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Accessing Supportive Services: Parents Caring for Children with Autism Spectrum Disorder

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Accessing Supportive Services:
Parents Caring for Children with Autism Spectrum Disorder

by

Karen M. Keegan, B.A.

MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work
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in Partial fulfillment of the Requirements for the Degree of
Master of Social Work

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Karen Janey, BS

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

Abstract

This qualitative research study focuses on exploring parent's strengths, challenges, and experiences of accessing supportive services when caring for a child with Autism Spectrum Disorder (ASD), also known as autism. Previous research has discovered gaps involving resource supportive services, navigation, and formal support systems for parents when seeking additional care for their child with ASD. Four caregivers (three women and one man) were recruited and completed a series of interview questions. This study's findings suggest that the above gaps remain present along with challenges ranging from the difficulties of interacting with other care systems, cost of services, lack of knowledge and service delivery from professionals, the need for a key worker to assist with navigation and coordination of services, and the desire for more general awareness and empathy for those managing ASD. Acquiring a better perspective as to what accessing supportive service involves will assist professionals working within the field to advocate and identify the most effective treatment options and service needs for families. Social workers also need to have a louder voice within the ASD community in order to help create change in the larger systems of medical and mental health care and support the individual needs of all families served.

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Accessing Supportive Services:

Parents Caring for Children with Autism Spectrum Disorder

The lobby has become quiet, and only the administrative assistant, myself, and two young boys at the ages of 2 and 5 remain. The boys peer out the window, slightly anxious for their mother to arrive. As the familiar van rushes into the parking lot, we gather up a number of items, including lunch boxes, coats, art projects, and daily forms describing their current treatment goals. The boy's mother hurries inside, and while catching her breath, apologizes for her late stay at the hospital between hugs with her boys. Speaking briefly about their therapy day, we are interrupted by the oldest son throwing his lunch box and crying out. After over eight hours of therapy, he has exhausted his patience and is making sure we are aware he's finished. Their mother and I spend the next five minutes redirecting behavior, gathering up thrown items, and calming the oldest son.

As we begin the walk outside, we start to discuss both of the boys' days and the progress they have made in their treatment plans. Their mother begins buckling them into their car seats as I begin to suggest skills to work on at home. Both boys begin to protest at having to wait for their snack in the car. Their mother sighs and asks them to be patient and use their words, but they continue to protest as I go to place their items in the front seat. I open the car door and daily forms from our previous day's together flutter to the ground from a large pile left on the seat of the car. The boys' mother meekly states that she needs to review the forms and then recycle them. Again, I attempt to suggest skills to work on at home, however, she appears distracted and provides me a quick nod, half-

smile, and states, “we’ll see you tomorrow.” I close the passenger door as she quickly drives off.

The Centers for Disease Control and Prevention’s (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network, supports programs helping to research the number of children with an Autism Spectrum Disorder (ASD) diagnosis in communities within the United States. They alarmingly found that 1 in 68 children are identified as being diagnosed with ASD. The CDC states, “This new estimate is roughly 30% higher than the estimate for 2008 (1 in 88), roughly 60% higher than the estimate for 2006 (1 in 110), and roughly 120% higher than the estimates for 2002 and 2000 (1 in 150),” (Centers for Disease Control and Prevention, 2014). ASD is a complex developmental disability that impacts one’s social, communicative, learning, and behavioral abilities. These impacts can create numerous challenges ranging from struggles with completing simple interactions with others, emotional regulation and to completing daily living skills (Centers for Disease Control and Prevention, 2014; Hoogsteen & Lynne, 2013; Foxx, 2008; Minnesota Department of Health, 2013; Spreckley & Boyd, 2009). Although ASD varies dramatically in characteristics and severity, it impacts individuals on an international level with differing socioeconomic statuses, ages, and ethnicities (Centers for Disease Control and Prevention, 2014; National Institute of Health, 2015). Understanding these social and economic impacts has become critical due to this rapid increase in diagnoses over the past twenty years.

Growing research has stressed the need for early intensive behavioral intervention for children with ASD; however, the costs for intensive therapy treatment can range from \$40,000-\$60,000 per year (Centers of Disease Control and Prevention, 2014; Hewitt et

al., 2013). These costs balloon further, and the economic impacts of caring for children with autism become substantial. Lavelle et al., (2014) found these additional costs involving health care, ASD related therapy, family coordinated services, education, and caregiver time, totaled to \$17,081 per year. They then applied these costs to the projected 673,000 children, ages 3-17 years, living in the United States with an ASD diagnosis and discovered that the total societal costs of caring for these children was estimated to be \$11.5 billion dollars in 2011 (Lavelle et al., 2014). Knowing that autism can at times be challenging to manage, along with its high treatment costs, the need to gather further information on families affected by this diagnosis and service delivery becomes critical.

According to the CDC, children can be diagnosed with ASD as early as two years of age; however, most children do not receive a formal diagnosis until the age of four. Caregivers typically notice differences within their child's development, such as fine motor skills, social communication, and vision/hearing impairments around the age of one (Centers of Disease Control and Prevention, 2014). A wide variety of literature has found that parents experience feelings of confusion, loss, being overwhelmed, fatigue, and burnout during the diagnostic assessment process and also after receiving a formal diagnosis (Hoogsteen & Woodgate, 2013; Mulligan, Macculloch, Good, & Nicholas, 2012; O'brien, 2007). Some research studies have also discovered gaps regarding resource supportive services, navigation, and formal support systems for parents when seeking additional care for their child with ASD. (Hoogsteen & Woodgate, 2013; McConachie & Robinson, 2006; Mulligan et al., 2012; O'brien, 2007). Research has shown these gaps exist, and continuing to attain a better understanding of what these

barriers are and how to effectively address them will help professionals working within the field to better serve parents caring for children with ASD.

Another complex element involved with parents navigating the next steps of the healthcare process for their child after a formal diagnostic assessment, is determining what therapy services would be most appropriate. After reviewing research of early intensive behavioral intervention therapy techniques and methods, one of the central themes discovered was the necessity for comprehensive early intervention and early diagnosis (Ortega, 2010; Rabinovich & Labat, 2006; Zachor & Itzhak, 2009; Foxx, 2008; Zachor, Itzhak, Rabinovich & Labat, 2006). However, narrowing what method of therapy will improve cognitive functioning, language development, and adaptive behaviors, continues to be researched and debated. This can potentially lead parents to not only experience further pressures in choosing appropriate therapy methods but also emotional stress and confusion. Due to caregivers experiencing heightened stress, fatigue, role changes, and being generally overwhelmed when caring for a child with ASD, the need to explore parents' own unique challenges with requiring social services, respite, and additional help for themselves also becomes imperative.

As a result of the complex nature of caring for and treating a child with autism, it becomes apparent that the social work profession needs a stronger voice within the ASD community. Social workers provide supportive services to a wide variety of vulnerable populations, along with therapy, care coordination, advocacy/policy changes, and resource navigation. Applying these skills, as well as social work professionals' ability to work with multi-disciplinary teams, acts as a significant resource for parents caring for children with ASD. With the diagnostic process and healthcare coordination of services

being intensive, having a social worker as an additional foundation of support and advocate for parents becomes critical. Recent research has concluded that many social workers lack specific knowledge of ASD and competencies needed to assist families coping and managing the diagnosis for their child (Dinecola & Lemieux, 2015).

However, the social work profession embraces the ethical responsibility to advocate and be knowledgeable of evidence-based practices when serving vulnerable populations (Dinecola & Lemieux, 2015; Mogro-Wilson, Davidson, & Bruder, 2014). Social workers' abilities of advocating for others should continue to be fostered further within the ASD community and will positively impact the families and clients served.

For the purpose of this study, the researcher conducted qualitative interviews of parents and caregivers caring for children with ASD. The intention of this research is to explore the strengths, challenges, and experiences of parents accessing supportive services for their children with ASD.

Literature Review

Autism Spectrum Disorder (ASD), also known simply as autism, is a set of neurodevelopmental disorders that impacts one's ability to process and learn information, which in turn impacts general functioning within the world. Children diagnosed with ASD can have a wide range of symptoms that may present as mild to severe and the impacts of a child's communication skills, behavior, and relationships with others will present differently with each child (MN Department of Human Services, 2015). Knowing that the prevalence of autism is on the rise, the need to explore parental involvement and their experiences surrounding accessing supportive services becomes vital. This literature review will focus on types of supportive services for children with ASD, parents' struggles with accessing services, emotional impacts and coping strategies regarding life after diagnosis, respite care options, and the need for a key worker to assist families caring for a child with ASD.

Access of Services for Children with ASD

The navigation of treatment options and access to supportive services for children with ASD can be a complex, confusing, and time consuming process. Literature has found that parents can experience a wide range of emotions after their child receives a diagnosis of ASD, including relief, happiness, and depression. This illustrates one of the many reasons achieving a better perspective in regard to the strengths, challenges, and general experiences parents face accessing services for their child and themselves is so essential. Cullen & Barlow (2002) interviewed 10 parents that attended a touch therapy program and discovered that they can experience feelings of isolation trying to find the best care for their child, as well as a sense of loss from having to adapt to a whole new

life with ASD. Exploring what therapy and supportive services are available to children with ASD will provide a better understanding of potential obstacles parents may face when accessing these services and the most commonly utilized options.

The need for early intervention becomes essential when caring for children with ASD, and a diagnostic assessment can be administered at the age of two. However, most children today are not receiving a formal diagnosis until the age of four (Centers of Disease Control and Prevention, 2014). Parents have articulated serious concerns about the general diagnosis process and the delays surrounding receiving a diagnosis after their child has completed the initial consultation. Some parents have reported that they have had to wait for over two years for diagnostic testing to be completed (Renty & Roeyers, 2005). Once a diagnosis is given, the implementation of early intervention techniques, along with other treatment modalities such as occupational or speech therapy, can help a child with ASD achieve significant strides in language, communication, and social interaction.

