

**INVESTIGATING THE EXPERIENCES OF FAMILIES OF YOUNG CHILDREN
DIAGNOSED WITH AUTISM SPECTRUM DISORDER (ASD) WITH THE USE OF
SOCIAL SUPPORT SERVICES**

by ©Maryam Ibrahim

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Abstract

Previous studies have indicated that families of young children with Autism Spectrum Disorder (ASD) experience challenges caring for their children and that social support services have been found to help families cope or deal with some of these challenges (Hall & Graff, 2010; Ludlow, Skelly & Rohleder, 2012; Lytel, Lopez-Garcia & Stacey 2008). This study used a qualitative research methodology to investigate the experiences of families of young children diagnosed with ASD and accessing and utilizing social support services within an urban center in Newfoundland and Labrador (NL). Themes were derived from the data and commonalities across participants were explored. This study employed purposeful sampling as the method of participant selection. Parents or guardians of young children [preschool - grade 3] diagnosed with ASD and using social support services from various services providers were invited to participate. Open-ended interviews were used as the primary source of data and thematic analysis was used as the methodology to analyze the data. The findings suggested three overarching themes which included; suitability, barriers to access, and quality. Results from this study suggested that families with young children with ASD had both positive and negative experiences when accessing and utilizing social support services for their children with ASD.

Keywords: Autism Spectrum Disorder (ASD), Social support services, young children with ASD, families.

Dedication

This thesis is dedicated to my family; both immediate and extended for all their prayers, support, and encouragement throughout the completion of my thesis. To the Autism Communities; for their continuous effort, strive, and advocacy to ensure the best support for their families with individuals diagnosed with ASD.

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Chapter 1: Introduction

Autism spectrum disorders (ASD) are characterized by deficits in social communication, social interaction, and adaptive functioning across environments in which the individual has to function, for example, home, school, and community (American Psychiatric Association, 2013). The essential features of ASD are “persistent deficits in social communication and social interaction... restricted, repetitive patterns of behaviours, interest, or activities” (American Psychiatric Association, 2013, p. 50). There are a wide range of signs and symptoms typically associated with ASD. Generally, these appear during the developmental stages and continue to manifest throughout the lifespan of the individual (Wozniak, Leezenbaum, Northrup, West, & Iverson, 2017).

ASD is “a spectrum disorder” as symptoms and characteristics vary greatly amongst individuals. This variation depends on a number of factors including the severity of symptoms, the individual’s intellectual and developmental levels, their chronological age, and sensory processing (American Psychiatric Association, 2013). Children with ASD may require varying levels of support throughout their life. The DSM-5 provides clinicians with the ability to assess the severity level of the sign and symptoms of ASD by evaluating the level of support required for the individual to function within the home and community environments. Three levels of support are provided. For the first level, the individual requires some supports, the second level the individual requires substantial supports, and the third level the individual requires very substantial supports to function (American Psychiatric Association, 2013, p. 52).

The diagnosis of ASD has continued to rise over the years (Matson & Kozlowski, 2011; Ozerk, 2016). ASD diagnosis has increased over time with variations across different countries (Elsabbagh et al., 2012; Poovathinal et al., 2018). This rise of ASD diagnosis may be due to

better diagnostic testing, expansion of the diagnostic criteria, more awareness of the condition, and an increase in research around ASD (American Psychiatric Association, 2013).

The American Psychiatric Association (2013) stated that “in recent years, reported prevalence for ASD across U.S. and non-U.S. countries had approached 1% of the population, with similar estimates in child and adult samples” (p. 55). In 2018, the Centers for Disease Control and Prevention (CDC) released new data on the prevalence of ASD in the United States (U.S). The surveillance study identified 1 in 59 children (1 in 37 boys and 1 in 151 girls) as having ASD (Autism Speaks, 2018b, para 1). A new survey, using parent-reported information about the diagnosis of their children with ASD (aged 3 to 17 years) was collected by the National Survey of Children's Health. Using the results of this survey the estimated prevalence of ASD was reported to be 1 in 40 in the United States (American Academy of Pediatrics, 2019). The Public Health Agency of Canada (2018), in a report on the National Autism Spectrum Disorder Surveillance System (NASS), reported the prevalence of ASD as 1 in 66 children in Canada. NASS also reported that Newfoundland and Labrador (NL) had the highest prevalence rate in Canada in 2015, with 1 in 57 children, with male prevalence at 1 in every 35 and females 1 in every 179 (Public Health Agency of Canada, 2018, p. 16). ASD is now regarded as the fastest growing and most commonly diagnosed neurological disorder in Canada (Public Health Agency of Canada, 2018).

ASD has no cure, but early identification and appropriate intervention can impact long term outcomes (CDC, 2017; Manning-Courtney et al., 2013). Intervention, compensation, and continuous supports for individuals with ASD may help individuals cope in certain contexts (American Psychiatric Association, 2013). Early intervention services can also help children

learn important skills, including therapies to help the development of language skills, motor skills, as well as social development (CDC, 2018, para. 6).

Once a child is diagnosed, families tend to be impacted in different ways (Hall & Graff, 2010; Ludlow et al., 2011). Numerous qualitative research studies explored families with young children with ASD and found families' experience challenges raising their children with ASD (Hall & Graff, 2010; Hutton, & Caron, 2005; Ludlow et al., 2011; Lytel et al., 2008). Children with ASD impact family functioning, their opinions, their perceptions, and they provide challenges, struggles as well as successes. Researchers suggest the need for additional supports that address the varying and unique needs of families (Hall & Graff, 2010; Hutton, & Caron, 2005; Ludlow et al., 2011; Lytel et al., 2008). With an increasing population of young children diagnosed with ASD, there is a need to focus on the support services required to meet the needs of these families (Cassidy, McConkey, Truesdale-Kennedy, & Slevin, 2008).

Social support (formal and informal) refers to the different forms of assistance found within group or individual relationships (Meadan, Halle & Ebata, 2010; Zimet, Dahlem, Zimet, & Farley, 1988). It can be emotional, instrumental, informational, and appraisal (Langford, Bowsher, Maloney, & Lillis, 1997). It includes supports from one's family, spouse, friends, available services and community programs (Meadan et al., 2010; Siman-Tov & Kaniel, 2011).

Social supports develop from the relationships and interactions between individuals, families, peer groups, and the larger social system (Ludlow et al., 2011). These supports have been known to act as a buffer against the demands of caring for a child with a disability (Renty & Roeyers, 2006). Studies have indicated that parents of young children with ASD identified services ranging from specialist care, other parent support, immediate family members, extended

family members, support groups, childcare services, respite services, home health care, family education and training, family counselling, insurance, and flexible financial assistance as important support and resources for them (Hall & Graff, 2010; Freedman & Boyer, 2000). Social support services can be categorized into formal and informal (Hall & Graff, 2010; Phelps, Hodgson, McCammon, & Lamson, 2009). Formal supports include support from professional practitioners, institutions, and governmental and non-governmental organizations. Informal supports can be interpreted as support from a spouse, family and friends, and the immediate community (Hall & Graff, 2010; Phelps et al. 2009).

Research studies on the role of social support services on the coping strategies for families caring for a child with ASD have suggested that support service plays an essential role within the adaptation process (Luther, Canham, & Cureton, 2005; Tétreault et al., 2014). Social support has been found to be a moderator of stress and negative outcomes, and essential in promoting resilience in families of young children with ASD (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Ekas, Lickenbrock, & Whitman, 2010; Rutstein, 2014; Siman-Tov & Kaniel, 2011).

According to Brown and colleagues (2012), several studies have grouped children in large age ranges (Kogan et al. 2008; Siklos & Kerns, 2006); therefore, possibly masking the unique needs of families within specific age groups. Children with ASD have development that is strikingly different from typical developing children (Beauchesne, Kelley & MeInyk, 2004). Families of young children with ASD can provide a unique and comprehensive understanding of their experiences of caring for their children with ASD and with the social support services available to them (Bloch & Weinstein, 2010; Brookman-Frazee & Koegel, 2004; Lytel et al., 2008).

Two Canadian cross-sectional studies investigated the social support services for families with children diagnosed with ASD. These studies investigated families met and unmet needs, the well-being of parents, and gaps in services (Brown et al., 2011; Brown et al., 2012). These studies used surveys to collect data from families of children with ASD who were school - aged (6 years) and above (Brown et al., 2011; Brown et al., 2012). Both studies indicated that families of children diagnosed with ASD tended to have unmet needs when it came to the provision of support services (Brown et al., 2011; Brown et al., 2012; Weiss, Cappadocia, MacMullin, Viecili, & Lunsky, 2012). Another Canadian study investigated families of children with ASD and their service needs. This study collected data from families of children diagnosed with ASD ranging in age from 2 years to 18 years old (Hodgetts, Zwaigenbaum & Nicholas, 2015). Findings from this study indicated families of children with ASD experienced certain unmet needs-specifically the need for more information on available services.

Shahidi and colleagues (2015), conducted a needs assessment survey commissioned by the Autism Society of Newfoundland and Labrador (ASNL). This needs assessment examined support services in relation to the needs of families of children with ASD. Data was collected from a large sample of individuals associated with ASD. These included parents of children with ASD, adults with ASD, educators, health service providers and key informants (Health and Education) (Shahidi et al., 2015). The needs assessment survey sought input from individuals from across the province to provide insight into the needs of the ASD community and to help identify gaps in services in NL (Shahidi et al., 2015). The investigation supports the service needs of the ASD community across the life span from preschool to adulthood. Findings suggested gaps in services, a lack of knowledge, training, and education of service providers, and limited programs for preschool age children. Findings from the survey supported the need for

more resources across NL and the importance of early intervention services. This survey stated that preschoolers need expedient diagnoses and treatment plans (Shahidi et al., 2015).

Previous research supports the need for further research into services for young children, as studies have pointed out the long-term positive outcomes of early intervention services and supports for families of young children (Troy, Connolly & Novak, 2007; Warren et al., 2011). Investigating the families' experiences with support services in this crucial stage of the life of a child with ASD is important. Families of young children with ASD can provide a unique and comprehensive understanding of their experiences when caring for their children with ASD and the social support services available to them (Bloch & Weinstein, 2010; Brookman-Frazee & Koegel, 2004; Lytel et al., 2008). Accounts of experiences from families of young children with ASD using social support services at this early stage could offer insights into service provisions for families of young children; thereby, providing a better understanding and possibly influencing practices and policy decisions with respect to support services provided for families of young children with ASD.

The current study focused on families of young children with ASD. It considered family characteristics and experiences with social support services. This study sought to understand families' unique accounts of their experiences with support services and hoped to help understand the perspectives of these families. The purpose of this study was to investigate the experiences of families of young children diagnosed with ASD and social support services available to them in NL. This study hoped to provide accounts of families' experiences with social support services from the point of diagnosis to their transition to school.

Qualitative research is based on the methodological pursuit of understanding the ways that people see, view, approach, and experience their world. Qualitative research attempts to make meaning of people's everyday experiences as well as specific phenomena under study (Ravitch & Carl, 2016; Whitt, 1991). This qualitative research study aimed to explore the experiences of families of young children with ASD, by gathering narrative accounts of their experiences with social support services available to them in NL (Creswell, 2015; Ravitch & Carl, 2016).

A purposeful sampling of participants was sought through recruitment letters emailed to various childcare and pre-school settings, and the Autism Society of Newfoundland and Labrador (ASNL) (Creswell, 2015; Creswell & Poth, 2017). Recruitment posters were also placed on bulletin boards at ASNL and Memorial University and posted on Facebook pages of individuals and groups associated with ASD. These venues were used to ensure that participants had experience with the phenomena under study and could provide the researcher with valuable and relevant experiences and insights (Ravitch & Carl, 2016). Five research questions were used to guide this study:

1. What are the services and support needed for young children with ASD?
2. What types of social support services are available to families of young children with ASD?
3. What forms of social support services do families with young children with ASD benefit from?
4. Are these support services meeting the needs of families with young children with ASD from the point of diagnosis to transitioning to school?
5. How do the support services address their unique diagnosis and needs?

Theoretical Framework

The theoretical framework that underlines and acts as the lens to provide an understanding of this research study is Bronfenbrenner's ecological models (1994) and T. S. Wiesner's Ecocultural theory (2002). These theories provide a framework for understanding the experiences of families of children with ASD within systems and structures and a culture that directly or indirectly impacts the children's growth and wellbeing in relation to support structures and services put in place (Algood, Harris & Hong, 2013; Brookman-Frazee, & Koegel, 2004; Garbacz, McIntyre, & Santiago. 2016; Gouin, da Estrela, Desmarais, & Barker, 2016; Irvin, McBee, Boyd, Hume, & Odom, 2012; Nihira, Weisner & Bernheimer 1994).

The ecological systems theory offers an understanding of the relationship between children and the various systems that supports their growth, learning and development. It focuses on the quality and context of their environments (Bronfenbrenner, 1994). It aims to provide an understanding that different factors in the ecological system serve as supports to ensuring families adapt to the challenges of caring for a child with ASD (Bronfenbrenner & Ceci, 1993; Garbacz, et al., 2016). As individuals, we move through a series of life transitions, which necessitate environmental support (Hepworth, Rooney, Rooney, Strom-Gottfried, & Larsen, 2010). To support children with disabilities and their families, we must consider the entire system in which growth, development, and learning occur. These systems comprise of five socially organized subsystems, which are the microsystems, mesosystems, exosystems, macrosystems, and chronosystems (Bronfenbrenner, 1994).

The microsystem is the complex relationship between developing persons and their environments or settings. The microsystem contains people, activities, or roles with which individuals engage with for a period of time (Bronfenbrenner, 1977). This interaction could be

between parents and the immediate or extended family, parents and the school or childcare staff, all with the goal of ensuring growth and development of the person (Bronfenbrenner, 1994).

Mesosystems comprise the linkages and processes taking place between two or more major settings containing the developing person (e.g., the relations between home and school, school and workplace, etc.) at a point in his or her life (Bronfenbrenner, 1977; 1994). An example of such linkages would be interactions among a family, school and peer group or these interactions may extend to church, camp, or workplace (Bronfenbrenner, 1977)

An exosystem is an extension of the mesosystem, embracing other specific social structures both formal and informal, but does not necessarily contain the developing person. These structures may have an impact on the settings that the person occupies thereby, influencing or even determining what goes on there (Bronfenbrenner, 1977). These structures include the workplace, the community, mass media, and government agencies (local, provincial, and federal). It may consist of also communication and transportation facilities, and informal social networks (Bronfenbrenner, 1977). Macrosystems are established arrangements of the various way of life institutional patterns of the culture or subculture (such as economic, social, educational, legal, and political systems), which tend to carry information and ideologies, which influences other systems implicitly or explicitly (Bronfenbrenner, 1977 p. 515). The importance placed on children and those responsible for their care within such macrosystems tends to determine how they are treated within the different settings in which they interact (Bronfenbrenner, 1977). For example, the socio-economic status or educational level, race or ethnicity of a person may influence the individual's interactions with the various societal institutions.

Chronosystems focus on transitions that individuals experience throughout their life and the impact on their development (Bronfenbrenner, 1986). It may encompass changes or consistencies in characteristics that occur over time within the individual as well as the environment where the individual lives (Bronfenbrenner, 1986). For example, family structures, socioeconomic status, employment, place of residence, the degree of hecticness, the individual's ability in their everyday life, and throughout their life (Bronfenbrenner, 1994, p. 40). These changes tend to have implications on how families and children interact with the various environments.

According to Gouin and colleagues (2016), “[t]he ecological models of human development points out that the social and family relationships are embedded in larger social structures such as communities, organization, institutions, and cultures” (p. 194). These social structures for families of children with ASD influences the accessibility and utilization of services important to the development of individuals (Gouin, et al, 2016). Factors associated with successful parenting of children with ASD are multifaceted, necessitating an ecological model of assessment of each individual caregiver and the environments in which children reside (Algood, et al., 2013). Services accessed by families of children with ASD often take place in multiple settings, and families may be involved with service delivery systems for many years before their children enter kindergarten or the school system (Garbacz, et al., 2016). In order for intervention programs and services to be successful in ensuring parenting success for families of children with disabilities, an assessment at the different levels of the ecological systems is needed (Algood et al., 2013). Using Bronfenbrenner's (1994) ecological model as a framework for understanding the experiences of families based on their accounts offers insights into families' experiences. Families accessing and utilizing social support services for their children within

these multi-systems, need the right supports and services to be able to function effectively within these systems.

Ecocultural theory (Wiesner, 2002) offers a lens to understand how families' cultural characteristics can provide a better understanding of their experiences with social support services. Ecocultural theory as a framework for this study enables us to consider the role of families in the support services made available to them and their children with ASD. Ecocultural theory considers the pathway of children's development, by providing an understanding of families' cultural niche in relation to supporting their children and their families (Wiesner, 2002). Wiesner (2002) pointed out that "cultural pathways consist of everyday routines, and routines are made up of cultural activities children engage in" (p. 275). These could consist of "bedtime, playtime, video games, homework, cooking dinner, soccer practice, visiting grandma" (Wiesner, 2002, p. 275). These routines are useful for understanding different families' cultures because they are meaningful to the parents and children's everyday experiences (Wiesner, 2002). These routines revolve around specific values and goals that tend to influence what families require /need of their children with a disability (Wiesner, 2002).

Ecocultural theory offers insights on intervention strategies on how to provide measures and intervention plans to fit into daily routines, goals and values of the families (Brookman, Frazee & Koegel, 2004; Nihira et al., 1994). With an understanding of families' experiences from an ecocultural framework, we can understand their experiences with support services and whether those services align with their family needs and goals. Does it enable their children to live a holistic life? Function effectively within multiple systems? What services do families

believe are needed to ensure healthy functioning and transitions for their children and their families?

Eco-cultural theory provides an understanding of ways in which families' function within their everyday lives due to their children's developmental problems (Nihira et al., 1994).

Ecocultural theory offers insights into the importance of considering families cultural niche when understanding the experiences of families with children diagnosed with ASD (Wiesner, 2002).

In this study, readers start to understand the various services beginning when children are diagnosed and coming together to promote goals of healthy wellbeing for children with ASD and their families. Families' of children with ASD interact, are influenced by, grow and experience changes within these ecological systems. The functioning of families within these systems are experienced within the frames of their unique family's cultural niches (Wiesner, 2002). In the current study, the ecological model and ecocultural theory were used to ensure a comprehensive understanding of families of young children with ASD and their experiences with social support services.

Conclusion

Growing research evidence has pointed out the increased prevalence of ASD diagnosis and the need for support services for families of young children with ASD (Elsabbagh et al., 2012; Tétreault et al., 2014). It is apparent that social support services can help families care for their children with disabilities such as ASD (Tétreault et al., 2014). By providing research results that are rooted in the understanding of people's everyday lives and experiences from the perspectives of those living it, qualitative research makes complex human issues comprehensive and clear (Creswell & Poth, 2017; Hatch, 2002; Welling Elton, 2015).

This research study aimed to understand the experiences of parents with support services for their children diagnosed with ASD. Knowledge of their experiences based on the findings in this study may offer insights into service provision for families, policy recommendation and modifications, improvement in professional practices, awareness and advocacy roles.

Chapter 2: Literature Review

Overview

Autism Spectrum Disorder (ASD) is among one of the most stressful childhood developmental disabilities families may face. This is often related to the complexity and the range of needs of children with ASD (Gray, 2006; Russa, Matthews, & Owen-DeSchryver, 2015). Once a child is diagnosed with ASD, the parent strives to care for the child and to ensure their family's functioning (Blackledge, & Hayes, 2006). With access to the right services and supports, families can cope and care for children with ASD (Russa et al., 2015; Gray, 2006). The need for effective and accessible support for families and their children with ASD needs to become a priority for service providers, professionals, and policymakers (Hall & Graff, 2011). Families of children with disabilities may face difficulties meeting the needs of their children due to challenges in accessing available resources (Tétreault et al., 2014). Families of children with ASD reported that support services may be insufficient and challenging to access (Bromley, Hare, Davison, & Emerson, 2004).

Early interventions can be helpful; however, they need to begin as early as possible for children with ASD to maximize and accommodate new forms of learning (Hall, 2009). Interventions may provide opportunities for significant impact on the development of children with ASD (Shen & Piven, 2017). Early interventions during crucial stages of development can result in notable, positive long-term outcomes for children diagnosed with ASD (Hall & Graff, 2010; Shen & Piven, 2017; Tway et al., 2007).

Intervention programs, support services, and educational programs can alleviate challenges for families and enhance long term developmental outcomes for children with ASD (Hall & Graff, 2011; Manning- Courtney et al., 2013; Warren et al., 2011). Intervention and

support for ASD need to be individualized, multidimensional and multidisciplinary to maximize an individual's functional independence and quality of life (Hall, 2009). Interventions that target children's needs, their strengths and weaknesses can make substantial differences in the lives of children with ASD by reinforcing replacement behaviors and promoting self-management (Hall, 2009).

Lloyd and Rosnam (2005) concluded in their study that for assessment, interventions or policies to support families of children with special needs like ASD to be successful, there needs to be an understanding of the “functioning of all the systems that a family must interact with” (p. 197) daily. Exploration of the ecological systems of development can increase our understanding of families' experiences, and possibly improve policies and practices. It may also help determine how to best support families when raising children with special needs (Algood et al., 2013; Bronfenbrenner, 1994). The ecological systems which include the microsystem, mesosystem, exosystem, macrosystem and the chronosystem according to Bronfenbrenner (1994), can help provide an understanding of how the all the systems function together to support families with a child with ASD.

Tétreault et al. (2014) described a variety of support services available to families of children with disabilities. These researchers divided the supports required by families into four categories: support, respite, childminding, and emergency support (Tétreault et al., 2014, p. 272). These researchers reported that this system of classification can provide a framework for service providers, professionals, and parents (regardless of the child's disabilities). This classification system can also identify the various support strategies and determine which specific supports to prioritize (Tétreault et al., 2014). Identifying needs and gaps in the services as indicated by families of children with ASD can help tailor support services to meet families'

needs resulting in improvements in their quality of life and ensuring more sustainable ASD services (Hodgetts et al., 2015). Parents experiences and perceptions of their met and unmet needs may potentially provide insights into support services that need to be modified or strengthened (Brown et al., 2012; Hall & Graff, 2010).

