictable patterns of values, beliefs, attitudes and behaviours (McDermont & Varenne, 1995). These patterns are learned and passed from generation to generation. In addition to these concerns, it should be noted that culture influences family structure and parental roles. This may, in turn, affect how parents experience their children's condition. For instance, in traditional views of gender roles, fathers provide instrumental, financial, and disciplinary support and are therefore less present in the child's day-to-day life (Hofferth, 2003). Thus, investigations of immigrant parents' stress must also take into account cultural differences regarding mothers' and fathers' respective responsibilities and contact with their children who have ASD.

Variations of cultural perspectives related to ASD are factors that immigrant families consider when seeking help and making decisions for their children. According to Habib, Prendeville, Abdussabur, and Kinsella (2017) norms associated with child development are clearly culturally shaped and have an impact on when a symptom may be recognized as problematic. As stated before, certain cultures may not consider lack of eye contact as a social difficulty, possibly preventing an early diagnosis. Ravindran and Myers (2013) suggest that recent immigrants may be at a disadvantage in accessing

services from health care settings based on potential preconceptions that may be held by service providers that people's cultural beliefs will be divergent from those of a Western perspective. If such preconceptions are not addressed, or if cultural perspectives are not truly understood or are ignored, a rift may develop with health care professionals being dismissive and families being distrustful of them.

Research Related to Newcomer Families and Engagement of Services

Barriers for immigrant families are most apparent at the outset of the diagnosis of ASD. Immigrant families have difficulty accessing services due to language barriers, low incomes, and transportation limitations (Sritharan & Koola, 2019). Greenwood and colleagues (2017) report that reduced social networks, lower employment rates, and marginalization can also act as barriers to access. Other contributing factors are the cultural beliefs about child development, knowledge about ASD, perspectives about disabilities, and awareness of available services (Magana et al., 2013). Aabe, Fox, Rai, & Redwood (2019) conducted 15 in-depth interviews with Somali parents affected by ASD. In this qualitative study, they found two major themes: perceptions of autism and navigating the system. The parents were exasperated due to being newcomers to a different country and having trouble with finding available resources and services for ASD. They found that lack of familiarity, in combination with a fragmented system and language barriers, contributed to delays for some families in accessing support for their children (Sritharan & Koola, 2019; Aabe et al., 2019).

Khanlou and colleagues (2017) also conducted a qualitative study with 21 immigrant mothers of children with ASD and found that the barriers to accessing services

were related to communication; not understanding medical terminology; lack of information; discord between health services, social services, and the school system; excessive paperwork; and lack of awareness of client needs by service providers. Millau and colleagues (2019) found that in comparison to non-immigrant families, immigrant families were twice as likely to lack sufficient sources of care and to report that physicians were not spending enough time with them. In addition, they found that in comparison to non-immigrant families, immigrant families were almost twice as likely to express a need for extra help for health care coordination and more than three times as likely to lack any health care coverage. Jegatheesan, Miller, and Fowler (2010) found that South Asian parents reported symptoms of ASD that were consistent with those reported by Western parents; however, they did not seek professional help immediately and instead took advice from extended family members. In addition, the families noted that medical personnel did not use simple language to explain their children's issues. This has been a common theme in other studies as well. Zuckerman and colleagues (2014) also revealed the struggles that families faced with therapists who worked with their children. They found that immigrant families were more likely to encounter a lack of support from their primary care provider and to report a lower satisfaction with physician-patient interaction. Khanlou and colleagues (2017) found that immigrant mothers expressed doubt that they would receive support and services when needed. One parent said, "We need more respectful translators with the knowledge about disability". The other mothers stated that they had expectations that their family doctors would be able to provide more information on ASD support and services for their children. There was an

overarching dissatisfaction with the nature of collaboration among health services, social services, and the school system.

Early intervention

Early intervention is critical for supporting the development and well-being of children with ASD. Camarata (2014) indicates that ASD is a lifelong condition; however, with early intervention many symptoms related to ASD may be reduced with children adapting alongside of their peers without the need for special support (Koegel & LaZebnik, 2014). However, without early intervention, this is unlikely. Most parents and professionals have the goal of alleviating symptoms that could negatively affect children's ability to engage in leisure activities and gain employment. Early intervention increases the likelihood of improved long-term outcomes.

Immigrant families also have additional barriers related to the migration and settlement process. In Canada, recent immigrants are three times more likely to live below the poverty line than people born within the country. Many newcomers experience unemployment, occupy low paying and precarious jobs, and are at a disadvantage in terms of learning opportunities and occupational advancement (Kazemipur & Nakhaie, 2013).

The expenses these families incur with regard to finding and accessing the necessary care for their children are challenging (Wang & Casillas, 2013). Some programs tailored for children with ASD may require additional funds that can be expensive for parents, especially those who may be facing other migration expenses and do not work full-time with benefits (Ennis-Cole, Durodoye, & Harris, 2013). For newcomers with

unstable and low paying jobs, there may be resource implications in the way families care for their children. For example, the financial resources required to ensure transportation to a medical appointment may be limited (Welterlin & LaRue, 2007).

Previous studies have also illustrated the importance of providing educational programs for parents in helping them navigate service systems. Such efforts provide needed information related to ASD and needed supports while reducing parental stress and increasing their quality of life (Rivard, Terroux, Parent-Boursier, & Mercier, 2014; Preese & Trajkovski, 2017). Providing information to parents on navigating support systems requires the use of straightforward language, ease of access to service networks, and services tailored to the needs of newcomer parents (Khanlou et al., 2015).

Families of children with ASD rely on more than one method or service sector in order to develop a successful education and integration plan for their children. Parents need to access a range of services simultaneously in order to support their children in different ways, inclusive of such resources as speech and language therapy, occupational therapy, and behavioural analysis. However, newcomer parents tend to use such services in different and more limited ways than do non-immigrant families. They also often access these services at a later age in their children's lives (Khanlou et al., 2017).

Challenges in navigating the health, social and educational systems may be a signal of the need to provide more individualized and family-centered programs and services that provide a direct access or clear pathway to services, accommodating the needs of newcomer parents. Stewart and colleagues (2000) argue that services may not be linguistically or culturally appropriate because they are often predicated on Euro-

Canadian standards of care. The challenges the service delivery system faces in terms of providing culturally sensitive services are complex, especially in the Canadian context where the population is increasingly ethno-culturally diverse (Khanlou et al., 2015). Furthermore, there is a layer of traditional reservation where some cultures will not acknowledge the developmental disabilities of children because of the lack of cultural acceptance that surrounds them. Familial and community support are factors affecting how newcomer parents perceive and move forward with an ASD diagnosis. In many cases, the result of a diagnosis may be perceived as the beginning of isolation for newcomer families (Stewart et al., 2000).

Concluding Reflection: Statement of Challenge and Need for Change

Families of children with ASD experience greater mental health, employment, social, and marital challenges in comparison to families of children with physical or intellectual disabilities (McIntyre, Blacher, & Baker, 2006). Unfortunately, these difficulties are widespread with one child out of every 68 receiving an ASD diagnosis. This prevalence rate has been increasing continuously in recent years (CDC, 2014). The stressors experienced by these families notably include delays in obtaining and confirming the child's diagnosis; seeking out and accessing appropriate services for both the child and the family; and transitioning between home and school as children and youth, and from school to community as young adults (McKenzie, Ouellette-Kuntz, Blinkhorn & Démoré, 2016; Osborne, McHugh, Saunders, & Reid, 2008). According to a recent study, between 54% and 60% of parents displayed clinically significant stress levels during the period following their child's diagnosis, as they were placed on a waiting list for services

(Rivard et al., 2014). These stress levels were influenced notably by the mother's education, the child's age, gender, and clinical profile, as well as waiting times for services. Immigrant families of children with ASD are doubly vulnerable to stress as they must tackle challenges inherent in their immigrant status alongside those of their child's condition (Berry & Sabatier, 2010). Their task of locating services and collaborating with professionals is made more complex by both language barriers and cultural differences (Pituch et al., 2011).

Immigrant families who have children with ASD face a variety of difficulties. Indeed, the symptoms associated with these diagnoses heighten the challenges of educating and caring for their children (McIntyre et al., 2006). Given the current situation facing newcomer parents of children with ASD in their efforts to access supports, it is imperative that researchers and practitioners gain greater insight into these caregivers' experiences and stories. Achieving a more in-depth understanding of potential barriers, gaps in services, and cultural dynamics experienced by newcomer parents will undoubtedly assist service providers from both health and education sectors in taking positive action to reduce or eliminate barriers related to accessing needed early intervention services for children with ASD and their families. It is my intention to carry out an investigation that gives voice to the stories of newcomer parents seeking the best support for their children within the Canadian health and education systems. As a newcomer to Canada over the past five years, I am excited to begin this research journey and to investigate potential directions for enhancing supports and services for newcomer families with children with ASD.

III. Research Design: Narrative Inquiry

Foundational Elements

Narrative Inquiry is rooted in the belief that people understand and derive meaning from their lives through the use of stories. Trahar (2009) describes Narrative Inquiry as a form of qualitative research that involves gathering narratives whether they be written, oral or visual and “attending to ways in which stories are constructed, for whom and why as well as the cultural discourse it draws upon” (p. 1). Stories are at the centre of Narrative Inquiry, whether they be stories of teaching, stories of and about students, stories of participants in programs, stories of fieldwork, stories of relationships or stories of illness. How to interpret stories and, more specifically, the texts that tell the stories is at the heart of narrative analysis (Patton, 2002).

According to Patton (2002a), two central questions are addressed related to Narrative Inquiry and participants’ shared stories. These include: *What does the narrative story reveal about the person and the world from which it came?* and *How can this narrative be interpreted to understand and illuminate the life and culture that created it?*

Narrative Inquiry has its underpinnings firmly rooted in hermeneutics, the theory and methodology of interpretation, and phenomenological research which involves the investigation of the essence of individuals’ lived experiences (Patton, 2002b; Josselson, 2006). Narrative inquiry has also been linked with the development of feminist and critical theory. Such research is also indicative of a post-modern perspective, embracing interpretive practices in every aspect. Interpretive processes are evident from the beginning point of framing research questions, to selecting participants, to posing

questions of inquiry and completing transcriptions of oral exchanges, to the final aspects of exploring the intrinsic meaning of written phrasing and observed verbal expression (Josselson, 2006).

Narrative Identity and Dialogical Features

The central thrust of the Narrative Inquiry design is to facilitate people's sharing of their stories through the development of rich descriptions that depict their sense of self, others, and the world in which they live. McAdams and colleagues (2001; 2006; 2011) explain that from individuals' stories flow their sense of self and identity, referred to as a narrative identity. As McAdams (2008) asserts, Narrative Inquiry investigates participants' internalized, evolving, and integrative story of the self.

According to Dorries and Haller (2001), although there are varied approaches for carrying out Narrative Inquiry, the central thrust remains the same in that "researchers seek to discover how social actors (participants) "perceive reality" and investigate their "stores about their reality" (p. 875). Researchers view narrative methods as an alternative to other literature approaches and, similar to the foundational assumptions consistent with grounded theory, emphasizing that meaning is explored through the use of conversation or shared dialogue embracing a dialogical approach. Noting the dialogical nature of Narrative Inquiry, Esterberg (2002) assumes that language and the nature of dialogue convey meanings, and that how a story is told is as important as what is said. Through conversation and dialogue, participants create the flow of experience in making meaning of events and actions in their lives. The ways of talking about sharing stories draws on the authenticity of participants and is influenced by both linguistic and cultural

resources in expressing the happenings, the sequence of content of what is exchanged and a clarification of how psychology and social aspects of how life has unfolded in the lives of individuals (Gubrium & Holstein, 2012).

Researchers and Participants in the Process of Narrative Inquiry

Narrative Inquiry “requires a great deal of sensitivity” between the researchers and participants (Marshall & Rossman, 1999, p. 86). Researchers are required to give their full attention to participants and employ active listening in interpersonal interactions. The development of rapport resulting from researcher-participants’ interactions sets the stage for storytelling and exploring personal experiences. Researchers value and reflect the “signs, symbols and expression of feeling” of participants and validate how they construct meaning through their shared stories (p. 87). According to Marshall and Rossman (1999), the relationship that emerges for narrative researchers and participants should be genuine, mutual, and collaborative in nature and one in which both voices are heard.

In the Narrative Inquiry process, researchers begin from a *curious*, rather than a *knowing* position. They focus on the use of areas of inquiry that assist participants in expressing “cultural context; their embodied engagement in the events, their senses, feelings; thoughts, attitudes and ideas; the significance of other people; the choices and actions of the teller: based on values, beliefs and aims; historical continuity; and metaphors, symbols, and creative, intuitive ways of knowing” (Etherington & Bridges, 2011, p. 12), which create pictures that capture vivid representations of experiences.