Treatment Options

Two of the most popular therapies widely used to treat autism are eclectic based programs and early intensive behavioral intervention using applied behavioral analysis. The eclectic approach uses multiple intervention techniques and philosophies, while applied behavioral analysis (ABA) consists of 1:1 therapy emphasizing specific individual goals and objectives that need to be met (Zachor & Itzchak, 2009; Fox, 2008). ABA seeks to improve a child's language, social, emotional, play, and daily living skills through discrete trial training, positive and negative reinforcements, and systematic prompting and fading procedures (Zachor & Itzchak, 2009; Turek, Turygin, Beighley, &

Rieske, 2012). One of the main goals of ABA is to motivate a child to learn and be successful. This method of therapy is unique in that it allows therapists to develop specific individualized treatment plans for each child with ASD (Foxx, 2008).

The practice of eclectic based therapy has found to be beneficial for children with autism as well. As stated above, eclectic based therapy draws from various intervention techniques and principles. Eclectic interventions uses techniques ranging from discrete trial training, to sensory integration, to group “circle time” and music activities for children (Zachor, et al., 2006; Howard et al., 2005) This therapy intervention may integrate less of a 1:1 therapy approach due to it typically being carried out in a classroom setting where therapists may be 1:2 or children will be engaging in more structured group activities (Howard et al., 2005). Although these main therapy interventions could be further explored and expanded upon, other information surrounding caregivers access to other social services would then become clouded.

Additional therapy options have been explored in literature as well, such as touch therapy programs. Touch therapy involves enhancing positive touch and closeness between parents and children while serving as an additional means of communication for caregivers (Cullen & Barlow, 2002). Cullen and Barlow’s (2002) study suggests that parents valued learning practical skills of caring for their child with ASD that they could implement at home. Other therapies and alternative strategies for addressing symptoms of ASD range from using psychopharmological prescriptions (Hsia et al., 2014), floor time therapy methods (Dymond & Gilson, 2007; Howard et al., 2005), and alternative approaches surrounding diet, mind-body interventions, and energy therapies (Kurtz, 2008). Again, these therapy options and alternative strategies are utilized by families but

are not as common of treatment methods compared to eclectic and applied behavioral analysis therapies.

Research has also discussed the importance of taking an ASD diagnosis with a family-centered care (FCC) approach. An autism diagnosis impacts the family unit as a whole and it becomes imperative to have treatments and supports in place to address the needs of the entire family. FCC embodies the philosophy that service providers and caregivers should work in collaboration regarding the needs and treatment decisions involving a child with autism (Hodgetts et al., 2013). Although the principles within this approach are attempting to address barriers parents face involving service options and improve family outcomes, gaps involving service delivery of this model still occur and will be discussed later within the literature review.

Reviewing the above therapy interventions and treatment options offered to assist children managing ASD, allows one to attain a small glimpse into the complex and substantial amount of available resources to families. Research has shown some of these interventions to work, however, still having to manage the unknown causes and vast treatment approaches for autism can lead caregivers to experience a number of emotions, especially uncertainty and confusion. Ultimately, these existing therapy options and services can lead to parents receiving conflicting information regarding the best methods of care for their child, which can promote further stress. Analyzing the frustrations caregivers face surrounding accessing services becomes a necessity as well.

Parents' Struggles and Frustrations of Services

Parents have reported receiving limited, confusing, and at times inappropriate advice regarding the navigation of care resources. Experiencing a lack of appropriate

services can be extremely stressful for caregivers and can lead to frustrations surrounding medical and mental health professionals (Cullen & Barlow, 2002). Renty & Roeyers (2005) reviewed literature that supported the need for parents to receive assistance early on within a child's development and to learn necessary skills that will assist them and their child throughout their lifespan while improving quality of life. However, after surveying 244 parents of children with autism, they found that both parents and professionals lacked information regarding available resources, social services, educational opportunities, and how services are accessed and organized. Professionals serving those with ASD also need to dedicate more attention towards the individual needs of parents caring for a child, especially if the child's symptoms are more severe (Lait et al., 2015). Concerns involving the lack of expertise involving health care and general knowledge of providers serving those with an ASD diagnosis was a central theme found within multiple studies (Chiri & Warfield, 2011; Dymond, Gilson, & Myran 2007; Smith, Chung, & Vostanis, 1994).

Dymond, Gilson, & Myran's (2007) study surveyed 783 parents of children with ASD in the state of Virginia. Parents reported a need of general increased awareness of autism, especially within professional supports, due to parents' perceptions that this lack of information impacts a child with autism and their family members on a negative level in terms of school and community inclusion. Studies have also found that families caring for children with autism need more formal supports and have higher needs for specialty cares. Due to the complex and unique qualities of these therapy skills and mental health practices, caregivers have either struggled to find service providers with these credentials or are met with insurance/financial restrictions (Chiri & Warfield, 2011).

Again, due to the unique nature of the needs of children with ASD, they are more likely to experience unmet needs and access of social services issues compared to other children facing a different diagnosis, such as a severe learning disability (Chiri & Warfield, 2011; Dymond & Gilson, 2007; Smith, Chung, & Vostanis, 1994).

The need for effective methods of information sharing between professional supports and caregivers is also critical. Hodgetts et al., (2013) study surveyed 152 parents caring for children with ASD and 146 professionals working with ASD clients in Alberta, Canada. Although these professionals believed their information sharing with parents was adequate, the model of Family-Centered Care revealed that in actuality, parents felt general information sharing by professionals, such as broad information about autism and finances for treatment options, was not satisfactory. The research reaffirms the fact that navigation of multiple service systems can be difficult and service professionals may not be meeting the needs of caregivers even if they perceive that they are doing so appropriately. If professionals empower families with this needed information and assist them by connecting them to other community providers, it may potentially lessen caregiver stress and confusion when sifting through the copious amounts of care options available (Hodgetts et al., 2013).

Furthermore, Hodgetts et al., (2013) study determined that the FCC model is meant to assist, inform, and improve outcomes for families caring for children with ASD, however, the “lack of transparency of service options” (p. 141) fostered an environment of mistrust and confusion within a system designed to help parents. Parents expressed frustrations that the system perpetuates the idea that they cannot choose the proper care for their children. Caregivers are also expected to bring an extreme amount of vigilance

to their child's care, which is a daunting, exhausting, and at times an infeasible task. Mulligan et al., (2012) emphasized that parents should be encouraged and given an opportunity to be part of the early care process for their child by professionals. Not only would this bolster parental empowerment, but would also provide parents the ability to learn and foster their involvement with care coordination.

Knowing that such a wide array of services for children managing autism exist it becomes essential to explore the process of accessing and acquiring these services, especially for those within the caregiver role. Identifying potential strengths and barriers will allow one to acquire a better understanding of how to make receiving assistance a more fluid process with better parental involvement. Having this knowledge provides further insight for professionals to grasp a more complete picture involving the needs and concerns of parents caring for children with ASD. Recognizing these concerns can also allow professionals to attune with the experiences caregivers may face and potentially attain a higher level of empathy.

Life After Diagnosis

A number of research studies have analyzed parental roles and family changes after a child has been diagnosed with ASD. Exploring the literature provides a small glimpse into the world of what caregivers face after the assessment process takes place. Obtaining knowledge regarding the transitions, challenges, emotions, and achievements parents may face will once again provide a better context as to how accessing and delivering social services for families can become more fluid, effective, and potentially better for all involved.

Studies have shown that differences in caring for children with autism verses other developmental disabilities can ultimately have more challenges. Research has discovered that parents caring for children with ASD experience higher stress and negative impacts towards mental health, such as experiencing depression and anxiety, compared to other parents caring for typical developing children or children with other developmental disabilities (Cullen & Barlow, 2002; Lai, Goh, Oej, & Sung, 2015; Smith, Chung, & Vostanis, 1994). One of the reasons caregivers experience these greater problems is due to the difficulties involving the diagnostic assessment, such as receiving a diagnosis later within a child's development or having to wait months to simply start the general assessment process. The complexities of the formal diagnosis can be challenging as well. No two children with ASD show the same symptom patterns or behaviors as another, which means one child may be concentrating on developing a completely different skill set than another when receiving intensive treatment. The ambiguous nature of the diagnosis can be stressful for parents, especially as they are unable to predict or plan for how their child will be functioning later in life (O'Brien, 2007).

Other challenges and stresses parents have expressed include managing various obstacles when addressing the challenging behaviors exhibited by their child. These can range from lack of social interaction and communication, constant demands, outbursts, and lack of independence. These stresses, along with needing to be present and available to address any issues 24 hours a day, resulted in complete mental and physical exhaustion (Cullen & Barlow, 2002). Studies have also found that caregivers encounter social isolation and feelings of helplessness when not able to participate in community activities with their child due to their symptoms. Also, caregivers having limited social/responsive

interactional experiences with their children can further feelings of helplessness and social isolation as well (Cullens & Barlow, 2002; Thompson & Emira, 2011).

Ambiguous loss and paradoxical emotions are other difficult problem parents may potentially face. Ambiguous loss can be experienced by families confronting change, such as when a child is diagnosed with ASD, and then not having clear-cut answers for the changes they are encountering. Facing the stress of unknown resolutions and having limited predictable outcomes can further distress families and foster ambiguous loss (Boss, 1999). As previously stated, children exhibiting various and challenging behaviors can be difficult to manage. Research has shown that caregivers as a result understandably experience a wide range of emotions, guilt being a predominant one. Caregivers managing guilt may then have this emotion become attached to other feelings, such as relief. Having these paradoxical emotions, such as love and dislike, in every day life was found in Cullen & Barlow's (2002) research. Parents reported loving their child with ASD but disliking the impacts of their disability on family life. O'Brien's (2007) study found mothers that identified higher with identity ambiguity, such as a child's condition strongly impacting how one views themselves as a person, reported more symptoms of depression and higher stress related to their child's condition.

