2012

Raising Children on the Autism Spectrum: Parental Needs

Kathleen A. Ryan

Raising Children on the Autism Spectrum: Parental Needs

by

Kathleen Ryan

B.S., Northeastern University, 2005
M.S., Antioch University New England, 2009

DISSERTATION

Submitted in partial fulfillment of the requirement
for the degree of Doctor in Psychology in the Department of
Clinical Psychology of Antioch University New England, 2012

Keene, New Hampshire

Department of Clinical Psychology

DISSERTATION COMMITTEE PAGE

The undersigned have examined the dissertation entitled:

RAISING CHILDREN ON THE AUTISM SPECTRUM: PARENTAL NEEDS

presented on May 21, 2012

by

Kathleen Ryan

Candidate for the degree of Doctor of Psychology

and hereby certify that it is accepted*.

Dissertation Committee Chairperson:
Kathi A. Borden, PhD

Dissertation Committee members:
William Slammon, PhD
Cassie Yackley, PsyD

Accepted by the
Department of Clinical Psychology Chairperson

Kathi A. Borden, PhD

on 5/21/12

* Signatures are on file with the Registrar's Office at Antioch University New England.

Dedication

To all the families that allowed me to understand of piece of their world! “If you know one child with autism, you know one child with autism.” Every person with an ASD is so drastically different and I am thankful to have learned more from the generous parents who took precious time to help educate me and influenced this study.

Acknowledgments

There are many people who I want to acknowledge for their support throughout my experience at Antioch. I never would have been able to finish my dissertation or doctorate degree without the guidance of my committee members, the encouragement from my friends, and the love and support from my family.

I gratefully and sincerely thank my advisor, Kathi Borden, for her wisdom, guidance, and support throughout my time at Antioch. Additional thanks are due to my entire committee, Kathi Borden, Cassie Yackley, and Bill Slammon, for their commitment to me and my research despite their many other academic and professional commitments. Not only am I grateful for the hard work my committee has dedicated to my dissertation, but also for the supervision, encouragement, understanding, and patience you have all shown me, which has helped me grow into the person I am today.

There were many people who were vital in supporting and guiding my research. I thank Sophia Zavrou, PsyD, for her generosity, humor, motivation, and support. I want to express gratitude to my uncle John for his willingness to help, his copious suggestions, and guidance with my research. I thank my father for being my personal editor and for all of his long nights and busy days of trying to convert all of my research into a functional program. Without his assistance, it would have been next to impossible to finish this dissertation.

I acknowledge my family and friends who have been supportive and understanding for the past 6 years and thank mother, father, and brother who have always been the best support system one could ask for. You have inspired me, believed in me, and loved me, encouraging sense of wonder, strength, and drive. I also am grateful for my grandmothers, both of whom are 94 years-old, and who continue to remind me that anything is possible, to follow my dreams, and to shoot for the moon. I would like to thank my future in-laws, Gail, Steve, Steph, and Pete, for providing us a home, supporting us from coast to coast, listening to me complain, and believing in me. Finally, and most importantly, I would like to thank my fiancé, Stephen. Your presence in my life has taught me how to be balanced. You have stood by me from the beginning of this long endeavor always willing to cheer me up, make me laugh, motivate me, and love me. I am grateful for your ability to make me stay positive and to give me a hug when I am in a vile mood. I am thankful for my large support system and all of the devotion, support, and advice you have all given me.

Table of Contents

List of Tables

Abstract

The rates of Autism Spectrum Disorder (ASD) diagnoses have increased rapidly in the past few years. This increase is affecting many American families but the current research literature fails to evaluate the needs of parents who are raising children on the spectrum. Parents of children with Autism experience grief, denial, anger, guilt, depression, isolation, stress, financial difficulties, and marital struggles. The author proposed a mixed methods study to determine services received and satisfaction with those services; level of parental interest in specialized services; how well parents' needs had been met with existing services; and what services parents of autistic children find they need the most. To answer these questions, parents of children on the autism spectrum were asked to complete a questionnaire about their interests, needs and the usefulness of existing services.

Raising Children on the Autism Spectrum: Parental Needs

The following literature review will discuss the characteristics and prevalence of Autism Spectrum Disorder (ASD). It will include the effects that autism has on family members, including grief and stress. The review will explore how parent involvement in the child's treatment is beneficial to the prognosis of a child. Finally, it will examine the range of emotional and cognitive (e.g., psychoeducation, parent skills training) support services currently available to parents, and will argue for the necessity to learn what parents perceive they need.

Characteristics and Diagnosis of Autism Spectrum Disorder

According to the American Psychiatric Association (2000), Autism Spectrum Disorder is also known as Pervasive Developmental Disorders (PDD). In this paper the term Pervasive Developmental Disorder (PDD) and Autism Spectrum Disorder (ASD) are used interchangeably. These terms will be used to represent the five Pervasive Developmental Disorders the Fourth Edition Text Revision of the Diagnostic and Statistical Manuel of Mental Disorders (4th ed., text rev.; *DSM–IV–TR*; American Psychiatric Association, 2000) includes under the Autism Spectrum: Autistic Disorder, Asperger's Disorder, Rett's disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder- Not Otherwise Specified (NOS; See Appendix A). Autism Disorder, Asperger's Disorder, and Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS) are the three most common of the ASDs.

"For the diagnosis of Autism, at least six criteria must be exhibited, including at least two criteria relating to social abnormalities and one each relating to impaired communication and range of interests and activities" (Volkmar & Klin, 2005, p. 21). There must be a delay in social interactions, language used in social communication, or symbolic play by the age of three (See Appendix A; *DSM–IV–TR*; American Psychiatric Association, 2000). Asperger's Disorder has been viewed in varying ways ranging from a higher functioning Autism to a totally different "neuropsychologic" disorder (Volkmar & Klin, 2005, p. 24). The major distinction between Asperger's Disorder and Autism is "the basis of a relative preservation of linguistic and cognitive capacities in the first three years of life" (See Appendix A; Klin, Mcpartland, & Volkmar, 2005, p. 88). Therefore there is difficulty in socialization but no delay in spoken and receptive language or cognition. According to Klin et al. some features used to help distinguish between Autism and Asperger's Disorder but, that are not diagnostic criteria are the child's interest in making friends and language used. Children with Autism tend to isolate while those with Asperger's Disorder frequently want friendships, but lack the skills to engage appropriately. Although language difficulties are not part of the diagnostic criteria for Asperger's disorder, language is often more precocious or pragmatically difficult for kids with Asperger's Disorder compared to delayed or stereotyped for kids with Autism (p. 96). Those with deficits in social learning and reciprocity and other deficits similar to Autism and Asperger's Disorder but the severity of the deficits do not meet criteria for a specific Pervasive Developmental Disorder, are diagnosed with PDD-NOS (See Appendix A; *DSM–IV–TR*; American Psychiatric Association, 2000).

Although each individual diagnosed with an ASD presents with the specific characteristics mentioned earlier, the manifestation of these features can differ drastically and vary in severity for each unique individual (Cole & Arndt, 1998; Exkorn, 2005; McConachie, Phil, & Diggle, 2007; Volkmar & Klin, 2005). There is major variation with in each of the diagnosis, Autism, Asperger's Disorder, and PDD-NOS (Klin et al., 2005). Diagnoses under the ASD umbrella can range from a child with no peer relationships and who follows a rigid routine, to a nonverbal, self-injurious, highly aggressive child with no social interactional skills (4th ed., text rev.; *DSM–IV–TR*; American Psychiatric Association, 2000; Cole & Arndt, 1998; Exkorn, 2005; McConachie et al., 2007; Volkmar & Klin, 2005).

Impaired social interactions, difficulty with communication, lack of imagination, and rigid and repetitive behaviors or interests are prominent characteristics of ASDs (Brown et al., 2006; Exkorn, 2005; McConachie et al., 2007; Volkmar & Klin, 2005). Other common characteristics include self-stimulating behavior, sensory atypicality, and a lack of empathic awareness (Cole & Arndt, 1998; Exkorn, 2005, Volkmar & Klin, 2005). Those diagnosed with Autism disorder frequently have more intense difficulties and deficits in cognitive abilities compared to typically developing children (Cole & Arndt, 1998; Exkorn, 2005; McConachie et al., 2007; Volkmar & Klin, 2005).

ASD affects social interactions and communications. This may be portrayed through poor eye contact, misunderstanding of or inability to use body language communication, limited facial expressions, lack of socio-emotional reciprocity, or restricted shared interests (Cole & Arndt, 1998; Exkorn, 2005; McConachie, Phil, & Diggle, 2007; Volkmar & Klin, 2005). Language and communication issues present a major struggle for many children with an ASD which often impacts their caregivers. A lack of general verbal ability, echolalia, insufficient communication skills, conversation initiation and maintenance deficits, and idiosyncratic language are common aspects of ASDs (Cole & Arndt, 1998; Exkorn, 2005; McConachie et al., 2007; Volkmar & Klin, 2005). Some behaviors and activities can affect daily living skills and interactions with others. Restricted, routine, or repetitive behaviors are seen frequently in children with an ASD. If interrupted, sometimes these behaviors or the need to complete such routines can lead to aggression, self-injury, or behavior difficult to manage (Cole & Arndt, 1998; Exkorn, 2005; McConachie et al., 2007; Volkmar & Klin, 2005).

Multiple psychological and medical disorders commonly are comorbid with an ASD. Seizure disorder, epilepsy, fragile X, and tuberous sclerosis are medical disorders that have been associated with ASDs (Volkmar & Klin, 2005). Psychological disorders often identified as comorbid with ASDs include Anxiety disorders, Obsessive-Compulsive disorder (OCD), Depression, Conduct disorder, Tic disorders, Attention Deficit Hyperactivity disorder (ADHD), Mental Retardation, psychotic disorders, and learning disorders (American Psychiatric Association, 2000; Volkmar & Klin, 2005). The Joshi et al. (2010) study compared comorbidity of children with an ASD to those without an ASD referred to the same psychopharmacological program. They found that children with an ASD have significantly higher rates of language disorders, anxiety disorders, encopresis, psychosis, OCD, behavior disorders, and depression compared to those without an ASD. “Anxiety conditions are known to be more common in ASD populations with higher intellectual and verbal capacity and with milder forms of ASD” (i.e., PDD-NOS; Joshi et al., 2010, p. 1367). It was found that children with milder forms of ASD frequently obtain psychiatric services due to attention received by comorbid conditions opposed to ASD symptoms. Therefore it is highly important that children are being identified with an ASD when referred to treatment and that treatment is focusing on both the ASD and the comorbid conditions (Joshi et al., 2010, p. 1370)

The etiology of ASD presently remains unknown and unidentifiable through medical tests or biological markers. Diagnosis is based solely on behavior (CDC, 2010; Cole & Arndt, 1998). Although ASD is conceptualized as on a spectrum of severity, the DSM-IV-TR does not quantify the level of severity (Coplan, 2003). Children diagnosed with an ASD can vary drastically in development, functioning, and characteristics (Cole & Arndt, 1998; Exkorn, 2005;

McConachie et al., 2007). The unknown etiology of autism, combined with varying severity, makes it difficult to predict outcome.

In America, the rates of autism have increased progressively over the past few decades. In 2002, 1 in 166 children where diagnosed with Autism (Kozub, 2008). In 2007 the prevalence of autism increased to 1 in 150 children (Kozub, 2008). "CDC's most recent data show that between about 1 in 80 and 1 in 240, with an average of 1 in 110, children in the United States have an ASD" (Center for Disease Control [CDC], 2010, para. 1). The variability in number of children diagnosed with an ASD differed between states. Autism is more common in boys than girls. Boys are 3 to 5 times more likely to have autism than girls, but there is no significant difference among races, geographical locations, or socioeconomic levels (CDC, 2010; Cole & Arndt, 1998). ASD has been found to run in families, with an increased risk of cognitive and language disorders in siblings of autistic children (APA, 2001).

Formerly, Autism was believed to be caused by a cold, detached mother who did not show maternal affection, and forced mental isolation (Sicile-Kira, 2004, p. 8). The "refrigerator mother" theory has been discredited in professional practice. However, among many professionals and the general public, there continues to be a "blame the parent" aspect related to having a child on the spectrum (Sicile-Kira, 2004). The unknown etiology, the increased rate of diagnosis, the varying severity of the disorder, and the lack of accessible resources produce stress within families affected by autism (Bebko, Konstantareas, & Springer, 1987; Cole & Arndt, 1998; Exkorn, 2005; Honey, Hastings, & McConachie, 2005; Linares-Gonzalez, 2006; Long, 2005; McConachie et al., 2007; Rogers, 2008).

The Effects of Autism on Parents and the Family

ASD affects the whole family. The needs of a child with an ASD can be very demanding and can cause great stress on the family unit. Parents may experience loss, denial, anger, guilt, depression, stress, financial difficulty, and marital discord. Siblings' lives change due to constraints placed upon their parents and the attention dedicated to their sibling with an ASD. An increased amount of stress may be placed upon the family due to behavioral issues, communication difficulties, increased parental responsibilities, time constraints, and increased familial strain (Bebko et al., 1987; Cole & Arndt, 1998; Exkorn, 2005; Honey et al., 2005; Kroodsma, 2007; Linares-Gonzalez, 2006; Long; 2005; McConachie et al., 2007.; Rogers, 2008). A diagnosis of autism can have a tremendous effect on a family.

Grief. When parents are presented with the diagnosis of ASD, their plans, dreams, and expectations for their child and family life change, often dramatically. Parents have to grieve the loss of these expectations and the idea of the "normal" child (Rarity, 2007; Rubens, 2009). Many of the child's milestones will not fit the normal expectations. "For example, the parents imagine their child's first holidays, the first day of school, teaching them [*sic*] how to drive on his or her 16th birthday, graduation from college, and what the wedding celebration will be like" (Rubens, 2009, p. 12). Fathers indicated feeling the loss of being able to play sports or enjoy athletics with their son (Long, 2005). Grief may be ongoing or episodic, as when these milestones are reached, a parent may experience loss or grief. According to Rarity, families that suffer a loss due to chronic illness, disability, or an accident experience nonfinite loss and grief. "The vital distinction between grief experienced from a physical loss and the 'loss of the perfect child' is the difference in the reoccurrence with time" (Rubens, 2009, p. 12). A family with a child on the autism spectrum will experience grief and loss at various stages throughout the child's life.

The Kübler-Ross and Kessler framework of grief appears to capture the spectrum of reactions of parents mentioned in the ASD literature, and therefore was used to look at a parent's experience of raising a child with an ASD. According to Kübler-Ross and Kessler (2005), individuals may undergo five different stages of grief. "The five stages—denial, anger, bargaining, depression, and acceptance—are a part of the framework that makes up our learning to live with the one we lost" (p. 7). Kübler-Ross and Kessler (2005) do not believe that every individual experiences every stage, nor are the stages linear. Families impacted by ASD initially may undergo the stages of grief when their child is diagnosed, but when triggered by an experience or during developmental milestones, parents may revert to different stages of grief (Rarity, 2007). The family experiences grief in varying cycles for differing amounts of time and this continues throughout the child's life.

A qualitative study by Collings (2008) examined parental grief in response to an acquired brain injury (ABI) in their child. Interviews were conducted with five parents to understand their experience of grief, the nonfinite nature of their loss, and the applicability of the traditional stage and task models of grief to their experience. Collings found that four of the five parents experienced acute grief which lessened, but was reoccurring and transitory. One participant reported ongoing grief for 26 years, but none reported the grief to follow the linear or time-restriction traditional grief models follow.

Denial and shock are qualities of grief that individuals frequently experience. Denial and shock help individuals deal with the overwhelming feelings and the part of life for which they had not prepared (Kübler-Ross & Kessler, 2005). When given the diagnosis of autism, families can experience denial in various fashions. Families may deny the diagnosis, the seriousness of the diagnosis, or that signs existed prior to diagnosis (Sicile-Kira, 2004). If the diagnosis is accepted, parents often deny the feelings or refuse to acknowledge their new reality (Rarity, 2007; Rubens, 2009). “I didn’t go through any denial of her condition. I went through a lot of denial of the fact that I was feeling anything about it. I didn’t let myself feel anything about it for the first year” (Kozub, 2008 p. 99). Denial can be used as a defense to help parents deal with their overwhelming change in reality, and allows the family to survive by limiting the emotions to a tolerable level (Kübler-Ross & Kessler, 2005; Rubens, 2009).

Parents may experience denial at the time of the diagnosis as well as at varying points throughout the child’s life (Rubens, 2009). When feelings become overpowering, parents may become numb or detached from reality, using denial to cope. At varying developmental milestones, parents may experience denial that they will not have the typical experience with their child. Different stages of the illness bring new challenges, and changes within the family dynamics present new hardships, allowing numerous opportunities for denial and shock to resurface. As the numbness and shock start to wear off and the family starts to understand the effects autism is having on the family, feelings of anger may begin to occur (Rubens, 2009).

Anger, another element of grief, is a common experience of family members of autistic children. Anger arises from feelings of pain, humiliation, self-doubt, disappointment, and fear (Kübler-Ross & Kessler, 2005; Rubens, 2009). The realization that one’s child is different yields a lot of pain and is often expressed with anger and blame towards others or even the disability (Rubens, 2009; Sicile-Kira, 2004). According to Exkorn (2005),

> I was furious and distressed about the diagnosis, and my anger seemed to extend to every aspect of my life. I was angry at myself, my husband, even at our poor defenseless son. I was angry that I’d have to give up my work. I resented all the mothers (many of whom

> were my friends) for having children who talked and played, while my own son was silent and passive: Why me and not them? (p. 181)

Professionals, siblings, grandparents, spouses, and God often are blamed or become the target for the anger of a family member (Kübler-Ross & Kessler, 2005; Rubens, 2009; Sicile-Kira, 2004). According to Kübler-Ross and Kessler, “anger does not have to be logical or valid" (p. 11). Anger is used to protect individuals from their deeper emotions until those emotions are bearable.

Throughout the child’s life a parent may attempt to bargain, which is another component of grief. During bargaining, parents may attempt to bargain with God, themselves, treatment providers, the disability, or the pain they are feeling (Kübler-Ross & Kessler, 2005; Rubens, 2009). Negotiations occur in hopes of a different outcome or sometimes to help regain control over one’s emotional state (Kübler-Ross & Kessler, 2005). Parents may bargain with God to help cure their child if they become better people. This bargain distracts the parents from the mental anguish they presently are feeling from the helplessness, allowing them to regain control.

The bargaining element of grief is often associated with guilt (Kübler-Ross & Kessler, 2005; Rubens, 2009). Bargaining consists of “if only I” or “What if I” which exaggerates one’s faults, and implies that the impairment was a result of something they did wrong (Johnson, O’Reilly, & Vostanis, 2006; Kübler-Ross & Kessler, 2005). Many parents feel as though they have caused this disorder somehow, and therefore feel immense guilt (Johnson et al., 2006; Rubens, 2009). Johnson et al. found “… for some parents, the development of guilt feelings is not entirely an internal process but the result of accepting others’ accusations and blame.” The feeling of guilt may increase the need to bargain, causing a cyclical reaction. The failed negotiations and bargains often leave individuals feeling empty. Kuhn and Carter (2006) found that feelings of guilt often interfered with parenting.

The anger, guilt, and futility of bargaining family members experience within the grieving process may contribute to the depression stage of grief, or parents may just experience the depression component of grief separate from the other phases. Depression can develop when the anger, pain, and guilt are turned inward. Feelings of resignation and despair overcome the individual. Depression, experienced when an individual loses a loved one, can feel as though it is going to last forever (Kübler-Ross & Kessler, 2005). Parents of autistic children may experience depression with the loss of their dream or perfect child following diagnosis, but they may also experience it throughout the child's life. The family does not experience one loss but several over time, leaving parents to feel that the depression will last forever (Rubens, 2009).

Many parents feel rejection, which results in isolation from friends and family. Families start to avoid social situations and friends who have children without a disability (Bromley, Hare, Davison, & Emerson, 2004; Johnson et al., 2006; Kozub, 2008; Long, 2005; Rubens, 2009; Siklos & Kerns, 2006). Parents might distance themselves from the other spouse or even reject their own needs (Bromley et al., 2004; Johnson et al., 2006; Rubens, 2009; Siklos & Kerns, 2006). Feelings of helplessness and low self-efficacy often decrease their satisfaction with being a parent and inevitably interfere with their ability to parent (Johnson et al., 2006; Kaminsky & Dewey, 2002; Sofronoff & Farbotko, 2002).