There is growing evidence that the needs of families of children with ASD are not being met in Canada and elsewhere. Therefore, there is a need for a comprehensive understanding of the needs of families and to effectively and efficiently allocate limited resources (Brown et al., 2012; Hodgetts et al., 2015; Shepherd & Waddell 2015). With higher rates of ASD in Newfoundland and Labrador (NL) and limited services available for young children with ASD (Pelly, Vardy, Fernandez, Newhook, & Chafe, 2015 & Shahidi et al., 2015), this study aimed to investigate families of young children and their experiences with social support services that were available to them within an urban centre in NL.

To begin this study a search of the relevant research literature was conducted using Google Scholar and Memorial University's library. This review of literature used a variety of resources and included relevant books, reports, and peer-reviewed published articles. Excluded were newspaper articles, conference proceedings, and appraisals. The initial search of "autism and social support services" revealed far too many resources an approximate of (381,000); many of which were not relevant to the current study. Therefore, the search terms were narrowed to include "preschool children with ASD and social support services"; "families of young children with autism and social support services"; and "experiences of families of young children with social support services". Any articles not specifically referencing ASD, families of young children with ASD, and/or social support services were excluded from the final selection of sources included in this review of the literature. A total of 136 peer-reviewed articles, reports and

publications were found for this review. The following literature review provides an overview of autism and families of young children with ASD accessing social support services.

Autism Spectrum Disorder and Prevalence

Autism Spectrum Disorders (ASD) are a set of heterogeneous neurodevelopmental conditions (Lai, Lombardo, & Cohen, 2014). The Diagnostic and Statistical Manual of Mental Disorders (DSM-5,2013) published by the American Psychiatric Association (APA), is one of the main classification systems used internationally by clinicians to understand the signs and symptoms of ASD (Hall, 2009; Manning- Courtney et al., 2013).

ASD, once considered rare, is now one of the most frequently studied neurodevelopmental disorders (Matson, & Kozlowski, 2011). The diagnosis of ASD has a spectrum of symptom and a range of severity which is caused by different combinations of genetic and environmental influences (Fakhoury, 2015). ASD is reported to occur in all racial, ethnic, and socioeconomic groups (CDC, 2018, para 6). ASD commonly co-occurs with other developmental, psychiatric, neurologic, medical, chromosomal, and genetic diagnoses (CDC, 2018, para 2). In general, the more co-occurring conditions, the greater the individual's disability (Lai et al., 2014). Validating ASD diagnoses requires multiple sources of information which includes clinician observations, caregiver observations of the children's behavior, and self-report information (American Psychiatric Association, 2013).

According to Autism Speaks Canada (2018a):

The timing and severity of ASD first symptoms can vary widely. Some children with ASD show hints of future problems within the first few months of life. In others, symptoms may not become obvious until 24 months or later. Some children with ASD

appear to develop normally until around 18 to 24 months of age and then stop gaining new skills and/or start losing skills (para 1).

There has been an increase in the prevalence of individuals diagnosed with ASD worldwide (Lai et al., 2014; Matson & Kozlowski, 2011; Ozerk, 2016). Ozerk (2016) completed a meta-analysis on research studies published between 2000 and 2016 investigating the prevalence of ASD. The study addressed the geographical and age dimensions of the prevalence of ASD in over 50 studies from 21 countries. Findings from the study suggested that there is significant evidence that the prevalence rates of ASD diagnoses among children are on the rise.

A variety of Canadian reports and research studies suggested that the prevalence rate of ASD in Canada has continued to grow (Matson & Kozlowski, 2011; Prior, 2003; Public Health Agency of Canada, 2018). Based on data collected from Newfoundland and Labrador, Prince Edward Island, and Southeastern Ontario, over a seven-year period (2003 - 2010), the prevalence of ASD in these three Canadian regions, appears to have significantly increased. These increases included all age groups with some variations by age and region (Ouellette-Kuntz et al., 2014).

A cohort study, by Pelly et al. (2015) reviewed the incidence rate of ASD over five years (2006-2010) among all children living on the Avalon Peninsula (a geographical region which comprises of over 50% of the population of NL). Data interpretation showed a high rate of diagnoses of ASD in children living in this region. Pelly et al. (2015) noted that at the end of 2013, the cohort of children born in 2006 had one of the highest prevalence rates ever reported for a population in Canada. Although the study was from a small sample and does not reflect possible rates in other geographical locations, it is an indication of the support resources needed within the specific region (Pelly et al., 2015). A more recent report from the Public Health Agency of Canada (2018) showed an approximate prevalence of 1 in 66 children were diagnosed

with ASD in Canada in 2015. Of the six participating provinces and one territory, Newfoundland and Labrador's ASD prevalence rate was the highest. The overall prevalence of ASD in NL was 1 in every 57, and the most common age of diagnoses was four years old (Public Health Agency of Canada, 2018).

Based on previous studies ASD affects more males than females (American Psychiatric Association, 2013; Lai et al., 2014; Werling & Geschwind, 2013). Lai et al. (2014) conducted a meta-analysis of research evidence examining the prevalence of ASD worldwide. The results suggested that ASD affects four to five times more males than females and some studies attributed this to females with ASD being under-recognised. In Canada, boys are diagnosed with ASD four times more frequently than females (Public Health Agency of Canada, 2018).

As the prevalence rate of ASD rises, more services are required; therefore, there is a need to better understand the experiences of families and their support needs (Davis & Carter, 2008; Cassidy et al., 2008). Studies investigating the service needs for families of children with ASD continues to grow as new families of young children with ASD require support services (Cassidy et al., 2008; Dymond, Gilson & Myran, 2007; Vohra, Madhavan, Sambamoorthi, & St Peter, 2014). Young children diagnosed with ASD have a cognitive profile that exhibits an impairment in social cognition and perception, executive dysfunction, and atypical perceptual and information processing (Lai et al., 2014). Due to the complex nature of ASD, and varying comorbidities; appropriate interventions and services for individuals with ASD are multi-faceted and these services are required across the lifespan (Lord & Bishop, 2010; Vohra et al., 2014). Insights into the experiences of families of children with ASD becomes important to investigate in the context of the growth of ASD diagnoses.

Family Experiences with Autism Spectrum Disorders

Raising a child diagnosed with ASD tends to be very challenging for families. Families face challenges when attempting to seek the diagnosis of ASD for their children, some families have a limited understanding of the diagnosis, and many face difficulties accessing information and services (Hutton & Caron, 2005). For many families, having a child comes with aspirations and hopes for the child's future. These aspirations can be influenced by cultural, religious, personal, and family values (Bloch & Weinstein, 2010). Having a child diagnosed with ASD can be a stressful and sometimes a devastating experience for families (Bloch & Weinstein, 2010). According to Altieri and von Kluge (2009), parents described their experiences in terms of "confusion that resulted from their child's behavioural presentation and the feelings of loss and devastation that occurred after discovering their child has ASD" (p. 142). Despite these feelings, in most cases, parents feel a certain relief that they now understand their children's behavior, they take up advocacy roles, and become eager to mobilize resources to help their children (Altieri, & von Kluge, 2009; Bloch & Weinstein, 2009). When parents observe suspicious behaviours or delays in development, their first step is to seek assessment services to enable them to be able to access services (Bloch & Weinstein, 2010). Families of children with disabilities, including ASD, face difficulties with regards to accessing available resources to meet their children's needs (Tétreault et al., 2014; Vohra et al., 2014).

Several studies with mothers of young children with ASD reported that mothers tend to take on a greater share of the caregiving burden when compared with fathers (Bromley et al., 2004; Ekas et al., 2010a; Nealy, O'Hare, Powers, & Swick 2012). These studies focused on mothers' perspectives and experiences of raising children with ASD because mothers are often the primary caregivers (Ekas et al., 2010a; Nealy et al., 2012). In one study, mothers were more

likely than fathers to report greater levels of distress, stress, and depression which could be a result of having greater involvement in raising children, exposure to dismissive social reactions by outsiders, and an absence of employment (Nealy et al., 2012).

A Canadian study aimed at understanding the lived experiences of parents who have children with ASD found that having children with ASD defined how they "lived their lives". Parents in the study indicated that they felt their lives revolve around the children's intervention programs, and they felt disconnected and isolated due to society's lack of support and understanding. These findings provided insights into what it is like to be the parents of children with a disability like ASD. Experiences shared by parents can also help influence how services are provided (Woodgate, Ateah, & Secco, 2008).

A study utilizing qualitative interviews explored the experiences of 20 parents of children with ASD. The researchers reported that parents experienced challenges and coping strategies when parenting children with ASD, and the results suggested five core categories of challenges experienced by parents. These included dealing with challenging behavior, dealing with judgments from others, lack of support, impact upon family, coping, and the importance of appropriate support. The study also examined how families cope and found parents placed more emphasis on the role of social supports and indicated the need for additional supports (Ludlow et al., 2012). Resources can be individualized to better serve families currently struggling with the challenge of raising children with ASD when there is an understanding of their various strains and stressors. These strains and stressors included a decrease in social opportunities due to behavioral concerns and stigmatization, changes in relationships with family and friends due to a lack of awareness and education and impacts on employment (such as reduced work hours or change in career paths) of families with children diagnosed with ASD (Nealy et al., 2012). The

need to acknowledge unique differences in families' experiences is essential when offering any form of intervention and support services (Davis & Carter, 2008).

Woodgate et al. (2008) interviewed parents of children diagnosed with ASD. Woodgate et al. reported one of the emergent themes found in their study was "vigilant parenting", as the parents noted that they have become "completely focused on every aspect of their child's world" (p. 1079). There is the need for service providers to be more attentive to concerns and questions raised by parents about their children (Woodgate et al., 2008). Families tend to cope with their children's diagnosis of a developmental disability in different ways (Jones & Passey, 2005; Twoy et al., 2007). Davis and Carter (2008) studied parents' experiences and opinions when dealing with their children diagnosed with ASD. They found that children and families have unique challenges (Davis & Carter, 2008). Studies have indicated that as part of the coping strategies and ways for parents to address challenges with services, they tend to seek out professionals, other parents, or access information through searching the internet (Altiere & von Kluge, 2009; Hall & Graff, 2010).

Information creates awareness; thereby, giving families a sense of control over their lives (Mitchell & Sloper, 2002). Davis and Carter (2008) pointed out when families have information about ASD, such as their children's diagnosis, and their children's strengths and weaknesses, there can be a reduction in feelings of stress and isolation that are often associated with raising children with ASD. Comprehensive information needs to be provided by professionals or key individuals working with children with ASD (health workers and social workers). Parents of children with ASD will need to involve professionals from different types of service, and these professionals should make an effort to work together (Mitchell & Sloper, 2002). Adequate, current, and up-to-date information is beneficial to families with children with ASD (Hall &

Graff, 2010; Mitchell & Sloper, 2002; Tétreault et al., 2014). Professionals caring for children with ASD should provide families with information about services, financial assistance, day care and programmes, as well as respite care (Tétreault et al., 2014).

Families have reported they are often faced with challenges due to limited publicly funded services and the quality of training of the personnel providing the services. Often, these challenges leave families with unmet needs (Ludlow et al., 2012). Families have also reported that the services are not able to address many of the needs they deem as important to the care of their children and their families. Therefore, resources need further expansion and development to be able to address the needs of children with ASD (Hall & Graff, 2010; Siklos & Kerns, 2006). Tway et al. (2007) indicated from their research study on coping strategies that parents adapted to the challenges of raising children with ASD through support from friends, families, other families with children diagnosed with ASD (informal supports), and from service agencies and programs (formal support) (Tway et al., 2007).

Importance of Social Support

Social support is defined as “an exchange of resources between at least two individuals perceived by the provider or the recipient to be intended to enhance the wellbeing of the recipient” (Shumaker & Brownell, 1984, p.1). Siman-Tov and Kaniel, (2011) also defined social support for families caring for children with disabilities as “a resource provided by others and may be tangible, instrumental, informational or emotional which indirectly affects parental adjustment and child’s severity of symptoms” (Siman-Tov & Kaniel, 2011, p. 886). These supports according to Meadan et al. (2010) are “instrumental or emotional support from formal (e.g., agencies and institutions) or informal (e.g., friends, relatives, community) sources” (p. 24).

Based on these description of social support services, it can be divided into formal and informal support services (Hall & Graff, 2010; Meadan et al., 2010; Siman-Tov & Kaniel, 2011).

Social supports are identified as key factors in reducing the challenges of raising children with ASD as well as other disabilities (Ekas et al., 2010a; Tway et al., 2007). Social support has been identified as a factor that helps counteract the adverse outcomes of stress which comes with raising a child with ASD (Desmarais, Barker, & Gouin, 2018; Ludlow et al., 2011; Park & Turnbull, 2002). Research across different age groups of children with ASD and their families suggested that social support promotes positive psychological wellbeing when dealing with the challenges of raising children with ASD (Ekas et al., 2010a; Ludlow et al., 2011). Increases in parents' social support networks are one of the major factors associated with optimism and wellbeing for families with children diagnosed with ASD (Ekas et al., 2010a). In terms of formal support, difficulties have been experienced by families with regards to “diagnostic process, with support and education provided by mainstream settings and with the accessibility of ASD-specific service provisions” (Renty & Roeyers, 2006, p. 371).

Based on ASD symptoms and differing levels of severity, many children diagnosed with ASD will continue to have life-long needs (Manning- Courtney et al., 2013). Lack of support and resources can make caring for children with ASD exhausting for families (Ludlow et al., 2012). Studies have indicated that both mothers and fathers reported that support services are important factors that help them cope with having children with ASD and that these services should be offered in different ways and at strategic times (Ludlow et al., 2012; Tétreault et al., 2014). It is important to note that needs are diverse when dealing with children with disabilities; opportunities and access to a wide range of services are crucial (Tétreault et al., 2014). Based on Tétreault and colleagues research findings categories of support discussed included informational

support, assistance and support, legal support, educational support, assistance with daily activities, leisure, sports and social activities opportunities, respite emergency support, financial emergency, and child minding (p. 276-277). With a wide range of service available, parents can identify effective strategies that fit their unique situation and their needs (Tétreault et al., 2014). Support services are therefore numerous and multifaceted (Tétreault et al., 2014). Since there are several factors associated with raising a child with disabilities, an ecological assessment of the child and his or her environment becomes necessary because growth and development occur and its influenced by the entire system (Algood, Harris, & Hong, 2013). Families experiences using the various support services can offer insights on the needs of families with young children with ASD. The needs of the children with ASD tend to be affected in different ways (Hall & Graff, 2010).

Families Experiences with Social Support Services

One major challenge amongst other factors for families/caregivers of children with ASD is difficulty accessing and using services (Vohra et al., 2014). Siklos and Kerns (2007) found that parents of children with ASD reported dissatisfaction with the services received after diagnosis as the services provided tended not to meet parents needs due to the demanding nature of children with ASD. Families have; therefore, identified the need for additional support for children with ASD (Hall & Graff, 2010). Revisions to *Diagnostic and Statistical Manual* over the years have improved the diagnostic categorizations of ASD, thereby, providing professionals and families with a better understanding of diagnosis. In the most recent DSM-5 a severity level is assigned and can be used to determine treatment options and services needed for children diagnosed with ASD (American Psychiatric Association 2013; Grzadzinski, Huerta, & Lord, 2013).

Interventions and support services for ASD are needed for but not limited to language and communication impairments, sensory issues, physical and psychiatric issues, issues with diets, behavioural and developmental issues, educational, medical, and social care (Volkmar, Siegel, Woodbury-Smith, King, & McCracken, 2014). In their review of the ASD literature, Manning-Courtney and colleagues (2013) highlighted examples of early intervention programs and services that are essential and required early for children diagnosed with ASD. These included Applied Behavioural Analysis (ABA), the JASPER (Joint Attention, Symbolic Play, Engagement, and Regulation), the Early Start Denver Model (ESDM), speech-language therapy, occupational therapy, educational programs, medical treatment, as well as ongoing follow-up.

Applied Behaviour Analysis (ABA) intervention programs are one of the main interventions used for the treatment of ASD within the Atlantic Provinces (Shahidi et al., 2015). Families of young children with ASD considered ABA-based interventions as the basis of the most effective intervention (McPhilemy & Dillenburger, 2013). “ABA uses discrete trial teaching. This method uses a systematic process of observing and recording an individual’s behavior with the information collected being used to shape instruction and diverse effective intervention strategies” (Bloch & Weinstein, 2009, p. 31). Results from research by McPhilemy and Dillenburger (2013), showed that ABA-based interventions had a highly significant impact on the social-communication skills and quality of life of young children with ASD. Reports from studies have also pointed out the effectiveness of the combination of ABA with different comprehensive and skilled-based methods for teaching a variety of skills (McPhilemy & Dillenburger, 2013; Vismara & Rogers, 2010).

Deficits in joint attention represent a key feature of ASD (Jones & Carr, 2004). JASPER (Joint Attention, Symbolic Play, Engagement, and Regulation) is an early intervention program

for children diagnosed with ASD. It is an intervention program recently introduced to families within NL. It is currently being introduced in this province as a pilot program and one of the participants in the current study was receiving this program at the time this study was conducted. Joint attention is a social-communicative skill in which two people use gestures and gaze to share attention to interesting objects or events (Jones & Carr, 2004, p. 13). This skill plays an important role in social and language development; therefore, early intervention strategies are needed to address this challenge (Jones & Carr, 2004). JASPER strategies have been identified as an important intervention approach for children with ASD (Kasari, Gulsrud, Paparella, Hellemann, & Berry, 2015). Research studies on the effectiveness or efficacy of targeted intervention approaches like JASPER for young children diagnosed with ASD have shown significant improvement in social responsiveness and communication levels even when the targeted intervention was brief (Goods, Ishijima, Chong, & Kasari, 2013; Kasari, Freeman, & Paparella, 2006; Kasari, Paparella, Freeman, & Jahromi, 2008; Kasari & Patterson, 2012). Longitudinal reports also indicated significant long-term outcomes with children with ASD receiving targeted interventions on joint attention and play intervention, on the quality of language and communication (Kasari, Gulsrud, Freeman, Paparella, & Hellemann, 2012; Lawton & Kasari, 2012).

More Than Words (MTW) is part of The Hanen Program and is a Canadian program widely used around the world and another intervention strategy used with young children with ASD. This intervention is aimed at improving social communication skills. It involves parent-implemented language intervention (Patterson & Smith, 2011). One of the participants in this study discussed using this intervention during their interview with the researcher. Studies have identified intervention implemented by caregivers are an effective way to engage parents in their

child intervention process (Patterson & Smith, 2011; Weitzman, 2013). Hanen's (MTW) parents' implemented interventions for families of children with ASD have been shown to produce effective outcomes for parents and children (Patterson & Smith, 2011). Patterson and Smith (2011) concluded in their research that information about families' experiences could be used to tailor the program to ensure its optimal benefit.

Many children with ASD have sensory issues which are frequently demonstrated in the different ways they respond to sensory stimuli (Hazen, Stornelli, O'Rourke, Koesterer, & McDougle, 2014). These responses contribute to the features and functional impairments in individuals with ASD (Hazen et al., 2014). The primary treatment option for sensory processing disorders associated with ASD is predominantly occupational therapy. Each child has a unique sensory profile, and occupational therapists tend to tailor their approach to meet the specific needs and challenges of each person with ASD (Hazen et al., 2014). Occupational therapists tend to be "members of an interdisciplinary team of professionals who evaluate, plan, and implement the child's program" (Case-Smith & Arbesman, 2008, p. 417). "Sensory integration therapy, sensory diet, and complementary interventions, and environmental modification" are components of a program of occupational therapy that can help with treatment for sensory symptoms (Hazen et al., 2014, p. 120). Hazen et al. (2014) stated the components of occupational therapy that can help with treatment of sensory symptoms include "sensory integration therapy, sensory diet, and complementary interventions, and environmental modification" (p. 120). "A sensory diet is a regimen of regularly scheduled, sensory-based activities provided throughout the day so that the child's sensory needs are met in a safe, controlled and socially appropriate manner" (Hazen et al., 2014, p. 119). Studies have indicated that sensory behavior in children diagnosed with ASD tended to affect families' choice of work

and outdoor engagement (Bagby, Dickie, & Baranek, 2012; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). Reports from studies have indicated that families of children with ASD face difficulties and challenges accessing OT services, quality of service, and personnel for their children (Hutton & Caron, 2005; Woodgate et al., 2008).

Findings from a hermeneutic phenomenological study conducted in Western Canada indicated that parents experienced systems of support in relation to service personnel that were inaccessible (Woodgate et al., 2008). Parents also reported needed resources such as respite care were limited, often resulting in parents or another extended family member staying home to care for their children with ASD (Hall & Graff, 2010). Noted in the findings of the survey conducted by Vohra et al. (2014), was that caregivers/parents of children with ASD were more likely to report difficulty using services when compared to parents of children with other developmental disabilities. Vohra et al. (2014) reported this finding to maybe due to the complex nature and comorbidities with the diagnosis of ASD which tend to require substantial health care need and several other professional programs. Understanding the experiences of families with ASD in dealing with support services is crucial to ensuring parent with children with ASD are given the right supports and opportunities to raise their children.

Lord and Bishop (2010) noted that research on ASD supports the notion that children and adults with ASD have varied and diverse needs across their lifespan, both in terms of assessment and intervention. ASD services using a “one-size-fits-all” approach to intervention often fail to recognize family variables during intervention plans (Irvin et al., 2012) Incorporating perspectives of families in intervention plans can better shape intervention processes and the services that are provided ((Lytel et al., 2008).

Diagnostic assessments need to provide sufficient opportunities for families to participate and learn from the assessment process as well as be involved in individualized treatment planning (Irvin et al., 2012). Careful assessment is needed to determine the most appropriate services for different children, as well as within the same child at different stages during their lives. To ensure individualized services are provided, parents and professionals must continuously work closely together (Dymond, et al., 2007). Working collaboratively with families is considered best practice when dealing with families of young children diagnosed with ASD (Hall, 2009).