Parents have also expressed that experiencing a lack of understanding from extended family and friends' regarding their child's behavior is also difficult to personally manage (Cullen & Barlow, 2002; O'Brien, 2007). Children with ASD often look like typical developing children, which can lead family or friends to discounting the diagnosis or the diagnosis process as a whole. This lack of understanding may limit parents' self-confidence in their decision making capabilities involving care for their child and lead to

further feelings of ambiguity (O'Brien, 2007). Hillman's (2007) review of empirical studies found that grandparents can have essential roles in assisting a nuclear family raising a child with ASD, however, grandparents need further education and support in order to engage with long-term family planning and advocacy. This need for further education and information to be obtained by extended family members is displayed in other research highlighting similar frustrations (Cullen & Barlow, 2002).

Trute's (2003) study displayed that support from extended family members is associated with reduced stress experienced by parents caring for children with a disability. It becomes important to note, however, that this research did not solely focus on extended family assisting parents caring for a child with ASD compared to other disabilities. Although conflicting results exist regarding the involvement of extended family members supporting parents caring for children with ASD, research does reveal the more knowledge one attains about the complexities of managing and caring for a loved one with ASD will most likely provide more positive outcomes for all involved.

Recognizing the impacts involving general family functioning and marital functioning is important as well. Caregivers typically have to take on multiple roles within the family and encounter significant role shifts. For example, parents must adapt to the roles of being an advocate, expert, and care coordinator for their child. The confusing nature of these roles can lead parents to feel disempowered, lost, and overwhelmed regarding their journey as caregivers (Mulligan et al., 2012). Cullen and Barlow (2002) further describe the impacts of general family functioning stating:

Family life had completely changed for all parents. In order to adjust to the behavioral demands of autism, parents described the necessary changes to family routines that left them feeling guilty and lacking family cohesion. Basic tasks (shopping) and leisure activities (going swimming) were impossible (p. 40).

As discussed earlier, parents also reported that some services that were provided to assist with family functioning were not appropriate or specific service suggestions and requests were never fulfilled. Meadan, Halle, & Ebata's (2010) systematic review found that limited information regarding the impacts of caring for a child with ASD on marriage is rather limited. They did emphasize that some research has shown that parents are more likely to experience a higher divorce rate, while some studies have found no differences of marital impact if a family is caring for a child with or without a disability. However, in Cullen and Barlow's (2002) research, parents reported having little to no personal time together. And when parents were able to go out as a couple it was difficult to find an appropriate person to watch their child with ASD (2002). Although information surrounding this topic is more limited, the varying nature of responses from caregivers warrants further investigation and may provide additional insight into services that may positively impact parents marital functioning as well.

Parental Coping Strategies

A number of coping mechanisms parents either consciously or unconsciously engage in has been reported in previous literature as well. When facing the difficult responsibility of caring for a child with autism, caregivers have expressed that maintaining a positive approach, humor, and acknowledging that they need help and support have been beneficial towards caring for their child (Cullens and Barlow, 2002). Reframing situations and seeking support from others also has positive mental health outcomes for parents (Lai et al., 2015). However, not all reported coping strategies are positive. Lai et al., (2015) study found that parents were also more likely to engage in maladaptive emotion focused coping and active avoidance coping. Avoidance coping involves a range

of negative coping strategies involving parents criticizing themselves, distracting themselves from thinking about issues of caring for their child with ASD, or giving up trying to solve issues altogether. Attaining more knowledge regarding why parents engage in specific coping mechanisms may provide further understanding into the stresses they face in daily life. Having this deeper understanding concerning the purpose of specific coping strategies used by caregivers may lend a broader perspective into social service options that are needed or would benefit parents caring for children with ASD.

Investigating life after diagnosis, especially the challenges, stresses, and general functioning families may face, is imperative towards potentially identifying any specific gaps in services families are encountering. Although studies have focused on difficulties surrounding the management of ASD, it becomes incredibly important to note that not all research has found that caring for a child with ASD has negative impacts. Some caregivers have reported that the experience involving caring for a child with autism to be a positive one (Meadan, Halle, & Ebata, 2010). Cullens and Barlow (2002) identified that caregivers gained multiple positive attributes when caring for a child with ASD, such as strength, love, and knowledge. Although life after diagnosis does involve varying experiences and challenges, categorizing them all as negative would be obviously inaccurate.

Acquiring more insight regarding the transitions, challenges, and experiences parents face after their child receives a diagnosis allows for the ability to assess and identify areas of need and concern involving the access and delivery of social services for families. Possessing this knowledge will allow professionals, family members, and friends to

better assist and support families caring for a child with autism. Although this information regarding access of services for children with ASD is essential towards attaining a greater understanding of what caregivers may face on a daily basis, examining what services parents may specifically need when caring for a child with ASD becomes critical as well.

Supportive Services for Parents and Children with Autism Spectrum Disorder

Respite Care. Respite care, within the context of the state of Minnesota, is defined as short-term care services provided to family members or a primary caregiver for an individual. Engaging in respite care services allows these individuals to have a brief time of relief or break from their caretaker role (Minnesota Department of Human Services, 2015). Investigating the impacts and potential needs for respite services of parents caring for children with ASD serves as another guiding piece towards determining if accessing these supportive services is crucial and beneficial for parents.

Conflicting information has been found regarding respite services for children and the benefits that they provide for a child with ASD and their family. Preece and Jordan's (2006) study conducted in the United Kingdom suggests parents caring for children with autism that engage in respite or "short breaks" provided multiple functions for caregivers. When a child spends time away from the home, parents were allowed to have a break from caring, obtain rest, and their child could be exposed to new social and educational opportunities (MacDonald & Callery, 2003; Preece & Jordan, 2006) Parents expressed that in order to make respite care effective for children, a number of factors must occur and effectively work together. These factors may range from the physical environment the child would be interacting in, use of varying therapy approaches, staff

knowledge and skills, and how children managing autism should be appropriately grouped with other children when engaging in respite services (Preece, 2009).

Social workers favored short in-home and overnight breaks verses respite placement facilities in MacDonald & Callery's research about respite services (2003). Results suggested that social workers felt that these respite breaks should only occur when a family is experiencing a form of crisis so a child would have more stability by not having to spend the night away from the familiarity and comfort of their family (MacDonald & Callery, 2003). It becomes important to note that the above study was also conducted in the United Kingdom and the sample size of social workers that were interviewed was small. However, exploring if this same sentiment is shared within the United States, especially in the Midwest, would be beneficial for a number of reasons. Investigating social workers and families perceptions of how they define respite care, when it should be utilized, and how to make it most effective ties directly to seeking out what social services parents caring for children with ASD can access and if gaps or barriers of receiving respite care are present within our society.

Another option worth noting as possible supportive services for parents involves leisure activities. Although leisure and respite services do not fall under the category of therapy, the need for children with ASD and their families to have an outlet of engaging in these activities can be essential in promoting physical and mental well-being as well. In Thompson and Emira's (2011) study, they sought to explore barriers families experienced when accessing activities, such as swimming, participating in community clubs or going to the movies. Results revealed that a sense of isolation was a major contributing factor towards families not engaging in such events. A child's ability to

participate in these activities may have been impacted by safety concerns of the family, such as their child wandering off, or having to manage challenging behaviors in public environments. These feelings had the potential to create isolation for the child and family. Thompson and Emira (2011) emphasized the importance of having support systems in place, such as having multiple forms of transportation available and the involvement of professionals. Having these extra supports could promote further connection and the possibility for a child with ASD to improve social and communication skills while fostering self-efficacy.

Need for a Key Worker. Research surrounding the barriers to accessing social supportive services available to families caring for children with autism range from having to acquire an understanding of what services are realistic options for a child, to various challenges and stresses surrounding life after diagnosis. Research studies have found that parents have expressed the need to have a “key worker” to help support the family not only during the assessment process but also for continued family support. However, this need for a key worker, parental support groups, and respite services has not been a central focus of many research studies.

The need for a key worker has been analyzed in some literature but major gaps still exist. Also, the ambiguous nature of what a “key worker” actually is and how their roles are defined have varied throughout literature as well. In McConachie and Robinson’s (2006) study, they defined a key worker to be a speech and language therapist, social worker, or health visitor that had been designated to support a family. Also, the key worker should be in charge of coordinating management of supportive services across all agencies after assessments are complete (McConachie & Robinson,

2006). As research has shown, if family involvement in services is necessary in order to promote better outcomes for their child managing autism, then service options must be put in place to assist already drained and busy families (Hodgetts et al., 2013).

Hodgetts et al., (2013) further emphasizes the need for this single person role to assist with access and supportive services stating

The adoption of a 'key worker' model of service delivery, where one person acts as a single point of contact to help a family navigate supports and services across sectors, could dramatically decrease burdens on families (...) and the need for a system-level intervention to integrate care across sectors, might improve the experiences of families. (p. 145)

Parents in other literature have expressed a similar sentiment of needing someone to act as a single point of contact as well. Dymond, Gilson, & Myran (2007) research found that many caregivers stated that they were unaware of all the different service options and treatment approaches available to children with ASD until they had completed their study. Parents stressed needing information regarding existing services, the location of facilities, and knowing whom they needed to speak with involving establishing services. Parents also emphasized the need to know who is the most qualified to provide specific treatment and support (Dymond, Gilson, & Myran, 2007). Renty and Roeyers (2006) found that both parents and professionals have commented on the limited amount of information available for families regarding service provision. Further recommendations involving the need for a key worker to assist with supportive services, trainings, and transitional planning were emphasized as well.

Summary

In reviewing the literature, it becomes clear that many elements influence parents' experiences involving caring for a child with ASD. The challenges of accessing and

knowing what service delivery options are available for children with autism was a strong theme throughout the literature. By not only focusing on the treatment options available but also exploring life after diagnosis provides a more holistic picture of potential needs and concerns parents caring for children with ASD encounter. Gaps involving service navigation including a key worker, respite options, and social work professional involvement were also identified. The purpose of this study is to explore the strengths, challenges, and experiences of families caring for children with ASD and accessing supportive services.

Conceptual Framework

Utilizing a specific conceptual framework when exploring parent's strengths, challenges, and experiences involving access to supportive services when caring for a child with ASD, will yield further insight towards the treatment of ASD and those impacted by the diagnosis. Applying the conceptual lens of the Ecological Perspective, which includes Systems Theory, to this research will help to attain a better understanding of each family's general functioning and how access to supportive services impacts their functioning within various environments they may encounter (Robbins, Chatterjee, & Canda, 2012).