Narrative researchers explore how participants derive meaning from their experiences and understand that meaning is often multi-layered and implicitly linked to the context in which participants have lived their experiences (Anderson & Gehart, 2007; Etherington & Bridges, 2011). Within qualitative investigations inclusive of Narrative Inquiry, researcher subjectivity is regarded as being linked to the process of gathering, organizing, interpreting, and co-constructing stories. Researchers are encouraged to be thoughtful, conscious, and critical of their own influences and how they may impact their participation in the research process (Goldstein, 2017). The expression “reflexive engagement” describes researchers’ intention “to own” and to be “reflective about their personal voice and perspective” throughout the research process, and to analyze and depict the shared stories of participants “authentically in all their complexities while being self-aware... and reflexive in consciousness” (Patton, 2002a, p. 41).

Types of Narrative Inquiry Research

Selecting a type of Narrative Inquiry entails defining how researchers decide to represent or retell stories based on the narrative form that best represents the research data (Barone, 2007). Generally, Narrative Inquiry research may be organized into three different types of genre. These narrative forms include autobiographical, biographical, and arts-based genres (Kim, 2016).

Autobiographical Narrative Inquiry may be divided into two forms: autobiography or autoethnography. In the study of literature, autobiography is often applied as an overarching term to define varied narratives that represent self within a historically situated context or setting. This type of genre focuses on the construction of identity

based on written narrative accounts or stories shared from a view from the past. In contrast, autoethnography is a type of Narrative Inquiry in which researchers systematically analyse their own personal experiences or stories in the context of the broader social or cultural setting (Kim, 2016).

In contrast to autobiography and autoethnography, biographical Narrative Inquiry investigates the lived experiences and perspectives of others. This entails exploring the narratives of individuals' daily lives in which their present and past experiences and future aspirations become the focus of how participants derive meaning (Denzin, 1989). Of all the genres, biographical Narrative Inquiry has become the most prolific application of all the Narrative Inquiry genres. Numerous research centres across academic settings have dedicated themselves to investigating the lived experiences of people through their personal narratives or stories (Kim 2016).

Finally, arts-based Narrative Inquiry applies literary and visual art to accompany narratives in order to communicate the meaning and essence of the stories shared by others. Examples of arts-based expressions may include short stories, fiction, poems, photography, or video.

The creation of literary or visual arts is integrated into the entire process of carrying out Narrative Inquiry research and may be part of framing, analyzing, interpreting or producing representations of shared stories. A key condition of conveying in-depth understanding of meaning in the lived experiences of others is empathy (Kim, 2016).

Applications of Narrative Inquiry

Narrative Inquiry has become recognized as an applied research design within the field of qualitative research since the early part of the 20th century. This research design makes use of artifacts inclusive of people's stories, journals, letters, conversations, family accounts and pictures, as well as other mediums that reflect meaningful life experiences. Such artifacts are engaged as units of analysis to investigate the ways people create meaning through narratives. Narrative Inquiry has been applied to numerous disciplines to describe the lifestyles, identity, and experience of people who share their stories with others. Such investigative methods focus on the essence of human experience through inquiry methods that generate records within a story layout, whether these be testimonies, oral histories, written autobiographies or biographies. According to cognitive science, the use of real-life narratives is more memorable and supports learning and positive change among people more so than those of nonstory narratives (Patton, 2002a).

Given Narrative Inquiry's potential to illuminate critical aspects of human experience and learning, it has emerged as an accepted cross-disciplinary research design being applied in such diverse domains as sociology, anthropology, history, nursing, psychology, education and communication studies. In particular, Narrative Inquiry has readily been embraced by both the educational and health professional communities as an approach for gaining insight into the lived experiences of people who have grappled with specific challenges or obstacles. The understanding of such insights has been regarded as critical for shaping the ways in which service providers and practitioners can

be more sensitive and responsive to the needs of people. Within education, this may entail exploring the lived experiences of teachers and students or their families within the context of learning or growing. Similarly, within in the health field, this may involve exploring the experiences of individuals living with challenging conditions or limiting diseases, and their journey of recovery or accessing supports or being resilient (Kim, 2016; Patton 2002a).

Narrative Inquiry research designs and methods are often more readily received by participants who have non-research backgrounds than research designs that are steeped in more formal language, concepts, or extensive explanation (Patton, 2002a). As Patton (2002a) expresses: “It makes quite a difference when talking to people in a community to say, ‘We’d like to hear and record your stories versus we’d like to do a case study of you’” (p. 199).

Benefits and Criticism Related to Narrative Inquiry

Etherington (2011) highlights a range of potential strengths associated with Narrative Inquiry and its application. She describes four key advantages of this research design:

- Narrative Inquiry brings together in-depth understandings and layers of meaning related to people, their culture and how they move or moved through change.
- Narrative Inquiry elicits meaning and brings organization to peoples’ stories of struggles in light of their values and beliefs, and how they shape their hopes and intentions for the future.

- Narrative Inquiry facilitates the exploration of how knowledge is situated and depicted through accounts of multiple voices, experiences and perspectives.
- Narrative Inquiry processes can be empowering for individuals not only in terms of validating their respective stories but also the insights they bring to illuminating areas of relevance and benefits in the lives of others.

Some theorists have also raised criticism associated with Narrative Inquiry methods because of their focus on the examination of individual stories to understand larger social dynamics or conceptual constructs. Such critics point to possible gaps in participants' experiences and the potential of individuals filling in missing aspects of stories with inferences or personal interpretations of past events. Other writers also caution narrative researchers in their analytical efforts to be careful of drawing conclusions related to cause and effect in their analysis of participants' stories or sequence of happenings. Two final challenges that have been cited in the literature related to Narrative Inquiry include the need for extended periods of time and resources in order carry out such research methods, as well as the need for Narrative Inquiry research programs to adequately delineate their actual implemented methods or approaches to analysis (Viney & Bousefield, 1991).

Position of the Researcher

According to Polkinghorne (2007), issues of validity in narrative research relate to how well the evidence is regarded as a portrayal of the participant's experiences. He asserts that the gap between the actual experience and the narration of the experience

may be limited by language, the time for reflection, and the complexity related to the cocreation of the narrative by the interviewer and the participant.

As a family physician, I understand the importance of family. Even more so as an immigrant, I recognize how family dynamics entwines with the collectivist culture that is common within South Asian communities. It is through these facets of my life that I found how closely family and health entwine. My son was diagnosed with ASD at a young age. As a mother and as an immigrant, I have had my own trials and tribulations when it came to identity and the healthcare environment. These two aspects of life should not be in conflict, but rather, create the opportunity to provide better service to those who are marginalized. I utilized my own experiences as an immigrant mother to sympathize and extend my concerns to immigrant mothers with children diagnosed with ASD.

I believe it is important to support the two sides: the immigrant mothers and their insights, and the healthcare system and its own approach. It is from there that we can identify flaws and start accumulating ways to bridge the apparent gap between cultural and medical intervention. Through communication, data, and testimonies, we can arm ourselves with valuable insights that go beyond shallow survey questions and determine where the disconnect begins between healthcare providers and immigrant families.

There is also the reality that many children of newcomer families receive a later diagnosis of ASD, which is detrimental to receiving earlier supports. Late diagnosis can serve as the most harmful consequence that comes from the culmination of the barriers encountered. This, in turn, could cause families to miss out on valuable support needed

to assist their children, further alienating them and causing feelings of depression and anxiety.

The problem has been exacerbated by the difficulties of identifying ASD. There is screening but no simple checklist that can be used for diagnosis because the disorder is a spectrum. This is especially relevant to young people in whom spectrum-like behaviour can be triggered by causes unrelated to autism. Most parents are not experts in mental health, which means that they may not be qualified to recognise all the symptoms of ASD, no matter how educated they are.

A recent study concluded from the U.S. Centers for Disease Control and Prevention indicated that white children were more likely to be identified with ASD than black or Hispanic children. About one in 63 white children were diagnosed, but only one in 81 black children and one in 93 Hispanic children. We need to understand that in the context of families with ASD, there exists an inequality of diagnosis and even the challenge of approaching a diagnosis at all.

Einstein has said “Insanity is doing the same thing, over and over again, but expecting different results”. I believe this sentiment to be true when we discuss the urgency for early diagnosis and for supporting children with autism. We tend to leave out marginalized communities, having them struggle for a voice, or even for the words to explain their exclusion or the hurdles they have come to face.

Very few research papers have been written on the subject of ASD and newcomers’ experiences. Inclusivity and health must be reconciled in order to fulfill the mandate of providing quality health care for all. As a physician, a mother, and an

immigrant, I believe in the vision of an effective healthcare system; however, its mission must be carried out without sacrificing culture. As service providers, we must be willing to adapt to new ways of thinking without sacrificing the health and well-being our children.

As we move towards the future, I hope to see the healthcare system broaden its scope of care and be immersed in new research that emphasizes the need for cultural sensitivity and the recognition of barriers that are prominent in its operations. The only direction we must choose is forward, one step at a time, with everyone.

IV. Research Methodology

Area of Inquiry

ASD is regarded as a spectrum disorder given the variability in the types and severity of clinical features that individuals may experience. This disorder is found across all ethnic, racial, and economic groups. Although ASD impacts the functioning of individuals across the lifespan, having access to the right services at the right time can make a positive difference in the daily adaptation, coping, and quality of life of children, youth and their families (NIMH, 2018). This study has assisted me in gaining insight into the stories of newcomer parents to Canada who have children identified with features of ASD. More specifically, my interest has been centered on gaining a greater understanding of the personal narratives of parents related to seeking, engaging and sustaining educational and health service system supports for their children with ASD. My central research question for this narrative investigation was: “What are the stories of newcomer

parents in seeking, engaging and sustaining system supports for their children with ASD?”. Within this global research question are various underlying areas of inquiry that have been investigated in the context of parents’ unfolding stories. These include questions focusing on seeking, engaging and sustaining support for their child with ASD:

Seeking Support

What specific influences preceded participants’ concerns related to the presence of potential ASD features in their children’s functioning? What were the initial experiences of participants in dialoguing with others in the educational and health system about these concerns? What challenges did they experience in initially navigating health and educational system supports? How did participants initially access and form connections with health and educational service providers? What experiences rendered greater ease or challenge in seeking support?

Engaging Support

What processes, events or experiences were part of assessing or exploring areas of need or concern related to their children’s functioning or adaptation? How did participants move forward with recommended services or programs? What challenges did participants experience in engaging support and how were they resolved or worked through? Did they feel part of the support process in terms of setting goals and directions related to areas of health or learning for their child? What experiences rendered greater ease or challenge in engaging support?

Sustaining Support

What aspects of service follow-up were noted in participants' stories? What were participants' experiences related to scheduled breaks in or absences of ongoing programs and supports (e.g., summer breaks, professional learning days; school transitions)? How did participants navigate these experiences and what sources of support did they pursue during these time periods? What lessons learned/insights would they share with other newcomer participants with children with ASD? How could the insights from their stories be most effectively shared with others?

Participants

Patton (2002a) defines purposeful sampling as the selection of "cases for study (e.g., people, organizations, communities, cultures, events, critical incidences)" that are "information rich" and "illuminative" in terms of providing authentic insights into the focus area being studied or investigated. For my research, I have included a purposeful sample of first or second generation newcomer parents to Canada who have distinctive linguistic, cultural and community backgrounds and experiences. These participants also have the experience of being parents to children with ASD. The selection of potential participants was carried out using my existing health and peer networks composed of my linkages with community-based and support agencies that assist newcomer families with children with ASD (e.g., Multicultural and Opal agencies). Through the leadership and administration of these support organizations, I distributed a letter of description outlining the purpose and activities of my research. Parents or caregivers who demonstrated an interest in being part of this study were given my contact information for follow-up. A total of six participants took part in this data collection effort.

Data Gathering

For my research, the chosen data gathering approach involved the completion of in-depth interviews with participants. According to Acosta and Douthwaite (2005) researchers apply “basic skills of active listening and probing” to draw out detailed descriptions of participants’ stories. Such stories provide the means of understanding settings and circumstances that were challenging or empowering for individuals, the role of previous history in people’s lived experiences, and how past stories connect with present realities and plans for the future.

The interview process involved the use of a semi-structured format that ranged from 60-90 minutes in length. In light of current COVID-19 restrictions, interviews were undertaken using online technologies (Zoom) and were digitally recorded for later transcription. The use of open-ended questions and probes were applied to invite participants’ sharing of detailed descriptions of lived experiences related to seeking, engaging and sustaining supports for their children with ASD. I developed an interview guide that was used throughout the data gathering process. This guide entailed three broad primary questions with each one accompanied by several probe-focused areas of inquiry.