Families' accounts of experiences tend to be different irrespective of similarities that may be shared based on diagnosis of their children (Irvin et al., 2012). Families' characteristics are important and affect the type and quantity of services used by families with children diagnosed with ASD (Irvin et al., 2012). The need to be aware of possible disparities when it comes to accessing and utilizing services for families of children with ASD is necessary to be able to remediate differences in services provision (Irvin et al., 2012; Sansosti, Lavik & Sansosti, 2012). Programs and services need to consider the realities of different families' lives (Bloch & Weinstein, 2009). Cassidy et al. (2008) stated there is "need for strategic planning of services for preschoolers with ASD that are family-focused, and which offer practical guidance and support to children and to their parents" (p. 126). We need to understand family characteristics in relation to their needs as it may help with meeting their support needs (Brown et al., 2011). Understanding families' experiences from an ecocultural framework enables service providers and policy makers to ensure services align with the expectations, goals and values of different families (Brookman-Frazee & Koegel, 2004).

Healthcare service is one of the major interventions and treatments needed by families to support their children with ASD (Kogan et al., 2008). Kogan et al., 2008 found that children with special health care needs such as ASD are significantly more likely to have problems accessing care and experience unmet needs when compared with children with other special health care needs. Silos and Kerns (2007) pointed out that for families the “combination of dealing with a saturated service delivery system and the pressures associated with parenting a child with ASD leads to many parents feeling stressed and in need of social supports” (p. 20). Families’ experiences provide an overview of how different families experience support services and how support services buffer the stress of caring for children with ASD (Bloch & Weinstein, 2010).

A study by Hutton and Caron (2005), conducted with 21 families living in a rural New England state, examined the impact of children with ASD on their families. When these parents were asked about services provided to support their children, most common services noted were; “speech therapy, occupational therapy, in-home behaviour specialist support, developmental therapy, ABA, respite, one-on-one, classroom support, counselling, music therapy, play therapy, neuro-feedback therapy, social skills training, life skills training, and group home placement for the child” (Hutton & Caron, 2005, p. 185). Parents in the Hutton and Caron study reported waitlists, numerous referrals, and in some cases late or inaccurate diagnoses. Polslawsky, Fabienne, Naber, Daalen, and Engeland, (2013) pointed out in their study that identifying parents’ initial responses to the diagnoses of their children with ASD can help ensure parental support programs are tailored to meet the needs of individual families. Therefore, there is a need for improvements in the health care system especially at the point of diagnosis and referral (Hutton & Caron, 2005).

Lai and Weiss (2017) in their Canada-wide online survey of caregivers of children with ASD, found that only a small proportion of individuals in their sample received services that corresponded to their priority needs. This highlights the need to align services to address the most pressing needs of families of individuals with ASD across the lifespan. Taking a family's perspective is likely to increase sensitivity of service providers to all the needs of families (Bloch & Weinstein, 2009).

ASD service providers and professionals need to understand how an individual child's diagnosis impacts the family systems to be able to provide the needed support and address their needs (Bloch & Weinstein, 2010). ASD service providers and professionals also need to be aware of possible challenges likely to occur during the different life stages of children with ASD and the impact these have on their families (Meadan, et al., 2010). Engaging families in support service provision leads to significant improvement in terms of long-term outcomes for children diagnosed with ASD (Bloch & Weinstein, 2009; Sheppard & Waddell, 2015). Involving families can also help influence policies that determine support service funding and ensure that available services align with the needs of families (Lai & Weiss 2017).

Shahidi et al. (2015) in their Needs Assessment Survey found that services available for individuals with ASD are very limited, particularly for preschoolers. They reported that preschoolers required a more expedient diagnosis and treatment plan (Shahidi et al., 2015). Experiences of families with young children with ASD may offer insights into services provision for ASD families in NL.

Conclusion

As studies on ASD and the need for support services grow, parents have indicated that social support are important to assist them with coping and adapting while raising their children

with ASD (Ekas, et al., 2010a; Tzoy et al., 2007). It is also important to understand and consider the families of children with ASD, their lifestyle, and to consider family goals and priorities in developing intervention approaches (Bloch & Weinstein, 2009; Weisner, 2002)

With growth in the prevalence of an ASD diagnosis and families' reported gaps in services comes the need for expansion and effectiveness in delivering social support services (Bloch & Weinstein, 2009; Russa et al., 2015). Challenges faced by families with children with ASD accessing services have been voiced through previous studies and has prompted the need for improvement and development of programs and services (Stoner & Angell, 2006; Vohra et al., 2014).

The needs of families of children with ASD range from information, intervention programs, services, training, community engagement, and long-term planning. Therefore, service providers, professionals, and individuals working with the ASD community need to acquire knowledge to organize and implement support programs that are comprehensive and of benefit to families (Russa et al., 2015). Families' views, opinions and experiences matters when dealing with children with ASD and can offer insights that can address the needs of families with young children with ASD (Bloch & Weinstein, 2009).

This study explored and investigated the experiences of parents or guardians of children with ASD and their access to social support services. The qualitative methodology used in this study will enable readers to understand how participants experienced social support services within their unique family systems. It considered families' values, and their goals. This study also considered how families negotiated access and how they utilized those services and what

these social support services have contributed to the care of their children with ASD and their family.

Chapter 3: Methodology

Overview

This research study investigated the experiences of four families of young children diagnosed with Autism Spectrum Disorder (ASD) and their experiences using social support services in an urban center in Newfoundland and Labrador (NL). The research addressed the following questions:

1. Based on the experiences of the participants in this study, what were the services and support needed for young children with ASD?
2. Based on the experiences of participants in this study, what types of social support services were available to families of young children with ASD that participated in this study?
3. Based on the experiences of the families in this study what forms of social support services did these families with young children with ASD feel they benefit from?
4. What were participants experiences with support services from the time their child was diagnosed to their transition to school? Based on these experiences did the support services meet the needs of their families from the time of diagnosis to transitioning to school?
5. Based on the experiences of the families in this study how did the support services address their child/ren and families unique characteristics?

The purpose of this study was to interview and gain the perspectives of families of young children diagnosed with ASD and their experiences with social support services that were available to them within their communities. Savin-Baden and Major (2013) noted that the way in which individuals experience their world directly influences the way in which they think about it.

By exploring families accounts of their experiences with social support services this study aimed to provide an in-depth understanding of the experiences of families of young children with ASD. This study explored families' experiences from the point of diagnosis to transitioning into school. It explored how families accessed and utilized various forms of social support services available to them in NL. This study aimed to discover the commonalities in experiences across the four families interviewed during this study. The study utilized narrative interviews as the primary source of data and analyzed them using a thematic qualitative analysis. The results from this study may inform practices and policy with regards to social support services for families of young children with ASD.

Recruitment of Participants

It is typical in qualitative research to study a few individuals or a few cases because of the need to report details about each individual, site, or case (Creswell, 2015). This research study focused on a few individuals and sought an in-depth understanding of the participants insights into the issue of social support services for families of children with ASD. Generally, in qualitative research, the selection of the sample is dependent upon the research questions (Merriam, 2009). In this study, the research sought to investigate experiences of families of young children with ASD and their use of social support services. Often, in qualitative research using purposeful sampling techniques is considered an appropriate method because the participants have to have experience with the topic under study, and the participants need to provide comprehensive data. Purposeful sampling is defined as deliberately selecting participants based on their ability to provide in-depth information and understanding on the research issue being studied (Creswell, 2015; Savin-Baden & Major, 2013). Purposeful sampling was used to provide a rich context and detailed accounts from a specific population, locations, and

individuals chosen to participate in the research. The participants selected for this study are believed to have had experience and knowledge of the phenomenon being studied (Ravitch & Carl, 2016).

The parents or guardians who participated in this study allowed the principal researcher to explore their experiences and their families' experiences by providing detailed accounts of the phenomenon being studied for this research project (Ravitch & Carl, 2016). The individuals who volunteered to participate in this study had the knowledge, insight, and experiences needed to provide detailed accounts of their experiences. They provided the researcher with their own understanding of the phenomenon being studied. Narratives from each parent(s) or guardian(s) provided a vivid and comprehensive understanding of the phenomenon studied. The participants willingness to share their experiences represented a range of views on the issues as well as provided insight and voice to individuals who may not otherwise be heard (Creswell, 2015).

To be able to participate in this study, participants were required to be parents or guardians of a young child or children diagnosed with ASD. After extensive recruitment only four parents or guardians of young children diagnosed with ASD volunteered to participate. Participants were required to be able to provide detailed information about their experiences with social support services. Three females (mothers) and one male (father) eventually volunteered to be interviewed for the study.

Participants for this study were initially recruited through the distribution of a recruitment request letter sent to the coordinators of various Family Resource Centers from an urban area within NL. The appropriate ethical approval was sought through the Interdisciplinary Committee on Ethics in Human Research, Memorial University (ICEHR, MUN) before the distribution of

the recruitment request letters. However, the researcher experienced challenges with recruiting participants through this medium. Subsequently, the researcher expanded the venue for recruitment. An amendment to the original recruitment letter was approved by ICEHR to include the Autism Society of NL. The Autism Society of NL were not initially included as a venue for recruitment. In October 2017, a recruitment request letter was sent to the Autism Society of NL via email to be distributed to families that met the recruitment criteria.

Due to further challenges with recruitment another amendment was required to broaden the age selection criteria. A second amendment sought and approved by ICEHR in November 2017, it extended the study to include children from Preschool to Grade 3 diagnosed with ASD and using support services (please see Appendix A, B, C). The original selection criteria for interested participant for this study was that participants be parents or guardians of a preschool children diagnosed with ASD and using support services. Due to the challenges faced with recruiting sufficient numbers of participants with preschool aged children and recognition that supports services continued until Grade 3, the researcher expanded the age for inclusion in the study. Previous research studies of families with children with ASD have pointed out similar challenges with recruitment or insufficient responses from families of young children (Dymond, et al., 2007; McLennan, Huculak & Sheehan, 2008) Therefore, the researcher extended recruitment to families with children diagnosed with ASD to include children up to Grade 3 (Preschool to Grade 3).

To avoid confusion and enable interested participants to understand that changes had been made to the age criteria for selection, the title of the Research study was changed from “Investigating the experiences of families with a preschool child or children diagnosed with ASD with the use of Social Support Services” and replaced with the title “*Investigating the*

Experiences of Families of Young Children Diagnosed with Autism Spectrum Disorder (ASD) With the use of Social Support Services". No changes were made to the purpose of the study.

A third amendment request was submitted and approved by ICEHR to include additional mediums for recruitment of potential participants. This meant a change to the recruitment process; participants were recruited through the various Family Resource Centres and the Autism Society of NL, as well as through websites, bulletin boards, and through various Facebook pages of individuals affiliated or associated with Autism Spectrum Disorders. This provided the researcher with more opportunity to obtain sufficient numbers of volunteers to participate in the research study. Recruitment of participants took place from September 2017 to February 2018 (6months).

Initially the researcher had hoped to interview both parents; however, only one member of each family that participated was eventually interviewed for this study. This was primarily due to challenges that families faced with the provision of childcare for their children while the interviews were being conducted. The principal researcher was not able to provide childcare support during the interviews.

Research Design

A qualitative research design was used in this study to investigate the experiences of four families of young children diagnosed with ASD living in an urban center in NL and their use of social support services. Qualitative research is a methodology that is aimed at understanding the ways people experience the world and make meaning of their experiences and situations

(Merriam, 2009). Qualitative research is more interested in people's subjective interpretations of their experiences in different circumstances (Merriam, 2009; Ravitch & Carl, 2016).

A qualitative research design was appropriate for this study because it offered the principal investigator the opportunity to collect accounts of events experienced or still being experienced with regards to accessing and using social-support services by the families of young children with ASD who volunteered to participate. The principal researcher was interested in understanding how families with young children with ASD interpreted their experiences and the meanings they attributed to those experiences when using social support services (Merriam, 2009). This study sought to provide an understanding through the stories told by participants. The participants stories constituted the primary source of data used in this study. This study gathered data through face-to-face, audio-recorded interviews and online interviews with the four participants. The researcher also kept extensive field notes during and after the interviews to provide details about the context and participants' reactions, these notes were also analyzed along with the transcribed interviews (Creswell, 2015).

Ethics

Ethical approval for this research study was sought and approved by the Interdisciplinary Committee on Ethics in Human Research (ICEHR) at Memorial University of Newfoundland and Labrador. It was required by the ICEHR to explicitly state that the study was not a requirement of the Family Resource Centers selected for this study. As well, the participants decision to take part in the study was voluntary and their participation had no implications for any services or programs provided to their family (ICEHR personal communication, 2017). This was clearly stated in the recruitment request letter and the recruitment letter (refer to Appendix A and C). The recruitment letter (refer to Appendix B) distributed to the families by the various

Family Resource Centers, the Autism Society of NL, Facebook pages, and bulletin boards, also contained information about the research study, the selection criteria, the length of the interviews, the venues, and what was required of each interested participant.

Pseudonyms were given for all identifying information (including names of children, organizations, institutions, or service providers) discussed during the interviews. Participants were also assigned pseudonyms. The researcher assigned participants names starting with the letter T and they included: Tina, Tom, Tiffany, and Teresa. Participants were also given the opportunity to approve of the pseudonyms that were selected as well as the pseudonyms of service providers, organizations, and agencies mentioned during their interviews (See Table 4:1, 4:2, 4:3, p.51-52)

Information regarding the issue of anonymity was clearly written on the consent form (please see Appendix C). Participants were required to read and sign the consent form before the commencement of the face-face, audio-recorded interview as well as the email interview. Consent forms were stored separately from collected data in a locked cabinet in the principal investigator's office. Transcripts of audio recordings of the interview, and the one email interview, and the researcher's fieldnotes were stored in a locked cabinet at the principal researcher's office. Demographic information, and background information of participants was stored separately from the transcripts in a locked cabinet in the researcher's office for security purposes and to ensure confidentiality was met. The principal investigator was the only one with access to the locked cabinets. The thesis supervisor had access to the printed transcripts; however, consent forms, demographic information, and identity of the participants was maintained by the principal researcher. Ethics was maintained throughout this research

procedure, as it is reflected in the recruitment procedure, consent from participants, ensuring anonymity and confidentiality.

Data Collection Process

Merriam (2009) pointed out that “interviewing is often the major source of qualitative data needed for understanding phenomenon under study” (p. 114). For this study, the major source of data were collected from interviews conducted with participants (refer to Appendix E). Data were also obtained through demographic information (refer to Appendix D), and background questions (See Appendix E), before the interview commenced.

Demographic information and background information was collected from each participant after they signed the informed consent form and before the commencement of the interviews. Both demographic questions and background questions were designed to provide an overview of each family’s characteristics, the structure, the family composition, and their needs (See Appendix D). All families who met the criteria for the study were eventually included in the study. The principal researcher did not collect data on the gender and sexual orientation of the participants. The background questions included questions such as age of the child at diagnosis, family members and extended family awareness of the diagnosis, and services used by family for their children with ASD.

Participants interested in the study were required to contact the principal investigator to arrange an interview date. The interviews were scheduled at a time convenient for each of the participants. Each participant was interviewed by the principal researcher using an open-ended interview design. Open-ended interviews are interviews using question(s) that allow the respondent the choice to provide their answers in their own words (Check & Schutt, 2012).

Open-ended interviews offered participants the opportunity to share their perspectives and experiences in unique ways (Merriam, 2009). All participants were asked one open-ended question (Refer to Appendix F), and follow-up questions were for clarification of any of the issues raised by the participants. All face-to-face interviews were audio recorded using a digital recorder. The audio-recorded interviews were approximately one hour each. The initial face to face interviews was approximately one hour each, and the follow-up interviews took another hour. The researcher spent approximately two hours with each of the participants that volunteered to be in this study.

Face-to-face, open-ended, audio-recorded interviews were eventually completed with three of the participants and an email interview was conducted with a fourth participant. Email interviews can allow access to varied participants including participants who experience barriers to participation because of distance, time commitment, or other factors (McCoyd & Kerson, 2006; Meho, 2006). The research literature examined as a part of this study indicated that families of preschool children tend to be overwhelmed dealing with the care of their child diagnosed with ASD and some may find it difficult to travel to a designated location (Dymond et al., 2007; McLennan et al., 2008). When one participant who volunteered for this study requested an interview through email, the principal researcher (in consultation with the thesis supervisor) agreed. Studies have shown that intensive email interviews are an additional tool for individuals to have a voice. Email interviews have an advantage because they allow for participant and researcher reflexivity and they provide researchers with opportunities to access difficult to reach population samples (James, 2007; McCoyd & Kerson, 2006). Data collected through email is considered as credible as traditional qualitative interviewing formats (McCoyd & Kerson, 2006).

For the email interview, all necessary documents were sent to the participants and received by the researcher through email. The consent form (refer to Appendix C) was attached with an email informing the participant of what was required. The consent form was signed, scanned and sent back to the researcher through email. The demographic information (Appendix D), background questions (Appendix E), and the interview questions (Appendix E), were then sent to the participant via email, which were also responded to, scanned, and sent back to the researcher. The participant was permitted to respond to the questions at their convenience. The participant was informed of that follow-up interview questions or clarification may be necessary after the principal investigator had read through the initial interview transcript. The follow-up questions requesting clarification and elaboration were sent through email and the participant responded through that same email. All communication with the participant was achieved through email.

At the end of each of the initial face to face interviews, participants were reminded that follow up interviews would occur after the audio-recordings were transcribed by the principal researcher. After the initial coding, the researcher sent the transcripts to the participants for their review. Once the interviews were transcribed the principal researcher generated follow-up questions that were meant to clarify any of participants statements or comments from the initial interviews. The goal of the follow-up questions was to clarify and seek further explanations on issues raised by participants during their initial interview. Participants were contacted by the principal researcher to schedule a follow-up interview at a time convenient for each of the participants.

Field notes were also taken during the face-to-face audio interview. The field notes were taken to support audio-taped interviews thereby ensuring triangulation (Sutton & Austin, 2015).

According to Sutton and Austin (2015), “Field notes allow the researcher to maintain and comment upon impressions, environmental contexts, behaviours, and nonverbal cues that may not be adequately captured through the audio-recording” (p. 227). Field notes and handwritten jot notes taken during the interview helped the researcher to provide context and clarity during the transcription of audio recordings, as well as during data analysis (Check & Schutt, 2012; Sutton & Austin, 2015).

An interpreter was requested by one participant during the face-to-face interview because the participant had limited English and experienced difficulties communicating her experiences effectively in English. The participant selected the interpreter. Questions were provided to the interpreter in English, and the interpreter translated them into the primary language of the participant. In turn, the interpreter translated the participants responses into English. The issues of confidentiality and anonymity were explained, and a verbal confidentiality agreement was made between the researcher and the interpreter before the commencement of the face-to-face audio-recorded interview. The researcher requested that the interpreter clearly explain the details of the consent and the information about anonymity before the participant signed the consent form.

All participants were reminded that they would be given extra time if they deemed it necessary. At the end of each interview, participants were thanked for participating in the research and were informed that they would be contacted and provided with the opportunity to participate in verifying the data collected and themes generated through the analysis from all the data. The data collection process (face-to-face interviews and email interviews) for the initial and follow-up interview was completed within seven months.

Data Analysis

Data collection and analysis of transcripts were done simultaneously (Merriam, 2009). The initial interview for the first participant was transcribed and verified by the principal researcher. The first interview was then analyzed, and themes were generated from the first interview transcript before commencing an interview with the second participant. Merriam (2009) pointed out that when a researcher transcribes interviews by themselves, it provides means of generating insights and hunches about what is going on in the collected data. Transcription involves converting audio recordings into text data (Creswell, 2015). The principal researcher transcribed the audio recordings from the face-to-face interviews verbatim (Savin- Baden & Major, 2013). The principal researcher, to ensure accuracy, reviewed the interview transcriptions and compared them to the audio recordings multiple times. The interview transcripts were then rewritten to follow a chronological sequence for better understanding. Participants interview transcripts were saved on a password-protected computer in a Microsoft word document for easy retrieval during data analysis.

The principal researcher created an inventory of the entire data sets using a Microsoft word processor (Merriam, 2009). The researcher coded the folders for the transcripts with a single word and a letter (Family A, B, C, and D) (Merriam, 2009). All data set were organized and labeled accordingly to provide the researcher with organizing schemes that made sense and provided easy access (Merriam, 2009). This also helped support the anonymity of participants information. The transcription of each participant's interview was sent back to the individual for verification (for example; Tina received Tina's transcript only), and validation of the information and the sequence. This provided the first form of member checking completed during the data collection process and data analysis. Three of the participants eventually responded.

The purpose of data analysis is to identify segments or statements from the data that are responsive to your research questions (Merriam, 2009, p. 176). In examining the data, the principal researcher identified a particular unit(s) of data that stood out and were responsive to the research questions (Merriam, 2009; Savin-Baden & Major, 2013). A unit of data can be as small as a single word used by a participant to describe a feeling or phenomenon, or as large as several pages. The unit needs to reveal information relevant to the study, stimulating readers to think beyond the bit of information (Merriam, 2009). Relevant words, phrases, sentences, and paragraphs were identified from the transcript of each participant and coded into themes.

Coding of data from the first interview was done through reading and rereading, making notes, observations in the margins, and commenting on the data (Merriam, 2009). Coding was done through making sense out of the text, dividing it into segments and labeling them with codes, examining the codes for overlaps and redundancy, and finally collapsing these codes into specific themes (Creswell, 2015). Ideas, reflections, and tentative themes from rereading the transcript were then written in separate memos based on the first interview. The researcher used open coding at the beginning of the analysis, by identifying any segment of data that might be useful (Merriam, 2009). Open coding required being open to anything possible during coding of data (Merriam, 2009). After working through the entire first interview transcripts in this manner, the principal researcher selected sentences, phrases or paragraphs that aligned with these ideas. Tentative themes from the data were written into a table with each having a thematic ending. This process was done digitally through a word processor, and the researcher could copy and paste sections that were of interest and aligned with the ideas and tentative themes emerging from the data.