The ecological perspective emphasizes the importance of viewing an individual and their environment as a unitary system that is also influenced by historical and cultural impacts (Germain & Gitterman, 1995). Although the ecological perspective continues to evolve when utilized in social work practice, the root concepts of focusing on transactions between people and their environment and the adaptations individuals make within these contexts remain highly important. The process of *adaptation* is fluid and consists of biological, social, psychological, and cultural elements impacting and interacting with one another (Robbins, Chatterjee, & Canda, 2012). Applying this theoretical concept of *adaptation* to parents caring for children with ASD is relevant due to the constant nature of change a family experiences with a child's diagnosis. For example, when parents are informed that their child has autism they will need to enlist the help of therapy services. Although parents may experience some relief of having answers as to why their child may be functioning in the manner that they have been, they now face the daunting task and responsibility of finding the most suitable services for their

child's needs and how those services can allow for them to best adapt to their current situation. Again, although this example merely highlights only one adaptation a family may encounter while caring for a child with autism, the need for this flexibility within one's environment becomes imperative towards the success of a child managing ASD.

Robbins, Chatterjee, & Canda (2012) also highlight that these transactions between an individual and their environment are often complex and have the potential to disrupt an individual's *goodness-of-fit*. Goodness-of-fit involves one's means of matching between their adaptive needs and the quality of environment. However, problems can arise in various forms to alter one's goodness-of-fit, which then causes stress. This internal stress response experienced by an individual would be due to the break down of the transactional nature of interacting with one's environment (Germain & Gitterman, 1995; Robbins, Chatterjee, & Canda, 2012). Relating this concept to ASD, a child with autism may lack the ability to communicate their needs causing them to have an angry outburst. This outburst and lack of communication can then cause parents to experience stress due to the inability to understand or meet the needs of their child. The ecological perspective also has the ability to be applied to various system levels as well.

When applying the ecological framework to this research it is important to also consider looking at the issues from a micro, meso, and macros systems perspective. A *micro-system* perspective involves looking at the current setting an individual is in and their immediate interactions with others in that environment (Bronfenbrenner, 1994) An example of this micro-system may involve exploring how parents are managing the care for their child with ASD. Examining this interaction between child and parent or even

from spouse to spouse, may provide another context into what challenges a family may face such as balancing schedules, time, and various emotions.

The *meso-system* of the ecological perspective involves looking at the coordination and interaction of multiple settings, such as work and school, involving a particular individual. A meso-system can essentially be described as a system of other microsystems (Bronfenbrenner, 1994). In reference towards how families need to coordinate care and interact with multiple service providers, such as health insurance companies, behavioral therapy services or occupational/speech therapy, the meso-system concept would be looking at this interactional process between settings as a whole rather than just focusing on a parent or child. Looking at parents' needs for a key worker/social worker to assist with navigating these multiple settings would be relevant as well.

Applying the *macro-system* concept of the ecological perspective involves identifying large systems as a means of promoting change, which are typically represented by values, belief systems, customs, and opportunity structures. The macro-system has been referred to and acts as a societal design for a culture (Bronfenbrenner, 1994). When considering parents caring for children with ASD, this may involve looking at the educational and supportive services that are offered to parents and the broader public in order to best care for a child with autism. Looking at respite and community services that parents can become a part of would be applicable to this concept. Issues of social stigma, in terms of how others may respond to a child with ASD and their families, should also be considered. Communities taking action to change legislation, policies, or educational offerings for parents caring for children with ASD would all fall under this macro-system category too.

Applying a conceptual framework to an individual's reality allows one to attain a better understanding of what their world may look like and to assist in the development of different questions to ask when addressing a significant problem. In this study the ecological framework was used in the development of research questions that were administered to respondents.

Methodology

Research Design

Past research utilizing qualitative interviews and questionnaires have sought to obtain a better understanding involving the access of services for children with ASD, parental experiences of life after receiving a diagnosis, and supportive services offered to parents caring for children with ASD. The purpose of this study was to determine the strengths, challenges, and experiences of parents accessing supportive services for children with ASD over time. Acquiring this information not only allowed parents to voice their personal experiences, but also provided a space to identify and reflect on what more can be done to assist families when accessing services for their children and themselves. Utilizing an exploratory qualitative design assisted in accessing the voices of parents closest to the problem being researched and strengthened findings.

Sample

This study utilized a snowball sampling method. By utilizing participants' knowledge of identifying other potential members that fit the appropriate characteristics needed for this study involved engaging in snowball sampling techniques (Monette et al., 2014). This researcher has worked within the ASD community in the past, and has been able to establish some contacts with professionals and parents within the field. The purpose of using the snowball sampling method allowed for the researcher to access more participants who fit the sampling criteria and contributed to the overall research process.

The following criteria implemented within the research consisted of participants being identified as parents (mothers, fathers, or primary adult caregivers) caring for children with an ASD diagnosis. The identified participants included in this study also

needed to have received a formal diagnosis of ASD for their child for a minimum of 6-months before engaging in this research. Only those caregiving and currently being provided services were able to engage in this study. Participants also needed to be caring for the child with ASD within the home and the child could be no older than 18 years of age. The sample did not need to meet specific requirements regarding race, gender, or level of education. The selection criteria for this research study was included on the flyer (Appendix A) given to potential participants and was confirmed with participants when the consent form was reviewed and signed just before the interview process took place.

Protection of Human Rights

A written proposal of this research was submitted to Saint Catherine University Institutional Review Board (IRB) and needed approval before the data collection process began. Before conducting interviews, a consent form (Appendix C) was provided and reviewed with each respondent and formally signed by participants. The consent form included the purpose, background information, and procedures of the study. The form also focused on the risks and benefits of the research, the voluntary nature for participants, and confidentiality. Individuals that chose to participate in this study were given the questions prior to the interview, to confirm that they felt comfortable participating in the research process. At any time, respondents were able to end involvement with the study and received no penalty.

To ensure confidentiality, the researcher reminded respondents that the only individuals that would have access to the interview transcripts would be the researcher and research chair. The researcher transcribed the audio files and no third party had access to the transcripts. All voice recordings were completed and stored on a password-

protected iPad owned by the researcher. Transcripts of the provided interviews were then saved on a USB drive and located in a locked bin in the possession of the researcher. The voice recordings allowed the researcher to transcribe the interviews word for word and assisted in the data coding process. Each participant and interview transcript was assigned a pseudonym to ensure further privacy. An identity key was created and stored separately from the original data on a second USB device. All contact information was held separately from the transcripts, which further protected confidentiality. Once transcription was complete, all voice recordings were destroyed by May of 2016. All transcripts stored on the researcher's USB drive were also destroyed by May of 2016. Each transcript completed from the interviews included no identifying information or names within the final works of the research presentation.

Potential risks respondents faced participating within the research involved time constraints, the possibility of being identified when sharing negative feedback about the agency they are receiving services from, and the emotional content of the questions asked. In terms of time constraints, participants may have experienced difficulties with planning around their family's schedule or leaving time for self-care. In order to address this concern, the researcher provided multiple times to complete the interview and agreed to meet at neutral locations that were best for the participants. The severity and likelihood of this risk to occur was minimal. The possibility of a participant being linked to negative feedback shared about a specific service provider, which could affect the relationship of the participant with the agency, was also a potential risk. To address this risk, all responses remained confidential and neutral of any identifying information. All quotes used were not identified by the participant's name or service provider. Due to the

sensitive nature of some of the research questions asking participants to reflect on potential challenges they faced while caring for a child with ASD, the possibility of encountering varying emotions such as stress, loss, and discomfort could have occurred. The researcher reminded participants that they did not have to respond to any questions that caused them to experience discomfort. In order to address these potential feelings, the researcher offered to debrief with participants after the interview and provided additional resources and contacts (see Appendix D) if they desired. The potential severity and likelihood of this risk to occur was also minimal.

Research Setting

The research setting for this study involved meeting participants in a neutral place, such as a private meeting room located in the closest library to the respondent. These varying and neutral locations all remained within the Minneapolis and St. Paul metropolitan area and were agreed upon by the participant and researcher. Each research interview was conducted in person with all participants as well.

Instrument

For this research study, the instrument used consisted of 9 open-ended questions (Appendix B) relating to caregiver experiences involving caring for a child with an ASD diagnosis and accessing supportive services. The questions were derived from information found within the literature review and developed by the researcher to solicit feedback from respondents. Elements of the ecological perspective were also utilized with the development of the instrument as well. All questions that were administered to respondents were reviewed by a committee of three members to ensure validity, eliminate any leading questions and biases, and to confirm cohesion. Demographic information that

was obtained included 9 questions regarding the caregiver and child currently in their care. Demographic information that was collected from respondents included gender, age, race, marital status, socio-economic status, and the age when their child was diagnosed with ASD.

Data Collection

Data collection was completed with the following steps:

- 1.) Participants were chosen regarding the qualifications of being a parent and/or caregiver of a child with ASD that is currently receiving social supportive services/ individual intensive behavioral treatment. Participants were not from one central agency but through multiple professional contacts that work within the ASD community. As stated above, sample collection was conducted by snowball sampling.
- 2.) Research respondents were introduced to the study by the researcher's committee members. Potential participants were given a flyer (see Appendix A) by the researcher's committee members, which included necessary information involving the purpose of the study and the researchers contact information. The researcher's committee members contacted 2-3 people.
- 3.) Potential subjects were contacted after the internal review board process was completed. Subjects were reached by either telephone or email by the researcher's committee members.
- 4.) If the potential participants agreed to this study, they were then contacted by the researcher via email. The researcher then provided the participants with the

- research questions (see Appendix B) and consent form by email for them to review.
- 5.) The researcher followed-up with participants and set up the interview during an appropriate meeting time in a neutral and private location, such as in a public library conference room.
 - 6.) All interviews were voice recorded with the use of an iPad that was password protected. A maximum of 60 minutes of allotted time was given to complete the interview and the transcription process took place upon the completion of each interview.
 - 7.) Each participant was also asked to provide an additional 1-2 potential participants at the end of the interview so the data collection process for this study could reach the projected 6-10 respondents. The researcher then reached out to the additional participants provided through email. Upon completion of the interview, participants received a \$10.00 coffee shop gift card.