Our society does not accept depression after a loss, and expects the afflicted to fix the problem. "But in grief, depression is a way for nature to keep us protected by shutting down the nervous system so that we can adapt to something we feel we cannot handle" (Kübler-Ross & Kessler, 2005, p. 21). Depression serves as a protective factor and is an essential step toward healing. Parents often have a “lack of validation of their loss and consequent lack of permission to grieve” (Collings, 2008, p. 1512). Instead of supporting, recognizing, or understanding a parent’s sense of loss, society attempts to force parents through this stage, reducing support and inevitably rejecting or isolating the parents further (Collings, 2008; Johnson et al., 2006).

Acceptance, another facet of grief, occurs when family members acknowledge the new reality they are faced with and develop a new perspective on their life (Rarity, 2007). “People in this phase of grief cycle begin to accept that they are both the person before the diagnosis and the person after the diagnosis” (Rarity, 2007, p. 45). In other words they accept that some good has come out of the change and that they are the same person, but have adopted a new perspective on life. During acceptance an individual experiences personal growth and is able to appreciate the positives of the disability (Rubens, 2009). In this stage, parents may start to reconnect with their friends and family, experience social events, implement daily routines, help others, and adapt for their future (Rarity, 2007; Rubens, 2009).

According to Kübler-Ross and Kessler (2005), a grieving individual constantly feels denial, anger, and bargaining, which may lead to depression, but with bits and pieces of acceptance along the way (p. 19). These stages do not happen in any particular order and they do not have to last for a long period of time. “[People] forget that the stages are responses to feelings that can last for minutes or hours as we flip in and out of one and then another” (Kübler-Ross & Kessler, 2005, p. 18). Parents of children with disabilities experience nonfinite grief. Throughout their child’s life, they will continuously revisit various stages of grief.

Rarity’s (2007) study looked at non-finite grief in 32 primary caregivers of children with an ASD. The parents completed the Anticipatory Grief Scale and the Impact of Events Scale (IES) through which she found that the sample reported experiencing grief and moderate levels of distress as a result of having a child with an ASD. There was no significant difference in the level of grief and the amount of time since the diagnosis, but the study did find that mothers reported stress, depression, and anxiety more than fathers. According to Rarity,

> This study also found that there was a statistically significant difference in the level of grief reported by families that had received counseling since the diagnosis and those that had not. Families in this sample that had gone to counseling reported lower levels of grief than families that had not received counseling. (p. 73)

This study demonstrates the importance of obtaining counseling services for parents and the need to support parents with the grief and distress they are experiencing.

Stress. Raising children can be a stressful endeavor. Children require parental responsibility, time, money, and resources. Families with children on the autism spectrum have been found to have more overall stress than parents of children with other chronic illnesses or typically developing children (Benson & Karlof, 2009; Davies, 2009; Erguner-Tekinalp & Akkok, 2004; Honey et al., 2005; Marcus, Kunce, & Schopler, 2005; Rarity, 2007;Rubens, 2009; White & Hastings, 2004). Parents, teachers, and professionals reported a strain placed on their own mental health due to the amount of stress involved in caring for a child with autism (Linares-Gonzalez, 2006, p. 27). According to Rogers (2008), symptoms of autism are a positive predictor of stress. Parents of children with autism commonly have increased stress due to their child's behavior problems; social, emotional, and cognitive impairments; and needs for care and advocacy (Kroodsma, 2007; Long, 2005). Parents face behavioral issues, communication difficulties, increased responsibilities, time constraints, financial burdens, marital discord, effects on siblings, a need for social supports, and a lack of accessible resources (Bebko et al., 1987;

Benson & Karlof, 2009; Erguner-Tekinalp & Akkok, 2004; Honey et al., 2005; Linares-Gonzalez, 2006; Murphy, Christian, Caplin, & Young, 2006; Rogers, 2008; Vogt, 2007).

Parents experience significant stress due to their child's behavioral issues (Bebko et al., 1987; Benson & Karlof, 2009; Bromley et al., 2004; Honey et al., 2005; Johnson et al., 2006; Kroodsma, 2007; Long, 2005; Rogers, 2008). Sharpley, Bitsika, & Efremidis (1997) found "Parents of a child with autism showed elevated levels of anxiety and depression when compared with the normal population, with the most common source of stress arising from parenting being that of their child's behavioral problems" (p. 25). Parent's stress often correlates with the level of behavioral issues (Bromley et al., 2004). The more significant the behavioral issues or adaptive skills deficits, the more stress experienced by the parents (Honey et al., 2005; Marcus et al., 2005; Rogers, 2008; White & Hastings, 2004).

Siklos and Kerns (2006) found that parents who indicated more behavioral symptoms on the Child Characteristics Questionnaire reported increased need correlated with increased behaviors (p. 928). Aggression, self-injurious behavior, tantrums, self-stimulating behavior, hyperirritability, pacing, constant vocalization, rigidity, and compulsive behavior increase stress within the family (Marcus et al., 2005; Rogers, 2008). Parents feel the pressure to plan carefully to avoid behavioral issues from occurring or escalating. Boys are more likely than girls to have autism, and parents of boys are likely to present with higher levels of stress. This could be due to boys' increased exhibition of externalizing behavior as compared with parents of female children with an ASD (Rogers, 2008). Participation in particular activities becomes daunting and stressful due to behavioral issues (Bebko et al., 1987; Marcus et al., 2005).

According to Siklos & Kerns (2006), "many of these parents deal with very difficult behaviors, have no way of functionally communicating with their child, and are not able to interact socially with their child" (p. 932). Language dysfunction, cognitive inconsistency, social impairment, and emotional ineptness are considerable stressors for parents (Bebko et al., 1987). Parents of autistic children have the burden of not knowing what to expect from the disability. As a spectrum disorder, each individual varies drastically in symptomatology and severity (Bebko et al., 1987). The unmet wants and needs of a nonverbal child often result in tantrums (Rogers, 2008). A lack of communication skills increases parental stress and may decrease a parent's feeling of self-efficacy (Benson & Karlof, 2009; Rogers, 2008). The uneven intellectual profile makes it difficult for parents to decipher the true intellectual potential of their child, and it becomes a strenuous task to determine how much their child can handle. Social and emotional impairments decrease the community activities available and increase social isolation (Johnson et al., 2006; Marcus et al., 2005). Parents often are forced to implement rigid schedules and be creative preparing activities and techniques to prevent irritability, tantrums, and difficult transitions . All of these stressors lead to an increased need for physical and emotional support for the caretakers.

The unrelenting needs of a child on the spectrum increase parental responsibilities (Erguner-Tekinalp & Akkok, 2004; Johnson et al., 2006; Linares-Gonzalez, 2006). The daily activities and stressors of a parent are exacerbated by the needs of an autistic child (Benson & Karlof, 2009). A child may require assistance in daily living skills. Toileting issues may be a life long challenge or just simply delayed (Bebko et al., 1987). Bowel and bladder problems may increase the amount of laundry a parent must do while further limiting the independence of the child. Bedtime and sleeping issues reduce the amount of personal time a parent may have and disrupt the parent's sleeping pattern (Bebko et al., 1987). Parents may have to work hard at preventing aggression or self-injurious behavior. Stereotypical behavior, rigid routines, or sensory problems may prevent a parent from progressing through daily tasks (Bebko et al., 1987). Children on the spectrum often have multiple therapies in which parents must participate and for which they must provide transportation (Rogers, 2008). The quantity of time dedicated to taking care of their child leaves limited time for themselves, and often can lead to parental burnout (Linares-Gonzalez, 2006).

Time often is a chronic stressor (Linares-Gonzalez, 2006; Long, 2005). Parents' free time and personal time decrease drastically (Johnson et al., 2006; Rogers, 2008). Family time diminishes due to time spent commuting to and from therapies, fighting for therapies or researching treatments, dedication to activities of daily living (ADL), implementing therapies, and maintaining behavior (Bebko et al., 1987; Benson & Karlof, 2009; Linares-Gonzalez, 2006; Rogers, 2008). Family vacations, family outings, and even family dinners may decline due to time restrictions (Erguner-Tekinalp & Akkok, 2004).

Rogers (2008) found that parents find it difficult to obtain services, and dedicate a lot of time trying to find the most appropriate services for their child. Although parents request multiple treatments for their child, the time constraint that these services place on the family is immense and stressful. "Services have increased my stress level because of all the paperwork, signing releases, doctor visits, therapy, respite care paperwork, and meetings, plus not knowing if Medicaid will pay for services or not" (Hutton & Caron, 2005, p. 186). Not only do parents have to worry about the time and energy spent on various treatments, but the cost of those treatments increases the stress upon parents and family resources (Honey et al., 2005; Linares-Gonzalez, 2006; Murphy et al., 2006; Rogers, 2008). Focusing on the needs of their child is a major stressor for many parents. Wood (2006) found that when parents are provided with information, especially empirical information about services for their child, including it can help decrease the level of stress. Many parents expressed that they must search for services on their own and then lack the information to make an informed decision about particular services (Wood, 2006). There was a decrease in stress level when a parent felt as though their child's needs were being met (Wood, 2006).

Families with autistic children often experience a strain on their financial resources (Benson & Karlof, 2009; Honey et al., 2005; Linares-Gonzalez, 2006; Murphy et al., 2006; Rogers, 2008). The numerous services and treatment modalities occupy a lot of time and can be very expensive. Often parents must decrease hours at work or quit work completely in order to attend to their children with autism, leaving them with a reduction in financial support, often during a time of increased financial need (Benson & Karlof, 2009; Murphy et al., 2006; Rogers, 2008). The stress of time constraints, parental responsibilities, and financial burdens commonly leads to worry about necessary resources and the welfare of the family (Linares-Gonzalez, 2006).

Immense levels of stress can manifest as anxiety and depression in the parents, often causing a decrease in marital satisfaction (Benson & Karlof, 2009; Kroodsma, 2007; Rogers, 2008; Rubens, 2009). Rogers found that stress can cause depression and anxiety, and when one parent experiences depression or anxiety, it elevates the stress level of the other parent, increasing that parent's susceptibility to depression or anxiety (p. 18). Vogt (2007) found that parents of children with an ASD were less intimate and were at a higher risk for divorce than parents of typically developing children. Parents are forced to put the needs of their child before their own needs and before the needs of their relationship (Rogers, 2008). Marital discord, lower levels of intimacy, and feelings of diminished spousal support result in marital dissatisfaction (Benson & Karlof, 2009; Erguner-Tekinalp & Akkok, 2004; Vogt, 2007). The conflictual relationship between the spouses affects their approach to parenting and the feeling of being supported in the stressful situation (Vogt, 2007).

Johnson, O'Reilly, and Vostanis (2006) conducted a study with a semi-structured interview of 18 participants, all having a child between the ages of five and 15 years, and with a moderate to severe learning disability. The interview was designed to determine how the interviewee and the family were affected by the occurrence of behavior problems. From the interviews, five themes were identified; isolation, conflict, limitation of lifestyle, self-blame, and coping strategies. Parental conflict was expressed throughout the family, but with an emphasis on marital conflict. Johnson et al.,(2006) found that partners frequently fight over differing views of how to parent or different responses to behavioral problems and the stress of raising a child with severe learning disabilities.

The stress placed upon the parents also affects siblings of children with an ASD. Decreased family time, martial discord, strained approaches to parenting, multiple providers within the home, and an uneven distribution of attention are stressful for the siblings and have the potential to cause further problems. Children's lives are changed drastically by having a sibling on the autism spectrum. The behavioral issues, and the unrelenting needs of the child with an ASD that take parent time and attention, also affect siblings (Perez, 2008). Siblings may experience embarrassment from the negative reaction of the public, frustration over their sibling's limitations, jealousy due to decreased parental attention, and worry about their parents' well being, stress levels, and grief (Lutz, 2008; Perez, 2008). Siblings often are looked upon to be the long term caregivers following the death of their parents, which increases the stress level and worry among parents and siblings (Bebko et al., 1987; Erguner-Tekinalp & Akkok, 2004; Linares-Gonzalez, 2006; Rogers, 2008).

Mixed findings exist among studies examining the effects of autism on siblings (Bågenholm & Gillberg, 1991; Kaminsky & Dewey, 2002; Perez, 2008). Siblings have been found to be at risk for internalizing problems, externalizing problems, depression, attention problems, conduct problems, and relational problems (Bågenholm & Gillberg, 1991; Perez, 2008). Kaminsky and Dewey did not find significant problems within siblings, but it is possible that this result reflects the fact that all of the participating parents were involved in a support group. According to Kaminsky and Dewey,

> Siblings of children with autism whose parents are active in support groups may be more privileged to information about autism and may be more likely to interact with other families of children with autism. The social support gained from membership in such groups may facilitate healthy psychological adjustment in siblings of children with autism. (p. 231)

Siblings appear better adjusted when social support exists and where there are more than two children within the family (Kaminsky & Dewey, 2002). When a sibling has others to relate to or seek support from, there appear to be lower levels of stress and healthier adjustments.

A study by Murphy et al. (2006) involved 40 volunteers with the Utah State Family Council (USFC). They developed four focus groups, one each from an urban, suburban, and rural area, with a fourth comprised of state and regional leaders of the USFC. The groups solicited the attitude of caregivers concerning the demands of providing care for children with disabilities, and the influence on caregiver's health. Five themes emerged from the focus group, (a) stress of caregiving, (b) negative impact on caregiver health; (c) sharing the burden, (d) worry about the future, and (e) caregiver coping strategies. Thirty two caregivers reported recurrent anxiety, depression, or guilt. Of those, 20 had received mental health interventions. It is apparent that parents need mental health support, but limited supports exist to help alleviate the related stress.

Positive influence. While most studies have focused on the negative attributes and effects of having a child with an ASD, several have examined the positive influences a child with an ASD can have on a parent or family. Johnson et al.,(2006) found that some parents felt that caring for their child with an ASD had brought them closer to their partner. Although there is an abundance of research on marital discord and divorce due to having a child with an ASD, there is little evaluating the positive effects on marriage, or what makes some couples develop a stronger marriage following the diagnosis (Murphy et al., 2006).

Parents and families often develop a new perspective on life and appreciate life in a new way (Bayat, 2007; Long, 2005). Studies have found that family members have increased sensitivity, enhanced empathy, improved patience, superior compassion, and a sense of humility (Bayat, 2007; Marcus et al., 2005). Parents frequently reported that they learned to respect others, and that it has helped them increase friendships with other families who have children with disabilities (Bayat, 2007; Marcus et al., 2005). Families frequently report improved communication, increased togetherness, sharing and support, and humility (Bayat, 2007; Marcus et al., 2005). Marcus, Kunce, and Schopler found that several parents felt fortunate to experience their unique parenting experience and often influenced family members to pursue healthcare careers.

Social Supports and Resources

Social supports appear to reduce the level of stress and increase positive coping skills of siblings and parents of children with an ASD (Benson & Karlof, 2009; Honey et al., 2005; Lin, Tsai, & Chang, 2008; Linares-Gonzalez, 2006; Murphy et al., 2006; Siklos & Kerns, 2006; Stuart & McGrew, 2009). Unfortunately, many parents find that there are limited social supports and resources for parents of children with autism (Bebko et al., 1987; Kroodsma, 2007; Linares-Gonzalez, 2006; Long, 2005). Johnson, O'Reilly, and Vostanis (2006) found that parents felt drained and isolated with limited social supports. They indicated the struggle to find appropriate sitters or alternative caregivers left them with limited time for themselves and minimal social networks. "Parents identified several barriers to addressing their own health needs; these included lack of time, lack of respite hours, lack of qualified alternative care providers, and low prioritization of the need" (Murphy et al., 2006, p. 183). Social support, accessible resources, and available services for parents are difficult to find.

When reviewing the services offered to families, the greatest improvement has been observed in parent training, early intervention programs, educational support groups, and online websites (Bebko et al., 1987; Erguner-Tekinalp & Akkok, 2004; Lin, Tsai, & Chang, 2008; Linares-Gonzalez, 2006). These options are highly beneficial but not sufficient.

> Although improvements have been made to services offered to families with autistic children, few of those services address the emotional stress parents of autistic children face daily. It is important that parents have access to as much support to help them feel more confident and to prepare them in facing the challenges that being a parent to an autistic child entails. Therefore, a group providing parents with essential coping skills must be an essential part of a family treatment program. (Linares-Gonzalez, 2006, p. 31-32)

Parents need helpful and available support in order to help control the level of stress involved in their lives and to increase effective coping strategies.

Parent training frequently was a service in which parents indicated that they had participated. Marcus, Kunce, and Schopler (2005) found improved family functioning and high involvement in families through parent training and other family-based approaches. Another program found to help parents handle stressors was an education based program called the Treatment and Education of Autistic and Communication related handicapped Children program (TEACCH; Marcus et al., 2005). White & Hastings (2004) found that spousal support or satisfaction helped decrease stress, which may demonstrate a need for couples therapy. Support groups that focused on parental emotional support or process oriented support groups, along with sibling support groups, have been reported as important programs for families (Bromley et al., 2004; Marcus et al., 2005; Kroodsma, 2007; Murphy et al., 2006). Marcus, Kunce, and Schopler found a desire for advocacy training, but limited accessibility. A study on parent-to-parent workshops demonstrated a strong parental desire and positive results (Akkok, 1994). One service that stood out in many studies was the need for respite care. Parents frequently reported that respite care was a strong need, but rarely was that need met (Bromley et al., 2004; Johnson et al., 2006; Ruble & McGrew, 2006; White & Hastings, 2004).

Parents who have adaptive coping skills and have an optimistic attitude exhibit lower levels of stress than their counterparts lacking such skills and outlook (Erguner-Tekinalp & Akkok, 2004; Honey et al., 2005; Solish & Perry, 2008). Parents who adopt negative or avoidant coping strategies often encounter more stress and personal mental health issues, while those who use more positive strategies show less stress (Honey et al., 2005). It has been found that parents have healthier coping when the child’s program has the family’s best interest in mind and when they think they are getting the appropriate services (Solish & Perry, 2008). Parental stress level greatly impacts the child (Erguner-Tekinalp & Akkok, 2004; Solish & Perry, 2008). Lower stress levels allow a parent more time and energy to dedicate to the child (Solish & Perry, 2008). The child’s treatment progress can be affected dramatically by high levels of parental stress (Solish &

Perry, 2008). Autism can cause high levels of stress throughout the entire family. Lacking positive coping skills and an optimistic outlook, stress levels have the potential to escalate in a cyclical pattern, causing mental health issues and familial problems.

Siklos and Kerns (2006) study presented a comparison between parents of children with an ASD and parents of children with Down Syndrome (DS). Eighty-eight total participants completed four questionnaires evaluating diagnosis, family needs, child characteristics, and demographics. The study found that the parents of children with an ASD did not vary in the number of needs compared to those with children with DS, but child-centered needs were more important, as were those for more ASD aware service providers, and for relations to professionals working with their child and family. All of the parents in the study felt as though there were inadequate services being provided. Parents of children with an ASD had significantly less satisfaction with the services they have received, and 93% expressed inadequate financial assistance. Support received was expressed to be more crisis management rather than proactive. Similar to other studies, they found that the more severe the child's behavioral problems the more stress and needs families expressed.

The Need for Research Concerning Parents Needs

When a child is on the autism spectrum, a parent has increased caretaking responsibilities. Although there may be a wide range of services in place for the child, often the majority of a child's time is spent in the care of a parent. "Parents of children with disabilities frequently take on an 'informal caregiving career' which frequently is for the rest of the child's life. As informal caregivers, parents provide long –term care that often requires extraordinary physical, emotional, social, and financial resources" (Murphy et al., 2006, p. 180). Evidence suggests that parent involvement in treatments is beneficial to the child (Akkok, 1994; Kuhn, 2006; McConachie & Diggle, 2007).

When parents are involved in early intervention or parent training, it increases the uniformity of care and interventions implemented throughout the child's day (Akkok, 1994; Kuhn, 2006; McConachie & Diggle, 2007; Wang, 2008). "Increased parental skills allow for continual opportunities for the children's learning in a range of situations" (McConachie & Diggle, 2007, p. 121). A study by Akkok entailed 12 middle class couples and their 12 children with developmental disabilities randomly assigned to an experimental group and a control group. Those in the experimental group underwent eight weekly training sessions. The results showed that the experimental group children demonstrated significantly larger gains than did the children in the control group.