Following completion of the interview analyses, a second interview was undertaken with participants to present to them the resulting codes and theme categories that emerged from the analyzed interviews. Participants’ responses to the presentation of this summary analysis of the interviews were digitally recorded and used to review, affirm, and carry out a final refinement of key themes codes and categories (Butina, 2015).

Data Management

Given that interviews are the primary data collection approach for this endeavour, I strived to create a positive environment that was psychologically safe and comfortable for participants within an atmosphere that facilitated the authentic sharing of their stories. As a result of the current government and university policies in place because of COVID-19, interviews were carried out using Zoom. To ensure a safe and secure environment for all participants, recommended procedures were implemented including assignment of a different ID and password for each scheduled data collection session, and the provision of a virtual waiting room with the admission of participants being coordinated by the researcher.

Individual interviews were digitally recorded (audio only) and subsequently transcribed. Field notes in the form of a reflective commentary were completed at the close of each interview. In addition to noting the time and location that interviews occurred, these written accounts included my descriptive reflections related to the interactions experienced during the interviews. All documents containing personal or confidential information were stored on a password protected computer and all electronic files were assigned an ID number for identification.

Data Analysis

A narrative thematic analysis process was undertaken for this research effort. The data analysis approach was divided into five discrete stages (Butina, 2015). The first stage involved the preparation or organization of the data by completing the transcriptions of each of the digitally recorded sessions. Transcriptions of the data were done in a timely

fashion following the completion of each interview. As data were being transcribed, any emerging themes or patterns were noted in the margins. Fictitious names were assigned to each participant and any personal information such as names or locations were changed or taken out of the written transcription. Transcription files were produced using a consistent presentation format with respect to font size, margins, questions and highlighted interviewer comments (Butina, 2015).

The second stage involved gaining a sense of the overall data collected. Once transcriptions were created, I read them several times with the intent of becoming reacquainted with the experiences of the participants and developing increased sensitivity to the range of potential themes found in the various transcribed stories. This stage is regarded as critical for initiating a “progressive understanding” of the themes that may emerge during the process of data analysis (Thomas, 2006).

The third stage involved carrying out the coding process. According to Butina (2015), the coding process involves “re-reading the transcripts and identifying recurring words, ideas, or patterns generated from the data” (Butina, 2015, p. 194). During this stage, I re-read each of the interview transcripts, highlighting any portions of text that involved emerging messages, ideas, or any recurring words or patterns. For each of these units of text, I developed a corresponding code. According to Saldana (2016), codes are often a word or short phrase that “symbolically assigns a summative, salient, essence capturing or provocative attribute to a portion of language or visual-based data” (p. 4).

Following the completion of the first transcript analysis, the preliminary master list of codes were produced. Subsequently, I moved on to the next transcription analysis. As

new data were analyzed, emerging codes were compared with those from the master code document. If existing codes were applicable, they were used and elaborated to reflect the richness of the analyzed data. In other instances, new codes were developed and added to the existing list of codes.

The fourth stage involved the creation of theme categories. Over the course of the analysis, codes were sorted according to common themes or areas of affinity to form categories. Saldana (2016) refers to process of developing theme categories as a method for “synthesizing the collective” or the process of moving towards “consolidated meaning” (p. 9). Following the initial process of coding and categorization during stages three and four, I repeated these analytical procedures in order to reduce areas of overlap or redundancy in original codes and categories, further refining initial conceptualizations of the data (Saldana, 2016). As a result of this second round of analysis, original codes and categories became more refined. Table 1 provides an example form for facilitating the development of codes and categories during the analysis process (Butina, 2015, p. 194).

Table 1

Data Analysis of Karen’s Narratives.

Table 1. Data Analysis of Karen’s Narratives. Example of the stages of narrative thematic analysis performed on Karen’s transcripts. The interviewer has been designated as “X”. The bolded lines, within the narrative, were originally highlighted and led to code development. The corresponding code is found in the middle column. In the last column is the category or theme that corresponded to the assigned code.

Transcript passage	Initial code(s)	Corresponding category/theme
X: Tell me about an incident or experience that made you proud to be a clinical laboratory practitioner.		
KAREN: My brother-in-law, this is a personal example, my brother-in-law was just recently diagnosed with Good-Pasteur’s syndrome. Before they diagnosed him, he was very sick, and they were running a lot of tests, and my sister called me a lot. This is what they are running and what does it mean, what are they looking for. It made me feel like she was recognizing what I do and letting me help her through this really difficult process, I think in a personal way, it made me feel proud that she looked to me as the source of knowledge to help her understand what was being done and what was going on. So that is probably the most immediate one I can think of. And here again, I’m sure there are others but I just can’t think of them right now.	1) Experiences of perceived recognition or respect 2) Proud to be practitioner	1), 2) Role and value of clinical laboratory practitioners
X: Tell me about an incident or experience in which you were disappointed with being a clinical laboratory practitioner.		
KAREN: Oh like the time the doctor said you are just a med tech. It was when I was in client services and I wish I could remember the specifics of what she had called for or called about but I’m trying to explain it to her and she wouldn’t listen and finally she just blurted out, “what do you know you’re just a med tech”. You are calling about lab tests this is what I do. That would be like me questioning her and I was just so stunned I couldn’t say anything. But it made me feel really diminished that she didn’t have any more respect for the profession or for me. Who else were you going to call with this question? You didn’t know it or you wouldn’t have had to ask. But that definitely was a humbling moment.	3) Negative experience with physician 4) Misunderstood 5) No respect	3), 4), 5) Being misunderstood by fellow healthcare team members

Butina (2015) refers to the final step of analysis as the process of “interpretation” or “making-meaning stage” (p. 194). Although this aspect is referred to as the final stage, it was actually intertwined with every aspect of developing and refining codes and categories. This part of the analytical process involved making sense of the data as codes and categories were created, refined and organized. Making meaning from the data also involved analyzing any emergent commonalities among categories, or overarching concepts, theories or frameworks that presented or conveyed important insights related to the major area of inquiry or underlying research questions. A summary of the final codes and categories was shared with participants for their consideration and feedback.

Trustworthiness of Data

Shenton (2004), based on Guba and Lincoln (1994), describes four main approaches for addressing the trustworthiness of data obtained from qualitative research

studies. These considerations are credibility, transferability, dependability, and confirmability. The following outlines the steps I undertook to address these criteria of trustworthiness in my research study.

Credibility

Credibility refers to ensuring confidence that the researcher has accurately recorded the data related to the focus of inquiry, and that these descriptions are congruent with the experience of the participants. In order to address this criterion, I implemented the following key actions:

- The selection of research design and methods that are recognized in the literature:
For my research I undertook a narrative inquiry design to investigate the lived experiences of newcomer parents in terms of their efforts to seek, engage and sustain services for their children with ASD (Shenton, 2004).
- The researcher's reflective commentary: A reflective commentary was completed at the close of each interview. This commentary included field notes, initial identification of recurrent themes, and my personal responses and reflections related to the conducted interviews (Shenton, 2004).
- Member checks: Upon completion of the analysis of interviews, a summary of the identified codes/categories, and overarching themes was presented to participants in a second round of briefer interviews. Feedback from participants provided the basis for reviewing, refining or elaborating key outcomes (Shenton, 2004).

Transferability

Transferability pertains to the possibility of applying the findings to other contexts beyond the investigation. Although it is impossible to ensure that the findings of the research were applicable to other situations, individuals or groups, I attended to the presentation of detailed descriptions related to the lived experience of participants. The intent was to provide readers with sufficient detail to consider the applicability of the given findings to their own situations or contexts (Shenton, 2004).

Dependability

Dependability entails providing sufficient details related to the proposed research design and methods to be carried out. This involves providing readers with a detailed understanding of the planned research program so that it could be implemented to explore similar research questions or be carried out in another setting. For my research, I outlined the key details of my research plan as well as outcomes associated with its implementation. This included the presentation of detailed descriptions related to the design that was undertaken, the specific methods that were implemented, as well as the descriptions of any challenges, successes or adaptations that were experienced (Shenton, 2004).

Confirmability

Confirmability requires that researchers to undertake efforts “to ensure as far as possible that the work’s findings are the result of the experiences and ideas of the informants, rather than the characteristics and preferences of the researcher” (Shenton, 2004, p. 72). This involves researchers being open and aware of their personal

perspectives and predispositions regarding the given area of investigation. For my research, confirmability was addressed through my use of reflective journaling following each interview and through the addition of member checking by including a second round of participant interviews (Shenton, 2004).

Ethics and Consent

The completion of ethics and appropriate consent processes is a critical part of participatory research programs and contributes to authentic, open and safe communications between researchers and participants (Butina, 2015). The University of New Brunswick has assigned Research Ethics Boards (REBs) with the responsibility of ensuring compliance with Tri-Council policies for all research projects at the University. Upon successful completion of my proposal defense, and when suggested revisions were finalized, I completed the required ethics forms and processes. When ethics clearance was received, I initiated my research plan under the supervision of my supervisor and committee.

V. Results

Introduction

This aspect of the thesis provides an overview of the outcomes of the narrative analysis process of participants' interviews. Upon completion of the initial interview analyses, a summary of emergent theme categories and sub-themes was shared with participants through short, individual follow-up interviews. As described earlier in the *Credibility* section, member-checking sessions resulted in the affirmation of the broader

categories that emerged from this research effort, and responses from participants indicated resonance with specific sub-themes and categories. At the close the member checking process, twelve theme categories and associated sub-themes were identified in response to the three areas of inquiry that guided the interviews with participants. The major theme categories (which expanded to include sub-themes within each category) were:

- 1) Recognizing ASD Features
- 2) Finding a Starting Point
- 3) Struggling to Access a Primary Healthcare Provider
- 4) Engaging Walk-in Clinics and Referrals
- 5) Experiencing Professional Support and Advocacy
- 6) Receiving ASD Support Services
- 7) Clarifying Educational Support Plans
- 8) Losing Confidence in Systems of Support
- 9) Grappling with Parental Concerns, Anxieties and Regrets
- 10) Emphasizing the Imperative of Mental Health and Well-being
- 11) Reflecting on the Encompassing Role of Parents
- 12) Extending Broader Community Awareness

The subsequent sections provide a brief background about research participants, followed by a presentation of the various theme categories and supporting sub-themes. Throughout the descriptions of each of the theme categories, quotes and interview excerpts are employed to illuminate perspectives and insights shared by participants.

Participants' Background

A total of six participants agreed to be interviewed for this research effort. All were married or living in a partnership relationship prior to coming to Canada and reported having more than one child, ranging from two to four children. Participants had also completed post-secondary education with at least an undergraduate degree and often accompanied by additional professional or certificate training. In terms of specific professions, two participants were in engineering or science-related fields, two others were involved in the business or private sector, with the remaining representing employment areas related to technology and communications. Two participants were also from the same family unit representing parental roles, but interviews focused on a different child within their familial context. All were fluent in more than one language and were proficient or possessed sufficient skills in English to adequately communicate their thoughts and feelings related to the research focus for this investigation.

Participants' places of origin varied, reflecting diverse regions from the Middle East, Africa and South Asia. All participants had also emigrated to another country from their original home country prior to coming to Canada. In addition, every participant had at least one child within their family who was diagnosed on the autism spectrum; however, knowledge of family history related to other family members with autism was not immediately recognized or reflected upon prior to the initial diagnosis of their child. For this participant group, descriptions of their experiences represent six individual children (three males and three females) diagnosed with Autism Spectrum Disorder (ASD) in Canada.

Theme Category 1: Recognizing ASD Features

Sub-Themes
<ul style="list-style-type: none">• <i>Differences, shifts and departures (Developmental milestones, observations)</i>• <i>ASD features and behavioural concerns</i>• <i>Impetus for immediate action (Information and supports)</i>• <i>Connection and access</i>

He had this different behaviour where he would repeat certain things.

So initially it did not really click...

He wasn't interacting with his older brother and sister at all.... He would not say anything...

At the outset of the interviews, participants described how they first noted or began observing differences in their children. Differences were often described in terms of departures from the developmental milestones they had experienced with their other children or shifts in their behaviour or interactions.

He was delayed, like he was not sitting or crawling on time like his older brother. ...he was not reaching his milestones...

...my daughter never looked towards me ...when I used to call her, she used to turn towards my direction.

Features of concern included “repetitive movements”, “lack of social interactions or responsiveness to others”, “verbal delays”, “sensory sensitivities”, and “behavioural issues”. In addition to these features, three participants highlighted other comorbid concerns, related to “inattention”, “hyperactivity” and “impulsivity”. At times, these behaviours were identified as worrisome and disconcerting for parents.