Data Analysis

The data analysis was based on a grounded theory methodology perspective, due to the raw data being “grounded” and representing the respondent’s answers as closely as possible (Monette et al., 2014). Data was then drawn from the interview after the researcher completed the assessment process of the transcript. The assessment process consisted of transcribing all voice-recorded interviews word-for-word. Concepts that emerged from the transcripts were categorized as themes and subthemes to provide broader perspective involving research outcomes. The level of strength of any identifying themes were then categorized and discussed as well.

Research Bias

Due to the nature of this study being a qualitative format involving a preferred topic by the researcher, some level of biases exists, which may have assisted or hindered the interpretation process of the results. The researcher has previously worked for employers assisting children with autism in an in-home and center based setting. During this time, the researcher interacted and communicated with a number of caregivers as well. These experiences resulted in the development and personal interest of the researcher. However, these previous experiences may also serve as a strength to this study and allowed the researcher to be more sensitive to issues parents encounter and may have assisted the researcher to ask more relevant questions. To address any potential biases, such as creating leading questions or being limited in scope surrounding supportive services available to parents caring for children with ASD, the researcher had all interview questions reviewed by members of the research committee. The research committee consisted of two community members and a research chair.

Findings

Sample

The participants featured within this study were parents caring for children diagnosed with autism spectrum disorder. Eight potential participants were offered to participate in this study. Four participants completed the interview process. Three individuals declined to complete the interview and one individual was planning to participate but was later unable to due to unforeseen health issues within their family. Interviews were conducted over a month time span, from February 18th to March 18th 2016. Three mothers and one father participated in the interview process. One mother included responses to the interview questions from her husband who was unable to attend the interview but wanted to provide feedback. All participants live within the Twin Cities Metropolitan area in Minnesota.

Sample Characteristics

The demographics that were reflected within this study featured more women than men (3 participants identified as female and 1 participant identified as male). Two of the participant's age ranges fell between 30-39 and the other two participants fell between 40-49. All four of the individuals that participated in this research identified as Caucasian so no other race/ethnicity was represented. All of the individuals were classified as being parents as a relationship to the child, three being mothers and one being a father, so no grandparents or guardians were represented. Two of the mother's were categorized as being married, one mother as single, and the father noted that he is now remarried but his child that was diagnosed with ASD was from his first marriage (See Table 1). For demographics that were listed specifically to the child, all of the

children were diagnosed between the ages of 18 months to 2.5 years. One mother has twins and noted that both were diagnosed at the age of 2.5. Two of the children began receiving services starting at the age of two, one at two and half, and the mother that has twins began services at the age of three (See Table 2).

The first question of the interview asked participants what services they are currently utilizing for their child and what have they used in the past. The responses certainly shared multiple similarities but also had enough variations to reaffirm that every child with autism has different skills and needs. Speech therapy is currently the most widely used service with 3 of the 4 parents stating that their children still engage in this treatment. Occupational therapy, center based therapy (involves learning daily living skills/ utilizing applied behavioral analysis), and partial special education support while attending main stream classrooms were each reported as being currently used by 2 out of 4 participants.

When reviewing past services, speech therapy and occupational therapy were the most widely used services with all participants reporting that their children engaged in these two types of therapy. Two participants reported that two of their children engaged in physical therapy in the past, although out of these two children one is still currently receiving this service. And 3 of the 4 participants stated that their children attended center based therapy programs for over a year. Interestingly, only one of the four participants reported receiving in-home therapy and dietary/eating assistance in the past and one of the four participants never participated in center based therapy.

Table 1: *Demographics Specific to Parent and/or Caregiver Participants (N=4)*

	DEMOGRAPHICS	PARTICIPANTS (N=4)
GENDER	Male	1
	Female	3
CURRENT AGE	30-39	2
	40-49	2
RACE/ ETHNICITY	Caucasian/White	4
RELATIONSHIP TO CHILD	Mother	3
	Father	1
RELATIONSHIP STATUS	Single	1
	Married	2
	Remarried	1

Table 2: *Demographics Specific to Child with ASD (N=5)*

	YEARS	PARTICIPANTS (N=5)
AGE DIAGNOSED	1.5	1
	2	2
	2.5	2
AGE RECEIVING SERVICES BEGAN	2	2
	2.5	1
	3	2

Multiple themes were generated throughout the coding process of the interview transcripts. Some of the themes that became apparent were caregivers needing direction and being overwhelmed, cost and interacting with other systems, wait time for services after receiving a diagnosis, relocation for services, lack of knowledge and service delivery from professionals, reliance on the internet, family and social work support, and the need for empathy and involvement from others. Due to having the small sample size of 4 participants within this study, the above themes were determined if at least 2 of the participants had the same impression.

Themes

Direction and Being Overwhelmed. When asked what social supportive needs have been identified by the participants the responses varied regarding specific needs when caring for their child ranging from in-home and center based therapy, grant supports for various home supports and sensory items, and navigating the county system. Although these variations in service needs existed among participants, the shared themes of needing assistance with accessing services/ care coordination and general feelings of being overwhelmed were expressed by 3 of the 4 participants. Two parents noted the confusion and complexity of working with the county system with one participant stating,

No, they didn't help. It was kind of like, here contact the county and they might be able to help with finances. Here's the number. And I think that's what's the biggest frustration with parents is, like there is so much paper work that goes through the county that you just kind of give up sometimes (Transcript 3, Page 2, Lines 7-10).

Another participant stated,

When we got on to MA that is when we decided to just go ahead and do the social worker assessment because we knew that we would qualify for it. So, it's that one thing that, I don't know, it's all so overwhelming and confusing to me anyway. (Transcript 2, Page 3, Lines 30-32).

An additional participant described when their child received the diagnosis of ASD they were greatly overwhelmed due to not knowing what autism was, the service options that were available and needing direction stating,

I think at first we were just overwhelmed. We didn't even know what autism was. We didn't know how to help him or what we needed to do. So I think direction, because we didn't really get any of that in the beginning (Transcript 1, Page 1, Lines 24-26) (...) What kind of help was out there, we had no idea (Transcript 1, Page 2, Line 24).

When discussing how service needs have changed over time, two parents expressed current concerns with their child's nutrition/ dietary needs as well. Both parents described

their children as being “picky” eaters and that they will only eat up to 10-15 variations of meals. For example, one parent reported that their child will only eat one specific brand of pizza and if any other types are introduced to his diet and are prepared differently he will not eat them. With the children only liking specific types of food (ie, mac and cheese and turkey sandwiches) parents expressed concern that they were not meeting nutritional needs and a balanced diet. Interestingly, these participant’s children are between the ages of 6-9 years of age. One parent also expressed their child receiving dietary assistance and sensory support with eating when they were 8 years old, but no longer receive this supportive service.

One of the questions that generated the most detailed and varying responses from participants was for them to describe some of their experiences regarding acquiring supportive services for their child. Three out of the four participants focused on specific challenges/ barriers they encountered, however, one participant stated that she had no complaints with accessing services and no delays with getting her child enrolled into therapy after receiving his diagnosis. Although one would hope this would be a common theme for this question, this was not reflected in the responses of the other participants.

Cost and interacting with other systems. Two of the four participants discussed concerns involving cost and the complexity of working with other funding systems, such as the county and health insurance companies. Both of these parents stated that they applied for medical assistance (MA) in order to help cover the cost of services their child utilizes. When discussing medical assistance one participant shared

The county is the most difficult thing to get through. Just because of the paper work, the yearly assessments that they need, and getting everything in on time. They hold you responsible as a parent and yet they are not exactly the most helpful unit in the world (Transcript 3, Page 3, Lines 24-26)

This parent elaborated further with challenges managing paper work and reapplying for medical assistance within Hennepin county every six months stating

We were on every 6 months and we just couldn't do it. Cause you have to get it for his MA to keep going. So, you would have to fill out all of this paper work and get all of these things from all of his doctors and, you know, show that he still has these diagnoses to continue the MA and the supportive services that the county gave (Transcript 3, Page 3, Lines 1-4).

In contrast, another parent emphasized that the cost of MA is dependent upon one's salary and when her children were initially diagnosed she could not afford to pay for the coverage of medical assistance stating *At that time MA was not affordable at all for us. It has come down enough in price where we now can afford it. It's not easy to afford it (Transcript 2, Page 7, Lines, 31-32).* Although beneficial and at times necessary for families, it becomes apparent that acquiring medical assistance and the overall cost can be difficult for families to manage. One parent spoke further about the difficulties of finding cost effective and appropriate coverage for services expressing

I think health insurance is the biggest thing. It is such a huge cost because we have to provide them with there-we have our health insurance through their Dad's employer, however, they don't cover ABA and they don't cover enough speech and OT because it is considered mental health verses a neurological disorder and we get 15 visits of therapy a year. But you're going 4 times a week. Literally 3 weeks of the year and we are already done. So, that's another big reason why we need MA besides the ABA therapy. We need it for our speech and OT (Transcript 2, Page 4, Lines, 8-15).

Wait time for services after receiving diagnosis. As participants continued to share their experiences regarding acquiring services for their children two of the four participants discussed having to wait close to six months after their child received an ASD diagnosis to engage in supportive services. One parent stated

And we just tried to keep them engaged with anything we could just to keep them out of their little worlds. But um, until we could get down here. But it just killed us to have to wait for therapy (Transcript 2, Page 6, Lines 30-32).