Parent involvement in their child's interventions resulted in an increase in consistency, structure, and constant child training, which often leads to improved prognosis for their child. When parents participated in early intervention, parent training, and group parent education programs, there was evidence of positive changes in the child's social relationships, communication skills, behavior, and parental interactions (Akkok, 1994; Kuhn, 2006; McConachie & Diggle, 2007; Schreibman & Ingersoll 2005; Wang, 2008). Involvement in the child's treatment increased parental skills in teaching, praise, appropriate responses, and strategies to minimize maladaptive behaviors (Akkok, 1994; Kuhn, 2006; McConachie & Diggle, 2007; Wang, 2008).

When parents receive training or are incorporated into the child's treatment, it has been shown to reduce stress, increase confidence, improve knowledge of autism, decrease depression, increase self-esteem, and increase the feeling of self-efficacy (Akkok, 1994; Kuhn, 2006;

McConachie & Diggle, 2007; Sofronoff & Farbotko, 2002). Parents involved in their child's therapies often show increased parenting skills and improved mental health. However, if parents do not have sufficient emotional strength to engage in the parenting intervention, it likely will not be successful. Many parents report strong feelings of guilt, which negatively affect their parenting skills and their ability to engage effectively in their child's treatment (Kuhn, 2006). Kuhn found that,

> It may be important to address a mother's depressive symptoms before involving her in parenting interventions because high levels of depressive symptoms such as hopelessness, helplessness, low motivation, difficulty concentrating, and negative beliefs about oneself and the future may interfere with her ability to engage in interventions. (p. 570)

It is important to meet the mental health needs of the parents to help facilitate a better prognosis for their child. It also is important to determine what those needs are, and how the parents feel they are best met.

A parent to parent training study by Akkok (1994) involved a group of 7 mothers of children with developmental disabilities who had several years of parenting counseling and training experience. They were to instruct a group of 40 untrained mothers of children with developmental disabilities in a parent to parent workshop. Parents were observed sharing their feelings of denial, shock, anger, depression, and adjustment, and reported feeling less stressed in caring for their child following the training. The untrained mothers indicated it helped improve their self-esteem and parenting skills. Interventions like this help parents increase their parenting skills while attending to their own mental health needs.

Although there are interventions that involve parents with the training or treatment of their child, there are limited programs like the aforementioned that focus on parental emotional and cognitive needs (Kuhn, 2006; Linares-Gonzalez, 2006; McConachie & Diggle, 2007). According to Kuhn, “Early home-based intervention programs rarely include an explicit component in which the service provider asks about a parent’s feelings and beliefs about parenting a child with autism, despite the known challenges inherent in this task” (p. 571). Parents need to be taught the skills to raise a child on the autism spectrum, and more emotionally supportive services should be made available to parents (Akkok, 1994; Kuhn, 2006; Linares-Gonzalez, 2006; McConachie & Diggle, 2007; Siklos & Kerns, 2006).

Studies have found that parent training, counseling, and support groups are extremely important for parents with children on the autism spectrum. However, limited research has been preformed to uncover what parents perceive they need for services, or how well those needs are being met (Akkok, 1994; Kuhn, 2006; Linares-Gonzalez, 2006; McConachie & Diggle, 2007; Siklos & Kerns, 2006). Research has shown that parents believe they receive inadequate counseling, emotional support, specific diagnostic support, and social support (Murphy et al., 2006). Bromley et al., (2004) found,

> At present, it is possible that such interventions are not being adequately provided, as the psychological wellbeing of parents does not necessarily come within the remit of services for children with developmental disabilities. This is a potentially important area of development for such service. (p. 421)

It is important for parents to have access to emotionally and cognitively supportive resources (Linares-Gonzalez, 2006; McConachie & Diggle, 2007). Future evaluations must consider what services are being offered for parents and what services parents feel are necessary to help them cope.

Method

This study was designed to answer the following research questions: What have parents experienced in terms of needs and services for themselves in relation to having a child with an ASD? How well are parents' needs being met for particular services? How interested would parents be in receiving particular services? What services do parents of autistic children find are most important for themselves and their families? These questions were answered through a questionnaire distributed to parents of children with an ASD.

Participants

Participants included 108 parents or primary caregivers of children diagnosed with Autism Spectrum Disorder, including Asperger's Disorder, Autism, and PDD-NOS. It was required that the child on the spectrum be between the ages of 3 and 21. Participants needed to have their primary residence within the United States of America and speak English. Initially 154 individuals responded to the multifaceted five-page survey. Of the questionnaires returned, 46 respondents consistently left required answers blank. These respondents were not included in the final sample, resulting in a total of 108 participants.

Participants were recruited through local ASD support centers including, but not limited to, North Shore Arc's Autism Support Group, Asperations, Asperger's Association of New England, Autism Speaks, Autism Society, and Autism Support Network. The questionnaire was posted on their websites, in their newsletters, and announced during support groups.

Measures

The study was designed to review the needs and service of parents with children on the autism spectrum from the perspective of the parent. The information was gathered through a questionnaire developed to evaluate those specific services parents perceived they needed for themselves and, if applicable, their children without an ASD (See Appendix B). The questionnaire was developed to evaluate those needs parents felt were not being met, and what services they desired, including aspects of the provider, places of delivery, and barriers. It assessed the services in which parents and siblings had participated, the extent the parent felt his or her needs had been met within existing programs, and whether their provider was ASD aware. Parents also were asked to rank order the top three types of programs they felt would be useful for themselves.

The questionnaire was developed using available literature and the personal observations of the researcher made while working in programs for children with autism and their families. After realizing that parents felt they did not have many resources for themselves, I investigated various services offered to parents by employing internet web searches, reviewing topical literature, and through collaboration with colleagues. A review of literature on parent focused services and resources specifically offered to parents of children with autism returned limited information. Studies focusing on services offered to children were used to identify those services parents used frequently or for which they expressed a need. Information surrounding the parents' perspectives of needs and services was limited. As a result, the list of services was derived from what parents had requested, from the services found in the aforementioned literature, and on websites. It was further refined for clarity through consultation with a group of psychology doctoral students who had experience working with individuals with an ASD.

While working in a psychiatric hospital setting, it became apparent there was a lack of resources for the family members, with limited parent training addressing the transition from the hospital to the home environment. As an in-home Autism Life Skills Specialist, time was dedicated to the needs of the children, not those of the parents. Limited parent guidance was offered to the family, with the majority of work dedicated to implementing discrete trials, and working on social skills with the child. During the provision of these services, many parents requested referrals for a therapist for themselves, preferring a therapist with a good understanding of autism and the effects on the family.

While leading social skills groups for children on the spectrum, parental referrals often were made to a parent support group. In line with related studies, parents subsequently reported the support group to be very helpful (Bromley et al., 2004; Marcus et al., 2005; Kroodsma, 2007; Murphy et al., 2006). Parental support groups were broken down into three different types; educational, process oriented, and online. A definition was established for each of these types of services that were used for this study (See Appendix D). An educational parent group was defined as in-person, professionally-facilitated support group for parents of children with an ASD, which provides psycho-educational information about having a child with an ASD. Topics may include information about the diagnosis, Special Education, medication, behavior plans, etc. A process oriented parent support group was defined as an in-person, professionally-facilitated support group for parents of children with an ASD, which provides a safe space for parents to explore their feelings, struggles, and needs among other parents of children with an ASD. These groups focus on the interpersonal and psychological needs of the parents, as opposed to educational trainings. An online support group was defined as an electronic community resource that grants access to individuals worldwide. Some groups allow individuals to exchange messages in real-time, while some can post a message or exchange messages via email, blogs, or internet bulletin boards. The groups can be peer-to-peer self-help groups or facilitated support groups. These groups meet in a virtual world and do not have a physical location, sometimes allowing members to stay anonymous (Bromley et al., 2004; Marcus et al., 2005; Kroodsma, 2007; Murphy et al., 2006).

While doing in-home parent training, I often heard parents state that they would like a therapeutic service for themselves, but parent training was the only service offered, which was consistent with the research done by Marcus et al. (2005). Parent skills training was defined as a trainer who works with the parents in order to teach them and other caregivers effective ways of helping their child further develop his or her skills. Numerous parents reported that their own therapist did not have significant ASD experience, and therefore was not meeting their needs (Erguner-Tekinalp & Akkok, 2004; Rogers, 2008; Vogt, 2007). Individual therapy was defined as psychotherapy or personal counseling with a psychotherapist, which involves working on a one-to-one basis with a therapist to prepare a plan to create positive changes in one's life.

It has been found that parents of children with an ASD have an increased risk of marital discord and were at higher risk of divorce (Benson & Karlof, 2009; Bromley et al., 2004; Erguner-Tekinalp & Akkok, 2004; Johnson et al., 2006; Rubens, 2009; Siklos & Kerns, 2006; Vogt, 2007). Therefore, parental desire for couples therapy was evaluated. Couples therapy was defined as psychotherapy, with a psychotherapist used to treat relationship distress for couples. The purpose of couples therapy is to restore a better level of functioning in couples who are experiencing distress. Parents have expressed difficulty in meeting the needs of their children without an ASD. Siblings of children with an ASD reported feeling stress, and worrying about both their siblings and their parents well being (Bågenholm & Gillberg, 1991; Bebko et al., 1987;

Erguner-Tekinalp & Akkok, 2004; Kaminsky and Dewey, 2002; Linares-Gonzalez, 2006; Lutz, 2008; Perez, 2008; Rogers, 2008). The need for sibling support groups was explored. A Sibling support group was defined as a support group for siblings of children with an ASD, which helps connect siblings with other siblings of children with autism and peer support. Research also has found that parents with access to respite care have more time to focus on their relationships with their spouse and with their children without an ASD (Bromley et al., 2004; Johnson et al., 2006; Murphy et al., 2006; Ruble & McGrew, 2006; White & Hastings, 2004). Respite care is short-term, temporary relief of care giving responsibilities so that caregivers can have time for themselves. This time is meant to enhance a parent or caregivers ability to continue in their role as a primary caregiver and to maintain a caring relationship.

Research has found that many parents do not know what resources are available to them or have asked for a case manager to help direct them in finding appropriate services (Akkok, 1994; Marcus et al. (2005). Two services mentioned in the literature were parent-to-parent workshops and parent advocacy groups (Akkok, 1994; Marcus et al. (2005). A parent to parent workshop is a group developed by parents of children with an ASD to help other parents with children on the spectrum. The group may teach skills, educate about rights, or offer support to their peers. This group is not organized or facilitated by a professional. A parent advocacy group is a parent run group whose focus is on advocacy and support. The group is dedicated to increasing awareness of autism. A Parent Advocacy Group often strives to receive funding for ASD needs, and help ensure an appropriate public education and equal opportunities for children and youth with an ASD.

The questionnaire was designed to determine those services parents of autistic children felt they needed for themselves. Since many of the parents had been or were then enrolled in one or more of the services identified, it was necessary to determine how satisfied they were with the particular services offered. In order to help determine what services parents found to be most important, the questionnaire requested participants rank order their top three desired services. Ranking responses helped determine particular services parents expected to be most helpful.

The demographic questions were refined throughout the development process. Initially, limited demographic information was to be collected. Through discussions with colleagues and parents of children with autism and literature review, it appeared that parents of different ages and varying marital status might desire different services (Civick, 2008). It was important to determine if the questionnaire would reflect this observation. Demographic information was gathered to help evaluate whether there were different responses based on particular situations. Bromley et al., (2004) assessed the needs of the children and found no significant differences between the varying demographic information. My study attempted to measure how parents' needs varied based on demographics.

The educational level of the parents, their incomes, occupations, residence, and culture all might impact parents' needs (Murphy et al.; 2006). If a family's income exceeded their basic financial needs, the family may have had wider access to services. Certain employment situations may have proven more flexible with work schedules or offered more in terms of family support. The local government programs and population density may have played a large factor in which services the family was offered or to which it had access. Cultural influences may have impacted how a family handled the diagnosis, as well as their openness to outside services.

It had been observed that "typical" siblings often helped parents and other family members cope with the diagnosis (Bebko et al., 1987; Erguner-Tekinalp & Akkok, 2004;

Linares-Gonzalez, 2006; Rogers, 2008). It was important to learn of the number of children in the family and, if more than one, how many of them were on the spectrum. Where a family had more than one child on the spectrum, it was anticipated they would need more services. The age of the child with Autism also was an important factor, as it was possible that parents with older children had overcome some difficulties and had learned how to cope (Kroodsma, 2007; Marcus et al., 2005; Murphy et al., 2006, Ruble & McGrew, 2006; Shea & Mesibov, 2005). It also was possible that, as the child aged, parents would feel they needed more services for themselves. Ruble & McGrew (2006) found that younger children used more services and reported better family outcomes. Studies have found that emotional stress, anxiety, and family distress increase over time and specifically during adolescence (Kroodsma, 2007; Marcus et al., 2005; Murphy et al., 2006, Shea & Mesibov, 2005). It was important to find whether parents had varying needs based on the age of their child or years since diagnosis.

Procedure

The questionnaire was uploaded on to surveymonkey.com which produced a secure link directly attached to the survey. Individuals were recruited through autism awareness and support group websites, newsletters, and list serves. Six organizations were contacted via email with the request to distribute the questionnaire. Two organizations did not respond while four responded positively. Individuals in charge of North Shore Arc's Autism Support Group, Asperations, Greater Lawrence Education Collaborative, and Asperger's Association of New England granted permission to publish the internet link for the questionnaire within their respective program's communication system. Following permission from the human research committee, a cover letter (See Appendix E) including the link to the questionnaire and a brief announcement about the study to be posted on websites and in newsletters was emailed to those organizations, as well as to Autism Speaks, the Autism Support Network, ant to national Autism Society groups.

Following the distribution of the cover letter the sites posted the link on their websites, e-newsletters, and on their Facebook accounts. The electronic link allowed parents to navigate directly to the questionnaire with one click or through typing in the link. Parents were encouraged to share the link with others. The questionnaire took 10-15 minutes to complete. Informed consent information, including risks, benefits, and confidentiality (See Appendix C), was presented to each individual prior to gaining access to the questionnaire. Consent was implied by completing the questionnaire. Operational definitions of services in question (See Appendix D) were supplied at the beginning and throughout the questionnaire to ensure that each participant had the same understanding of each service. Information was gathered through surveymonkey.com and imported into Microsoft Access Database for further filtering and data summation. The data analysis was completed through Microsoft Excel which produced means, standard deviations, and percentages. Participants were offered the opportunity to obtain the research findings by emailing a request following the study to ASDKateRyan@gmail.com or to type in the request on the final screen of the survey.

Data Analysis

The study combined both quantitative and qualitative methods to assess the needs and services to which parents or caregivers had access or were in need, and their level of satisfaction with the services. Quantitative analysis was used to evaluate the demographic, multiple choice, and ranking questions within the questionnaire. Qualitative analysis was used to examine the open ended questions on the questionnaire.

Descriptive statistics were used to evaluate the results of the questionnaire. The level of parent interest and satisfaction was evaluated for each service. Frequency distributions were presented for each of these variables. Averages and standard deviations were determined for the questions pertaining to age. Parents also were asked to rank order the top three services they felt were most useful. For each service, the frequency of being ranked first, second, or third most important was presented. It was further dissected to determine how many people had used the services they ranked first, second, and third most important. The parent responses were screened to determine differences based on parent gender, age, marital status, state of residence, population density, educational level, income, race/ethnicity, time since diagnosis, or number of children on the spectrum.

The open ended questions were evaluated using a phenomenological qualitative approach. This approach was used to determine the parents' or guardians' perspective, and to understand better the values and realities of those completing the questionnaire (Ryan & Bernard, 2003; Smith & Osborn, 2003). The phenomenological approach looks at what the caregiver's experience of being a parent of a child with Autism is like by hearing the parents' opinion of their needs, experiences, and satisfaction (Smith & Osborn, 2003).

Qualitative data were evaluated using a phenomenological analysis. A peer and I independently reviewed the responses for all of the questions and developed a series of categories into which the responses appeared to fit. We then compared our categorical listings, merging similar categories and separating out differing categories which, determined an agreed upon set of categories for each question. We then each sorted the responses independently into one or more of the agreed upon categories. The responses were straightforward in that some of the responses included one word answers, using the names of specific services that matched category names, while other responses included more detail, but primarily uncomplicated descriptions of services (e.g. “respite” and “A good program of support or counseling for parents of children with ASD”). We subsequently compared our sorting of responses into the categories. If there was initial disagreement, we discussed the responses and the categories involved until an agreement was reached. As the researcher, my response was chosen when discussion did not settle the disagreement. Where one reviewer assigned a response to more than one category and the other reviewer did not, the responses were discussed to determine the categories in which they would be placed. Most of the disagreements between raters stemmed from one rater assigning more than one category to a response; these responses were counted as disagreements in calculating the rate of agreement, Interrater reliability was established by counting the number of differing responses and dividing that number by the total number of responses (i.e., agreements plus disagreements) yielding a 97.3% rate of agreement (Ryan & Bernard, 2003).

Results

The purpose of this study was to determine the needs of parents or caregivers who had a child with an ASD. This study used both qualitative and quantitative methods to determine the needs and services that caregivers feel were necessary or desired. The use of open ended questions allowed parents or caregivers to express their experiences and needs in their own words. The quantitative methods were demographic and multiple choice questions.

Participants

The questionnaire had 154 initial respondents. However, 14 respondents did not complete the required demographic questions, while another 32 did not complete questions beyond the initial demographic section. These 46 respondents were redacted from the analyses. The resulting sample consisted of 108 parents or caregivers of children who were diagnosed with an ASD, ages 3 through 21. The caregivers volunteered to take an anonymous questionnaire online to provide information about the needs and services they were presently receiving or felt were needed. The participants were predominantly mothers (92.6%, n= 100; Table 1). The other parental groups identified were less frequent. Only seven (6.5%) were fathers and one (.9%) was a stepmother. The average age of the participants was 40.8 years old (SD=7.48). Parents in the sample were 79.6% Caucasian (n= 86) followed at a great distance by Hispanic-American (5.6%, n=6), Asian-American (4.6%, n=5), and African-American (4.6%, n=5; Table 2). The remaining racial/ethnic groups (Native American/American Indian, Biracial, and Multiracial) accounted for only 5.6% (n=6).

Table 1

Relationship to Child with an ASD

	n	%	Avg Age	SD
Mother/Step Mother	101	93.5%	40.2	7.17
Father/Step Father	7	6.5%	47.9	8.78
Other	n/a	n/a	n/a	n/a
Total	108	100.0%	40.8	7.48

Table 2

Ethnic Group

	n	%
Caucasian	86	79.6%
Hispanic-American	6	5.6%
African-American	5	4.6%
Asian-American	5	4.6%
Multiracial	3	2.8%
Native American/ American Indian	2	1.9%
Biracial	1	0.9%

The majority of the respondents were married (81.6%, n=87; Table 3). The next highest response was from those who were divorced (7.4%, n=8). The majority of the respondents were very well educated, with over 68% holding at least an associates degree (Table 4). The largest of this group was those in possession of a bachelor’s degree (28.7%, n=31). The next frequent group of respondents possessed a masters degree (24.1%, n=26), and third most frequent grouping stated they had some college (20.4%, n=22).

Table 3

Marital Status

	n	%
Married	87	80.6%
Domestic Partner	1	0.9%
Divorced	8	7.4%
Widowed	1	0.9%
Separated	4	3.7%
Never Married	7	6.5%

Table 4

Education Level

	n	%
Grammar School	0	0.0%
Some High School	0	0.0%
High School/GED	12	11.1%
Some College	22	20.4%
Associates Degree	11	10.2%
Bachelors Degree	31	28.7%
Masters Degree	26	24.1%
Doctorate	6	5.6%

Participants reported their total household income by income range, and three of the respondent groups were responsible for more than 72.2% of all responses (Table 5). The largest respondent group in this category was those whose income was between $60,000 and $99,999 (25.9%, n=28). Those making $20,000 to $59,999 (24.1%, n=26) followed them, with those making $100,000 to $139,999 (22.2%, n=24) close behind. The remaining three responding groups accounted for 27.8% of the survey, and of that 6.5% (n=7) preferred not to state their income. The majority of the respondents identified their employment status as employed by an employer (61.1%, n=66), while the second highest response was from homemakers (25.0%, n=27; Table 6). The third highest responding group were those who were self-employed (5.6%, n=6).