Overarching themes and subthemes were generated and discussed during the coding process by the principal researcher with the thesis supervisor. Some of the themes were generated from some notable statements, and words from participants own interview transcripts about their experiences that align with the principal researchers and the thesis supervisor's analysis and ideas. Reflections from the principal researcher's experiences during the research interview process and data collected during the interview resulted in the themes that emerged from the data collected.

Once tentative themes were derived, evidence for each theme was sorted into categories (Merriam, 2009). The name of each category or theme was conducted through data analysis by the principal researcher and then discussed with the thesis supervisor. The categories or themes were generally informed by the purpose of the study and the research questions. Through discussion, the principal researcher and the thesis supervisor established an agreement on designated themes that were the most suitable representation of participants' narrations of their experiences. This process helped the principal researcher achieve analyst triangulation and mitigated potential bias (Merriam, 2009).

Triangulation

Triangulation can be achieved by using multiple investigators, multiple sources of data, or different data collection methods, and using multiple analysts to confirm emerging findings from the collected data (Oliver-Hoyo & Allen, 2006; Merriam, 2009; Patton, 1999). Researchers use triangulation to enhance the validity of a study (Ravich & Carl, 2016). For this study, triangulation was achieved through multiple sources and analyst triangulation.

Interview transcripts were sent back to each participant for validation of interpretation and accuracy of information; thereby achieving triangulation through member-checking (Savin-Baden & Major, 2013). Member checking is a process of verifying data collected to ensure accuracy (Birt, Scott, Cavers, Campbell, & Walter, 2016). Participant validation of the data collected was done after the audio-recordings of the interviews were transcribed, and the email interview read thoroughly. All participants were asked during the follow-up interview if they would be willing to participate in member checking. Participants were informed that after the initial interview, the audio recording would be transcribed, and the participants would be sent their transcript for validation. Participants were also told that once themes were generated, the researcher would send the tentative themes to determine if they resonated with their interpretation of their experiences. Participants were given preliminary analysis generated from their responses to the interview questions to see if it correlates with the description of their experiences; thereby, validating statements provided by participants (Merriam, 2009; Ravich & Carl, 2016). Participants were given pseudonyms which they approved during member checking. The idea was to solicit feedback on the emerging findings from the people that were interviewed and to help rule out the possibility of misinterpretation of meaning by the researcher (Merriam, 2009). Participant validation also occurred formally during the follow-up interview (Ravich & Carl, 2016). The goal of sharing your research with others is to create conditions in which you and your interpretations can be challenged (Ravich & Carl, 2016). Three of the participants in this study were actively involved and agreed with the themes generated by the principal researcher. Member checking was also completed within seven months of the end of the data collection process.

Analyst (researcher) triangulation required using multiple analysts as oppose to a single analyst to reduce potential bias that comes from a single person analyzing all the data (Patton, 1999). To achieve researcher triangulation; transcripts were analyzed for themes by the principal researcher and discussed with the thesis supervisor. Themes generated were then explored and analyzed by the principal researcher and discussed with the thesis supervisor. The thesis supervisor suggested a limited number of themes, instead of having numerous themes, leading to a reduction of three overarching themes with three or four subthemes under each overarching theme. The themes and subthemes were agreed upon by both the researcher and the thesis supervisor. The thesis supervisor also made suggestions regarding the terms used for the themes; for example, she suggested placing certain themes under the overarching theme for example, “Barriers to Access” because statements from the data suggested barriers to accessing services as experienced by these participants. Some word choices were also discussed, and agreement was reached by both the principal researcher and the thesis supervisor on suitable thematic definitions. This process of discussion and agreements enabled triangulation to be achieved through data analysis.

The credibility of data was ensured in this study through a careful recording of notes during the interviews and verbatim transcription (Merriam, 2009; Savin- Baden & Major, 2013). Transcripts were emailed to each participant for verification. Participants were asked to verify their transcripts during their follow-up interviews. Participants were asked to elaborate or provide additional information and clarification of their initial interviews. The follow-up interviews were also audio-recorded, transcribed verbatim and returned to each participant for verification and validation. The credibility of transcripts was achieved through member checks and researcher triangulation with the research supervisor.

Chapter 4: Results

This study investigated the experiences of families with children diagnosed with ASD regarding social support services available to them in a city in Newfoundland and Labrador (NL). The goal of the study was to gather information concerning families' experiences with social support services from the beginning of their children's diagnosis. The study also searched for commonalities in the experiences of families who participated in social support services.

This chapter provides the analysis of the data gathered from four participants interviewed for this study. Data were collected and analyzed using qualitative methods (Creswell, 2015; Merriam, 2009). Data were analyzed thematically, and themes were generated to provide a better understanding of the experiences of participants. Three overarching themes were generated from the data collected during this study.

The themes were, first, *Suitability*; with three subthemes: (1) *suitability of services*, (2) *accessibility and discrimination*, and (3) *suitability of personnel*. The second theme was *Barriers to accessing services*; with two subthemes: (1) *timing and scheduling*, and (2) *distance and lack of transportation*. The third theme identified from the data was *Quality*; with this theme there were two identified subthemes: (1) *quality of services*, and (2) *quality of personnel*.

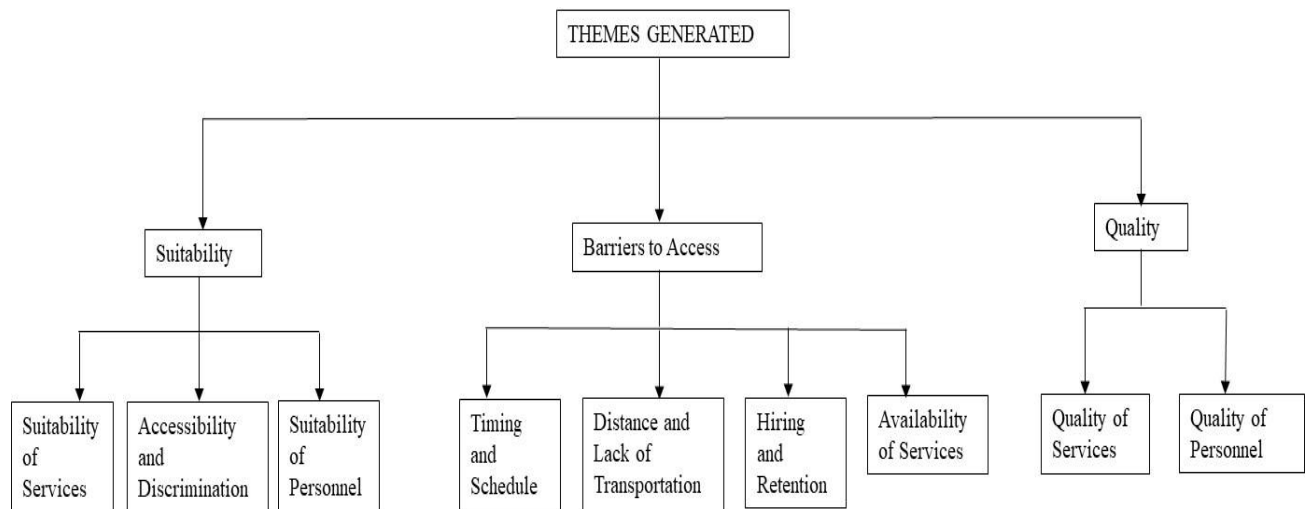


Figure 4. 1- Theme Generated

Table 4. 1- Pseudonyms of Participants, Parents and Children

Participant	Pseudonym for parents	Pseudonym for children
Parent A	Tina	No name given
Parent B	Tom	Timothy
Parent C	Tiffany	Thomas
Parent D	Teresa	Tyler

Table 4. 2 *ASD Service Personnel Mentioned.*

Pseudonyms of Parents	Service personnel	Pseudonyms
Teresa	Home Therapist (Teresa)	Tessa
Tiffany	Social Worker (Tiffany)	Tabitha
Teresa	Naturopathic Doctor (Teresa)	Dr. T

Table 4. 3 Organization/Agencies Mentioned by Participants

Pseudonyms of Parents	Organization	Pseudonyms
Tina	Childcare Centre	Child Development Centre
Tina, Tiffany, Tom, Teresa	ASD Family Resource Centre/Organization	Non-Governmental Organization (NGO)
Tom, Teresa	Medical Centre	Health Authority
Teresa, Tiffany	Medical Centre for kids	The Local Children’s Hospital
Tom	Daycare Centre	D-daycare Centre

Demographic Information of Participants

Four participants representing four families with a young child or children with ASD were interviewed for this study. As stated earlier, this was due to the challenges with recruitment. Three females and one male participated in two interviews- the initial interview and the follow-up interview. Participants were between 26 and 45 years of age. Three were married and one was single (divorced) but in a current relationship in which they are both raising their child together. Three families had one child each diagnosed with ASD and one family had two children diagnosed with ASD. The children with ASD ranged from 3 years to 8 years old. The educational level of each participant ranged from graduate degree, some graduate education, some university completed, and some high school.

Two of the participants were not working at the time they participated; one was on a temporary leave from work, and one was working. The participant on leave usually works full-time. The participant's reported that their leave was to care for the needs of her child with ASD (Participant noted this during the interview; Field Notes).

Background Information on Participants

Background questions collected provided an overview and understanding of the ages of the children when diagnosed, family members' awareness of the children's diagnosis, and the type of services required for the children diagnosed with ASD and the family. These questions helped provide an understanding of each unique family structure and needs within the specific context of the research study.

The age of diagnosis for the children reported by participants ranged from 22 months to 3 years. All participants indicated that every member of their family was aware of the diagnosis of their children with ASD. Services required for the family and their children with ASD mentioned

by participants included: Developmental Pediatrician, Student Assistant, Teaching Assistant, Instructional Resource Teacher (IRT), Applied Behavioural Analysis (ABA), JASPER, Home Therapist, Nutritionist, Speech Language Pathologist, Occupational Therapist, and Naturopathic doctor.

Suitability

Kasari (2002) stated that a striking feature of ASD is variability. This variability is also found in children's responses to intervention. Families of young children with ASD seek support services to enable them to provide care and support to their children in hopes to improve their long-term outcomes and make them active members of the society. Suitability is defined as, "the fact of being acceptable or right for something or someone" (Cambridge Dictionary, 2018). Based on the data provided by the participants in this research study, not all supports services worked well for all children, and the participants identified several factors that can make support services suitable or unsuitable for their families with young children with ASD. It is important to understand and be aware of these factors when planning intervention programs. Issues of suitability were discussed from different points represented with subthemes.

Suitability of services. All participants in this study experienced issues with the suitability of services they accessed and utilized. They provided their opinions and perspectives based on their experiences with their children and the family at various points in time. Their statements showed that intervention services and decisions needed to be individualized after assessment to be able to provide appropriate support services for their children and their family. This is evidenced in the quotations derived from Tina's interview transcript. Tina spoke about how she had to discontinue support/intervention services because she did not believe it was working for her child or her family. Tina stated:

We did participate in ABA therapy for a year and a half but discontinued it two years ago. It did not suit our family. Our children learn better through naturalistic, play-based learning as opposed to discrete trial methods of ABA at that time.

All of the participants in this study pointed out that ABA discrete trial training offered in their community might not be suitable for all children diagnosed with ASD. Therefore, participants identified the need to provide families with options and to focus on what would work best for each child and his or her family. Tom stated,

Let's be frank, different children have different needs too depending on the severity.

What might work for Timothy might not necessarily work for another child. What [the] government (ABA) offers, these might work for some kids and not work for others.

Based on his statement, what might be suitable for a child in terms of intervention services may not be appropriate for another or even for the same child at a different stage in their development. Teresa also indicated the need for more choice if services are to be beneficial for each individual child with ASD. Teresa reported that she learned that there are many different forms of treatment for ASD. Therapies such as Pivotal Response Therapy, JASPER, or Denver is offered in other provinces, however, Teresa discussed how the province that she lives in offers only one. Teresa mentioned that in another province, a set amount of money is given to families, so they can choose what type of therapy to utilize for their child (such as occupational therapy, speech therapy, or ABA therapy). However, it is not the same for the province Teresa lives in. She stated, "Whereas in NL you just have the ABA that's available to you now, they are just bringing along JASPER which my son has been taking part in since September of 2017, which is been fabulous". Based on Teresa's experiences with JASPER, she had a positive experience with

an alternative program and stated it has been “fabulous.” Again, lending support for the need for more choices available for families in this province.

Based on Tina’s experience, even though certain social programs were available at the NGO in the city, it was not right for her child and she needed other alternatives. Tina said:

Social programming available at the NGO, [in NL] did not suit our children’s needs at all so they could no longer attend. We have consequently had to pay for private alternatives, like Child Development Center. The programming they offer is amazing! The Child Development Center uses a much more naturalistic learning atmosphere and employs a setting similar to school to encourage learning. This helped generalize skills.

Children with ASD have unique needs, and families have preferences with regards to how their needs should be met. Parental preference should be considered by service providers or other professionals when providing interventions for young children with ASD. Teresa shared her perspective on this. Teresa stated:

I know several of our family friends, whose children have Autism, who gave up ABA all together because they felt they weren’t really getting anywhere, which is sad, so we were really lucky that we had that. But we also had to advocate too, we knew the traditional ABA discrete trial wasn’t working and we knew that we had to change that, so we were lucky in advocating that and our therapist was willing to go there with us. Because the biggest thing with the ABA in Health Authority is, the good thing is that everything they do is evidence based, but a lot of the things are not necessarily proven to be evidenced based yet, they are kind of approaching to be evidence based and because they are not officially evidenced based, they won’t do them, so like “Zones of Regulations”, “Social

thinking” those type of things, even “Sensory diets”, they don’t really, not that they don’t promote, because they know there is value to them, but because they are not evidenced based, they are not trained or approved to use them.

Suitability of services for one of the parents meant that services met not just their intervention needs but also provided opportunities for their family to socialize with other families who had children with a similar diagnosis. This can be understood from the point of view that families’ desires, values, and goals may differ; however, they all reported they wanted the positive long-term outcomes intervention services offered. The approach they chose, and their beliefs may vary, but the end goal was to attain support services that help their children meet developmental outcomes. As Tina pointed out that:

We did participate in an autism playgroup at the NGO, but it was a newer group on weekends at the NGO, so there weren’t many other families attending to socialize. The playgroup allowed us to meet other Autism families and have a place that suits both our children with Autism and our neurotypical children. The support of meeting other similar families through the playgroup helped us tremendously.

Tina shared her experience with regard to how the hiring process required her to access an ABA home therapist. She reported that in NL families are required to advertise, interview, hire, and complete all the necessary paperwork required by an employer. She noted that the process and expectations were difficult for her family; therefore, this process was not suitable.

Tina stated,

The expectation of being an employer and having employees in our home for 30 hours a week is very difficult for a family (Hiring ABA therapist). We instead opted for me to do

some private training in other methods such as Pivotal Response Training and Hanen's More Than Words program so that I could work with our children using techniques that worked for us.

For this participant, the supports available were not suitable to her family. She reported this experience was challenging. She also found that accessing and utilizing alternative social support services was challenging. Teresa also shared that her experiences were similar to other families' experiences. She reported that ABA intervention services and the school system's intervention and supports did not meet her family's needs. She reported that her family's needs and goals were often not understood; thereby, making such support services not suitable for her family. Teresa said:

There are some parents that you know are not doing ABA therapy through [name] health, they are choosing to pay and do other things, so, you know there are parents who are choosing to homeschool and not send their kids to school because they don't feel like they are understood, and you know, supported and those kind of things, they feel like they are not going to get the education that they need by going to the traditional school system, so that is the kind of the things you struggle with all the time.

Teresa made a very important point in her narration regarding suitability of services. She stated that parents of children with ASD need to have choices in terms of the type of support services they access; even though needs of families may be similar at times, families may also require specific unique services. The goal of support services is to ensure successful positive long-term outcomes; therefore, services need to be suitable to their users. Teresa pointed out that she continued to seek the services she believed would be suitable for her child to ensure the desired long-term outcomes. Teresa noted services such as horseback riding to treat hyperactivity

can be effective because some parents she knew that accessed found it calmed children with ASD.

Teresa also pointed out that she believes that her son is different in the way he learns and thinks, but the system does not always take that into consideration. She described the system's methods of responding as attempting to fit a, "square peg [in a] round hole" and noted, "that is what the education system is trying to get him to [do]". She noted that there is a need to change people's perspectives in order to successfully address the needs of different children with ASD. She stated that, "It's almost like with autism ... you know, the thing is that with autism [it is] all so different, meeting the need of one is not necessarily meeting the needs of the other, so I think that is why so many people are struggling to help meet the needs...".

In summary, the participants in this study indicated that there are challenges with respect to determining the suitability of the services for individual children. The government wants children to fit the services versus the service fitting the needs of children and their families.

Accessibility and discrimination. Another sub-theme that was generated was Accessibility and Discrimination. Some of the parents who interviewed noted issues with accessing certain services, and the discrimination encountered hindered families from accessing or utilizing support services suitable for their children with ASD and their families.

The narratives of the families in this study indicated that the families of young children with ASD tended to be discriminated against when seeking certain services. For example; accessing childcare or daycare services was reported as challenging by some of the participants. As Tina stated, "We have in the past tried typical playgroups, but they were too difficult". Tom also experienced challenges with typical childcare centers. Tom noted that his son Timothy was

discriminated against due to his diagnosis. He said “[Timothy] was at another daycare, I can’t even remember their name now, but they did not allow him to come back because he was diagnosed”. Tom explained that he then realised that children with a “mental disability” can be rejected or sent away from daycare but one with a physical disability cannot. Tom pointed out that Timothy was only in daycare for a few months; however, he was concerned that Timothy was not provided with the level of care he required. He stated, “Frankly, no one cared...they did not want to deal with him”.

Tom further elaborated on his experiences accessing and utilizing these support services as follows:

You know that there are some daycares that would not take a child with ASD, alright, or if they have a child with Autism, they have no problem kicking them out. For me personally, it’s a moral [issue] and frankly I think it should be against the law. You know, a disability is a disability right! You know, to say a daycare wants to kick out a child in a wheelchair, the place will get sued you know, but if your child has a mental disability be it ASD, Hyperactivity, ADHD, something like that, apparently, they don’t have to keep them. Right! That was a troubling revelation.

Parents in this study shared both positive and negative experiences when accessing support services. While some parents shared negative experiences with regards to accessing services, some parents also shared positive experiences. For example; Tom, shared his positive experience with access to services. Tom stated the following:

Access is pretty good [NGO]. They only have so many slots and part of that is dependent on funding. You know the government has had to cut funding, unfortunately, in recent

years. So of course, they are left to have to find the funding from outside, but I will say, given that the fact that they had a sizeable chunk of their budget cut from government they still manage to hold things together pretty well. I don't think Timothy [has] ever been turned away from any type of program [at the NGO] or anything due to unavailability, or it was blocked or what not. But not to say it doesn't happen, but I have yet to see it.

Although Tom raised an issue regarding funding, he stated that based on his experiences accessing services from the NGO for ASD it was a positive experience. Teresa also shared her families' positive experiences accessing services stating that: "So, we reached out to the NGO and started programs there. He has Social club groups that he attended, we did horseback riding through them and swimming, so that was what we started with".

Suitability of personnel. The third subtheme that emerged under theme of Suitability is the suitability of personnel. Three of the participants interviewed voiced their experiences which resonated with the theme suitability of personnel. Participants had both positive and negative experiences with regards to support service personnel. Participants described suitability of the personnel providing social support services in relation to their language, attitudes, personality, and flexibility. Tiffany noted; for example, when she first met her family doctor, because of her limited English ability, she was advised to find a doctor that could communicate with her in her own language. She explained, "when I saw the pediatrician... I think he [was] from a country that speaks my language; I was able to explain everything about Thomas". The ability of the doctor to communicate in her language made the service with the pediatrician more suitable for her family. Tiffany also experienced a home therapist from her country that she felt was suitable for her child with ASD. Tiffany stated: "a woman from [my] country... [she speaks my language]

was Thomas' home". Tiffany was able to utilize this support service more effectively because they shared the same language. However, unfortunately this worker was unable to commit to working with Thomas long term. Tiffany reported the ability of support personnel to communicate in her native language was an important aspect that allowed her to access and utilize support services. Language is important in making social support services accessible and suitable for her child and family.

Tom reported a different experience regarding the suitability of the home therapist personnel he accessed for his child with ASD. Tom's home therapist was not suitable for his family because she fell below their expectations. Tom stated, "the home therapist that we [had] didn't [measure] up to stuff; I think there was more of the personality kind of issue. I say a mix between chemistry between them and our son and just the job itself". Tom further explained that people may seem the right fit when you interview them; however, some personnel change after they start the job, for example; they lose interest or realise it was not the right occupation for them. He gave the following example, "I found especially one in particular that the interest in the job was just down all-together. Just no motivation...". Tom also stated a need for changes in the process of recruiting a home therapist in the province. He stated that there are people advocating for home therapist personnel to be employed by the Health Authority and be full time employees of the Health Authority. However, Tom stated this would not suit his family "my problem ... is what happens when you get someone who doesn't match with your child, you had no say in the matter... they are completely ineffective just because the child would refuse to work with them". Tom indicated that services accessed and utilized by the families can only be beneficial and achieve desired outcomes if the personnel delivering such services are suitable for the job and the needs of the family.

Teresa had experienced suitable personnel who were flexible and willing to work together. She pointed out that:

The Naturopath is new to us, we were kind of like looking, as parents we are always trying to find anything that would help our child, so we just started this year with the Naturopath, who is working with our developmental pediatrician, they have been working together in terms of any medications, vitamins or things that we are trying to make sure our medical partners also understand and know what the Naturopaths are doing. We wanted them to work together; it's been good that they are working together.

Teresa reported that the ability of personnel involved with her child and family working together helped make the services suitable for her child and her family. This made her experience with this social support service a positive one.