Another participant had to wait six months to begin services as well after their child received an autism diagnosis. They also elaborated on the difficulties of switching services and wanting to work with a specific center based therapy agency within the metro that had over a two year wait list stating *their wait list is absolutely astronomical. Like, 2 years (Transcript 3, Page 4, 15).*

Relocation for services. Surprisingly, two of the four participants reported that they relocated to the Twin Cities Greater Metro area to acquire better services for their child. One participant moved from northern Minnesota and another moved from Texas. Although their circumstances were some what different as to what lead them to relocate, both stated that they wanted to do what was best for their children and realized that being in the metro area would give them the most opportunities. When describing relocating and being able to try different services one participant stated,

And people don't have knowledge too. I mean, because I'm here now and not up north we can...we hear about things and you know of therapies that are at least available but, I mean, the greater part of MN has no clue. No one up north even knew that centers existed down here (Transcript 2, Page 5, Lines 16-19).

Another participant shared a similar perspective stating,

Honestly, I literally stayed up in this state with nothing because of the services here. I couldn't, maybe, maybe if people understood what it was normally like in other places because I have looked into it and had that comparison. And then people would understand more, or maybe it is just luck of the draw. I'm not really sure why I got so blessed with the people that were in my life (Transcript 4, Page 6, Lines 6-10).

Although participants have spoken to challenges involving accessing services within the metro area, two of the four participants noted the benefits of living within the Twin Cities (which lead them both to relocate) and being able to engage in varying supportive services for their children.

Lack of Knowledge/ Service Delivery from Professionals. Another theme that became prevalent between participants involved having feelings that professionals either lacked knowledge surrounding ASD or had limited understanding as to what resources they should refer for caregivers. Two of the four participants noted these struggles with one parent while discussing resources shared,

For me, I find a lot of professionals are just going through the motions. They are not trying to understand what the family is going through. I feel like that is where if you could think “what is this family going through right now and how can I dispense this information to them so it’s not overwhelming and it’s helpful. And try to customize it instead of like, “here’s a hundred pamphlets.” (laughs) “You don’t qualify for these, but read them all and figure that out for yourself,” (Transcript 1, Page 3, Lines 10-15).

This parent highlights the need for professionals serving families and children with autism to be mindful as to what services a family may want and/or need for their child while maintaining a level of empathy during this process as well. This parent later discussed interactions with another professional and this individual’s limited knowledge involving ABA therapy services stating

The therapist we were working with, I felt like she didn’t have a lot of experience in autism. And I think she was a really great girl and was trying her best but I think she was probably, you know, had a lot of cases and tried her best but...had limited resources (Transcript 1, Page 6, Lines 13-15).

One of the most powerful elements of this respondent’s answer was not necessarily the therapist’s lack of experience, but concerns that the professional did not have enough resources to support her within her work too provide effective therapy. While discussing therapy another parent displayed concerns surrounding a professional’s level of experience and general perceptions of ABA therapy expressing,

I mean, the things she said about ABA therapy were so outdated. And, she had no idea about the centers. And, to think she is the one who is working in the school

system. But all she talked about was it being a robotic therapy and that sort of thing. And it's so not what it is these days (Transcript 2, Page 5, Lines 1-4).

Although these concerns of lack of knowledge and skill level of professionals supporting families with ASD were expressed by two of the four participants, this concern still emphasizes the importance of professionals to be connected and up to date with resources, services, and trainings to help parents feel better supported.

Reliance on Internet. The last theme found within the barriers and challenges caregivers face of accessing supportive services for their children was two of the four respondents having to rely on the internet to act as an informal source of support and educational tool for navigation of resources. Although both respondents displayed humor with having to turn to Google to help find resources, they did state feelings of being overwhelmed and confused with finding appropriate supportive services during the interview. By utilizing the internet, this respondent speaks to connecting with other parents caring for children with ASD stating

I did a lot of googling, using the internet. So, I always think of parents back in the 80's or kids that were diagnosed with autism back before the internet and it would have been a lot harder. And now we have autism bloggers we have, I mean, mostly that's what we relied on and then I would educate myself (Transcript 1, Page 3, Lines 1-4).

Another parent speaks to having to rely on the internet to find services expressing

So, the lack of knowledge as far as the therapies that are out there, you know, it's pretty daunting. We found it because of doing Google searches on what we did with both kids. I mean, it's the only reason we found out all this (Transcript 2, Page 5, Lines 32-33).

Both of these parents articulate the significance of using the internet to connect with other parents and find appropriate supportive resources for their children.

Family and Social Worker Support. Another question posed to participants involved indicating who has helped them access resources/ supportive services professionally and personally and three of the four participants noted family members and social workers. The participants spoke highly of the support and guidance they have received from family members. One parent emphasized the significance of the assistance she received surrounding resource support stating *we call her his guardian angel because she led us and found us resources that we would have never have found on our own* (Transcript 1, Page 2, Lines 36-37).

Another participant shared a similar sentiment when talking about his mother sharing

You can only find one or two people that will actually watch him so you can get away as a parent. Grandma, my mother by far has been the biggest support system that I have had through his life because she knows him as well as I do (Transcript 3, Page 7, Lines 17-19).

These parents speak to the benefits of having support from family, whether it involves resource navigation to leaving their child with a trusted care provider so they can have a break. Three of the four participants also noted that social workers have assisted them with acquiring resources, however, one participant expressed mixed feelings regarding their social workers level of engagement stating

We, at some point, the county usually gives you a social worker but now it's a social work team. So you don't have a name. But when we had a name, he never showed up for appointments that we scheduled, like at schools for IEP's when the county wanted him there. So we got rid of that person and then we got put on a team. So we are a number now...you don't have the individual care that you would get back a few years ago (Transcript 3, Page 8, Lines 6-10).

This parent expresses the desire for not only direct care support from an individual social worker verses a team but also if families are receiving support from a social worker they need to remain actively involved in order for them to feel supported. Another parent

discussed her involvement with a county social worker and how she helped her in acquiring grant supportive services. And an additional parent described her experience working with a social worker through her child's therapy center to be immensely helpful stating

Sometimes she would call me and be like can we go have lunch? And we would just go and have lunch together and she loved (child's name) and she was amazing. It was pretty incredible to have her part of my life (Transcript 4, Page 4, Lines 20-23).

With this particular social worker being more involved with this participant and her child, it lead her to have a deeper connection and feel better supported by the agency her child was enrolled in.

Need for Empathy and Involvement from Others. The final two questions of the interview asked participants to discuss what recommendations they would have for professionals and to share any other information they felt would be pertinent to this study. One general theme that was shared by all four participants was a need for professionals and the general public to be more empathetic and/or involved with families caring for a child with autism. When discussing recommendations for professionals one parent shared *I think it would help all providers or therapists, if they tried to put themselves in the family's shoes (Transcript 1, Page 8, Line 15)*. Another participant stated this need for professionals to have empathy as well stating *a personal touch is one of the biggest things parents are looking for and someone to lean on for where to go. What avenues. What's the best route for this kid (Transcript 3, Page 9, Lines 6-7)*. These responses display the need for professionals to provide empathy and further involvement to families in order for them to feel best supported.

This theme of needing empathy and involvement from others was also expressed at a community level by respondents as well. One parent shared an experience involving a lack of general awareness while out in public stating *(...) you walk around and people still look at you. Like, what's wrong with them? And it's just that lack of...life is hard enough but then to have that (Transcript 2, Page 7, Lines 38-39)*. Another parent shared a similar situation sharing *the only thing that I dealt with, you know, that was negative had nothing to do at all with professionals it was just people. Always being judged (Transcript 4, Page 7, Lines 12-13)*. These responses from all participants speaks to the need for professionals and the general public to remain empathetic and understanding.

Additional Findings

Although many themes were found among the research, two of the research questions did not generate any themes across participants. These two questions were *What outside service providers have you accessed, if any? If not, what outside service providers do you feel would be beneficial to you and your family?* and *Are there any family or cultural impacts that have influenced your level of engagement with social supportive services? If so, please describe and do you have any recommendations for service providers?* Due to participants having varying responses or information being overlapped with previous questions no themes were found.

Discussion

Sample

The demographics that were reflected within this study featured more women than men (3 participants identified as female and 1 participant identified as male). Two of the participant's age ranges fell between 30-39 and the other two participants fell between 40-49. All four of the individuals that participated in this research identified as Caucasian so no other race/ethnicity was represented. All of the individuals were classified as being parents as a relationship to the child, three being mothers and one being a father, so no grandparents or guardians were represented. Two of the mother's were categorized as being married, one mother as single, and the father noted that he is now remarried but his child that was diagnosed with ASD was from his first marriage (See Table 1).

For demographics that were listed specifically to the child, all of the children were diagnosed between the ages of 18 months to two and half years. One mother has twins and noted that both were diagnosed at the age of 2.5. Two of the children began receiving services starting at the age of two, one at two and half, and the mother that has twins began services at the age of three (See Table 2).

The sample was established by the following criteria: 1.) participants were identified as caregivers (mothers, fathers, or primary adult caregivers) caring for children with an ASD diagnosis; 2.) the child had at least 6 months post diagnosis of ASD; 3.) participants must be currently caring for and having the child receive services; 4.) caregivers needed to be caring for the child with ASD within the home; 5.) and the child could be no older than 18 years of age. The target participant response rate for this study

was 6, however, only 4 respondents participated in this study out of the estimated 10 contacted.

Lower response rate may have been impacted by a number of reasons, one being the time constraints with when the interviews needed to be completed. The hour time commitment to complete the interview may have also impacted the response rate due to caregivers having to alter their schedules and take time away from other responsibilities such as their child/children, work, or other obligations. One potential participant had confirmed that they would participate in this study but then had to cancel due to unexpected family events. A small monetary gift (10.00 dollar coffee gift card) was provided to participants in hopes of generating a larger response rate as well.

Barriers and Challenges of Accessing Services

Participants described a difficult world involving concerns for wait times for service delivery after receiving a formal diagnosis, a lack of knowledge from professionals, concerns surrounding cost of care, complexities of working with other systems, and needing general empathy and understanding from others all of which were very similar themes found within the literature. It also became evident that further assistance with accessing social supportive services would be beneficial in order to help reduce parents feelings of being overwhelmed upon their child receiving an ASD diagnosis and interacting with different service agencies, such as the county. These responses sadly mirrored Renty & Roeyers (2005) review of literature that parents of children with autism found that both caregivers and professionals lacked necessary information involving available resources, social services, educational opportunities, and how services are assessed and organized. This lack of information and direction can

produce significant stress for caregivers and lead to further frustrations with mental health and medical professionals (Cullen & Barlow, 2002) which was also articulated by the participants in this study.