Table 5

Household Income

	n	%
Prefer Not To Say	7	6.5%
Less than $20,000	8	7.4%
20000 To $59,999	26	24.1%
$60,000 To $99,999	28	25.9%
$100,000 To $139,999	24	22.2%
$140,000 or More	15	13.9%

Table 6

Employment Status

	n	%
Employed by employer	66	61.1%
Homemaker	27	25.0%
Self-Employed	6	5.6%
Student	4	3.7%
Out Of Work – Looking for Work	2	1.9%
Out Of Work – Not Currently Looking	1	0.9%
Retired	1	0.9%
Unable to Work	1	0.9%

Primary state residence of those who responded to the questionnaire resided in 17 different states (Table 7). New Hampshire had by far the highest number of respondents (41.7%, n=44). Massachusetts followed as the next highest (14.8%, n=16). The remaining 15 states had fewer than 10% of the respondents. Of these 17 states the settings where caregivers reside in dominantly suburban (58.3%, n=63; Table 8).

Table 7

State of Residence

	n	%
New Hampshire	44	40.7%
Massachusetts	16	14.8%
New York	9	8.3%
California	7	6.5%
Connecticut	7	6.5%
Maryland	6	5.6%
Texas	6	5.6%
Ohio	3	2.8%
Florida	2	1.9%
Alabama	1	0.9%
Indiana	1	0.9%
North Carolina	1	0.9%
Oregon	1	0.9%
Utah	1	0.9%
Virginia	1	0.9%
Washington	1	0.9%
Wisconsin	1	0.9%

Table 8

Neighborhood Type

	n	%
Suburban	63	58.3%
Rural	31	28.7%
Urban	14	13.0%

Most participants had two children (50.9%, n=55; Table 9). Families with three children was next (22.2%, n=24), followed closely by families with one child (20.4%, n=22). Families having one child with an ASD was the most frequent group (83.3%, n=90; Table 10). Only 14.8% (n=16) of the families had two children on the spectrum, and 1.9 %(n=2) of the families had three children with an ASD. Of the families with only one child with an ASD, the average current age of the child was 9 (SD= 4.4), the average age of diagnoses was 4 years old (SD=3.0) and the average years since diagnosis was 5 years (SD=3.5; Table 11). Two respondents reported years of diagnosis greater than their child's age, therefore their information was omitted from the analyses of current age, age diagnosed, and years since diagnosis.

Table 9

Number of Children

	N	%
2	55	50.9%
3	24	22.2%
1	22	20.4%
4	5	4.6%
5	1	0.9%
7	1	0.9%

Table 10

Number of Children W/ASD

	N	%
1	90	83.3%
2	16	14.8%
3	2	1.9%

Table 11

Child Information When Only One Child W/ASD

	n	Average	SD
Current Age	88	9.0	4.4
Age Diagnosed	88	4.0	3.0
Years Since Diagnosis	88	5.0	3.5

Families that reported having more than one child on the spectrum on average had their second child diagnosed around the same time as their first child (Table 12). The first child on the spectrum was an average age of 11.7 years old (SD=5.7), with a diagnosis age of 4.7 (SD=3.9) and 6.9 (SD= 4.4) years since a diagnosis. The second child’s average age was 9.8 years old (SD=4.8) with a diagnosis age of 3.6 (SD=3) and 6.2 (SD=4.7) years since a diagnosis. Two families had three children with an ASD and in both of these families the third child was 2 years old (SD=0). The average age of diagnosis was 1.5 (SD=0.7) and 0.5 (SD=0.7) years since a diagnosis.

Table 12

Child Information When More Than One Child W/ASD

	Child 1			Child 2			Child 3		
	n	Avg	SD	n	Avg	SD	n	Avg	SD
Current Age	18	11.7	5.7	18	9.8	4.8	2	2.0	0
Age Diagnosed	18	4.7	3.9	18	3.6	3	2	1.5	0.7
Years Since Diagnosis	18	6.9	4.4	18	6.2	4.7	2	0.5	0.7

Parental Needs and Services Results

The open ended questions where coded into themes and then categorized based on those themes. Questions were open-ended, allowing the respondent to answer with multiple themes. While the total number of themed responses is greater than the 108 respondents, due to the multiple responses per question, the calculated percentage remains based on the 108 respondents.

Unmet parental needs and services. The first open-ended question asked, “As a parent of a child with Autism, are there specific needs that you feel have not been met for you or your partner?” The coding rendered eleven general categories, which ranged in the number of responses from No Services are Accessible (0.9%, n=1) to Respite (24.1%, n=26; Table 13). In between, there were responses to nine other categories that covered a broad set of needs, including but not limited to Education and Training (13.0%, n=14), Professional Support/Resources (20.4%, n=22), and Financial Assistance (11.1%, n=12). The second open ended question evaluated the specific services the parents desired (Table 14). The most desired services were similar to those expressed in the prior question on unmet needs, with Professional

Support/Resources (18.5%, n=20) and Respite (16.7%, n=18) as the highest desired service, although 25.9% (n=28) indicated "No Need."

Table 13

Unmet Parental Needs

	n	%
Respite	26	24.1%
No Need Indicated	22	20.4%
Professional Support/Resources	22	20.4%
Answer Addressed Needs of Child, Not Parent	19	17.6%
Education & Training	14	13.0%
Financial Assistance – including Insurance Needs	12	11.1%
Networking/Social Support	10	9.3%
Community Advocacy/Awareness	7	6.5%
Positive Response – no specifics	5	4.6%
Home-based Services	3	2.8%
No Services Are Accessible	1	0.9%

Table 14

Specific Desired Services Not Presently Offered

	n	%
No Need Indicated	28	25.9%
Professional Support/Resources	20	18.5%
Respite	18	16.7%
Positive Response – no specifics	14	13.0%
Answer Addressed Needs of Child, Not Parent	14	13.0%
Education & Training	12	11.1%
Financial Assistance – including Insurance Needs	11	10.2%
No Services Are Accessible	7	6.5%
Home-based Services	5	4.6%
Networking/Social Support	4	3.7%
Community Advocacy/Awareness	2	1.9%

Open-ended questions evaluated the parents' view of unmet needs and desired services for siblings without an ASD. This question was not applicable for many of the families, as there were either no siblings or no siblings without ASD. Those responding to questions that were not applicable were omitted from the analyses leaving only the responses of those 69 parents of children without an ASD. The most frequent response for both unmet needs (Table15) and desired services (Table 16) was No Need Indicated (28.7%, n=31; 41.7%, n=45). Parents often responded to these questions with answers that addressed the needs and services of their child with an ASD (See Appendix F), and not those for the parent or for a sibling without an ASD. Answers addressing the needs of the child with an ASD was the fourth most common response category for unmet needs (6.5%, n=7) and third most common response for services (5.6%, n=6). The highest categories of specific unmet needs was Respite (12.0%, n=13) and Professional Support/Resources (10.2%, n=11). As for desired services for siblings without ASD, parents indicated Professional Support/Resources (12.0%, n=13) and a Positive Response which did not specify services (5.6%, n=6).

Table 15

Unmet Needs of Children Without ASD

	n	%
No Need Indicated	31	28.7%
Respite	13	12.0%
Professional Support/Resources	11	10.2%
Answer Addressed Needs of Child with an ASD, Not Sibling	7	6.5%
Positive Response – no specifics	7	6.5%
Education & Training	4	3.7%
No Services Are Accessible	3	2.8%
Financial Assistance – including Insurance Needs	2	1.9%
Networking/Social Support	2	1.9%
Community Advocacy/Awareness	1	0.9%
Home-based Services	0	0.0%

Table 16

Services Desired for Children without ASD

	n	%
No Need Indicated	45	41.7%
Professional Support/Resources	13	12.0%
Answer Addressed Needs of Child with an ASD, Not Sibling	6	5.6%
Positive Response – no specifics	6	5.6%
Education & Training	3	2.8%
Financial Assistance – including Insurance Needs	2	1.9%
Networking/Social Support	2	1.9%
No Services Are Accessible	1	0.9%
Respite	1	0.9%
Community Advocacy/Awareness	0	0.0%
Home-based Services	0	0.0%

Satisfaction with services rendered and interest if not participating. Parents and caregivers were questioned concerning 11 different services and whether they had participated in those services. If a parent indicated that they had participated in the service, they were asked further to rate on a Likert scale how well their needs were met and, if applicable, how ASD aware the service provider was. If the parents reported that they had not used the service indicated, they were asked further to rate on a Likert scale how interested they would be if the service were to be offered to them in the next three months.

Of the 32 parents who reported participating in Individual Therapy, most stated their needs were only slightly met (34.4%, n=11; Table 17). Services where the satisfaction level scored very well included Sibling Support Groups (50.0%, n=5), which reported nine participants (Table 25), Respite (34.5%, n=10 with 29 participants (Table 27), Parent Advocacy Groups (34.3%, n=12) with 35 participants (Table 24), Process Oriented Parent Support Groups (34.2%, n=13) with 37 participants (Table 23), and Educational Parent Groups (33.3%, n=15) reporting 45 participants (Table 21). Of the 45 participants responding affirmatively to Online Support Groups (Table 23), responses produced a dichotomy, as the most frequent responses with respect to the level of needs met were both slightly (26.7%, n=12) and very (26.7%, n=12) satisfied. Those who received services stated that all of the service providers had some awareness of ASD; however, the greater part found service providers to be only slightly ASD aware with respect to Couples Therapy (50.0%, n=6; Table 18), Individual Therapy (40.6%, n=13; Table 17), and Respite Care (27.6%, n=8; Table27). The only service where most parents found the providers to be extremely ASD aware was Online Support Groups (37.8%, n=17; Table 23).

Of those who had not received specific services, the respondents were predominantly extremely interested in Parent Skills Training (45.5%, n=15; Table 20), Respite (37.3%, n=22; Table 27), and Educational Parent Groups (27.9%, n=12; Table 21). Services in which parents indicated that they were predominantly not interested in participating included Online Support Groups (Table 23) and Sibling Support Groups (Table 25). In order to assess an accurate level of need for the Sibling Support Groups (Table 25), responses were adjusted, removing those who did not have a child without an ASD.

Table 17

Have You Participated in Individual Therapy as a *Parent of an ASD Child*?

Parents Who Participated

	How Well Needs Were Met		How ASD Aware Was Provider	
	n	%	n	%
Not At All	2	6.3%	0	0.0%
Slightly	11	34.4%	13	40.6%
Moderately	5	15.6%	6	18.8%
Very	9	28.1%	6	18.8%
Extremely	5	15.6%	7	21.9%
Total	32	100.0%	32	100.0%

Parents Who Have Not Participated

	Interest Level If Offered	
	n	%
Not Interested	6	10.5%
A Little Interested	8	14.0%
Interested	14	24.6%
Very Interested	16	28.1%
Extremely Interested	13	22.8%
Total	57	100.0%

Table 18

Have You Participated In Couples Therapy as Parent of ASD Child?

Parents Who Participated

	How Well Needs Were Met		How ASD Aware Was Provider	
	n	%	n	%
Not At All	2	16.7%	0	0.0%
Slightly	3	25.0%	6	50.0%
Moderately	4	33.3%	4	33.3%
Very	2	16.7%	0	0.0%
Extremely	1	8.3%	2	16.7%
Total	12	100.0%	12	100.0%

Parents Who Have Not Participated

	Interest Level If Offered	
	n	%
Not Interested	15	22.7%
A Little Interested	15	22.7%
Interested	17	25.8%
Very Interested	11	16.7%
Extremely Interested	8	12.1%
Total	66	100.0%

Table 19

Have You Visited a Drop-In Center Related to ASD?

Parents Who Participated

	How Well Needs Were Met		How ASD Aware Was Provider	
	n	%	n	%
Not At All	0	0%	0	0%
Slightly	0	0%	0	0%
Moderately	1	100%	0	0%
Very	0	0%	1	100%
Extremely	0	0%	0	0%
Total	1	100%	1	100%

Parents Who Have Not Participated

	Interest Level If Offered	
	n	%
Not Interested	16	18.2%
A Little Interested	18	20.5%
Interested	30	34.1%
Very Interested	15	17.0%
Extremely Interested	9	10.2%
Total	88	100.0%

Table 20

Have You Participated in Parent Skills Training Related to ASD?

Parents Who Participated

	How Well Needs Were Met		How ASD Aware Was Provider	
	n	%	N	%
Not At All	1	1.8%	0	0.0%
Slightly	8	14.3%	3	5.4%
Moderately	23	41.1%	11	19.6%
Very	17	30.4%	24	42.9%
Extremely	6	10.7%	17	30.4%
Total	55	98.2%	55	98.2%

Parents Who Have Not Participated

	Interest Level If Offered	
	n	%
Not Interested	2	6.1%
A Little Interested	1	3.0%
Interested	9	27.3%
Very Interested	6	18.2%
Extremely Interested	15	45.5%
Total	33	100.0%

Table 21

Have You Participated in Educational Parent Groups Related to ASD?

Parents Who Participated

	How Well Needs Were Met		How ASD Aware Was Provider	
	n	%	N	%
Not At All	0	0.0%	0	0.0%
Slightly	8	17.8%	2	4.4%
Moderately	15	33.3%	8	17.8%
Very	15	33.3%	20	44.4%
Extremely	7	15.6%	15	33.3%
Total	45	100.0%	45	100.0%

Parents Who Have Not Participated

	Interest Level If Offered	
	n	%
Not Interested	6	14.0%
A Little Interested	3	7.0%
Interested	12	27.9%
Very Interested	10	23.3%
Extremely Interested	12	27.9%
Total	43	100.0%

Table 22

Have You Participated in Process Oriented Parent Support Groups Related to ASD?

Parents Who Participated

	How Well Needs Were Met		How ASD Aware Was Provider	
	n	%	n	%
Not At All	1	2.6%	1	2.6%
Slightly	7	18.4%	3	7.9%
Moderately	11	28.9%	6	15.8%
Very	13	34.2%	14	36.8%
Extremely	5	13.2%	13	34.2%
Total	37	97.4%	37	97.4%

Parents Who Have Not Participated

	Interest Level If Offered	
	n	%
Not Interested	4	8.2%
A Little Interested	6	12.2%
Interested	20	40.8%
Very Interested	9	18.4%
Extremely Interested	10	20.4%
Total	49	100.0%

Table 23

Have You Participated in On-Line Support Groups/Chat Rooms Related to ASD?

Parents Who Participated

	How Well Needs Were Met		How ASD Aware Was Provider	
	n	%	n	%
Not At All	5	11.1%	0	0.0%
Slightly	12	26.7%	2	4.4%
Moderately	11	24.4%	8	17.8%
Very	12	26.7%	5	11.1%
Extremely	5	11.1%	17	37.8%
N/A	0	0.0%	13	28.9%
Total	45	100.0%	45	100.0%

Parents Who Have Not Participated

	Interest Level If Offered	
	n	%
Not Interested	13	30.2%
A Little Interested	8	18.6%
Interested	11	25.6%
Very Interested	6	14.0%
Extremely Interested	5	11.6%
Total	43	100.0%

Table 24

Have You Participated in Parent Advocacy Groups Related to ASD?

Parents Who Participated

	How Well Needs Were Met	
	n	%
Not At All	2	5.7%
Slightly	8	22.9%
Moderately	9	25.7%
Very	12	34.3%
Extremely	4	11.4%
Total	35	100.0%

Parents Who Have Not Participated

	Interest Level If Offered	
	n	%
Not Interested	13	30.2%
A Little Interested	8	18.6%
Interested	11	25.6%
Very Interested	6	14.0%
Extremely Interested	5	11.6%
Total	43	100.0%

Table 25

Have Your Non-ASD Children Participated in Sibling Support Groups Related to ASD?

Siblings Who Participated

	How Well Needs Were Met	
	n	%
Not At All	1	10.0%
Slightly	0	0.0%
Moderately	3	30.0%
Very	5	50.0%
Extremely	0	0.0%
Total	9	90.0%

Siblings Who Have Not Participated

	Interest Level If Offered	
	n	%
Not Interested	14	28.6%
A Little Interested	7	14.3%
Interested	8	16.3%
Very Interested	10	20.4%
Extremely Interested	10	20.4%
Total	49	100.0%
Not Applicable	14	28.6%

Table 26

Have You Participated in Parent-To-Parent Workshop Related to ASD?

Parents Who Participated

	How Well Needs Were Met	
	n	%
Not At All	1	2.9%
Slightly	3	8.8%
Moderately	15	44.1%
Very	11	32.4%
Extremely	3	8.8%
Total	33	97.1%

Parents Who Have Not Participated

	Interest Level If Offered	
	n	%
Not Interested	7	13.0%
A Little Interested	11	20.4%
Interested	14	25.9%
Very Interested	16	29.6%
Extremely Interested	6	11.1%
Total	54	100.0%

Table 27

Have You Participated in Respite Care Related to ASD?

Parents Who Participated

	How Well Needs Were Met		How ASD Aware Was Provider	
	n	%	n	%
Not At All	0	0.0%	1	3.4%
Slightly	4	13.8%	8	27.6%
Moderately	10	34.5%	8	27.6%
Very	10	34.5%	6	20.7%
Extremely	5	17.2%	6	20.7%
Total	29	100.0%	29	100.0%

Parents Who Have Not Participated

	Interest Level If Offered	
	n	%
Not Interested	13	22.0%
A Little Interested	7	11.9%
Interested	7	11.9%
Very Interested	10	16.9%
Extremely Interested	22	37.3%
Total	59	100.0%

Most important needs, services, and focus of services. Open-ended questions five, six, and seven asked parents to rate the most important needs (Table 28), services (Table 29), and focus of services (Table 30) for the parent in the context of parenting a child with an ASD. The most important need for parents was Respite (31.5%, n=34), with Education and Training (25.9%, n=28) second. The services desired and the focus of services that parents found most important predominantly addressed the needs of their child with an ASD (29.6%, n=32; 33.3%, n=6) and did not focus on services delivered directly to the parents (See Appendix F). When parents focused on their own needs, the majority of the parents identified Professional Support/Resources (25.0%, n=27) and Respite (14.8%, n=16) as the most important services, and for the most important focus of services, Professional Support/Resources (12.0%, n=13) and Education/Training (10.2%, n=11) were identified.

Table 28

Most Important Parental Need

	n	%
Respite	34	31.5%
Education & Training	28	25.9%
No Need Indicated	15	13.9%
Professional Support/Resources	14	13.0%
Positive Response – no specifics	11	10.2%
Community Advocacy/Awareness	11	10.2%
Answer Addressed Needs of Child, Not Parent	11	10.2%
Financial Assistance – including Insurance Needs	10	9.3%
Networking/Social Support	10	9.3%
Home-based Services	1	0.9%
No Services Are Accessible	0	0.0%

Table 29

Most Important Parental Service

	n	%
Answer Addressed Needs of Child, Not Parent	32	29.6%
Professional Support/Resources	27	25.0%
No Need Indicated	26	24.1%
Respite	16	14.8%
Education & Training	13	12.0%
Financial Assistance – including Insurance Needs	10	9.3%
Networking/Social Support	10	9.3%
Home-based Services	3	2.8%
Positive Response – no specifics	1	0.9%
No Services Are Accessible	1	0.9%
Community Advocacy/Awareness	0	0.0%

Table 30

Most Important Focus of Services

	n	%
Answer Addressed Needs of Child, Not Parent	36	33.3%
No Need Indicated	34	31.5%
Professional Support/Resources	13	12.0%
Education & Training	11	10.2%
No Services Are Accessible	9	8.3%
Respite	6	5.6%
Home-based Services	6	5.6%
Networking/Social Support	3	2.8%
Positive Response – no specifics	2	1.9%
Financial Assistance – including Insurance Needs	0	0.0%
Community Advocacy/Awareness	0	0.0%

Most useful present service/ most desired service not obtained. When asked what parental services or support that they were presently receiving was most useful (Table 31), the majority of the parents responding indicated Respite (20.4%, n=22), followed by Educational and Training (16.7%, n=18) and Professional Support/Resources (16.7%, n=18). These same services were identified as the top three for parents who were not presently receiving such services (Table 32), but would find them most useful; Respite (33.3%, n=36), Professional Support/Resources (27.8%, n=30), and Education and Training (24.1%, n=26).