Barriers to Access

Barriers to Access was the second over-arching theme which emerged from the participants' narratives of their experiences with social support services. Barriers to access represents issues, situations, circumstances, and events that participants may have experienced or are experiencing that makes accessing and utilizing social support services challenging. The subthemes for barriers to access included: Timing and Schedule, Distance and Lack of Transportation, Hiring and Retention, and Availability of Services and Personnel.

Timing and schedule. Three of the participants in this research study reported difficulties or challenges with timing and scheduling. These experiences can be better understood from statements extracted from their interviews. Participants experienced issues with timing and

scheduling of services in relation to the process of hiring a home therapist for ABA, waitlists for occupational therapists, and the initial official diagnosis.

Based on experiences of participants, challenges were faced regarding accessing ABA home therapists and other support services because of conflicts in schedules with the families and the ABA home therapist. Trying to get the schedules of home therapist personnel to continuously match with the families was a big challenge and led families to experience challenges with access and use of this support service.

Tom explained in his interview that one of the shortfalls of hiring a home therapist in the city where he lives is their “schedule” is not consistent and “it is a roll of the dice”. You may be lucky enough to get one with a schedule that works for your family. For Tom, the challenge was getting people whose schedule worked with his schedule. Tom discussed what process his family took when hiring the ABA home therapist staff. He pointed out that first you find someone who is available, then you figure out the schedules “which is generally a big filter”. He noted that “someone comes in, you are interested and soon you find out they cannot work on the day that you need them, that’s it, they are out the door and you are back to looking for people again”. Tom also noted that although “you have people that do this [Home therapy] as a full-time job, their schedule is a little rigid, but generally speaking if you can make it work, then the person is generally there for a long time”.

Based on Tom’s interview, the challenge is getting the right personnel with flexible schedules to meet each his family’s unique needs. Tom also shared his opinion and recommendations based on this experience and what he heard from other families. He stated that collaboration between childcare providers and the ABA service providers may help address the challenges. He said, “I was fortunate enough that my schedule allowed me to work with the

home therapist... we [could] conduct the therapy during the daytime... a lot of parents don't have that". Tom pointed out the need for flexibility and suggested that the ABA program be completed in collaboration with childcare, implying the need for cooperation amongst ASD service providers.

Tina also shared her experience in relation to timing and schedules for services she accessed or intended to access. For Tina, these services were available, but the timing and schedule made it difficult to access. Tina stated:

Other sensory playgroups existed, but they took place on weekdays when we were unable to attend. Barriers to accessing weekday playgroups included transportation and conflicting schedules with ABA and when my husband would work since I would need someone to come with me to help with the children.

Based on the experiences of families in this study, the subtheme of timing and scheduling was also reported with waitlists for diagnosis, intervention programs and services. The participants in this study expressed serious concerns over having to wait for diagnosis and intervention services. The families in this study reported they were waitlisted for diagnosis, which interfered with accessing early intervention from the government, and in some instances resulted in families paying privately for support services. Participants' reported families viewed these experiences as a barrier to accessing services when they were needed. Participants reported waitlists for intervention services as an issue of concern. Teresa stated that they spent a lot of money on speech therapy for her son Tyler. Teresa noted that they started seeing a speech therapist privately because of speech problems; however, this was prior to Tyler's official diagnosis. Teresa noted, even after Tyler was diagnosed he was not able to access speech therapy due to the waitlist. She stated that, "he did get put on the waitlist in [the local children's

hospital], so Tyler started school in September... he finally got into [the local Children's Hospital] speech therapy in August of that year... so, we had officially three weeks of free speech”.

In her interview Teresa reported that due to the long waitlist in the province, Tyler was unable to access intervention services when they were needed. Teresa pointed out that they had to pay privately for the service. She noted that Tyler was on the waitlist for about two years with no form of communication, assessment, or therapy from the hospital. Three weeks before the start of kindergarten he was assessed by the speech therapist so that the information could be passed on to his receiving school for follow up services. Teresa reported that the speech therapist at her son's school advised her that services would be consultation only and not treatment or therapy. Teresa believed the lengthy waitlist prevented her son from getting the therapy he required through the local children's hospital. She stated, “If we had got in earlier... the hopes would have been that he could have got some treatment... [when] we got the appointment it was only enough time to do the assessment and then pass it on to school”

During Teresa's interview she reported that Tyler only received three weeks of speech therapy; however, he had no opportunity for long term treatment or therapy. In NL once children begin school they no longer qualify for speech therapy through the local children's hospital. Teresa reported that school-based speech services are aimed at providing information about the child to enable the teacher to provide programming for the child.

Tiffany reported that she too experienced waitlists for the assessment and subsequent diagnosis. Tiffany explained that when she saw the pediatrician, she reported Thomas' symptoms such as crying, being angry, lack of communication and feedback, and a lack of understanding of safety. She noted that the pediatrician assessed him and then referred them to a “specialist”.

Tiffany's son was then placed on an 18-month long waitlist to see the specialist; therefore, her son experienced a delay in receiving the diagnosis of ASD and a delay in accessing and utilizing service. Based on her perspective, not getting an official diagnosis limited her access to needed services for her son. She believed the wait period negatively impacted him as she said, "when Thomas had some kind of help, he was getting better, but when I came to Canada... Thomas regressed. He got angrier and he hits his sister...because it takes a while to see the doctor [specialist]".

During Tiffany's interview she reported that the long waitlist did not allow her to access services. Tiffany attributed the wait-time for diagnosis and intervention after arriving in Canada as contributing to her child's regression in functioning. Tiffany reported that although Thomas did not have an official diagnosis before coming to Canada, she stated that he had previously had services while living in her home country and Thomas had made improvements. For Tiffany, the waitlist was a barrier for accessing support services for her son at the right time and this was a challenge that affected her family.

Distance and lack of transportation. Another subtheme that was generated from the interview data that fit with the overarching theme of "Barrier to Access" surrounded distance and lack of transportation. Two of the participants shared their experiences in relation to this theme.

The distance from where the participants in this study lived and the place where services were provided, as well as a lack of transportation hindered the families from accessing and utilizing services. This was especially true for families that live a distance from where the intervention services for ASD are provided. Two participants expressed that distance and a lack of transportation were the barriers that hindered them from accessing certain support services for their children and families.

Tina stated that: “Barriers to accessing weekday playgroups included transportation” and Tiffany also noted that:

I am not really a member of the NGO. When I arrived, I was taken to the NGO, I registered but I couldn’t go due to lack of transportation. There was a playgroup for kids there, once a week but I could not go and never went back. Lack of transportation was the main reason for not going in my first year here.

Hiring and retention. Hiring and retention was the third subtheme that emerged from participants interviews and fit with the theme of “Barriers to Access”. Two of the participants shared their experiences in relation to hiring and retaining service personnel.

Based on two of the participants’ interviews, the process of hiring support services in NL required that families handled the hiring process while the government took care of some aspects of the administrative process and fully funded the service. Two of the participants in this study reported that the hiring process was challenging and interfered with their ability to access and utilize social support services for their children with ASD. Tom described the process in his interview. He stated that:

The process here is that the parents do the hiring. The provincial government pays for the therapy, but parents have to register with CRA (Canada Revenue Agency), and then they become the employer. So, it is up to the parent to find one, interview them, and see if they are a fit, and yes! put them through the program if they haven’t done the course already (their ABA therapy course).

Teresa also discussed the process of hiring an ABA therapist for her child. She reported that based on her experiences, the process of hiring the ABA therapist added more stress to her

and her family. She reported that her son had ABA therapy for 30 hours a week until he entered school. She stated that it was quite challenging for her because she had to become the employer and be responsible for all tasks associated with the role of employer. She reported:

When you have a child diagnosed, you become kind of a business worker, so you have to get an accountant, you have to have a worker coming into your home everyday, even things like safety, in terms of making sure the light is working in the stairwell because if your worker gets injured, you know that comes back to you.

She further elaborated on the challenges of being an employer. She stated that the responsibility of hiring personnel was demanding. She reported on her the joy of having a child and caring for him. After the diagnosis she became a manager of a staff; however, she felt she unaware of the therapist roles and responsibilities. She said, "when you first start out, you have no idea... no idea of really what [their] role would be as an ABA therapist... as we have moved along... [we] have really figured out what we are looking for". Teresa found being an employer was challenging because of the demands that came with the role, and she reported these responsibilities also added to the challenge of being a parent of a child with ASD because he had to be responsible for the welfare of her staff as well.

Tom also elaborated that the hiring process was not the only challenge for families, but the retention of the support worker was also a major challenge. Tom reported that during the first few years after his child was diagnosed with ASD he found it difficult to retain home therapists. He gave the following example; "I think Timothy might have gone through five or six [therapists] just because a lot of them were university students, schedule[s] change, people graduate". He also reported that once you find a person that suits your family retaining them becomes a major issue. However, if you are able to retain them it's, "easy sailing from there".

Teresa shared her perspective on the proposed changes to the hiring process of ABA home therapist services in the province. Teresa noted that the health authority in the NL does not take on the role of hiring the ABA therapist and parents have to take on much of this responsibility. She reported she was aware that some parents were advocating that the health authority take on this role rather than parents. She stated, “You know we already have so much on our plates and now we have that on top of it. So, it is really overwhelming. We have had four in total and he started when he was three”. For this participant, the proposed changes would take some of the responsibilities of hiring and retaining ABA therapists away from parents; therefore, alleviating some of this stress. Teresa offered her ideas on ways in which the process could be improved. For example; she noted an “employment center” could aid families with the hiring process. Teresa stated, “I think it would be nice not having to find an accountant, not have to do those managerial things would be nice, if they had an employment center where they are kind of doing the screening of candidates”. She further elaborated, stating that an employment center could be responsible placing home therapy ads or posters required to hire ABA therapists, screen potential applicants, interview potential candidates, because as Teresa stated that the interview process, “is kind of daunting”. However, she reported parents still have a vital role to play. She stated that if the government took on the role of the initial interviewing and screening, then parents could choose from a list of qualified candidates and decide on the most appropriate ABA home therapist to work in their home.

Somebody saying, you know, here is three, four names that [we] feel would be beneficial for your child and then you go ahead and [complete a final] interview, but then they take care of paying them, the finances... that would be great.

Teresa noted that something such as an “employment center” would be quite beneficial for parents and may allow families to avoid issues with hiring their ABA home therapist in the future. Teresa mentioned that people have, “had issues with therapist[s] stealing from your home, we haven’t had that, but like issues of... coming late and leaving early, somebody that can... support you as a parent to help you... move forward...so it would be nice”.

Availability of services. Availability of services is the last subtheme that was generated from the participants interviews that fit with the overarching theme of “Barrier to Access”. Issues with availability of services was experienced by all participants. Participants in this study reported both positive and negative experiences when discussing availability of services.

Participants in this study had different experiences with the availability of different services ranging from an ABA therapist, services within the school system (such as use of a sensory room), occupational therapy, social skill programs, services at the NGO, and a teaching assistant in the school system (Teaching assistant are employed in the K-12 school system in NL to support teaching and learning in an inclusive environment). (Newfoundland and Labrador English School District (NLESD), 2019b).

In her interview, Tina stated: “There have not been very many services for our family to access”. Tom also shared his experiences about the availability of ABA home therapist, in his interview he stated:

You know, we are in like NL. We are in [city], out of all the other places in the province. We’ll probably have the easiest in finding a home therapist. But even then, it’s still considered difficult, I know many parents out there that are still looking. The moment you go off the [city] the ability to find a home therapist drops dramatically.

Tom's statement raised questions about whether services are more available in the urban centers compared to rural communities. Tina lived in a small suburb outside a city [Researcher's field notes], this may be the reason that she had limited options when it came to the availability of services.

Experiences with ABA therapist services were discussed by all participants. Based on their interviews they had both positive and negative experiences. The availability of services was reported as important issues families must deal with when caring for their children with ASD.

Teresa also shared her experiences with availability of ABA training services in the province. During her interview, she indicated that because the government funds training services, all her family members had the opportunity to be trained, not just immediate family. She pointed out that:

I think, well the thing is with NL we really lucky that we have ABA funding and my husband, my parents, my husband's mum, all did the ABA training, which was great, so we could support our child and support the home therapist and it is great that it is all available to us.

Teresa also reported on her experience with services to her family:

So, with him getting the diagnosis at the age of three, we started right away with getting ABA so within a month of receiving his diagnosis. We had hired a home therapist and started receiving ABA at home. So, he has been receiving ABA ever since that time, so it was around September of the year he turned three, so 2011. He graduates out of the program in August of this year, 2018, because you finish at the end of Grade 3.

Tiffany also reported on her experiences with availability of services and her experiences with ABA home therapist services. She stated:

During 5 months of waiting for paperwork sent to the government, I took care of him, he was good because I learnt from the (senior therapist) that came for one hour every week. When I saw what she did with Thomas during her visit, I copied every time. But after the new home therapy came and spent three hours, every day, I became relaxed.

The experiences of the participants with the availability of ABA home therapy services indicated that the availability of this support services was of great value as it helped better care for her child with ASD.

Tom shared a negative experience which indicated a lack of available ABA Home therapist service. He stated that:

We did go through one period, where we couldn't find a home therapist for six months. I say the biggest problem right now is the pool of candidates. We very rarely ever interviewed more than two or three people anytime we needed one and that's here in [city name]. I can just imagine what it would be like [outside the city]. You know, that's the biggest challenge is having enough people. The hardest part about the hiring process is finding someone to hire.

Teresa also reported her experience with lack of available ABA home therapists. She said, "there has been about [a] two to three-month period where we are looking [for an ABA home therapist]". Teresa reported that searching for professional personnel over that period of time was a misuse of time of family time and she described that experience as "scary".

Teresa also shared her concerns and fears about services becoming unavailable as her child gets older. During her interview she reported on her experiences and fears while seeking services and her uncertainty surrounding availability. Teresa explained that one shortcoming of the NGO that provide services to support families is their ability to provide enough services to meet their needs. Teresa reported that she fears when Tyler ends the ABA program with the health authority that would be the end of the service and she would have to depend on the NGO for programs. Teresa indicated that there were a few other programs such as “Special Olympics and Easter seals”; however, Teresa stated that working on her son’s social skills was mainly a service provided through programming from the NGO. However, she noted that she faces challenges because the NGO does not have the capacity to provide services to meet all families needs. She said, “he hasn’t been able to get in to a Social Club group because of lack of space... I have written letters to the Government saying, ... the lack of support and funding is detrimental to our child”. Teresa further elaborated that she was aware of services available through her son’s school; however, she stated they needed more professional programs. She noted that without these programs her child will be further impacted because he would continue to lack the social skills he requires.

During Teresa’s interview she discussed the increasing rates of ASD and provided her perspectives regarding the NGO as well as other services. She reported that the availability of services from the NGO had an impact on her child and the family. However, she expressed significant concerns that the NGO cannot meet the needs of all families and individuals with ASD that require services. She stated that, “We have seen for years that the building is not big enough, they don’t have enough staff, you know, more and more children are getting diagnosed with Autism”. She elaborated that she believed the number of children diagnosed with ASD in

NL that would be entering school will also place a burden on the supports available within the education system. She estimated that “150” children with ASD will be starting school this year and with that there are increasing demands on services and supports.

During both Teresa’s and Tom’s interviews, they indicated that many parents rely on the NGO to provide different intervention services for their children with ASD and their families. Tom, for example indicated a lack of funding poses a challenge for the NGO and Teresa pointed out, “the building is not big enough, they don’t have enough staff”. Based on these participants' perspectives, they reported that this was an issue for families who sought services through the NGO and suggested the availability of services for families and individuals with ASD does not meet the demands. Teresa expressed her concerns about the availability of support services and her child’s learning needs once her son ages out of the ABA therapy program. She stated, “You know, where do we go besides the NGO to get that support...”.

Teresa’s reported that the NGOs that provided services and supports to individuals with ASD in NL seemed to be oversubscribed; therefore, families have difficulty accessing services, leaving them with limited or no options. Teresa also stated that other families with young children with ASD use the services of the NGO for Autism as a means of dealing with the challenges associated with ASD especially when services are not otherwise available. She pointed out that she is aware that a few families with children with ASD employ the services of ABA professionals privately. She said that “you know, you feel the guilt of, you know how I can’t afford to pay for a senior therapist privately, I can’t afford to pay for [an] ABA therapist privately, so where does that leave us... most parents can’t [pay]...it’s really scary when that comes”.

Teresa's statements raised concerns about whether families without the financial resources to provide private services have the same opportunities for their children with ASD. None of the parents interviewed indicated that they could not access publicly funded services because of their financial status. However, when some of these support services are not available because of waitlists, or when their children with ASD age out of the publicly funded services, families with a higher financial status may be better able to access and afford services privately. Those without the financial ability to pay for private services may feel added financial stress or guilt for not providing private services when caring for their children with ASD.

Apart from the ABA therapy service, Tiffany shared positive experiences with accessing speech services. She successfully accessed and utilized speech services for her child with ASD before school. She stated,

Before Thomas started school, I think around 2 months, I was told I had an appointment, when I went for the appointment she told me she was the speech pathologist and she need to a schedule couple of appointment with Thomas, if I would like, she could start immediately So, I went one day every week. She plays with him and teaches him certain sounds.

Participants in this study discussed transitioning from their current support services to public-school. Parents of children with ASD reported they that were informed about services their children would receive at school during transition meetings. Participants discussed that transition meetings provided them with a better understanding of the support services plans for their children with ASD. During Tiffany's interview she indicated that she felt that her son, Thomas required a "teaching assistant" to be successful within the school environment. She stated that she was assured during the "transition meeting" at Thomas' school that he would have

a teaching assistant. She reported that she was informed by her school that the classroom teacher was unable to give him the attention he needed but with a “teaching assistant” he could be successful. However, subsequently she noted once Thomas started school he did not get adequate supports in his class. She stated,

I asked the teacher why Thomas is yet to have an assistant because it was part of the services they told me he was going to get during the transition meeting... she told me no, Thomas has [one], I told her yes but [a] few days a week is nothing”.

Tiffany further elaborated that her son’s teacher indicated that his school team was attempting to create an inclusive environment where Thomas was able to have fun and interact with other kids. She noted that the teacher stated that he was able to seek assistance as required and they met his needs when required. But Teresa felt he needed more. She stated, “I am still worried he needs special help, because at home he is good, the Home therapist comes everyday, the senior therapist comes every two weeks”.

Tiffany discussed further her negative experiences with the services provided at school especially the lack of “teaching assistant” support she was promised during the transition meeting. She reported that the teacher and school staff were aware that her son required extra support. However, she advised her child’s school that she was not looking for preferential treatment because there are “other children” to educate as well, rather she wanted her son to have the supports that were promised during the transition meeting. She reported that even when the specialist doctor who monitors her son with ASD advocated on her behalf by sending a message to the school that he should be given a student assistant, he did not receive the level of support expected. Tiffany mentioned that the school provided excuses for not providing services. She stated, “The school counsellor told me “it’s not my job” ... the government did not send [a]

“teaching assistant” ... Thomas is very active, but the school has provided him with limited choices”.

Teresa also shared her experience with an ASD intervention service at her son’s school. She stated,

You know we are lucky that Tyler’s school, he has a sensory room, his occupational therapist goes in, you know, usually two or three times a year, you know, kind of keeping him up on his sensory diet, his needs, because Tyler is a very hyper-active child.

Teresa reported that she feels lucky that this service was available in her child’s school and he benefited from it. She also reported on other services she accessed and those she was denied through the NGO for her child. Teresa noted that:

He (Tyler) is doing Lego club through them (NGO) and swimming, you know, which is still good, but in terms of working on his social skills directly through a social club setting, is what we are really missing out on.

During Teresa’s interview, she reported that she wanted Tyler to have the opportunity to develop his social skills within a social setting. However, she indicated she was not able to access this type of service when she needed it for her son.

Overall, based on the interviews conducted with the participants in this study, having services available meant they could get the needed care for their children and support for their families. It also meant they were able to attain their families’ goals for their children. Lack of ABA therapist services, limited services from the NGO, and lack of school-based supports and resources were raised as significant issues, and families felt their choices were limited.

Quality

This is the third overarching theme generated from interviews with the participants in this study was quality. Quality was divided into two subthemes, quality of services and quality of personnel. All the participants' in this study discussed this theme.

Quality of services. Quality of service is the first subtheme for the overarching of theme of quality raised by the participants in this study. All the participants' raised the issue of quality of services when accessing and utilizing social support services. The participants discussed the quality of programs offered at the NGO; they discussed the quality of various interventions programs that were offered (such as ABA therapy and JASPER), quality of childcare programs accessed and utilized, quality of supports offered by the school system, and medical services supports. The participants shared both positive and negative experiences with the services mentioned above. During the interviews with the participants, they discussed their experiences with services and how they felt utilizing those services.

Tom shared his opinion about the NGO, the programs accessed, and his experiences with the programs. He said, "I have to say it's a wonderful resource over there [NGO]... You know, as a parent, I feel like I can go there for questions anytime". Tom noted that his son still attends the social play and social thinking every Saturday at the NGO. Tom further elaborated about the program his son utilized at the NGO. Based on Tom's interview, he reported that they spend 2 hours there [NGO] every Saturday. Tom reported the goals of the program were to work on his child's social communications and interactions such as "playing with others, understanding cues, learning through play with others and what to expect in social situations". Tom indicated that his son Timothy is cognitively 'high functioning' and over a period of six year he has made improvements with his social skills (High functioning ASD is an unofficial term used by people

to describe individuals with ASD who are cognitively higher in functioning and may live independently with some support) (WebMD, 2019). Tom also noted that a priority goal was for Timothy to improve social communication and engage socially with others.

Tom spoke further about his experiences with the NGO for Autism. He provided details about the program he accessed for his son. He stated he had a positive experience, pointing to the quality of the services. He said that:

With the NGO, once registered and paid, ... I will drop Timothy off around 11:30am Saturday morning and I will come get him at about 1:45pm ... They take care of things on their side. I think part of it is to get children away from mom and dad. To help them learn with their peers' and with people... it has done wonderful for Timothy just in his interaction with other children and to help bring the community a little bit better. Because now he's got friends there, playdates, parents start talking. I think it is a positive experience all round and they do fantastic programming over there... I mean Timothy has benefitted a lot from their program.