He was hyperactive and he didn't respond to his name...no sense or feeling about danger. He can walk cross the street in front of cars...

Participants spoke of making comparisons based on their experiences with their older children and their development. Children's siblings gave participants a reference point from which to consider and seek understanding of features of ASD. Differences and shifts in observed behaviour and interactions, as well as growing concern regarding their children's development, served as an impetus for participants to initiate the search for additional information, support or assistance. In terms of general knowledge, most participants had minimal or no knowledge of ASD. Various participants reported seeking information regarding the features they observed in their children prior to coming to Canada in their home country or other places to which they had emigrated. In these contexts, ASD had not been entertained as a possible condition linked to their areas of reported concern. In terms of the Canadian setting, one participant highlighted reaching out and having a seamless and accessible point of contact based on previous connections or interactions with specific health providers. As this participant stated, *"I immediately called my nurse practitioner and explained to her what was happening. She sent me to Dr....., the pediatrician"*. For others, sources of immediate support or care were not as evident and pathways to such sources of assistance were not initially clarified.

Theme Category 2: Finding a Starting Point

Sub-Themes
<ul style="list-style-type: none">• <i>Navigation Challenges (Awareness/Knowledge of Services)</i>• <i>Informal Networks and Pushing for Services</i>• <i>Service Guidelines and Peer Support Groups</i>• <i>Barriers to Access (Finances, Transportation, Lack of Specialized Services)</i>

My biggest barrier was and is that I'm not aware...

We were not well informed. We were already struggling...then to navigate and find services on our own was a challenge...

Five of the six participants described their initial efforts to navigate systems of health support. At the outset of seeking services for their child, the main challenge for participants was being knowledgeable about services, especially in terms of the importance and nature of beginning with assessment, essential information about ASD and the applicability and availability of support services. Participants often began inquiring about potential services and access points through their own community networks. Other newcomers, colleagues at work and neighbourhood acquaintances relayed their own stories or accounts regarding accessing intervention or support services for their children. These initial network contacts served as a starting point for becoming aware of community autism centres and potential supports or resources available through the Department of Social Development.

Yeah, I had to ask my friends and other people who are getting the same services.

We met the people there (autism support centre), and we asked them about their services and what they do...we asked if they can do assessments ...so we could find out for sure if he has autism or not...they started connecting us with people that might help him.

Although these informal networks did not necessarily result in specific referrals or actual appointments, they did contribute to participant awareness of essential service information that was regarded as helpful as they continued to navigate the system. Some participants indicated that they found out about services because others had engaged them; therefore, they would in turn seek them out for their child. Beyond health and the social development services, accessing educational supports with their child's school or district was also identified as initially challenging. Even when a diagnosis of ASD had been established, developing plans and engaging resources in a timely manner was described as "not an easy process" and one where they required to insist or "push" for services. As one participant asserted:

...They didn't offer all the services from the beginning...

I had to push and push to get what I'm getting now.

Overall, participants described accessing the right supports at the right times as very difficult, especially without knowledge of existing services and without support in navigating how to access such programs. Participants recommended that specific guidelines should be available to families about what services were available to them and how to access them. Having written material as well as support personnel were identified as important components in helping newcomer parents navigate educational,

health and social supports, especially when they are newcomers to the community. One participant also highlighted the need for such guidelines to be available in diverse languages appropriate for the cultural and language background of parents.

There should be some kind of guide that should be given for the families that have a child with a disability... this guide should be explained by someone who already has experience in getting those services and experience with the system.

Another participant highlighted the potential benefits of organizing parent support groups composed of newcomers and their peers. This individual advocated that such groups have the potential to “help”, “guide” and “mentor” those experiencing challenges and who are discouraged regarding their efforts to effectively navigate and access essential services and supports for their children.

Other barriers related to accessing services involved competing challenges and priorities related to settling into new communities as newcomers. Adapting to new community settings entailed making transitions to new living circumstances and neighbourhood relationships, new work contexts and employment responsibilities, adapting to unfamiliar school routines, and finding daycare supports.

I couldn't maneuver everything... it's very tough... My job search...

My credentialing process...not being able to work.

Lack of financial resources and transportation to support access to assessment services and more intensive services were also highlighted. Another participant underscored the lack of access to sufficient specialized or trained personnel in their

region as a barrier to meeting the level of need for assessment and intervention services.

Theme Category 3: Struggling to Access a Primary Health Care Provider

Sub-Themes
<ul style="list-style-type: none">• <i>Shortage of Primary Healthcare Providers</i>• <i>Absence of a Hub to Connect with Services</i>• <i>Engagement of Private Services</i>

*The only challenge I would say is **No** family doctor!*

Newcomers need family physicians. They are necessary...

Closely related to participants' initial efforts in seeking out potential supports for their children was the reported service gap related to insufficient numbers of primary healthcare provider in their immediate regions. All participants indicated that they did not have a primary healthcare provider or doctor at the time of their initial arrival in New Brunswick. The shortage of primary healthcare providers was highlighted as a gap faced by many Canadians and more specifically by newcomers.

For participants, access to a primary healthcare provider represented a connection to other services or supports, or at least the possibility of a connection. In other words, the family physician or primary healthcare provider was regarded as a hub around which needed services could be accessed through referral or direct efforts made by the physician on behalf of the parents to specialists with knowledge and expertise related to ASD. Without a primary healthcare provider or other advocate, participants viewed themselves as being "on their own" in seeking out services in the community,

both in terms of locating assessment services and with connecting to recommended service supports. Without access to a primary healthcare provider, referral to specialized health services was either limited or absent.

A key concern was that without a primary healthcare provider there would be no file and no plan for moving forward. At the time of the interviews, only one of the participants had succeeded in identifying a physician for their family. One participant also mentioned the challenge of finding a physician who spoke French, which was a more comfortable language for family members.

In the absence of a primary healthcare provider, two participants pursued private specialized services to expedite assessment and intervention activities for their child. These services included engaging a psychologist with expertise in ASD, and a speech language pathologist and occupational therapist to assist in the design of interventions that could be used in the home or school settings.

Theme Category 4: Engaging Walk-in Clinics and Referrals

Sub-Themes
<ul style="list-style-type: none">• <i>Lack of Service Continuity and Retelling Stories</i>• <i>Delays and Wait Times</i>• <i>Lack of Sufficient Services Intensity</i>• <i>Need for Follow-up and Check-ins</i>

I went to a walk-in clinic at the beginning because I didn't have a family doctor.

I looked around I went to the walk-in clinic and asked the family doctor... to guide me.

For participants, walk-in-clinics were used as a primary means for seeking access to additional services within the system. The challenge with such services was the lack

of continuity of consistent personnel when appointments were necessary to move plans forward to address the needs of their children. As one participant highlighted, having to go through a walk-in clinic meant retelling their story to new health personnel and “delaying the process” and “prolonging the time” to access more specialized assessment or intervention services such as those provided by hospital services or rehabilitation centres.

It took a long time until I received the first support.

I don't believe that we have a lot of autistic children here... the bureaucracy and then the paperwork and all that.

Although it was difficult to establish continuity of relationship through the walk-in clinics, participants persisted, and referrals were undertaken by health professionals to connect them with assessment or intervention services for their children. When referrals took place, significant time to process these referrals was noted with delays ranging from eight months to two years in duration. One participant expressed a level of frustration with the paperwork required to formalize a referral or to complete the intake information for the given request for service.

He referred us to be included into an autism intervention service. So, the autism intervention service literally took six months, we had to wait...The challenge was the timeline...every step of the process...too long ...and we are not in a big city.

With respect to assessment referrals, participants noted that following through on recommended supports meant completing new referrals or contacts which invariably resulted in more delays for securing needed supports or services in the home and or

school settings. As one participant highlighted: “I struggled for more than two years to access services... I would have liked to put my child into early intervention services.”

In one participant account, when specialized assessment services were engaged as a result of a referral through hospital services, the resulting recommendation highlighted specific services or supports that would be beneficial to have in the school setting. Although these services were suggested, the availability of such resources was not readily accessible at the right intensity through other government departments such as social development or education. When such challenges were encountered, participants were often limited in terms of whom they could turn to or speak with regarding their concerns. Without the continuity of a consistent primary healthcare provider, access to ongoing check-ins or follow-up appointments related to specific referrals or recommended program supports were not always options for participants.

Theme Category 5: Experiencing Professional Support and Advocacy

Sub-Themes
<ul style="list-style-type: none"><li data-bbox="349 1287 820 1318">• <i>Provider Sensitivity and Listening</i><li data-bbox="349 1325 820 1356">• <i>Communication and Connectivity</i><li data-bbox="349 1362 846 1394">• <i>Pediatrician Advocacy and Support</i>

Despite challenges associated with initiating services through walk-in clinics, participants reported that their decision to seek support through these clinics was an important turning point in their efforts to find services for their children. It was through these initial appointments with health professionals in these contexts that they encountered physicians and nurse practitioners who actively listened and conveyed understanding of their stories. These interactions were linked with a sense of receiving a

level of personal support and advocacy. These emotional responses were further bolstered when followed by concrete action to ensure communication and connection to referred programs of support or services.

The doctor saw her... communicated to all relevant places...everything is systematic... communicated with the centre (RHA/hospital related) and with the pediatrician...all relevant other people. And she also got a social worker ... everyone was informed about her, and they communicated with us and we did not face any difficulty in this process...

Referrals resulting from walk-in clinics appointments often included a priority referral to a pediatrician. With the engagement of pediatricians, participants reported that other essential services were subsequently identified and engaged. In many instances, the pediatrician was the first to diagnose the children with ASD, as well as to identify other comorbid conditions or features.

A helpful pediatrician makes a difference...

Perceptions regarding the role of pediatricians were very positive, especially when participants perceived from these health professionals a conveyed sensitivity or understanding of their concerns and a sense of advocacy in moving services forward.

Immediately, the pediatrician was aware that this is what is going on and he wanted to have a direct communication.... He is very nice...very helpful.... he always replies promptly. So, if we cannot reach him, we would just leave a message with his assistant, and he would call us straightaway...

Advocacy was described in terms of evidence of action in organising or linking services and follow through in communication and check-ins.

Theme Category 6: Receiving ASD Support Services

Sub-Themes
<ul style="list-style-type: none">• <i>Types of Support Services</i>• <i>ASD Worker Training Needs</i>• <i>Confidence in ASD Leads</i>• <i>Passionate and Compassionate Support</i>• <i>Role of Respite Care</i>

Referrals to pediatricians culminated in the establishment of a diagnosis of ASD and in some instances, it was accompanied by the completion of a psychoeducational assessment. Recommendations from these evaluations included suggestions and referrals related to supports and services for the home, school and community settings. Some of the recommended services cited by participants included autism support workers with backgrounds in applied behavioural analysis, ABA supervisors, speech language pathologists, respite and summer programs, and financial resources provided through the Department of Social Development.

Autism support workers provided services in participants' homes and for some, in the school as well. Various participants reported that support workers possessed a basic understanding regarding ASD; however, they were unsure regarding the extent or sufficiency of training prior to providing services to children.

They are sending...new recruits...it's only three months or four months of training... they learn on the job.

They need like more training and more education about the kids with special needs, how to handle them, how to work with them.

One participant highlighted that it might be beneficial if autism support workers also had supplementary training in how to collaborate effectively with parents and family members. Such training would focus on engaging parents to better understand the unique needs of the child as well as what strategies worked well at home.

So, every child will be kind of unique... Every kid will be unique...So we (parents) know certain behaviour and what works, what doesn't work...the worker should too.

Participants spoke very positively about and appeared to have greater confidence in the supervisors who provided oversight to autism support workers. Supervisors carried out visits to school or home settings, playing a coaching role with assigned autism support workers.

When the supervisor is there, you can see the difference because each team lead makes the decision, and you see the difference in your child.

I would prefer the lead to be there. I mean, the therapist manager because they have more experience, they can quickly adapt to certain things.

Another participant highlighted the benefits of having ASD workers who possessed understanding of the family's language and asserted the need for cultural sensitivity in terms of their family backgrounds, values, and traditions.

...in a perfect world <we would> have workers who are bilingual and understand Arabic as well as English.

One other quality viewed as advantageous was having support workers who demonstrated a passion and compassion for working with children, especially having a positive disposition, and calling to work with young persons with disabilities.

I think they should be a person who has really good motivation to work with disabled children...more than just a job.