Table 31

Types of Parental Services/Support Currently Most Useful

	n	%
No Need Indicated	29	26.9%
Respite	22	20.4%
Education & Training	18	16.7%
Professional Support/Resources	18	16.7%
No Services Are Accessible	15	13.9%
Answer Addressed Needs of Child, Not Parent	12	11.1%
Networking/Social Support	11	10.2%
Financial Assistance – including Insurance Needs	2	1.9%
Community Advocacy/Awareness	2	1.9%
Home-based Services	1	0.9%
Positive Response – no specifics	0	0.0%

Table 32

Types of Parental Services/Support Not Currently Received

	n	%
Respite	36	33.3%
Professional Support/Resources	30	27.8%
No Need Indicated	26	24.1%
Education & Training	26	24.1%
Answer Addressed Needs of Child, Not Parent	9	8.3%
Positive Response – no specifics	5	4.6%
Financial Assistance – including Insurance Needs	5	4.6%
Networking/Social Support	4	3.7%
Community Advocacy/Awareness	0	0.0%
Home-based Services	0	0.0%
No Services Are Accessible	0	0.0%

Ranked top three services. In the final section of the questionnaire, parents were asked to rank order the top three services they would find most useful for themselves, regardless of whether they had received them in the past (Table 33). Parents were provided with the list of services identical to those to which they had responded in the previous section, as well as three open-ended options. This latter addition allowed respondents to identify up to three additional services they would find most important. The majority of the respondents indicated that the first most important service was Individual Therapy (23.0%, n=20). The second most important service was Educational Parent Groups (18.4%, n=16), and the third most important service was Process Oriented Parent Support Groups. The chart below also demonstrates the number of respondents indicating each service as being in their top three, with Parent Training (39.1%, n=34) being the highest indentified among each level of importance. More than half of responding parents had participated in six of the 11 services that were ranked first or second most important. There was an exception for the services ranked third most important. The majority of these services had not been utilized by parents.

Table 33

The Top Three Services Parents Find Most Importan

	First Most Important		Second Most Important		Third Most Important		Top 3 Responses	
	n	%	n	%	n	%	n	%
Parent Training	15	17.2%	11	12.6%	8	9.2%	34	39.1%
Individual Therapy	20	23.0%	6	6.9%	7	8.0%	33	37.9%
Educational Parent Group	5	5.7%	16	18.4%	6	6.9%	27	31.0%
Parent Advocacy Groups	5	5.7%	10	11.5%	11	12.6%	26	29.9%
Couples Therapy	6	6.9%	8	9.2%	9	10.3%	23	26.4%
Sibling Support Groups	4	4.6%	10	11.5%	5	5.7%	19	21.8%
Parent-To-Parent Workshops	7	8.0%	3	3.4%	9	10.3%	19	21.8%
Drop-In Center	6	6.9%	5	5.7%	7	8.0%	18	20.7%
Process-Oriented Parent Support Groups	2	2.3%	4	4.6%	12	13.8%	18	20.7%
Other – Respite	10	11.5%	3	3.4%	5	5.7%	18	20.7%
On-Line Support Groups	2	2.3%	8	9.2%	5	5.7%	15	17.2%
Other – Child Social Groups/ Workshops	2	2.3%	0	0.0%	1	1.1%	3	3.4%
Other – Financial	1	1.1%	0	0.0%	1	1.1%	2	2.3%
Other – Family Therapy	0	0.0%	1	1.1%	0	0.0%	1	1.1%
Other – Case/Social Worker	1	1.1%	0	0.0%	0	0.0%	1	1.1%

The demographic information was compared with the responses to the services that were first most important. The results were evaluated to determine if parents with particular demographics demonstrated a need for specific services. Parents between the ages of 30-39 ranked Individual Therapy as the highest need, while those between ages 40-49 ranked Parent Training, followed closely by Respite, as most important (Table 34). Viewing responses from an attained education perspective (Table 36), the majority of those ranking Parent to Parent Workshops as most important possessed an Associates degree. Married couples were most interested in Parent Training (Table 35). Respite and Couples Therapy were ranked highest by those with a Bachelors degree. Individual Therapy was the highest ranked service across income levels (Table 37) Individual Therapy and Respite were ranked most important most frequently by those who were Employed by Employer (Table 38). When comparing neighborhood type (Table 37), those residing in an Urban setting predominantly wanted Individual Therapy, while those in a Rural setting ranked Individual Therapy and Parenting Training highest. When looking at who ranked Respite as most important, the majority of them had more than one child, but not necessarily more than one child with an ASD, which was consistent with the demographics of the respondents (Table 40 & 41). Parent Training appeared highly important to families who obtained a diagnosis 0-7 years ago (Table 42). Parent to Parent Workshops were most popular for those whose children were diagnosed 4-7 years ago. The majority of those who received a diagnosis 8-11 years ago ranked Respite as most important, and Individual therapy was the most desired service for those whose children were diagnosed 0-3 or 12 or more years ago.

Table 34

First Most Important Service Sorted By Parent Age

	under 30 (n=6)	30-39 (n=27)	40-49 (n=39)	50+ (n=10)
Individual Therapy	1	10	5	4
Parent Training	1	2	11	1
Respite	0	1	9	0
Parent-To-Parent Workshops	1	4	2	0
Couples Therapy	0	4	2	0
Drop-In Center	0	1	3	2
Educational Parent Group	1	1	1	2
Parent Advocacy Groups	1	2	2	0
Sibling Support Groups	0	2	1	1
Process-Oriented Parent Support Groups	1	0	1	0
On-Line Support Groups	0	0	2	0

Note: Total n=82 due to the other category being removed (n=6)

Table 35

First Most Important Service Sorted By Marital Status

	Married (n=64)	Domestic Partner (n=0)	Divorced (n=7)	Widowed (n=1)	Separated (n=4)	Never Married (n=6)
Individual Therapy	12	0	3	0	2	3
Parent Training	15	0	0	0	0	0
Respite	7	0	1	0	1	1
Parent-To-Parent Workshops	6	0	1	0	0	0
Couples Therapy	6	0	0	0	0	0
Drop-In Center	6	0	0	0	0	0
Educational Parent Group	3	0	0	1	0	1
Parent Advocacy Groups	3	0	0	0	1	1
Sibling Support Groups	3	0	1	0	0	0
Process-Oriented Parent Support Groups	1	0	1	0	0	0
On-Line Support Groups	2	0	0	0	0	0

Note: Total n=82 due to the other category being removed (n=6)

Table 36

First Most Important Service Sorted By Educational Level

	High School/ GED (n=10)	Some College (n=15)	Associate Degree (n=14)	Bachelors Degree (n= 23)	Masters Degree (n=17)	Doctorate (n=3)
Individual Therapy	4	5	1	6	3	1
Parent Training	0	2	4	4	4	1
Respite	1	2	1	4	2	0
Parent-To-Parent Workshops	0	1	5	1	0	0
Couples Therapy	0	1	0	4	1	0
Drop-In Center	1	1	1	0	3	0
Educational Parent Group	0	1	1	1	1	1
Parent Advocacy Groups	3	1	0	0	1	0
Sibling Support Groups	1	0	1	1	1	0
Process-Oriented Parent Support Groups	0	1	0	1	0	0
On-Line Support Groups	0	0	0	1	1	0

Note: Total n=82 due to the other category being removed

Table 37

First Most Important Service Sorted By Income Level

	Prefer Not To Say (n=5)	Less than $20,000 (n=8)	$20,000 To $59,999 (n=21)	$60,000 To $99,999 (n=20)	$100,000 To $139,999 (n= 18)	$140,000 or More (n=10)
Individual Therapy	1	4	6	4	4	1
Parent Training	2	0	3	2	4	4
Respite	0	1	2	3	4	0
Parent-To-Parent Workshops	0	0	1	4	2	0
Couples Therapy	1	0	2	1	1	1
Drop-In Center	0	0	2	1	1	2
Educational Parent Group	0	0	2	1	1	1
Parent Advocacy Groups	1	3	0	0	0	1
Sibling Support Groups	0	0	1	3	0	0
Process-Oriented Parent Support Groups	0	0	2	0	0	0
On-Line Support Groups	0	0	0	1	1	0

Note: Total n=82 due to the other category being removed

(n=6)

Table 38

First Most Important Service Sorted By Employment Status

	Home maker	Student	Employed by Employer	Self-Employed	Out - Looking for Work	Out - Not Currently Looking	Retire	Un able to Work
Indiv. Therapy	3	1	13	0	1	0	1	1
Parent Training	4	2	7	2	0	0	0	0
Respite	1	1	7	0	0	1	0	0
Parent to Parent Work-shop	2	0	5	0	0	0	0	0
Couples Therapy	3	0	2	1	0	0	0	0
Drop-In Center	2	0	4	0	0	0	0	0
Ed. Parent Group	1	0	2	2	0	0	0	0
Parent Advocacy Groups	1	0	3	0	1	0	0	0
Sibling Support Groups	1	0	3	0	0	0	0	0
Process-Parent Support Groups	1	0	1	0	0	0	0	0
On-Line Support Groups	1	0	1	0	0	0	0	0

Note: Total n=82 due to the other category being removed (n=6)

Table 39

First Most Important Service Sorted By Neighborhood Type

	Urban (n=13)	Suburban (n=47)	Rural (n=22)
Individual Therapy	6	9	5
Parent Training	1	8	6
Respite	2	8	0
Parent-To-Parent Workshops	1	5	1
Couples Therapy	1	4	1
Drop-In Center	0	4	2
Educational Parent Group	0	3	2
Parent Advocacy Groups	1	2	2
Sibling Support Groups	0	2	2
Process-Oriented Parent Support Groups	0	1	1
On-Line Support Groups	1	1	0

Note: Total n=82 due to the other category being removed (n=6)

Table 40

First Most Important Service Sorted By Number of Children

	1 (n=19)	2 (n=41)	3 (n=18)	4 (n=3)	5+ (n=1)
Individual Therapy	7	7	5	1	0
Parent Training	7	5	2	0	1
Respite	1	5	3	1	0
Parent-To-Parent Workshops	2	4	1	0	0
Couples Therapy	1	4	1	0	0
Drop-In Center	0	5	0	1	0
Educational Parent Group	0	4	1	0	0
Parent Advocacy Groups	1	3	1	0	0
Sibling Support Groups	0	1	3	0	0
Process-Oriented Parent Support Groups	0	1	1	0	0
On-Line Support Groups	0	2	0	0	0

Note: Total n=82 due to the other category being removed (n=6)

Table 41

First Most Important Service Sorted By Number of Children with an ASD

	1 (n=70)	2 (n=11)	3 (n=1)
Individual Therapy	16	4	0
Parent Training	13	2	0
Respite	8	2	0
Parent-To-Parent Workshops	7	0	0
Couples Therapy	4	1	1
Drop-In Center	5	1	0
Educational Parent Group	5	0	0
Parent Advocacy Groups	5	0	0
Sibling Support Groups	4	0	0
Process-Oriented Parent Support Groups	2	0	0
On-Line Support Groups	1	1	0

Note: Total n=82 due to the other category being removed (n=6)

Table 42

First Most Important Service Sorted By Years Since First Diagnosis

	0-3 (n=30)	4 to 7 (n=29)	8 to 11 (n=16)	12+ (n=7)
Individual Therapy	8	6	2	4
Parent Training	7	5	2	1
Respite	1	2	6	1
Parent-To-Parent Workshops	1	5	1	0
Couples Therapy	4	1	1	0
Drop-In Center	3	2	1	0
Educational Parent Group	2	3	0	0
Parent Advocacy Groups	2	1	1	1
Sibling Support Groups	0	3	1	0
Process-Oriented Parent Support Groups	1	0	1	0
On-Line Support Groups	1	1	0	0

Note: Total n=82 due to the other category being removed (n=6)

Providers, barriers, location, and ASD aware. Specific qualities of service providers, location, and barriers to services also were assessed in the open-ended questions. Aspects or qualities that parents looked for in a service provider (Table 43) demonstrated that Knowledge and Experience (43.5%, n=47) with ASDs were important qualities, followed by Kind, Compassionate, and Empathy (19.4%, n=21). Many responses were categorized under an "Other" (27.8%, n=30) category, due to a wide range of responses. Examples of these responses include, “not one to rigidly adhere to specific practices or their past experiences,” “same socio-economic background that we have,” “efficiency is very important,” “good word-of-mouth from other parents,” “professionalism,” “access to information within the community/state,” and “open-mindedness of all treatments.”

There were several barriers indentified by parents as interfering with their obtaining services (Table 44). The most frequent response of the parents indicated that Cost/Money (42.6%, n=46) was a barrier. Additionally, parents stated they were Unaware of Needed or Available Services (28.7%, n=31), and that Limited Time/Office Hours (27.8%, n=30) interfered. Insurance (26.9%, n=29) and having No Services Available or Accessible (26.9%, n=29) also were frequent barriers.

To determine how to decrease barriers, the parents were asked about where services would best be delivered (Table 45). The best place for delivery of a service was the Caregiver’s Home (51.9%, n=56), followed by the Therapist’s Office (17.6%, n=19). Many of the parents did not respond (21.3%, n=23). Parents also indicated that the Community (10.2%, n=11) is the best place while the same number indicated that Anywhere (10.2%, n=11) would be best.

Table 43

Aspects/Qualities in Provider of Support Services

	n	%
Knowledge and experience	47	43.5%
No Answer/Uncertain	31	28.7%
Other	30	27.8%
Kind/Compassionate/Empathy	21	19.4%
Good Communication/Listening Skills	19	17.6%
Understanding	14	13.0%
Patient/tolerant	11	10.2%
Respectful/Non-Judgmental	7	6.5%
Parent of ASD/Parent	3	2.8%

Table 44

Barriers Interfering with Obtaining Services

	n	%
Cost/Money	46	42.6%
Not aware of needed/available services	31	28.7%
Time/Office Hours	30	27.8%
No services available/accessible	29	26.9%
Insurance	29	26.9%
Childcare	25	23.1%
No Response	23	21.3%
Other	10	9.3%
No Barriers	4	3.7%

Table 45

Best Place for Service Delivery

	n	%
Home	56	51.9%
No Answer	23	21.3%
Therapist's Office	19	17.6%
Community	11	10.2%
Anywhere	11	10.2%
School	7	6.5%
Depends on Service	6	5.6%
Local	3	2.8%

To determine how important it was to parents that their provider be specifically trained to work with ASDs, they were asked to respond on a Likert scale of one being Not at All to five being extremely important (Table 46). Half of the parents indicated that it is extremely (50.0%, n=54) important. When asked why it was important to have an ASD aware provider, parents were allowed to answer freely (Table 47). The responses were sorted into five categories, with the highest percentage saying that providers need to Understand ASD and its Uniqueness (38.9%, n=42).

Table 46

How Important To You That Provider is Trained In ASD

	n	%
Not At All	0	0.0%
Slightly	3	2.8%
Moderately	11	10.2%
Very	22	20.4%
Extremely	54	50.0%
Did Not Respond	18	16.7%

Table 47

Why ASD Training is Important

	n	%
Understand ASD/Uniqueness	42	38.9%
Knowing right services/resources/responses	25	23.1%
No Response	22	20.4%
Not relevant/Specific	19	17.6%
Untrained person can make matters worse/difficult	10	9.3%

Discussion

While the incidence of ASD is increasing, services for caregivers of children with an ASD are lacking. Most ASD needs based studies have focused on the services and needs of the child with an ASD, but few have focused on the needs of their caregivers. This study was designed to determine those needs and services the parents or guardians of children with an ASD felt to be most important for themselves. This study provided a forum for parents to express the needs and services they felt have not been met, as well as those they believed were most important to them. Caregivers were asked whether they had participated in the various services. If so, they were asked to indicate their level of satisfaction with the service, along with the ASD awareness level of the provider. If the respondents had not participated in the service, they then were asked how likely they would be to use it if offered to them within the next three months. Respondents further were asked to rank the top three services they found most important, whether or not they had participated in those services

Participants

The demographics of those answering the questionnaire were less diverse than anticipated. It was expected that the demographics would reflect those of the United States, due to the potential for widespread distribution of the questionnaire via the internet. An exclusionary criterion eliminated individuals residing outside of the United States. However, it does not appear that the survey was that broadly distributed, as there were limited responses from states outside New England. The demographics do, however, match the general population of New Hampshire (US Census Bureau, 2011) and may be an accurate representation of parents in New Hampshire. A very high percentage of respondents were mothers, and there are numerous possibilities as to why. For example, some researchers believe that mothers are more involved in their child's day to day care than fathers (Civick, 2008), they may be better connected with autism societies, searching for help more than other caregivers, or maybe fathers and other caregivers are less likely to be reached through support websites, or to respond to online questionnaires. Research has found that when parents have a child with a disability, mothers are stressed more than fathers, and therefore it is possible that more mothers were searching for assistance (Civick, 2008).

A majority of the respondents were married, which presented another unexpected result. Research has found an increased risk of divorce among parents who have a child with an ASD (Benson & Karlof, 2009; Erguner-Tekinalp & Akkok, 2004; Hartley et al., 2010; Vogt, 2007). It was expected that the study would have a higher number of respondents who were divorced. Hartley et al. found that parents of a child with an ASD had a divorce rate twice the size of the comparison group of parents without a child with an ASD (Hartley et al., 2010). It also was found that, for a comparison group of families without a child with an ASD, the rate of divorce decreased drastically during their child’s late childhood. This was not apparent in Hartley et al.’s sample of families with a child with an ASD. Rather, divorce rates remained high into their child’s adulthood (Hartley et al., 2010).

Parents of a child with an ASD suffer increased parental demands and stress. Although most new parents and those with young children experience increased stress, lack of sleep, and extensive parental responsibilities, this appears to carry on into adulthood for many parents of children with an ASD. These parents may never find themselves as “empty nesters,” as their children may never be able to live independently. “As children without a disability age, they launch into their own independent lives and parenting demands and stress often decrease, affording a renewed focus on the marital relationship” (Hartley et al., 2010, p. 455). The continuous demands on the parents often leave limited time for themselves or the relationship. Studies have found that those with support from their partner have less stress than those without a supportive partner (Johnson et al., 2006; Marcus et al., 2005). It is possible that those with the time and energy to complete the questionnaire were subject to lower stress due to the presence of a supportive partner, therefore explaining the high rate of participants who were married.

Another unexpected finding was that a majority of respondents possessed an Associates degree or higher level of education. It is uncertain whether those with higher education have greater access to the internet, or have an interest in research, and therefore participated. Socio-economic status (SES), which is measured as a combination of education, income, and occupation, does not affect the incidence of ASD (CDC, 2010; Volkmar & Klin, 2005). Therefore, it was expected that the demographics would reflect the SES spectrum. The lack of variation in SES supports the idea that those without higher education either chose not to participate or the questionnaire did not reach them.

According to the CDC (2010), “parents who have a child with an ASD have a 2%–8% chance of having a second child who is also affected” (para. 6). A recent study found that these numbers may be even higher (Ozonoff et al., 2011). Dr. Ozonoff’s study found that “18.7% of infants with at least one older sibling with ASD developed the disorder. The two strongest predictors of an ASD diagnosis were the gender of the infant and the number of affected older siblings” (Ozonoff et al., 2011, p. 5). The highest reoccurrence risk, 32.2%, was for a male infant with multiple siblings diagnosed with an ASD (Ozonoff et al., 2011). In the present study, most of the families responding had two children, with only one child diagnosed with an ASD. A possible explanation is those with more than one child with an ASD struggle to find the time to participate in such research, or that the children’s needs come before the parent’s need, and the parent opted out of participating.

Although there were fewer respondents having more than one child with an ASD than expected, the study had an interesting finding in cases where there was more than one child with an ASD. When two siblings were diagnosed with an ASD, frequently both siblings were diagnosed within the same year, or the younger child was diagnosed before the older child. It is uncertain if the younger child’s diagnosis led to the older child obtaining a diagnosis, or if the older child was in the process of being diagnosed. It is also possible that presently there are more evaluation services and more appropriate evaluations for ASDs, so therefore the older child may be getting identified and diagnosed now. Due to anonymity and the inability to question further, I was unable to determine if the younger child’s diagnosis led to the older child’s diagnosis, or how the diagnosis process ensued. It is recommended future studies examine the diagnostic process for different families.