Three of the four respondents articulated concerns surrounding minimal experience or receiving up to date information provided by professionals (therapists, school teachers, etc.). A participant also spoke that her child's therapist had a large caseload, which may have impacted her ability to devote time to learning more about therapeutic strategies and what autism is in general. By the respondent noting this, it may be highlighting a larger systematic problem where professionals working within this field may be over worked and have limited time to bolster education involving therapy, resource navigation, and care coordination.

Having more general awareness about autism and empathy by professionals and the public was expressed by all four of the respondents within this study. This theme was found within the literature as well. Dymond, Gilson, & Myran's (2007) found that parents reported needing a general increase of awareness of autism due to perceptions that a lack of information impacts families and children with autism on a negative level in terms of school and community inclusion. Having a better understanding of the potential strengths and barriers to services caregivers encounter will hopefully allow for the development of improved service delivery, parental involvement, and a higher level of empathy by professionals and those within the community.

Surprisingly, when discussing supportive resources no respondents discussed engaging in respite services. The Minnesota Department of Human Services (2015) defines respite care to be a short-term service to caregivers for an individual to have a

brief break from their caretaker role. Although all the parents endorsed varying coping strategies involving managing life while caring for a child with autism, none mentioned utilizing respite services. Respondents may not have engaged in this resource for a number of reasons such as simply not needing respite care or using other avenues of support like family members. Another variable to consider could be that parents were unaware of respite services they could utilize. Preece (2009) study did however find that parents articulated that in order for respite services to be effective a number of varying factors must be in place and work effectively together. For example, these factors may range from appropriate staff knowledge and skills, therapeutic approaches used with children, and the physical environment, etc. It may be a possibility that parents within this study have not explored this option due to their own comfort level of placing their child in an environment that is unfamiliar and the above factors listed.

Family Support

Within the literature review conflicting results existed with the involvement of extended family members supporting parents caring for children with ASD. In Cullen & Barlow (2002) and O'Brien (2007) research, parents expressed that experiencing a lack of understanding from family and friends regarding their child's behaviors was difficult to manage. An additional study found the support of grandparents in assisting caregivers raising a child with autism was beneficial but they needed to acquire further education in order to be an active part in long-term care planning and advocacy (Hillman, 2007). These negative experiences and concerns were not represented within this study's respondents. Three of the four participants emphasized the importance of family (grandparents and aunts) acting as a strong source of support by helping them within the

home or assisting them with becoming connected to services. The participant's reactions aligned more with Trute's (2003) study that receiving support from family members is associated with reduced stress when caring for a child with a disability.

Need for a Key Worker

The theme of needing a key worker was shared by three of the four participants within this study and their responses were similar to previous literature. The respondents noted the overwhelming nature of not only navigating multiple service agencies but knowing what resources they would qualify for and what they should specifically use for their children. Respondents discussed the importance of having someone act as a single point of contact during the assessment process and continued family support for resource navigation and coordination. Dymond, Gilson, & Myran (2007) discovered that caregivers expressed being unaware of all the different service options and treatments that were available for children with ASD. They also found that parents stressed needing more information as to who to contact to establish services and where facilities were located. On a positive note, one participant within the study adamantly stated that she would not change anything involving the establishment and coordination of services for her son. This respondent received testing for her son within less than a week after a referral was placed by her primary care provider and services began after receiving the diagnosis. Although this was not a shared experience by the other participants within this study, hopefully this shows that service delivery to help caregivers access supportive services may be moving in the right direction.

It is important to note that a possible strength of this study involves attaining a greater understanding of the challenges and experiences of accessing supportive services

parents caring for children with ASD face within the Minneapolis and St. Paul metro area. Also, exploring what professionals have or have not been able to assist with supportive services and accessing resources will hopefully provide a wider lens of how those within the mental health and healthcare field can better serve families. Other findings in this study may support the need for a key worker to assist families and the role of social work to develop a more prominent stance within the ASD community.

Researcher Reaction

Although the researcher did not anticipate any of the participants to speak negatively of their children, the level of love, devotion, and initiative dedicated to supporting their children was extremely powerful to see. All of the respondents have essentially become experts surrounding resources and services for children with ASD due to not only receiving various forms of guidance (family members, social workers, primary care providers, etc.) but by their own will power as well. The level of time and effort spent by these parents to find the best care for their children while managing feelings of stress and being overwhelmed makes listening to their experiences even more of a privilege.

Limitations/ Recommendations for Future Research

This researcher did anticipate having a lower response rate, so the wider range of interviewing 6 to 10 participants was put in place. However, only four participants chose to participate, which was a surprise. A monetary incentive was also offered in hopes to generate a larger response number but this did not seem to be a major incentive for the participants. One parent even tried to give the gift back to the researcher stating that she was happy to give her time to the study and did not need the monetary incentive. The

researcher also changed the age requirement of the child parents were caring for and that are currently using services from 12 years of age to 18. This allowed for one more respondent to engage in the study. Also, the use of snowball sampling was used to recruit potential participants through the researcher's committee members, which may have impacted sample size. A future alternative that could potentially be beneficial to offer participants would be to conduct the interview online, such as using skype. By completing interviews online, it would eliminate travel time and lessen the amount of time commitment by potential participants. Another alternative to consider would be contacting specific agencies that serve families and or children managing autism. By reaching out to a more concentrated population of people, most likely experiencing similar situations, it would hopefully generate a larger sample size.

All of the respondents, three women and one man, identified as being Caucasian and no other races were represented. Having individuals of different races/ethnicities would benefit this research for a number of reasons. One reason being participants would be able to provide a unique lens into what accessing services for children with ASD would involve and if they encounter any varying barriers and challenges. This information could hopefully improve service delivery and determine if any particular gaps were experienced due to these differences. Perhaps contacting different organizations that support families of different cultures would yield more results in future research.

The location of where this study was conducted is also a limitation. Due to this research taking place in a Twin Cities metro area located in the Midwest, the respondents answers cannot necessarily be applied or represent those living in rural communities or in

other urban areas of the United States. The information gathered in this study can only represent Caucasian individuals and Twin Cities residents. A recommendation would be creating a larger study that would include rural and urban communities across the Midwest or potentially conducting an online nationwide study to capture a larger and more diverse population.

A final limitation for this study would be that self selection biases might exist among respondents. Meaning, the participants of this research were likely passionate about the topic of accessing supportive services, which may have contributed to them wanting to complete this study. However, individuals that may be overwhelmed with caring for their child with ASD or accessing supportive services were not as likely to be represented. Increasing the sample size by accessing a variety of populations would benefit future research and perhaps providing a monetary incentive that included more choices would assist in reaching a wider selection of people. For this study, a monetary incentive of a ten dollar coffee gift card was provided but perhaps offering the choice of a coffee, gasoline, or department store gift card may increase the chances of attaining a larger sample size.

Implications for Social Work

It becomes apparent that this research found multiple themes regarding caregiver's access of supportive services while caring for a child with autism. Major findings included types of services utilized, the need for direction, a multitude of challenges and barriers to accessing services, importance of family support, need for a key worker to assist with coordination and navigation of potential resources, and desiring understanding and empathy from professionals and the general public. As participants

provided information involving their experiences to accessing services, it became clear that every child with autism has unique needs and services that are provided need to be tailored to the child and family.

The above themes link to a plethora of elements held within the core values of social work, one being the significance of providing competent service and helping those in need. This value can be applied to working with families and children with autism. Although all of the participants noted working with a social worker at some point in time while accessing services, the theme of parents feeling overwhelmed before and after their child received their diagnosis and needing someone to act as a single point of contact to support families becomes evident by all four of the participants sharing these ideas. The themes of cost and interacting with other systems being complex, parent's having to rely on the internet to find information involving supportive services, and expressing significant reliance on family members to assist with resource navigation and general support all interconnect and display the need to create a position that's purpose is to serve and provide resources to families. Research has discussed different interpretations of the exact role of a key worker but the wide range of skills and experiences that social workers embody could help define and assist in developing this position.

If social workers can become a single point of contact during and after the diagnosis process for families, it would hopefully provide needed support, guidance, and potentially limit the amount of stress caregivers are encountering. Social workers could help advocate for agencies to embrace changes within their policies, practices, and help find funding for the development of a key worker or case coordinator. Looking at various mental health models, involving a key worker, that are utilized at other agencies would

provide further clarity as to what is needed to develop a successful position. Creating this key worker role would most likely be cost effective for agencies and would be better for the families being served.

All four participants within this study identified the need for professionals to be more empathetic, have a greater understanding of appropriate resources to recommend to families, and to develop a greater awareness of potential challenges families caring for children with ASD may face. Perhaps creating an advisory board between practitioners/ staff at various agencies and families caring for children with ASD could create regular contact while minimizing parent's concerns. Staff would have more available time to become attuned with family's experiences, key concerns, and questions regarding accessing resources and service delivery as well. Implementing regular staff meetings would also assist with this process of attunement and empathy. Having scheduled time set aside for staff to meet could provide more opportunities to complete trainings and practice validation, open-ended questioning, reflective listening, and summarizing parent concerns. These meetings would not only be educational but would foster better communication skills among individuals being served and other colleagues within the agency. Encouraging families to complete an exit interview with agencies that have been assisting with supportive services, once assistance would be formally ending, would also be helpful. Having an agency take the time to schedule an exit interview displays empathy and interest regarding caregiver's perspectives. This would also allow for parents to discuss what has or has not worked while accessing services and if any changes should be implemented to make accessing services easier and more successful. Recognizing that gaps within service provision and access of resources still exists, the

social work profession needs to develop a louder voice of support within the ASD community and advocate for the needs of these families.