In terms of receiving respite support, one participant highlighted initially feeling not at ease because of lack of familiarity or knowledge of support personnel. As this individual asserted, she was worried because it was the first time that her daughter left home because this service had not been available in their previous country. One other participant spoke of their efforts to explain aspects of their family culture and background to respite workers and hoping this was sufficient. As this person stated: “I’m relying on their understanding for this, but I can’t do more than this”. One other participant spoke of the benefits of summer camps and the extended hours that were given to children with ASD and their families.

Theme Category 7: Clarifying Educational Support Plans

Sub-Themes
<ul style="list-style-type: none">• <i>Personalized Plans and Goals</i>• <i>Assessing Strengths and Challenges</i>• <i>External Consultation and Support</i>

I want help and support. My goal is to make her independent.

Autism support services were initially engaged in the home setting often prior to children’s first school experiences. In terms of the educational context, participants expressed a level of concern regarding the clarity and direction of school-based plans. In their sharing, they highlighted the importance of every child needing to be known and having access to personalized services. Participants underscored that support plans

should be tailored to the needs of their child and guide the development, adaptation or structuring of learning

Each child needs to be known; unique strategies... personalized programs.

Concerns were also expressed that those assigned to support their child in roles such as educational assistant or support worker did not always have sufficient knowledge of their child's needs, strengths or interests; or perhaps did not take the time necessary to inquire or explore these specific areas with the family or through interactions with the child. Two participants felt that their child's progress was slow, in part, because learning plans and goals were not clarified, and strategies were not sufficiently structured or targeted to move forward. As one explained: "They have a plan but actually, his progress was very slow...because when you ask them for more goals or for anything they will tell you that the resources are limited."

One participant indicated that there was a need for a more detailed assessment of their child's strengths and challenges; however, this participant did not find availability of such services to explore these domains in their immediate school setting.

I wanted a detailed assessment...But no detailed assessment about their strength and their challenges or their needs. Unfortunately, I didn't find anything like that here.

In some instances, there was evidence of consultation with professionals outside of the immediate school (e.g., speech language, pediatrician, psychologist) in helping to structure the role of support workers or educational assistants. For example, one participant reported that the pediatrician had written to the school explaining ASD to

the teacher and educational assistant. This pediatrician had also expressed a willingness to meet with individuals from the school and district.

Personalized planning for their child and tailoring strategies were viewed as critical for both school and home. For various participants, the level of intensity of services offered in support plans was not always enough. In such cases, participants asked for additional support or for the length of time of services to be extended.

Category 8: Losing Confidence in Systems of Support

Sub-Themes
<ul style="list-style-type: none">• <i>Inadequate Communication</i>• <i>Lack of Openness to Inquiries</i>• <i>Slow Processes and Waiting</i>

All participants shared that at certain points in their experience of seeking or engaging services, they lost a level confidence in system structures, especially when communication was absent, infrequent, or not consistent. When there were emerging questions regarding their child's progress at times, responses to questions seemed to be inadequate or inconsistent with the impressions of the participants. Two participants highlighted that they perceived that support personnel were not open or comfortable in receiving feedback or responding to questions.

He is not someone you can engage in conversation with.... I feel like we're not really there... yet. I don't know their plan...

I wasn't happy because... the teacher wasn't friendly or supportive, unfortunately.

Questions that emerged for participants included inquiries about their child's ongoing progress, future prognoses and strategic actions (goals, plans and

expectations), where to access needed supports, and concerns about the use of medications.

It's very frustrating because you don't know...It is sad and you feel that you're not achieving anything with so much time... just talking to people.

Clarifying areas of concern and procedures for initiating referrals were often described as a slow process. One participant spoke of spending “more time in meetings” or in “telling your story multiple times” than actually focusing on determining the nature of needed services or supports. Even when there was advocacy from physicians and pediatricians, participants reported struggling with wait times. As one participant noted:

He's (pediatrician) the one who pushed everything faster. So, at a time when we were waiting and struggling...he will follow up for us...But he would apologize, because as far as he's concerned, he sent the file. It is up to them how they process it.

Theme Category 9: Grappling with Parental Concerns, Anxieties and Regrets

Sub-Themes
<ul style="list-style-type: none">• <i>Breaks and Suspension of Services</i>• <i>Losing ground</i>• <i>Intensity and Dosage</i>

I was always after the interventionist asking him what's the output of early intervention for my son. Will he be able to talk to me? Will we be able to have a normal conversation? Would he be able to smile one day...when will he look at me? Give me assurance, something good will happen as I am in a new city; he is a new boy with a new diagnosis and so alone.

Lack of consistent communication and not having the opportunity to ask questions or clarify concerns seemed to contribute to a sense of unsettledness and perhaps anxiety among some participants, especially related to their child's functioning and future progress. With the onset of COVID, the closure and or suspension of services for certain periods left gaps in essential supports. Such gaps were experienced in both educational and health settings.

With COVID... there are breaks here and there.

In March, there was a break of three months, okay. And with those three months,

I asked questions.... I didn't want him to fall back again

She is eligible to get 10 hours per week of support, but here the difficult part is that now

because of Covid, it is very challenging to find someone you know to work with her.

At times, participants also highlighted the need for more intensive services for their children in relation to speech language or occupational therapist supports accessible in the school. In light of breaks in services and insufficient intensity of services, participants expressed primary concerns related to lack of continuity in treatment services or lack of sufficient intensity of services in line with their children's needs.

The only thing we knew is that therapy will be there available to him...I never really

asked the question whether they will disappear at some point...

The intensive therapy is required, and the hours are not enough.

We started with a half hour and then say it's expanded to three hours. So, he doesn't go to the class. He is having three hours of school.... He is going three hours to school.

When participants talked about the level of intensive services, they spoke of needing more hours of support or interventions to promote a greater level of progress. In contrast, when services were intermittent or not frequent enough, some participants reported experiencing either minimal progress or a perceived loss of existing gains.

...the program was really slow. And it's like it was a few visits from the OT and the language therapist. So, there weren't any improvements.

We have limited resources... we have only one language pathologist for now. So, it's not possible for him to be seen more than once a month <at school>.

Accompanying parental concerns and anxieties, three participants conveyed feelings reflecting a level of personal regret related to having a delayed diagnosis and starting late to provide services. Other feelings reflecting regret focused on “wishing to have done more” or the recognition of competing priorities with their child’s needs related to employment or professional requirements as newcomers to Canada.

I feel so bad that he's diagnosed very late. Because if we got this diagnosis earlier, we could have started to plan ABA and his goals earlier.

Theme Category 10: Emphasizing the Imperative of Mental Health and Well-being

Sub-Themes
<ul style="list-style-type: none">• <i>Stressful interactions (assertion and offence)</i>• <i>Walking with Others (friendships)</i>• <i>System Navigators (assurance)</i>

I need help not only for my kid, but for myself, too. I don't want to break down, I need to be strong. I need answers for myself and for my kids; we need mental health services.

Mental health and well-being were also themes that emerged in participants' interviews. Participants spoke about significant stressors associated with navigating the system, but also those involving interacting in varied relationships with workers and service providers. At times, participants reported stressful feelings regarding how to present their concerns assertively, but in a way that would not offend others (*I'm trying to convey my point without offending her, being assertive, right?*). One participant highlighted that if service providers or professionals felt offended, then perhaps they would not readily assist or offer services to them.

The imperative of being mentally healthy or emotionally well was underscored by all participants. One participant spoke specifically about benefits associated with having a support group of newcomer parents who have already been through this journey with their children with ASD or other disabilities or exceptionalities. Ideally, having experienced peers come alongside would not only serve as a valuable source of information related to accessing or engaging service, but would also provide a level of social support or friendship during such processes.

I have nobody to talk or go out with, you know, just for break. And with ASD kids, you cannot take a break.

A parents' group would be amazing, too. Because they might help each other to guide in tough times. I think there should be mentorship of the parents too, and the mental support as well.

Mental health is an ongoing thing...We need a kind of check... as a mother that we are doing fine because of the new challenges we face each day.

Carrying out daily check-ins between parents was noted as a potential point of support or encouragement. In addition, having formal peer supports or system navigators who understand the educational, health and social service systems and how to access services was regarded as a potential practical and emotional support for parents. The importance of being aware of and having access to individual mental health services for their children or themselves was also affirmed. Such services should be flexible and accessible to parents in comfortable settings and should also be affordable without placing additional financial burdens on families.

You need to be told that everything will be okay...the key word would be okay.

Theme Category 11: Extending Broader Community Support

Sub-Themes
<ul style="list-style-type: none">• <i>Knowledge and Understanding</i>• <i>Stigma and Sensitivity</i>• <i>Empathy and Relationships</i>• <i>Networks and Hubs</i>

Participants highlighted the need for community service providers to have a greater understanding of their children including their exhibited features of ASD, challenges with adaptation, and differences related to culture and language. Specific challenges encountered in the community setting included not having services or program information in the family's language, lack of understanding from others related to food preferences and preparation (for example only being able to eat halal food), and

inadequate knowledge by community members related to their child's ASD and behavioural presentation. One participant acknowledged that their concern that their child might be stigmatized because of their behaviour and that others might choose to withdraw from them, resulting in social isolation or rejection for their child. Beyond ASD, other areas of participant concern emphasized the importance of community members and service providers understanding and being sensitive to the context of newcomers and the challenges they experience in not only accessing supports but also in seeking understanding related to their language, culture and beliefs. These areas of understanding were viewed as critical for establishing positive and collaborative working rapport with newcomer parents and families.

The importance of feeling accepted and safe within community relationships was identified as a prerequisite for feeling at ease, opening up and sharing stories and concerns with others. Participants highlighted the importance of having people who are close by who they call friends. It seemed that being welcomed, received and understood were interactions associated with the formation of friendships. The simple approach of greeting someone or acknowledging their presence at the outset of a meeting or gathering was associated with more positivity and more hopeful interactions.

I think it's more cultural. We do not open up, not even in front of the doctor. We don't open up publicly; we cannot <easily> share our feelings. But there should be a place where we can go and seek help - where we can express ourselves better.

Community networks or agencies where families felt attended to and heard were recognized as starting points for seeking support and as a hub from which a range

of services could be accessed. Such agencies (e.g., multicultural associations) were identified as having personnel and workers who were attuned to the experiences of newcomers and who also had experience in linking them with support services related to ASD.

Theme Category 12: Reflecting on the Encompassing Role of Parents

Sub-Themes
<ul style="list-style-type: none">• <i>Transitioning and Bridging</i>• <i>Front line Actions</i>• <i>Cultural Links and Values</i>• <i>Strong and Persistent</i>

In reflecting on their individual stories of seeking and engaging services and supports for their child, all participants described a multiplicity of roles they carried out related to their child’s development, learning, health and well-being. Their active roles as parents increased in intensity during times of transition and when natural or unexpected breaks in services or supports occurred. With new services or supports emerged new workers, and parents played a crucial role in bridging these relationships with their children through planning new introductions and routines through social stories.

The strategy I came up with...we go through the pictures on the phone, and he will come and say, Oh, look, Doug...we will have printed his picture. And we stuck it on the fridge....

just pretend that he's part of the family then he gradually accepted him.

Parents were also the primary navigators of system services and frontline supports in their advocacy for their child’s needs:

We met the people there, and we asked them about the services, what do they do...

I observed my child...I went and found the autism support centre.

They were also the link to others in terms of communicating cultural values and practices related to such areas as food choices and language:

At school she used to take our own food.... I used to prepare the lunches... I spoke with my daughter that we only eat halal food, no bacon, no ham.

Participants asserted the importance of being “strong” and “persistent” in finding the right supports for their children because they know their child best beyond any other source of information.

We need training for the staff and for the parents...

There should be a place for parents where they can receive all the information about the autism resources for kids.

The benefits of providing hands-on training for parents was also highlighted by participants. Hands-on training was described as the provision of essential information related to child development, understanding features of ASD, gaining knowledge of beneficial supports and treatments, as well as awareness of available community programs and departmental support for their children. Training options were described in terms of having a place where parents could go, or the provision of such resources online.

VI. Discussion

Overview of the Discussion Chapter

The intent of this research endeavour was to gain insight into the stories of newcomer parents to Canada who have children identified with features of ASD. The central area of inquiry involves investigating the personal narratives of parents related to seeking, engaging, and sustaining educational and health supports for their children. For this investigation, I employed a narrative inquiry design, completing in-depth individual interviews and check-back sessions with six participants. The completion of the interview analyses resulted in the emergence of twelve theme categories and the associated sub-themes that emerged within each category.

The final chapter provides a synthesis and discussion of the overall findings of this investigation, taking into current insights from the literature and implications related supporting newcomer parents with children with ASD. Consistent with the focal area of research inquiry, the discussion of results is presented into three distinct sections related to seeking, engaging, and sustaining essential supports. At the close of this chapter, limitations and directions for subsequent research are outlined.