Most respondents had, on average, five years or more experience in raising a child with an ASD. There were very few who obtained a diagnosis recently. It is possible that families with a new diagnosis may have denied the diagnosis, their feelings, their needs, or not have been aware of how to access basic services (Rarity, 2007; Rubens, 2009). It is probable that those with a new diagnosis were still in shock, and not ready to participate in a study that evaluated their needs as a parent of a child with an ASD. Additionally, the overwhelming experience of receiving a diagnosis of ASD, or the daily time constraints of having a child with an ASD, may have prevented parents of newly diagnosed children from participating. This may be the result of parents' needs being suppressed for the first few years after diagnosis, with parents focusing on meeting the needs and obtaining the services required for their child. It is also possible that newly diagnosed families have support right after diagnosis, and did not need to seek help on the internet.

Parental Needs and Services

This study allowed parents to express their perspectives on the needs and services that they required. Providing a forum for parents to convey their own experiences contributes to a better understanding of the needs of parents. Respondents were asked about specific needs they felt had not been met. When parents were offered a forum to express what they needed, most requested similar services.

As found in the literature, parents expressed a strong need for respite services (Bromley et al., 2004; Johnson et al., 2006; Ruble & McGrew, 2006; White & Hastings, 2004). Respite services were indicated as needed for both the parents and siblings. Parents indicated they do not have enough time to perform daily tasks or errands, and they certainly do not have time for themselves. "The most difficult thing is feeling like you don't have a life of your own.

Everything revolves around the kids, or at least it feels that way. A safe place/person for the kids to give me a chance to pursue something for myself (if even just a pedicure) would be great.” Many parents indicated respite care was needed because “my partner and I don’t ever get breaks or time to nurture our marriage.” Parents continued to verify what studies have found in the past.

Parents felt drained, isolated, and stressed. Due to time constraints, financial struggles, increased parental responsibilities, behavioral issues, and familial strain, parents often found it difficult to reserve time for themselves or for the needs of other family members as has been found in past studies (Bebko et al., 1987; Cole & Arndt, 1998; Exkorn, 2005; Honey et al., 2005; Kroodsma, 2007; Linares-Gonzalez, 2006; Long; 2005; McConachie et al., 2007.; Rogers, 2008). Parental needs frequently became low priority, a situation that can have an adverse effect on the entire family. Parents who developed adaptive coping have been found to have lower stress (Erguner-Tekinalp & Akkok, 2004; Honey et al., 2005; Solish & Perry, 2008). Parents with supportive partners also have been found to have less stress (Johnson et al., 2006; Marcus et al., 2005). Providing parents with time to nurture or work on their marriage or individual health potentially would increase their ability to serve their children better. Respite support needs to be offered to help parents reduce their levels of stress in order to meet the needs of their child and attend to their own needs. When parents ignore their own basic requirements, their ability to adequately address the needs of their child is diminished.

Those who also had other children without an ASD indicated that respite time would be helpful in providing the non-ASD child with support and attention that often was forfeited due to time and resource constraints. “My younger son has issues of his own that aren't even being addressed. I don’t have the energy or focus to advocate for him, because his older brother is taking up every ounce of my time and energy. The guilt I live with......” Siblings frequently became substitute caregivers or respite providers for parents, which was a major concern for parents. “I do not have a caregiver or respite caregiver...this makes it very difficult to leave the home for errands, etc. My other two teenage daughters and I take turns staying with the teenager with autism while the others go out of the home.” Parents struggled to satisfy the needs of siblings and to find qualified caregivers to help care for their child’s needs. A priority for policy makers should be the funding and development of respite services.

As found in other studies, parents struggled to find qualified alternative caregivers (Murphy et al., 2006). They frequently turned to siblings or family members as alternative caregivers or babysitters, due to a lack of knowledgeable or trained outside providers. This task can interfere with the family members’ ability to participate in desired activities and getting their own needs met, which can increase familial strain. It is important that respite providers are aware of the needs and unique qualities of those with an ASD. While parents need respite, untrained providers of respite care will not meet this need (Murphy et al., 2006).

Parents most frequently expressed a desire for knowledge and experience as required qualities of service providers working with ASDs. When parents were asked to rate how important it was that the service provider (e.g. respite care, individual therapy, couples therapy, and parent training) be ASD aware, most of the parents indicated it was extremely important, stating providers needed to be knowledgeable and understand ASD and its uniqueness. Many parents expressed the need for ASD aware providers so that they would not have to educate the providers. Being ASD aware made it “easier to understand the whole picture.” “We'd prefer to have someone trained to work with ASD so we don't have to educate the provider on the ins and outs of the disorder.” Parents often found that an ASD aware provider made services more effective. “A provider that has been specifically trained to work with ASD makes our job as parents that much easier. We aren't having to first educate them and then navigate/search for the answers to our questions together. Hopefully they will have the answers or be able to provide us the information on where to find it." Several parents found service providers who were not knowledgeable and experienced with ASDs had "looked down their nose at me" or "make it that we were bad parents." "10-15 years ago, I had to train my therapist. Schools treated her as though she was retarded. Last year, her 4-H leaders treated her the same way. I have been on my own in this journey. The "professionals" are still treating the parents like they are stupid and only the professionals know anything. This is bull! The parents don't know why but they do know their kids." A number who received services were not satisfied with the services due to the provider's lack of ASD knowledge. In reviewing the responses, a parent's level of satisfaction appeared to be related to the ASD awareness of the provider.

Having an ASD aware therapist is a pressing issue for parents of children with an ASD. This may be a particularly pressing issue for parents due to the all encompassing and isolating job of raising a child with an ASD. It may be important to help parents sort out the overwhelming amount of information and deciphering what is "real" versus "rumor". There appears to be more reasons for a specifically trained therapist for ASDs compared to hyperactivity or depression. Therapist should be aware that parents and families need an ASD aware therapist. It may be beneficial for future research to further examine the specific attributes of clinicians that parents find helpful and what it is that makes having an ASD aware provider so important.

Parents presented a strong desire for professionals who offered effective support and resources. Many parents expressed that there appeared to be limited professional resources to help them emotionally while understanding the effects of ASDs on the family. "There are few emotional supports for parents of children on the spectrum," "easy access to counselors with intensive knowledge of autism," "personal emotional support and assistance in finding resources," and "therapist with knowledge of what parents go through is hard to find" were a few of the responses from parents expressing this concern. It was evident parents were in need of services for themselves.

While the study specifically focused on parental needs and services, many respondents indicated needs and services for their child with an ASD, implying that their child's needs are highly important, and need to be addressed before they are able to attend to their own. Parents frequently requested physical therapy, occupational therapy, social skills groups, Applied Behavioral Analysis (ABA), and speech therapy for their child. "Anger management classes for my child with ASD would be very helpful." "We have not been given substantial social skills training for the kids." "Playgroups or similar types of groups with other age appropriate ASD children and to be affordable." Many parents continued to request these services when being asked about services for themselves. Practitioners need to be aware that parents are struggling to meet their child's needs, and so having the child's needs met does in fact meet the parents' needs. "Proper schooling is necessary, The closest school in NY is 3 hours away from me so they send my son to a Boces program which is just a school they send kids they don't want to deal with or feel they are troubled and a danger to be in regular school and none of these teachers or staff have the proper training to help these children. They feel that my son should be like any normal 7th grader but he is autistic." A parent is unable to reflect on their own needs when their child's needs are being neglected. "At this point, I think anyone trying to discuss emotional support with me would just make me cry. I have to maintain focus on the importance of getting my child the supports and services he needs for optimal development." Children with an ASD usually look typical on the outside but have extreme behaviors which subject parents to a lot of judgment. Parents may fail to focus on their own needs due to their defenses. They may fear that the perception that they caused the disorder, linked with the fact that they are in need of services, confirms others assumptions that it is their fault. It appears that for some parents, when their child's needs are being met, then their own needs are being met. If meeting the child's needs will alleviate parental stress, practitioners should be evaluating the needs of the children first, and once those are met, to then begin working to understand what specific services parents feel they need. It may also be necessary for practitioners to help parents focus on their own needs and self-care because the parental mental and physical health directly impacts their child (Akkok, 1994; Kuhn, 2006; McConachie & Diggle, 2007; Sofronoff & Farbotko, 2002).

When parents were able to concentrate on the needs and services that were most important to their health, they consistently indicated respite care, educational and training support, and professional support and resources. Marcus, Kunce, and Schopler (2005) found that parents were regularly involved in behavior training programs for their children, and this was identified as an important service for parents. Services that are provided to children with an ASD need to incorporate parents or families better. Parents will continue to focus on the needs of their children. However, emphasis also must be directed to their own mental health. It is possible that parents are focusing on the needs of their child given that they are defensive against the feeling of being blamed by others and not wanting to acknowledge that they need services for themselves. Research shows that parental stress influences the child, and parents with positive coping skills present decreased levels of stress (Erguner-Tekinalp & Akkok, 2004; Solish & Perry, 2008). It appears that service providers must increase integration of the family in the treatment of children with an ASD while providing more educational and training support, professional support and resources, and respite than is typical presently. This is necessary not just for handling the ASD child, but also for addressing the parents own stress and coping skills. If services are available to parents, there needs to be an improved system as to how this information is conveyed to parents or implemented. Many parents indicated a need for a case manager or a roadmap to obtaining services. “I find the lack of consistent support challenging. When we got the diagnosis, we left the office with a list of names and numbers for possible help and that was it. We felt like a cork bobbing in the ocean.” “There is no central location or organization as there would be should she have a medical diagnosis.” “Need to find a partner to help me navigate the universe of services and needs. Medically almost no one takes responsibility for recommending anything I have to be reading and asking, or convincing professionals.” It is possible that all of the necessary services for parents and the children with an ASD are out there, but that the organization and navigability are lacking.

It was evident from the responses that most parents had not participated in many of the services identified. Parent Skills Training, Educational Parent Groups, and Online Support Groups were the only services in which more than half of the parents had participated. Responses echoed the ASD literature, reinforcing the notion of limited services available for parents, and when a service did exist, it usually involved parent skills training or a support group (Bebko et al., 1987; Erguner-Tekinalp & Akkok, 2004; Lin, Tsai, & Chang, 2008; Linares-Gonzalez, 2006). Parents had not obtained the services that they felt would meet their needs. There were a number of services where parents expressed an interest in participating, but had not had an opportunity to do so.

A number of barriers confronted parents in their search for services. Parents frequently were under enormous time constraints, often attending multiple services for or meetings relating to their child. Parents found that trying to travel to the various service sites as well as the multiple tasks needed to prepare the child with an ASD for the travel routine stressful and often hindering. Similar to other studies, respondents indicated the best place a service could be delivered was in the caregiver's home (Rogers, 2008). Therefore, service providers should assess their ability to provide multiple family oriented services at the same location and time to reduce the demand on impacted families. Money appeared to be the largest barrier to parents seeking help. Parents were faced with a strong need or desire for services, but often encountered limited availability of services, difficultly in obtaining services when available, or services were unaffordable. When planning services for families, service providers should consider their office hours, the insurance they accept, and the accessibility of their location. Responses indicate many parents were unaware of services being offered, which suggests that service providers need to help make their services more accessible and better advertised.

Respondents were asked to rank the three services they felt were of most importance. Individual Therapy for the parent, Parent Training, and Respite received the highest ranking. The responses reemerge in various questions throughout the study. Curiously, Parent Training was the only service where the majority of parents who actually received the service also found it highly important. Parent training has been found to result in improved prognosis for children with an ASD (Akkok, 1994; Kuhn, 2006; McConachie & Diggle, 2007; Wang, 2008).The study shows parents were asking for services that other research has found to be of value. Of the other services deemed important, fewer than half of the respondents actually had participated in the services. It appears that, apart from parent training, other services that parents felt were highly important either were not being offered or parents were not aware of the available services.

This study was designed to help obtain a better understanding of the needs and services desired by parents of children with an ASD. From the research, it was evident that parents continued to focus their time and attention on the needs of their child with an ASD while their personal needs went unmet. Questions were presented in three different formats, allowing for diversity within responses. However, the same needs and services, individual therapy, parent training, and respite, repeatedly were ranked as being most important.

This study was rich with parental feedback. Obtaining 108 completed responses within six weeks from very busy and hard working parents was exceptional. Parents were successful in providing feed back and advocating for their families. “Good luck in your research. I don't know what your relationship with autism is, but I think oftentimes "outsiders" think that parenting a kid with autism is exceptionally hard. It is hard, but not necessarily because of the kid or the autism. Most of the difficulty comes from dealing with other people's ignorance, discrimination, school systems that are not set up to really serve our kids, and fighting the hugely negative stereotype that most people have about autism. If everyone accepted my kids just the way they are my life would be a lot easier. I have always felt it is important that researchers understand that more often than not it is *other people* who make parenting a kid with autism difficult, not necessarily the kids themselves.” Parents also were very thankful for research being done on their needs. Many expressed that parents were forgotten and no one asked their opinion. “Thanks for caring about the parents - this is a hard job, and even harder to do all by yourself.” Parents’ needs must be met so that they will be better able to address their child’s needs. The importance of meeting the needs of the family must receive more attention from policy makers and service providers. Service providers need to incorporate the family into treatment, address the needs of the entire family, and work with the parents to determine the best possible approach to services for the whole family.

Limitation of the Study

The study was not without its limitations. Flyers recruiting participants were sent to societies, associations, and support groups for ASD. Many of the participating organizations included a link to the questionnaire on their website, or a reference in their newsletter, list serves, and emails. The link to the questionnaire should have reached a wide population within the ASD community. A small number of those who received the link participated. In addition, the sample was self-selecting, limited to those parents who chose to participate. It is possible that the majority of the sample were parents whose needs were not being met and opted to answer the questionnaire. Parents whose needs were being met may have chosen not to participate, artificially inflating the needs identified in this study. On the other hand, it is possible these participants had more needs met and therefore had time and energy to participate. Therefore it is unclear if the participants were representative of all parents of children with an ASD. The response rate and motivation of those responding is unknown. The participants also may not be representative of the general ASD caregivers population, as the largest volume of respondents was from New England, with a disproportionate number being Caucasian. The study was nonrepresentative of minority ethnic groups and lacked true geographic dispersion. The questionnaire was distributed such that most parents were associated with an ASD-related organization and all had access to the internet. For the aforementioned reasons, generalization is cautioned.

The anonymity of the questionnaire prevented further querying or asking the participants to clarify information. This prevented triangulation, multiple checks, and clarification. I was unable to communicate with the participants, or to determine whether the responses provided fit within the themes assigned. The questionnaire did not include any process of verifying that the child was diagnosed with an ASD. This important factor was based solely on the parent report. Another limitation was the variability of the spectrum which prevented the parents from identifying if their child was higher functioning Autism, Asperger's disordered, or PDD-NOS. It is uncertain if the needs would vary or look different based on the diagnosis or the level of functioning. Parents of higher functioning children may be getting fewer of their needs met than parents of lower functioning children who are getting more services because of the severity of their child's problems.

The study's main limitation is its generic application to all families with an ASD and therefore future research may consider integrating an in-depth interview guided by the open-ended questions, allowing for more developed responses and clarification. A diagnostic assessment, including the characteristics of the child with an ASD, would help verify that the child does have an ASD. It would also allow for the researcher to evaluate whether parental needs differ based on the child's characteristics. Broader circulation of the questionnaire also would be beneficial. Paper copies with return addressed, stamped envelopes, distribution through schools, and other ASD programs and child service providers may help establish better representation of the general population.

Closing Thoughts

This study was a small step toward encouraging further research into hearing parents' perspective on their needs. The research was a needs based assessment and was successful in uncovering the needs and services deemed most beneficial for those completing the questionnaire. Study responses indicate a strong need for services focusing on the parent of a child with an ASD. In addition to demonstrating a shortage of current services, respondents expressed a desire to participate in particular services if offered. It is hoped that, this study will help service providers develop a better understanding of the services parents need and want, and will encourage more providers to develop such services.

References

Akkok, F. (1994). An overview of parent training and counseling with the parents of children with mental disabilities and autism in Turkey. *International Journal for the Advancement of Counseling, 17,* 129-138.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed. Text revision). Washington, DC: Author.

Bågenholm, A., & Gillberg, C. (1991). Psychosocial effects on siblings of children with autism and mental retardation: A population-based study. *Journal of Mental Deficiency Research*, *35,* 291-307.

Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research, 51,* 702-714.

Bebko, J. M., Konstantareas, M. M., & Springer, J. (1987). Parent and professional evaluations of family stress associated with characteristics of autism*. Journal of Autism and Developmental Disorders, 17,* 565-576.

Benson, P. R. & Karlof, K. L. (2009). Anger, stress proliferation, and depressed mood among parents of children with ASD: a longitudinal replication*. Journal of Autism and Developmental Disorder*, *39,* 350-362.

Bromley, J., Hare, D.J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autism spectrum disorders*. Autism, 8,* 409-423.

Brown, R.T., Antonuccio, D.O., Dupaul, G.J., Fristad, M. A., King, C. A., Leslie, L. K., McCormick, G. S., Pelham, W. E., Piacentini, J. C., Vitiello, B. (2008). *Childhood mental health disorders*: *Evidence base and contextual factors for psychosocial,* *psychopharmacological, and combined interventions*. Washington, DC: American Psychological Association.

Centers for Disease Control and Prevention (2010). *Autism Spectrum Disorder fact sheet*. Retrieved from http://www.cdc.gov/ncbddd/actearly/facts.html

Centers for Disease Control and Prevention (2010). *CDC study: An average of 1 in 110 children have an ASD.* Retrieved from http://www.cdc.gov/features/countingautism/

Civick, P. (2008). *Maternal and paternal differences in parental stress levels and marital satisfaction levels in parents of children diagnosed with autism spectrum disorders.* (Doctoral Dissertation). Retrieved from ProQuest.

Cole, C.L., & Arndt, K. (1998). Autism. In L. Phelps (Ed.), *Health-related disorders in children and adolescents: A guidebook for understanding and educating* (pp. 82-92). Washington, DC: American Psychological Association.

Collings, C. (2008). That's not my child anymore! Parental grief after acquired brain injury (ABI): Incidence, nature, and longevity. *British Journal of Social Work, 38,* 1499-1517.

Coplan, J. (2003). Atypicality, intelligence, and age: a conceptual model of autistic spectrum disorder. *Developmental Medicine & Child Neurology, 45,* 712-716.

Davies, J. M. (2009). *Autism spectrum disorder: impact of severity and emotional availability in the parent-child dyad.* (Doctoral Dissertation). Retrieved from ProQuest.

Erguner-Tekinalp, B. & Akkok, F. (2004). The effects of a coping skills training program on the coping skills, hopelessness, and stress levels of mothers of children with autism. *International Journal for the Advancement of Counseling, 26*, 257-269.

Exkorn, K.S. (2005). *The autism sourcebook: Everything you need to know about diagnosis, treatment, coping, and healing.* New York: HarperCollins Publishers Inc.

Hartley, S. L., Barker, E.T., Seltzer, M. M., Greenberg, J., Floyd, F., & Orsmond, G. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology, 24,* 449-457.

Honey, E., Hastings, R. P., & McConachie, H. (2005). Use of the Questionnaire on Resources and Stress (QRS–F) with parents of young children with autism. *Autism, 9,* 246-255.

Hutton, A.M., & Caron, S. L. (2005) Experience of families with children with autism in rural New England. *Focus on Autism & Other Developmental Disabilities, 20*, 180-189.

Johnson, R.F., O'Reilly, M., & Vostanis, P. (2006). Caring for children with learning disabilities who present problem behaviors: A maternal perspective. *Journal of Child Health Care, 10,* 188-198.

Joshi, G., Petty, C., Wozniak, J., Henin, A., Fried, R., Galdo, M., Kotarski, M., Walls, S., & Biederman, J. (2010). The heavy burden of psychiatric comorbidity in youth with Autism Spectrum Disorders: A large comparative study of a psychiatrically referred population. *Journal of Autism and Developmental Disorders, 40,* 1361-1370.

Kaminsky, L. & Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry, 43,* 225-232.

Klin, A., McPartland, J., & Volkmar (2005). Asperger's Syndrome. Volkmar, Paul, Klin, & Cohen (Eds) *Handbook of Autism and Pervasive Developmental Disorders* (pp. 5-41). Hoboken, NJ: John Wiley & Sons.