During Teresa's interview she discussed her experiences with regards to the ABA therapy and pointed out both the quality of the program as well as shortfalls of the program. Teresa described the components of the program and noted that the program was valuable to her son. She stated the program helped with vocabulary development, fine motor skills, social skills and social competence. These skills and abilities became more obvious when he started kindergarten. But despite the benefits Teresa described with ABA therapy, she felt that ABA therapy also has its downfalls. She stated,

some of the downfall of the ABA is that using the discrete trial of ABA, which is what they were focusing on in NL and that is what the training we received on the discrete trial, but it did not really lend itself really well to social learning because, you know how do you make that a discrete trial type of thing; its more anecdotal and those types of things as opposed to data.

During Teresa's interview, she also reported positive experiences with the JASPER intervention programs she accessed for her son. This intervention was new and was being piloted in NL. Teresa pointed out that JASPER benefited her son, Tyler, by helping him make improvements in "imaginative play". She noted that before Tyler started JASPER he did not engage in appropriate play with his toys, his play skills were delayed, and he primarily used toys by smashing them. However, once he engaged with the JASPER program he became more engaged with a variety of toys and he became more productive and inventive. Teresa attributed this improvement to the program because the program engaged her son with an intervention called "substitutions". Teresa described the changes she noticed in Tyler and stated that it explained the impact of "substitutions" used as part of the program. She said:

He is learning that you can take this and pretend that is a phone, whereas before Tyler would be like, "No, no! It's a recorder, that is!" Whereas he is a bit more flexible and he is able to, what they call substitutions, use different things. He might think of this, "oh! We can pretend this is an alligator because it is green." He is able to kind of go along with those things, whereas before he was very stuck on, "No! that's tape, that's it, that's the only role of that is tape!" So, he is a lot more flexible and can be more imaginative. So, I would think that would be the biggest thing and also, he is generalizing.

Teresa further elaborated that the changes in Tyler due to his participation in the JASPER program were also noticed by others including his teachers at school. Teresa noted that the changes were substantial. She reported that she was satisfied to know that Tyler generalized the skills he learned through JASPER beyond his immediate environment. She also reported an improvement in Tyler's "joint attention" skills, which is a part of the program. She described the impact she noticed with Tyler. She said,

they work on like joint attention, say you were looking at something over there. Before he wouldn't follow, so with the joint attention now, he has learned that if you say, "look over there" he would look. And he is actually starting to point too... whereas before you would probably not know what he is talking about. He will be like "oh look at that red thing" but you don't, but now he will be like (Teresa pointing-field notes) look at the red thing.

Teresa concluded that Tyler improved significantly since beginning the JASPER program and has developed skills such as "pointing" and "referencing". Tyler became aware that he can communicate, and Teresa believed this was huge progress for her son and she reported that the program to date was wonderful. Teresa's description of the changes she noticed in her child showed the quality of the services.

Teresa also shared positive experiences with the preschool service she used for her child. Teresa reported that the childcare program worked with her family and supported her child and her family during his preschool years. She reported that before Tyler was diagnosed, the childcare staff were observant and recognized Tyler's delayed development. Teresa reported that she also observed certain signs and because of his speech delays she also thought he has ASD. She also reported that when Tyler started "preschool" the educators at the childcare center

observed that Tyler experienced difficulties interacting with other “neurotypical children”. Teresa further elaborated on process after these observations were made. She noted that the childcare center obtained the services of private speech therapist and they were referred to the “developmental pediatrician and the direct home services”. The daycare center staff also provided him with an inclusion worker. Teresa further described the services of the inclusion worker and how she supported her son. She reported that she felt lucky they were provided with such quality service. She stated,

So through the inclusion worker, they started putting in place support like a visual schedule to help him get through the afternoon, just a worker there to kind of help him navigate playtime and participating, like he struggles with utensils, like his fine motor was really lacking, so he had an inclusion worker to help him with that so,... like I said a lot of bells went off, like I said we did get support, we were lucky enough when we went to the preschool, you know they did notice and came to us and said, you know you can have an inclusion worker do an assessment and they can provide you with supports and those types of things, and it was through that process, you know,... there was a person hired to... After he got his diagnosis at the age of three, he continued with the preschool, three afternoons a week and what ended up happening was that we had the preschool hire our ABA therapist, so our ABA therapist went with our son for the three afternoons in a week on top of his 30 hours of ABA.

Tom also reported on his experience with childcare services for his child prior to school. However, for him the services were not “optimal” due to funding. During his interview Tom stated that he believed his child experienced quality services. Timothy attended a daycare called the “D-daycare” and they had a few “programs” available to support him. He also had a childcare

worker dedicated/appointed to him at the childcare centre to care for his needs. Tom; however, noted that due to lack of financial support, the childcare worker supported more than one child. Tom reported that he was satisfied with the level of supports but felt that with one-on-one support the program would have been better.

Tom stated his families overall experience with childcare services was positive. Tom noted that having his son at the D-daycare provided him with the opportunity to get the care he needed. He said, “We got him into D-daycare center and he just blossomed. Got the attention he needed...They just did a phenomenal job with him. Once we got him to D-daycare center all worries were satisfied”. Tom reported that he initially felt anxious, but the daycare was able to put his mind at rest. He added that with the care at his son’s daycare (D-Daycare) along with ABA therapy he felt the services really had a positive impact on his son. He also reported that the length of time he was able to access the services had an impact. Tom concluded during his interview that there is a need for “more education and support” for families of young children with ASD. He stated that, “There definitely needs to be more education and support for daycare out there. I will put that out there. Especially for parents that are not fortunate enough to have time during the day to help with their child”.

Tina also reported positive experiences with childcare services. Her report showed the quality of services offered. Based on Tina’s interview, childcare services were viewed as very important to parents of young children; therefore, having childcare centers offer programs that meet the needs of children with ASD was essential to families of young children with ASD. Tina said that,

We have consequently had to pay for private alternatives. The Child Development Center; the programming they offer is amazing! Child Development Center uses a much

more naturalistic learning atmosphere and employs a setting similar to school to encourage learning.

Tiffany also shared her positive experiences with childcare services for her child, Thomas.

Tiffany said:

Daycare experience for Thomas was good, it helped Thomas. He has four teachers, they play with him, singing. I think the daycare had 10 kids and 4 teachers. The daycare was really good for him, the daycare teachers told me Thomas loves singing and loves jumping. I told her yes, I know that. She told me don't be scared, Thomas will get better.

Tina shared another experience with a family resource center service she accessed for her child and family. Based on her interview, the center met her family needs and values. Tina stated, "the support of meeting other similar families at (the playgroup) helped us tremendously. We've developed some great friendships; the playgroup filled that void for us". Based on Tina's reports, the program offered them services that met their needs.

The quality of services provided for young children with ASD and their family prior to the beginning of school was also an issue experienced by participants. The transition services were reported to be very important to the success of the child with ASD. Teresa provided information on her experiences with the transition process and services that were provided. She noted that they had Tyler's first ISSP when he was almost five, while he was in preschool and attending Kinderstart. "Kinderstart is a school transition program offered in the year prior to kindergarten entry" by the public school system NL (Newfoundland and Labrador English School District (NLESD), 2019a, para 1). She reported that the counselor from the receiving elementary school, the teacher from the childcare center, the senior ABA therapist, and a

spokesperson from the elementary school attended Tyler's ISSP meeting. Teresa believed this was great as it provided the opportunity to discuss Tyler, his developmental achievements, and the types of interventions he had experienced. The meeting assisted Tyler's school with understanding Tyler allowed for preparation before he began Kinderstart. Teresa stated she felt the elementary school's engagement at the ISSP and follow up after the first ISSP was a great effort. She said:

it [ISSP] was good and the school was receptive in terms of coming to the ISSP...and kind of starting, like discuss[ing] the need list, those kinds of things and then after Kinderstart... they were observing him and kind of seeing what he was like in the school environment and then that May before he started school in September (Kindergarten). We had another ISSP, where the school was able to then kind of tell me what they saw through the Kinderstart sessions, and... what Tyler would need. So, we knew in September that... as soon as they knew he was a runner and that he has issues regulating himself ... [when] following along his classroom routine, they saw that he would need support in those areas...

Based on her interview data, the services and cooperation offered during the ISSP meeting ensured that the needs of her child were prioritized. Teresa provided more detail about her experience during the transition meetings, and recommendations for improvement based on her experiences. Teresa reported that many families tended to fight to ensure that they got quality service for their child with ASD. Teresa said:

I have always been about the Team approach and I bring a picture, an 8x 10 picture of Tyler to every meeting to... say this is why we are here because you kind of forget...in my experience, it's the school side and then it's the home side and we always advocate that

we wanted to be “TEAM TYLER”. I always said and joke that I am going to get a t-shirt made team Tyler, because it’s all about him, it’s not [taking] sides its was [is] best for him.

She further elaborated that she felt that at times “we” (representatives at the transition meeting) lost focus on what was important during school meetings. She stated that we argued whose perspective was correct. She used an example, “you know, the school is saying, well you don’t really know what he is like here, and then the home saying well you don’t know what he is like here”. Teresa believed that the way to resolve conflict was through transparency from both sides (the home and school) and reporting exactly what happened in the different environments (home and school).

During Teresa’s interview she reported that as a parent of a child with ASD, she wanted her child to be able to communicate about his daily activities both at home and at school and to share his experiences. Teresa reported that her child was not communicating about his day at school; therefore, to get this important information, she educated herself, and requested information from his school. She asked “[What does] Tyler’s day looks like? What does he do when he first gets in? Who does he play with? Who does he talk to? Is it mostly adults? Is it other children?” This provided her with an understanding of his daily activities and interactions. With that information, his home team (the senior therapist, the [ABA] home therapist and the speech therapist) offered recommendations based on what he was doing at home and in school. Teresa reported on her meetings with school and about what is needed to ensure her child’s needs were prioritized. She said:

I think the biggest thing is... being a team, being a team for that child and I think that’s been a learning process for us because we have had our ups and downs...we’ve left

meetings crying and upset because we feel like the school doesn't understand or we've left feeling like wow they are really getting it, they are really trying, so, it's really hard. The ISSP meetings, I am exhausted and drained out after, because your child is there, like I said 195 days a year, for 5 hours a day, you know it's being able to trust them that they are doing what is best for you child and that they really get your kid and, that's scary to have to put that trust into them. Do they have the understanding? I think the biggest thing like I said is that understanding from both sides.

Based on Teresa experiences she provided recommendations for change. Teresa felt that positive communication between the school and the family benefited everyone. She stated that, "it's a team approach" and that working together provided a better understanding of what worked best for the child instead of pitting the school and the family against one another. Teresa also discussed the ISSP process. She stated, "that it wouldn't be so challenging if there was open communication all year, not just those 2 or 3 meetings... it has to be realistic... you do not expect... a [written] book everyday about your child".

Another important point that Teresa raised was receiving positive feedback about her child from his school, not just negative feedback. She believed this form of communication helped her support and praise her child about his positive behaviour. She also noted that continuous communication between the school and the family helped prepare her for the ISSP meetings. She stated, "then I think that the ISSP meetings would be more focused and narrowed on what the real needs and strengths are because we are always communicating". Teresa recommended that teachers be more proactive with communication. She stated she experienced situations where information from the teacher could have prepared her for the ISSP meetings; these situations had a negative effect on her relationship with the teacher and the school. Lack of

communication was a problem for Teresa, “when you have the ISSP meetings you spend a lot of time trying to catch up... neither side knows what is going on... I think that would be the biggest improvement is if communication... [was] on-going all year round”. Teresa also noted she needed cooperation between service providers and felt that her contributions to her son’s programming were valuable. She valued information, insights, and perspectives from all those involved with her son when providing social support services for her son and family.

During Tom’s interview he reported on his experiences with child's transition from community-based services to public school. He reported that the overall experience with the transition process was a positive one, which he felt showed the quality of services offered. Tom noted that the assistance he received from his son’s school was satisfactory and that the “transition process” was above his expectation as he was concerned about how his son was going to manage. However, he believed his son was good in school. He noted that his son was doing well with his school work; however, he occasionally required assistance with understanding. Tom reported the teachers and school staff supported him and his son, and he believed the teachers and school staff were reliable. He said, “We meet with school on a yearly basis and... look if there [were] any needs. ... But overall, I can say the experience itself has been mostly positive”.

Tiffany also shared her experiences during her son’s first few weeks in school. During her interview Tiffany stated that she felt the school was not meeting the need of her child. Not meeting her son’s needs suggested a lack of quality of services offered. She said:

When I stayed in Thomas classroom for few days to help him with transitioning to school, he just sits looking around, looking at other children doing something, but he does not understand what they are doing. He is just left to go around the class, making

noise, singing, and the teacher keeps sending me notes that, “your son does not listen” “your son makes noise”. She makes comment. Every day when I read those notes, I just sit and cry because I don’t know what to do because I told them in school before he started that Thomas behaves like that, that he runs around, he does not understand. When I went to his school, I told them that when Thomas goes outside, he does not know the rules, he does not know what is safe, I told them everything in the school. But every time I open his bag and read the notes sent from school, I am sad.

Teresa also experienced difficulty accessing and utilizing an intervention service for her son. During her interview Teresa noted that speech therapy services provided at school were “shared service amongst schools” and that amount of time allotted for her son and quality of service was not satisfactory. She reported that the service provided by school speech therapy was mainly consultation. She explained this better saying, “they did a CELF test when he was in Grade 1 and... he had a 90% language delay...for a child that has a 90% language delay, he is only getting consultation... [and] not... intense speech therapy”. Teresa noted, based on the severity of her son’s language delay, consultation only was insufficient to meet his needs and reported she accessed private speech therapy, which was expensive, costing, “\$105 dollars per hour,” and she said was, “really overwhelming” for her.

During her interview, Teresa discussed her expectations of her son’s school based on the transition meeting discussions. She stated that she expected to get report cards, similar to other children, outlining her son’s progress in school as well as a more individualized report (insert). She explained that the IRT in her son’s school provided an “alternate program” and also provided what she described as, “an insert, it is an extra report on top of the traditional report they receive, so not every child gets an insert”. She was expecting to get an insert, which was a

form of reporting that detailed progress of her son and the programs that provided for her son. Teresa said she thought she would get a similar report from the speech therapist, that's when she realised that the service was mainly consultation.

During Teresa's interview, she provided examples of some of the expectations that she had when it came to the support services in school. These expectations offered insights into the quality of ASD services. Teresa reported that Tyler gets very little time on his alternate programs designed to develop social skills. She reported that his classroom teacher is not professionally educated to support her son with ASD. She explained further stating that, "I know they are not trained in ABA, [and] not trained in social thinking... [the education] they get from the University... [where] they are not formally trained in teaching social skills to a child with Autism". Teresa recommended more education for teachers, so they are able to meet all the programming needs of children with ASD, including the development of social skills.

Tiffany reported her experience with the quality of ABA service she utilized. According to the participants in this study, this support service was largely provided by the government. Tiffany shared positive experiences about how the service was provided through the support of the government funding. Tiffany stated she valued having regular home therapist services. She reported the services provided by the home therapist helped Thomas improve his speech. She noted that the home therapist supported Thomas at home and in the daycare setting. While this level of support was exhausting for him, he improved. She stated, "He can speak now a little and when he needs something... he asks, "Please I need help, please I need water". Before he couldn't, he would just say mum! Wa wa! Water! Mum!... he cannot speak, but now a little". Tiffany also reported that with support from the senior therapist, she got the service she needed. Tiffany said:

The senior therapist came to my house and registered Thomas's name requesting for home therapy. A representative from a company I guess came to my house. I am just like an employer, but I do not pay for the home therapy. Everyday I have to fill a sheet and I send it to the company. It is sent to the government who pays the company. Every second week, the company gives money for home therapy.

Tiffany also shared her experience with medical services. She indicated that she trusted the medical system in Canada. Tiffany stated that: "In Canada, I gave them the documents that shows he had a hearing test done in my home country, but the doctor says they have to do another one and the doctor confirmed his hearing is good". She also reported getting an official diagnosis meant she could access quality services. She stated,

I got... the support for Thomas and official diagnosis in Canada after one year after we came to Canada. Thomas was around four then because after that Thomas started daycare. When a diagnosis was given that he had Autism in Canada, I felt good, not because he has Autism but now I know that he would get the help he needs.

The experiences of the participants with the various services accessed and utilized and their satisfaction and lack of satisfaction with the overall outcome, benefits or impacts on the care and improvements in their children with ASD indicated the quality of the various service available.

Quality of personnel. Quality of personnel is the second subtheme that fit the overarching theme of quality. Three of the participants' raised the issue of quality of personnel. The three participants noted how their senior therapist was very professional and how the senior therapist went above and beyond providing services for their children with ASD and their

families. Tom spoke about his experience with his child's senior therapist; about how valuable they were. Tom noted that his son's senior therapist was wonderful. He pointed out the types of support the senior therapist offered. He said

they are a great source of information. They are not just there to conduct therapy, they oversee it. But they can definitely [steer] you in the right direction of who you have to talk to regarding certain services or what not. If they do not know the answer, they know someone who does. And it's good to have them as the single point of contact.... they are your connection to the... health authority. They are the ones that are guiding your home therapist. They are the ones that are supervising them... making sure that you know that your child... has achieved mastery... they are the ones that are filtering your information... and a lot of time they will speak on your behalf. They are quite valuable.

Tom also mentioned that his child's senior therapist played a role in helping him get a home therapist. Tiffany also spoke about the quality of services provided by her son's senior therapist. She noted,

Based on my experience, when a child is diagnosed with autism, he is given a business number special number given to him or her by the government. I guess the senior therapist does the whole filing of information about the child. I am not too good with English or anything about computers. But now, I am learning, she shows me, she puts number and she gave me a number to keep it because it is important for Thomas. She found the company, arranged a meeting at my house. I filled some papers. It was the senior therapist that helped with the arrangement of the home therapy. After this I felt very happy because when I came to Canada, I believe I needed home therapy every day in my house, she told me when you have the paper work done and sent to the

government. You will get a home therapist every day for Thomas. She told me okay Tiffany, “I know everything because he is my job [Thomas] and I want the best for my job”. She is a very good person.

Teresa also discussed the flexibility of her son's senior therapist. She felt the senior therapist was able to work around her family’s specific needs. She stated that not all families were as fortunate as she was with the services provided to them. She stated,

we had a senior therapist who put the discrete trial on the back burner a little bit and did a lot more of social interactions and our therapist would just take anecdotal notes based on his progress and his problem areas.

However, she reported some of her friends weren’t as fortunate because some senior therapists aren’t flexible and insist on the “discrete trial format” for their child with ASD which at times the discrete trial format does not match with the needs of the child with ASD. Teresa also shared she felt her senior therapist was fully committed to supporting the family. How she went above and beyond. Teresa said:

I feel so lucky to have the support of our senior therapist... this year, you know I have cried on her shoulders, she’s come to the house... when she is not scheduled to provide us with support. I can call her when I need to, like to say Tyler is struggling with this, this is a new thing he is stemming on, what do I do? How do I handle this? He is licking things, what do I do? It is great to have that kind of support.

Tiffany also shared her experiences with her senior therapist and the support her child and family received during the waitlist period. The senior therapist provided supports prior to her child’s official diagnosis. Tiffany said:

The senior therapist from the hospital came every, one week, one day and spent one hour. She came every Thursday. She teaches Thomas, plays with him, teaches him everything about himself. After 6months, she came every two weeks, one and a half hours because the specialist was yet to see him. It was just to help him until the specialist sees him.

The experiences shared by participants in this study showed that the senior therapist played an important role in supporting families of children with ASD. Though as Teresa pointed out not everyone was lucky to have a senior therapist willing to go above and beyond for the family; however, the participants in this study valued the quality of the senior therapist and the support they provided.

Three participants shared some their experiences with the ABA home therapist. During their interviews these participants indicated they had both positive and negative experiences with the quality of services provided by ABA home therapists.

Teresa shared a negative experience she had with her son's ABA home therapist. She stated that, "We have had our doozies of ABA therapist[s] too...Yes, doozies, we have had ABA therapists that were not very [professional]. We have had some challenging experiences with ABA therapist[s]". She discussed having home therapists who lacked discipline and having to correct them. Teresa concluded these experiences make parents uneasy with their ABA home therapists. Teresa stated,

You know we have had ABA therapists that show up late, leave early, don't really have the passion, compassion, understanding, for our children. It's just a job. We have had three previous ones that, you know, just [are] not professional.

Teresa noted that even though as a parent you were present during the ABA therapy sessions it was difficult to have confidence in the ABA therapist's ability to deliver the program. The ABA therapist was following directives from the senior therapist. She believed it was a huge task to ask of parents. Teresa also reported on a positive experience with an ABA home therapist she employed. She noted that:

So, we have been really lucky in terms of our last ABA therapist that she is so understanding, empathetic, and caring, and a professional. We are really lucky with our ABA therapist Tessa, she is an educator herself, that she has an understanding of what all this entails, so we have been really lucky.

The experiences shared by Teresa highlighted the quality of personnel providing the services was an important aspect of support services for her son and her family. Participants in this study also discussed their experiences with other personnel such as at the childcare centers, family resource centers, with social workers, nutritionists, and school personnel. These experiences were both positive and negative. Tiffany indicated that during his initial months at day care Thomas experienced difficulties. She stated she reported her fears regarding Thomas' safety to his senior therapist. Tiffany's initial negative experience with daycare was mitigated through support from her son's senior therapist.

Tiffany noted that the ECE educator at the daycare regularly made statements such as "Thomas has Autism, it's hard, maybe sometimes he hurts children". Tiffany indicated that with help from the senior therapist, they provided the ECE educator and the daycare staff with information about her child and about autism. Tiffany stated that the senior therapist also provided advocacy support to assist her and Thomas with the quality of services received through his day care. According to Tiffany, the senior therapist informed the childcare workers,

“If you cannot take care of Thomas, I can bring someone, a specialist in the hospital to stay with Thomas here”. But they told her, “No! No! Its good, we can care for him, everything is good, it’s okay, no problem”. This, Tiffany believed led to changes in the quality of care provided at Thomas’ daycare. Tiffany elaborated further how the daycare personnel were instrumentals in terms of teaching her son replacement behaviors. She said:

Now Thomas is learning to sit, before he [did] not sit. They help Thomas [to] learn to sit, wash his hands, brush his teeth. Because before Thomas never brushes his teeth at home. He just puts his hand in the water with a lot of soap, just for bubble.