An additional theme of needing empathy and involvement from others was also expressed by all four participants at a community level as well. Social workers working within this population could better support families by developing further expertise within the field, such as attending educational courses and continually striving to learn and understand the latest research and information involving ASD. This knowledge could then be shared with other professionals in the field and the general public to create an environment that fosters understanding and empathy for families.

Social workers could also advocate to work more collaboratively with other interdisciplinary teams with resource navigation and service coordination to ensure families receive appropriate support and guidance to best help their child. As expressed by one participant, if social workers supporting families carry a large case load and may be overworked, this concern would need to be addressed on a more systematic level and adjustments would need to occur to better support all of those involved.

Conclusion

The purpose of this study was to explore parent's strengths, challenges, and experiences of accessing supportive services when caring for a child with ASD. Previous research studies have discovered gaps regarding resource supportive services, navigation, and formal support systems for parents when seeking additional care for their child with ASD and gaps were found within this study as well. Attaining a better understanding of what these experiences involve, especially the challenges and barriers

caregivers face, will allow professionals working within the field to better recognize and advocate for the most effective treatment approaches and needed services for families. Parents within this study articulated challenges ranging from cost and complexities of interacting with other care systems, navigation of services, and lack of knowledge and service delivery from professionals, and the need for general awareness and empathy by professionals and the general public to name a few. Acquiring this information and developing a clearer perspective as to what works with supporting families and what gaps still exist, not only contributes to implicating positive change within the larger system of medical and mental health care but how to best support the unique needs and challenges of each family caring for a child with autism. One mother provided a powerful response describing access to supportive services, delivery of care coordination/ resources, and empathy and supportive direction from professionals can create an environment that fosters growth not only for children but their caregivers. She spoke highly of the support she received from professionals and shared

(...) they taught me how to talk to my son. When he was 2 he didn't speak. And they taught me to connect with him and help with that relationship. So, it was beyond any kind of schooling or helping him with his motor skills. It was beyond that. It was helping a mother have a relationship with her son (Transcript 4, Page 7, Lines 17-20).

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Appendix A

Recruitment flyer

**PARENT'S EXPERIENCES
ACCESSING SUPPORTIVE SERVICES FOR
CHILDREN WITH
AUTISM SPECTRUM DISORDER**

**Graduate Social Work Student
Seeking Parents/Caregivers
Of Children With Autism**

Graduate student looking to interview parents/caregivers caring for children diagnosed with autism to learn about their experiences with accessing supportive services.

- Children must be 18 years of age or younger and have had diagnosis for 6+ months.
- Interviews will take no more than one hour of time, will be conducted face to face, and will be voice recorded.
- All participants will receive a \$10.00 Caribou Coffee gift card.

All acquired information will be compiled and presented in the form of a research presentation and paper. **Any identifying information will remain 100% confidential.**

Appendix B

Qualitative Interview Questions

**Accessing Supportive Services:
Parents Caring for Children with Autism Spectrum Disorder**

Instructions: *Please fill out all questions thoroughly and to the best of your ability.*

Demographics specific to Parent and/or Caregiver:**1. Gender:**

- Male (a)
 Female (b)
 Other (c)
 Prefer Not to Answer (d)

2. Current Age:

- 20-29
 30-39
 40-49
 50-59
 60-69
 70-79

3. Race/Ethnicity:

- African American (a)
 Caucasian/ White (b)
 Hispanic/ Latino (c)
 Asian (d)
 Native American (e)
 Native Hawaiian or Pacific Islander (f)
 More than 2

_____ races/other: _____ (g)

4. Relationship to Child:

- Mother (a)
 Father (b)
 Grandparent (c)
 Guardian (d)
 Other (e)

5. Relationship Status:

- Single (a)
 Married (b)
 Divorced (c)

____ Separated (d)
____ Widowed (e)

Demographics specific to Child with ASD:

6. **Age when diagnosis was given:**
____ Years Old

7. **Age when receiving services began:**
____ Years Old

Instructions: *Please, review and write down key ideas for the following questions before the interview. Please, bring this form to the interview.*

- 1.) What services are you currently using? What have you used in the past?

- 2.) What social supportive service needs, if any, have you identified as necessary to assist with caring for your child? How have they changed over time?

- 3.) Describe some of your experiences regarding acquiring supportive services for your child.
 - a. What has worked and/or been successful?
 - b. What challenges/barriers have you faced on a personal level?

- 4.) What outside service providers have you accessed, if any? (ie, speech/physical therapy, dietary/ nutritional support) If not, what outside service providers do you feel would be beneficial to you and your family?

- 5.) What recommendations do you have, if any, to improve services for children with ASD on an individual, agency, and community level?
 - a. Availability
 - b. Navigation/coordination of services
 - c. In an ideal world, what would this look like?

- 6.) Who has helped you with accessing supportive services and/or resources professionally and personally? What qualities/actions of the person was appreciated?

- 7.) Are there any family or cultural impacts that have influenced your level of engagement with social supportive services? If so, please describe and do you have any recommendations for service providers?

- 8.) What recommendations would you have for professionals?

- 9.) Is there any pertinent information that would be beneficial for this study that you would like to share?

Appendix C

Research Study Consent Form

Accessing Supportive Services: Parents Caring for Children with Autism Spectrum Disorder **INFORMATION AND CONSENT FORM**

Introduction:

You are invited to participate in a research study investigating the strengths, challenges, and experiences of accessing supportive services of parents caring for children with Autism Spectrum Disorder (ASD). This study is being conducted by Karen Keegan, a graduate student at St. Catherine University under the supervision of Michael Chovanec, a faculty member in the School of Social Work at Saint Catherine University. You were selected as a possible participant in this research because of your engagement in supportive services for your child with an ASD diagnosis. Please read this form and ask questions before you agree to be in the study.

Background Information:

The purpose of this study is to attain insight regarding the strengths, challenges, and experiences of accessing supportive services of parents caring for children with ASD. Approximately 6-10 people are expected to participate in this research.

Procedures:

If you decide to participate in this study, you will be asked to sign and date this consent form. We will meet at one time at your convenience and the meeting will take approximately one hour. I will be asking you to answer approximately 12 interview questions. There are no right or wrong answers. The interviews will be recorded with the use of the *Super Note* voice recording application in order to transcribe the data, which will be used for further data analysis. Your name will not be recorded or used at any time within this research study. I am simply interested in hearing and learning about your experiences.

Risks and Benefits of being in the study:

Potential risks you may face from participating within this research involve time constraints, negative feedback involving your agency, and the emotional content of the questions asked. In terms of time constraints, you may experience difficulties with planning around your family's schedule or leaving time for self-care. In order to address this concern, the researcher will provide multiple times and agree to meet at neutral locations best for you. The severity and likelihood of this risk to occur is minimal. The possibility of you being linked to negative feedback shared about a specific service provider, which could affect the relationship of you with the agency, is also a potential risk. To address this risk, all responses will remain confidential and neutral of any identifying information. The researcher will also be using quotes not identified by your name or service provider. Also, all data will be kept on the researcher's password

protected iPad and computer. The severity and likelihood of this risk to occur is minimal. Due to the sensitive nature of some of the research questions asking to reflect on some potential challenges you may have faced while caring for a child with ASD, the possibility of encountering varying emotions such as stress, loss, and discomfort may occur. The researcher will remind you that you do not have to respond to any questions that cause you to experience discomfort. In order to address these potential feelings, the researcher will offer to debrief with you after the interview and provide additional resources and contacts. The potential severity and likelihood of this risk to occur is minimal.

There are no direct benefits to you for participating in this study, however, your involvement and the information gained from this process will add value to current research surrounding accessing supportive services of parents caring for children with ASD.

Compensation:

Participants will receive one \$10.00 coffee shop gift card at the end of the interview. This gift card will be given whether participants choose to skip interview questions or end the interview at an earlier time.

Confidentiality:

Any information obtained in connection with this research study will be kept confidential. In any written reports or publications, you will not be identifiable. I will be using quotes that not will be identified by name, your child's name, or the agency in which you are currently utilizing services. However, I cannot ensure complete anonymity that someone close to you may not be able to recognize a quote that you may use often.

The *Super Note* recording application that will be used for the interview does not connect any data to the Internet and all data will remain on the researcher's iPad. Once the transcription of the interview is completed, data will be immediately deleted from the iPad. The iPad is password protected and only the researcher will be able to access the audio recording. No identifying information will be used throughout the recording.

Transcripts of the provided interviews will then be saved on a USB drive and located in a locked bin in the possession of the researcher's home. Only my research advisor and I will have access to these records as I work on this project. Data analysis will be completed by May 16th, 2016. I will then destroy all original reports, recordings, and any identifying information that can be linked back to you. No identifying information or names will be used within the final works of the research presentation.

Voluntary nature of the study:

Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with Saint Catherine University in any way. Also, your decision whether or not to participate will not affect your relationship with this researcher or with your service providers. If you decide to participate, you are free to stop at any time without affecting these relationships. A \$10.00 coffee shop gift

card will be awarded as compensation for your time. Should you decide to withdraw your participation at any time you may do so without penalty. Compensation will still be given and data collected will not be used.

Contacts and questions:

If you have any questions, please feel free to contact me, Karen Keegan, at 715-210-0504 or keeg1922@stthomas.edu. You may ask questions now, or if you have any additional questions later, the faculty advisor, Michael Chovanec at 651-690-8722 or mgchovanec@stkate.edu, will be happy to answer them. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739 or jsschmitt@stkate.edu.

You may keep a copy of this form for your records.

Statement of Consent:

You are making a decision whether or not to participate. Your signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that you may withdraw from the study.

I consent to participate in the study and agree to be audiotaped.

Signature of Participant

Date

Signature of Researcher

Date

Appendix D

Additional Resources and Contacts for Participants

1. The Arc, Autism Now. <http://autismnow.org/>
2. Autism Support Group (Stillwater, MN). The support group is for parents of children with ASD. For more information, call Arc at 952-920-0855.
3. Autism Society of Minnesota (AuSM). <http://www.ausm.org/>