Seeking Supports

Aggregate analysis of the individual participant interviews revealed three primary theme categories that emerged related to seeking initial supports. These included: *Recognizing ASD Features; Finding a Starting Point; and Struggling to Find a Primary Healthcare Provider.*

The impetus for engaging services began as a result of participants' observing or *recognizing features of ASD* in their children's functioning or adaptation. Such departures were depicted in terms of departures or differences in developmental milestones compared to other children within or outside the family. In addition, features of ASD were also described in terms of behavioural concern related to repetitive movements or lack of social responsiveness. Most participants had minimal knowledge or information related to ASD prior to coming to Canada; however, they were compelled to investigate potential avenue of support in light of their concerns regarding their child's functioning. According to Benallie (2019):

Before children start preschool or kindergarten, parents are the ones who see them most often. In many cases, parents are the first to be exposed to the early signs of ASD. However, some parents may not be aware of the early signs, making it challenging for them to recognize signs and seek professional services (p. 2).

Consistent with participants' observations, current research indicates that the earliest signs of ASD included delayed acquisition of social skills milestones inclusive of joint attention, social orienting and pretending behaviours. In addition, delays in language, restricted interest, and communication may also accompany concerns related to social skill concerns (Carbone, Farley, & Davis, 2010). Carbone, Farley, and Davis (2010) affirm that parents are often the first to observe such features in children and that primary healthcare providers should routinely perform surveillance of child development through exchanges with parents using appropriate screening instruments.

Such surveillance involves inquiring of parents during health appointments about specific developmental or behavioural concerns they may have, observing early signs of ASD, and documenting any family history related to ASD. Health providers may integrate into regular health appointments key clinical probes that correspond to specific developmental time periods as highlighted in Table 2 (Carbone, Farley, et al., 2010, p. 454).

Table 2

Clinical Probes for Autism Surveillance

Age	Social skill probes*	Language probes	Restricted interests or repetitive behavior probes
Nine months	(-) Turning and making eye contact when hearing his or her name called (social orienting)	(-) Babbling (-) Taking turns vocalizing back and forth (-) Developing more varied vocalizations (-) Waving "bye-bye" or raising arms to be lifted (-) Responding to caregiver's voice as well as environmental sounds (+) Making unusual or high-pitched sounds	(+) Carrying an unusual comfort item (e.g., hard items such as pens, sticks, rocks) (+) Demonstrating unusual or intense attachments, stereotypic movements, self-injurious behaviors, or unusually severe temper tantrums with transitions or for no apparent reason (+) Engaging in repetitive behaviors, such as lining objects in a row
12 months	<i>Repeat social orienting probes from nine months</i> (-) Turning and looking if the caregiver or physician points at an object across the room and asks the child to look (joint attention) (-) Pointing to request an object (imperative pointing)	<i>Repeat language probes from nine months</i>	<i>Repeat restricted interests or repetitive behavior probes from nine months</i>
15 months	<i>Repeat joint attention and imperative pointing probes from 12 months</i>	(+) Repeating only what he or she hears (echolalia) (+) Demonstrating regression in language milestones	<i>Repeat restricted interests or repetitive behavior probes from nine months</i>
18 months	(-) Pointing for experience sharing (declarative pointing) (-) Engaging in pretend play	<i>Repeat language probes from 15 months</i>	<i>Repeat restricted interests or repetitive behavior probes from nine months</i>
24 months	(-) Engaging in declarative pointing and showing of objects (joint attention)	<i>Repeat language probes from 15 months</i>	<i>Repeat restricted interests or repetitive behavior probes from nine months</i>

*—Delayed attainment of social skill milestones is the earliest and most specific sign of autism.
 (+)—The presence of this behavior suggests autism.
 (-)—The absence of this behavior suggests autism.
 Information from reference 19.

In addition to clinical probes, the application of validated screening tools such as the Modified Checklist for Autism in Toddlers (M-CHAT) may also be completed with parents during child health visits (Johnson & Myers, 2007). Although autism is denoted as a lifelong condition, early recognition and subsequent diagnosis and treatment can significantly enhance the prognosis for children with ASD. As Carbone, Farley, and Davis (2010) assert, "With earlier recognition and diagnosis, more intensive treatment, and

increased acceptance and social support for families, physicians caring for children with autism can now be more optimistic regarding their prognosis” (p. 459).

The American Academy of Pediatrics (AAP) indicates that developmental and behavioural screening should be undertaken for all children during regular physician visits at nine, 18 and 30 months. AAP also suggests that formal screening targeting ASD features should be completed during regular doctor visits at 18 months and 24 months. Additional screening efforts may also be considered more frequently for children deemed at higher risk for ASD, including those who have a sibling or other family member diagnosed with ASD (CDC, 2022).

Although research and knowledge related to ASD has increased among health professionals world-wide, there are still wide variations in practices related to diagnostic and treatment practices. Current investigation in several studies across developed countries also point to later diagnoses of ASD. For example, within the United Kingdom, the average age of ASD diagnoses in children is seven years of age. Ideally, diagnosis should be made before three years of age to ensure a better prognosis for children (Salama, 2017). In light of later diagnoses, Salam asserts that, “There is a lack of knowledge of autism among family physicians; they need more training on autism to increase their awareness to improve early detection and intervention so as to improve the quality of life and care of children with autism” (p. 266).

The majority of participants reported that *finding a starting point* for seeking services was difficult. For many, the initial challenge was having sufficient knowledge of what services would be important for their children and how to access them, especially

in terms of initial assessment and the availability of support services. Participants' informal personal networks were often the first points of consultation or inquiry related to seeking services or supports. They highlighted the process of navigating systems of support as not an easy process, and one in which they were required to be assertive and insist or push for services. In reflecting on their personal experiences, they spoke of the benefits of proactively providing families with guidelines on how to access services or supports, as well as the value of having peers or others who had previously navigated the system and who were knowledgeable about accessible avenues for acquiring supports.

Theorists and practitioners underscore the benefits associated with the development of community networks of supports for newcomer families as they navigate services for their children. Such networks should be responsive to the needs of newcomers and be made known to them (Maiter & Stalker, 2011). Brown and colleagues (2020) underscore the value of creating a peer-to-peer support system to bring together newcomer parents with peers from their own culture who may mentor or guide them in “informing” and “educating” newcomer parents about essential services and supports. Although such efforts may assist with the navigation of service systems within health and education sectors, they also provide opportunities to build new social networks. A province-wide collective of over 80 organizations in British Columbia described the use of Cross-Cultural Health Brokers to assist newcomers in navigating systems of support. They define this role as follows:

Cross-cultural health brokers are members of a particular cultural community who have knowledge of the health-related values and beliefs of their own culture, as well as knowledge of the values and beliefs of mainstream Canadian culture. They sometimes have a professional background in health. Cross-cultural health brokers use their knowledge of health in various cultural contexts to bridge the gap in knowledge, expectations, and understanding between newcomers and health care providers (AMSSA, p. 1).

Consistent with participants' experiences, family members of children with ASD frequently report a range of challenges related to navigating systems of support and locating accessible resources (Pizur-Barnekow, Lang, & Barger, 2021). Further to this point, Rivard and colleagues (2020) contend that newcomer families of children with ASD "are less likely to access evidence-based specialized intervention services due in part to service accessibility barriers" (p. 2), such as language barriers or a lack of familiarity or understanding of existing health, education, and social supports or services.

Research reveals that newcomer families experience significant barriers as they try to navigate the complex systems to meet their needs. Further, how newcomer families experience social determinants of health such as employment and working conditions, food and housing insecurity, social exclusion, and discrimination may increase vulnerability and limit access to supports (Brown et al., 2020, p. 187).

Participants shared experiences related to the challenge of adapting to new community settings, making transitions to new living circumstances, and becoming familiar with new neighborhood relationships and work routines. Rivard and colleagues (2020) indicate that it is critical for service providers to acquire a better understanding of the unique experience of newcomers and the realities they face in adapting to new community situations and systems of support. Similarly, they encourage service providers to “ground their programs in the realities encountered” by newcomers and to “identify facilitators and barriers to optimal interventions and, by extension, adapt supports to optimize the effectiveness” of their respective services and supports (p. 2).

A central challenge for participants related to initially seeking supports for their children was the shortage of primary healthcare providers in their regions. Without access to a family physician or other healthcare provider, there was also recognition of the additional difficulty related to accessing referrals to specialized professionals or programs of support. In the absence of primary healthcare providers, two participants pursued private health services to expedite early assessment and interventions for their children. According to Malko and Huckfeldt (2017): “Currently, there is a well-recognized physician shortage in Canada. Statistics Canada reported that 15.3% of Canadians aged 12 and older lack a regular family physician” (p. 68). This situation is even more critical in rural areas with data demonstrating that less than 10% of Canadian physicians practice in more remote or rural regions. In addition, the present shortage of physicians is also impacted by an aging pool of older physicians (Malko & Huckfeldt, 2017). Within the province of New Brunswick alone, thousands of individuals have been

added to the waiting list for a family doctor. As of the end of 2021, a total of 44,226 people were registered with the Patient Connect New Brunswick program, which pairs residents with a family physician (CBC, 2022).

Given that physicians are often the first healthcare professionals who interact with children who may present with ASD, the lack of access to such services may delay initial assessment of ASD and subsequent early intervention responses. Primary healthcare providers play an essential role in the early identification of ASD features and serve as the hub or the point of connection for referral to specialized assessment or intervention services. Over the long-term, physicians also play a key role in the case management and review of ongoing service support for children with ASD and their families (Carbone, Farley, et al., 2010).

Engaging Supports

In terms of engaging support, four theme categories emerged from participant interviews, including: Engaging Walk-in Clinics and Referrals; Experiencing Professional Support and Advocacy; Receiving ASD Support Services; and Clarifying Educational Support Plans. In the absence of a primary healthcare provider, participants used walk-in clinics as the primary avenue for engaging initial supports for their children. Given rotating clinic schedules with different physicians serving during various time periods, participants reported recounting their stories multiple times, prolonging the length of time related to the initiation of referrals for specialized assessment or intervention services. Lack of continuity of service relationships often contributed to fragmented service responses related to follow-up appointments or check-ins. Within the Canadian

context, walk-in clinic are services intended to provide episodic care. Episodic care involves a single visit or encounter with a physician focusing on a presenting concern. Walk-in Clinics are resources that are part of Canada's public and provincial service system, whereby governments provide compensation to health care professionals for their services in these settings (College of Physicians and Surgeons of Alberta, 2019). A key challenge with individuals attending a Walk-in Clinic is that that individuals or families often can only be seen for one issue per visit. In light of the complex needs of ASD, families may be placed in a situation where they need to triage a multiplicity of concerns or symptoms (Adhopia, 2019). Further to the preceding discussion related to the shortage of physicians, having access to a primary health care provider for families underscores the importance of the continuity of services, being able to expedite referrals to appropriate assessment and early intervention specialists, and the provision of timely follow-up case management services and supports.

Despite challenges associated with walk-in clinic services, positive outcomes experienced by various participants included encountering health professionals who offered both support and advocacy, inclusive of referrals to pediatricians who provided them with needed diagnostic services. Brown and colleagues (2020) indicate that parents' and family members' perceptions and feelings related to health services and providers are often shaped by their first experiences with the system. Poor initial impressions may contribute to negative feelings and the potential avoidance of accessible care or support programs. In approximately one third of the investigation reviewed by Brown and colleagues, parents reported experiencing levels of

discrimination in their efforts to engage system supports. Recommendations from these reviewed studies underscored the importance of health care providers being knowledgeable, friendly, empathic, and culturally sensitive in their interactions with newcomers. Allotting sufficient time to spend with parents and practicing active listening was viewed as essential for eliciting and responding to any concerns that parents may have regarding their children or their functioning. A key concept in the literature related to creating positive health care exchanges for newcomers where individuals perceive both support and advocacy is the notion of *cultural humility*. When embraced by health care providers, cultural humility is defined as “an approach to health care that recognizes not only the need to understand how differences in culture might affect the health care experience, but also that it is not possible to know everything about another person or group. This approach emphasizes that individuals need to be continually learning and listening to others’ perspectives and encourages health care providers to take cultural differences into account by asking questions rather than making assumptions” (AMSSA, 2016, p. 2).