She also noted that she started getting positive feedback from the daycare about the progress he was making. “She told me Thomas is okay [and] no problem, he is good, he does not hit anybody, he plays with all children, he does not play with himself. He loves all his teachers at the daycare”.

During her interview Tiffany also discussed her experience with her son’s social worker. Tiffany reported her son’s social worker was professional and committed to her work. She noted that her social worker “Tabitha” assisted her and organized coverage for services prior to going for her maternity leave. Tiffany indicated that Tabitha also supported and addressed her husband’s fears regarding Thomas' care.

Tiffany further elaborated on her experiences with other personnel. She indicated that she worked with a nutritionist because of Thomas’ issues with eating. She stated that she provided the nutritionist with information about Thomas’ eating habits and she reported she was satisfied with the support provided by the nutritionist. She noted that the nutritionist informed her that Thomas was growing and was a healthy weight; however, he had issues with eating. The

nutritionist organized a plan in conjunction with his home therapist to assist Thomas with healthy eating. Tiffany noted changes in Thomas' eating once the plan was implemented. She stated,

Now when I place different food[s] in front of him, he mixes them together, plays with it, smells it. Now he eats a little, [and] drinks too. But the doctor (nutritionist) told me that is normal for now, that Thomas will get better.

Tiffany believed that the plan put in place by the nutritionist enabled Thomas' eating habits and made him "comfortable with food". Tiffany also reported that the nutritionist provided her with information that assisted Thomas with his eating. She stated the nutritionist informed her not to pressure Thomas to eat any particular food and suggested that she should provide a variety of foods and not worry whether he eats. The nutritionist also suggested that Thomas eat meals with his family. Tiffany stated the nutritionist told her to always say to Thomas, "Thomas this is for you", but don't tell him, "eat that!" whenever she provided food. She concluded that this method gradually changed Thomas eating habits, and that now Thomas "taste[d] the food she cooks at home" and this truly amazed her.

Another support raised by the participants was with services provided by school personnel. During the interviews with participants in this study they provided a better understanding of the support services promised during transition meetings. Three of the participants shared their experiences with services provided by the school system after their child transitioned to school.

During her interview Tiffany reported that she had a meeting with Thomas' teacher before he started school. She stated she had information sent home by Thomas' classroom teacher. She also indicated that she asked Thomas' teacher if she was aware that Thomas had

ASD. The teacher responded that she was aware; however, the teacher reported that she was directed to send home details regarding Thomas daily routine and his activities in school. Teresa noted changes in the communication sent home to her, she stated:

Now She [the teacher] tells me he is cleaning up well when I ask her because he never could...Because I told her before Thomas never cleans up when he plays... Now she tells me Thomas cleans up well, when I ask him nicely always.

Tiffany also experienced difficulty with her son's school counselor. During her interview, Tiffany reported that she felt school personnel showed a lack of professionalism. She said that the "transition meeting" for Thomas was held before the school year began in September. Tiffany noted that the school counselor informed her that he would be on holiday until the end of August. Tiffany noted the "school counselor" did not fulfill his responsibilities because he did not follow up on the senior therapist email which contained valuable information and plans discussed during the transition meeting, instead when he was asked for feedback on the email from the senior therapist when school resumed, she stated, "he responded that" "I have not checked my email".

Teresa shared some of her experiences with other ASD service personnel. She reported on the collaboration she experienced when she faced challenges with her child's behaviour. These collaborations were helpful to her son. She stated this year has been challenging due to anxiety issues and Tyler was seeing a "child psychologist" at the hospital for treatment. The psychologist completed a comprehensive evaluation of her son. She noted Tyler's behaviour deteriorated in the school environment and they withdrew him from school. She stated that it became a safety issue and the school was calling her every day. Teresa noted she took a temporary leave from work to decide the next approach. She stated the team effort by the

professionals caring for Tyler helped her family get through this difficult phase. She stated that, “... between our Developmental Pediatrician, our Naturopathic Doctor... and the child psychologist at the children hospital, we’ve... got him where he is more regulated, and we are starting to get him to go back to school”.

Conclusion

Participants in this study shared their experiences with accessing and utilizing social support services for their children with ASD and their families. During the interviews the participants indicated they had both negative and positive experiences accessing and utilizing social support services. The themes generated from the interviews completed during this study suggested issues with the suitability of services accessed and utilized, the barriers that impeded access and use, and quality of services and personnel. The data provided by participants in this study suggested the need for support service providers to consider the unique needs of families, consider the barriers that hinder families from accessing services, and the quality of services and personnel when supporting families of young children with ASD.

Chapter 5: Discussions and Conclusions

This chapter provides a summary of the results of this research study as well as a discussion of the relationship to previous research studies on social support services accessed and utilized by families of young children with ASD. This chapter also provides an overview of the strengths and limitations of this research study and recommendations for future research.

Summary of Results

This study investigated the experiences of four families of young children diagnosed with ASD using social support services. During their interviews, the participants provided in-depth information on their experiences when accessing and utilizing social support services for their children diagnosed with ASD. The open ended-interviews asked participants to provide a chronological narrative of their experiences with social support services for their children with ASD. The participants were asked to focus on the period of time from diagnosis to transitioning to school.

The results of this study indicated that families of young children had different experiences when accessing and utilizing social support services for their children and their families. There was considerable overlap in participants' experience with their use of social support services. The themes generated in this current study reflected issues regarding the suitability of services, barriers to accessing and utilizing services, and quality of services and personnel. During their interviews the participants shared both positive and negative experiences using social support services. The participants' also made recommendations for improvements and future research considerations. Most of the themes that emerged from the data analyzed during this study resonated with findings from studies found in the research literature. Specially, the research literature suggested families of young children with ASD faced significant barriers

in accessing services and received less than an adequate quality of care (Fish, 2006; Stoner et al., 2005; Vohra et al., 2014). The remaining chapter is organized by the themes generated from data collected from the participants' interviews.

Suitability

Suitability was an overarching theme that resonated with all the participants' and their experiences with social support services. While participants had different points of view and experienced different contexts, the results suggested four different subthemes. These subthemes provided an overall understanding of the different experiences of the participants in this study and their views on the suitability of these services for families of young children with ASD. This theme and the subthemes were generated based on the services families in this study accessed or utilized, attempted to access or utilize, or was related to the personnel who provided the social support services.

Some of the subthemes generated from this study were also found in the research literature on support services accessed by families of young children with ASD. These included issues such as the suitability of services and personnel, accessibility of services, and quality of services and personnel (Hutton & Caron, 2005; Shahidi et al., 2015). Previous research studies found that families needed to be satisfied with the support services available to them (Hutton & Caron, 2005; Shahidi et al., 2015). Findings from previous studies indicated both satisfaction and dissatisfaction with support services. Findings suggested some families experienced ease when accessing services while many other families reported difficulties accessing services. For example, in previous studies, families suggested they experienced problems with services they used, satisfaction with medical personnel, lack of professionalism, and suitability of services provided after their child was diagnosed (Hutton & Caron, 2005; Shahidi et al., 2015). These

findings were also found when analyzing the data from this current research study. Families in this study had both positive and negative experiences with accessing and utilizing social support services.

Based on the experiences of participants in this current research study, they reported a need to understand that different children with ASD had different needs depending on the severity level of the ASD diagnosis. Children diagnosed with ASD tend to manifest variations in the presentation of their symptoms and behaviors as they develop (Kasari, 2002). Intervention services such as behavioural treatments, therapies, and educational programs need to be individualized to meet the needs of the child diagnosed with ASD (Freeman, 1997; Kasari, 2002).

When evaluating intervention services available to families of children with ASD and the suitability of these services, participants in this study highlighted the need for more social support services. The participants suggested families required more choices, that services be easily accessible, and that services meet the support needs of children with ASD and their families. Specifically, participants emphasized the need for government to acknowledge their social support and service needs, to provide more services, and expand services to allow more choices for families with diverse needs. These recommendations were also reported by Dymond et al. (2007) in their research study which obtained “recommendations from parents on how to improve services for young children with ASD in West Virginia” (p.135). Parents in the study recommended improvements in the provision of services by ensuring that there were quality services (including the education and training of personnel working with families of young children with ASD), expansion in funding, and establishing suitable educational programs for children with ASD (Dymond et al. 2007).

Two studies, one by Kohler (1999) and another by Kogan et al. (2008), investigated the experiences of families of young children with ASD who received early intervention services. These studies explored health care experiences of children with ASD and the challenges related to accessibility of services. Findings indicated that some families had positive experience with services while other families reported challenges. Some families; for example, reported challenges accessing needed services due to misdiagnosis or delayed referrals to the appropriate service personnel. Wait times and delayed referrals made it impossible for families to get required services in a timely manner. These studies also reported delayed diagnoses because of wait times, ineffective delivery system, lack of financial support, and a lack of collaboration with families. Similarly, some participants in the current study noted that they were able to access some but not all of the available services. The majority of the participants in this study reported challenges with accessing services. These challenges sometimes resulted in the delivery of unsuitable support services for their children with ASD and their families.

Barriers to Access

All participants in this current study experienced different forms of barriers when accessing and utilizing social support services. These findings resonate with a previous research study where parents of young children with ASD reported barriers to access services (Shahidi et al., 2015). Findings from the “Needs Assessment Survey” by Shahidi et al. (2015) reported that some barriers included distance and lack of transportation, high turnover rate with certain service personnel such as ABA home therapists and student assistants, and limited resources. Similarly, barriers were reported by participants in this study. The participants noted barriers due to issues around timing, schedules, distance, lack of transportation, hiring and retention, and availability of suitable services.

The participants in this study expressed that barriers hindered access and use of support services. They believed that service personnel should be aware of these barriers when providing services for families of children with ASD. Participants identified issues around wait times for diagnosis, and then accessing subsequent services such as speech and occupational therapy. Other studies also echo this finding (Dymond et al., 2007; Shahidi et al., 2015; Siklos & Kerns, 2007). Families in these studies reported similar barriers to the current study, including long wait times for medical services including diagnosis. Parents reported waiting for years to receive an official diagnosis. Waiting for diagnosis prevented children with ASD from accessing required services and early intervention. The inability to access needed services at appropriate times, especially in the early years, was described as frustrating by participants in this current study. Multiple research studies had similar findings and showed that early intervention was crucial to improving long term outcomes for children with ASD (Hall & Graff, 2010; Manning- Courtney et al., 2013; Twoy et al., 2007; Warren et al., 2011). Reduced wait times for diagnosis and intervention services was described as necessary. Participants reported that access to early intervention services at the appropriate time ensured improvement in developmental outcomes (Hutton & Caron, 2005; Osborne & Reed, 2008; Shahidi et al., 2015; Siklos & Kerns 2007).

In this current study, distance and a lack of transportation were also reported as barriers when accessing and utilizing support services for families of young children diagnosed with ASD. Participants in the current study indicated that the location of certain services and a lack of transportation prevented them from accessing services. These findings were also echoed in previous research (Dababnah & Bulson, 2015; O'Callaghan, McAllister & Wilson, 2005; Shahidi et al., 2015). For example, one participant in the current study noted that access to the social programs available at the NGO for Autism was not possible because of transportation issues.

Parents in this current study felt more support was needed because the NGO lacked the resources and the capacity to meet the demands of all families in need of services. This was also a finding reported by Shahidi et al., (2015), who stated that the NGO “is an advocacy group with the primary role of advocating and lobbying government, actively engaging in outreach, and educating service providers and the public regarding the best practices for individuals living with ASD” (p.138). Therefore, families felt they had no choice but to rely on the NGO to provide services: this was an issue that needed to be addressed by the government (Shahidi et al., 2015). Based on experiences of the participants in this study, they recommended that the government provide more support to families with young children with ASD as well as financially support the NGO. In addition, the findings of the current study are consistent with the recommendations found by Shahidi et al. (2015) that families of children with ASD needed more programs and choices.

Challenges with hiring and retention of personnel providing services to families of children with ASD was an issue experienced by all participants in this study. This was raised as a serious concern for the families of young children diagnosed with ASD in this current study. Participants reported on the ABA home therapy programs and the challenges their families faced with the hiring process. Participants in this study reported that they found the role of employer overwhelming. This role was reported as entirely new to them and it consumed a great deal of their time. They also reported difficulties finding the best candidates and completing all the necessary things expected of an employer. As noted by the participants this became a barrier for some families in accessing services. When personnel were employed, participants found the turnover rate was high. Participants reported many of the home therapists were university students and this may have accounted for some of the turnover. Participants recommended that

the government create an agency that screened personnel, thus taking the administrative load off parents. The participants reported as parents of children with ASD they already had a lot to deal with in caring for their children with ASD. One participant believed the current process of hiring ABA therapists was working. However, this participant recommended more personnel be available to families, that services are flexible, and support services providers cooperate. Some recommendations from the Shahidi et al. (2015) study addressed the need for more ASD service personnel such as student assistants, flexibility amongst ASD service providers (such as ABA home therapists), and the need for various departments involved in the care and support of families with children with ASD to work together. For example, a collaboration between the health care, childcare and the school system. In their study the need for increased personnel did not focus specifically on ABA therapists; however, it pointed to the need for more ASD personnel and cooperation across various sectors that care and support families of young children with ASD. The families in the current study recommended the need for improvement in the hiring process of ASD service personnel (such as ABA therapists) in their community.

The majority of participants in this study reported that they used financial support from the government to access ABA services. They reported on the availability of ABA training for their home therapists; however, they also indicated the availability of ABA training for family members of children with ASD. The participants in this study discussed the difference in availability of services in the urban centers in comparison to the rural areas. Participants reported variations in terms of availability and accessing support services which also resonates with the previous research literature (Chen, Liu, Su, Huang, & Lin, 2008; Mandell, Novak, & Zubritsky 2005; Murphy & Ruble, 2012). These studies also reported disparities in services for children with autism and their families in the rural and urban areas. Parents reported significant

difficulties and dissatisfaction when accessing services for children with ASD in rural areas when compared to the urban center (Murphy & Ruble, 2012). Other research also reported that limited resources and medical services led to late diagnoses for children in the rural areas compared to the urban areas (Chen et al., 2008; Mandell et al., 2005).

Participants also expressed concerns regarding limited space and limited services available at the NGO. The participants reported a lack of available home therapy services and student assistants in the school system. Based on the participants' suggestions, provision of financial support for the NGO and addressing the insufficient ASD supports within the school system would go a long way in making services more effective for families with young children with ASD. Shahidi et al. (2015) also showed similar findings. These authors found that the NGO's effort to provide services for the community was impeded by a financial constraints and limited public funding. Shahidi et al. (2015) raised the issue of limited number or insufficient student assistants in schools; these authors also recommended an increase in allocation of student assistance to ensure availability of services to children with ASD in the school system.

Quality

All participants in this study reported experiencing issues surrounding quality of services and quality of personnel. Quality of services and quality of personnel were subthemes generated from the data of this project. These themes resonated with previous research findings that considered issues of quality of support services for families with children diagnosed with ASD (Bitterman, Daley, Misra, Carlson & Markowitz, 2008; Vohra et al., 2014). Bitterman et al. (2008) and Vohra et al. (2014) reported poor quality of care resulted from a lack of coordination and inadequate insurance coverage. Dissatisfaction with the quality of services and programs for children with ASD led to difficulties using support services. Quality of services in this current

research study was described in relation to the content of the program, the organization, the ability of programs to meet the needs of their children, and the perceived changes in terms of improvement with their children with ASD. Fish (2006), and Stoner et al. (2005) studied IEP meetings for families with young children with ASD. Similar to these findings participants in this current study reported both positive and negative experiences during IEP meetings for their children diagnosed with ASD. They indicated that their experience depended on the individuals involved or with the specific service provided. Though this research study did not focus on families' satisfaction with such services; some participants reported satisfaction with the quality of the IEP process, which was similar to Fish's (2006) findings. Parents in this study reflected on the quality of services and quality of personnel. Specifically, parents reported concerns about the IEP process and the way the IEP was coordinated. Notably, these findings were also supported by previous research by Stoner et al. (2005). This current study found parents reported dissatisfaction and lack of trust with the services provided and the service providers. Participants' in this current study reported that services provided in their children's schools fell below their expectations and often below what was promised during transition meetings. Parents expressed disappointment with the services provided and reported that advocacy was required to ensure better services for their children at school. Parents in this current study wanted their children to have access to such services as sensory rooms, inclusion staff, and quality speech and language therapy. These findings aligned with some of the recommendations from the Needs Assessment Survey completed by Shahidi et al. (2015), that reported the need for improvement in the transition planning process for children with ASD. Recommendations from parents from the current study; therefore, suggested the need for services promised during the transition

meetings be fulfilled and for schools to provide sufficient services to meet the needs of children with ASD.

Participants also reported the importance of continuous collaborative efforts between parents and school all year round. They suggested open and honest approaches that focus on their children with ASD. These recommendations resonate with findings by Slade, Eisenhower, Carter and Blacher (2018), and Stoner et al. (2005), who suggested the need for regular open and honest communication between parents and teachers. Engagement and collaboration between families and teachers and school staff helped to improve the IEP process to a satisfactory level for families of children with ASD.

Participants in this current study suggested ASD service personnel were not properly trained to work with children with ASD and their families. This result was also found in other research studies (Woodgate et al., 2008). Participants reported professional training should be required for all personnel that deal with families of young children with ASD (this included personnel in childcare services, school systems, counsellors and administrators). Training and education of personnel ensured quality services are provided for children with ASD and their families. Participants in this current study believed that teachers and childcare workers did not have the required training or education to provide quality services to their children with ASD. These findings are similar to the finding from Shahidi et al. (2015), who commented on the need for compulsory job training for all teachers and school staff (teaching and administrative). Cooperation and collaboration between ABA home therapists, childcare service providers, and the school system were recommendations made by participants if quality in the delivery of services is to be guaranteed. These recommendations were similar to findings from both Dymond et al. (2007) and Shahidi et al. (2015). Dymond et al. (2007) reported that parents recommended

the need for personnel working in the school system and other sectors, as well as the community, work together to provide effective services for families of children with ASD. Shahidi et al. (2015) found that caregivers of children with ASD also recommended partnerships within different departments (medical, childcare and education) when dealing with families of children with ASD. These partnerships helped to ensure families were able to navigate the support service system.

The majority of the participants in this study reported positive experiences with healthcare professionals and service providers such as the senior therapist. Parents reported that the senior therapist sided with the family and assisted with advocacy. Parents viewed the support provided by the senior therapist as above and beyond expectations. Previous research on experiences of families with young children and health care professionals have reported both positive and negative experiences. Positive experiences included professionalism, flexibility and compassion, while negative experiences were described in terms of lack of professionalism, lack of knowledge, and poor communication when dealing with families of young children diagnosed with ASD. These negative experiences were similar to findings from Osborne and Reed (2008). These researchers found that parents reported the need for professional training for personnel in order to increase their knowledge and awareness about ASD as well as enhance their social-communication skills (Osborne & Reed, 2008). Awareness of autism and professional training/education of personnel that provide support services to families of young children with ASD was highly recommended by the participants in this current study.

Strengths and Limitations

The purpose of a qualitative research study was not to generalize findings but rather to develop an in-depth exploration to provide understanding of the phenomenon under study

(Creswell, 2015). Using a qualitative research methodology, this study investigated the experiences of four families of young children with ASD and their experiences with social support services. This study provided an in-depth understanding of the phenomenon within the context of the participants' lives. The participants in this study were given a voice through their interviews and this provided the participants with the opportunity to present their own situated perspectives in which the context plays a role in the understanding of their experiences (Merriam, 2009).

This study has several limitations including a relatively small sample size and one small geographical region. The sample size was limited due to difficulty with recruitment within the population of families with young children with ASD; all participants with young children with ASD who volunteered were included. This study was also limited to participants from one city and surrounding suburbs in the province of NL. Although studies with larger population sizes tend to provide more varied insights into experiences of family, findings from this study offered subjective accounts of parental experiences of social support services. The overlap in participant experiences in this study showed shared experiences of families with young children with ASD, and their use of social support services.

Another limitation was the number of participants interviewed from each family. Only one of the parents or guardians were interviewed. This is primarily due to the challenges the researcher faced with the provision of childcare for families while participating in the study.

Another limitation was the use of the email interview for the collection of data from one of the participants. The content of the information provided by the email interview was not as voluminous when compared with the face to face interviews. However, the participant

interviewed by email provided vital information that overlapped significantly with of the experiences of parents who provided face-to-face interviews.

Despite the limitations, findings of this study supported the value of considering family perspectives when providing social support services for their child or children with ASD and their families. These findings are comparable to those of Renty and Roeyers (2006), and Sperry, Whaley, Shaw, & Brame (1999). The results from this study added to a large body of research on social support services and families of young children with ASD. Part of what this study hoped to identify was commonalities between experiences of the families that participated. The results and the themes generated in this study indicated overlap in the families' experiences, even though they offered different perspectives. The findings further our understanding of the social support services needs of families of young children with ASD.

Some themes and findings from this study resonate with previously published research (Dymond et al., 2007; Shahidi et al., 2015): however, these results cannot be generalized to a larger population. Instead, the findings provided insight into the understanding of experiences of the families in this study using social support services.

The use of member checking, validation from participants, and triangulation to confirm the data collected and ensure the accuracy of transcribed data further strengthen the findings of this research study. With a few selected participants, the research study provided a rich, in-depth understanding and gave insights into the experiences of parents with a young child with ASD who access and utilize social support services.