Kozub, M. L. (2008). *The diagnosis of autism spectrum disorders in the US: trends and family experiences.* (Doctoral Dissertation). Retrieved from ProQuest LLC.

Kroodsma, L. (2007). *An educational workshop for parents of children with asperger's syndrome.* (Doctoral Dissertation). Retrieved from ProQuest LLC.

Kübler-Ross, E. & Kessler, D. (2005). *On grief and grieving*. New York, NY: Scribner

Kuhn, J. C. & Carter, A. S. (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry, 76,* 564-575.

Lin, C., Tsai, Y., & Chang, H. (2008). Children and their parents coping mechanisms of parents of children recently diagnosed with autism in Taiwan: A qualitative study. *Journal of Clinical Nursing, 17,* 2733-2740.

Linares-Gonzalez. L. (2006). *A supportive training program for parents of autistic children.* (Doctoral Dissertation). Retrieved from ProQuest.

Long, A. (2005). *Understanding father's experience of raising an autistic son: A qualitative study.* (Doctoral Dissertation). Retrieved from ProQuest LLC.

Lutz, H. R. (2008). *Coping with autism during childhood and adulthood: Mothers' journeys toward adaptation.* (Doctoral Dissertation). Retrieved from ProQuest LLC.

Marcus, L. M., Kunce, L.J., & Schopler, E. (2005). Working with families. In F. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds) *Handbook of Autism and Pervasive Developmental Disorders* (pp. 1055-1086). Hoboken, NJ: John Wiley & Sons.

McConachie, H., Phil, M., & Diggle, T. (2007). Parent implemented early intervention for young children with autism spectrum disorder: a systematic review. *Journal of Evaluation in Clinical Practice, 13,* 120–129.

Mertens, D. (2005). *Research and evaluation in education and psychology: Integrating diversity with quantitative, qualitative, and mixed methods.* Thousand Oaks, CA: Sage Publications.

Murphy, N.A., Christian, B., Caplin, D.A., & Young, P.C. (2006). The health of caregivers for children with disabilities: Caregiver perspectives. *Child: Care, Health, and Development, 33,* 180-187.

Ozonoff, S., Young, G. S., Carter, A., Messinger, D., Yirmiya, N., Zwaigenbaum, L., Bryson, S., Carver, L.J., Constantino, J.N., Dobkins, K., Hutman, T., Iverson, J.M., Landa, R., Rogers. S.J., Sigman, M., & Stone, W.L. (2011). Recurrence risk of autism spectrum disorder: A baby siblings research consortium study. *Pediatrics.* Retrieved from http://pediatrics.aappublications.org/content/early/2011/08/11/peds.2010-2825

Perez, T. (2008). *A sibling support group for siblings of children with autism.* (Doctoral Dissertation). Retrieved from ProQuest LLC.

Rarity, J.C. (2007). *Nonfinite grief in families with children on the autism spectrum.* (Doctoral Dissertation). Retrieved from ProQuest Information and Learning Company.

Rogers, M. L. (2008). *Can marital satisfaction of parents raising children with autism be predicted by child and parental stress*. (Doctoral Dissertation). Retrieved from ProQuest LLC.

Rubens, J. D. (2009). *Effects of contextual influences on stress level for caregivers of children diagnosed with autism*. (Doctoral Dissertation). Retrieved from ProQuest LLC.

Ryan, G.W., & Bernard, H.R. (2003). Techniques to identify themes. *Field Methods, 15,* 85-109.

Ruble, L.A., & McGrew, J.H. (2007). Community services outcomes for families and children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 1,* 360-372.

Schreibman, L. & Ingersoll, B. (2005). Behavioral interventions to promote learning in individuals with Autism. In F. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds) *Handbook* *of Autism and Pervasive Developmental Disorders*. (882-896). Hoboken, NJ: John Wiley & Sons.

Sharpley, C., & Bitsika, V. (1997). Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. *Journal of Intellectual & Developmental Disability*, *22*, 19.

Sicile-Kira, C. (2004). *Autism spectrum disorders: The complete guide to understanding autism, asperger's syndrome, pervasive developmental disorders, and other ASDs.* New York: A Perigee Book.

Siklos, S. & Kerns, K. (2006). Assessing need for social support in parents of children with autism and down syndrome. *Autism Development Disorder, 36,* 921-933.

Smith, A. & Osborn, M. (2003). Interpretative phenomenological analysis. A. Smith (Ed.) *Qualitative psychology: A practical guide to research methods* (pp. 51-80). Thousand Oaks, CA: Sage Publications.

Sofronoff, K. & Farbotko, M. (2002). The effectiveness of parent management training to increase self-efficacy in parents of children with asperger's syndrome. *Autism, 6,* 271-286.

Solish, A. & Perry, A. (2008). Parents' involvement in their children's behavioral intervention programs: Parent and therapist perspectives. *Research in Autism Spectrum Disorder, 2,* 728-738.

Stuart, M. & McGrew, J. H. (2009). Caregiver burden after receiving a diagnosis of an autism spectrum disorder. *Research in Autism Spectrum Disorder, 3,* 86-97.

U.S. Census Bureau (2011). *New Hampshire Fact Sheet*. Retrieved from http://factfinder.census.gov/servlet/ACSSAFFFacts?_event=Search&_lang=en&_sse=on&geo_id=04000US33&_state=04000US33

Volkmar, F. & Klin, A. (2005). Issues in the classification of Autism and related conditions. Volkmar, Paul, Klin, & Cohen (Eds) *Handbook of Autism and Pervasive Developmental Disorders* (pp.5-41). Hoboken, NJ: John Wiley & Sons.

Vogt, E. P. (2007). *Marital and parenting satisfaction in families of children with autism*. (Doctoral Dissertation). Retrieved from ProQuest LLC.

Wang, P. (2008). Effects of a parent training program on the interactive skills of parents of children with autism in China. *Journal of Policy and Practice in Intellectual Disabilities, 5,* 96-104.

White, N. & Hastings, R.P. (2004). Social and professional support for parents of adolescents with severe intellectual disabilities. *Journal of Applied research in Intellectual Disabilities, 17,* 181-190.

Wood, A. (2006). *Assessing roles, expectations, and needs of parents of children with autism in behavioral treatment using the A-Parent survey.* (Doctoral Dissertation). Retrieved from ProQuest LLC.

Appendix A: Diagnostic Criteria from the American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders- IV, Text Revision (DSM-IV-TR, 2000)

Diagnostic Criteria for 299.00 Autistic Disorder

A. Six or more items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

  1. qualitative impairment in social interaction, as manifested by at least two of the following:

     a. marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

     b. failure to develop peer relationships appropriate to developmental level

     c. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

     d. lack of social or emotional reciprocity

  2. qualitative impairments in communication as manifested by at least one of the following:

     a. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

     b. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

     c. stereotyped and repetitive use of language or idiosyncratic language

     d. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

  3. restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

     a. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

   b. apparently inflexible adherence to specific, nonfunctional routines or rituals

   c. stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements)

   d. persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Diagnostic Criteria for 299.80 Asperger's Disorder

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

   1. marked impairment in the use of multiple nonverbal behaviors such as eye-to eye gaze, facial expression, body postures, and gestures to regulate social interaction

   2. failure to develop peer relationships appropriate to developmental level

   3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)

   4. lack of social or emotional reciprocity

B. Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least one of the following:

   1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity of focus

   2. apparently inflexible adherence to specific, nonfunctional routines or rituals

   3. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)

   4. persistent preoccupation with parts of objects

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

299.80 Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes "atypical autism" - presentations that do not meet the criteria for Autistic Disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

Diagnostic Criteria for 299.80 Rett's Disorder

A. All of the following:

   1. apparently normal prenatal and perinatal development

   2. apparently normal psychomotor development through the first 5 months after birth

   3. normal head circumference at birth

B. Onset of all of the following after the period of normal development:

   1. deceleration of head growth between ages 5 and 48 months

   2. loss of previously acquired purposeful hand skills between 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., hand-wringing or hand washing)

   3. loss of social engagement early in the course (although often social interaction develops later)

   4. appearance of poorly coordinated gait or trunk movements

5. severely impaired expressive and receptive language development with severe psychomotor retardation

Diagnostic Criteria for 299.10 Childhood Disintegrative Disorder

A. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.

B. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:

    1. expressive or receptive language
    2. social skills or adaptive behavior
    3. bowel or bladder control
    4. play
    5. motor skills

C. Abnormalities of functioning in at least two of the following areas:

    1. qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity)
    2. qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play)
    3. restricted, repetitive, and stereotyped patterns of behavior, interest, and activities, including motor stereotypes and mannerisms

D. The disturbance is not better accounted for by another specific Pervasive Developmental Disorder or by Schizophrenia

Appendix B: Parent Questionnaire

Study Name: Raising Children on the Autism Spectrum: Parental Needs
Researcher: Kathleen Ryan, 5th Year PsyD Student, Clinical Psychology, Antioch University New England. ASDKateRyan@gmail.com

Purpose of the research: Research usually focuses on the needs of the patient, the child with Autism Spectrum Disorder (ASD). This research is designed to help identify services parents with children with ASD believe they need for themselves and their families. Parents best understand which of their needs are not being met and the impact of their own stress. For treatment to be most effective, it is important that professionals understand the needs of parents. This research will evaluate what range of services parents feel would be beneficial to them.

What you will be asked to do in the research: Parents and Caretakers of children ages 3-21 diagnosed with ASD will be asked to complete a questionnaire that will take 10 to 15 minutes.

Risks and discomforts: Because the survey will be anonymous, we do not foresee any risks or discomfort from your participation in the research.

Benefits of the research and benefits to you: This research will benefit parents of children with ASD because it will allow professionals in the field to hear what parents feel they need.

Voluntary participation: Your participation in the study is completely voluntary and you may choose to stop participating at any time. Your decision not to volunteer will not influence any treatment that you or your child are receiving presently, or the ongoing relationship you may have with the researcher or any healthcare provider.

Withdrawal from the study: You can stop participating in the study at any time, for any reason, if you so decide. Your decision to stop participating or to refuse to answer particular questions will not affect your relationship with the researcher or any other group associated with this project or the services your child receives.

Confidentiality: All information you supply during the research will be anonymous. The data will be collected through surveymonkey.com. The data will be owned by the researcher, not surveymonkey.com, and will be kept private and confidential. Surveymonkey.com uses a state of the art security infrastructure, as well as an enhanced SSL encryption package to protect your responses during transmission. The researcher will be the only person with access to your responses but will not know your identity. The researcher will keep the data for several years but all data will be anonymous.

Questions about the research? If you have questions about the research in general, or about your role in the study, please feel free to contact me ASDKateRyan@gmail.com. This research has been reviewed and approved by the Human Research Committee. If you have any questions about your rights as a research participant, you may contact Dr. Kevin P. Lyness, Chair of the Antioch University New England Human Research Committee, (603) 283-2149, or Dr. Katherine Clarke, ANE Vice President for Academic Affairs, (603) 283-2450.

Do you consent to participate in the study?

O I **consent** to participate in the study Raising Children on the Autism Spectrum: Parental Needs conducted by Kathleen Ryan. I understand the nature of this project and wish to participate. I am not waiving my legal rights by signing this form. By checking this box I agree that I have read the informed consent and am providing my consent to participate in this study.

O I **do not consent** to participate in the study Raising Children on the Autism Spectrum: Parental Needs conducted by Kathleen Ryan. I understand the nature of this project and wish not to participate. (if selected will skip to disqualification page)

1. What is your relationship to the child?
O Mother O Father O Step-mother OStep-Father
O Other (please Specify) ________________________________

2. How old are you?_____________________

3. What is your current marital status?
O Divorced O Married O Separated
O Domestic Partner O Never Married O Widowed

4. What is your educational level?
O Grammar school or less O Associates degree O Master's Degree O Some High school
O High School Diploma or GED O Some College O Bachelor's Degree
O Doctorate Degree

1. What is your total household income?
O Less than $20,000 O $20,000 to $59,999 O $60,000 to $99,999
O $100,000 to $139,999 O$140,000 or more O Prefer not to say

2. What is your primary employment status?
O Employed by employer O Self-employed O Out of work and looking for work
O A homemaker O A student O Retired
O Out of work but not currently looking for work O Unable to work
O Other (Please Specify) _____________________
____

3. What state is your primary residence? ______________

4. Which of the following best describes the area you live in?
O Urban O Suburban O Rural

5. What racial/ethnic group do you identify with?
O African-American O Hispanic-American O Biracial
O Asian-American O Native American/American Indian O Multiracial
O Caucasian O Other (please specify)_______________

1. How many children do you have? ______________

2. How many of those children have been diagnosed with ASD?_______________

(Skip Logic: If only one child with ASD)

3. How old is your child with ASD? ______________

4. How many years ago was your child diagnosed?______________

1. How old are your children with ASD?

Child 1______ Child 2______ Child 3______ Child 4______

Child 5 _____ Child 6______ Child 7______ Child 8______

Child 9______ Child 10______ If more that 10 Children with ASD

____

2. How many years ago were your children diagnosed?

Child 1______ Child 2______ Child 3______ Child 4______

Child 5 _____ Child 6______ Child 7______ Child 8______

Child 9______ Child 10______ If more that 10 Children with ASD

____

1. As a parent of a child with autism, are there specific needs that you feel have not been met for you or your partner? ______________________________

2. As a parent of a child with autism, are there specific services that you desire that have not been offered for you or your partner? ______________________

3. As a parent of a child with autism, are there specific needs that you feel have not been met for your children without an ASD? __________________________

4. As a parent of a child with autism, are there specific services that you desire that have not been offered for your children without an ASD? ______________

5. What needs of yours or your partner’s do you feel are most important in the context of parenting a child with ASD? __________________________________

6. What services do you feel are most important for you as a parent of a child with ASD? ___________

7. What specific focus of services have you found most important or most helpful? __________

8. What types of parental services/supports that you receive presently do you find most useful (emotional support, respite care, educational, etc.)? ____

9. What types of parental services/support that you do not presently receive would you find most useful (emotional support, respite care, educational, etc.)? _______________________________

10. What are particular aspects or qualities that you would look for in a provider of support services? _

11. What is the best place a service can be delivered to you (in-home, therapist's office, etc.)? ________

12. What are barriers that interfere with you obtaining services (e.g., Childcare, not aware of services, access, transportation, time, office hours, money, insurance, difficulty acknowledging need for help, etc.)? ___________________

13. How important is it to you that the provider is specifically trained to work with ASD? ------
O 1- Not at all O 2- Slightly O3- Moderately O 4- Very O 5- Extremely
- And why? ____

Below you will find definitions of the services in question in this survey. Please read through these definitions to help better understand the services in question.

Individual Therapy: Psychotherapy or personal counseling with a psychotherapist which involves working on a one-to-one basis with a therapist to prepare a plan to create positive changes in one's life.

Couples Therapy: Psychotherapy with a psychotherapist used to treat relationship distress for couples. The purpose of couples therapy is to restore a better level of functioning in couples who are experiencing distress.

Drop In Center: A center staffed with a psychotherapist that offers psychotherapy to an individual or a couple on an as needed bases

Parent Skills Training: A trainer works with the parents in order to teach them and other caregivers effective ways of helping their child further develop his or her skills.

Educational Parent Groups: An in person, professional facilitated support group for parents of children with an ASD which provides psycho-educational information about having a child with an ASD. Topics may include information about the diagnosis, Special Education, medication, behavior plans, etc.

Process Oriented Parent Support Groups: An in person, professional facilitated support group for parents of children with an ASD which provides a safe space for parents to explore their feelings, struggles, and needs among other parents of children with an ASD. These groups focus on the interpersonal and psychological needs of the parents as opposed to education trainings.

Online Support Group: An electronic community resource that grants access to individuals worldwide. Some groups allow individuals to exchange messages in real time while some can post a message or exchange messages via email, blogs, or internet bulletin boards. The groups can be peer-to-peer self-help groups or facilitated support groups. These groups meet in a virtual world and do not have a physical location sometimes allowing members to stay anonymous.

Parent Advocacy Groups: A parent run group whose focus is on advocacy and support. The group is dedicated to increasing awareness of autism. A Parent Advocacy Group often strives to receive funding for ASD needs as well as to help ensure a free appropriate public education and equal opportunities for children and youth with an ASD.

Sibling Support Group: A support group for siblings of children with an ASD which helps connect siblings with other siblings of children with autism and peer support.

Parent to Parent Workshops: A group developed by parents of children with an ASD to help other parents with children on the spectrum. The group may teach skills, educate about rights, or offer support to their peers. This group is not organized or facilitated by a professional.

Respite Care: Short-term, temporary relief of care giving responsibilities so that caregivers can have time for themselves. This time is to enhance a parent or caregivers ability to continue in their role as a primary caregiver and to maintain a caring relationship.

1. Have you participated in individual therapy related to being a parent of a child with an ASD?
○ Yes ○ No

Individual Therapy: Psychotherapy or personal counseling with a psychotherapist which involves working on a one-to-one basis with a therapist to prepare a plan to create positive changes in one's life.
Please answer the following questions on a scale of 1-5. 1- Not at all, 2-Slighlty, 3- Moderately, 4-Very, 5- Extremely

(Skip Logic- answer if Yes)
How well were your needs met?
○ 1- Not at all ○ 2- Slightly ○3- Moderately ○ 4- Very ○ 5- Extremely

How ASD aware was your therapist?
○ 1- Not at all ○ 2- Slightly ○3- Moderately ○ 4- Very ○ 5- Extremely

If offered in the next 3 months: (On a scale of 1-5, 1 being the lowest and 5 being the highest)

1=Not interested/ would not use it, 2=A little interested/probably wouldn't use it,
3=Interested/would use it infrequently, 4= Very interested/ would use it frequently,
5=Extremely interested/ would use it regularly

(Skip Logic- answer if No)
If offered individual therapy for yourself in the next 3 months how interested would you be?
O 1=Not interested/ would not use it O2=A little interested/probably wouldn't use it
O3=Interested/would use it infrequently O 4= Very interested/ would use it frequently
O 5=Extremely interested/ would use it regularly

2. Have you participated in couples therapy related to being a parent of a child with an ASD?
O Yes O No O N/A (No Partner Involved)

Couples Therapy: Psychotherapy with a psychotherapist used to treat relationship distress for couples. The purpose of couples therapy is to restore a better level of functioning in couples who are experiencing distress.
Please answer the following questions on a scale of 1-5. 1- Not at all, 2-Slighlty,
3- Moderately, 4-Very, 5- Extremely

(Skip Logic- answer if Yes)
How well were your needs met?
O 1- Not at all O 2- Slightly O3- Moderately O 4- Very O 5- Extremely

How ASD aware was your therapist?
O 1- Not at all O 2- Slightly O3- Moderately O 4- Very O 5- Extremely

If offered in the next 3 months: (On a scale of 1-5, 1 being the lowest and 5 being the highest)
1=Not interested/ would not use it, 2=A little interested/probably wouldn't use it,
3=Interested/would use it infrequently, 4= Very interested/ would use it frequently,
5=Extremely interested/ would use it regularly

(Skip Logic- answer if No)
If offered couples therapy in the next 3 months how interested would you be?
O 1=Not interested/ would not use it O2=A little interested/probably wouldn't use it
O3=Interested/would use it infrequently O 4= Very interested/ would use it frequently
O 5=Extremely interested/ would use it regularly

3. Have you visited a drop-in center related to ASD?
O Yes O No

Drop in Center: A center staffed with a psychotherapist that offers psychotherapy to an individual or a couple on an as needed bases
Please answer the following questions on a scale of 1-5. 1- Not at all, 2-Slighlty,
3- Moderately, 4-Very, 5- Extremely

(Skip Logic- answer if Yes)
How well were your needs met?
O 1- Not at all O 2- Slightly O3- Moderately O 4- Very O 5- Extremely

How ASD aware was your provider?
O 1- Not at all O 2- Slightly O3- Moderately O 4- Very O 5- Extremely

If offered in the next 3 months: (On a scale of 1-5, 1 being the lowest and 5 being the highest)
1=Not interested/ would not use it, 2=A little interested/probably wouldn't use it,
3=Interested/would use it infrequently, 4= Very interested/ would use it frequently,
5=Extremely interested/ would use it regularly