Positive experiences with pediatricians resulted in the completion of initial ASD assessments and referrals for both home and school ASD supports. Initial intervention supports were undertaken in the home setting and involved the engagement of Autism Support Workers (ASWs). Specific areas of concern reported by participants related to home supports included a perceived lack of training on the part of some ASWs, minimal engagement of parents in planning and understanding the unique needs and strengths of their children, as well a lack of attention given to the cultural values or perspectives of

the family. In contrast, participants expressed confidence in home-based services when the ASWs' clinical supervisors provided coaching support to individual workers, and when they perceived ASWs to be passionate and possess a positive disposition about their role. Participants' perspectives related to home-based services underscored the importance of ASWs being well-prepared to respond to the needs of individual children with ASD in the context of each family's situation and background and in collaboration with parents or caregivers.

A recent investigation (Williams & Haranin, 2016) exploring the training of those providing direct services to individuals with ASD administered surveys and completed in-depth interviews with health, social care, and educational professionals as well as with services users, inclusive of parents of children with autism. Findings of this study indicated a significant lack of adequate professional training among service providers with many having no formal or targeted training in addition to their professional competencies and others having received limited training experiences comprised of participation in a few professional learning events. There was also awareness among study participants of the inherent stress and potential burnout associated with being asked to carry out specific intervention activities without feeling equipped to carry them out effectively. According to the authors of this study: "Well-trained staff are crucial for those directly affected by autism who need support and intervention, as well as for their caregivers" (Williams & Haranin, 2016, p. 93). Recommendations related to training direct service professionals included the provision of more intensive training programs, the delivery of professional learning in varied formats, tailored learning

content focusing on specific support roles and inclusion of more 'real-life' examples, and training content that is informed by or reflective of service user perspectives (Williams & Haranin, 2016).

One UK publication entitled *Autism skills and knowledge list* suggests that support workers from social services and health care backgrounds should possess more than a basic awareness and understanding of ASD and have intermediate knowledge and competencies that allow them to:

- Apply appropriate communication skills when supporting individuals with ASD
- Support family members, caregivers, and friends in applying their understanding to enhance intervention approaches for those with ASD
- Recognize when individuals with ASD experience stress or anxiety and be able to support them in such situations
- Understand the sensory needs and differences among individuals with ASD and incorporate such knowledge within support strategies
- Have knowledge and skills in the delivery of interventions that support the development of social interaction skills of those with ASD
- Provide support strategies to those with ASD during times of change or transition
- Be sensitive to issues which may arise from a co-occurrence of mental health concerns and ASD (Skills for Care and Skills for Health, 2011)

In addition to engaging initial home-based autism services, participants also shared their subsequent experiences related to school-based supports. Areas of cited educational supports included individual learning plans, assessment of learning needs,

consultation with varied professionals, and some team-based approaches. For some participants, moving support from the home to the school appeared to result in less intensive supports than previously experienced. Participants emphasized the need for the development of more personalized educational plans with parents playing a greater role in conveying the unique needs and strengths of their child. Others conveyed areas of concern focused on ensuring sufficient intensity of support related to more in-depth assessment, the coordination of health and educational services (e.g., pediatrician recommendations and the types of educational supports provided), accessibility to specialty support personnel, and/or an extension of the duration of interventions.

The transition to school (i.e., kindergarten) for children with ASD often represents the termination of specialized early childhood ASD services for families and the introduction of less intensive supports focusing primarily on the child's learning or educational development. According to Rival and colleagues (2020): "Early intervention services are generally personalized to children's needs in different developmental spheres as well as to their families' priorities, whereas school-based services are mainly oriented toward supporting children academically" (p. 2). In addition, the transition to school may also include a reduction in communication and follow-up with families, especially in terms of reported parental needs pertaining to family adaptation. Some research suggests that the transition to school may reflect a breakdown in service continuity, with insufficient program supports or resources and a lack of professional training or learning opportunities for educators within the school context (Rival et. Al, 2020).

Ideally, more personalized approaches working with children with ASD requires a strengthening of partnerships between health and educational service providers and parents or caregivers. The development of a more cohesive and collaborative working alliance would entail bridging and integrating services and supports across home and school settings with the direct participation of parents. Francis and colleagues (2016) highlight a series of key principles related to enhancing partnership approaches between home and support professionals. These include:

- Communication (empathy, non-judgmental listening, clarity of language, and coordination of information)
- Professional competence (personalized learning plan for children, professional learning for educators, and high expectations)
- Advocacy (champions children and families, positive parent collaborations, problem identification and solution building)
- Respect (exploration and application of child and family strengths, honouring cultural diversity)
- Commitment (persistent and determined support)
- Equality (participation of family and children in planning and decision-making)
- Trust (reliability and consistency) (adapted from Francis et al., 2016)

The trust in such partnerships is developed over time and provides greater continuity of support (especially during times of developmental transitions), and

ensures the provision of support at the right intensity across school, home, and community settings (Rivard, et al., 2020)

Sustaining Supports

With respect to engaging supports, four theme categories emerged from participants' narrative interviews, including: Losing Confidence in System Supports; Grappling with Parental Concerns, Anxieties and Regrets; Emphasizing the Imperative of Mental Health and Well-being; and Extending Broader Community Support.

Over the course of seeking, engaging, and sustaining services, the majority of participants reported losing confidence in system supports. Loss of confidence was linked with inadequate or inconsistent communication, perceived lack of service providers' openness to listen or respond to concerns and lack of clarity related to intervention plans coupled with lengthy time periods to process referrals or to wait for services.

In their review of studies related to newcomer experiences with programs and services supporting child development, Brown and colleagues (2020) found that "woven" through these investigations were reported "feelings of mistrust, disrupted support systems, and challenges with establishing supportive formal and informal relationships" (p. 191). Rivard and colleagues (2020) highlight a range of factors that may impede newcomers' parental trust in systemic supports for their children with ASD, including not feeling at ease or comfortable in professional exchanges; perceiving a lack of openness or transparency related to the service context or on the part of personnel; feeling a sense of dismissal of their parental concerns or fears; experiencing inadequate

communication related to changes in service provision, especially during periods of transition; and concluding that their child's needs had not been prioritized.

Brown and colleagues (2020) contend that in their efforts to sustain essential support for their child, newcomers may feel isolated, and that it is imperative that service providers reach out providing guidance and support. Caulford and Mayhew (2014) underscore the importance of service providers undertaking intentional efforts to build an alliance of trust with newcomers. They recommend a series of practices that are beneficial for promoting trust and ensuring a positive and continuous working relationship with newcomer parents and family members. These include building trust by:

- Conveying clear messages that personal and family information is confidential
- Providing flexible meeting times to accommodate family and work schedules
- Providing printed reminders of appointments and monitoring access to care
- Encouraging positive interactions among newcomer parents and families with all clinic staff.
- Providing training and professional learning opportunities to ensure a minimum standard of culturally competent care among personnel
- Offering proactive services that demonstrate the benefits of continuity of care, screening, and early intervention
- Engaging an 'interprofessional team approaches, including referrals to community organizations that provide services to newcomers

- Supporting the autonomy and engagement of parents and family members as team partners with support from allied services and professionals (social work, transportation, interpreters, financial aid, settlement services)
- Optimizing health outcomes through the development of family linkages with school and community-based programs that provide access to positive social connections and wrap-around supports (adapted from Caulford and Mayhew, 2014, p. 7).

The preceding practices point to the importance of maintaining an ongoing collaborative relationship with newcomer families, one that builds trust through the engagement of a continuum of support in a coordinated way. Such efforts involve the application of proactive planning strategies and responsive service responses, especially during times of planned or unexpected interruptions in essential supports.

Participants of the current study also reported intensifying parental concerns and anxieties during breaks in or suspension of services related to holiday time periods or closure of programs and services due to Covid 19. For some participants, there was sense of losing ground related to their child's progress and a diminishing of intensity of supports over time. For a few, feelings of personal guilt were evident related to receiving a delayed diagnosis of ASD for their child, starting late to provide services, and wishing they could have done more. Concern related to personal and family well-being were also highlighted, and significant stressors were associated with ongoing efforts to navigate and manage system of support, at times coupled with strained interactions arising from exchanges with service providers or personnel. As Milieu and colleagues

(2016) assert, newcomer families of children:

“...are doubly vulnerable to stress as they must tackle challenges inherent to their immigrant status alongside those of their child’s condition. Their task of locating services and collaborating with professionals is made more complex by language barriers and cultural differences in terms of, for instance, their intervention priorities and their perceptions and understanding of disabilities and mental health. Families of children with ASD who belong to ethnic or cultural minorities are indeed at a disadvantage in accessing quality services and with respect to their child’s prognosis and their family’s quality of life (p. 312).

According to McStay, Trembath and Dissanayake (2014), parents of children with ASD are engaged in “a continuous process of adaptation throughout their children’s development” (p. 2). Adaptation is impacted by a variety of influences inclusive of parental perspectives regarding the nature of immediate stressors both within and outside the family, as well as family access to essential resources and social supports (internal and external), and the application of plans and strategies that facilitate positive coping and development. When access to services is impeded or continuity of support is disrupted or fragmented, stress may be exacerbated and access to resources to support parent, child and family coping and well-being may be limited. For newcomer parents, the stress may be further intensified by feelings of isolation they have experienced after leaving their home countries, leaving behind family members, and the familiarity of their surroundings. A recent Canadian study of newcomer parents of children with ASD indicated that participants “spontaneously reported that feelings of isolation, loneliness,

and powerlessness had been an obstacle in accessing an ASD diagnosis for their child” (Rivard, 2019, p. 533).

Rivard and colleagues (2019) assert that newcomer parents of children with ASD should be provided with accessible mental health supports from front-line professionals (e.g., psychologists, social workers). Such services should ideally assist them in developing positive coping strategies related to meeting the needs of their children, as well as addressing areas of personal distress or feelings of isolation. In addition to direct mental health services, the provision of information regarding accessible networks of support inclusive of community organizations and parent groups that bring together parents of children with ASD or parents from the same culture is also beneficial. Finding peer supports with individuals from similar backgrounds or experiences reduces feelings of being alone and promotes the development of social support networks. Overall, community networks or organizations where parents felt attended to and heard by individuals attuned to the experiences of newcomers and those with experience related to ASD was viewed as beneficial both in terms of emotional support and also in navigating service systems.

At the close of individual interviews, participants were invited to reflect on their personal narratives of seeking, engaging, and sustaining supports for their children with ASD. Participants described the multiplicity of parental roles they played in terms of the provision of essential supports for their children, inclusive of advocating and navigating support systems,

increasing intensity of direct parental supports during times of service transition or breaks in service, bridging the introduction of new service relationships, and communicating cultural values and practices to service providers.

Given the multiple roles that parents play in the lives of their children with ASD, Macfarlane and Macfarlane (2011) affirm the importance of their engagement and participation as central participants in team-based or community-based approaches for the provision of essential supports. In contrast to traditional expert- or professionally-driven models of support, parent-service partnerships are strengthened through family-focused empowerment team approaches that value and draw on the perspectives and knowledge of parents regarding service planning for their child, and serve to reduce parental stress and anxiety. Such team approaches are often referred to as *family-centered care* (FCC) in that they “value the central role families play in children’s health and well-being and encourages collaboration, information sharing, empowerment, and joint decision making” (Gabovitch and Curtin, 2009, p. 469). Key elements of FCC that have demonstrated efficacy related to promoting positive and constructive interactions among parents and service providers include: “listening, honoring, and respecting the child and family; sharing information and collaborating; and recognizing and building on the strengths of the child and family” (Myers et al., 2021, p. 3074).

Policy and Practice Implications

The focus of this research endeavour has involved the exploration of rich narratives with newcomer parents and their experience with seeking, engaging, and sustaining supports for their children with ASD. My initial review of the literature and

my return to the literature to examine the findings of this study have been thought provoking and reaffirming for me in light of my own experiences as a newcomer and parent of a child with ASD. This research effort has served to clarify the potential implications of this study in terms of possible policy and practice directions. After re-reading my findings and discussions, I have created a summary of key considerations or implications that I would like to share with others to promote professional dialogue and perhaps lead to subsequent actions for enhancing supports for newcomer parents of children with ASD. These considerations are considered under four key headings: Role of Primary Healthcare; Parent Education and Support in Navigating the System; Adaptation and Continuity of Support; Training Implications for Service Professionals; Strengthening Partnerships with Parents; and Accessible Mental Health Supports.

Role of Primary Health Care

- Access to a family physician or nurse practitioner is critical for newcomer families of children with ASD, and lack of access to such services may delay initial diagnosis and subsequent early intervention responses. Over time, physicians play a critical role in the case management of services and supports, inclusive of the engagement of interprofessional team approaches and monitoring children's ongoing development, health and well-being.
- Primary healthcare providers play a key role in routinely monitoring children's development and health. Routine developmental screening at regular health appointments to detect ASD features may be critical for carrying out earlier diagnosis and early intervention responses for children and their families. In New

Brunswick, the *Healthy Toddler Assessment* targets 18-month-old children and is provided by public health nurses in each of the two Regional Health Authorities (Province of New Brunswick, 2022).