Recommendation for Future Research

There is a significant amount of research around families of young children diagnosed with ASD in relation to social support services (Bitterman et al., 2008; Bromley et al., 2004; Cassidy et al., 2008; Dymond et al., 2007; Hodgetts et al., 2015; Kohler 1999; Vohra et al., 2014). The findings from the current research study supported the findings and discussions from previous research studies on families of children with ASD and their service needs (Dymond et al., 2007; Shahidi et al., 2015). Issues were raised in this study that require further investigation and exploration. Issues such as collaboration between families and service providers, the role of families with intervention programs, families' experiences with the hiring of ABA personnel, and experiences of families of school-age children with support services.

Previous research valued giving a voice to families of children with ASD as it provided researchers, health and community service providers, educators, as well as the families themselves an understanding of the issues surrounding social support services (Renty and Roeyers 2006; Sperry et al., 1999). Woodgate et al.'s (2008) findings reported that parents of children with ASD helped professionals understand the services required and ultimately the provision of social support services. Future research is needed to explore collaborative experiences between families of young children with ASD and professional service providers/ personnel, to help understand the value in the role of parents. It is important to gain an understanding of the impact of parental contributions to improving services and the creation of collaborative relationships.

Another issue raised in this study is on the various early intervention approaches and their suitability for families. There were several different intervention programs mentioned by participants in this study, such as ABA, JASPER, Pivotal, and Hanen's More Than Words

programs to mention a few. JASPER, according to one participant, is an intervention program recently provided by the government of this province. Future research is needed to investigate the experiences of families with the various intervention programs and approaches available to families. It is also important to investigate the role of families in understanding and providing suitable intervention services based on the unique and diverse needs of children with ASD and their families that care for them.

Another issue encountered in this study was the different level of services available in urban areas as compared to the rural communities. Although this research was limited to an urban community, participants did highlight barriers when accessing and utilizing services when they lived outside the major metropolitan area, this was also echoed in previous studies (Mandell et al., 2005; Murphy & Ruble 2012; Shahidi et al., 2015). These studies found a notable disparity in support services between the rural and urban area with regards to differences in the age of diagnosis, access to services, and trained ASD personnel. It would be interesting to compare the availability and accessibility of social support services in urban versus rural communities. Future research is needed to investigate the experiences of families within rural communities and provide a comparison to the experiences of families living in urban centers.

Challenges around the hiring process of ABA (discrete trial) home therapists was an issue of concern for all participants in the current study. Numerous research studies have already investigated the effectiveness of the ABA treatment approaches for young children with ASD and have found evidence of its' effectiveness (Harris & Delmolino, 2002; Jensen & Sinclair, 2002; Schoen, 2003; Simpson, 2001; Smith, 2001). However, future research is needed to explore issues around the hiring processes, retention of personnel, and the challenges and experiences of families who use the service.

Finally, this study investigated the experiences of families of young children with social support services; however, some of the participants recruited were families of school-age children. The focus of this study was from diagnosis to school entry; therefore, privileged the experiences of families during the pre-school years. Parents reported issues around services that are limited to a specific age range and parents reported feeling lost once their children were no longer eligible for services. Participants reported having nowhere to turn for services after their children aged out of services which was also found by Shahidi et al. (2015). Key informants, healthcare practitioners, educational divisions, and caregivers all commented on the improvement of service provisions to families of children with ASD. Future research is needed to investigate school-age children with ASD and their families access to available services. What challenges do families with school-aged children with ASD face with publicly funded services such as ABA are no longer available?

Conclusion

The current study indicated that families of young children had both negative and positive experiences when it came to accessing and utilizing social support services. All the themes generated in this study reflected the issues or concerns experienced by parents of young children with ASD interviewed during this study.

The participants in this study made recommendations regarding these issues and concerns and how they believed these issues may be addressed in the future. Participants recommended the provision of more programs, intervention choices, and more effective collaboration and cooperation between ASD service providers and other persons involved in providing education or services to children with ASD and their families. This recommendation was also reported by Dymond et al., (2007), and Shahidi et al. (2015), when they suggested that collaboration and

cooperation begin with medical health care and then extend to all other services including childcare providers, home services, respite care, recreational, and social/educational service personnel.

Participants in this study indicated they were provided with a limited choice of intervention services, with the province offering just one: ABA (discrete trial approach). Recently the government of NL introduced JASPER; however, it is still being piloted and not widely available to families. The participants in this study reported they needed investment, provision, and easier accessibility to other intervention approaches, and for other interventions to be funded by the government. Several interventions approaches raised during this study included Pivotal Response therapy, Jasper, Denver, and Hanen's More Than Words programs. These approaches could help address some of the challenges experienced by families when it comes to accessing and utilizing social support services in this province.

Participants identified the need for individualized services for their children. Individualized services should be developed through an understanding of each families' needs, goals, and strengths. Participants suggested this be achieved through professional service providers working together as a team with families of young children with ASD. Participants recommended changes within the delivery system and the need to address the waitlist for diagnosis and other ASD medical services, and improvements in the hiring processes of ABA services personnel.

Findings from this study add to the understanding of families' experiences accessing and utilizing social support services. It also offers insights which could help improve the practices of service providers and provides insights into policies regarding social support services for families of young children with ASD in this province. Contribution from this study and studies

that investigate experiences of families or considers voices of families with young children with ASD can provide better understanding and tailoring of support services to meet the needs of families when it comes to the provision of social support services.

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Appendices

Appendix A

Recruitment Request Letter

My name is Maryam Ibrahim, and I am a graduate student of the Faculty of Education, Department of Curriculum, Teaching and learning studies (Language and Literacy) at Memorial University of Newfoundland and Labrador.

I am conducting a research project called “*Investigating the experiences of families of young children diagnosed with Autism Spectrum Disorder (ASD) with the use of social support services*”. This research project will be used to fulfill the requirements for my master’s degree. The research will be conducted under the supervision of Dr. Sharon Penney, Associate Professor, Faculty of Education, Memorial University of Newfoundland.

The purpose of the study is to identify and explore the experiences of families with preschool child or children diagnosed with Autism Spectrum Disorder who also access and utilize support services for their families and children.

I am looking for your help to recruit families from your Program/ Center as participants to be interviewed for the research study. Families would be selected based on having a preschool child or children with ASD and their use of Family Resource Center around metro St-Johns. To participate in this study, you must be a parent(s) or guardian(s) with at least a child (preschool-grade 3) with ASD and using a Family Resource Center within Metro- St-Johns area.

A letter of consent approved by the Interdisciplinary Committee on Ethics in Human Research (ICEHR) from the University is attached with this email to be distributed to families identified as having a child (preschool- grade 3) with ASD and using the Resource Center, interested in participating in the Research Study.

Thank you for your anticipated cooperation.

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

Appendix B

Recruitment Letter for Families

Recruitment Letter

My name is Maryam Ibrahim, and I am a student of the Faculty of Education, Department of Curriculum, Teaching and learning studies (language and literacy) at Memorial University of Newfoundland. I am conducting a research project called “*Investigating the experiences of families of young children diagnosed with Autism Spectrum Disorder (ASD) with the use of social support services*”. This research project is for my master’s degree. The research will be conducted under the supervision of Dr. Sharon Penney.

The purpose of the study is to identify, explore and provide an understanding of experiences of families with a preschool child or children with Autism Spectrum Disorder who access and utilize support services for their family and/or children.

Families would be selected based on having a preschool child or children with ASD and their use of Family Resource Center around metro St-Johns. To participate in this study, you must be a parent(s) or guardian(s) with at least a child (**preschool- grade 3**) diagnosed with ASD and using a Family Resource Center within Metro- St-Johns area. Interviews would be conducted with one or both parents or guardians and it would be for approximately 2 hours in total.

I am contacting you to invite you to participate in two interviews (an initial interview and a follow-up interview). During the initial interview, you will be asked to give accounts of your experiences with accessing and utilization of social support services for your preschool child or children with Autism Spectrum Disorders. The interview will be an open-ended format. The follow-up interview will be conducted to review your initial interview and to allow you to add or provide more details to your initial information.

Participation will require approximately 1 hour of your time on each interview and it will be held privately at an allocated center at Memorial University of Newfoundland and Labrador.

The study is not a requirement of the Family Resource Center and your decision to participate or not will not have any implication on any services or programs provided to your family.

If you are interested in participating in this study, please contact me to arrange a meeting time.

If you have any question about me or my project, please contact me by email at moi604@mun.ca

Or by phone at 7096908896

Thank you in advance for your interest in this study.

Maryam Ibrahim

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

Appendix C

Informed Consent Form

Title: Social support services for families of young children diagnosed with Autism Spectrum Disorder (ASD)

Researcher: Maryam Ibrahim

Faculty of Education, Memorial University

Supervisor: Dr. Sharon Penney,

Faculty of Education, Memorial University

You are invited to take part in a research project entitled “*Investigating the experiences of families of young children diagnosed with Autism Spectrum Disorder (ASD) with the use of social support services*”. This form is part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. It also describes your right to withdraw from the study. In order to decide whether you wish to participate in the research study, you should understand enough about the risks and benefits to be able to make an informed decision. This is the informed consent process. Take time to read this carefully and try to understand the information given to you. Please contact the researcher, **Maryam Ibrahim**, 709-690-8896 or moi604@mun.ca if you have any questions about the study or would like more information before you consent

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

Introduction

My name is Maryam Ibrahim; a graduate student of Curriculum Teaching and Learning Studies, Faculty of Education, Memorial University. As part of my masters’ program, I am conducting a research under the supervision of Dr. Sharon Penney, Faculty of Education, Memorial University.

Purpose of Study

The purpose of this qualitative research study is to identify, explore and provide an in-depth understanding of your experiences accessing and using various forms of social support services available to your child or children. This study also hopes to discover commonalities in your experiences with other families who also use social support services for their children diagnosed with Autism Spectrum Disorder. The study hopes to provide insights that may influence practices, how services are provided, and policy decisions on social support services for families such as your family.

What Will be Done in the Study

For this study, two interviews would be conducted with parent(s) or guardian(s) from each family with a child or children diagnose with ASD. Interviews would be done with one or both parents or guardian(s). The child or children will not be part of any of the interviews.

I intend to conduct 2- interviews (an initial interview and a follow –up interview). It would be for approximately 1 hour for each interview. The interviews will focus on your experiences accessing and utilizing social support services for your child or children with Autism Spectrum Disorder. During the initial interview, you will be asked to give accounts of your experiences with the accessing and utilization of social support services for your preschool child or children with Autism Spectrum Disorders. The follow-up interview will be conducted to review your initial interview and to allow you to add or provide more details to your information.

The interview question will be an open-ended interview format. A few background questions about your child with ASD and the family will be asked before of the interview question. The interviews will be audio recorded.

Length of Time

The interview would be conducted with one or both parents or guardians. The overall estimated time for the interviews would be approximately 2hours. Each interview (the initial and the follow-up) would be approximately 1hour per session.

I will provide additional time if you are not satisfied with the amount of time allocated to your family.

Withdrawal from the Study

You are free to withdraw from the study without consequences now or in the future. If you wish to withdraw you should contact the Principal Investigator (Maryam Ibrahim) immediately at 709-690-8896 or moi604@mun.ca. However, once the data has been analyzed and written into my thesis, you will no longer be able to withdraw the data. This will be approximately 6 weeks after the final interview.

Possible Benefits

This study hopes to provide insights and understanding into a very important issue based on the accounts of people directly involved. The insights and understanding generated from the study are aimed at creating awareness, improving practices and services and inform policy decisions on social support services for families with children diagnosed with ASD.

Possible Risks

The research study aims to minimize your risks. However, there may be instances where you may find disclosure of sensitive information distressful. Should this occur you will be provided with the opportunity to discuss feelings and concerns that arise from participating in the research study. I am not able to provide on-going counseling support as this is not my area of expertise. In the event this study does cause continued difficulties for whatever reason, you are encouraged to:

(1) Contact your family physician or primary care physician for follow-up services

(2) For ASD family counseling services, contact the Canadian Health Mental Association, Newfoundland and Labrador. This service is free.

603 Topsail Road St. John's, NL, Canada A1E 2E1

Phone: (709) 753-8550

(3) Should you be in urgent need, you may contact the 24hr Mental Health Emergency Services: Eastern Health for immediate service: Contact number: 709-7374668 or tolls free 1-888-737-4668

Confidentiality:

Your participation in the study would be confidential and you would not be identified. No personal information will be included in any of the publication. Although the data from this research project will be printed into my thesis, the data will be reported in aggregate form, so that it will not be possible to identify you.

Your consent form will be stored separately from your data collected, so it will not be possible to associate a name with any given set of responses. All research materials and data collected would be stored in a locked file cabinet in my office at the Faculty of Education, Memorial University that I only have access to.

Although the thesis report will include direct quotations from the interviews, you will be given a pseudonym and all identifying information such as your name, job position, the childcare centers you use will be removed from our report.

Anonymity:

You have an opportunity to exercise control of your personal information and its use either through consenting to participation or withdrawal from it. Participation in the research study would be anonymous, in that information gathered for this study would not be published or presented in a way that would allow you to be identified.

You will be asked to choose a pseudonym to use in place of your name and the researcher would ensure that no other individual details would be used to identify you.

Anonymity of data for this study would involve encrypting data information with special identifying codes, thereby removing any identifiable information from the data.

All research materials and data collected would be stored in a locked file cabinet in my office at the Faculty of Education, Memorial University that I only have access to. Consent forms and contact information would be kept apart. At the completion of my thesis and the required holding period for primary data sources (5 years) by Memorial University; all research materials including field notes, interview scripts, audio-tapes, transcription and emails would be destroyed.

Recording of Data:

The initial and the follow-up interviews with one or both parent(s) or guardian(s) would be audio recorded.

Use, Access, Ownership, and Storage of Data:

The data will be stored in an external hard drive which will be kept in a safe locked file cabinet in my office. Electronic data files would be password-protected and stored on password-protected device

Transcribed and printed data will be stored in a secure location in a locked filing cabinet in my office. Consent forms would be stored separately from the other data collected.

My supervisor and I would only have access to the data. Data would be not archived or be made accessible to other researchers. Data will be kept for a minimum of five years, as required by Memorial University's policy on Integrity in Scholarly Research

Reporting of Results:

The data collected and analyzed will be published as my master's degree thesis. Upon completion and submission, my thesis/dissertation will be available at Memorial University's Queen Elizabeth II library, and can be accessed online at:
<http://collections.mun.ca/cdm/search/collection/theses>.

Sharing of Results with Participants:

After the completion of the project, you will be informed via email and provided with a synopsis of the findings.

Questions:

You are welcome to ask questions before, during, or after your participation in this research. If you would like more information about this study, please contact: Maryam Ibrahim by e-mail (moi604@mun.ca) or phone (709-690-8896) or Dr. Sharon Penney (Supervisor) by e-mail (scpenney@mun.ca) or phone (709-864-7556).

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

Consent:

Your signature on this form means that:

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

Regarding withdrawal during data collection

You understand that if you choose to end participation **during** data collection, any data collected from you up to that **point will be destroyed**.

Regarding withdrawal after data collection

You understand that if you choose to withdraw **after** data collection has ended, your data can be removed from the study up to **6 weeks after the final interview** is conducted.

Circle Yes or No to the following

I agree to be audio- recorded YES NO

I agree to the use of direct quotation YES NO

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

Your Signature Confirms:

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

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

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

Signature of Participant

Date

Researcher's Signature:

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

Signature of Principal Investigator

Date

Appendix D
Demographic Information

Demographic information would be collected to be able to identify the variations in family's characteristics

Please answer each question below. Pick the one answer that best describes your situation

1. Who is filing out this questionnaire?

- (a) Father*
- (b) Mother*
- (c) Both parents*
- (d) Guardian*
- (e) Other (specify please)*

2. Which age range do you identify with?

- (a) 18- 25*
- (b) 26- 35*
- (c) 36- 45*
- (d) 46- 55*
- (e) 56- above*

3. What is your marital status?

- (a) Married*
- (b) Single {never married, separated, divorced, widowed}*

(4). How many children do you have in your family? _____

(5). How many children do you have diagnosed with Autism Spectrum Disorder _____

(6) *Select the grade level that applies to each child in the family*

- (a) *Prekindergarten*
- (b) *Kindergarten*
- (c) *Grade 1 to 3*
- (d) *Grade 4- 6*
- (e) *Grade 7 -12*
- (f) *Beyond high school*

7. *What is the highest level of education you've completed? {please check one}*

- (a) *Elementary*
- (b) *Some high school*
- (c) *Finish high school*
- (d) *Some college*
- (e) *Completed college*
- (f) *Some University completed*
- (g) *Bachelor's degree*
- (h) *Some graduate education*
- (i) *Graduate degree*

(8). *Are you currently working?*

1. *Yes* _____

2. *No* _____

(8a). *If yes, what type of work do you do?*

(8b). *How much time do you currently work outside the home?*

(a). *Full- time*

(b). *Part-time [please specify percentage of time spent at work]*

(8c). *How many months during the past 4years were you employed?* _____

(9) *Which item best describes your family income?*

(a) *Family earns less than \$20, 000 per year*

(b) *Family earns between \$20,000 and \$ 30,00 per year*

(c) *Family earns between \$30,000 and \$50,000 per year*

(d) *Family earns between \$50,000 and \$75,000per year*

(e) *Family earns between \$ 75,000 and \$100,00 per year*

(f) *Family earn \$100,000 and above per year*

Appendix E
Interview Questions
Open- ended Interview

Parent(s) or Guardian(s)

Background Information about the Child or Children with Autism Spectrum Disorder

1. At what age was your child or children diagnosed with Autism Spectrum Disorder (ASD)?

2. Is every member of your family aware of the diagnosis of your child or children with ASD?

3. What type of services does your family require for your child or children with ASD?

Interview Question-Open-ended question

Parents or Guardians

1. Tell me about your Family's experiences accessing and utilizing Social Support Services for your child or children with ASD since diagnosis.

Appendix F

Resume

MARYAM IBRAHIM

30A Eastbourne Crescent • St. John's, NL • A1A 5G8 • Phone: (709) 315-1541 • E-mail:
maryamibrahim056@gmail.com

SUMMARY OF QUALIFICATIONS

- Currently completing master's degree in Curriculum, Teaching and Learning Studies;
 - Master's degree in Early Childhood Studies
 - Childcare Centre Level four certification -Infant, Preschool, and School Age
 - Family Home Level four certification -Infant and Mixed Age
 - Experienced working in retail and educational institutions
 - Solid communication and interpersonal skills; well-developed organizational, time management and problem-solving skills
 - Able to adapt to new work environments; able to work as a team member or independently
 - Proficient with Microsoft Suite; attentive to details
-

EDUCATION

Master's Degree (Curriculum, Teaching and Learning Studies) January 2016 – Present
Memorial University of Newfoundland (MUN), St. John's, NL, Canada

Master's Degree (Early Childhood Studies) March 2012 – December 2013
Walden University, Minneapolis, USA

Bachelor's Degree (Language Arts Education) September 2001 – November 2006
Obafemi Awolowo University, Ile-Ife, Nigeria

WORK EXPERIENCE

Classroom Assistant (ECE) February 2018 – July 2018
Early Achievers Montessori + Educational Centre, St. John's, Canada

- Supported ECE in carrying out programs that promote the physical, cognitive, emotional and social development of children
- Engaged children in activities by telling stories, teaching sings and preparing crafts
- Maintained materials and assisted in housekeeping duties
- Prepared the classrooms for snack, lunch, and rest periods

Research/Teaching Assistant (Part time) January 2017 – April 2018
Memorial University of Newfoundland, St. John's, Canada

- Organized reference materials and visuals aids as required by university professor.
- Assisted in the administration of exams and graded term projects
- Conducted literature reviews and other research for use in scholarly publications
- Provided assistant with ongoing research projects
- Development and collection of online publications for the Memorial University Singing Coral Institute

Classroom Teacher (Full time) March 2008 – March 2009
Golden Abbey Schools, Lagos, Nigeria

- Planned and delivered lessons to improve skills such as reading, writing, listening and speaking according to the approved curriculum
- Taught students individually or in small groups
- Assessed student progress and performance
- Established positive relationships with parents, students and staff.

Language Art Teacher (Full time) February 2007 – January 2008
Junior Secondary School, Sokoto, Nigeria

- Used a variety of teaching strategies to promote literacy and language efficiency to students with learning
- Assisted with selecting appropriate reading and literacy texts and materials based on skill levels
- Conducted progress assessments and supervised exams
- Collaborated with staff and administrators to ensure positive relationships with parents and provided constructive feedbacks on their children's progress

Sales Associate (Full time) June 1999 – September 2001
Abbey Jewelers, Lagos, Nigeria

- Arranged display items in show cabinets
- Provided customers with product information and suggestions
- Answered telephone calls and responded to general inquiries
- Accepted payments for items purchased including issuing receipts and guarantees

PROFESSIONAL MEMBERSHIPS

Association of Early Childhood Educators, NL January 2018 – Present
St-John's, Canada

Canadian Society for the Study of Education October 2018 – Present
Ottawa, Canada

ZERO TO THREE January 2018 – Present
Washington DC, United States of America (USA)

National Associations for the Education of Young Children October 2015 – Present
Washington DC, United States of America (USA)

High Scope Educational Research Foundation January 2018 – Present
Ypsilanti, Michigan, United States

PROFESSIONAL DEVELOPMENT & TRAINING

AXIS Career Connections Workshop Series November – December 2017
St. John's, NL, Canada

Entrepreneurship Training Program (MUN) October 2016 – May 2017
St. John's, NL, Canada

Teaching Skill Enhancement Program (MUN) September 2016 – May 2017
St. John's, NL, Canada

Professional Development Training (MUN) January – November 2017
St. John's, NL, Canada

Emergency Child care First Aid & CPR/AED (Level B) March 2018
St. John's, NL, Canada

AWARDS

Students Volunteer Bureau (Bronze and Silver Level Award) March 2017
Memorial University of Newfoundland, St. John's, Canada

VOLUNTEER EXPERIENCE

Food Bank (MUN) June 2016 - May 2017
St. John's, Canada

Student Parent Association and Resource Center (MUN) September 2016 - December 2016
St. John's, Canada

Career Development (MUN) October 2016
St. John's, Canada

REFERENCES

Available upon request