(Skip Logic- answer if No)
If offered a drop in center in the next 3 months how interested would you be?
O 1=Not interested/ would not use it O2=A little interested/probably wouldn't use it
O3=Interested/would use it infrequently O 4= Very interested/ would use it frequently
O 5=Extremely interested/ would use it regularly

4. Have you participated in parent skills training related to being a parent of a child with an ASD?
O Yes O No

Parent Skills Training: A trainer works with the parents in order to teach them and other caregivers effective ways of helping their child further develop his or her skills.
Please answer the following questions on a scale of 1-5. 1- Not at all, 2-Slighlty, 3-Moderately, 4-Very, 5- Extremely

(Skip Logic- answer if Yes)
How well were your needs met?
O 1- Not at all O 2- Slightly O3- Moderately O 4- Very O 5- Extremely

How ASD aware was your trainer?
O 1- Not at all O 2- Slightly O3- Moderately O 4- Very O 5- Extremely

If offered in the next 3 months: (On a scale of 1-5, 1 being the lowest and 5 being the highest)
1=Not interested/ would not use it, 2=A little interested/probably wouldn't use it,
3=Interested/would use it infrequently, 4= Very interested/ would use it frequently,
5=Extremely interested/ would use it regularly

(Skip Logic- answer if No)
If offered parent skills training in the next 3 months how interested would you be?
O 1=Not interested/ would not use it O2=A little interested/probably wouldn't use it
O3=Interested/would use it infrequently O 4= Very interested/ would use it frequently
O 5=Extremely interested/ would use it regularly

5. Have you participated in educational parent groups related to being a parent of a child with an ASD?
O Yes O No

Educational Parent Groups: An in person, professional facilitated support group for parents of children with an ASD which provides psycho-educational information about having a child

with an ASD. Topics may include information about the diagnosis, Special Education, medication, behavior plans, etc.
Please answer the following questions on a scale of 1-5. 1- Not at all, 2-Slighlty, 3-Moderately, 4-Very, 5- Extremely

(Skip Logic- answer if Yes)
How well were your needs met?
O 1- Not at all O 2- Slightly O3- Moderately O 4- Very O 5- Extremely

How ASD aware was your leader?
O 1- Not at all O 2- Slightly O3- Moderately O 4- Very O 5- Extremely

If offered in the next 3 months: (On a scale of 1-5, 1 being the lowest and 5 being the highest) 1=Not interested/ would not use it, 2=A little interested/probably wouldn't use it, 3=Interested/would use it infrequently, 4= Very interested/ would use it frequently, 5=Extremely interested/ would use it regularly

(Skip Logic- answer if No)
If offered an educational parent group in the next 3 months how interested would you be?
O 1=Not interested/ would not use it O2=A little interested/probably wouldn't use it
O3=Interested/would use it infrequently O 4= Very interested/ would use it frequently
O 5=Extremely interested/ would use it regularly

6. Have you participated in process oriented parent support groups related to being a parent of a child with an ASD?
O Yes O No

Process Oriented Parent Support Groups: An in person, professional facilitated support group for parents of children with an ASD which provides a safe space for parents to explore their feelings, struggles, and needs among other parents of children with an ASD. These groups focus on the interpersonal and psychological needs of the parents as opposed to education trainings.
Please answer the following questions on a scale of 1-5. 1- Not at all, 2-Slighlty, 3-Moderately, 4-Very, 5- Extremely

(Skip Logic- answer if Yes)
How well were your needs met?
O 1- Not at all O 2- Slightly O3- Moderately O 4- Very O 5- Extremely

How ASD aware was your leader?
O 1- Not at all O 2- Slightly O3- Moderately O 4- Very O 5- Extremely

If offered in the next 3 months: (On a scale of 1-5, 1 being the lowest and 5 being the highest) 1=Not interested/ would not use it, 2=A little interested/probably wouldn't use it, 3=Interested/would use it infrequently, 4= Very interested/ would use it frequently, 5=Extremely interested/ would use it regularly

(Skip Logic- answer if No)

If offered a process oriented parent support group in the next 3 months how interested would you be?
O 1=Not interested/ would not use it O2=A little interested/probably wouldn't use it
O3=Interested/would use it infrequently O 4= Very interested/ would use it frequently
O 5=Extremely interested/ would use it regularly

7. Have you participated in online support groups/ chatrooms related to being a parent of a child with an ASD?
O Yes O No

Online Support Group: An electronic community resource that grants access to individuals worldwide. Some groups allow individuals to exchange messages in real time while some can post a message or exchange messages via email, blogs, or internet bulletin boards. The groups can be peer-to-peer self-help groups or facilitated support groups. These groups meet in a virtual world and do not have a physical location sometimes allowing members to stay anonymous.
Please answer the following questions on a scale of 1-5. 1- Not at all, 2-Slighlty, 3-Moderately, 4-Very, 5- Extremely

(Skip Logic- answer if Yes)
How well were your needs met?
O 1- Not at all O 2- Slightly O3- Moderately O 4- Very O 5- Extremely

How ASD aware was your leader?
O 1- Not at all O 2- Slightly O3- Moderately O 4- Very O 5- Extremely

If offered in the next 3 months: (On a scale of 1-5, 1 being the lowest and 5 being the highest)
1=Not interested/ would not use it, 2=A little interested/probably wouldn't use it,
3=Interested/would use it infrequently, 4= Very interested/ would use it frequently,
5=Extremely interested/ would use it regularly

(Skip Logic- answer if No)
If offered an online support group in the next 3 months how interested would you be?
O 1=Not interested/ would not use it O2=A little interested/probably wouldn't use it
O3=Interested/would use it infrequently O 4= Very interested/ would use it frequently
O 5=Extremely interested/ would use it regularly

8. Have you participated in parent advocacy groups related to being a parent of a child with an ASD?
O Yes O No

Parent Advocacy Groups: A parent run group whose focus is on advocacy and support. The group is dedicated to increasing awareness of autism. A Parent Advocacy Group often strives to receive funding for ASD needs as well as to help ensure a free appropriate public education and equal opportunities for children and youth with an ASD.
Please answer the following questions on a scale of 1-5. 1- Not at all, 2-Slighlty, 3-Moderately, 4-Very, 5- Extremely

(Skip Logic- answer if Yes)
How well were your needs met?
O 1- Not at all O 2- Slightly O3- Moderately O 4- Very O 5- Extremely

(Skip Logic- answer if No)
If offered a parent advocacy group in the next 3 months how interested would you be?
O 1=Not interested/ would not use it O2=A little interested/probably wouldn't use it
O3=Interested/would use it infrequently O 4= Very interested/ would use it frequently
O 5=Extremely interested/ would use it regularly

9. Have your children without ASD participated in sibling support groups related to being a sibling of a child with an ASD?
O Yes O No

Sibling Support Group: A support group for siblings of children with an ASD which helps connect siblings with other siblings of children with autism and peer support.
Please answer the following questions on a scale of 1-5. 1- Not at all, 2-Slighlty, 3-Moderately, 4-Very, 5- Extremely

(Skip Logic- answer if Yes)
How well were your child/children's needs met?
O 1- Not at all O 2- Slightly O3- Moderately O 4- Very O 5- Extremely

(Skip Logic- answer if No)
If offered a sibling support group for one or more of your children without an ASD in the next 3 months how interested would you be?
O 1=Not interested/ would not use it O2=A little interested/probably wouldn't use it
O3=Interested/would use it infrequently O 4= Very interested/ would use it frequently
O 5=Extremely interested/ would use it regularly

10. Have you participated in parent to parent workshops related to being a sibling of a child with an ASD?
O Yes O No

Parent to Parent Workshops: A group developed by parents of children with an ASD to help other parents with children on the spectrum. The group may teach skills, educate about rights, or offer support to their peers. This group is not organized or facilitated by a professional.
Please answer the following questions on a scale of 1-5. 1- Not at all, 2-Slighlty, 3-Moderately, 4-Very, 5- Extremely

(Skip Logic- answer if Yes)
How well were your needs met?
O 1- Not at all O 2- Slightly O3- Moderately O 4- Very O 5- Extremely

(Skip Logic- answer if No)
If offered a parent to parent workshop in the next 3 months how interested would you be?

O 1=Not interested/ would not use it O2=A little interested/probably wouldn't use it
O3=Interested/would use it infrequently O 4= Very interested/ would use it frequently
O 5=Extremely interested/ would use it regularly

11. Have you participated in respite care related to your child's ASD?
O Yes O No

Respite Care: Short-term, temporary relief of care giving responsibilities so that caregivers can have time for themselves. This time is to enhance a parent or caregivers ability to continue in their role as a primary caregiver and to maintain a caring relationship.

Please answer the following questions on a scale of 1-5. 1- Not at all, 2-Slighlty, 3-Moderately, 4-Very, 5- Extremely

(Skip Logic- answer if Yes)
How well were your needs met?
O 1- Not at all O 2- Slightly O3- Moderately O 4- Very O 5- Extremely

How ASD aware was your respite worker?
O 1- Not at all O 2- Slightly O3- Moderately O 4- Very O 5- Extremely

If offered in the next 3 months: (On a scale of 1-5, 1 being the lowest and 5 being the highest) 1=Not interested/ would not use it, 2=A little interested/probably wouldn't use it, 3=Interested/would use it infrequently, 4= Very interested/ would use it frequently, 5=Extremely interested/ would use it regularly

(Skip Logic- answer if No)
If offered respite care in the next 3 months how interested would you be?
O 1=Not interested/ would not use it O2=A little interested/probably wouldn't use it
O3=Interested/would use it infrequently O 4= Very interested/ would use it frequently
O 5=Extremely interested/ would use it regularly

Please rank order the top 3 services you would now find most useful for yourself whether or not you have sought them or received them in the past. (In the first row select the most important service, in the second row select the second most important services, and in the last row select the 3rd most important service.)

	First Most Important	Second Most Important	Third Most Important
Individual Therapy:			
Drop in Center:			
Parent Sills Training:			
Educational Parent Groups:			
Process Oriented Parent Support Groups:			

Online Support Groups:
Parent Advocacy Groups:
Sibling Support Groups:
Parent Advocacy Groups:
Sibling Support Group:
Parent to Parent Workshops:
Respite:
Other: Please Specify
Other: Please Specify
Other: Please Specify

1. What other support services have you used?_____________________________________

2. What other services have been offered?____

3. What other support services would you use if they were available? __________________

(Skip logic: Skip to this page if you do not qualify to participate)

Disqualification Page
Sorry but unfortunately your response indicates that you do not qualify to participate in this study. Participants must reside in the United States and have a child who has been diagnosed with an Autism Spectrum Disorder, including Autism, Asperger's, and PDD-NOS. The child diagnosed with ASD must be between the ages of 3-21. A parent of multiple children on the spectrum may participate.

If you believe you have obtained this message in error. Please return to the start of the questionnaire an make sure you have answered the questions appropriately.

If you do not qualify for this questionnaire I want to thank you for taking the time to answer this questionnaire and apologize for any inconvenience.

Final Page

Thank you for your participation. If you have an questions or concerns pleas feel free to contact the researcher Kate Ryan at ASDKateRyan@gmail.com.

Please add any additional comments below about the services available to you as a parent of a child/children with an ASD.

1. Questions or Comments?____

Appendix C: Informed Consent Form

Study Name: Raising Children on the Autism Spectrum: Parental Needs

Researchers: Kathleen Ryan
5th Year PsyD Student, Clinical Psychology, Antioch University New England
ASDKateRyan@gmail.com

Purpose of the Research: Research usually focuses on the needs of the patient, the child with Autism Spectrum Disorder (ASD). This research is designed to help identify services parents with children with an ASD believe they need for themselves and their families. Parents best understand which of their needs are not being met and the impact of their own stress. For treatment to be most effective, it is important that professionals understand the needs of parents. This research will evaluate what range of services parents feel would be beneficial to them.

What You Will Be Asked to Do in the Research: Parents and Caretakers of children ages 3-21 diagnosed with an ASD will be asked to complete a questionnaire that will take 10 to 15 minutes.

Risks and Discomforts: Because the survey will be anonymous, we do not foresee any risks or discomfort from your participation in the research.

Benefits of the Research and Benefits to You: This research will benefit parents of children with an ASD because it will allow professionals in the field to hear what parents feel they need.

Voluntary Participation: Your participation in the study is completely voluntary and you may choose to stop participating at any time. Your decision not to volunteer will not influence any treatment that you or your child are receiving presently, or the ongoing relationship you may have with the researcher or any healthcare provider.

Withdrawal from the Study: You can stop participating in the study at any time, for any reason, if you so decide. Your decision to stop participating or to refuse to answer particular questions will not affect your relationship with the researcher or any other group associated with this project or the services your child receives.

Confidentiality: All information you supply during the research will be anonymous. The data will be collected through surveymonkey.com. The data will be owned by the researcher, not surveymonkey.com, and will be kept private and confidential. Surveymonkey.com uses a state of the art security infrastructure, as well as an enhanced SSL encryption package to protect your responses during transmission. The researcher will be the only person with access to your responses but will not know your identity. The researcher will keep the data for several years but all data will be anonymous.

Questions About the Research? If you have questions about the research in general, or about your role in the study, please feel free to contact me ASDKateRyan@gmail.com. This research has been reviewed and approved by the Human Research Committee. If you have any questions about your rights as a research participant, you may contact Dr. Kevin P. Lyness, Chair of the Antioch University New England Human Research Committee, (603) 283-2149, or Dr. Katherine Clarke, ANE Vice President for Academic Affairs, (603) 283-2450.

Implied Consent:

O I consent to participate in the study Raising Children on the Autism Spectrum: Parental Needs conducted by Kathleen Ryan. I understand the nature of this project and wish to participate. I am not waiving my legal rights by signing this form. By checking this box I agree that I have read the informed consent and am providing my consent to participate in this study.

O I do not consent to participate in the study Raising Children on the Autism Spectrum: Parental Needs conducted by Kathleen Ryan. I understand the nature of this project and wish not to participate.

Appendix D: Operational Definitions

Individual Therapy: Psychotherapy or personal counseling with a psychotherapist which involves working on a one-to-one basis with a therapist to prepare a plan to create positive changes in one's life.

Couples therapy: Psychotherapy with a psychotherapist used to treat relationship distress for couples. The purpose of couples therapy is to restore a better level of functioning in couples who are experiencing distress.

Parent Skills Training: A trainer works with the parents in order to teach them and other caregivers effective ways of helping their child further develop his or her skills.

Drop in Center: A center staffed with a psychotherapist that offers psychotherapy to an individual or a couple on an as needed bases.

Educational Parent Groups: An in person, professional facilitated support group for parents of children with an ASD which provides psycho-educational information about having a child with an ASD. Topics may include information about the diagnosis, Special Education, medication, behavior plans, etc.

.

Process Oriented Parent Support Groups: An in person, professional facilitated support group for parents of children with an ASD which provides a safe space for parents to explore their feelings, struggles, and needs among other parents of children with an ASD. These groups focus on the interpersonal and psychological needs of the parents as opposed to education trainings.

Online support group: An electronic community resource that grants access to individuals worldwide. Some groups allow individuals to exchange messages in real time while some can post a message or exchange messages via email, blogs, or internet bulletin boards. The groups can be peer-to-peer self-help groups or facilitated support groups. These groups meet in a virtual world and do not have a physical location sometimes allowing members to stay anonymous.

Parent Advocacy Groups: A parent run group whose focus is on advocacy and support. The group is dedicated to increasing awareness of autism. A Parent Advocacy Group often strives to receive funding for ASD needs as well as to help ensure a free appropriate public education and equal opportunities for children and youth with an ASD.

Sibling Support Group: A support group for siblings of children with an ASD which helps connect siblings with other siblings of children with autism and peer support.

Parent to parent workshops: A group developed by parents of children with an ASD to help other parents with children on the spectrum. The group may teach skills, educate about rights, or offer support to their peers. This group is not organized or facilitated by a professional.

Respite Care: Short-term, temporary relief of care giving responsibilities so that caregivers can have time for themselves. This time is to enhance a parent or caregivers ability to continue in their role as a primary caregiver and to maintain a caring relationship.

Appendix E: Sample Cover Letter

To Whom It May Concern:

My name is Kathleen Ryan and I am a 5th year doctoral student at Antioch University New England. I am presently doing my dissertation on the needs of parents when they have a child with Autism Spectrum Disorder (ASD). I have developed an anonymous questionnaire to be completed by parents of children with an ASD in order to look at the needs of parents from the perspective of the parent. I understand that your organization has a strong connection with a large number of parents with children on the spectrum. I was hoping you would be willing to distribute my questionnaire to the parents connected with your organization. Attached you will find an internet link to my questionnaire as well as a brief advertisement suitable for a webpage or a newsletter. Thank you in advance for your support.

Sincerely,

Kathleen Ryan

Advertisement:

If you have a child between the ages of 3-21 who has been diagnosed with Autism Spectrum Disorder (ASD), please fill out the short questionnaire attached. The questionnaire is anonymous and its purpose is to determine what services parents feel they need for themselves and their families. (Survey monkey link here) If you would prefer a paper form please contact Kate Ryan at ASDKateRyan@gmail.com.

Appendix F: Responses Addressing Child's Needs

Answer Addressed Needs of Child
The school lacks knowledge of various transitional programs for my child.
Anger Management classes for the child with an ASD would be very helpful.
My child does not receive enough therapy, he only gets 2wo hours a week because, this is all that medicaid covers
Just trying to get an appointment for an evaluation was frustrating.
Not enough support in the educational level, and in the community
It has nothing to do w/parents. The kids we have are our responsibility. Neither of our kids receive any support.
Have not been given substantial social skills training for the kids
Need school help
More information and tools for the older child. To help in developing tools that help with jobs, dating and real world skills
public schools not providing enough paraprofessionals or behavioral therapists for my child's needs
More information on alternative therapies (weighted blankets, swimming therapy) I can get through the state or insurance.
ABA services for my child
needs not met: education for child lack of teacher training lack of appropriate therapies. lack of everything.
Social/emotional for my child
Days when they rent out Chucky Cheese and movie theaters for only children with Autism.
Playgroups or similar types of groups with other age appropriate ASD children & to be affordable!
There are so many things I'd like to try for my sons that are prohibitively expensive, and insurance won't cover - like HBOT, chelation, hippotherapy, social skills groups, recreational needs, etc.
Yes, HIPPO therapy and funds for communication needs like an iPad.
I would love for my teenager to attend a special camp for one week in the summer.
proper schooling. the closest school in NY is 3 hrs away from me so they send my son to a boces program which is just a school they send kids they don't want to deal with or feel they are troubled and a danger to be in regular school. and none of these teachers or staff have the proper training to help these children. they feel that my son should be like any normal 7th grader but he is autistic.
Continuing Education for my child
None of my children received early intensive programming. The oldest two received 2.3 hours/day 5 days a week and the 1 year old gets 3 hours a week through the school district. ITS A JOKE.
All therapies from speech, life skills, sensory integration, music, vision, physical therapy.
DAN doctors are few and far between.
There are no specialized training in any extra-curricular activities. Some people say they do, but they really don't.
I need an appropriate educational setting for my teenager with ASD.

Biomedical intervention: Vitamin B-12 injection and mercury chelation in addition to other supplements
schooling and services wait list
Behavioral
There needs to be a practice that specializes in autism spectrum disorders that is not a research facility (such as LADDERS). It should have pediatricians, neurologists, psychotherapists, psychiatrists, etc. who all work together providing care for these kids with a team approach. As it stands now pediatricians can 't seem to recommend any good psychs for kids, then when you find one, they don't take insurance. You have to travel all over the state to receive care.
Him being happy and healthy.
Speech Therapy/Occupational Therapy
Better educational services before, now we're searching for employment and appropriate social goals.
ResHab (Residential Habilitation), respite, parenting classes for parents of kids on the spectrum that also deal with sibling issues, marriage counseling, classes on how educational system works
speech and OT at school. Therapeutic riding, special swim classes
Took kids out of public school...........because the I.E.P. looks great on Paper But.....it doesn’t really get followed.
I do not receive any services/supports other than the IEP at school. I am hoping to be able to get social worker services for Child #2.
educational, medical
At this point, I think anyone trying to discuss emotional support with me would just make me cry. I have to maintain focus on the importance of getting my child the supports and services he needs for optimal development.