- Current research indicates that in many jurisdictions there continues to be a lack of professional knowledge about ASD among family physicians and other healthcare providers. Targeted professional learning for medical programs and practising physicians may be critical for improving early identification of ASD and enhancing quality of life for children with ASD and their families.

Facilitating Early Access to Care

- The provision of parent training in child development and promoting awareness of ASD features may assist in the early detection of this condition and facilitate the implementation of early intervention responses.
- The engagement of cross-cultural brokers or service navigators (i.e., individuals with ASD experience or peers from same cultural background who have experience in navigating service systems) may play both a supportive and guiding role for parents of children with ASD as they seek and engage services.

Responsive Services

- Service providers from health, education, and social service sectors inclusive of community-based personnel need to increase their awareness of the unique experiences of newcomers and the challenges they face in adapting to new home, school, and work settings. Ideally, service professionals should have a thorough understanding of the barriers and facilitators of newcomer

engagement, and adapt and optimise their programs to be responsive to and optimize their program supports to address the needs of families of children with ASD.

- Efforts should be made to ensure the continuity of services and supports for parents and families of children with ASD. When walk-in clinics remain a singular point of service access for parents, program policies and practices could consider potential enhancements to support the move from episodic care to a greater emphasis on the provision of follow-up or continuity relationship support for those with more complex or multifaceted needs.
- Ongoing coordination of health and education supports may be critical for determining the types of supports required for children with ASD within home, school and community settings, inclusive of the level of intensity and duration of such supports based on current levels of need.

Training implications for Direct Service Professionals

- Some evidence points to the need for more adequate professional training among service providers who work with newcomer families with children with ASD. Recommendations related to such training includes the need for more intensive training programs, the delivery of varied learning formats, tailored content specific to support roles, and the inclusion of more ‘real-life’ applications informed by service-user perspectives – in this case, newcomer parents and families.

- Current research underscores the benefits of service providers being knowledgeable, friendly, empathic, and culturally sensitive in their interactions with newcomers. This entails providing adequate time to listen and convey understanding of the concerns of newcomer parents of children with ASD, and being responsive in advocating for essential supports and services. Training in cultural humility for service professionals may be beneficial in this regard.

Strengthening Partnerships with Parents

- It is critical that service professionals strive to build trust with newcomer parents by attending to their concerns related to their child's care and progress, being careful not to respond in ways that could convey messages of dismissal or disregard.
- The development of more personalized educational approaches for working with children with ASD entails strengthening the partnerships between school service providers and parents. Such efforts are enhanced through the direct participation of parents in educational planning, ongoing communication, mutual respect, advocacy, and the development of trust over time.
- The application of family-centered care (FCC) approaches supports the autonomy and the meaningful engagement of parents and family members as active team members in collaborative approaches with service professionals in the care planning of services and supports for children with ASD.

Accessible Mental Health Supports

- Newcomer parents of children with ASD should have access to mental health supports from front-line professionals such as psychologists or social workers. Such services would be beneficial in terms of assisting them in developing positive coping strategies related to meeting the needs of their children and in addressing areas of personal distress or feelings of isolation.
- Access to community agencies or peer support networks with individuals from similar backgrounds or experiences may play a key role in reducing feelings of loneliness or isolation. Community support networks or organizations should provide safe spaces for newcomers and be attuned to the experiences of newcomers, and should provide emotional and practical support for them.

Research Limitations and Directions for Future Research

The completion of this research investigation provided an opportunity to gain greater insight into the narratives of newcomers and their experiences of seeking, engaging, and sustaining system supports for their children with ASD. The findings of this research endeavour uncovered twelve theme categories, each one representing a key aspect of participants' stories related to their navigation of health and education services. Some key limitations of this study were the boundaries of time and the scope of the questions that provided structure for the interviews and the flow of conversation, but also that potentially limited digging or delving into the major theme categories that emerged over the course of participant interviews. On the other hand, identified theme categories, in particular those related to emphasizing the imperative of parental mental

health and well-being, reflecting on the role of parents, and experiencing professional support and advocacy would provide new directions for investigation and going deeper into these newcomer experiences.

Another possible limitation was the nature of the background of newcomer participants who participated in this study. All participants were married or living in a partnership relationship prior to coming to Canada, had completed post-secondary education, had emigrated to another country from their original home country prior to coming to Canada, were fluent in more than one language, and were proficient or possessed sufficient skills in English to participate in this study. Given the background of participants, other newcomers, especially those who have not emigrate in the past, who do not possess proficiency in English or French, and who do not have similar levels of professional training or educational background may report varied experiences, barriers and facilitative factors related to navigating health and educational system supports. As with the preceding limitation, research involving participants from different backgrounds may provide new insights into the varied experiences of newcomers in seeking, engaging, and sustaining system supports for their children. According to Ghahari (2021), common challenges that may impact newcomers and their families in relation to health and quality of life outcomes include housing insecurity resulting from employment and financial instability, language barriers that may interfere with communication related to health, safety and community engagement, loss of social supports, and concerns about family members outside of Canada. Again, the preceding common experiences may be areas for further investigation related to the experience of

some newcomer parents with children with ASD.

Participants in this research study resided within the New Brunswick region, and their stories unfolded in the context of this jurisdiction. Therefore, participants' narratives often have common contextual factors or structures that potentially influence or shape personal experiences of navigating service systems. It is possible that regional differences in service systems or the delivery of support from other Canadian regional jurisdictions may account for varied newcomer experiences in seeking or engaging supports for their children. Although identified as a limitation, this observation could also serve as an impetus for carrying out future investigations in other Canadian jurisdictions in Central, Western or Northern Canada. In addition, given the rural nature of New Brunswick regions, newcomer stories from urban centers might also yield additional insights related to navigating system supports for children with ASD.

In summary, as a mother and as a physician, the diagnosis of my son was the bridging point between my research and the broader conversation around ASD. There has seldom been much information released on autism and how it manifests in people and even less so how it interacts between different cultures. Medicine is often characterized as a Western science and thus, tends to follow the guidelines that are ordained by Westerners. However, this type of approach often leads to misunderstanding and delayed diagnosis of autism. Along with this, the issue of navigating a healthcare system that is unfamiliar with an outside culture can inflict on families a sense of apprehension and confusion when it comes to interpreting and

conveying their thoughts and concerns. Accommodations are not so easily found, and the burden of care is a pressing issue that permeates in the minds of newcomer parents. My research is dedicated to bringing these issues to light and addressing the ways in which their struggles are invisible to the medical community and social, health and educational care systems. The thrust of professional and research efforts focuses on clarifying the nature of challenges faced by newcomer parents and their children with ASD and the necessity of providing the essential care and support to adapt and be successful into society. I hope that my research will be able to illuminate what has been buried under the surface and amplify the voices of the people who need it the most.

VII. References

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Appendix A: Research Information Letter

INVESTIGATING NEWCOMER PARENTS' STORIES OF ACCESSING SUPPORTS FOR THEIR CHILDREN WITH AUTISM SPECTRUM DISORDER

The information letter describes a research project as part of my Master's program in Inter-disciplinary Studies at the University of New Brunswick. My research is designed to gain a greater understanding of the personal stories of parents related to seeking, engaging and sustaining educational and health supports for their children with Autism Spectrum Disorder (ASD).

This study will include the completion of interviews with five to eight newcomer parents who have direct experiences regarding support for their children with ASD. These individual interviews last approximately one hour. Following the interview and analysis of the information gathered, I will email or provide participants with a copy of a summary of the major ideas or themes that were identified in the interview. In a second short interview with individual participants, I will ask for their feedback on the themes that I have identified.

Due to the current restrictions due to COVID-19 pandemic, interviews will be held using Zoom. For security, we will assign a different ID and password for each interview. Interviews will be digitally recorded (audio only). All information from the sessions will be analyzed so that individual responses from participants will not be identifiable. Your name, your child's name or any other identifiable information will not be used in the final interview summaries. All audio recordings will be stored in password protected files on a password protected computer in my home office.

There are no anticipated risks associated with your involvement in this study; however, it is your choice whether or not to become a participant in this research. If you agree to participate now, but later change your mind, you may withdraw from this study at any time with no consequence. You may choose to refrain from answering specific interview questions, or choose to discontinue your participation in this research altogether. The results of my study will be presented in my final thesis document. Upon completion of my Master's program, I would be pleased to provide you with a copy of my thesis or a short summary of my overall findings.

If you have questions regarding my research study, please do hesitate to contact me at (506) 292-6664 (mobile) or by email at khashmat@unb.ca. If you would rather speak with someone else about this research please contact my thesis supervisor Dr. Bill Morrison, at (506) 429-9864 or by email at wmorriso@unb.ca. You may also contact the Assistant Dean-IDST, Dr. Mary McKenna at 506 447 3044 or by email at mmckenna@unb.ca.

I am very grateful for the time you have taken to consider my request for your participation in this study. I believe that your personal experiences would bring important insights to my area of research focus, and ultimately help to inform how health and education services for newcomer parents of children with ASD.

Sincerely,
Kanza A Hashmat
Masters IDST Student
UNB Fredericton

Appendix B: Consent Form

I have read the Research Information Letter explaining the purpose and methods of study entitled: *Investigating newcomer parents' stories of accessing supports for their children with autism spectrum disorder.*

I am aware that it is ultimately my choice whether to become a participant in this investigation. I understand that if I agree to participate now, but later have a change of mind, I may withdraw from this study at any time with no consequence. I also understand that there is no consequence if I do not participate, or wish to refrain from answering specific interview questions, or choose to discontinue my participation in the study altogether.

I consent to participating in an individual interview via Zoom. _____
I consent to participating in a shorter follow up interview via Zoom _____
I do not wish to participate in this study. _____

Name Signature Date

Preferred method for communication:

_____ Phone: _____
_____ Email: _____

If you would like to receive a summary of this research following the completion of my thesis, please indicate below your preferred method of receiving this information:

- Email: _____
- Mailing Address: _____

Appendix C: Individual Interview Guide

The purpose of the interviews is to draw out the individual narratives of participants related to their experiences in seeking, engaging and sustaining services for their children with ASD.

How did you initially seek support?

Prompts or Potential Areas for Exploration

- Specific influences that preceded participants' concerns related to the presence of potential ASD features in their children's functioning
- Initial experiences of participants in dialoguing with others in the educational and health system about these concerns
- Challenges they experienced in initially navigating health and educational system supports
- Formation of preliminary connections with health and educational service providers
- Experiences that rendered greater ease or challenge in seeking support

How did you engage support?

Prompts or Potential Areas for Exploration

- Processes, events or experiences that were part of assessing or exploring areas of need or concern related to their children's functioning or adaptation
- Moving forward with recommended services or programs
- Challenges experienced in engaging supports-how were they resolved or worked through
- Nature or approach to setting goals and directions related to areas of health or learning
- Experiences that rendered greater ease or challenge in engaging support

How did you sustain support?

Prompts or Potential Areas for Exploration

- Examples of service follow-up in participants' stories
- Time of scheduled breaks in or absences of ongoing programs and supports (e.g., summer breaks, professional learning days, school transitions)
- Sources of ongoing support
- Lessons learned/insights from participant they would share with other newcomer participants
- Suggested recommendations for service providers
- Future hopes for their children

Curriculum Vitae
Kanza Aslam Hashmat, MD

PROFESSIONAL AFFILIATIONS

- Section 26, College of Physicians and Surgeons of New Brunswick CPSNB
 - Clinical Trainee License #4860 CPSNB
 - Member, Pakistan Medical Council (PMC) License # 7851-N
 - Member, College of Family Medicine, Pakistan Registration #95
-

EDUCATION

Resident General Surgery (1997)

Hayat Shaheed Teaching Hospital, Peshawar, Pakistan

Resident Internal Medicine (1996)

Hayat Shaheed Teaching Hospital, Peshawar, Pakistan

Medical Doctor (1990 - 1996)

Khyber Medical College, Peshawar, Pakistan

CONFERENCES

2020 Presented at psychology colloquium Department of Psychology UNB, Fredericton

2021 Peer Reviewed UNB Graduate research Conference (GRC), Fredericton

2020 Presented at UNB Graduate research Conference (GRC), Fredericton

2020 Presented at Atlantic Provinces Autism Conference UNB, Fredericton

PUBLICATIONS

2020 Better Practices for equipping educators to create a culturally safe learning environment for newcomer students with ASD. Graduate Student Presentation (ED6056), Faculty of Education, UNB